Alzheimer's Disease International
The global voice on dementia

World Alzheimer Report 2025

Reimagining life with dementia – the power of rehabilitation

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Acknowledgements

ADI would like to extend its gratitude to the teams at the universities of Exeter and Sydney, with particular thanks to Charlotte Jones for her vital support and coordination throughout the production of the report. We would also like to acknowledge Alex Kornhuber and Lee-Ann Olwage, who have once again generously provided their photographs to illustrate this report.

Deep thanks go to ADI member associations and colleagues in dementia advocacy and research for bringing case studies to illustrate what rehabilitation can look like around the world. ADI would also like to give special thanks to The Mary Oakley Foundation, Inc. for its generous support this year.

ADI would like to thank our corporate partners and donors:

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Otsuka Pharmaceutical Development & Commercialization, Inc.
Parexel
Diane and Dan Riccio
Roche
Van Otterloo Family

Published by Alzheimer's Disease International.
September 2025

Suggested citation:
Alzheimer's Disease International, Clare, L, Jeon, YH. 2025. World Alzheimer Report 2025: Reimagining life with dementia – the power of rehabilitation. London, England: Alzheimer's Disease International.

Cover photo: Tatie Voahangu Rasoarihanana, 82, (centre) is assisted by carers (from left) Voahanginirina Razafindravola, Holimboahangy Razafimahatra, and Yollande Rason-Andriamaro at the Masoandro Mody centre in Fenomanana, Antananarivo, Madagascar. (Photo courtesy of Lee-Ann Olwage)

Contents

Glossary

- **Allied health professionals:** A group of trained healthcare workers such as occupational therapists, physiotherapists, and speech and language therapists, who are not doctors or nurses but provide essential services to support recovery, independence, and quality of life.
- **Assistive technologies:** Devices, equipment, or systems that help people carry out daily activities, maintain independence, and improve quality of life, such as memory aids, wheelchairs, hearing aids, or communication devices.
- **Cognitive rehabilitation:** A therapeutic approach designed to help people improve or compensate for problems with thinking skills such as memory, attention, problem-solving, or planning, often after brain injury, stroke, or a diagnosis of dementia.
- **Function:** A person's ability to carry out everyday activities related to wellbeing and independence, such as eating, dressing, moving, or managing personal care.
- **Function-focused care:** An approach to care, usually used in long-term institutional care, that actively encourages people to use and maintain their existing abilities, rather than doing tasks for them.
- **Hand-over-hand/hand-under-hand:** Techniques used to guide or assist someone with limited ability to complete a task. Hand-over-hand means placing the support person's hand over the person's hand to help them move; hand-under-hand means supporting from beneath, allowing the person to feel more in control.
- **Life story work:** An approach in health and social care that helps people share and record their personal histories and experiences, often using photos or memory books. It is especially useful in dementia care, supporting person-centred care and stronger relationships.
- **Long-term institutional care:** Residential care services usually for older people, such as nursing homes or care homes, where people live for an extended period because they can no longer manage their day-to-day activities independently at home.
- **Manualised intervention:** A structured programme or treatment that follows a written "manual" or set of guidelines, in contrast to a person-centred approach adapted to each individual.
- **Occupational therapy:** A healthcare profession focused on enabling people to participate in meaningful everyday activities by adapting the environment, teaching new skills, or providing tools and strategies to overcome challenges.
- **Person-centred/personalised approach:** A way of delivering care that focuses on the individual's unique preferences, needs, values, and goals, ensuring they are actively involved in decisions about their support.
- **Physiotherapy:** A healthcare specialisation helping people improve movement, strength, balance, and physical function. Physiotherapists use exercise, manual therapy, education, and guidance to reduce pain, restore mobility, and support independence.
- **Reablement:** A care approach (often provided at home) that focuses on improving and maintaining a person's daily function and independence after illness, injury, or hospital admission.
- **Speech and language therapy:** A healthcare field that helps people with difficulties in communication, speech, language, voice, or swallowing. Speech and language therapists support people with understanding and expression, as well as safe eating and drinking.

Foreword

Paola Barbarino,
Chief Executive Officer, Alzheimer's Disease International

> **"People with dementia [...] rarely have access to rehabilitation, despite the evidence that they can benefit from it. Often, people with dementia are explicitly excluded from rehabilitation. It is time to question the reasons why this occurs and to challenge this exclusion."**
>
> *Linda Clare and Yun-Hee Jeon (page 109)*

I am a strong believer in rehabilitation, having experienced its benefits first-hand after I developed severe back pain in my mid-thirties. Back then, my doctor told me that I would be on painkillers for the rest of my life. But after a year of research and speaking with friends and healthcare professionals, I encountered the concept of rehabilitation, using targeted exercise and tailored tools to manage my condition.

This personal experience taught me that rehabilitation is only effective if you set your own improvement goals and have the motivation and perseverance to see them through in the long term. I also learned that having a support network of family, friends, and healthcare professionals who care and root for you is a key to success.

When Alzheimer's Disease International published *World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support*, we identified rehabilitation as a key area in the vast field of dementia care that needed further exploration. Rehabilitation was repeatedly mentioned as an effective, lower-cost non-pharmacological intervention that could significantly help people living with dementia as well as their carers. After talking with people living with dementia, carers, and healthcare professionals in many countries, it has been clear that the benefits of rehabilitation remain largely unknown and unimplemented when it comes to dementia.

This is in large part due to a lack of awareness and understanding about what rehabilitation might look like for people living with dementia. There are many kinds of rehabilitation, including physical (the most commonly recognisable), cognitive, spatial, visual rehabilitation, and so on. The key to effective dementia rehabilitation, no matter with which condition someone has been diagnosed, is for the intervention to be tailor-made to individual requirements and circumstances. This person-centred precision approach yields better chances of effectiveness, as described across the essays in this report, allowing people living with dementia to maintain their functional abilities and independence and remain in their home for longer – factors that undoubtedly have an impact on private and public care costs.

The issue of costs is an unavoidable one when it comes to dementia. New anti-amyloid treatments, while promising, remain expensive and inaccessible for the vast majority of people living with dementia in lower- and middle-income countries – in addition to not being suitable for all people impacted by dementia in any case. While there is much hope and enthusiasm for new pharmacological solutions to dementia, we remain far from finding a cure.

In this context, we believe rehabilitation to be a sustainable alternative worth exploring in more depth alongside treatment options. Some rehabilitation interventions can be supported by advanced assistive technology – but a lot can be achieved with a simple whiteboard, pen, or timer. The report also explores how informal carers can be active participants in the rehabilitation process, accompanying their loved ones in ways that feel empowering for both parties. The many techniques and strategies detailed throughout the report will, we hope, help demystify rehabilitation and provide tangible tools for its implementation in real life.

As ADI, in partnership with Professors Linda Clare from the University of Exeter and Yun-Hee Jeon from the University of Sydney, delved deeper into the production of this report, a number of critical issues emerged.

First was the current dearth of studies into the economic evidence for dementia rehabilitation – in no small part due to the relative novelty and limited dissemination of these interventions.

We need a lot more research into the issue if we want governments to buy into rehabilitation as an effective intervention for dementia. The essay by Justin Mazzotta and Brenda M. (page 101) is one concrete example of a project seeking to capture the savings their local authority could make by delaying admission to care homes. Shouldn't it be in the interest of governments to fund more such studies?

Secondly, we faced difficulties in finding examples of best-practice dementia rehabilitation in lower-income settings. A reason for this, of course, is the continued economic and social barriers to dementia care as a whole – but current best practices call for complex multidisciplinary teams of professionals that are, more often than not, unrealistic in many lower-income countries at present. Best practice examples currently appear to be mostly driven by pilot programmes, which further emphasise inequalities in access. For rehabilitation to be accessible to the largest number of people, adjustments need to be made in countries with limited resources, and further efforts must be made to make these practices as affordable as possible.

As Antony Duttine points out in his essay (page 122): "*Rehabilitation is an essential health service*". No ifs, no buts. Rehabilitation should be an integral part of what is offered to people diagnosed with dementia to enable better outcomes, and it should be offered as soon as they are diagnosed. So why has the vast majority of people yet to hear about cognitive rehabilitation?

Well, they will now.

The sheer volume of interest in this report before its publication by committed professionals, advocates, people living with dementia, and carers has been beyond our wildest expectations. We hope this will kindle broader global interest in this hugely important discipline.

I leave you with a positive quote from the report:

> **"We often think and talk about dementia in terms of decline, impairment, and loss, but what if we focused instead on what people with dementia can still do? People with dementia can still learn new information and skills and adapt their activities if they have the right support as part of their rehabilitation plan."**
>
> *Linda Clare and Yun-Hee Jeon (page 43)*

Wherever you are, you can make a difference by raising awareness of all aspects related to dementia. We continue to be stronger when we are a united community. Spread the word.

London, September 2025

Executive summary

The dementia statistics at this stage are well known. Some 55 million people were estimated to have dementia across the world in 2019, a figure the World Health Organization (WHO) has predicted will rise to 139 million by 2050. The annual cost of dementia was estimated to stand at US $1.3 trillion in 2019, a figure set to more than double by 2030 to $2.8 trillion.[1]

Every three seconds, someone, somewhere, develops dementia. As our understanding of the condition progresses and diagnostic tools become more advanced, more people will receive a diagnosis at a much younger age than before, and in the earlier stages. Despite persistent misconceptions and erroneous beliefs,[2] the face of dementia is changing. We now know a lot can be done before and after a diagnosis to reduce the risk of developing dementia or slow down the progression of the condition.[3]

One post-diagnostic intervention that remains relatively unknown to the health and care community, as well as the wider public, is dementia rehabilitation. Misunderstandings remain regarding what rehabilitation means in the context of dementia, the ability of people living with dementia to engage successfully with the rehabilitative process, and whether it is worth investing time, effort, and resources into individuals with a condition that is currently incurable.

This report aims to illuminate the concept of dementia rehabilitation and, we hope, serve as a resource and roadmap for more individuals to adopt and adapt rehabilitation practices, regardless of their location.

> **"This report aims to illuminate the concept of dementia rehabilitation and, we hope, serve as a resource and roadmap for more individuals to adopt and adapt rehabilitation practices, regardless of their location."**

The report is divided into five parts. The introduction will define dementia rehabilitation, explaining why it is vital for people living with dementia, and issues around accessibility. Section 1 looks into the core components of rehabilitation, namely person-centred, goal-oriented, and collaborative approaches. Section 2 delves into strategies and methods to support the attainment of rehabilitation goals, providing practical techniques to implement a rehabilitation goal. Section 3 tackles the implementation of rehabilitation across various environmental settings and stages of dementia. Finally, Section 4 discusses system readiness for rehabilitation, taking a critical look at what can and should be done for rehabilitation to become a more mainstream part of post-diagnostic care for dementia in various contexts.

Each section is composed of an overview written by report authors Professors Linda Clare and Yun-Hee Jeon; expert essays from leading figures in the rehabilitation field, looking into major topics and themes related to each section; and case studies from people living with dementia, informal and formal carers, and advocates, looking at the practical applications of rehabilitation across the world.

In our ageing world, dementia is one of the most significant public health challenges of our time, and one that will only grow in importance in the years and decades to come. Rehabilitation is a proactive pathway to improve the quality of life of people living with dementia and their carers and mitigate the impact of the condition on health and social care systems. It is Alzheimer's Disease International's hope that this report will become key to raising awareness of rehabilitation and increasing its reach – and its implementation – as widely as possible.

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Recommendations

- **Rehabilitation should be embedded within national dementia plans (NDPs) – and implemented.** Encouragingly, 65% of current national dementia plans mention rehabilitation, but with 75% of World Health Organization (WHO) member states yet to develop national plans, ADI calls on all governments and stakeholders to recognise, embed, and implement rehabilitation into their strategic responses to dementia, in alignment with Action area 4 of the WHO's Global action plan on the public health response to dementia, namely 'diagnosis, treatment, care and support'.
- **Rehabilitation should be a right.** Dementia is recognised as a disability under the Convention on the Rights of Persons with Disabilities (CRPD), and rehabilitation is generally recognised as supportive care for disabilities. ADI calls on governments to fully embed rehabilitation for dementia in their policies and to start to report on progress at the annual Conference of State Parties (CoSP).
- **Rehabilitation should be embraced as part of 'precision care'**. Recent scientific innovations, such as blood-based biomarkers, have enabled the dementia community to focus more on precision medicine and personalised care. The new dialogue is around 'precision diagnosis', 'precision treatment', and 'precision risk reduction'. Now we need to ensure that rehabilitation is more consistently included as part of 'precision care' – personalised and focused on the needs of the individual.
- **Good rehabilitation is on a continuum.** While this report aims to paint a picture of the golden standard of rehabilitation care, there is a whole continuum of good practices that can be tailored to varying resource contexts. While specialised healthcare professionals can – and should – play an important role in supporting people living with dementia with their rehabilitation goals, this report provides many resources that people living with dementia, their doctors, families, friends, and other informal carers can use at little to no cost. This can be implemented when the general health and care workforce, as well as the public, are equipped with dementia rehabilitation literacy.
- **We need more implementation research and evaluation.** Rehabilitation is an emerging field of practice and, as such, there is a paucity of longitudinal data. What is needed is implementation research that evaluates the benefits of integrating rehabilitation for people with dementia into health systems in different contexts. We need to explore real-world practice – how rehabilitation can fit into a case management model of care that integrates the needs of the whole person, as opposed to a 'one-off', task-based model.
- **We need to measure economic impact**. Improving functionality through rehabilitation should extend independence, enabling people with dementia to remain in work, live at home, stay active in the community, and delay hospital and residential care admissions for as long as possible. Economic impact measurement and cost saving, including for carers is needed alongside further research to substantiate the argument for investment in rehabilitation as a cost-effective measure.
- **Quality of life and ageing well don't have to be a luxury.** We need to normalise rehabilitation and encourage governments to invest in healthcare systems that integrate rehabilitation as part of the regular care pathway. Healthcare professionals need to be trained and encouraged to discuss and undertake rehabilitation with dementia patients. Interventions need to be timely to make the greatest impact – we cannot wait until it's too late.
- **Carers should be actively involved in the rehabilitation process.** The benefits of rehabilitation are not just felt by the person living with dementia but also their carers, improving their own wellbeing and caregiving experience. Carers should be educated about the importance of rehabilitation, its principles, and the role they can play, and supported throughout the process as essential actors in the dementia journey.

Introduction

Pedro Azabache, then 92, was an Indigenist Peruvian painter, picture here in his studio in Trujillo, Peru in May 2010. (Photo courtesy of Alex Kornhuber)

Introduction

Linda Clare[1] and Yun-Hee Jeon[2]

[1] *University of Exeter Medical School, NIHR Policy Research Unit in Dementia and Neurodegeneration, University of Exeter, and NIHR Applied Research Collaboration South-West Peninsula, Exeter, UK*

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Rehabilitation improves everyday functioning, activity, and participation. What could possibly be more relevant for people with dementia? Over 55 million people live with the condition worldwide, and all of them experience challenges with functioning – one of the criteria for making a dementia diagnosis. Many people with dementia, especially in older age groups, also have other health conditions, physical challenges, or frailties that make it harder to stay active and participate in everyday life.

This means there is a vast potential for people living with dementia to benefit from rehabilitation and a vast need for access, even though the practice is largely underutilised, understudied, and misunderstood. This report seeks to shed light on what dementia rehabilitation is, how it can be put into practice, and why it deserves to gain further recognition as a person-centred method of precision care.

What is rehabilitation?

The World Health Organization describes rehabilitation and its role in healthcare as:

> *…address[ing] the impact of a health condition on a person's everyday life by optimising their functioning and reducing their experience of disability. Rehabilitation expands the focus of health beyond preventative and curative care to ensure people with a health condition can remain as independent as possible and participate in education, work and meaningful life roles. Anyone may need rehabilitation at some point in their lives, whether they have experienced an injury, disease, illness, or because their functioning has declined with age.*[1]

Rehabilitation aims to support functioning and reduce disability for individuals with health conditions or age-related frailty and other challenges in the context of their own environment, enabling them to:

- function as well as possible, given their capabilities and health
- be as independent as they can and wish to be
- have as much control as possible over daily life
- engage in meaningful roles and activities
- integrate the changes they are experiencing into a coherent and enduring sense of identity.

Why is rehabilitation important for people with dementia?

We often tend to think and talk about dementia mainly in terms of changes in cognitive or mental abilities. People diagnosed with Alzheimer's disease might talk about 'memory loss' or 'forgetfulness', and professionals refer to cognitive 'deficits' or 'impairments'. It is rare to hear dementia described in terms of changes to the things people do – skills, habits, everyday behaviours, and actions – but as cognitive abilities change, so does the ability to function.

Challenges to functioning can result from physical changes such as arthritis or loss of a limb. Challenges to functioning can also arise from changes in the brain that give rise to difficulties with memory, concentration, planning, problem-solving, communication, visual perception, or mobility, as is the case in dementia. Often, these two types of challenges occur together, particularly in older age. Such challenges to functioning require a holistic rehabilitative approach that considers all aspects of functioning – mental, social, physical, and environmental. Changes in functioning have both direct effects, like having difficulty doing everyday tasks, and indirect effects, such as loss of confidence or increased anxiety.

These changes in ability to function have a profound impact on a person's life. For example, they could mean:

- losing the ability to participate in meaningful activities, to experience reciprocity in relationships, and to feel part of a community
- difficulty looking after oneself or one's home, also known as self-care
- finding it harder to self-manage and recover from illness, falls, or after a hospital stay
- having to give up one's home and move into residential care.

It is not surprising that these functional changes are closely linked to reductions in wellbeing. Researchers grouped people living with dementia who were participating in the British IDEAL cohort study according to the extent of their challenges with functional ability. The study examined how individuals with varying degrees of functional difficulty rated their quality of life, satisfaction with life, and wellbeing. The greater the functional challenges experienced, the less positive people felt about themselves and their lives.[2]

This highlights the fundamental importance of functioning[3] and the urgent need for approaches that enable people with dementia to maintain or regain functional ability or adapt to altered functioning as dementia progresses:

> *…the message for policy makers, practitioners, families, and persons with dementia needs to be… a focus on maintaining function for as long as possible, regaining lost function when there is the potential to do so, and adapting to lost function that cannot be regained.* [4]

This is where rehabilitation comes in.

Rehabilitation for people experiencing challenges to functioning due to changes in the brain, whether or not this also addresses physical challenges, is sometimes called 'cognitive' rehabilitation, 'neuropsychological' rehabilitation, or 'neurorehabilitation', to distinguish it from rehabilitation for people with purely physical problems.

Cognitive rehabilitation is not the same as so-called cognition-oriented treatments, such as cognitive training or cognitive stimulation, that primarily aim to improve performance on cognitive tasks. Nor is it the same as cognitive behaviour therapy, which addresses unhelpful thinking patterns. This is how the UK National Institute for Health and Care Excellence defines cognitive rehabilitation for people with dementia:

> *Identifying functional goals that are relevant to the person living with dementia and working with them and their family members or carers to achieve these. The emphasis is on improving or maintaining functioning in everyday life, building on the person's strengths and finding ways to compensate for impairments, and supporting independence.*[5]

Rehabilitation, or cognitive rehabilitation, for people with dementia focuses on functioning. In this report, both 'rehabilitation', sometimes referred to as 'reablement', and 'cognitive rehabilitation' will be used to denote rehabilitation approaches designed to meet the needs of people with dementia.

With a progressive condition like dementia, rehabilitation is an ongoing journey starting from the earliest stages, as soon as the person is ready, and continuing as dementia progresses. There may be periods of active rehabilitation interspersed with periods where strategies and routines are working well, and only ongoing monitoring and review are needed. Periods of more

Dementia rehabilitation helps people to attain and maintain the best possible functioning in areas of life that are important to them, enabling them to remain as independent as possible and participate in meaningful life roles.

intensive input will be necessary at times of significant change in ability to function and at transition points, such as discharge from a hospital admission or a move to a new setting.

> **"In this report, both 'rehabilitation', sometimes referred to as 'reablement', and 'cognitive rehabilitation' will be used to denote rehabilitation approaches designed to meet the needs of people with dementia."**

We may not be able to halt or reverse the changes that dementia brings, but rehabilitation allows us to manage the effects of these changes, for example, through slowing down functional decline. Because many people living with dementia are living with other health conditions or age-related physical changes that also affect their functioning,[6] rehabilitation must address the impact of both cognitive and physical challenges in an integrated way. Understanding how to work with cognitive challenges is central to helping with physical challenges in a holistic rehabilitative approach. Sometimes people with dementia may require rehabilitation for physical problems, for example, after a hip fracture. In this situation, there can be an assumption that the person with dementia is 'unsuitable for rehabilitation' because of their cognitive impairment. This is inappropriate. Instead, it is incumbent upon us to find ways of offering rehabilitation for physical problems that are adapted to take into account cognitive difficulties.

What evidence do we have that rehabilitation benefits people with dementia?

Personalised, goal-oriented rehabilitation helps people to attain and maintain the best possible functioning in areas that are important to or for them. Evidence from research confirms that people with dementia benefit from rehabilitation. They function significantly better in the areas targeted in rehabilitation and make significant progress towards attaining their goals. This is evident in home-based cognitive rehabilitation[7] whether provided by an individual practitioner[8] or by an interdisciplinary team.[9] These benefits are still present several months after the rehabilitation sessions end. It is also evident where rehabilitation principles are translated into function-focused care for people at all stages of dementia living in nursing homes and long-term care facilities.[10]

Researchers studying the effects of interventions are usually limited to capturing the effects a few months or at most a year after the end of the intervention and have little opportunity to consider long-term benefits. One research study carried out in France[11] was an exception. The researchers tested the benefits of cognitive rehabilitation addressing functional goals over a two-year period. After two years, people who had engaged in individual cognitive rehabilitation had lower levels of disability than people who had received only usual care, and on average, they remained in their own homes for six months longer before moving into residential care. In contrast, more typical manualised group interventions – in this case either group cognitive training using standard tasks chosen for relevance to daily activities (such as doing calculations and counting money) or themed group reminiscence sessions – produced no long-term benefits, and results for people receiving those interventions were the same as for people who had only usual care. The researchers commented that:

> *…these findings challenge current management practices… While cognitive-oriented group interventions have gained popularity, this trial does not show improvement for the patients. The individualized cognitive rehabilitation intervention provided clinically significant results….*[11]

They recommended making individualised cognitive rehabilitation widely available to delay the need for long-term residential care.

How can people with dementia access rehabilitation?

For many people experiencing some forms of disability, rehabilitation is an established and accepted service they can access. Rehabilitation is effective across a range of physical conditions, such as hip fractures,[12] cardiac failure,[13] neurological conditions such as brain injury[14] and stroke,[15] and progressive neurological conditions such as multiple sclerosis[16] and Parkinson's.[17] Rehabilitation services are accepted as relevant for people with disability arising from these and other conditions, even if such services are not always available. Indeed, rehabilitation is considered a fundamental right for people with a disability. Countries that are signatories to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) agree to provide rehabilitation services for people with a disability to ensure they can attain and maintain the best possible level of independence, and of physical, mental, social, and vocational ability, and experience full inclusion and participation in all aspects of life.[18]

People with dementia, in contrast, rarely have access to rehabilitation, despite the evidence that they can benefit from it.

Often, people with dementia are explicitly excluded from rehabilitation. It is time to question the reasons why this occurs and to challenge this exclusion.

> **"Often, people with dementia are explicitly excluded from rehabilitation. It is time to question the reasons why this occurs and to challenge this exclusion."**

In this report, we will address this inequality. We will explore in detail what rehabilitation involves and gain inspiration from case studies shared by pioneers around the world. We will consider how rehabilitation can become part of routine service provision and practice for people with dementia, and how people with dementia and their families and supporters can adopt rehabilitation principles in their daily lives.

Why dementia rehabilitation is urgently needed: key messages

- Changes in the brain and thinking ability, often occurring alongside other physical changes, affect how people with dementia function in everyday life, what they can do and how much they can participate in their families and communities.
- Rehabilitation, also referred to as reablement, **focuses on optimising everyday functioning, activity and participation** – areas where everyone with dementia experiences challenges. Rehabilitation for people experiencing challenges to functioning due to changes in the brain is sometimes called 'cognitive rehabilitation' or 'neurorehabilitation'.
- Rehabilitation enables people with dementia to function better in the targeted areas. Long-term effects include **reduced disability and longer time spent at home before moving into residential care**.
- People with dementia rarely have access to rehabilitation services, despite evidence that they can benefit. This report considers how we can reduce this inequality.

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Section 1:

The core components of rehabilitation

Dinwaak Laar and Poasam Yakubu cook dinner at a camp in Gambaga, Northern Ghana. (Photo courtesy of Lee-Ann Olwage)

Section overview

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Rehabilitation is a collaborative journey, a partnership between the person, the practitioner or rehabilitation team, and others such as family members or care staff. It is about working together and making choices; 'doing with' rather than 'doing for' or 'doing to'. It is a practical demonstration of how to put person-centred principles into practice to support the person's everyday functioning in a fully personalised approach.

What is a personalised approach?

A personalised approach focuses on what matters to the individual. Some health professionals are trained to offer personalised therapies; for example, clinical psychologists, occupational therapists, speech and language therapists, and physiotherapists are used to working in this way, often on a one-to-one basis. However, manualised group interventions are more common in dementia care. These can be delivered by staff who have no, or only limited, professional training or qualifications, following a structured manual or handbook. They are relatively low-cost and allow participants to meet others who are having similar experiences, which is potentially valuable. However, they do not address what is important to the individual in that individual's own environment, so benefits may be more limited, and directing resources towards providing personalised rehabilitation could be more beneficial.[1]

In a personalised approach, the person and the practitioner know what they aim to achieve by working together and agree on a plan of action. In rehabilitation, these aims are called 'goals'. Goals reflect what matters to the person; rehabilitation practitioners do not impose their own ideas, expectations, or values. Identifying goals makes it possible to focus on practical solutions that support functioning in a way that is meaningful for the individual. These goals are at the heart of the plan of action, which is called a rehabilitation plan.

Components of a rehabilitation approach

The rehabilitation plan is based on a comprehensive understanding of the person's rehabilitation needs and provides a goal-oriented action plan for addressing these needs. The first core component of rehabilitation is a holistic assessment with detailed consideration of the person's cognitive and functional abilities and challenges. This leads to the second component: collaborative selection of rehabilitation goals and creation and implementation of the rehabilitation plan. The third component is monitoring and evaluation of progress, leading to reviewing and updating the rehabilitation plan as it evolves throughout the lifelong rehabilitation journey. Here, we will look in more detail at each of these components.

Component 1: Understanding the individual

Where changes in functioning result from changes in the brain and cognitive ability, it is important to understand these changes in cognition and how they relate to a person's behaviour and functioning when planning rehabilitation.

For a given dementia diagnosis, we know the general profile of changes in cognition and how these might affect behaviour. For example, we expect issues with memory, planning, and problem-solving in typical Alzheimer's disease, with language and communication in primary progressive aphasia, with visual and spatial perception in posterior cortical atrophy, with control of movement in Parkinson's or Lewy body dementias, and so on. However, we also know that every person with dementia is a unique individual. When embarking on a rehabilitation journey, we need to go beyond these general expectations to understand people as individuals, to map their profile of strengths and challenges in cognition and function, and to identify what they want and need to do.

The starting point for understanding the person as an individual is a comprehensive, holistic assessment that considers the person as a whole and not just the symptoms of dementia.

Susan Kurrle describes the process of comprehensive assessment on page 23. When planning rehabilitation for a person with dementia, the information gained in a comprehensive assessment needs to be augmented by a more detailed evaluation of cognitive and functional ability, considering:

- How changes in the brain are affecting the full range of cognitive functions, such as memory, language, visuospatial perception, planning, and so on; and

- How the person is functioning in everyday contexts and environments

Loren Mowszowski and Jacqueline Wesson discuss cognitive and functional assessment on page 26. Yun-Hee Jeon and Alexandra Rauch delve deeper into functional ability and functional independence on page 33.

Assessment could be carried out by one practitioner or by team members from different disciplines. If the latter, it should ideally be coordinated by one practitioner, who can draw together the results and discuss them with the person and, where relevant, family members or other supporters. Understanding the person's unique profile of strengths, needs, challenges, preferences, and any possible factors that could enhance or interfere with the ability to engage in rehabilitation is the starting point for rehabilitation planning and leads to the selection of rehabilitation goals.

With the support of family or friends, people with dementia may be able to evaluate their strengths and needs and identify what areas of functioning they want to focus on in a rehabilitative approach. Emily Ong discusses how she devised her own rehabilitative journey on page 37. She was inspired by becoming part of a group that codeveloped the My Life, My Goals resource.[2,3] This resource was designed to enable people living with dementia who do not have access to a practitioner to create their own rehabilitation plan and set and achieve their rehabilitation goals. The story of John Quinn and Glenys Petrie (page 39) teaches us about their determination and resilience to improve and maintain John's independence after his diagnosis in his 50s. John developed his own rehabilitation framework: "NAMES: Nutrition and hydration; Attitude, Acceptance and Art Therapy; Mental activities, Music and Meditation; Exercise, Enjoyment and Ecotherapy; and Social engagement, Support, Sleep and Setting goals". Glenys' journey as a care partner involved finding information through her research and self-education and making ongoing adaptations to life to enable John to live as independently as possible.

Component 2: Identifying goals and creating and implementing the personal rehabilitation plan

Rehabilitation goals form the core of the rehabilitation plan. Rehabilitation goals are designed to help maintain function and autonomy or to manage the effects of changes in function. The plan outlines the functional goals and how the person with dementia and the practitioner will collaborate to achieve them. For some people, the term 'goals' may not be familiar, and it may be more helpful to use familiar terms like 'things you want to do', 'things you would like to manage better', or 'things that matter to you'. Jackie Pool and Sue Evans describe the process of identifying goals and evaluating progress in cognitive rehabilitation on page 30.

There are several tools that practitioners can use to help with collaboratively setting goals, for example:

- The Pool Activity Level instrument,[4] discussed on page 31, can help practitioners ensure that goals are formulated and addressed in a way that is suitable for the person's level of functioning by matching the demands of the activity to the person's capabilities.

SMART goals for dementia rehabilitation are:

Specific
'I will walk to the newsagents every day to buy my daily paper'

Measurable
'I will remember the names of all 10 people in my bowls club'

Achievable
A goal to visit the library once a week might be unattainable if it is too far away

Relevant
Getting to know the person is essential to understand their priorities and what brings joy to their life

Time-Bound
Goals with a defined timeframe create a sense of purpose and accountability to achieve the goal

- The Canadian Occupational Performance Measure[5,6] can be used to identify problems in areas of self-care, leisure, and productivity and to formulate goals, allowing people to rate their own performance.
- The Bangor Goal-Setting Interview,[2,3] designed to aid goal-setting and evaluate progress in rehabilitation for people with dementia, offers a structured but flexible approach to exploring needs and identifying goals and defining levels of attainment, and provides an accessible way for people with dementia, carers, and practitioners to rate current goal-related performance. It is available in full and short versions.

It is challenging to tackle difficult activities, so experiencing success helps with keeping motivated. When choosing goals, it is vital to be realistic and make sure they are within the person's capability. Effective rehabilitation goals give a clear statement of what the person will do and when. That is, they describe a specific action or behaviour that can be observed and measured, and the time frame within which the action will be done successfully. The behaviour is within, or potentially within, the person's capability, and is relevant to the person's preferences and wishes. Rehabilitation goals are specific, measurable, achievable, relevant, and time-bound – in English, this gives the acronym SMART, which is a good way to remember these characteristics. Goals can reflect small, incremental changes, and major long-term goals can be broken down into shorter steps. Jackie Pool and Sue Evans go into more detail about SMART goals on page 30.

The personal rehabilitation plan outlines the person's goals, how these will be addressed, who will be involved in the process, and when and how the goals and overall plan will be reviewed and updated. The plan can take various forms but should be a collaborative record shared between the practitioner and the person with dementia, and with others involved where relevant, such as informal carers. The extent and complexity of the plan, the number of practitioners involved, and the level of coordination required will depend on the individual situation; the plan might cover one or a few goals or be more extensive.

Typically, SMART rehabilitation goals are addressed collaboratively through a series of tailored individual sessions with a rehabilitation practitioner. These sessions take place in the person's usual place of residence or in the everyday settings the person uses. This means that sessions are hands-on and directly relevant, giving the best potential for benefit. Family members, other supporters, or paid carers are involved in these sessions where possible. Evidence shows that this approach can enable people to function better, achieve their goals, and maintain these improvements for months or longer, even as dementia progresses.[1,7] In later sections, we will look in more detail at the methods and strategies used to address functional goals (see Section 2) and how these are applied in diverse contexts and settings (see Section 3).

Sometimes, existing evidence-based interventions may be used to support goal attainment or tackle barriers that hinder progress in rehabilitation.

> **"Collaborative goal setting means the person with dementia is provided with the information, opportunity, and support for shared decision-making."**

An example would be where the person with dementia is experiencing depression that interferes with engaging in activities and could benefit from a psychological therapy such as cognitive behaviour therapy. Another example would be where the person is at significant risk of falling and could benefit from an evidence-based falls prevention intervention. The World Health Organization has compiled a Package of Interventions for Rehabilitation (PIR) which includes a section on dementia.[8] This provides details of evidence-based interventions addressing various aspects of functioning. These are not in themselves rehabilitation, but they can be incorporated into the rehabilitation plan for specific purposes and complement, support or become part of the rehabilitation process. For example, rehabilitation addressing mobility goals may be complemented by participation in a group exercise programme. Where possible, the selection should reflect the person's preferences, for example, regarding group-based versus individual interventions. Yun-Hee Jeon and Alexandra Rauch discuss how discrete evidence-based interventions can form part of the personal rehabilitation plan and help to address rehabilitation goals on page 33. A different service or practitioner might provide these interventions, so good communication and coordination are essential.

The rehabilitation plan may include a focus on enabling the person to engage in activities that work well alongside the rehabilitation goals, providing enjoyment and promoting wellbeing as well as helping to maintain functioning. This might mean, for example, supporting the person to identify and join social activities in the local area, or to become more physically active, depending on the person's values, preferences, and goals.

As part of the rehabilitation plan, the practitioner provides relevant information and support to enable the person, family members, paid carers, and, if the work is being done in a residential setting, the care staff to understand and where necessary contribute to the rehabilitation process.

Collaborative goal setting means the person with dementia is provided with the information, opportunity, and support for shared decision-making. In shared or supported decision-making, the practitioner works with the person to identify and prioritise goals based on the information gathered through the holistic assessment as well as the interactions and observations that shed light on the person's values and preferences. Carers may offer information that helps with the process. Some people may be able to come up with their own goals, while others are less able to do so. In this instance, the practitioner does not prescribe a goal; rather they provide a range of areas or options that the person may consider as goal(s). In the end, the decision about the choice of goal is made by the person with dementia with the support and accessible information from the practitioner. Often depending on the person's capacity, the practitioner may need to provide varying levels of prompting, guidance, and support for that decision to occur. Nevertheless, it is the role of the practitioner to enable the person to experience a sense of agency and control over their decision.[9,10]

The personal rehabilitation plan covers:

- Current personal rehabilitation goals
- Details of any other evidence-based interventions indicated, if relevant
- Advice and support for engaging in activities that complement rehabilitation goals and promote wellbeing
- How members of the person's care and support network will be informed and involved
- Details of who is coordinating the plan, when, and how it will be reviewed and updated

Component 3: Evaluating progress and updating the rehabilitation plan

Rehabilitation is a personalised, goal-oriented approach that addresses a range of needs, depending on the person's preferences, strengths, and difficulties. It is essential to understand whether the approach taken is proving effective in enabling the person to attain the desired goals. The rehabilitation plan is flexible and can be adapted and adjusted as necessary. If something is not working well, it can and should be changed. Sometimes it can take several attempts before arriving at the best strategy to support goal attainment.

For each goal, we need to know whether the rehabilitation process has had the desired impact on the person's functional ability related to that goal. At a simple level, we can record whether the person did the activity and how often, or use a metric specific to the type of goal, such as distance walked unaided. To get a more comprehensive picture, tools used for goal-setting, such as the Canadian Occupational Performance Measure[5,6] and the Bangor Goal-Setting Interview (BGSI)[2,3], where individuals, carers and practitioners rate current performance, can be used to assess progress. Ratings can be made at any stage during and after a series of rehabilitation sessions. The BGSI full version also allows practitioners to rate the extent of goal attainment. Another way to evaluate progress is the GAS-light method based on goal attainment scaling.[11] In this approach, the practitioner rates progress on a five-point scale, where zero indicates the expected outcome:

- +2 much more than expected
- +1 more than expected
- 0 as expected
- -1 less than expected
- -2 much less than expected, or no change

These methods offer a uniform way of rating progress across all types of goals, which helps evaluate outcomes across a number of people or in the context of a rehabilitation programme or service.

Rehabilitation for someone with a long-term, progressive condition like dementia is an ongoing journey. It should start from the earliest stages of dementia, as soon as the person is ready, and evolve in line with changing needs and situations as the condition progresses.

> **"Rehabilitation for someone with a long-term, progressive condition like dementia is an ongoing journey. It should start from the earliest stages of dementia, as soon as the person is ready, and evolve in line with changing needs and situations as the condition progresses."**

Rehabilitation goals can change in the short term, sometimes suddenly, as the person's situation and needs change. A bout of ill health, a hospital admission, or a bereavement can result in significant changes and require revision of goals, and perhaps a stepping-up of rehabilitation support. On the other hand, an experience of successful goal attainment can prompt the selection of new, perhaps more ambitious goals or herald a period of less intensive support. The rehabilitation plan needs to be flexible and adaptable to allow for short-term changes. Rehabilitation goals are also likely to change considerably over time as dementia progresses. More intensive rehabilitation support might be needed at times of marked changes to functioning and at times of transition, such as moving home or moving into residential care. Towards the end of life, rehabilitation may give way to a more palliative approach, with goals focused primarily on comfort.

Rehabilitation is relevant for people with dementia from the point of diagnosis onwards. It can be a valuable part of support in the period following diagnosis, preparing people to manage life with the condition. It remains relevant through living with dementia at home and the possible eventual transition to residential care, where supporting optimal functioning is paramount.

Components of the rehabilitation approach: key messages

- Rehabilitation is a personalised approach in which the person and others involved, such as family members or care staff, work collaboratively with the practitioner or rehabilitation team to identify and attain functional goals that are important to the individual.
- The core components of rehabilitation are holistic assessment, collaborative selection of rehabilitation goals with supported decision-making, creation and implementation of the rehabilitation plan, and ongoing review and updating of the plan.
- Rehabilitation goals describe specific actions or behaviours that are within, or potentially within, the person's capability and the time frame in which the action will be done successfully. They are SMART: specific, measurable, achievable, relevant and time-bound.
- SMART rehabilitation goals are usually addressed collaboratively through a series of tailored individual sessions with a rehabilitation practitioner. Sometimes, existing evidence-based individual or group interventions are included in the rehabilitation plan, either to support goal attainment, to tackle barriers that hinder progress in rehabilitation, or to complement the rehabilitation process.
- Many people experiencing the earlier stages of dementia may be able to set their own rehabilitation goals and plan how to work on them with the support of family or friends.
- Rehabilitation is an ongoing journey, and the rehabilitation plan is reviewed and adapted as goals and needs change with the progression of dementia.

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Expert essays

Holistic and comprehensive assessment for rehabilitation

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A thorough and holistic assessment is very important for understanding the needs of a person with dementia and their informal carer in order to develop a rehabilitation plan with interventions that optimise function and independence and promote quality of life. The assessment needs to be broad and comprehensive and cover medical, daily activities, cognitive, psychological, and social domains.

Establish consent and understand the goals of the person with dementia

Before commencing the assessment process, it is important that the person with dementia gives consent to be involved. If they are unable to provide explicit consent, then assent should be gained with the person clearly being comfortable to undergo the assessment. If the person has a substitute decision maker, then they need to consent.

It is essential to understand what the person with dementia hopes to achieve with the rehabilitation process, as this can direct the assessment process. What is important to the person with dementia, and what do they want to achieve? Is the carer agreeing with these goals, and are they feasible? For example, wishing to return to driving after a loss of license is unlikely to be feasible. Improving mobility after a fall and fracture is very feasible. Improving speech in a person with progressive primary aphasia is possible with speech pathology input. These goals will inform how the assessment is carried out and what areas are examined. The rehabilitation plan is then developed, taking into consideration both the person's goals and their abilities.

Use a multidisciplinary approach

The person with dementia may have a number of different symptoms and signs depending on the type and stage of dementia, so the assessment must take a multidisciplinary approach. This can involve geriatricians or rehabilitation medicine physicians, nurses, physiotherapists, occupational therapists, speech pathologists, social workers, and psychologists. For example, a person with a type of frontotemporal dementia may have major issues with communication but otherwise function relatively independently. A speech pathologist can assist with improving communication, and an occupational therapist would be able to establish the level of functional independence. A person with vascular dementia may have a number of neurological impairments affecting mobility and balance and a physiotherapist is well placed to assess mobility, standing and moving balance, and risk of falls.

Tools to help determine the stage and severity of dementia

Staging dementia requires the use of different tools. For example, the Mini-Mental State Examination (MMSE)[1] or the Montreal Cognitive Assessment (MoCA)[2] are often used to provide information on the level of cognitive impairment, but need to take into account the person's first language and their level of education, as a degree of literacy is important for completion of these. Functional ability can be assessed using scales such as the Functional Independence Measure (although this requires specialised training and credentialling)[3] or the Barthel Index.[4]

Information from the family and carer is very important, and the use of tools such as the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)[5] provides valuable information on the changes in a person's function over the previous ten years as reported by a family member or carer. The Global Deterioration Scale[6] is a tool used to describe the clinical stage of a dementia. It has seven stages, from Level 1 (no cognitive decline) to Level 7 (very advanced dementia). Each stage has clearly described clinical characteristics. Some of the tools have been translated and validated in various languages, and equivalent tools in the national language or a person's first language can be considered.

Be aware of cognitive fluctuations

Cognition and function can fluctuate significantly during the day, with late afternoon and evening being times when cognitive functions can deteriorate significantly. Cognitive function may also vary from day to day depending on the presence of illness, or changes in the person's routine or activities. These fluctuations need to be considered when planning the timing of interventions and activities. Finding the right time is important, and most often this is in the morning.

Review and manage changed behaviours

Approximately 90% of people with dementia will experience some behaviours and psychological symptoms of dementia, also referred to as neuropsychiatric symptoms, during the course of their illness.[7] If anxiety or agitation are prominent, people with dementia may have problems cooperating with rehabilitation strategies, and a simplified approach may need to be taken. Hallucinations and delusions can interfere significantly with interventions and often require medication if they are distressing. Depression can often be treated with psychological intervention with or without medication, allowing people with dementia to participate in rehabilitation. Apathy is one of the hardest symptoms to manage as the person loses their initiative, and it is very hard to generate motivation to cooperate with treatment strategies. It is important to understand the triggers of symptoms like aggression and resistance to care, and clearly communicate to avoid them. For instance, if a female resident with dementia refuses male care workers' assistance with showering and screams when they try, only female staff should be rostered to provide care, ensuring successful rehabilitation efforts for personal care. Addressing undiagnosed pain or discomfort can also help enable the person to engage in rehabilitation.

Assess the environment and safety with activities of daily living

It is important to understand the living arrangements of the person with dementia and their carer. Living in a familiar environment is very important, and any change in environment, such as moving to a different house or into a residential care setting, is likely to cause a change in function and the emergence of changed behaviours. Checking for hazards and addressing safety issues is a simple way to reduce risk and allow a person to stay longer in their own home.

Assessing basic and instrumental activities in daily living is key to planning for the future. Understanding the capabilities of the person is as important as recording the difficulties, and being able to note the changes over time allows an estimate of future function. Assessing ability and safety to use household appliances is important, and ensuring the use of automatic off switches for stoves and irons can greatly reduce risk. Making sure that stairs have a clearly marked edge and a railing will reduce the risk of falls. Good lighting and removing cords, loose rugs, and carpets are also simple ways to improve home safety.

Ensure optimisation of the management of medical conditions

People with dementia who are older often have a number of other diseases. Hypertension, heart disease, frailty, stroke, diabetes, lung disease, renal disease, osteoporosis, and joint and muscle disease are all common. Optimal management of these will improve function and reduce the presence of pain and discomfort. It is important to review medication, both prescribed and over the counter, and consider deprescribing those medications that may be having unwanted side effects, such as muscle pain, incontinence, or constipation.

Understand social and cultural considerations

If the local majority language is a second language for the person with dementia, they may gradually lose the ability to understand and speak that language and revert to their first language, which is not understood by those providing care. Use of interpreters or family is important to ensure the person with dementia understands what is being asked of them in terms of therapy. Cultural issues are important when considering how therapy is delivered. In some cultures, receiving care from a person of the opposite sex may be unacceptable, for example.

Remember the physical comorbidities of dementia

There are a number of conditions that occur more commonly in people with dementia than in those of the same age without dementia. These include epilepsy, delirium, falls, oral disease, malnutrition, frailty, incontinence, sleep dysfunction, and visual problems. It is important to look for these in people with dementia as they are often ignored, and to consider them in rehabilitation planning. Importantly, the likelihood of falling and sustaining an injurious fall is two to three times more common in dementia. Seizures are up to seven times more common in dementia. Frailty and dementia are interlinked, with physical frailty predicting the development of dementia, and people with dementia becoming frail more often than those without dementia. Visual problems such as poor visuospatial perception and loss of contrast sensitivity are often undetected but can greatly impact day-to-day function and the ability to be involved in rehabilitation. Urinary and faecal incontinence can greatly restrict daily activities, including being able to participate in rehabilitation or be involved in social activities. Sleep disruptions can greatly increase the challenge of caregiving and need to be asked about and addressed.

Examples

1. Betty is 88 years old, previously fit and mobile, with moderate dementia. She falls and sustains a hip fracture. She has surgical fixation, and mobilisation is attempted on the first post-operative day. She has a type of delirium, is drowsy, confused and slow to respond and is unable to cooperate with the physiotherapist. She requires assistance for all her meals despite previously being independent. Her delirium persists for two weeks, and she is not considered appropriate for inpatient rehabilitation. She returns to her nursing home and is initially cared for in a chair with transfers by a mobile lifter. She is assessed by the visiting geriatrician and physiotherapist who work with her to develop a simple graduated mobilisation plan. Although she is initially resistant to the approach, she is keen to be able to walk again. As a result, she is able to stand in a frame and march on the spot. Rehabilitation is only delivered in the morning, as she is agitated and resistant to any intervention in the afternoon. Her family assists staff on weekends and provides encouragement and repetition with the exercises. Over the following three months, she gradually improves with transfers and walking short distances in a forearm support frame, but remains withdrawn and slow to respond. Five months after her fall and fracture, she appears to have "woken up" from her delirium and independently gets out of her chair and takes several steps. With regular physiotherapy input, she improves her mobility and is able to mobilise inside the facility without a frame. She is also able to eat independently again.
2. Mary is 66 years old with young-onset dementia. She lives at home with her husband and ongoing support with personal care and housekeeping from a community support package. During the comprehensive assessment, the visiting nurse learns that she loved outings for fish and chips, and coffee and cake, but her worsening urinary incontinence restricted her ability to leave the house. Assessment by the occupational therapist around appropriate clothing, and by the continence nurse adviser about the best continence aids, allowed Mary to return to the daily outings and social activities that gave her so much joy and satisfaction, and helped her husband, who is a main carer.

In summary, for the best results from rehabilitation, it is critical to have an assessment that is very broad and covers the person's medical conditions, memory and thinking, day-to-day function, social situation, and environment. It is also important that the carer is involved in the assessment and that the person and carer work together with the clinician to develop a rehabilitation plan that addresses their goals.

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Assessing cognitive and functional abilities

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Neuropsychological assessments help to understand a person's cognitive strengths and weaknesses, and highlight concerns, challenges, or safety risks in daily life to guide the goals or process of rehabilitation. However, results are most useful in combination with real-world information about how effectively the person is able to carry out purposeful tasks in their usual environment. Functional assessments look at a broad range of real-world tasks, including meaningful activities and routines. These assessment types provide different information and therefore work well together to comprehensively inform rehabilitation planning. Here, we discuss both types of assessment.

Neuropsychological assessments

Neuropsychological assessments examine cognition (thinking skills) to understand how the brain is working (see Box 1)**.** They help medical teams understand changes in brain function to assist with diagnosis – for example, whether memory problems are due to normal ageing processes, or whether they reflect an underlying condition such as dementia. Results are also useful for understanding how our thinking skills translate to everyday abilities, which is very important for planning and carrying out rehabilitation.

Clinicians use paper-and-pencil or computer tasks involving answering questions, remembering words or pictures, drawings, and puzzles, to understand cognitive abilities. They also ask questions about health, mood, sleep, medications, drugs, diet, environment, social contact, support, earlier life experiences (e.g., learning difficulties, trauma, etc.), education, work, and hobbies. Usually, they will ask to speak with someone who knows the person well (e.g., family or care partner) to understand things from another perspective. Clinicians interpret the test scores in the context of all this information to understand the person's cognitive strengths and weaknesses, and how this impacts their functioning. Comprehensive assessments take around 3–4 hours (with breaks), ideally completed by specialised psychologists. Other trained clinicians (e.g., doctors, nurses or occupational therapists) may complete screening tests (e.g., 10–15 minutes) for a broad snapshot of cognition. Clinicians must consider a person's level of alertness and engagement, motivation, and their language and/or cultural background, to ensure that the tests and interpretation of results are appropriate, and the assessment is useful and valid.

> **"Clinicians must consider a person's level of alertness and engagement, motivation, and their language and/or cultural background, to ensure that the tests and interpretation of results are appropriate, and the assessment is useful and valid."**

Box 1. Neuropsychology assessments typically examine:

- **Memory**: How we absorb and remember information.
- **Information processing**: How quickly we take in and respond to information from the world around us; how well we concentrate; and our 'working memory' (holding information 'in the moment' – e.g., remembering a telephone number while dialling).
- **Language**: How we communicate using words to express our ideas and understand others.
- **Visuospatial skills**: Processing and understanding colour, shape, position, depth, distance, faces, etc.
- **Executive functions**: Higher-level thinking skills (e.g., planning, organisation, problem-solving, decision-making, initiating tasks, identifying and regulating emotions, social behaviours, etc.) and coordination of other thinking skills (e.g., memory, attention). Executive functions allow us to perform our everyday tasks effectively and efficiently.

Box 2 gives an idea of what to expect when undergoing this kind of assessment.

Box 2. What should a person know before having a neuropsychological assessment?

- The appointment may take longer than other health appointments.
- The assessment requires a lot of concentration and may be tiring.
- Usually, there are some breaks to use the bathroom or have a snack.
- Some people may feel like they are back at school or may find some tests confronting as they involve skills that may be challenging (e.g., memory tests)
- Try not to worry about getting all the answers 'right'. The clinician looks at the overall *pattern* of strengths and weaknesses across the assessment to understand how the brain is functioning.

Cognitive assessments are important for rehabilitation planning, as the process allows clinicians to understand a person's day-to-day experiences (e.g., tasks they find difficult, or skills that have deteriorated) and activities that are important/meaningful to them. This can be used as a starting point to guide collaborative goal setting in rehabilitation. Test results and assessment insights also allow clinicians to tailor rehabilitation techniques to play to the person's strengths whilst addressing their weaknesses, and to suit their needs and preferences. For example:

- Peter is an 80-year-old man with Alzheimer's disease. His neuropsychological assessment showed a characteristic pattern of difficulties with memory, language, and visuospatial skills. One of his rehabilitation goals was to become more independent in remembering to take his medications. A closer look at Peter's test results showed that his memory was slightly stronger for visual information compared to remembering words. His clinician introduced compensatory memory strategies involving visual resources rather than verbal information to utilise this strength.
- Mei is a 76-year-old woman in the early stages of vascular dementia. Her daughter noticed that she has become quieter during conversations and less interested in socialising. A cognitive screening test showed that she has some difficulty finding words to express herself, but her speech and comprehension work well. Mei explained that she feels embarrassed when she can't think of words and prefers to listen these days. Her clinician used this information to explore setting a goal around feeling more confident with her conversational skills, to help Mei get back to enjoying social interactions.

During cognitive assessments and rehabilitation, it is important to understand and address how factors such as fatigue, pain, or sensory limitations (e.g., poor vision, hearing loss) may impact thinking and behaviour. This may require discussions with other health professionals involved in the person's care (e.g., reviewing medications that might be affecting sleep, or exploring causes of pain), or may inform the selection of appropriate rehabilitation strategies. Further, detailed information about the role of neuropsychology in rehabilitation can be found in a recent clinical guidance paper.[2]

Functional assessment

Functional assessments help clinicians **understand how cognitive impairment affects daily life**.[3] They focus on people's routines and roles, including basic personal care tasks like eating, bathing, toileting and dressing, and **more complex** tasks such as managing medication, using technology like phones and computers, managing finances, shopping, and preparing meals. Complex everyday activities are more sensitive to change and decline first,[4] so assessments often focus on these skills, and can be in-depth. For example, if assessing money management, all aspects might be included, such as developing a budget, taking money out of the bank, paying bills on time, using cash and calculating change, as well as planning for the future. Basic activities, like bathing and toileting, remain intact for longer, but still may be assessed, depending on the severity of symptoms and reason for the assessment.

Occupational therapists (or nurses/ other healthcare clinicians) skilled in understanding cognitive disorders complete functional assessment, offering a 'top-down' view by observing people doing everyday activities such as those mentioned above. They consider the interaction between three elements of functioning: the person (cognitive abilities), the task or occupation (what is being done), and the environment (where it is done).[5]

Functional cognition – combining thinking/ memory with functioning – is key to understanding 'the person'.[1] For example, asking someone to make lunch shows how thinking influences their actions. Clinicians assess how cognitive skills are utilised, identify any gaps that limit task performance, and determine which skills remain intact (see Box 3). Functional assessments are usually done in the home, as this is where people need to function. Environments significantly influence performance, either helping or hindering what people can do.[6] Familiar home environments usually support functioning. Clinicians also assess what the person is able to pay attention to within that environment.[7] For example, information that is not 'concrete' or visibly obvious (such as abstract ideas like social rules, or time of day) can be difficult to notice and respond to for people living with dementia. Activity analysis is central to 'functional cognitive' assessment.[8] Clinicians closely observe whether problems are caused by poor cognitive skills rather than physical issues.

For example, someone may not 'remember' what was said due to hearing loss (physical problem – i.e., they did not hear it), not memory failure (cognitive problem). Understanding this interaction helps guide the most appropriate rehabilitation strategies, such as providing hearing aids.

Clinicians look for performance patterns, identifying similar mistakes across activities. Understanding which functional tasks are difficult is important because even 'simple' tasks, like dressing, can feel complex for people with more severe cognitive impairment. Matching abilities with task requirements (or steps within a task) and using intact skills to inform goal setting is part of rehabilitation[9]. It helps to work out the type and level/amount of help that is needed, aiming for continued engagement in chosen activities and roles. Providing the 'just right' support promotes participation and independence.

> **"Activity analysis is central to 'functional cognitive' assessment. Clinicians closely observe whether problems are caused by poor cognitive skills rather than physical issues."**

Functional assessments also consider behavioural changes (such as possible emotional reactions when tasks exceed ability)[10] and how people manage other coexisting health conditions (e.g. arthritis increasing fall risk), including whether they have the cognitive ability to adapt to these physical problems. Clinicians assess whether the task itself or the environment (or both) might need changing. Understanding the practical impact of functional cognitive impairment guides rehabilitation (e.g. in the example, visuospatial impairments mean step edges are hard to see, and environmental adjustment by putting coloured tape on step edges reduces fall risk; see Section 2 for more detail). Sometimes specialised functional assessments are needed, such as occupational therapy driving evaluations, or assessments of specific roles, such as childcare or work. These depend on the type of dementia, age, life-stage and context of the person.

Finally, assessment results inform family members (carers) and care workers, providing information about what people can do, not just what they can't do. Tailored cognitive support might involve giving less, but more effective help (e.g., verbal prompting rather than taking over and doing the task for them).[11] When functional assessment results are considered alongside carers' understanding of dementia and their communication skills, participation in meeting rehabilitation goals of people with dementia can be optimised.

Box 3. What does 'functional cognitive assessment' consider?

Clinicians identify which part of an activity causes problems so they can advise when and what type of help is needed. They assess quality and safety by looking for missing steps, ineffective performance, or inconsistencies. For example, when cooking, there could be difficulty with[1]:

- Planning the 'task setup' – not checking supplies or gathering ingredients effectively
- Starting (initiating) the task – needing someone to tell them to start
- Leaving out or adding extra steps or items – such as not turning on a stove or where steps are in the wrong order
- Items not being used properly – e.g., using the wrong utensil to chop vegetables, causing a safety risk
- Monitoring task progression – steps are not checked for completion before moving to the next step (e.g., is the food cooked properly before serving?)
- Noticing and/or correcting mistakes during the task to 'fix' problems, showing poor problem-solving skills – e.g., leaving the stove on while retrieving more ingredients, leading to burnt food
- Completely disregarding or forgetting the goal of the task (i.e., making lunch)

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Goal setting, goal attainment, and evaluating progress

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Identifying needs and formulating goals with the person with dementia is central to a rehabilitation process. This ensures that the cognitive rehabilitation plan is personalised and meaningful to the individual. Having a specific therapy goal provides a positive focus for the person, their care supporters and the rehabilitation practitioner.

Goal setting

Goals can be anything that the person wishes to do. This could be a functional activity, such as using a mobile phone or finding the way to the shops, or an intellectual activity, such as remembering the names of friends and family or being able to recall the storyline when reading a book or watching a television programme. Some functional and intellectual activities might be done alone, and others might involve social interaction. Goals can involve either or both.

The cognitive rehabilitation practitioner needs to be aware of the relationship between the person with dementia and those supporting them to ensure that the selected goal is one that the person has chosen and not one that only the carer wishes them to be able to achieve. The practitioner must also ensure that the person with dementia has the capacity to understand the goal and to consent to working towards achieving it. People who are following a self-help programme can consider the difficulties that they are having that are caused by their dementia and decide which of these are the most important to them.

Whether working with a practitioner or independently, it is important to consider what support is available from family and friends, whether the activity is safe to practice, how the timing of the activity will fit with the person's lifestyle and whether the person's general health condition will allow them to participate in their chosen activity. Chosen goals should have the features captured by the acronym SMART:

- **Specific**. By clearly defining the goal and avoiding vague language, the person with dementia can better focus on what they are aiming to achieve, and it will be easier to identify the rehabilitation strategies that will make this possible. An example of a specific cognitive rehabilitation goal is: 'I will walk to the newsagents every day to buy my daily paper'. This is more specific than the similar but vague 'To get my newspaper'.
- **Measurable**. Measurement can involve the frequency or the quantity of the desired activity. For example, a measurable goal focusing on quantity might be 'I will remember the names of all 10 people at my bowls club', while a measurable goal that focuses on frequency might state 'I will visit my bowls club twice a week'.
- **Achievable**. The goal must be realistic and attainable, considering available resources and capabilities. For someone wanting to obtain books to read, a goal to visit the library once a week might be unattainable if it is too far away and there is no public transport, so another means of obtaining books would have to be found. This example illustrates how important it is that the rehabilitation practitioner or care supporter is knowledgeable about local resources. To be achievable, whilst some challenge is good, the goal needs to be within the reach of the person and allow for any health difficulties and the degree of effort required.
- **Relevant**. It is important that the person finds a goal that really matters. Getting to know the person is essential to understanding their priorities and what brings joy to their life, and will help guide the discussion. This focus is also crucial if the person is following a self-help rehabilitation plan. Oftentimes, people focus on practical chores that they feel are necessary or have a duty to perform. However, at least initially, while learning rehabilitation strategies, fun and enjoyment will keep the person motivated to succeed.
- **Time-bound**. Goals with a defined time frame create a sense of urgency and accountability to achieve the goal. The time frame also provides an understanding of the commitment needed from all involved and ensures that those supporting the person are available. Having a time-bound goal provides focus to help the person make a start without unnecessary delay.

> **"Larger goals can be broken down into smaller components, using a graded activity approach. This enables the person with dementia to easily recognise and celebrate progress."**

This SMART goal approach ensures that the intervention is measurable to allow for evidence of effectiveness. It also means that larger goals can be broken down into smaller components, using a graded activity approach. This enables the person with dementia to easily recognise and celebrate progress, which is motivating. The grading of goal activity also supports the practitioner in their clinical reasoning about which cognitive rehabilitation strategy and approach to use. When stating goals, it is important not to specify the rehabilitation techniques and strategies that will be used when working towards the goal. These might change as the performance and progress are reviewed during the cognitive rehabilitation process.

Tools that the cognitive rehabilitation practitioner can use to guide the person in their goal selection include the Pool Activity Level Instrument (PAL),[1] Canadian Occupational Performance Measure (COPM),[2] Bangor Goal-Setting Interview (BGSI) full or short versions[3,4] and Goal Attainment Scaling (GAS-light).[5] These are all evidence-based tools for supporting people with dementia to identify and prioritise everyday issues that restrict their participation in everyday living, including self-care, leisure, and productivity.

The PAL assessment[1] allows the practitioner to understand the person's level of functional ability and what this means in terms of everyday activities and support needs. For example, a person at the 'planned' level will be able to engage in complex activities requiring planning and decision-making, while a person whose ability is at the 'exploratory' level will need support to start activities and carry them out, but can engage in practical and hands-on activities. At the 'planned' level, a person could likely achieve an intellectual goal that focuses on the use of memory and recall, such as 'I will be able to call my grandchildren by name when they visit'. At the 'exploratory' level, a person would be more likely to be successful in an activity-focused goal that utilises procedural memory for the actions involved. An example for someone who has recently moved into a care home would be 'Every morning I will find my way from my room to the dining room for breakfast'.

Developing the personal cognitive rehabilitation plan

The plan provides the structure for the cognitive rehabilitation programme. It should indicate whether there is anyone available to support the person in practising the strategies between rehabilitation sessions with the practitioner. It is helpful to build pacing and rest time into the plan to guide the person and their care – so that the person does not become exhausted. The plan will identify the strategies that will be used to achieve the collaboratively developed goals. In addition, the plan will consider the needs of any carers involved and identify coping strategies for them. It should also state where the person could put their new learning into practice and signpost them and any carers to other services.

My Life, My Goals[6] is a practical self-help guide co-developed by people living with dementia and researchers to help people in the early stages of dementia identify their own goals and strategies. The step-by-step digital guide, available for download onto a computer, tablet, or phone – or to print at home – offers an individualised approach in which a care partner may be able to help develop practical strategies for rehabilitation and support problem-solving.

The cognitive rehabilitation practitioner will select the most appropriate techniques to support the person achieve their specific goal in line with their current abilities and levels of support. Many goals will reflect one of these four aims:

- To relearn lost information
- To learn new information
- To relearn a lost skill
- To learn a new skill

If the person is at an early stage of dementia, they should be able to cope with any of these four types of goals. If they are learning or relearning information, mnemonics might be used, and the actual wordplay will be selected by the individual so that it is meaningful and therefore memorable, with guidance and encouragement from the practitioner. One person wanted to remember to take important items with him when he left the house and chose the acronym '**BMW**' as a prompt to remember to pick up his **B**us pass, **M**obile phone and **W**allet. This was particularly meaningful as he previously drove this make of car. A person at a moderate stage of dementia would more likely be successful in this action if the memory is established through movement. Work on this goal could involve choosing a special container in a specific place to hold these important items, and using repeated practice, known as expanding rehearsal, to collect the items from there when going out and replace them when returning home.

Evaluating performance and progress

Throughout the cognitive rehabilitation process, the practitioner will review the person's performance and progress to ensure that the strategies and techniques are effective and adapt them as needed. Repeating the ratings made before starting work on the goal, using one of the tools described earlier, will identify how the person's performance has changed since the initial assessment. If using the BGSI full version[4], the initial goal specification includes identification of what would indicate 25%, 50%, and 75%, as well as full goal attainment. This helps to quantify progress even if the goal is not fully attained. In addition, the practitioner might use other measures or data to explore broader issues such as general functional ability, wellbeing, distressed behaviour, falls, or medication use.

Measuring the outcome of work on the SMART goal provides an indicator of the impact of the cognitive rehabilitation programme on the person living with dementia. Evaluations that use both baseline and outcome measurement can also investigate the impact on the service and on the service providers in terms of use of the service or job satisfaction of practitioners and support workers.

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Functioning, rehabilitation, and the role of non-pharmacological interventions

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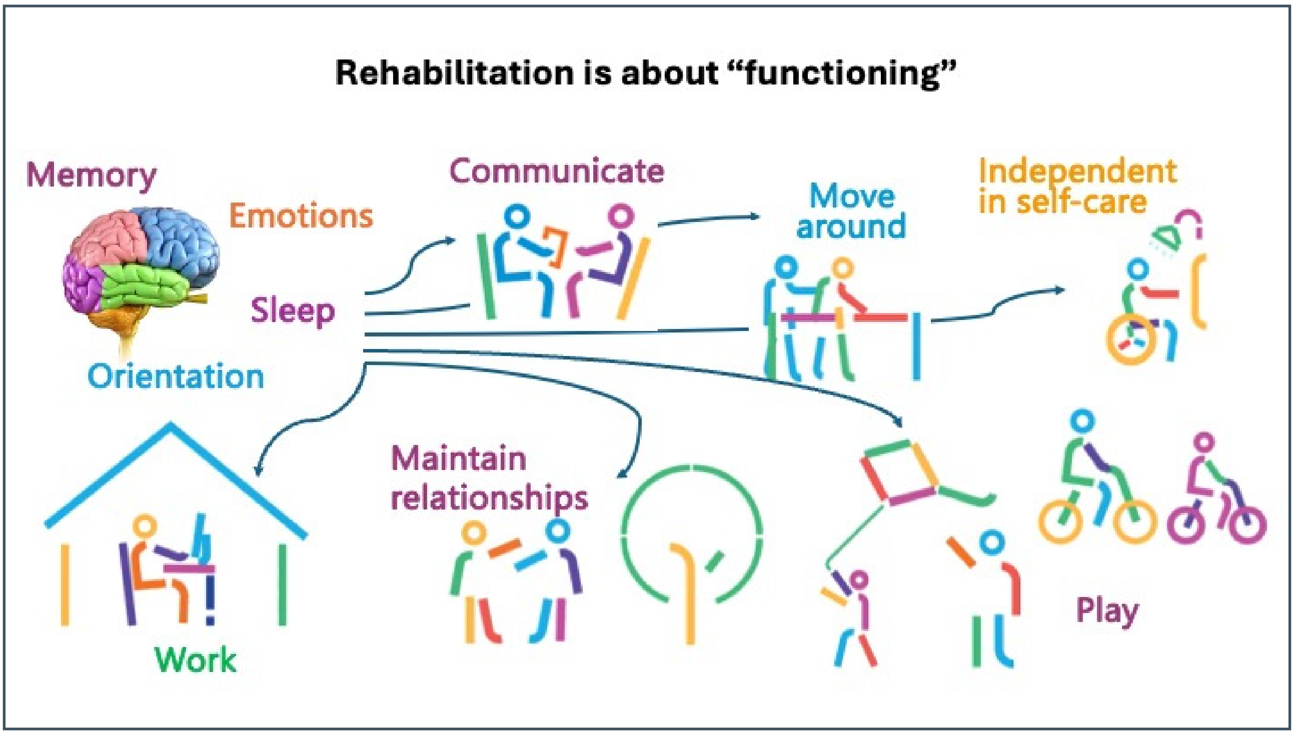
"As many as one in three people globally experience a health condition over the course of their life that would benefit from rehabilitation."[1] Dementia is no exception; research in the past 50 years has shown that rehabilitation can improve and maintain functioning among people living with dementia.

What do we mean by independent functioning?

Functioning encompasses various domains of body functions, and every individual experiences both good capacity and problems in different domains throughout their lifespan. Dementia is long-term and progressive, inevitably affecting the person's functioning and independence in the early stages of the condition. How the person living with dementia experiences decline in day-to-day life can vary depending on their intrinsic capacity (e.g., genetic, biological, physical, mental, personal) and extrinsic factors (e.g., physical, social, financial, resource/service environment). We also know that while functional decline is inevitable, the rate of decline differs markedly between individuals with dementia, for example, by type of dementia,[2] coexisting health conditions,[3] cognitive reserve (brain resilience associated with education, lifestyle and occupation),[4] and genetic factors.[5] Rehabilitation intervenes or disrupts such progression in dementia. Without any timely rehabilitative intervention, it is likely that there will be a rapid decline in functioning in the course of illness.[6]

Functioning involves body structures and functions, performance of activities and participation in life roles and community, as shown in Figure 1. A holistic understanding of the person is therefore essential to rehabilitation in dementia care. Independence in performing activities and participating in meaningful life roles, such as work or social relationships. However, independence in performing activities and participating in meaningful life roles, such as work or social relationships, is often narrowly associated with physical

Figure 1. Examples of functioning



functions or mobility alone, or sometimes misconstrued as requiring complete functioning across all domains of function (e.g., physical, mental, cognitive). For example, see Mr. Smith's case in Box 1. below.

Box 1. Mr. Smith

Mr. John Smith is 68 years old and was diagnosed with early-stage Alzheimer's disease six months ago. While he is still undertaking his volunteer work at a local church providing clerical support, his wife has been concerned that soon he will no longer be able to continue the role as she has noticed further decline in his memory and decision-making in the last two months. He gets easily irritated by others and shows bouts of low mood throughout the week, and is gradually moving away from his social gatherings. He is still able to help with gardening and house chores, and enjoys joining his local bush walking group and cooking meals with his wife.

Here, Mr. Smith's mental and cognitive functions have somewhat declined, but are not completely lost; his sensory, voice, speech, neuromusculoskeletal, and movement functions are largely intact. His ability to perform daily activities and to participate in meaningful life roles in general is largely unaffected. He also has family and social environments that can be tapped into as sources of support and resources when needed. All these aspects can be used as strengths while addressing the challenges associated with limited cognitive and mental functions in the rehabilitation process.

Evidence of improving the functional independence of people living with dementia

Despite the medical scepticism and hopelessness that have been prevailing in the way dementia is understood and talked about in our society, research has consistently shown that personalised or individually tailored care approaches and non-pharmacological interventions can improve and/or maintain independent functioning of people living with dementia. In his review of evidence, albeit mostly based on small-scale research experiments conducted more than 25 years ago, Woods[7] discussed a wide range of potentially effective non-pharmacological interventions designed to improve the independent functioning of people with dementia across care settings. The interventions targeted various care areas, including training and supporting self-care skills (e.g., bathing, dressing, grooming, managing money), mobility (e.g., using aids, less assistance in walking or transferring), orientation, and participation in activities, as well as providing supportive physical, social, and interpersonal environments. These interventions often combined the use of environmental modifications and memory aids, as well as positive rewards and prompting.[7]

> **"Despite the medical scepticism and hopelessness that have been prevailing in the way dementia is understood and talked about in our society, research has consistently shown that personalised or individually tailored care approaches and non-pharmacological interventions can improve and/or maintain independent functioning of people living with dementia."**

Fast-forwarding the clock 25 years, we observe that these interventions, or elements of them, are incorporated into rehabilitation programmes and recommended in dementia clinical guidelines.[8] Notable multicomponent rehabilitation programmes, summarised below, have shown promising results in terms of improving and maintaining functional independence among people with mild to moderate dementia (Box 2). Common elements of these programmes include individualised planning based on comprehensive assessments, personalised goals and approaches tailored to the person's needs and preferences, addressing multiple domains of function when appropriate, and taking environmental factors into consideration.

Box 2. Evidence on multicomponent rehabilitation programmes

At home

- Care of People with Dementia in Their Environments (COPE),[9] (USA)
- Community Occupational Therapy in Dementia (COTiD)[10] (Netherlands)
- Goal-oriented cognitive rehabilitation (GREAT CR)[11] (UK)
- Interdisciplinary Home-based Reablement Programme (I-HARP)[6] (Australia)

In nursing homes

- Function-Focused Care (FFC-CI)[12] (USA)

In the past 50 years, research on general (often standalone) non-pharmacological interventions has substantially increased to address various domains of functioning in the care of people living with dementia. Notable areas of focus include addressing behaviours by reducing neuropsychiatric symptoms that impede daily life and cause distress to the person and carers (e.g., agitation, aggression, depression, and wandering) and other functions such as cognitive, mental, physical, daily and relational functioning, with an aim to enhance functioning in life roles and daily and community activities, and ideally quality of life. With varying degrees of effectiveness, beneficial interventions include physical activity, cognitive training, cognitive stimulation therapy, reminiscence therapy, sensory interventions, art therapies, and carer communication skills training, to name a few.

The WHO mhGAP[13] that generally targets primary care settings recommends physical activity, with physical exercise delivered 3–4 times per week for 30–45 minutes for more than 12 weeks, cognitive behavioural therapy (CBT), cognitive stimulation therapy, and cognitive training for people living with dementia as means to improve aspects of function. Evidence for those interventions suggests that they are usually offered in a manualised way, and not necessarily on the basis of personalised goals and plans – see Chapters 11–15 in the World Alzheimer Report 2022.[14] Those interventions may be considered as part of the personalised rehabilitation plan, if the person's goals are likely to be attained by involving them as strategies. However, offering them to everyone in a standardised way does not align with the principles of rehabilitation. Other leisure and pleasurable activities of the person's choice are also important considerations. Box 3 suggests how evidence-based non-pharmacological interventions can be incorporated into the rehabilitation plan.

Box 3. Mr Smith in rehabilitation

In the case of Mr Smith, he is already experiencing increasing difficulties in his day-to-day functioning, and without rehabilitation, the challenges are likely to become more extensive or complex. Timely and appropriate rehabilitation can help him and his wife to figure out how to adapt their environment, compensate, or develop new strategies. Based on a comprehensive assessment of his clinical history, daily activities, mobility, psychosocial and environmental aspects, a rehabilitation team (occupational therapist, nurse, psychologist) can work with him and his wife to develop a set of goals that he wishes to work on and devise a rehabilitation plan including strategies he could use.

For example, the core of the plan includes personalised strategies to support his everyday situations, strength and balance exercises to help his continued bush walking, an assistive device that prompts/reminds him of his activities to support his volunteer work, which can also boost his confidence. There is also scope to draw on evidence-based interventions such as CBT for his depression.

WHO Package of Interventions for Rehabilitation (PIR) for Dementia

The *Package of Interventions for Rehabilitation* (PIR) for dementia[15] outlines the most essential interventions for people with dementia relevant at all care levels (including more specialised rehabilitation programmes), drawn from a review of high-quality clinical guidelines combined with global expert consultations. The PIR has been developed to strengthen the integration of rehabilitation into health systems, and thus, targets primarily ministries of health in the planning and budgeting of interventions for rehabilitation to be included in health systems. However, it is also a useful resource to support the implementation of rehabilitation at the care level, including the strengthening of the rehabilitation workforce and rehabilitation research in all resource contexts.[8] The PIR provides a frame of reference and lists evidence-based interventions to address specific aspects of functioning, for example, mental or cognitive functions (e.g., cognitive stimulation therapy, cognitive training, reminiscence therapy), problems with behaviours (e.g., person-tailored activities), speech, language, and communication (e.g., communication skills training), motor functions and mobility (e.g., strength and balance exercises), exercise and fitness (e.g., aerobic exercises), and interpersonal relationships (psychosocial interventions), as well as cognitive rehabilitation to support functioning in everyday activities.

Notably, every intervention in the PIR is preceded by the individual assessment of the target function (e.g., assessment of communication for communication skills training), and the stage of dementia is noted for each intervention. Furthermore, the PIR specifies the required essential material resources (e.g., treatment table, exercise mat, weights, resistance bands, and resistive exercise putty for muscle strengthening exercise) and suggests a list of occupations to deliver these interventions (e.g., nursing professional, occupational therapist, and physiotherapist for ADL training), which however is not exhaustive and not meant to be prescriptive. The PIR also includes interventions for informal carers (friends, family, close network) who are often playing an important role as partners in rehabilitative care. This also acknowledges the need to address the impact of carer health and wellbeing on the recipient of their care, the person with dementia, and vice versa. Whilst the PIR addresses key areas of functioning with evidence-driven interventions, the next step of work is needed to determine how best to use these interventions alongside individual rehabilitation approaches and incorporate them into rehabilitation plans, where relevant, to support goal attainment.

Conclusion

Rehabilitation is about improving and maintaining day-to-day functioning, not necessarily about restoring it to the exact level experienced before an illness. Functioning is multifaceted, hence the need for personalisation, tailored to the individual's needs, strengths, limitations, and preferences in all rehabilitative care. The very first step in rehabilitative care is therefore understanding the person through comprehensive assessments of body functions, activities and participation (often through a life story approach), and the impact of their environment. Individuals' functional abilities are not static, instead moving back and forth along their lifespan continuum, resulting from dynamic exchanges between intrinsic and extrinsic capacities. Rehabilitation in dementia care is about optimising functional ability (strength-focused), creating enabling environments and treating the person with dignity and respect for their preferences and choices, while addressing impairments and disabilities through appropriate strategies, care and support. Non-pharmacological interventions could be a valuable addition when used as a means of supporting attainment of personalised goals in the rehabilitation plan based on individual assessments.

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Case studies

Rehabilitation offers us hope in the absence of a cure

Emily Ong

Advocate living with cognitive decline, Singapore

When I was diagnosed with cognitive impairment in 2017 due to an initial diagnosis of Fatal Familial Insomnia (FFI), a type of prion disease, my world fell apart. I was advised to stop cooking, and my family was advised to consider having a live-in maid to care for me. It is like saying: "We have no faith in your ability, and you must be put into full protection." I thought my life was over!

It cannot be denied that a diagnosis is hard to accept, but nothing can be as devastating as being told: "There is nothing that we can do for you. There is no cure for dementia." Such a mentality only perpetuates fear and helplessness. While a cure for dementia is yet to be discovered, it does not mean that nothing can be done to minimise the impact of cognitive impairment on my overall health. I believe with appropriate treatment and management, I can lead a fulfilling life, even if it is progressive dementia in the case of FFI.

Eureka moment: seeing it as an acquired disability

As a person who spent her life supporting young learners with autism and learning disabilities, I am aware that early and timely intervention, strength-based SMART personalised learning goals, and a supportive environment are enablers in helping them become independent individuals and realise their full potential. Despite my familiarity, I did not see the changes in my cognitive functioning abilities as an acquired disability until I came across goal-oriented cognitive rehabilitation for early-stage Alzheimer's and related dementias.[1]

Reframing cognitive changes as an acquired disability helps me see the light at the end of the tunnel and offers a sense of hope in life again. It helps me to regain control of the situation because there are measures you can take to compensate for the impairment to the body functions and structure,[2] just like a wheelchair to a person with mobility issues. The person with the wheelchair can still move around independently, instead of being confined to a place and restricted from participation. Having that mindset paradigm shift changes how I think about what is possible in achieving and maintaining optimal levels of functioning and independence, and continuing to live my life meaningfully and purposefully as long as possible.

The journey to self-empowerment

Even though I had no access to an occupational therapist trained in cognitive rehabilitation, I used my work experience on strength-based SMART personalised learning goals and tested them over three months. The first two goals I worked on were cooking with minimal error and better management of noise sensitivity. These two goals mattered because I wanted to continue cooking confidently and enjoy going out. I know I can still cook delicious food, but my sequencing ability is slightly impaired, which makes it harder for me to execute the task successfully. Furthermore, my noise sensitivity makes everyday background noise, such as people talking and TV volume, irritating and makes it difficult for me to stay focused on a given task.

Once I understood what was causing me to make mistakes in my cooking, I implemented strategies to reduce the impact of sequencing difficulty and noise sensitivity to ensure that I could continue to cook with a higher probability of success and enjoyment. I gave myself more time for food preparation, roughly two hours to prepare a dinner for three people consisting of two dishes and rice. Ingredients that need to be marinated will be done separately in the morning, after they are defrosted. This is to minimise forgetting or being over-seasoned when in a rush. A clutter-free kitchen countertop and quiet environment are necessities, not nice-to-haves, to maintain my focus and enable me to see what ingredients need to be prepared. To prepare food safely, I always have the chopping board in the middle, the ingredients on the right, and a drainer tray on the left, by the sink, where I put the knife each time after use. The conscious effort of bringing the knife from the right to the left saved me from making an emergency visit to my doctor due to knife-handling accidents. The prepared ingredients, including cooking condiments, are arranged in the order I use them in the cooking.

It takes repeated practice to strengthen new procedural memory, making it less effortful over time, so I can enjoy what I am doing. Other than doing my groceries on weekdays and going to shopping malls and eateries at non-peak hours, I use noise-cancelling headphones to manage my noise sensitivity. However, it is not a practical solution because it defeats the purpose of going out if I cannot listen to what others are saying to me. I want to normalise living with noise sensitivity, in which the impairment would not limit what I can do and restrict my social participation. A year and a half ago, I accidentally discovered that playing repetitive instrumental music in the background with my headphones helps me manage my noise sensitivity in public spaces. I can stay focused better and am hardly overwhelmed by most environmental noise. With unwanted noise filtered out by the background music, I can enjoy conversations better and not feel restricted by the places I can go. However, I have not successfully found another instrumental music piece that works so well.

It takes more effort and time to learn, but it isn't impossible

A breakthrough I made with rehabilitation is not cooking, but relearning to do Microsoft PowerPoint slides and learning to make cashless payments. I cannot remember when I started to lose my confidence and ability to do slides, and had to depend on my daughter during my initial years of advocacy. I struggled to pinpoint the key points I wanted to convey and to navigate the features of each tab. It was full of frustration and repeated disappointments, leading to more self-doubt and fear of doing the slides. As my advocacy work increased, I knew I had to face my fear and start learning from scratch. To minimise overwhelming myself and reduce errors in learning, I focused on the basic tabs needed to create a slide as a starter. I used a mix of learning approaches, such as show-and-tell, making notes, and incremental learning. To help myself with identifying the key points, I would scribble all my thoughts in the Simplenote app. I revisit the notes, and sometimes I can see the pattern and identify the key points, but other times it takes repeated revisits. Sometimes a discussion with my daughter helps me to have a clearer picture of what I want to put on the slides.

Early on, I started having issues with handling money. I struggle to count and add different notes and coins to make payments. I also fear being short-changed when coming to bigger notes like $50 because I find it hard to count my change. Therefore, when Singapore started to promote cashless payments with options including digital wallets like GrabPay and PayLah!, mobile payment apps, and contactless cards, without using physical cash, it worked to my advantage. I gave myself a few months to learn the concept and another few months of guided practice with my daughter in making cashless payments in real time. Initially, I found it confusing, but over time, I started to appreciate the stress it takes away from handling physical money. Of course, learning is much more effortful and does not mean that, once learned, I will be able to perform it successfully each time. Every month, my daughter helps me withdraw $300 from my bank account in smaller notes, such as $2, $5, and $10. This way, I have the confidence to make payments where there is no contactless payment option.

Conclusion

The value of rehabilitation in improving my quality of life, health outcomes, and wellbeing is priceless. Rehabilitation has helped me maintain a positive self-belief and confidence in adapting to cognitive decline instead of fearing it.

I also learned that it is possible to learn new things, though it requires a lot of work and time. It is perfectly fine when we fail to execute a learned task consistently. The main thing is we must not be disheartened by the outcomes of the intervention or what others think of our capacity. We need to have a mindset shift and adopt a broader acceptance of the benefits and values of rehabilitation to the lives of those living with dementia, from clinicians, therapists, researchers, family members, to the state. Rehabilitation offers us hope when a cure is yet to happen.

> **"Rehabilitation has helped me maintain a positive self-belief and confidence in adapting to cognitive decline instead of fearing it."**

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Dementia rehabilitation involves 'thinking outside of the box'

John Quinn and Glenys Petrie

A person living with dementia and a carer, Brisbane, Australia

John – confusing and uncertain times

Fifteen years ago, at the age of 59, I was diagnosed with Alzheimer's disease. Difficulty performing everyday tasks forced me to leave my position as a school principal in 2008. It took two years before I received a correct diagnosis from a neurologist who reflected on both the diagnostic assessments to date and my family history. He felt that a significant factor in the lateness of my referral to him was, firstly, my age of 51 when initial symptoms surfaced; and secondly, that because I had continued running numerous half-marathons and City to Surf fun runs with mates, I didn't fit the typical stereotype of a person living with dementia. My primary symptoms included issues with executive function, processing, and communication. My neurologist later also diagnosed me with the sensory challenges of dementia, particularly affecting my vision, hearing, and touch. He explained, for example, that although there was nothing wrong with my eyesight, my brain wasn't processing the information when tired.

Whilst the neurologist's diagnosis gave me a sense of relief that I had at last been diagnosed appropriately and prescribed galantamine, during this time, I became depressed. I kept up with few, if any, positive lifestyle choices, because regardless of any diagnosis, I realised that I couldn't continue to work in the career I'd always enjoyed. Glenys, my care partner, noticed that I had become disengaged from life, spending years staring at four walls and only participating in my regular exercise. I didn't want others to remember me the way I recalled my dear mum, who had dementia in her 50s, dressed in her nightie, being taken home from the nearby shopping centre by the police. However, throughout this period of depression and apathy, I always knew that I had Glenys' unconditional love and support.

We were able to use our backgrounds in education and our mindsets of wellbeing, focused on my passions (exercise and cooking) and our skills (education-based activities) to incorporate these wellbeing principles into my life, whilst acknowledging my constantly evolving symptoms. Glenys' support and advocacy for her parents, who had dementia, no doubt helped us in this transition, as she became my advocate too.

Glenys – the turning point, and care partner perspective

At the time of John's diagnosis, care for someone diagnosed with dementia was viewed predominantly through a biomedical, deficit-based lens where the care was focused ostensibly on the pathology of the disease, with the expectation that the gradual decline of a person's physiological and cognitive functions would inevitably lead to a diminution of a person's quality of life, then complete dependency, and ultimately to death. As people can imagine, this care pathway provided NO HOPE for John. There were certainly no conversations between the specialist, the GP, or John and me about adopting rehabilitation interventions to help John continue what he had always enjoyed doing: physical activity and educating young people. Even then, I tried to include some fun educational activities and increased connections with family and friends, hoping to make John feel more positive and hopefully slow the progression.

Fortunately, there was a significant turning point in John's attitude about his diagnosis when we attended a Dementia Australia event in 2014. The national president of their board spent a great deal of time talking to John about his interests and finding out about who he was as a person. The positive and encouraging language he received that night had a profound effect on John's attitude to the possibility of having a good quality of life – particularly the board president's words: 'I really do believe that you can live well'.

That's when I got John back. I saw a spark and determination in him that had been missing for years. He had some hope again. I decided to do all that I could to support him. I honestly believe that if that event hadn't occurred, John's disengagement would have continued, and he would have been in full-time residential care within a few years. Neither of us had anything to lose.

John – the beginning of my rehabilitation journey

In hindsight, that evening was the catalyst for me to recommit to working with Glenys on strategies for maintaining my current strengths and improving and maintaining my independence. These strategies focused on me as a person – connecting with others, participating in things that I found meaningful, having autonomy, and maintaining wellness through a healthy diet. I did not want to be just another statistic. We were hopeful that these approaches would slow down the progression of my condition and thereby delay the need to go, or prevent me from going, into full-time care. I undertook my own research about what I needed to introduce, with the result being my NAMES: **N**utrition and hydration; **A**ttitude, **A**cceptance, and **A**rt therapy; **M**ental activities, **M**usic, and **M**editation; **E**xercise, **E**njoyment, and **E**cotherapy; and **S**ocial engagement, **S**upport, **S**leep, and **S**etting goals. We were both aware that the goals would need to be reviewed and reset as my dementia symptoms evolved, and that it was imperative to continue to work as a team to support each other. Since 2016, my neurologist has said on numerous occasions that he believes that because of my approach to my lifestyle, the trajectory of my condition has not advanced at the rate that he initially envisioned. He encourages me to continue with this positive focus and attributes the slow progression of my dementia to the 'across-the-board strategies' designed to optimise physical, cognitive, social, and healthy functioning, rather than only addressing one aspect.

Glenys – dementia closed many doors, but it opened many others that we couldn't have envisaged

A complexity was that neither of us knew of anyone else diagnosed under 65. I contacted Dementia Australia and learnt of others living with younger-onset dementia (YOD). Throughout this learning process and John's newly found vigour and energy, we continued to make adjustments, like including Wheelchair Assist when travelling. Strategies were developed and evolved through discussions with fellow advocates, specifically allied health practitioners, and John's neurologist, to ensure a safe and relaxed journey (see Box 1).

John – my goals and strategies for driving, biking, and cooking

After the diagnosis, I was not prepared to forego my driving licence. Glenys was concerned about my safety when I was independently out and about in the neighbourhood. Therefore, we together brainstormed and developed a range of strategies, starting with an occupational therapist's complex assessment for an off-road test involving perception and thinking skills, followed by a drive with a driving school instructor, whilst she observed from the backseat. While this assessment incurred a cost and was not an ongoing form of support, the peace of mind this gave us justified any costs. Because I could still drive with restrictions, Glenys asked whether I'd consider buying a bicycle as well. I had never owned a bike before, so I took advantage of the Council's free, supervised, six-week group cycling initiative, where I learned about changing a tyre as well as cycling. During those next two years, I would cycle to my mate's place for a lift to the nearby pool for water running and my two-kilometre swims. I also cycled to different friends' homes for tea and to my weekly Spanish lessons. I'd begun these because Glenys and I were planning to trek across the top of Spain. For someone living with dementia, riding a bike is definitely a cognitive challenge, but it was an ideal transition to maintain my independence.

Box 1. Key learning and strategies to help rehabilitation goals

- Allied health professionals have specific and relevant knowledge that leads to further learning for people living with dementia and carers. This includes information about assistive technology.
- The day of travel is just that, the day we travel. Nothing else matters.
- Often, we'd have a practice run the day before our travel, such as finding and catching the airport bus in London and then returning to the city. These trips weren't initially planned, but John would become more confused and concerned the longer we were away from home.
- We'd always arrive at our destination days before the conference so that John could recover from the flight. The following three to four weeks after travel were low key with nothing planned. Rest periods happened throughout travel and continued once home.
- We accessed the few airport "quiet rooms" that exist. Dementia conferences also have them.
- Confusion can occur at any time of day due to cognitive overload. When we can, we access cafés according to enabling environmental principles to minimise stimuli.
- We've agreed that, whenever possible, we need to be in the same room to speak to each other and look at each other's faces, to ensure that I can see whether he's heard me or is confused. I often use shorter sentences or rephrase – too much detail confuses John.
- I always gain John's attention by saying his name at the beginning of a new discussion and often ask if I can turn the TV or radio down or off to avoid extraneous stimuli.
- If John goes out, for example, when I'm at an appointment, he writes into a book where he has gone, the purpose, and the duration of his outing. Currently, John's still able to go out independently and doesn't have wayfinding or directional issues. Therefore, I encourage his independence and autonomy.

Dementia Australia learnt about our story and organised a fundraising challenge of 562 km through Vietnam/Cambodia to raise awareness and funds for YOD. This experience not only made me feel valued but also provided an opportunity for me to share my experience of living with dementia, thereby reframing my role as an educator. I saw it as a form of cognitive rehabilitation, and whilst training for the fundraiser, I attended a physiotherapist's clinic weekly for core strength and cross-training of all muscle groups. I continue eleven years later because during those years I also ran the Great Wall of China half-marathon, climbed, and went on many treks. The physiotherapist introduced specific activities that engage more concentration to assist cognition.

Glenys has continued to engage occupational therapists. For example, I had major issues with our gas stove, so we now have an induction stovetop. To support my interest in cooking, as I couldn't follow recipes and process information, the occupational therapist rewrote recipes to integrate the ingredients with the method. We now have modifications to both our bathroom and kitchen, including dementia-enabling environmental principles personalised to my symptoms, and assistive technology.

Conclusion

By incorporating John's NAMES into his, and therefore our, lives, we recognise the benefits to his wellbeing and happiness, as well as heart and brain health. Balance is vital: exercise, sufficient sleep, good diet, plenty of water to minimise UTIs, social activities, Zoom meetings and so on, noting that John has more difficulty when he doesn't get this balance correct. Everything has a cumulative effect on his cognitive tiredness. But John believes that the alternative pathway back in 2010 would have had a very different outcome. We consciously plan and review real-life, meaningful goals for John to maintain his autonomy and independence. Together, we decide on strategies and adapt accordingly to enrich our lives.

Although driven by my determination to do everything that I possibly could to assist John and help him to realise he had a purpose, I believe that my level of health literacy led me to combine what I knew and how I could find out more. Not everyone has the passion, determination, or literacy that I was able to layer over the top of us as a couple with a good relationship and respect for the importance of people living with dementia and their care partners not sitting back and accepting the expected trajectory of the condition.

Section 2:

Strategies and methods to support the attainment of rehabilitation goals

A "Body Dynamics" class at the Mission district YMCA, created and taught by Atlantic Fellow for Equity in Brain Health, Rowena Richie, in San Francisco, California, USA in December 2019. (Photo courtesy of Alex Kornhuber)

Section overview

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In this section, we look in more detail at the strategies and methods that support attainment of rehabilitation goals across a range of needs and across the stages of dementia.

Focusing on what people can still do

We often think and talk about dementia in terms of decline, impairment, and loss, but what if we focused instead on what people with dementia can still do? People with dementia can still learn new information and skills, and adapt their activities if they have the right support as part of their rehabilitation plan.[1]

Let's take the example of memory. Memory problems are central to the experience of many people with dementia. Yet as one person with dementia commented: *'It's not a complete disaster'*. Research tells us that memory is not a single entity, but consists of various systems and processes that draw on activity in different parts of the brain. For a person with dementia-related memory difficulties, some of these systems and processes are badly affected, but others are more preserved. Memory for recent events is usually more affected than memory for facts or memory of skills and habits ('procedural' memory). This means we can harness those better-preserved aspects of memory to support the person's functioning.

Similarly, we can think of memory as a series of stages, involving taking information in, processing it and storing it in the brain, and retrieving the information again when we need to use it. The ability to take in information in the first place is usually more affected than the ability to store and retrieve it. This suggests that it would be worthwhile targeting extra support to ensure the information is taken in or encoded, as it is then more likely to be remembered. Research on how people learn suggests some approaches that might be helpful. For example, we know that rehearsing or practising newly acquired information is more effective if it is spaced out in time, and students revising for an exam do better if they test themselves on the material at gradually increasing intervals. These kinds of insights translate into practical rehabilitation strategies to enable people with dementia to attain their personal goals.

Strategies for goal attainment

Because rehabilitation goals are personal goals that matter to the individual, the practitioner does not define the goals to be worked on. The practitioner does, however, make sure the goal is expressed in SMART terms – specific, measurable, achievable, relevant and time-bound – and plays a key role in developing the action plan for addressing the goal (see Box 1).[2]

Box 1. Planning how to address rehabilitation goals: questions to ask

- What are the motivations underlying the selection of this goal?
- What difficulties are interfering with being able to do the activity?
- Could the activity be simplified?
- Which strategies would be helpful for addressing the goal?
- How might the practitioner apply these strategies with the person directly?
- Can a carer be involved, if available?
- What other issues might need to be addressed to support goal attainment?
- What support can the person's wider network provide?

The same goal could be selected by two people for very different reasons, with different underlying motivations, and the challenges that interfere with the activity and make it difficult to achieve could also be different. For example, a goal of being able to make and receive calls using a mobile phone could be chosen by the person with dementia to increase independence, confidence, or social contact, to promote safety, or to reassure the carer. Challenges could include never having used a mobile phone before, forgetting to charge the phone or to take it when going out, or being afraid of making a mistake. The practitioner needs to understand the motivations for selecting the goal, why it is important, and what the challenges are. The practitioner also needs to analyse the task to understand what is involved in using the phone in the desired way, where problems are arising, and whether the activity can be simplified. In this case, there could be an option to choose a simple mobile phone designed for older people or people with a disability rather than a typical smartphone. The practitioner also needs to consider what support is available from a carer or others in the person's network.

All this means there is no standard prescription for how to address a given goal and no standard set of strategies. It requires creativity, flexibility, and a problem-solving approach. As one practitioner commented after the experience of providing cognitive rehabilitation: *'That it allowed creativity in my work… was brilliant.'*[3] The practitioner can, however, draw on an established range of evidence-based strategies and combine these in a way that suits the person's capabilities and preferences and supports attainment of the goal.[4] These strategies are relevant for many kinds of goals, and in this section, we explore how they can be applied to address goals in various domains. These include everyday activities, discussed by Sue Evans and Jackie Pool (page 51), communication, discussed by Emily Rogalski and Angela Roberts (page 53), visual and spatial perception, discussed by Nathalie Bier and Aida Suarez-Gonzalez (page 57), and mobility, discussed by Katherine Lawler (page 60).

The strategies can be broadly grouped into three categories: enhanced learning strategies, compensatory strategies, and environmental adaptation. We briefly summarise these here.

Enhanced learning strategies

Rehabilitation goals often involve learning or relearning information or skills, as Jackie Pool and Sue Evans explained in the previous section. Enhanced learning strategies can be internal (involving mental processing) or action-based (involving learning by doing). Sometimes, these are called 'restorative' strategies. Usually, enhanced learning or restorative strategies will be the first port of call when considering how to address a goal.

General principles include keeping strategies as simple as possible and making use of effortful processing, multiple modality processing and dual cognitive support:

- Effortful processing means getting the person as actively involved as possible; for example, rather than giving the person a list of steps required to complete an activity, the practitioner will encourage the person to generate the list.
- Using multiple modalities means processing information through as many channels as possible; for example, when learning a new action, the practitioner may want the person to observe it, hear a description, say it themselves, write it down, and perform it.
- Dual cognitive support means ensuring that, in addition to supporting learning the information or action, there is also support for recalling or using it when needed, for example, by providing prompts and cues.

Examples of internal strategies that can be helpful include expanding rehearsal (sometimes called spaced retrieval), mnemonics and semantic elaboration:

- Expanding rehearsal builds on research about how we best learn. The target information is stated, and the practitioner asks the person to recall it several times at gradually increasing intervals. The first might be very short, even as little as 30 seconds, and the interval would then be doubled each time until recall is well established. This can be introduced as 'say it before you forget'.
- Mnemonics can help with planning, organising and remembering; in the previous section, Jackie Pool and Sue Evans described how the mnemonic BMW reminded one person with dementia to take his bus pass, mobile phone and wallet when leaving the house (page 30). Linking a person's name with a key feature of their appearance can help with recalling the name.
- Semantic elaboration means linking new information to something that is already familiar; for example, when meeting a new acquaintance, focusing on details like the person having the same name as your brother, or working in the same profession, makes retrieving the person's name more likely.

Action learning strategies include modelling, shaping, backwards chaining, prompting, and expanding rehearsal:

- Modelling means demonstrating the activity so the person can emulate it. This can be explained as 'do what I do'.
- Shaping means gradually working towards the target action or skill. For example, when teaching a person with dementia to relearn how to feed herself using a spoon, the necessary actions were taught starting with a large scoop and scooping first beads, then rice, then sand, and then liquids, and gradually reducing the size of the scoop.[5]
- Backwards chaining means breaking the activity down into a series of steps and teaching each step in sequence, starting with the final step and working backwards. Sue Evans and Jackie Pool describe the use of backwards chaining on page 51. This is motivating because the final step completes the activity and provides an experience of success.
- Prompting means giving prompts at each step to help establish the target actions and ensure successful execution; the prompts can be gradually reduced and ultimately withdrawn.

- Expanding rehearsal means practising the action or behaviour at gradually increasing intervals. This can be explained as 'do it before you forget'.

These strategies help to keep errors to a minimum during learning. While avoiding errors is not essential for goal attainment in the case of people with dementia,[6] it ensures the experience is largely one of success. This makes the process more enjoyable and maintains motivation. Loren Mowszowski discusses the ways in which judicious selection of strategies can support motivation and engagement in rehabilitation (page 63).

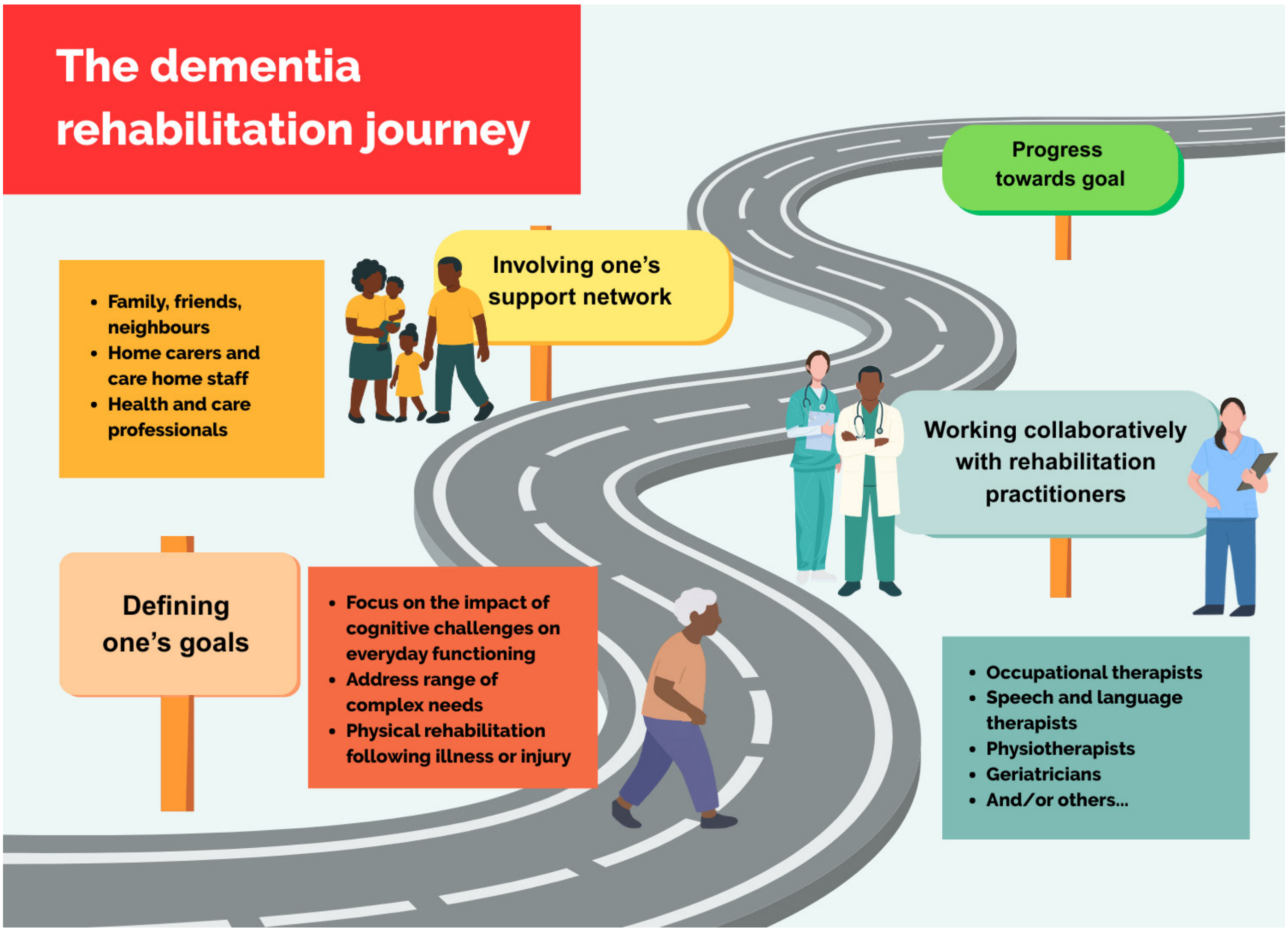
Compensatory strategies

Compensatory strategies provide external support that takes over some of the cognitive demands of an activity and makes it easier to accomplish. We are all familiar with this principle as part of everyday life; for example, we rely on calendars and 'to-do' lists to help us get things done or be in the right place at the right time. For people with dementia, goal-oriented work involving compensatory strategies might mean introducing a new strategy or adapting the use of an existing strategy to make it more effective.

Compensatory strategies often involve the use of external aids, but can also take the form of planned responses for specific situations. Compensatory strategies should always be considered in relation to the person's goals; simply providing a compensatory aid will not suffice. The goal provides the rationale for using the strategy, and achieving the goal provides an experience of success and reinforces the application of the strategy. Whatever form the strategy takes, it is highly probable that the person with dementia will need support to engage with and use it; we cannot assume that this will happen automatically. In some cases, enhanced learning methods may be applied to support the adoption of a compensatory aid or strategy. Developing a consistent routine for using the aid or strategy, so that it becomes a habit, is important. If the strategy involves an external aid or device, ensuring it is easily accessible and visible is essential.

Using compensatory strategies to address functional goals may involve using commercially available products or devices, external aids specifically developed for the individual, or plans for coping with specific situations:

- Commercially available products often used to support goal attainment include low-tech items and more complex assistive technologies. Examples of the former are diaries, calendars, whiteboards, adapted cutlery, or adapted clothing. Some simplification may be needed; a diary with unstructured pages might be replaced with one that lists times of day when entering appointments correctly is difficult, or a week-to-view diary might be replaced with one that has a full page for each


The dementia rehabilitation journey

day where handwriting is harder to control. Examples of more complex assistive technologies are smartphones or voice-activated virtual assistants. In some cases, simplified versions can be obtained. We will look in more detail at assistive technology in the next section.

- Bespoke external aids include things like memory wallets, memory books, photograph albums, and life story books to support engagement in conversation. In one example, screens placed in the living room and bedroom showing the time of day and messages about planned activities and activities appropriate to the time of day helped reduce distress and improve orientation.[7]
- Coping strategies for situations known to be difficult can be pre-planned and used when needed. For example, a person who found it challenging to receive and pass on messages over the telephone worked with a speech and language therapist to develop a short script, written down and placed by the phone, explaining and asking the person to call back later, when her husband would be at home. This prevented her from getting flustered and trying but failing to take the message. Carers can be part of the strategy; a couple might agree on a signal to use in social situations that would alert the carer to the need for support with remembering a person's name or information about the person. Emily Rogalski and Angela Roberts discuss strategies to support functional communication on page 53.

Adapting the environment

Sometimes, goal attainment can be supported by making changes to the environment in which goal-related activity takes place. Claire O'Connor discusses environmental adaptation on page 47, and Nathalie Bier and Aida Suarez-Gonzalez discuss adjustments for people experiencing challenges with visuo-spatial perception on page 57. Adapting the environment can reduce barriers or distractions that interfere with what the person wants to do. Ideally, the environment will be set up to make it straightforward for the person to engage in the goal-related activity. Environmental adaptations can take several forms, for example, making features more prominent, facilitating movement, removing distractions, providing visual cues, and defining locations linked to tasks or activities.

Combining strategies to form an action plan for goal attainment

Strategies from each of these three types can be combined to form an action plan for goal attainment.[8] This is illustrated in relation to a specific goal in the second case study in this section (page 69), which describes how Gareth used a combination of strategies to regain the ability to prepare hot meals. In the first case study (page 67), Anita Plateris describes how input from members of a multidisciplinary team made it possible to apply diverse strategies to address a range of goals, keeping her mother '*steady and stable in her familiar environment, her home*'. Finding the right combination of strategies to enable people with dementia to attain their rehabilitation goals is a problem-solving process involving a detailed understanding and creative use of evidence-based methods. Sometimes, it takes several attempts to find the right combination, and the action plan may need adjusting. This is to be expected. By engaging collaboratively in this process, the person with dementia and, where available, the carer will be better equipped to solve new problems that arise and learn strategies they can apply in different situations.

Strategies and methods for attaining rehabilitation goals: key messages

- **Rehabilitation focuses on what people can still do.** People with dementia can learn new information and skills, and adapt what they do, if they have the right support as part of their rehabilitation plan.
- Developing an action plan for addressing rehabilitation goals is **a creative, problem-solving process**.
- Goals are addressed by drawing on an established range of strategies and combining these in a way that suits the person's capabilities and preferences and supports attainment of the goal.
- Strategies can be broadly grouped into three categories: **enhanced learning strategies, compensatory strategies and environmental adaptation**. Often, these are used in combination.

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Expert essays

Person-environment fit: adapting the environment to support the rehabilitation plan

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A person's ability to participate effectively and meaningfully in life is impacted by the interactions between the person, their environment, and the various activities and tasks they want to do. It is well known that dementia impacts a person's ability to do the things they want to do. And as dementia is more prevalent in older age, the prevalence of comorbidities such as frailty also increases, which may further contribute to the challenges people experience.[1,2] In the earlier stages of dementia, people may notice challenges around managing the household finances, or planning the weekly grocery shop. As dementia progresses, the person may need support to manage dressing or bathing.[3] Importantly, the way that dementia impacts these abilities varies person to person, and the strategies that we use to support someone will depend on that person's specific needs within their specific environmental context.

For example, for a person with dementia who is having difficulty with showering, there could be a range of potential reasons behind this. Perhaps they are experiencing changes to their visual processing abilities, and they are having difficulty navigating the shower and identifying the difference between the hot and cold taps; in this instance, we could consider installing red and blue coloured taps and colour-contrasting tape along the edge of the shower recess. Perhaps the person is struggling with planning how to shower and remembering all the steps; in this instance, we could consider providing a step-by-step instruction for how to shower on the bathroom wall, with support from a family member or friend to set up and start the showering activity. Perhaps the person has experienced changes to their mobility and is having difficulty stepping into the shower and standing safely while showering; in this instance, we could consider installing handrails, and perhaps a shower chair and a shower hose. This example of showering provides insight into the varied challenges people living with dementia may face and how modifying the environment can assist with their day-to-day living activities.

Example of a shower setup to support independent showering, including colour-coded taps, a shower hose, and handrails.

Person-environment-fit

Rehabilitation is about optimising a person's independence and functioning within their environmental context.[4] Person-environment-fit refers to the interaction between a person, including their functional abilities (e.g., activities of daily living, cognitive, social) and other personal characteristics, such as their personality and preferences, with their environment, such as their physical, social, and cultural environments.[5] Optimal person-environment-fit contributes to a person's optimal functioning to do the things they want to do. Within the context of dementia care, a person's environment can enhance function. For example, independence in dressing may be supported by reducing the contents of a wardrobe to be season-specific, ensuring adequate lighting, and adding labels to identify clothing placement within the wardrobe. In contrast, a wardrobe with too many options may limit a person's ability to choose or identify what to wear.

Consideration of person-environment fit when planning rehabilitation in dementia is vital. This involves assessing both the person's abilities and their environmental context. Where misalignment in person-environment-fit is identified, adaptations or modifications to the person's environment can be implemented to realign this fit, thus optimising the person's functioning and independence.

Adapting the environment to support the dementia rehabilitation plan

There is a broad variety of changes that can happen in dementia, ranging from cognitive (e.g., memory, planning, reasoning, language, coordination), behavioural (e.g., apathy, impulsivity), social (e.g., communication), perceptual (e.g., visual), to physical (e.g., mobility).[6] The changes experienced in dementia vary from person to person, and can interact with a person's environment in different ways. For example, one person may have difficulty with navigation and may benefit from clear signage for the toilet location, whereas another person may have visual perception challenges and may be able to find the toilet but may benefit from a colour-contrasted toilet seat to use the toilet. Therefore, there is no 'one-size fits all' when it comes to developing a plan around which environmental adaptations and modifications may be appropriate in each situation.[7,8]

As previously noted, a person's context consists of their physical environment, social relationships and networks, and cultural milieu.[7] Social considerations may include who is available to support the person to engage in their rehabilitation programme, and cultural considerations may include what activities are valuable and acceptable for the person living with dementia. The focus here is on adapting physical environments to support functioning as part of the personalised rehabilitation plan.

Ten key principles have been recommended for planning supportive environments: **unobtrusively reduce risks; provide a human scale; allow people to see and be seen; reduce unhelpful stimulation; optimise helpful stimulation; support movement and engagement; create a familiar place; provide opportunities to be alone or with others; provide links to the community; consider a vision for way of life.**[9] In practice, adaptations to the physical environment are used alongside a range of complementary approaches, such as activity setup and simplification, compensatory strategies, and carer involvement. For example, for a person who wanted to continue contributing to the laundry, physical environment adaptations may involve using a trolley to push the laundry basket and providing a seat next to the clothesline for a break. In parallel, skill development can be provided for a family member (and/or a friend) on how to break up the activity into steps and effectively communicate to prompt the person and support their engagement in the laundry activity.

Table 1 highlights five common physical environments that may be considered as part of the rehabilitation plan. For each physical environment, an example activity has been presented to illustrate how a range of strategies could be used to support dementia rehabilitation and participation in that activity. The examples provided here are not exhaustive, as each person will have a unique person-environment fit to maximise functioning and engagement in desired everyday activities within their own home and context. The allied health team and/or health and care practitioners involved will be able to evaluate and provide specific recommendations to each individual within their context.

Table 1. Examples of environmental adaptations and modifications to support dementia rehabilitation and activity engagement and participation

Physical environment and example desired activity	Strategy examples to support continued engagement in desired activities within the environmental context
Environment: Living room **Activity example: Jigsaw puzzle (or any other hobbies/activities)**	• Ensure the living room table is clear of any clutter, such that only the jigsaw puzzle is visible. • Ensure the living room table is well lit. • Sturdy seating at the correct height to allow the person to comfortably interact with the puzzle. • Whiteboard with daily activities listed, including jigsaw puzzle. • Reduce distractions in the room (e.g., turning off television or radio, or moving to a quiet area to support engagement and focus). • Ensure appropriate, clean eyewear.
Environment: Kitchen **Activity example: Cooking dinner**	• Reduce visual distractions by clearing away unnecessary items from the kitchen counter. • Labels in the kitchen to indicate where items are kept. • Colour-contrasting plates, chopping boards, cutlery, etc. • A whiteboard in the kitchen can be used to show what day it is and what the evening meal will be. • Ensure sufficient lighting in the kitchen. • Set the person up with a supportive chair at the dining table to prepare the vegetables for dinner.
Environment: Bathroom **Activity example: Toileting at night**	• Sensor lighting in the hallway and bathroom, or bathroom light left on. • Bathroom door left open. • Sign indicating the location of the toilet. • Colour-contrasting toilet seat. • Colour contrasting around light switches. • Over-toilet aid to provide stable seating high enough for the person to get on and off the toilet independently. • Handrail next to toilet. • Sensor mat to alert the care partner that the person with dementia is out of bed and might need assistance. • Reduce physical obstacles or trip hazards between the bed and toilet, for example, rugs, furniture in walkways, etc.
Environment: Garden **Activity example: Maintaining a vegetable garden**	• Consider accentuating step edges around the garden with colour-contrasting strips. • Appropriate walking aids. • Sturdy footwear. • Smartphone, medical alert system that the person might use if they were to fall in the garden. • Raised garden beds to increase accessibility of the garden for the person. • Retractable hose to limit the possibility of tripping. • Sturdy chair in the garden to allow for rest breaks. • Colour-contrasting garden tools.
Environment: Outdoor **Activity example: Checking the letterbox**	• Sign inside the front door prompting the person to remember to take their house key or to leave the door unlocked. • Sturdy footwear. • Appropriate walking aids. • Handrail down the stairs. • Minimise obstacles in the front yard. • Colour-contrasting strips on the edge of steps or pathways. • Identify or create a clear pathway, if possible, with minimal trip hazards, e.g. try to avoid cracked pavements, uneven surfaces, etc. • Clear potentially slippery objects off pathway e.g., sweep away leaves. • Accentuate or apply colour contrasting to letterbox. • Sturdy chair next to letterbox to allow for a rest break.

Conclusion

When planning rehabilitation programmes, environmental adaptation is a key element to complement a range of strategies to ensure a holistic and personalised approach to care. Supportive environments align with a person's abilities to enhance their independence and potential for meaningful engagement. Person-environment fit and facilitating supportive environments should be considered at all stages of dementia and across all contexts – in the community, at home, and in residential care.

Meal preparation: Example of an activity setup to support meal preparation, including a colour-contrasted chopping board, unnecessary items cleared from the work area, and the activity materials placed out ready to use.

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Addressing functional goals related to everyday activities

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Engaging in everyday activities is an important part of life for everyone. These kinds of activities encompass self-care (such as washing, dressing, and eating), productivity (such as housework, cooking, volunteering, and being a grandparent), and leisure (such as walking, watching films, and visiting friends). Doing these things gives our lives meaning, purpose, and structure. Our activities help shape who we are, connect us with others, and create our identity and sense of belonging.[1] For people with dementia, continuing to engage in meaningful, everyday activities can enhance their quality of life and sense of wellbeing and support their coping skills.

Strategies for improving or maintaining a person's ability to engage in an everyday activity will focus on overcoming the barriers that get in the way of achieving this. The person's chosen activity will need to be observed, in the usual environment in which it is completed, to identify any barriers. These barriers could be due to cognitive challenges, such as difficulty with memory, maintaining focus on the activity, or planning, or could be due to environmental barriers, such as a necessary item being out of sight or in a cluttered environment. The strategies chosen will depend on the identified barriers for that individual and what is likely to help overcome them, while making them person-centred.

The environment in which daily activities are carried out can have a major impact on the ability to complete them. Extra demands on attention, such as visual distractions, noise, or the presence of other people, can reduce focus. On the other hand, reducing visual clutter by placing items out of sight can increase cognitive demands as the person needs to remember where the item is kept in order to use it for the activity. For example, it is much easier to remember to brush your teeth when the toothpaste and toothbrush are on a shelf by the sink than when they are kept out of sight in a cupboard. People with dementia may rely on visual cues to prompt them to complete routine activities,[2,3] and so altering the environment to increase the presence of such cues is a useful tool.

Strategies used in cognitive rehabilitation[4] can focus on teaching new skills or relearning skills (restorative strategies), taking over the cognitive demands of an activity (compensatory strategies), or adapting the environment to support the activity (environmental modification). I will explain each of these approaches in more detail with a real-life example from my own experience.

Restorative strategies

An example of an everyday activity where performance was enhanced by using restorative strategies involved learning to use a microwave to heat up a ready meal. Observing the person using the microwave to heat up a meal showed that the person was able to read and understand the instructions on the packaging. Barriers were evident when using the microwave, as the person did not know which buttons to press in which order to heat up the meal. This meant they either had to seek help from others or abandon the attempt and go without the meal. The restorative strategies used were:

1) Learning one new instruction at a time using backwards chaining and expanding rehearsal

The activity could be broken down into several sequential steps, meaning that it was possible to learn one step at a time. Backwards chaining is a technique where the last stage in completing the activity is learnt first, followed by the second-last and so on. In this case the final step was pressing the 'start' button to initiate the cooking. The CR practitioner modelled how to locate and press the start button (usually the biggest), and the person immediately copied this action. The CR practitioner then employed the expanding rehearsal technique, where the action is repeated after a short interval and then at gradually increasing intervals as the time between repetitions is doubled. In this case, the first interval was 30 seconds and the longest was 20 minutes. Once this last step was well established, the previous step in the sequence was taught in the same way, until the person could carry out all the steps. Practice between sessions is valuable in supporting action learning and can be assisted by a family member or friend.

2) Effortful processing through writing own instructions

Rather than the practitioner providing a list of steps for the person to follow, the person created their own list as each step was learned. This meant the instructions were processed verbally and provided a complementary route to the action learning described in point 1, enhancing the likelihood of recall.

3) Multimodal processing by saying the steps out loud

To complement the action learning and effortful processing, the person also said each step out loud as it was completed. Developing a narrative of the process, for example, 'first I'm going to set the time, then I'm going to press start,' and saying this out loud provided another channel for learning and aimed to focus attention on the specific step as it was carried out.

Compensatory strategies

An example of an everyday activity where performance was enhanced by using compensatory strategies involved knowing what activities are planned for this week. This person was using a monthly calendar to keep track of both regular activities and one-off activities, such as a doctor's appointment. Observation showed that the person was unable to locate the current day or week on the calendar and was relying on knowledge of regular routines and prompts from the care partner to keep track of activities. If the care partner was not present on the day, one-off activities were missed. The compensatory strategies implemented were:

1. Introducing a whiteboard marked with the days of the week.
2. The person and care partner decided on the best place to put the whiteboard, ensuring it would be readily seen several times a day.
3. Introducing a routine of completing the whiteboard for the coming week with support from the care partner every Sunday evening
4. Having the care partner give prompts to refer to the whiteboard whenever the person asked what was planned for that day or for the week.

It is important to support the introduction of a compensatory tool, such as a whiteboard with prompts, and to develop a routine around its use, and to make sure it is ideally located to be easily seen.

Environmental modification

An example of an everyday activity that was supported by environmental modification is remembering to take essential medication twice a day, every day. Observation showed that the person knew it was necessary to take diabetic and cardiac medication in the form of tablets twice a day, but did not have a routine or structure, and was regularly missing doses. The person tended to go to where the medication was stored, but then leave again to get a drink of water from the kitchen, only to be distracted and start doing other things, such as washing up the dishes or making a cup of tea.

The environmental modification strategy used was to set up a medication 'workstation' next to the favourite armchair in the living room, where the person spent much of the day. A small table was placed next to the chair. The table was set up with a bottle of drinking water, an alarm clock, and the medication, which was sorted into a pill organiser by the pharmacy. The alarm clock was set to the same time for morning (7 am) and evening (7 pm) medication to support the development of a daily routine. By setting up the workstation and having everything in one place, there was no need to get distracted by going in search of a drink of water. The person followed the medication regimen more reliably, resulting in improved physical health.

Combining strategies

In practice, these three types of strategies – restorative, compensatory and environmental – are often combined to support the person to engage in everyday activities in the best possible way.

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Beyond words: the role of functional communication goals in dementia care

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Imagine the frustration of struggling to find the right words when ordering a morning coffee, recalling the name of a close friend, or following a family conversation, yet finding it hard to contribute. Such distressing everyday moments can be overlooked if they are uncommon. However, when they occur more frequently, they adversely affect one's engagement in life, disrupt daily routines, and contribute to social isolation. These are everyday realities for individuals living with Alzheimer's and related dementias (ADRD), particularly those with primary progressive aphasia (PPA), a clinical dementia syndrome where neurodegenerative disease disrupts the functioning of the brain, initially in the language regions. However, new evidence-based approaches in speech-language therapy are shifting the focus from achieving perfection in communication to preserving meaningful connections and enhancing quality of life. These person-centred approaches are grounded in functional communication goals: *practical, real-world objectives reflecting what is most important to the individual*.

Functional communication encompasses using language through multiple modalities (e.g., spoken, written, or non-verbal) to navigate daily life.[1] It includes the ability to request assistance, express opinions, show affection, indicate preferences, and respond to others appropriately with or without support. Functional communication goals do not aim for perfection in grammatical structure or word production; instead, they emphasise the ability to communicate effectively in meaningful, real-life situations.

Functional communication is closely linked to *communication participation*, which refers to the extent to which individuals actively engage in their social roles through communication.[2,3] This may include attending community events, enjoying conversations with friends, or participating in a book club. Though seemingly simple, these goals carry profound significance; they help sustain autonomy, identity, and joy. Importantly, the *ability* to communicate does not always translate into participation. Losing confidence, changing social environments, or lacking supportive communication partners may limit individuals' engagement in everyday communication activities. As such, interventions should prioritise maximising communication ability, scaffolded support for communication (i.e., providing just the right level of support for communication), and facilitating the confidence to communicate (with or without supports) in daily life. Providing tools that help a person communicate more effectively by reducing demands, compensating for challenges, and building on their existing strengths is a strong recipe for maximising quality of life.

Access to care remains a significant barrier for individuals living with Alzheimer's disease and related dementias (ADRD), particularly when it comes to receiving support from clinicians with specialised training in communication interventions. This includes speech-language pathologists (SLPs, also called speech therapists), occupational therapists (OTs), social workers, nurses, and psychologists, each of whom could play a key role in supporting communication participation. However, the challenge often begins at the educational level: for example, SLP students may receive as little as a single one-hour lecture on all dementia syndromes from Parkinson's disease dementia to primary progressive aphasia (PPA). As a result, many clinicians enter practice underprepared to address the complex and evolving communication needs of people living with ADRD. There is growing recognition of the need for expanded education and formal certification pathways to better equip clinicians with the knowledge, skills, and confidence required to provide person-centred communication support across the continuum of care.

As clinicians, it is important to think about how to measure the impact of care, not just in terms of words remembered or tasks completed, but in terms of how well a person with dementia is able to connect, participate, and feel confident in everyday life. Put simply, evaluating the clinical meaningfulness of care. There are several tools that may be helpful for practical and meaningful evaluation, including patient-reported, carer-reported, and clinician-evaluated tools.

Patient-reported outcome measures (PROMS) such as the Communicative Participation Item Bank (CPIB) and the Communication Confidence Rating Scale for Aphasia (CCRSA) assess how individuals perceive their participation and confidence in communication, respectively.[4-7] *Carer-reported* outcome measures (CROMS) can also contribute to understanding of the strengths and challenges in engaging in activities using measures such as the Communicative Effectiveness Index (CETI), American Speech-Language-Hearing Association Functional Assessment of Communication Skills for Adults (ASHA FACS).[1,8,9,10]

Additionally, *clinician- and participant-informed measures* of Goal Attainment Scaling (GAS) allow for creating and tracking highly individualised communication goals. GAS was initially used for mental health programmes and, more recently, extended across dementia syndromes.[11-14] It is a flexible tool that allows clinicians and individuals (and often families) to set personal goals together and then track how much progress is made. Together, these tools provide a more holistic understanding of intervention outcomes, beyond traditional clinical metrics. These tools do not require perfect English or high-tech systems. Many can be adapted to suit your setting. What they share is a focus on what matters most to the person and those around them. Capturing what matters to individuals living with dementia creates opportunities for better alignment among the clinician, individuals living with a diagnosis, and those providing care. It may also strengthen buy-in, trust, and motivation, key ingredients for maximising intervention effects. This approach demonstrates that clinicians are listening to the goals and priorities of the person with PPA and their carer(s), rather than merely tracking errors in clinical test scores.

Communication is inherently social and requires more than one person. Recognising this, many interventions now actively involve communication partners: family members, friends, or carers integral to daily interaction and support. Together, the couple (dyad) can develop strategies for maximising communication – including key gestures, understanding when the communication partner should "fill in the word" – that works best for the dyad's preferences.

A notable example is the Communication Bridge™ intervention programme, which uses telehealth to deliver therapy to individuals with PPA and their partners in their home environment.[14-16] Within this model, care partners receive tools including exercises, strategies, and knowledge alongside individuals living with a diagnosis, contributing to shared communication goals. Table 1 provides an example goal for the person with PPA and a summary of the approach used to address the goal. Communication partners learn that talking louder is not the solution; instead, they learn about slowing down, providing time for the person with PPA to respond, and how to use strategies such as key wording. The programme is dyad-centred, tailored, and designed to build self-efficacy and resilience, which will help the dyad today and in the future as needs change with the progression of the condition.

Table 1. Example of Goal Attainment Scaling (GAS) in the Communication Bridge™ intervention for a person with primary progressive aphasia (PPA)

Simplified Goal		When ordering from the menu at a restaurant, I find the words to order for myself.
3	Better than expected	**OPTIONAL**: When ordering from the menu at a restaurant, the person with PPA finds the words to order for themselves **almost all of the time**, whether they prepare in advance or not. They may use communication strategies/supports.
2	Expected goal	When ordering from the menu at a restaurant, the person with PPA finds the words to order for themselves **almost all of the time** after preparing in advance AND **most of the time** when they are unable to prepare (e.g., no menu online, need to change order spontaneously, etc.). They may use communication strategies/supports.
1	Close to reaching goal	When ordering from the menu at a restaurant, the person with PPA finds the words to order for themselves **almost all of the time** after preparing in advance OR **most of the time** when they are unable to prepare (e.g., no menu online, need to change order spontaneously, etc.). They may use communication strategies/supports.
0	Starting Point	When ordering from the menu at a restaurant, the person with PPA finds the words to order for themselves **most of the time** after preparing in advance and **some of the time** when they do not or are unable to prepare (e.g., no menu online, need to change order spontaneously, etc.). They use communication strategies, including previewing the menu & practising his order at home.
-1	Losing ground	When ordering from the menu at a restaurant, the person with PPA finds the words to order for themselves **some of the time** after preparing in advance OR rarely when they are unable to prepare (e.g., no menu online, need to change order spontaneously, etc.). They may use communication strategies/supports.
-2	Worse off than when started	When ordering from the menu at a restaurant, the person with PPA finds the words to order for themselves **some of the time** after preparing in advance AND **rarely** when they are unable to prepare (e.g., no menu online, need to change order spontaneously, etc.). They may use communication strategies/supports.
-3	Non-participation	**OPTIONAL**: Person with PPA **no longer** orders for themselves from the menu at a restaurant or are only able to do so with maximal support from others.

This table illustrates how progress toward a functional communication goal was tracked using GAS, a flexible outcome measure that captures progress toward personally meaningful goals. The person with PPA began at baseline (Level 0) and worked toward accurately ordering their preferred meal at a restaurant more frequently. Intervention strategies included script development and practice through the Communication Bridge™ web platform, creation of portable script aids, environmental modifications, and education. Script practice was undertaken to improve automaticity and fluency. Web application script training was delivered through an interactive module that included guided visuals, opportunities to read the script aloud repeatedly, follow a video model of a clinician producing the script, and attempt the script spontaneously with varying levels of visual and auditory cueing. The clinician also supported functional communication by helping the person with PPA create a portable script card to bring to restaurants, which could be read aloud or shown to staff to facilitate the order. As writing abilities were relatively preserved, the person with PPA was encouraged to jot down their order in advance for future visits. Environmental strategies were also provided, for example, requesting a quieter seating area to reduce cognitive and auditory load. These layered supports promoted independence, self-efficacy, resilience, and communication participation, which led to meaningful change in daily life and helped reduce the burden on the communication partner.

Findings from research on Communication Bridge demonstrate that this person-centred, goal-oriented approach can significantly enhance communication participation for people with PPA.[14-16] Importantly, success in communication interventions is not solely measured by improved clarity of speech or vocabulary expansion. It is reflected in outcomes that have clinically meaningful impacts on people's lives, including renewed enjoyment and participation in conversations, greater confidence and engagement in social interactions, reduced risk of isolation, and increased ability to express personal needs and preferences. In essence, success is about enhancing life participation and emotional wellbeing – not just linguistic accuracy. Communication participation may require supports such as notebooks, devices, or joint signals developed between the individual living with a diagnosis and their communication partner. Signals may include a code word or gesture that the person with dementia gives when they want their carer to 'fill in the word' that the individual is struggling to retrieve. Paper- or digital-based communication aids can support individuals in activities such as shopping, interacting with others in the community, or following step-by-step instructions for preparing a favourite recipe, as shown in Figure 1.

The salad recipe communication aid supports individuals with PPA in independently shopping for and preparing their favourite salads, activities they had previously abandoned due to communication challenges. The aid was designed to promote autonomy, reduce reliance on the carer, and re-engage the person with PPA in meaningful daily routines.

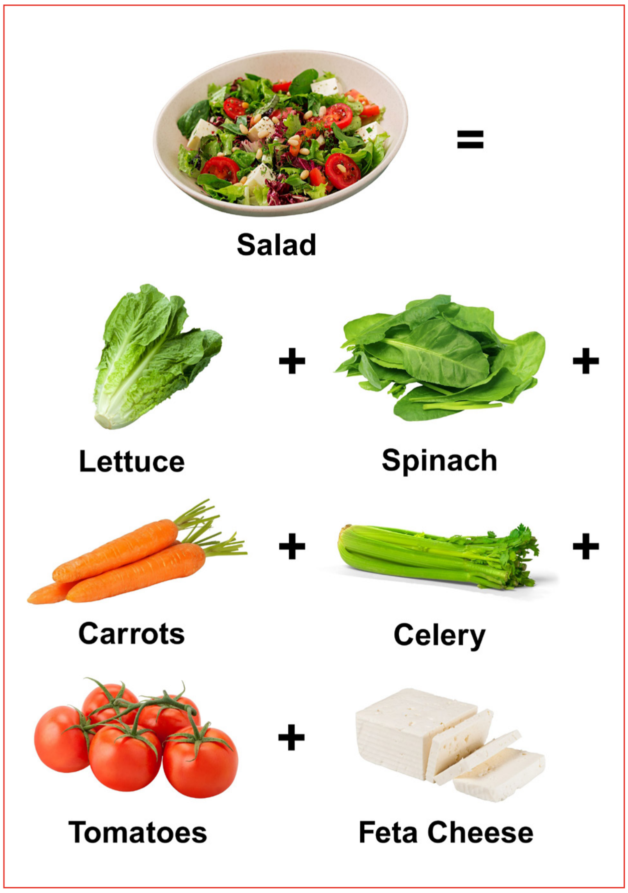

Figure 1. Paper-based communication support for functional activities.

At a time when disease-modifying pharmacological treatments are emerging, but not yet fully effective at halting or reversing clinical symptoms, communication interventions have the potential to offer a powerful complement. Future research would benefit from evaluating these approaches.

Globally, millions of individuals live with dementia or related neurodegenerative conditions, many of whom experience progressive communication challenges. While pharmacological treatments may be limited, interventions that prioritise functional communication provide a vital pathway to maintaining connection and dignity. For individuals and families facing the realities of ADRD, setting and working towards functional communication goals can be transformative. These goals empower people to remain active participants in life, affirming their voices, identity, and meaningful relationships in ways that somewhat transcend language loss. It is not about regaining every word but about maximising engagement in life. Communication is more than words; it is connection and identity, bringing richness to life. Professionals and care teams are encouraged to integrate functional, person-centred communication goals with culturally appropriate adaptations into assessment and intervention planning. Such approaches can support communication that not only shows significant benefits in research trials but is also practically life-enhancing.

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Addressing functional goals arising from dementia-related visuospatial and perceptual challenges

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The impact of visuospatial and perceptual impairments on everyday life

Dementia-related visuospatial and perceptual impairments can affect people with the most common forms of dementia, like Alzheimer's disease (AD) and Lewy body dementia.[1] Typically, these difficulties are not the most prominent symptoms, and by themselves, they do not lead to significant disability in daily life. In contrast, these kinds of difficulties are the core feature of an atypical type of AD called posterior cortical atrophy (PCA). In PCA, these symptoms stem from changes in how the brain processes information ('brain-sight'), rather than from eye-related problems. People with PCA may struggle to:

- judge distances, such as when parking the car
- reach objects right in front of them, such as when trying to pick up an alarm clock at the bedside or a glass of water from the table
- navigate their surroundings, for example, confusing their door with a neighbour's door
- position their body in space, for example, when getting into bed, getting into a car, or sitting down on a chair
- use knowledge about the space around them, for example, confusing up and down, or right and left
- read, for example, finding that lines clutter up, or getting lost on the page, or that words and letters clutter up or disappear
- get dressed, for example, being confused about which is the front or back of a garment, or having difficulties visually locating armholes in clothing.

In spite of these difficulties, people with mild to moderate PCA generally have good memory and communication abilities and awareness of the challenges their symptoms present. Therefore, they can learn how to use other senses, such as tactile cues, assistive technologies, and adaptations to the home environment to compensate.[2,3] This means they are well able to benefit from rehabilitation. However, early visual symptoms in PCA are often mistaken for eye-related issues, delaying diagnosis and timely support for individuals and their families.[4]

Strategies for addressing functional goals

Identifying activities that are personally meaningful to the individual is key to setting practical and motivating goals. For example, one person with PCA we saw in clinic, a former handyman, wanted to return to fixing appliances and carpentry to help regain his sense of identity. Another who volunteered at a food bank wanted to regain the ability to read checklists and organise food on the shelves. Others chose setting the table,[5] finding objects in space, reading, or pouring drinks[6] as their goals.

Because the difficulties are due to changes in how the brain processes information, rather than eye or vision problems, the kinds of assistive devices that people with visual disabilities find helpful may not be effective for people with PCA.[3] For example, the ability of the brain to combine information from different senses to make sense of the world, called 'sensory integration', is often affected in PCA. Assistive tools that rely on this ability, such as white canes to assist navigation, are unlikely to help. Sensitivity to colours may also change in PCA, so using colour codes to help with navigating the environment or finding objects may not work either. Instead, other strategies can be used to support people with PCA to reach their goals. Table 1 lists some practical examples. These strategies make use of the person's other senses and can be combined with adaptations of the home environment or assistive products.

Table 1. Examples of rehabilitation strategies applied to functional goals

Examples of the impact of visuospatial and perceptual difficulties	Example of related functional goals	Examples of rehabilitation strategies to address functional goals
Cannot find a glass of water on the table	"I would like to be able to locate and reach cups and cutlery on the table during meals without assistance."	● Training in strategic visual and tactile scanning. ● Using high-contrast coloured cups; decluttering the table surface; using fewer items of cutlery.
Gets lost in familiar environments or buildings	"I would like to be able to find my way from the bedroom to the kitchen and the front door without getting lost or going into the wrong room."	Strategic placement of distinctive visual cues (e.g. flower garland on the door); use of motion-activated lighting to guide the path; simplification of surroundings.
Cannot get dressed without help due visuospatial difficulties	"I would like to be able to put my jumper on by myself without getting the sleeves twisted or putting it on back to front, every morning."	● Breaking the activity into repeatable steps; simplifying the process of putting on the jumper; repeating the action. ● Using visual cues on clothes (e.g., coloured fabric on collar/sleeve); using adaptive clothing like ponchos or Velcro-fastened items.
Cannot read favourite novels due to visual crowding and losing their place on the page	"I want to be able to read four pages of my novel or magazine every day."	Using e-readers with adapted font size and spacing; using reading guides (rulers or stripes).

Using touch to compensate for the visual impairments

Education is the first step toward helping a person with PCA adopt effective strategies to increase their participation and attain functional goals.[7] Education aims to help the person better understand the nature of their visuospatial and perceptual impairments and how to recognise them in everyday life. This helps increase awareness about their difficulties. Then, **strategies** can be learned to compensate for the impairments. For example, a person with PCA can make use of other senses, like touch, to identify objects more easily than when relying on vision only.[8] They can also break the activity into a consistent sequence of small, adapted actions that can be done in the same way each time, making it easier to learn, or develop a simpler way to complete it. Carers can assist in helping the person with PCA practice using their other senses or by supporting them in simplifying activities.

Modifications to the home environment and assistive technologies

To attain functional goals, very simple, yet useful, **modifications to the person's home** can be used, such as minimising clutter and keeping items in consistent and easily accessible locations, such as always keeping the shampoo in the same place. **Adding sensory inputs** to objects in the home can also help with identifying and locating objects.[3] For example, adding bright solid colours to enhance contrast, such as using red glasses on a white tablecloth, can help with finding objects. Adding a textured adhesive can make it easier to recognise an object by touch.

Numerous **assistive technologies** are available, ranging from simple low-tech solutions such as a ruler to support reading when changing lines to more advanced technologies. Voice-activated systems, such as connected speakers and smart home devices, simplify access to various electronic devices and objects in the home, including smart lights, thermostats, smart coffee machines, and Bluetooth door locks. Mobile apps, including those codeveloped with individuals with dementia-related visuospatial difficulties, can provide tailored support for activities such as reading.[2] Accessibility features, such as voice access, screen readers, and magnifiers, can help the person use electronic devices such as smartphones or tablet computers.

Carers play an important role in applying environmental strategies consistently in the person's home and during transitions in different housing solutions, for example, in a vacation home or in a new home following a relocation.[9] They can also support in using assistive technologies daily, such as reminding the person to use them, charging the technological aids every day, and helping make better use of certain applications.[10]

Conclusion

People with dementia-related visuospatial and perceptual impairments, such as those experienced by people with PCA, experience significant challenges in their daily lives. Based on an understanding of the person's strengths and limitations, functional goals can be identified and attained through collaboration between the person and their carer, utilising a variety of strategies. These strategies can support engagement in meaningful activities despite the challenges and contribute to a better quality of life.

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Addressing functional goals related to mobility

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Mobility refers to a person's ability to move around. At a basic level, mobility is about getting in and out of bed, or navigating things like bathrooms, showers, steps and stairs. At a broader level, it is about being able to walk or run or use an aid such as a wheelchair to access the community and participate in the outside world. Dementia can affect physical functioning as well as memory and thinking, making mobility an important issue to consider.

How might dementia affect mobility?

The brain controls how we move

Mobility is a complicated task, requiring a lot from our brains. To get where we want to go, stay upright instead of falling over, and avoid obstacles along the way, our brain needs to:

1. Decide we want to move.
2. Plan where we will move to and how.
3. Process and respond to complex information from our environment.
4. Control messages to our muscles so they move at exactly the right times.
5. Adjust our movements if we face obstacles or other unanticipated challenges.

Different types of dementia affect mobility differently

Each type of dementia will affect different 'steps' in this mobility process in different ways as dementia progresses. For example, Lewy body dementias are often associated with slow movement, stiffness, and tremors. This makes controlling muscle messages difficult, and it can also be difficult to rapidly react to changes in the environment, resulting in falls or other mobility challenges. These physical features often occur early in Lewy body dementias[1] and worsen over time. Alzheimer's disease, on the other hand, is not well known for its physical symptoms. However, in the very early stages of Alzheimer's disease, before changes in memory and thinking emerge, subtle changes in movement may begin. Walking may slow, or the length of each step may become slightly more variable.[2] Nevertheless, in the earlier stages of Alzheimer's disease, it is the desire to move (or not), planning how and where to move, and navigating the environment that can have a more substantial impact on mobility. In the later stages of Alzheimer's disease, changes in muscle function may gradually lead to a loss of the ability to walk.

Some dementias have a mix of underlying causes, so people living with dementia may experience a range of symptoms influencing mobility.[3] Examples include:

- Slowed reaction time
- Weaker muscles
- Changes in coordination
- Trouble doing more than one thing at a time, e.g. walking while carrying a cup of water
- Balance problems, including falls
- Difficulty with wayfinding
- Challenges identifying objects such as furniture or changes in surfaces

People with dementia may also have other health conditions

In addition to dementia, a person's other health conditions, such as arthritis, diabetes, or stroke, can affect mobility. General health and physical activity levels can also influence mobility.

What mobility-related rehabilitation goals might be relevant?

Each person living with dementia may experience different mobility needs depending on their type of dementia, stage of dementia, other health conditions, and where they live. Many use walking aids like canes, walking frames, or wheelchairs. Every person has different interests and responsibilities that will influence which aspects of mobility are most important to them. This means there are a variety of mobility-related goals that may be relevant for people living with dementia, from the very simplest of mobility tasks like moving from lying down to sitting up or standing, to running, jumping, or walking long distances on uneven surfaces (Figure 1).

Figure 1. Potential rehabilitation goals across the spectrum of mobility.

Moving about at home – in the community or a nursing home e.g. getting in and out of bed, walking to the kitchen with a walking frame.

Moving to manage daily life – e.g. keeping balanced while gardening or cooking, walking longer distances to be able to visit a market or shopping centre.

Moving to do things we love – e.g. looking after grandchildren, playing a sport like golf or pickleball, visiting friends or a library.

Who can help with mobility rehabilitation?

Physiotherapists are the main health professionals who can help a person living with dementia achieve their mobility-related goals. Physiotherapists can also help with other physical issues affecting mobility, such as pain. If a physiotherapist is not available, nurses, doctors, community health workers, or aged care workers may offer advice about rehabilitation or who else can help. Sometimes, family members can be trained to help.[4]

What does rehabilitation for mobility-related goals include?

Assessment

We start with assessment: finding out a person's capabilities to help work out the best way to achieve their goals. A physiotherapist or other health professional will ask about what is important to an individual and seek to understand their general health, usual amount of physical activity, and abilities relating to memory and thinking. Physical tests will depend on a person's goals, capabilities, and other health conditions. Examples may include measuring walking speed or the length of time someone can balance in a certain position. Functional tests can include how long it takes to get up and down from a chair a certain number of times, or how long it takes to get up from a chair, walk, turn around, and return to the chair.

Setting mobility-related goals together

Next, the person living with dementia, their family or care partner, and the health professional can work together towards setting rehabilitation goals. This includes combining personal goals with physical assessment findings to help identify *achievable* goals. It is also important for goals to be **specific** and **measurable**, so you know when they are achieved. Examples of mobility-related rehabilitation goals are:

- To manage the stairs at home without losing balance.
- To get up from the ground in the garden safely and without pain in my knee.
- To walk two kilometres on an uneven footpath to reach the local shops.

Participating in evidence-based rehabilitation activities or developing strategies

Goals set through the rehabilitation process will then direct the kinds of activities or strategies that might help. Some rehabilitation activities are designed to address the root cause of the problem and help it improve. For example, depending on the findings of an assessment, strengthening and balance exercises might help someone manage the stairs at home without losing balance. Tailored physical exercises can help improve strength, balance, mobility and endurance for people living with dementia[5] and they should be offered an exercise programme to prevent falls.[6] Rehabilitation may also focus on addressing things like knee pain from arthritis,[7] that may cause mobility problems for a person living with dementia, even though it is unrelated to dementia itself.

To improve mobility, exercises need to be individualised. For instance, someone whose legs are weak might benefit from practising getting up and down from a chair. This kind of exercise, like a normal daily activity, might also make more sense to someone with dementia than more complicated exercises. A person who wants to walk to the shops might benefit from balance exercises. Balance exercises can include activities such as tapping a foot on the floor and then onto a step repeatedly.

Balance and strength exercises need some effort to be effective. They also need to be safe to prevent injuries. This is why the advice of a health professional is helpful. Exercises also need to be repeated frequently to make a difference, like three or more times each week, starting at an easy level and getting progressively harder over 12 weeks or more.[6] Exercises might be done at home or in a group. It is possible to find an exercise routine that fits between usual life activities, so it feels manageable.

Sometimes we cannot improve the underlying physical problem. When this happens, there are still options available to improve mobility and participation in life. This might be through the prescription of assistive devices such as walking frames, or machines like hoists that can help someone spend time out of bed even if unable to achieve this independently. Getting the right kind of assistive device, that is the right size or height, can help with achieving mobility goals. A person with dementia will often find learning to use a new device difficult, but training with a health professional over a period of weeks can help.[8]

Regardless of a person's physical status, an important component of mobility rehabilitation is maximising physical activity. Physical activity can range from sitting in a chair and punching in the air, through to gardening, walking, and playing games like football. Physical activity is good for brain health even after a dementia diagnosis. It is good for mental wellbeing, lungs, muscles, bones, and joints – all important contributors to good health and mobility.[9]

Repeating the rehabilitation cycle

After participating in rehabilitation, it is good to revisit goals, check progress, and adjust expectations and/or treatment approaches. We can do our best to maintain brain health, but we cannot stop the progression of dementia. We can, however, work together to improve or manage the impact of dementia on mobility, to support people with dementia to maximise their participation in life, at home, and in the community.

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Motivation and engagement in rehabilitation

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Participating in rehabilitation requires effort, insight, and motivation. It can therefore be challenging to facilitate rehabilitation if the recipient is not engaged with the process or appears to lack motivation. Practicalities such as distance or time commitments can affect motivation among people living with dementia and their carers.[1] Where possible, these issues may be addressed through strategies such as travel assistance, telehealth, or careful timetabling. However, reduced engagement may also reflect cognitive, psychological, or interpersonal factors. Identifying and addressing relevant factors can help the person become more actively involved or able to participate.

Rehabilitation aims to improve functional independence through behaviour change. A well-known framework for health interventions suggests that changing behaviour requires the interaction of three key ingredients: capability, opportunity, and motivation,[2] summarised in Figure 1 and described in Table 1.

Exploring these components can help us identify and understand some of the common barriers to engagement that people with dementia may experience. We can then tailor our approach, techniques, or communication style to address relevant issues and help people living with dementia to become more actively involved and enthusiastic about rehabilitation.

Setting up for rehabilitation success

Rehabilitation planning should allow for autonomy through shared or supported decision-making to enhance the individual's **motivation**. We need to consider whether the person has understood the rehabilitation aims, agreed to be involved, remembered these discussions, or can be supported through reminders and prompts. Sometimes, well-meaning health professionals or care partners may enthusiastically offer rehabilitation without directly or sufficiently explaining to the person what is involved and how they may benefit. Clear and repeated explanations, along with opportunities for the person to ask questions or clarify information, can be key to facilitating active participation in rehabilitation.

Additionally, as highlighted in the essay on neuropsychological and functional assessment (page 26), medical or psychological factors that can affect a person's mental state (e.g. confusion, pain, fatigue, depression, etc.) should be identified early and addressed through proactive collaboration with other health professionals, to minimise their potential impact on motivation and attention during rehabilitation. Some people may have ongoing physical issues that can affect their engagement, for example, sensory impairments where poor eyesight or hearing create barriers, which also need to

Figure 1. Key elements in behaviour change

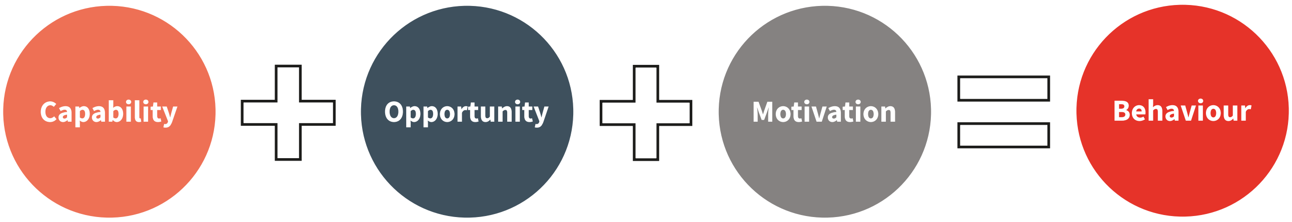

Table 1. Key ingredients for behaviour change

Capability:	Having the skills and abilities required to engage in new behaviours
Opportunity:	Having appropriate physical resources, environment, and social support to facilitate engagement
Motivation:	The individual's internal processes around recognising a need for change, planning their approach, and making decisions about behaviour

be addressed as part of rehabilitation. An interdisciplinary approach enhances the rehabilitation experience and outcomes for the person and for carers.[3]

Cognitive impairment

People with dementia can identify meaningful, relevant goals;[4] however, this may be more difficult for those with more severe cognitive impairment.[5] Dementia can affect various cognitive domains (see the essay on neuropsychological and functional assessment, page 26, for descriptions), depending on which brain regions are involved and the stage of disease progression. Table 2 shows examples of how various cognitive difficulties may impact a person's **capability** or **opportunity** to engage with rehabilitation. Importantly, reduced capability or opportunity may lead to frustration or slow progress, which can then impact **motivation** to remain involved in rehabilitation.

While people with cognitive impairment may require additional support for effective and sustainable behaviour change,[6] this can be achieved with appropriate planning, tailoring, structure, and collaboration. Reviewing results of available cognitive assessments prior to commencing rehabilitation is important, as awareness of a person's particular cognitive difficulties and their strengths allows us to adjust the rehabilitation plan (e.g., selecting strategies or resources, timing, etc.). Concurrently, talking with the person and those who know them well about their usual interests can be helpful for facilitating engagement before and during rehabilitation,[5] as background knowledge enables us to individually tailor the rehabilitation process.

Motivation and readiness for change

Sometimes, a person may have optimal **capability** and **opportunity** to move towards behaviour change but may be reluctant to engage in the rehabilitation process, or have difficulty considering or committing to goals, new skills, or different ways of doing things. Lack of **motivation** may need to be addressed at the outset, for example, to facilitate initial engagement or goal setting, and addressed throughout rehabilitation – such as when introducing new strategies or ideas, or if the person appears 'stuck' or unhappy with their progress. The practitioner's ability to build rapport with the person is important throughout the process.

For people who are closed to new ideas or ambivalent about adopting new routines or strategies, *motivational interviewing* may be useful to address the complex relationship between knowledge, motivation, and resistance that determines whether and how successfully individuals can change their behaviour and habits.[7] This technique relies on collaboration between the person and the clinician and/or carer to explore the person's beliefs and values about themselves and about change, facilitate their awareness of problems, and eventually, facilitate

Table 2. Potential impacts of cognitive difficulties on rehabilitation engagement

Cognitive domain or area of impairment	How could this affect rehabilitation engagement?
Memory	• Difficulty recalling who the clinician is or why they are meeting • Difficulty remembering goals or learning new strategies/skills
Processing speed and working memory	• Becoming easily overwhelmed or distracted during sessions • 'Missing' information if presented too quickly • Difficulty understanding concepts • Difficulty keeping in mind a sequence of steps required for a new skill or process
Executive functions (higher-level thinking skills)	• Reduced insight or awareness of day-to-day challenges • Difficulty understanding the relevance of rehabilitation to their personal circumstances • Difficulty coming up with ideas or making decisions during goal setting • Difficulty seeing the 'bigger picture' to apply skills learned in rehabilitation to everyday activities • Difficulty following the sequence of steps required for a strategy • Difficulties initiating or planning to use strategies in daily life • Reduced drive or determination (apathy) to attend appointments or to actively participate in sessions • Difficulty regulating emotions and/or behaviour, which may disrupt sessions or make therapeutic interactions more challenging
Language	• Communication difficulties, e.g., problems understanding information and/or expressing thoughts, questions, or concerns • Difficulty reading or understanding written information, such as lists
Visuospatial skills	• Difficulty understanding or interacting with visual materials, e.g., charts, diagrams, or pictures • Difficulty identifying or using objects involved in a task (e.g., distinguishing bank notes or telling white plates apart from a white tablecloth)

their commitment to change. The concept of "readiness for change"[8] is key to recognising that behaviour change is a dynamic process, with several stages:

1. Recognising and acknowledging a problem
2. Considering taking action
3. Preparing to take action or make changes
4. Actively participating in relevant strategies to address the problem.

Readiness or willingness to make goal-related changes significantly affects the outcomes of rehabilitation for people with dementia.[4] For those in the earlier stages of acknowledging or contemplating change, open-ended questions, validation, and reflective listening are key motivational interviewing tools for exploring a person's past experiences, practical and emotional concerns, openness, and willingness to commit. We can use these tools in conversation to increase the person's perception of problems within their current situation, identify potential risks and benefits of changing the situation and available options for change, and build confidence in their ability to make relevant changes. Where appropriate, acknowledging that any feelings of hopelessness or self-doubt are normal while providing the opportunity to share these feelings is an important part of the conversation. Language is also important during these conversations: for example, the aim is to move from hesitant or uncertain phrases (e.g., "I might…"; "Maybe…"; "I suppose…") towards commitment talk (e.g. "I will…"; 'I can…"; "When…"). Eventually, this leads to more structured goal setting and action planning.

Measuring (and celebrating) progress

During rehabilitation, recognising engagement and incremental progress towards goal attainment is critical for maintaining **motivation**. Many structured goal-setting tools involve setting benchmarks for measuring progress. For example, keeping a tally of falls or near-falls, or updating a progress chart for the number of steps completed independently while dressing, can provide objective evidence of progress and a strong incentive to persist with strategies. Concurrently, evidence of slow progress may be helpful for evaluating barriers and revisiting readiness for change, if needed. Recognising and celebrating even small signs of progress towards goal attainment provides important feedback and reinforcement for the person and for carers that can aid motivation by acknowledging their efforts, encouraging and empowering them, and highlighting potential rehabilitation benefits.

Carer and family involvement

While some carers can experience stress or logistical difficulties related to rehabilitation, generally, carer involvement is associated with benefits for the person with dementia (e.g. cognition, quality of life) and the carer themselves (e.g. quality of life, social support, increased knowledge).[1,3] Carers often understand the person's values, past experiences, and current circumstances, and can therefore help to identify potential goals and resources for rehabilitation (whilst ensuring that the client remains the focus of collaborative goal-setting). Involving carers provides opportunities for setting realistic and consistent expectations for rehabilitation outcomes. Carers can also assist in reinforcing new behaviours (e.g. strategies) outside of the rehabilitation setting (e.g., at home) to facilitate continuity,[1] which can enhance the person's **opportunity** and **motivation** (see the essay on involving carers in rehabilitation, page 83).

Examples: addressing engagement in rehabilitation

- Mark was a 69-year-old man participating in a home-based rehabilitation programme for people living with dementia.[3] During our first meeting, he was happy to talk with us but seemed disinterested in goal setting. His wife, Anne, became increasingly frustrated and angrily asked why he did not seem to care about improving his memory. We paused the goal-setting conversation to review with Mark why he and Anne had decided to become involved in the rehabilitation programme. Rather than focusing on his diagnosis of Alzheimer's disease (which Mark did not remember), we focused on the opportunity to learn some tips and techniques to help maintain his independence in some of his day-to-day activities. Mark understood this explanation and said that it was important to him to reduce the load on Anne. He asked some questions about what the sessions would involve, and we provided some examples of common rehabilitation goals and strategies to make the ideas clearer. Mark was more interested after this conversation and contributed some ideas to goal setting. We then arranged a separate appointment for Anne to provide her with education about Mark's diagnosis and cognitive difficulties and an opportunity to discuss her feelings, worries, and questions. We discussed expectations of rehabilitation and how to maximise her role as a partner in the rehabilitation process. At each subsequent session, we briefly reviewed with Mark the overall rehabilitation aim (to help maintain his independence and reduce the load on Anne) before introducing new strategies. We continued to provide Anne with support and coping strategies.

- Sofia was a 78-year-old woman with vascular dementia and frailty living in residential care. Her care team recommended regular exercises to reduce her risk of falling. However, Sofia was not interested in the exercises when the physiotherapist, Nancy, came to see her. After a team discussion about how to better engage Sofia, Nancy set aside more time on her next visit to talk with Sofia about her response to the exercises. Using open-ended questions, Nancy learned that Sofia was worried that the exercises would be too difficult, as Sofia felt her body had become weak. Nancy was able to adjust the exercises for a more graded approach, increasing in difficulty as Sofia became stronger. Together, they created a chart to document Sofia's progress and set small goals to work towards. Sofia loved music, so Nancy arranged for Sofia's son to create a playlist of favourite songs, which Sofia could choose from when it was time for her exercises. This helped to make the experience more enjoyable, and it became something that Sofia looked forward to during the week.

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Case studies

Reflections on Mama's reablement and my journey as her carer

Anita Plateris

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My Polish Mama (Babcia, as she liked to be called) was always active. My parents migrated to Australia in 1950. My father's death in 1990, after 41 years of marriage, left her with heavy grief and depression; however, we all kept her very busy and showered our Babcia with great love and affection. Mama took great pride in her much-loved home and wished to die there. As a family, we made sure everything was done to ensure her wish was fulfilled.

In 2015, at age 87, Mama was diagnosed with vascular dementia and Alzheimer's. The process of navigating Mama's home care had commenced a few years prior to this diagnosis, and I, as her main carer, was faced with the responsibility of introducing 'strangers', by way of support workers, into her home. As a survivor of the trauma of World War II, Mama was suspicious by nature. I encouraged her by suggesting that she would meet wonderful people coming to help, and they would become her new friends. I also needed their help and support, as, having given up work, I had very little idea of the enormous role I had taken on and the repercussions to come.

I was introduced to a reablement programme[1,2] in January 2016 by a local dementia advisor. I had no experience in caring for someone with dementia, and I saw this invitation to participate in the reablement programme as an opportunity for help, support, encouragement, and education. The programme's focus was on improving self-care ability and mobility by intervening directly on these abilities as well as health and environmental factors that alter them. Mama was intrigued, humbled, and grateful to be part of the programme, which would enable people like herself to stay in their homes and receive extra assistance and care. I gratefully welcomed suggestions and advice from the programme team, which enabled and assisted us to keep Mama safe, more independent, and comfortable in her home.

Over the four-month period of the programme, Mama had six home visits from the occupational therapist (OT), Niki, four from the registered nurse (RN), Helen, one from a neuropsychologist, and one from a clinical psychologist. I also received a psycho-education session, where the meaning and importance of reablement was explained, as well as the importance of my own health and wellbeing whilst I juggled my many responsibilities. This reablement team reinforced the fact that, while dementia affected Mama's memory, mood, decision-making, and day-to-day life, she still had a great opportunity to do things independently through collaboration and support. They explained that Mama needed to regain her confidence and sense of purpose, therefore it was important that the team direct all communication to Mama rather than myself as the main communication point. I learnt that Mama's need to feel she was the centre of the team's attention was the first step to give her sense of control back. At the same time, they reassured me of my role as a care partner and that my view was also important.

Mama responded very well to Niki's (the OT) home visits, assessments and exercise sessions. Mama's goals were, by the end of the programme, to be able to: 1) move around the house more freely, 2) get off her chair and get into her bed when she wanted, without having to rely on me all the time, and 3) go outside with her walker using the rubber grading slopes organised for her. Niki taught Mama to use a four-wheel walker safely and independently when sitting down and getting up to transfer from her bed, the lounge, and dining chair. To achieve these goals, Mama learned a set of exercises to improve her leg strength and balance. Niki also reminded us of the importance of these daily exercise goals, which I continued and encouraged other family members and support workers to do daily or as often as possible. These exercises consisted of such simple movements as: the "side-by-side step" outdoors while holding onto an external windowsill, "sit to stand", "lifting knee and lowering", and "small ball throwing". All exercises were to help mobility, strength, and reflex function. Niki offered helpful suggestions for Mama to help her get in and out of her kitchen chair as well as her recliner chair. Mama enjoyed Niki's visits and her new friendship. Mama's self-esteem and determination were boosted by every one of these sessions.

Niki assessed Mama's home to find out whether this environment was meeting her needs for independence. Consequently, Mama received home modifications and assistive device support, for example, the rubber grading slopes for the back door that enabled access to the back veranda and backyard, and casters to raise/boost her lounger, therefore enabling her to sit and get up. This was of great financial help.

Helen (the RN) spent intimate time with Mama discussing a variety of issues, including pain, depression, anxiety, panic attacks, confusion, strength, balance, incontinence, and bowel function. Helen also called monthly to get medical updates. Helen explained that she needed to understand if any of these areas prevented Mama from doing things she wanted. Helen's discussions with Mama were gently and sensitively conducted, and Mama felt most reassured and more confident after spending this time with her. Mama had nagging, dull arthritis and back pain most of the time, especially during the winter, post-war traumatic nightmares, and migraines that left her feeling nauseated and washed out. Helen provided clinical and mental health support as all those things affected Mama's desire to work on her goals.

Another goal was for Mama to assist with meal preparation, which was not happening at that time, according to the programme team, due to her low tolerance to standing, her arthritis and back pain, and limited ability to plan, remember, and follow things through. Niki worked with us to find a simple strategy which allowed Mama to be part of the meal preparation (Mama had spent many decades cooking delicious food for so many!). Mama would sit at the kitchen table, cut up and prepare food items, and assist as I prepared meals.

We also learned that Mama wished to be more involved in taking her own medication, rather than her medication being given to her without any involvement. Helen took the time to carefully explain all of Mama's medications to her and suggested that, while I oversaw Mama's pill pack, Mama could press out the tablets when needed, and I could prompt her to count them. This gave Mama more control over her own medication.

Another goal was for Mama to be able to know what was happening in the family. The programme team suggested a whiteboard, which was a great way for Mama, me, home care workers, and family members to keep up to date with daily occurrences and appointments. Mama viewed the whiteboard daily, and we would ask her for any contributions. We kept a daily journal as suggested, keeping track of Mama's food intake, medications, as well as journaling her bowel functions, incontinence, and anything else that occurred.

Overall, Mama responded well to the home visits with increased confidence and assuredness, and it was only on a few occasions when she wasn't wishing to get out of bed due to being very tired, unwell with a urinary tract infection, or bowel issues. Mama's mobility improved significantly so that she was able to move safely about her home without assistance, enabling her to feel more engaged than before she started on the programme. Mama felt happier with herself for being more active, and she felt more useful being able to perform small tasks. The programme was exactly what we needed at the time to achieve our goal of keeping Mama steady and stable in her familiar environment, her home. I believe this helped keep Mama's dementia from progressing so quickly. I always felt supported by the reablement team and therefore, as a carer, I didn't feel invisible.

Mama passed away peacefully, in her own home, at the age of 95; however, my journey as Mama's carer didn't end when she died. I needed time to recover from exhaustion, feeling lost and finding my purpose beyond my grief. Upon reflection, I can now have a little chuckle to myself instead of tears of sadness. I am left with peace in my heart knowing that I did everything to facilitate Mama's wishes of dying in her home. It was a great privilege to give my Mama such care.

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Gareth: 'I'll never give in'

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This essay is based in part on the BBC2 programme Horizon, which aired an episode produced by Charles Colville on Gareth on May 11, 2016.

Gareth, a man in his 70s, lived alone and was fiercely independent. He was determined to continue managing by himself and to keep living in his bungalow despite the challenges of Alzheimer's disease and other health problems. He had the support of his daughter, who lived nearby but was occupied with work and her own family.

Despite his desire to remain independent, many people were worried about Gareth. He was not eating well. He often went to the local pub, enjoying a drink and a bowl of fries or a pie instead of a healthy meal, which was affecting his health. When he did try to cook meals for himself, he usually ended up burning the food. This triggered a smoke alarm and meant the local fire brigade were called out. As a result, the adult social services team got involved. The social worker became so concerned about Gareth's safety that she suggested disconnecting his gas cooker to reduce the risk of starting a fire. Gareth's continued independence seemed under threat.

Fortunately, there was another option. Gareth and his daughter heard about a rehabilitation project, and Gareth was keen to give it a try. Cognitive rehabilitation practitioner Sue Evans got involved. Gareth told her he wanted to continue living in his own home and to be able to cook food for himself. Sue spoke to the social worker, who agreed not to go ahead with the plan to disconnect the gas cooker and to wait and see whether cognitive rehabilitation could help. Gareth's first rehabilitation goal was to cook a hot meal for himself each day without burning the food.

Sue could quickly see why Gareth was burning his food. He would put food on the stove or in the oven without planning how long it would take or when he needed to check on it. He would then go into another room and do something else; usually, he would start to watch television. He would get engrossed by the TV programme and forget about the cooking. He had lost his sense of smell, so he could not detect when the food started to burn. Sue watched as Gareth, prompted to go and see what was burning in the kitchen, extracted a pie from the oven that was, as he said, 'burnt to a cinder' and completely inedible. Gareth needed a strategy for planning his cooking and a prompt to check on the food at the appropriate time.

The strategy Sue and Gareth devised for planning the cooking was based on effortful processing, involving multiple modalities, and dual cognitive support, with the use of compensatory aids. First, with his daughter's help, Gareth obtained a whiteboard and a kitchen timer. When starting to prepare his meal, Gareth was to check the cooking time and write it on the whiteboard. For example, if the packaging said that a pizza required 20 minutes' cooking time, he would read the time, say it, and write it down. As Sue told him, this was because 'it's making you think more about it – by seeing it, saying it and writing it down, it's going through multiple processes in your brain.' Then, having done so, he was to set this time on his kitchen timer, which would serve as a recall prompt, and take the timer with him when he left the kitchen. Usually, Gareth would go and sit in his chair in the living room, and so he got into the routine of placing the timer on the table next to his chair. For the timer to be effective as a prompt, Gareth needed to connect the sound of the timer with the act of checking on the cooking. Sue got Gareth to practise going to check the cooker in response to hearing the timer, using an expanding rehearsal schedule during her visits. The strategies Gareth used are summarised in Table 1.

Table 1. Gareth's strategies for goal attainment

Target behaviour	Aid	Strategy
Note the cooking instructions – read, state out loud, and write on the whiteboard	Wipe-clean whiteboard and marker pen	Effortful processing using multiple modalities
Set the timer to sound when the cooking time is complete	Kitchen timer	Information from the encoding stage used to set up a recall cue
Respond to the timer alarm by going to the kitchen and checking the cooker	Kitchen timer	Practice using an expanding rehearsal schedule

Gareth practised these strategies for several weeks following the instructions he and Sue put together, with support from his daughter. Sue visited regularly to check on his progress. Once he was no longer burning his food, Gareth and Sue then agreed that he might be able to rely on the timer alone, without writing down the cooking time on the whiteboard. Gareth found that setting the timer and keeping it with him was enough to make sure he cooked his food for the correct time and did not burn it. After three months, this new routine was well established. Gareth was remembering to set the timer, which prompted him to go and check on the food at the right time. He fully achieved his goal, and the social worker no longer needed to disconnect his cooker. Six months later, Gareth was still cooking for himself using the timer.

Gareth's progress in cognitive rehabilitation was filmed for a science documentary that was broadcast on British public television; he was keen to share his story. Asked by the interviewer how he felt about his experience, Gareth said: 'I do believe I've improved tremendously… I'll never give in. They can put me in my box [coffin] but I'll never, ever give in.'

Section 3:

Implementing rehabilitation across stages and settings

Surfer, sailor, and wood turner Jerry Kermode in his workshop with a student in Point Reyes, California, USA in February 2019. (Photo courtesy of Alex Kornhuber)

Section overview

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Strong evidence exists that rehabilitation enables people with dementia to do the things they want and need to do to feel more confident, and to be as independent as they can be and wish to be. There has been growing evidence on implementing rehabilitation, as "the planned process for putting something into effect."[1] As presented in this section, we demonstrate how rehabilitation for people with dementia can be introduced or rolled out in various care settings in ways that can be acceptable, feasible, and sustainable at individual and service levels.

There has been a significant shift in narrative about rehabilitation among global dementia communities, which coincides with a growing research interest in the implementation of this area. The term Prescribed Dis-engagement™, coined by Kate Swaffer over 15 years ago, represents the negative experience of post-diagnostic dementia care, or lack thereof, reflecting societal and systemwide injustices and inequities in the care and support available to people with dementia, resulting in feelings of disempowerment and hopelessness.[2] For example, instead of a referral to a rehabilitation service after the diagnosis, Kate Swaffer was advised to give up all the meaningful work and life she had before the diagnosis and to prepare for a life in a care home. Her experience is not an isolated case, and such inappropriate treatment towards people living with dementia is a major barrier to rehabilitation implementation efforts.[3]

In the absence of available rehabilitation services, some people decide to find their own course of action. For example, in a previous section, we saw how John Quinn and Glenys Petrie (page 39) were determined to improve and maintain John's independence after his diagnosis in his 50s. The lack of rehabilitative care and support, or of any guidance from health professionals after the diagnosis, inflicted a heavy price given that John had to give up his work and experienced depression and despair in the early stages of his journey. Had an effective rehabilitation programme or service been in place, their experience would have undoubtedly been much more positive.

Rehabilitation pathways and unique considerations

Rehabilitation offers a set of guiding principles for providing services, support, and care. Rehabilitation is grounded in the understanding that disability and associated challenges can be addressed by enabling people to function optimally through proven strategies and methods in the context of their health and capability. Here, the focus is on working collaboratively with the person to strengthen what they can do, while addressing the very challenge that is disabling them. These principles can be flexibly applied to address different types of need at various stages of dementia, for people with various types of dementia, and in various settings (e.g., home, hospital, clinic, day centre, or care home).

There are various rehabilitation options that could be introduced in routine practice following a diagnosis of dementia. Ideally, the diagnosis of dementia should mark the beginning of rehabilitation through appropriate channels and referrals from a diagnostician who may be a general practitioner (family physician), geriatrician, old age psychiatrist, or neurologist. Depending on the availability and accessibility of rehabilitation services, the person may receive rehabilitation through the following broad pathways:

1. A home-based rehabilitation programme or service from visiting rehabilitation practitioners in the person's own home
2. A centre- or clinic-based rehabilitation service at a day centre or a memory clinic with or without an option of a limited number of home visits
3. A hospital-based rehabilitation service at a geriatric hospital or a general rehabilitation hospital after an episode of an acute health issue, fall or injury
4. A care home-based rehabilitation programme or a model of rehabilitation where the person had a diagnosis well before they came to the care home, or the diagnosis has been made while they are in the care home

Commonly, rehabilitation is seen as a specialist area involving specialist allied health professionals only; for example, physical therapists, exercise physiologists, occupational therapists, speech therapists, (neuro)psychologists, nutritionists, or dieticians. They may work as a single practitioner addressing a particular area of function (e.g., mobility, communication, daily living activities). However, regardless of settings, specialist rehabilitation practitioners and others providing rehabilitative care, as well as those who provide the care and support in general, will usually have the opportunity to work with each other. The key is establishing a process that enables those involved in care to collaborate with each other, underpinned by the principles of rehabilitation.

Stage of dementia and coexisting health issues

Rehabilitative care can be introduced at any stage of dementia, provided that it is tailored to the individual's needs and wishes and that goals are appropriate. For example, the goal of improving or maintaining the person's self-care ability in the early stages might involve mastering the use of a smartphone to order food online. In the moderate stages, however, the same goal might involve having the carer's help to order food while the person learns to unpack the food delivered and prepare the meal with the help of the carer.[4]

In the early stages of dementia, rehabilitation tends to involve specific approaches focusing on areas of cognitive disability, delivered by a single practitioner. For example, Maureen Schmitter-Edgecombe and Katelyn Brown (page 79) discuss ways in which compensatory strategies, aided by various devices and tools such as labels, smart pillboxes, reminder apps, and home safety devices, can enable the person's daily functioning. Rosalie Wang and colleagues (page 82) further explore the role of assistive technology and devices in rehabilitation and provide product examples that facilitate goal attainment during the rehabilitation process. Compensatory strategies and assistive devices are most commonly used in the early stages of dementia. In the context of early stages of dementia, rehabilitation can be offered by a single rehabilitation practitioner during the person's clinic visit or as part of a home-based rehabilitation programme. The choice of assistive device, along with compensatory strategies, needs to be made following a holistic assessment.

Whilst these methods are often used in the early stages of dementia, they can also form an important part of the rehabilitation plan for people with moderate or advanced dementia, regardless of a care setting. For example, in a care home environment, the person's goal can be to shower themselves, aided by a laminated sheet of simple, large, printed labels on the wall. If the person has moderate dementia, the practitioner involves a care worker who provides prompts for the resident to use the sheet at the beginning and end of the shower. Such an approach can engender a sense of achievement and empowerment over time in the person with dementia. Importantly, the person needs to be supported to test, practice, and use these strategies and tools, with the level of support needs calibrated based on the person's ability and stage of dementia (see Section 1).

The authors of the case studies in this section have all been inspired to find new ways of making home-based rehabilitation available for people with dementia, based on the GREAT cognitive rehabilitation (CR) model.[5] Jackie Pool and Sue Evans focus on training practitioners to deliver cognitive rehabilitation (page 95). The training they developed has enabled Mona Michelet and colleagues in Norway to introduce cognitive rehabilitation into the work of municipal memory services (page 97) and supported Michelle Kelly and colleagues in Ireland in their work providing specialist training placements for psychologists (page 99). Practitioners equipped with the skills to provide cognitive rehabilitation can identify innovative ways of making it available; Justin Mazzotta and Brenda M, who lives with dementia, describe how the approach has been used in a not-for-profit community organisation in the city of York, UK (page 101), and Reinhard Guss explains how he incorporates cognitive rehabilitation flexibly into his clinical practice in memory and psychology services in the UK (page 103).

The role of carers in rehabilitation

The majority of people with dementia live at home, often with support from their family, friends, and paid carers. It is not surprising that most dementia-specific rehabilitation services and programmes have been developed as home-based. When rehabilitative care is implemented in the person's home environment, the involvement of the primary carer (often a spouse or adult child) as a collaborator and care partner has been well acknowledged. Research evidence on the association between the level of carer involvement in rehabilitation and the success of rehabilitation for people with dementia is weak, largely due to a lack of rigorous research on this topic. However, there is a good amount of evidence suggesting that developing and implementing a personalised rehabilitation plan can benefit from collaboration with the primary carer.[6] In involving carers as partners in rehabilitation, it is important that carer needs are acknowledged and appropriate support and resources are provided or recommended, and that the carer is educated and supported in rehabilitative approaches where the person with dementia is not a passive recipient of care, but rather an active collaborator and decision maker in goal-setting, planning, and implementing. The role of the care partner is to enable the person with dementia to achieve their goals in a supportive manner, in collaboration with the rehabilitation practitioner, not taking over.[4,6] Maud Graff discusses the crucial role that carers play in rehabilitation (page 84).

Importantly, for those people with dementia living alone, the absence of a primary carer needs to be carefully considered throughout the rehabilitation process. In this context, building a collaboration with home and community workers or volunteers involved in the person's care is important. These workers may need to be provided with information about rehabilitative approaches as well as the person's rehabilitation plan, as some aspects of their work may involve the expectation of doing things for or to the person, instead of doing them with the person. Working alongside external services may require an integrated system of health and social care. Whether the partner in rehabilitative care is a family carer or a paid carer, the practitioner with team leadership qualities can drive collaborative care; through rehabilitative approaches, the person can build or regain confidence and have a meaningful life. Rehabilitation is a collaborative journey, a partnership between the person, the practitioner, and others involved, such as family members or care staff. It is about working together and making choices; 'doing with' rather than 'doing for' or 'doing to'.

> **"Rehabilitation is a collaborative journey, a partnership between the person, the practitioner, and others involved, such as family members or care staff. It is about working together and making choices; 'doing with' rather than 'doing for' or 'doing to'."**

Teamwork among practitioners from diverse disciplinary backgrounds

Broader multidisciplinary approaches that consider a range of complex needs, often in the context of comorbidities, are relevant at any stage and in any setting, including implementation in long-term institutional care settings and transition between settings. Laura Gitlin and Sarah Szanton (page 76) highlight the importance of multidisciplinary and interdisciplinary teamwork. This is particularly the case when the person with dementia, even in the early stages, has multiple coexisting health and physical issues. In this context, the need to involve a multidisciplinary team of practitioners becomes paramount. Multidisciplinary teamwork and interdisciplinary teamwork are often used interchangeably, but differ in the way they integrate their expertise. In both approaches, several practitioners (e.g., nurses, physiotherapists, occupational therapists) work with the same person to bring about the best health outcome for that person. Each practitioner in multidisciplinary teamwork works within their own scope of practice, with a separate intervention plan, and information sharing may be one way. For example, the nurse assesses the person's clinical and medical conditions and passes the information (usually through a medical record system) to an occupational therapist or a physical therapist for consideration. However, practitioners in interdisciplinary teamwork collaborate closely with each other, sharing and integrating their expertise and knowledge about the person to develop a collaborative rehabilitation plan. For an interdisciplinary approach to work well, coordination and respectful relationships among team members are essential, often becoming time-intensive, but the approach strengthens the opportunity for holistic and person-centred care. In implementing an interdisciplinary rehabilitation model, it is critical that the model provides tools for coordination, such as structured communication tools for case conferences, handovers and referrals, role clarification tools, and additional time for case conferences and team meetings, for example, as shown in the I-HARP and I-CHARP models.[4,7] In the previous section, Anita Plateris (page 67) provided a detailed account of her mother's rehabilitation goals and strategies, addressing her unique needs and circumstances resulting from older age and dementia coupled with various health and mobility issues. In addition to the support, they benefited from the interdisciplinary teamwork between the occupational therapist and the registered nurse as part of I-HARP.

Notably, most rehabilitation programmes are designed for people with common types of dementia, such as Alzheimer's disease or vascular dementia, and people with rarer forms of dementia may not be fully accommodated. The interdisciplinary rehabilitation model (e.g., I-HARP as home-based[4] and I-CHARP as care home-based[6]) attempts to address this gap. The model is co-led by the occupational therapist and the registered nurse, who collaborate with each other as well as with the person with dementia and their care partner, and then determine the need to engage an additional rehabilitation practitioner, for example, a speech therapist if the person has primary progressive aphasia (PPA). Nevertheless, much more work is needed in rehabilitation to cater for people with rarer types of dementia such as PPA and posterior cortical atrophy (PCA).

Unlike a home-based rehabilitation service, implementing rehabilitation as a model of care or as a distinct programme in a care home setting requires the involvement of the whole of the organisation, leadership and management, and the consideration of policies and rules that may determine the parameters of goals and strategies. The collaboration between the person with dementia and the practitioner extends to other personal and professional care staff employed by the care home, external agencies (hospital, primary care, ambulance service, to name a few), as well as the person's regular visitors, including their family. Yun-Hee Jeon (page 86) discusses key considerations for rehabilitation in this unique environment, highlighting the importance of addressing the readiness of staff and management, work environment, and culture for rehabilitative care using her I-CHARP model as an example. Barbara Resnick and Elizabeth Galik (page 106) illustrate their Function-Focused Care approach in nursing homes in the USA that addresses those care home context considerations, leading to improved functioning of residents with dementia.

Inclusive rehabilitation

Rehabilitation enables people to do what they want and need to do through creating and implementing an individual rehabilitation plan that is tailored to their needs and preferences and focuses on what matters to them. People living in remote areas or coming from minority communities, sometimes with communication difficulties, can experience added challenges in accessing appropriate and timely rehabilitation. Kate Laver and colleagues (page 89) explore these issues and provide ways to overcome or reduce such barriers through telerehabilitation and cultural competency training, demonstrating the need for inclusive efforts to facilitate rehabilitation access for all. Another important context for consideration is transitioning between care settings, often resulting from deterioration in the person's health, an operation or injury requiring hospital admission, or due to a need for respite care. Such transitions can occur in any setting, including between the person's home and hospital or care home for respite, or between care home and hospital. For example, the person may require an episode of rehabilitation that focuses on mobility, strength, and balance exercises after a corrective procedure due to a fracture. Lauren Beaupre and colleagues (page 92) discuss the importance of education and training for staff and practitioners and provide practical guidance and strategies that can be used in the rehabilitation process after a fracture or operation. Their essay also highlights the importance of a person's right to access rehabilitation following physical challenges. The emphasis here is that the need for rehabilitation after discharge from the hospital, either back to the person's own home or to their care home, is paramount, and having a dementia diagnosis should not be a reason for depriving the person of the benefit of rehabilitation.

Implementing rehabilitation: key messages

- **Rehabilitative care can be introduced at any stage of dementia** providing that it is tailored to the individual's needs, wishes and goals and that the evaluation outcome of rehabilitation aligns with the targeted area of function.
- Rehabilitation offers a set of guiding principles for providing services, support, and care. These principles can be flexibly applied to address different types of need at various stages of dementia, for people with various types of dementia, and in various settings (e.g., home, hospital, clinic, day centre , or care home).
- **Ideally, the diagnosis of dementia should mark the beginning of rehabilitation**. The first step of rehabilitation implementation at an individual level is understanding the person's context: where the person is in their progression of dementia (e.g., early, mild, moderately, or advanced stages), their background (e.g., age, socio-economic situation, employment, language, and culture), personal resources and support including their carer, social and support network, and community environment.
- Rehabilitation can be offered by a single practitioner where the focus is on addressing aspects of cognitive disabilities affecting daily functioning, but often needs to be multidisciplinary, and ideally interdisciplinary, as dementia progresses and coexisting health and physical issues become more prominent in the person's day-to-day living.
- Whether it is home-based or institution-based, the focus of rehabilitation should be on working collaboratively with the person to strengthen what the person can do while addressing the very challenge that is disabling them.
- **Carers of people with dementia (and paid carers and volunteers for those without a primary carer) play a pivotal role in the rehabilitation process** as partners in care working collaboratively with practitioners. To ensure a successful outcome, the needs of carers (e.g., support and education about rehabilitation) must be considered.

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Expert essays

Multi- and interdisciplinary rehabilitation models to enhance everyday function of people with dementia and their care partners

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A hallmark of dementia is the progressive loss of an individual's ability to carry out everyday activities such as bathing, dressing, or managing household tasks. This is a core characteristic of the disease process regardless of the cause or type of dementia. The functional decline that is characteristic of dementia is a consequence of neurodegeneration but may be worsened by other factors related to the person and/or their environment. For example, experiencing pain, poor sleep, or disorientation – referred to as factors intrinsic to the individual – can contribute to poor function in daily activities. Living in a cluttered environment, being confronted with complex or multi-step tasks such as dressing or overly complex communications by family members, or even background noise, are extrinsic factors that can interfere with an individual's participation in everyday activities.[1]

As most people with dementia live at home, they become increasingly dependent upon family members, friends, or neighbours to assist with daily activities. However, family members or care partners may not receive dementia education or be told about strategies that can help them and the person they care for function better in their environment.

The good news is that there are emerging rehabilitative approaches that strive to slow the rate of functional decline, even for a brief period, and/or minimise what is referred to as "excess disability" or dependence over and above the declines which are a consequence of underlying neurodegenerative processes. Optimising an individual's function at any stage of the condition can improve their quality of life, lessen the time care partners spend providing hands-on assistance, and alleviate some of their physical and emotional burdens. As such, helping people engage in everyday activities or participate in aspects of these activities as long as possible is a key treatment goal in dementia care.[2]

> **"Optimising an individual's function at any stage of the condition can improve their quality of life, lessen the time care partners spend providing hands-on assistance, and alleviate some of their physical and emotional burdens."**

Rehabilitative approaches can be introduced at any stage of the condition from mild to advanced, and in any care environment – including homes, assisted living or nursing home facilities, adult day services, or hospitals. For those in the early stages of dementia, a professional from a single discipline (a speech and language therapist for communication, or a clinical psychologist or neuropsychologist for memory difficulties, for example) may drive rehabilitation. As the person experiences more challenges overall in day-to-day activities, often made more pronounced by coexisting health conditions, coordinated input from various professions is needed. These approaches share common features. First, they are often multidisciplinary and at times interdisciplinary, drawing upon the expertise of a wide range of health providers, including but not limited to occupational therapists, nurses, physical therapists, speech and language therapists, psychologists, social workers, and others.[3,4] These disciplines all work with families somewhat differently, but each provides non-pharmacological strategies that can help individuals continue to engage in valued activities. They also share the common goal of supporting individuals at any stages of dementia and provide care partners with the requisite dementia education and actionable strategies they can use to support care and address their own wellbeing.

A second common feature is that, regardless of their disciplinary focus, effective interdisciplinary rehabilitative approaches assume a family-centric approach such that care partners are viewed as valued members of the treatment team and treatment process. Care partners are also typically responsible for continuing to use rehabilitative approaches on their own with the person with dementia, so their involvement in the rehabilitative process is central to the effectiveness of the approach. As such, consideration of their viewpoints, abilities, availability, and treatment preferences is critical to the rehabilitative process.

Care partners typically need instruction and support to implement prescribed strategies or oversee and supervise recommended exercises, techniques, or other approaches. Concomitantly, providing dementia education and helping care partners understand the cognitive and functional abilities of the person for whom they care is an important element of effective rehabilitative models in dementia care.[1] Many care partners overestimate the abilities of the person with dementia. This can lead to their use of overly complex communications and expectations that may exceed the capabilities of the person with dementia. This, in turn, may result in anxiety, agitation, or other behaviours in the person with dementia.[5] Also, the opposite may occur. Some care partners underestimate the abilities of the person. Underestimation of the individual's abilities can similarly lead to negative consequences. For example, in this scenario, care partners may limit the person's participation in daily activities and do more for the person than may be necessary. This, in turn, can contribute to the person experiencing excess disability, a feeling of a loss of control and purpose, and increased anxiety.

Third, regardless of approach, rehabilitation is personalised to the abilities, interests, and preferences of both the person with dementia and the care partner. As a "one-size-fits-all" approach is ineffective in addressing functional challenges, customising strategies is critical and based on assessing and understanding the care context in which daily function occurs.

A fourth shared characteristic is that promising approaches target either the person living with dementia directly, the physical environment or living space, the care partner, or a combination thereof. Approaches targeting the person, in addition to specific goal-oriented rehabilitative work, may support the rehabilitation programme by designing activities that are tailored to the person's abilities at whatever stage they may be across the spectrum of dementia. For example, at a mild stage, setting up a multi-step craft activity can provide a sense of purpose, reduce boredom and agitation, and support function. At an advanced stage, providing sensory experiences such as listening to calm music or chair exercises are a way to engage individuals and preserve a sense of purpose. When targeting the care partner, instruction in effective ways to communicate or simplify everyday tasks can reduce their burden and align their expectations with the capabilities of the individual. Similarly, setting up environments to enhance safety, reduce fall risk by decluttering, or using signage, other visual cues, and/or assistive devices such as grab bars or handheld showers, all help to reduce the complexities of environments and facilitate their navigation by a person with diminishing cognitive and functional abilities. Regardless of the target or particular strategy, these approaches are typically dependent upon the availability, capability, and readiness of care partners to enact strategies as part of daily routines or to oversee, supervise, or fully implement a given function-enhancing strategy.[6]

Finally, rehabilitation can involve introducing an array of non-drug strategies. For example, occupational therapists may help families modify their physical environment by decluttering, regulating over- and under-stimulation, and using assistive devices, grab bars, memory-enhancing whiteboards, calendars, labels, pictures, or other demarcations. Social workers may work with families on emotional regulation and cognitive framing techniques. Psychologists may introduce techniques to address how changes in cognitive functioning impacts everyday activity. Nurses may help care partners address daily health concerns such as hydration, pain management, or sleep disturbances. All health professionals, regardless of the rehabilitative approach, may help care partners communicate effectively, such as using verbal and/or nonverbal cues, one-step directions, speaking slowly and clearly, simplifying activities, or a combination thereof.[7,8]

> **"Approaches [...] personalised to what matters most to individuals with dementia, care partners, and families help direct the rehabilitation process to assure alignment of strategies with their goals and preferences."**

In conclusion, as a complex progressive degenerative condition, rehabilitation models for people with dementia generally require at least a multidisciplinary, and ideally an interdisciplinary, approach. Additionally, effective rehabilitation approaches are person centred and person directed. Addressing what matters most to the person and their care partner is paramount. That is, these approaches are personalised to what matters most to individuals with dementia, care partners, and families help direct the rehabilitation process to assure alignment of strategies with their goals and preferences. Every health provider has a role in providing supportive rehabilitative approaches to address functional challenges and care partner wellbeing. Although more research is needed in this area, there are evidence-based approaches available now that can improve the quality of life of families. The challenge remains instructing health providers in these programmes and implementing them in home and healthcare settings.

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Finding the rhythm: everyday strategies for living well with mild dementia

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Compensatory supports are tools or strategies that help with tasks someone may have trouble doing on their own, like remembering things. For example, someone might use a written checklist to keep track of daily routines or a voice recording to recall instructions. Devices like smartphone apps that provide reminders can further enhance the effectiveness of some strategies.[1] Among older people, using these kinds of supports has been linked to slower memory decline and better day-to-day functioning.[2] Even for healthy brains, helpful strategies can be hard to learn, so how they are taught and practised matters. This is even more important for people with dementia.

How to teach and support compensatory strategies

Developing effective compensatory strategies for people with mild dementia as part of a rehabilitation plan works best when it is based on habits, tailored to the individual, and flexible. It is important to focus on what the person can still do and build on their strengths, so they can stay involved in daily life as much as possible. Flexibility is key, since the person's needs and abilities will change over time, or even from day to day. There will be ups and downs, with some 'good days' and some 'bad days', so strategies need to be adjustable depending on how the person is doing. To help new compensatory strategies work well, here are some things that can make them more successful:

1. **Making strategies into habits**: When a strategy becomes a habit, it is easier to use, especially on days when memory or thinking is harder. Just like brushing your teeth, a habit can happen automatically, without needing to think about every step. To support habit formation:
    a. **Use daily routines**: Habits built into daily routines are more likely to be successful. Try to connect the new strategy to something the person already does every day, for example, checking a calendar right after breakfast.
    b. **Cues and triggers**: Doing the task the same way each time – same time, same place, same order – helps the compensatory strategy become more automatic and easier to use over time.
    c. **Be consistent**: Consistency is also important for reinforcing habits. Keep tools in the same spot (like a calendar on the refrigerator) and maintain a predictable routine (like taking medicine with lunch).
    d. **Start small and build slow**: Begin with one or two strategies. Give them time to become part of the routine before adding more. This may take several weeks.
2. **Layering strategies**: Sometimes, using more than one strategy at the same time makes things work better. For example, using both a calendar and an alarm to remember appointments, or a pill organiser along with a checklist to keep track of medications. Think of it like adding extra support, just in case one method does not work.
3. **Visual and environmental support**: Simple changes in the home can make a big difference. Keeping items in the same place, labelling drawers, colour coding, and putting up signs can make it easier for someone to find what they need without having to remember everything. These visual and environmental cues take some of the pressure off their memory.
4. **Getting back on track after disruptions**: If the person falls out of a routine, that is okay. A clear, gentle way to get back on track can help. Familiar reminders – like a note on the refrigerator, a carer walking through steps, or returning to past strategies – can support reconnection. Practising the habit again in the same way, at the same time, or in the same place can build comfort and confidence.
5. **Carer support**: Carers play a big role in helping strategies work day-to-day. They can remind the person to use the strategy, keep things consistent, and step in gently when routines are forgotten or disrupted. The goal is to support the person in a calm, patient way – without pressure or frustration – so the person feels confident and respected.
6. **Mood and motivation matter**: How someone feels can affect how well they use a strategy. If they feel sad, anxious, or unmotivated, they may not follow through, even with strategies that usually work. This is why it helps to notice their mood, adjust support as needed, celebrate small wins, and keep activities meaningful. A positive mood can make strategies easier to use.

7. **Trial and error are normal**: Not every strategy works for every person – and that is okay. Dementia affects everyone differently, so it may take some experimenting to find what helps most. If something isn't working or is causing frustration, it is okay to stop and try something else. Flexibility and patience are key.

> **"It is important to focus on what the person can still do and build on their strengths, so they can stay involved in daily life as much as possible."**

Finding a new rhythm: supporting daily routines with compassion

George, 74, was diagnosed with mild dementia a year ago. He lives at home with his wife, Linda. He has always been independent and enjoys doing things around the house, especially watering the backyard plants and making breakfast. Lately, though, Linda has noticed some changes. George sometimes forgets to water the plants and starts breakfast, but leaves the stove on or walks away mid-task.

Linda wants to help without taking over, so she starts by focusing on the parts of the day that are still working well – like George's habit of reading the newspaper with coffee each morning. She uses that routine to build a new one: right next to the coffee maker, she places a simple laminated "Morning Checklist" with just two tasks: "Water the plants" and "Make breakfast." She also adds a small sign near the back door that says "Watering Can" with a photo of their garden.

At first, Linda completes the routine with George, guiding him through the checklist. Some days go smoothly; other days, he seems distracted or frustrated. On those days, they take it slow. If it doesn't work out, Linda reassures him, and they try again the next day. They also experiment with different things. A voice reminder from Linda's phone felt too jarring for George, so they dropped it and stayed with visual cues instead. Over time, checking the list became part of the morning rhythm, and George began reaching for it on his own. Linda reminds herself to stay flexible. On days when George is feeling low or confused, they sit outside with coffee instead of pushing the checklist. She has found that keeping the mood light and adjusting expectations helps them both feel more successful.

With a mix of routine, visual prompts, patience, and trial and error, George continues to take part in his morning activities. Linda also feels more confident supporting him without taking away his independence.

Beyond the strategy: what helps it work

There are several other things that can help make compensatory strategies work better. These do not replace the strategies themselves – but they can support brain function, mood, and overall wellbeing, which makes it easier to use strategies consistently.

1. **Medication review**: Some medications can affect memory or thinking. For example, anticholinergics, a group of drugs used for things like allergies, bladder issues, or depression, can block a brain chemical called acetylcholine, which is important for memory and learning. Benzodiazepines, which are often used for anxiety or sleep, can make people feel drowsy or foggy, and may slow down thinking. It can be helpful to talk with a doctor or pharmacist to review current medications and see if any changes might help improve focus or reduce confusion.
2. **Managing mood and mental health**: Depression, anxiety, and other emotional changes can make it harder to use strategies. For example, someone might feel more anxious in the evening or get upset when routines are disrupted. Treating these conditions and understanding what triggers distress can help the person feel calmer and more capable.
3. **Brain healthy habits**: Healthy habits that support the brain – like regular exercise, staying socially connected, doing new or interesting activities, getting good sleep, and managing stress – can help the person function at their best. When someone feels better physically and mentally, it is easier for them to remember and use their strategies.
4. **Tracking progress**: Tracking how strategies work can help individuals and caregivers see what is going well and what may need to change. This can be as simple as taking notes or using a checklist to spot patterns over time.
5. **Using technology thoughtfully**: Technology can be helpful, but only if it fits the person's needs and comfort level. It is important to make sure the tools are easy to use and feel natural in a person's daily life. If a device feels confusing or stressful, it may not be the right fit.

Concluding thoughts

Compensatory strategies can support many areas of daily life for people with mild dementia, not just memory. From hearing aids and large-print labels to smart pillboxes, reminder apps, and home safety devices, there are a growing number of tools designed to help individuals stay safe, independent, and engaged. As technology advances and our understanding of dementia expands, so do the possibilities for meaningful support. The key is finding the right mix of strategies that align with the person's needs, preferences, and daily routines. With patience, creativity, and collaboration, individuals with mild dementia and their carers can navigate challenges and use compensatory support in ways that feel manageable and empowering. Progress may not always be linear, but with time and teamwork, it is possible to find a rhythm that works.

> **"The key is finding the right mix of strategies that align with the person's needs, preferences, and daily routines. With patience, creativity, and collaboration, individuals with mild dementia and their carers can navigate challenges and use compensatory support in ways that feel manageable and empowering."**

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The role of assistive technology in home-based rehabilitation for people with dementia

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Assistive technology includes products and services that can help people with dementia to maintain or improve daily functioning, reach their rehabilitation goals, and live independently and safely at home for longer. During rehabilitation, practitioners can complete assessments and match products and services with people's goals, abilities to use or learn to use products, and personal preferences and situations. Other important services can involve follow-ups to monitor for changes and maintenance or repair of broken products.

As a tool used in rehabilitation, assistive technology can help people with dementia to help themselves, which can improve their health, wellbeing, inclusion, and life choices. Assistive technology can help carers to support the people they care for more easily and safely. Society can benefit from this technology as well. The improved health, wellbeing, productivity, and economic situation of people with dementia and carers can result in decreased health and social services costs.[1]

Assistive technology products for diverse goals across the stages of dementia

There is an increasing focus on designing and evaluating assistive products and services and understanding how these can support rehabilitation for people with dementia. These products can assist people with dementia and carers with single or multiple rehabilitation goals.[2] Products may be designed for people with specific abilities or may be consumer products that anyone can use. Assistive technology products range from simple aids, such as magnifying glasses, to complex systems, such as smart home technology installed to monitor people's activities.[3] In many cases, simple products that are familiar are best. Even with complex products such as smartphones, there are versions designed to be easy to use.

There are products to help functioning in every life area. These are some examples of products that support various types of rehabilitation goals:

- Mobility goals: wheelchairs, walkers, stair lifts, and canes allow people to move around more easily.
- Self-care goals: adaptive utensils support independent eating, modified clothing supports easy dressing, and grab rails help with getting in and out of the bath independently.
- Memory goals: simple products like whiteboards, clocks, diaries, and calendars assist with memory-related goals; electronic calendar apps and scheduling apps on smartphones help with planning and remembering appointments; and more complex memory aids like voice-activated devices with virtual assistants provide reminders and other functions.
- Communication goals: video chat apps on tablets or smartphones help maintain social connections.
- Safety-related goals: wearable devices such as smartwatches can detect falls and provide alerts to carers through a smartphone, and automatic door locks and tracking devices can monitor a person's whereabouts.

Virtual reality systems can support multiple functional goals. For example, in rehabilitation, someone can practise goal-oriented activities such as paying for groceries or withdrawing money from a bank machine in a simulated environment prior to carrying out the activities in real life.

The changing abilities and needs of people with dementia mean that the products that can support their functional goals change as their condition progresses. A range of products is available across all stages, but most assistive technology is directed at people experiencing the earlier stages of dementia.[4] People with mild or moderate dementia are most likely to use various types of assistive technology to support functional goals related to maintaining daily routines and independence. As dementia progresses, the use of assistive technology tends to reflect different goals, such as the application of weighted blankets or music-based devices to help manage anxiety. There is scope to further develop the application of assistive technology for people with more advanced dementia. With technology changing quickly and the number and type of products growing, people with dementia and carers have more ways to support their functional goals, which often require multiple products to assist with everyday functioning.[2]

Improving access to and use of assistive technology

For people with dementia and carers to benefit from assistive technology, they require the means to access and use it. Many people cannot afford what is needed because of the high costs of products and the need for multiple products and services. They may require funding to pay for products and services through public or private schemes. Also, the vast amount of information available on products and services can be overwhelming. People with dementia and their carers require clear guidance on costs and benefits to inform decisions about purchasing products and services that support their rehabilitation goals. Additionally, information and guidance on the different functions and features of products specific to their situations, as well as the risks associated with using or not using different products in their rehabilitation, can aid in decision-making. This information can be delivered through trusted websites, trained rehabilitation practitioners, and service centres where people can learn about products and borrow some to try for themselves. Importantly, all information needs to be provided in formats and language that are understandable by people with dementia so they can be involved in decisions that affect them.

Access to and use of products and services vary worldwide.[5] In some countries, products like mobility aids may be available and locally made to suit the environment. Generally, there is less awareness of products that help to manage cognitive challenges and promote function and independence. Complex electronic products like smartphones can be particularly useful since they are multipurpose and not stigmatising. However, these devices and the infrastructure to use them may be unavailable or unaffordable. Rehabilitation services to support product access and use may also be unavailable. There is a need to create lower-cost products that can be easily used by people with dementia and for larger-scale regional purchasing by funders to reduce costs. Ongoing advocacy on a global level is needed to improve access to assistive products to support rehabilitation services for people with dementia.

The right training and support at the right time is important to making the best use of products to achieve functional goals. The rehabilitation plan can include a focus on learning how to use products and their features to assist with these goals. Training needs to be personalised to a person's cognitive abilities and other strengths, as well as the level of carer support available to assist with product use. In the early to moderate stages of dementia, people are often able to learn skills needed to use products that are new to them. People can benefit from opportunities to test different products to choose the ones that work for them. Learning strategies that involve direct practice of skills in a distraction-free environment related to their goals, such as a home kitchen for assistance with meal preparation, can often help. It is also helpful to break down complex tasks into simpler tasks to assist with gradual learning. Familiarity with products is valuable, and introducing products in the earlier stages of dementia can give people a chance to learn how products work so they can continue to use them even as their condition progresses. Ongoing learning can be supported with written or video-recorded instructions. "As needed" support to answer questions, such as through a telephone service or local service centre, can help to maintain product use. Follow-ups and maintenance training can be beneficial to address changes in abilities or technology updates. People with dementia and their carers may have different goals when using the same products, but support from carers to learn how to use and include products in daily routines is beneficial.

In summary, assistive technology can help people with dementia to achieve a wide range of functional goals, from promoting home safety to participation in social activities in the community. As such, assistive technology is a vital tool in home-based rehabilitation that enables people with dementia to improve their health and wellbeing and to live at home for as long as possible.

Acknowledgements

Thanks to Amy S. Hwang and Erica Dove for their assistance in earlier versions of this essay.

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The role of carers in rehabilitation for people with dementia

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> *'Look, he is happy doing the gardening by himself with the adaptations I made. Now I don't feel helpless and stressed anymore, and I have time to relax and do my own activities.'*
>
> *A carer*

About 70% of people with dementia in the Netherlands live at home with support from an informal carer, in most cases a family member ('carer' hereafter). Most carers are partners (70%) or daughters (28%) of people with dementia. They devote many hours to providing care,[1-4] increasingly so as the person with dementia becomes less able to function independently in daily activities. This gradual loss of self-reliance not only affects the person with dementia[1,4] but can also put pressure on relationships, increase the demands on family members and other carers such as neighbours or friends, and lead to a need for support from paid and unpaid professional carers.[1-6] At least a quarter of carers say they find their role highly challenging, and half experience signs of depression.[4,7] Effective rehabilitation interventions that decrease or compensate for disabilities in carrying out daily and social activities and promote independence are beneficial not only for people with dementia, but also for their carers. These interventions help to sustain the caring relationship and enable people with dementia to be as independent as possible and stay at home longer, which is especially important in our rapidly ageing societies. [1-4, 8-9]

Multicomponent, individualised, and tailor-made interventions that are focused on the needs of the person with dementia and their carer and on feasible goals that are related to dealing with cognitive impairment are most effective in enabling both people with dementia and their carers to participate and remain engaged in daily and social activities, preventing social exclusion and a decrease in quality of life.[9-11] For example, a community occupational therapy in older people with dementia and their carers (COTiD, *or EDOMAH in Dutch*)[5-7,9] is grounded in the life stories and needs of both the person with dementia and the carer. It focuses on collaboratively setting realistic goals related to improving self-direction and autonomy, addressing the impact of cognitive, physical, and social disabilities, and reducing the carer's sense of burden. The aim is to improve meaningful daily functioning, social participation, health, and quality of life for both the person with dementia and the carer. Evidence from this Dutch research shows the programme is effective[5,7] and cost-effective,[6] and it has been implemented in several European countries. A similar focus on the needs of both the person with dementia and the carer can be found in multi- or interdisciplinary rehabilitation approaches in community, outpatient and nursing home settings (see page 85).

Experience from the COTiD programme illustrates the importance of including the carer in rehabilitation interventions. Both the person with dementia and the carer are experts on their own living situation; they know best what is meaningful to them, what their wishes, interests, routines, roles, and abilities are, and what emotions and feelings they experience in challenging situations. Therefore, the starting point is to hear the personal life stories and needs of the person with dementia and the carer and understand their motivation for retaining a meaningful life and learning to deal with the cognitive disabilities. Their stories, together with the observations of the occupational therapist, form the basis for the shared goal-setting process undertaken by the person with dementia, the carer, and the occupational therapist. In this meeting, they define together the most important and feasible goals that the person with dementia wishes to achieve. Carers are involved in finalising the goals as they may have additional insights to help ensure the goals are achievable.

The occupational therapist coaches the person with dementia in retaining their self-direction and autonomy by taking the lead in carrying out meaningful activities. This involves effectively using the person's various abilities and strategies in daily activities, supported by making adaptations to their physical and social environment if needed. To make this possible, the carer has an important *role as carer* in supporting and sustaining their relative's success in carrying out meaningful activities. Carers are coached and trained in effectively supporting the self-direction and autonomy of their relative, in effective problem-solving and supervision, resulting in solutions for adapting the physical environment, and in effectively supervising and supporting their relative with dementia in doing meaningful activities. At the same time, carers have their own needs and problems in dealing with their caregiving role. They therefore also have the *role of client* in this programme. They have their own needs and wishes for living a meaningful life and achieving a good balance between their care tasks and their own preferred activities. How they deal with the caring role is important to enable them to live a meaningful life as well, and to support their relative in staying at home as long as possible. The occupational therapist coaches carers to retain their self-direction and effectively use their coping strategies to better deal with their caring role, continue meaningful activities and achieve a good balance in life.

Some family members readily take up this crucial role in rehabilitation, while others may not. It is important that rehabilitation professionals discuss the carer's needs, explain the carer's role in the rehabilitation process, and outline the likely benefits to the person with dementia and to the carer, as well as the anticipated challenges. The programme may reduce carer distress as carers are able to share their concerns with rehabilitation professionals, become more competent in supporting their relative, and develop effective ways of managing difficult situations. Learning to better handle their caring situation can give them more space for their own meaningful activities and balance in life. The rehabilitation professional has a key role in informing and engaging both people with dementia and their family members in participating together in the rehabilitation process.

In the absence of a willing and available partner or offspring, another family member, neighbour, friend, volunteer, or paid or unpaid professional can take the carer role and participate in the rehabilitation intervention. The decision about who will take the carer role and support the rehabilitation process should always be discussed right at the outset, in the very first meeting. It is important that all rehabilitation professionals ask the carer whether they are willing to take part in the intervention, ensure the carer's role is clear, and explain what to expect. In COTiD, this is always discussed in the introductory meeting, so the carer understands their role as both a carer supporting the intervention and a recipient of support. Sometimes, family members are not motivated to participate in rehabilitation because they do not consider themselves carers and feel they are managing alright. If the person with dementia shares this view, information about rehabilitation options and likely benefits can be shared, and an option to revisit the rehabilitation opportunity later can be offered.

In summary, carers play a crucial role in rehabilitation.[12] Carers are indispensable for setting shared and feasible goals together with the person with dementia and the health or social care professional. Goal setting can be challenging for people with moderate to advanced dementia, and carers can give vital assistance where needed. It is important that the goals are supported by both the person with dementia and the carer. This gives the best chance of success in improving everyday functioning, maintaining abilities and strategies, and adapting the physical environment. Carers are key to enabling people with dementia to stay at home for as long as possible, sustaining the effects of rehabilitation in the longer term, and securing additional support from their social network and from paid home carers if needed. In rehabilitation, it is important to focus not just on the needs of the person with dementia but also on the needs of the carer. Enabling the carer to deal with the challenges of their role, stay engaged in meaningful activities, and maintain balance in life is crucial to preserving care at home for the person with dementia.

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Rehabilitation in long-term institutional care

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The overwhelming majority of older people wish to remain in their homes until they die. Long-term institutional care (LTIC), e.g., long-term care facilities, nursing homes, or residential care homes, are seen as a last resort. Yet, transitioning to LTIC becomes inevitable for many due to their increased healthcare needs, limited support either from a family or home and community services that would otherwise enable them to stay at home, and occasionally because of their desire for a safer environment and social connectedness. In most high-income countries, a growing emphasis has been on the provision of long-term care for older people at home, with trends of declining LTIC bed numbers, reflecting individuals' desire and choice and high costs of institutional care.[1]

Surgeon and writer Atul Gawande poignantly described that:

> *Our elderly are left with a controlled and supervised institutional existence, a medically designed answer to unfixable problems, a life designed to be safe but empty of anything they care about.*[2]

Sadly, most people still hold this view about LTIC, despite increasing efforts of governments, regulators, and service providers in many countries that have focused more attention on person-centred care, respecting individual choice, dignity, autonomy, and independence.[3] We know that most residents in LTIC are in their 80s, although the entry age for people living with dementia tends to be younger than for those without. Contrary to the common belief that LTIC is the place people go to die, the average length of stay in LTIC falls between 1.8 and 3.1 years.[4] As people get older, the chances of having multimorbidities, which refers to multiple coexisting chronic conditions (particularly dementia, stroke, diabetes, arthritis, Parkinson's disease, hypertension, heart disease, lung disease, depression, anxiety, visual and hearing impairments, sleep disorders, and incontinence) increase substantially and almost all residents in LTIC have multiple chronic conditions concurrently.[5] Despite their complex care needs, care is provided largely by personal care workers, with a limited number of qualified nursing workforce, many of whom are trained to focus mostly on clinical care tasks, rather than holistic care,[6] while often no or limited numbers of allied health workers are available. Access to primary care physicians and specialists, as well as allied health practitioners, is usually outsourced, which means multidisciplinary rehabilitation is often limited.

Key considerations for rehabilitation in LTIC settings

The location of care or the person's residence does not alter the principles of rehabilitation. A main distinction from home-based rehabilitation is the involvement of the whole of the LTIC organisation and its proactive leadership, often requiring changes in the culture of individual care homes and work environments, as well as improving staff knowledge, attitudes, and behaviours concerning dementia rehabilitation. Individual care home policy can also play a role. For example, some care homes do not allow residents to go out on their own, to iron their clothes, or to use a kettle to make tea in their room for safety reasons, which can severely impact the resident's rehabilitation plan without due consideration of the individual residents' ability.

> **"A main distinction from home-based rehabilitation is the involvement of the whole of the LTIC organisation and its proactive leadership, often requiring changes in the culture of individual care homes and work environments, as well as improving staff knowledge, attitudes, and behaviours concerning dementia rehabilitation."**

Unlike home-based rehabilitation, there are multitudes of care staff (e.g., nurses, care workers, allied health professionals, pastoral care, and diversional therapists or lifestyle coordinators), managers, domestic care staff (cleaners, kitchen staff, and facility repair staff), and regular visitors (family, relatives, and friends) who play an important role in the resident's day-to-day life and independence.

Two other major considerations are the residents' complex care needs due to multiple coexisting health conditions and their age, often in their 80s and 90s. As a result, frailty is highly common, with a high risk of malnutrition and limited mobility, relying on assistive walking devices or a wheelchair. They may have more advanced stages of dementia than those in non-LTIC settings and may take more than five medications at the same time regularly, including medicines for mood and behaviours.

All of these may in turn adversely affect the resident's daily function, especially their motivation and capacity to participate in rehabilitation.

Therefore, rehabilitation plans for residents in LTICs usually require interdisciplinary teamwork involving nurses, allied health professionals (e.g., physiotherapist, occupational therapist, dietician, or speech and language therapist), as well as doctors. Notably, as the complexity of the resident's care needs grows, their rehabilitation plan is less likely to focus on or involve enhanced learning strategies; instead, compensatory strategies are more commonly used, aided by assistive devices. Their goals tend to be smaller in scale to ensure feasibility and motivation.

Rehabilitation models in LTIC settings

Compared to community and home-based rehabilitation, rehabilitation for people living with dementia in LTIC settings receives little attention from both care and service providers and those who are using the service, largely due to a combination of ageism and stigma towards dementia and LTIC. A small but steady number of studies have shown the benefits of rehabilitation for residents with dementia in LTIC, for example, improvements in their mood, functioning (mobility, physical activity, and self-care), activity engagement, and quality of life.[7,8] Function-Focused Care (FFC) in the USA, and LifeFul[9] and Interdisciplinary Care Home bAsed Reablement Programme (I-CHARP)[10] in Australia are care models based on the principles of rehabilitation that implement rehabilitation at the organisation or individual LTIC setting level. For example, implementing an FFC approach involved environmental and policy assessment, staff and family education, developing personalised goals with residents, and ongoing mentoring and motivating nursing staff and people with dementia.[11] The aim was to change the attitudes and behaviours of staff to focus more on improving residents' functional independence, by teaching and mentoring staff to implement appropriate strategies and skills, and to actively engage residents in person-centred, physical, and functional activities, while engaging management to enhance organisational processes. In a study of an FFC approach to the care of residents with moderate or advanced dementia in nursing homes, short-term improvements in residents' daily function (e.g., personal care and mobility) were observed at three months, but these were not sustained at six months[11] (page 106).

Mary's story

Here, Mary's story from I-CHARP illustrates the complexity of care needs but also shows how her rehabilitation plan has positively impacted many other people in the care home. Mary is in her early 70s and has been living in a care home for the past two years. She has a daughter visiting her regularly, and enjoys crafts, music, board games, films, and aromatherapy. She is a stroke survivor and has moderate dementia, chronic mental health issues, hypercholesterolaemia, hypertension, asthma, chronic lung disease, chronic back pain, and Parkinsonism. She needs assistance with walking, is incontinent, and is currently on 17 regular medicines, including regular pain medicine. She speaks slowly and has some difficulties with communication caused by neurological impairment resulting from her long-term medication use for a chronic mental illness.

Mary's goals are to increase confidence in grooming and showering, to complete strength/balance exercises three times weekly, and to attend the garden daily. These goals require a registered nurse working with a doctor and a pharmacist to review her medications, while ensuring pain is well managed for exercise and walking; and an occupational therapist working with Mary and care staff to assess and break down components of showering and grooming to understand her capability. Care staff are involved in managing Mary's incontinence by taking her to the bathroom on a regular basis rather than relying fully on incontinence pads, and prompting and encouraging Mary to do parts of showering and grooming herself. The care home team worked with Mary's daughter, who was happy to visit Mary frequently and be part of Mary's daily walk to the garden. The care home built a vertical garden for Mary and several other residents who expressed interest in gardening.

Mary is now able to enjoy attending a vertical garden three times weekly with her daughter, other residents, and lifestyle staff. Before the rehabilitation programme, her daughter did not know how best she could support her mother; she is now visiting her mother daily and has taken a volunteer role to support other residents, which helped her gain an additional sense of achievement, rather than focusing on difficulties with care. The care home manager is also involved in gardening, and several staff, residents, and Mary have been planting and nurturing different plants since the commencement of the vertical garden. Mary still needs prompting for her personal care and exercise, but is willing to continue work on those areas.

Conclusion

The person's desire to have a purposeful life and a degree of independence despite disabling health conditions is not diminished just because they rely on LTIC or have dementia. Rehabilitation for people living with dementia in an LTIC environment can cause extra challenges, as its success often requires multiple parties and components. However, as growing evidence has shown, it provides a unique opportunity to influence the culture of LTIC towards person-centred, function-focused care that can positively impact not only the resident's independence, but also those who are involved in the rehabilitation journey.

> **"The person's desire to have a purposeful life and a degree of independence despite disabling health conditions is not diminished just because they rely on LTIC or have dementia."**

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Approaches to meeting the rehabilitation needs of hard-to-reach individuals and communities

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Improving access for people in remote areas through telerehabilitation

Reducing health inequalities for people in remote areas is a global priority.[1] People in rural and remote areas who require dementia rehabilitation often either travel to metropolitan areas, depend on home visits from health professionals, or access generalist services. For this group of people, telerehabilitation services have emerged as a useful and low-cost option to provide high-quality care remotely. The use of telerehabilitation has increased over the last two decades, and society has quickly become more accepting and more competent in using telerehabilitation.

The main **benefit of telerehabilitation** is that where the person with dementia lives is no longer a barrier to accessing care. In theory, this means that the person and their family can access dementia care experts regardless of location. For many families and services, telerehabilitation can be a more convenient option as it eliminates the need for travel. This can be very useful for people with dementia who may become anxious or overwhelmed in hospitals or clinics and are more comfortable at home. Reducing the need to travel is also desirable for people with physical disability who may not be able to drive or can only walk short distances.

There are some **challenges in using telerehabilitation**. It can be hard for the health professional to thoroughly assess the home environment, complete physical assessments, or demonstrate activities remotely (for example, demonstrating grooming and dressing techniques). In these instances, asking family to help and giving clear instructions is important. Hybrid approaches to care are ideal, if possible, where remote consultations are supplemented with the occasional in-person consultation. Telerehabilitation can also be difficult when the person with dementia does not have family or friends on hand to help, and when they have higher levels of cognitive impairment and therefore cannot remember appointments or follow instructions to use technologies.

Historically, there has been concern that older people do not like to use technologies or cannot learn how to use technologies. However, while this may be true for some people, many studies have now demonstrated that telehealth is a feasible and acceptable way to offer care for people with dementia and their families.[2-4] Key enablers to success are using simple technologies, involving family, and encouraging the person to be open-minded and 'give it a go' if they are unsure. Other strategies to **maximise the chance of successful telerehabilitation** delivery are presented below:

For the person living with dementia and their family or other support person

- Ask the health professional if you are unclear about the arrangements for the consultation. For example, do you need to wait for them to call you, or do you need to join a meeting?
- Larger screens (such as iPads or laptop computers) tend to be better than smaller screens like smartphones, as they are easier to see.
- If you are having any difficulty hearing or seeing the health professional, let them know as soon as possible so they can either adjust their communication style or help troubleshoot.
- Choose a quiet space and a convenient time. Small children, pets, and visitors in the background can be disruptive and make it hard to focus.

For the clinician

- Try to use equipment the person already owns (such as a desktop computer) to enhance comfort and familiarity using the technology.
- Prepare for consultations in advance, for example, sharing videos of how to do exercises on the screen can support time management and sustain rapport.
- Make a backup plan with the client in case telehealth technologies fail, such as having a family member troubleshoot or using the phone instead of videoconferencing.

- Provide advice, if needed, on how the client and family should position the device to give a clear view so that the interaction is more natural.
- Clarify who is present and who will be part of the consultation. There may be family members out of view who would like to be involved.
- Remember usual communication techniques for working with people with dementia. Avoid talking too fast and overwhelming the person with choices.

In summary, while telerehabilitation is a new way of delivering services, consultations should involve usual rehabilitation processes (such as goal setting, education, and problem solving). However, the clinician, person with dementia, and family may have to be open-minded and make some adjustments to the process to ensure success.

Improving access to dementia care services for people from ethnic minority groups

People migrate for different reasons: to get better jobs, reunite with family, study, or to escape natural disasters, war, and persecution. Nowadays, the number of people living outside their birth country is higher than ever.[5] This has led to an increase in cultural diversity within countries. The term "ethnic minority" refers to communities in a country that are culturally different from the majority population. Ethnic minorities often have their own traditions, languages, or religions and tend to have lower incomes, education, and social status than the broader population. Some ethnic minority groups are immigrants, and others are Indigenous peoples who became minorities due to colonisation.[6] Importantly, people from ethnic minorities have different ways of knowing and doing. For example, culturally safe rehabilitation that is tailored to work in partnership with Aboriginal and Torres Strait Islander peoples in Australia would not necessarily suit Chinese Australians who prefer their rehabilitation provider to hold a position of authority. An overview of barriers to dementia rehabilitation and strategies to improve access and effectiveness is presented in Figure 1.

Figure 1. Potential barriers and strategies for accessing effective rehabilitation for people with dementia from ethnic minorities

	Barriers to dementia rehabilitation	Strategies to improve access and effectiveness
People with dementia and family	● Family feel responsible for all care ● "Do for" person, not encouraging ongoing activity ● Language barriers	● Ask for help and rehabilitation ● Ensure that clinician understands person with dementia's personal values and goals ● Bring someone to interpret
Communities	● Stigma, fear, dementia not seen as a health issue ● Health services not culturally appropriate ● Unfamiliar with concept of rehabilitation and allied health professions	● Build partnerships with rehabilitation providers to build understanding of culture and improve access ● Hold community talks about dementia and treatments, including rehabilitation
Care practitioners and service providers	● Difficulty engaging person from ethnic minority background because: ○ Unable to communicate in shared language ○ Unfamiliar with values, beliefs, and ways of living ● Ethnic minorities seen as a homogenous group ● Inflexible funding and care provisions that do not allow for additional time and language support	● Hire bicultural clinicians/bicultural workers ● Have and apply cultural competency training for clinicians ● Use trained health interpreters, or family or friends can help interpret ● Provide culturally relevant and translated information ● Provide flexible service models and more funding ● Consider different ethnic minority groups in service design

Barriers to rehabilitation

People from ethnic minority backgrounds who have dementia face extra challenges accessing rehabilitation.[7] Some communities do not see dementia as a health issue, and stigma or fear can stop people from seeking help.[8] Many families feel responsible for looking after their person with dementia. Instead of encouraging the person to stay involved in daily life, they may do everything for them, as this is seen as an expression of love and respect.

Improving access

A major service gap is that there are often no programmes that meet the cultural needs of ethnic minority communities. Funding and commitment from organisations are needed to make it easier to access dementia rehabilitation. Focus should be on mapping out how people from different ethnic minority backgrounds might use services. This helps identify barriers, such as whether the service feels culturally inclusive, information is available in their preferred language, or they need internet skills to sign up. Once barriers are understood, organisations can work to remove them. For example, they could translate materials or promote the service through partnerships with local organisations.

Providing services

Some ethnic minority communities may not know about rehabilitation or may feel unsure about its usefulness. Many may not have heard of 'occupational therapy' or 'speech pathology'. They may need more explanation about the benefits of rehabilitation. Services should be flexible, including offering extra sessions to build trust, involving family or cultural advocates for support, or adjusting how or where therapy is delivered.

Trust is required for clinicians to establish meaningful, personal rehabilitation goals. People with dementia often feel more comfortable with clinicians who share their culture and speak their language. However, even when culturally aligned clinicians are not available, trust and a positive therapeutic relationship can be established.

If clinicians and clients do not share a language, professional interpreters trained to work with people with dementia can be used. If that is not possible, a family member, friend, or community advocate can help interpret. Written information should be translated, using infographics and pictures if literacy levels are low. Focus should be on engaging the person with dementia, even through non-verbal communication; understanding what matters to them and working with them to set rehabilitation goals; and understanding that standard ways of doing assessments may miss important cultural differences.[9] Instead, rehabilitation goals can be set by researching their daily routines and identifying activities that are meaningful, like finding music or games from their culture.

Cultural competency training is essential for rehabilitation teams to better understand the communities they work with. Clinicians who have cultural competency and use it in their practice better meet the needs of their clients.[10] Clinicians can avoid stereotypes, such as prioritising rehabilitation goals of independence in everyday activities. Some people may have a strong cultural tradition of providing care for their family members with dementia and would prefer rehabilitation to focus on social or leisure activities. Focus should be on staying open to learning about other cultures and culturally adapting rehabilitation goals and strategies to each person.

Conclusion

In summary, telerehabilitation enables access to high-quality care for people in rural and remote areas while requiring adaptability from health professionals, people with dementia and families. Furthermore, rehabilitation services must embrace cultural awareness, tailor services to meet the needs of ethnic minority groups, and commit to flexible, inclusive care that supports diverse communities.

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Older people living with dementia benefit from physical rehabilitation after hip fracture

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People living with dementia benefit from rehabilitation after a hip fracture (broken hip), but are often not offered the same rehabilitation opportunities as those living without dementia. In this essay, we will discuss current best rehabilitation practices for people living with dementia who are recovering from a hip fracture across hospital, community, and permanent residential care (e.g., nursing home) settings. We also offer some recommendations to better prepare care providers, including family members, to help people living with dementia experience their best recovery.

Fragility fractures (e.g., hip, wrist, arm) are common in older people due to changes in bone health and typically occur after a simple fall.[1] Falls usually happen because people lose their balance for reasons including, but not limited to, weakening muscle strength, vision problems, or effects of medication. Hip fractures, the most serious injury, will need surgery in more than nine of 10 cases. Worldwide, approximately 2.6 million people experienced a hip fracture in 2020.[1] Nearly one-third of those who experience a hip fracture also live with dementia.

Recovery after a hip fracture can take more than a year, and fewer than half of people completely recover. People living with dementia tend to have lower recovery, and some will die as a result of their injury.[2,3] They are frequently excluded from research studies,[4] and often people living with dementia, even those who were walking and living at home before their injury, receive limited rehabilitation opportunities.[5] People living in nursing home settings are more likely to fall and have a hip fracture, and are even more likely to live with dementia.[6] They have the shortest hospital stays and often quickly return to their residential 'home', with limited or no access to rehabilitation.[2,3] This limited access to rehabilitation appears to stem from the beliefs of many clinicians,[7] and indeed, family members, that these individuals will not benefit from rehabilitation.[8]

Rehabilitation for people living with dementia can be successful when we use the following approaches:[9]

- Understand the individual's needs and create a **relationship** between the person living with dementia and the care provider(s)
- Use short, simple instructions with cues to improve **communication** and understanding
- **'Learn by doing'** using repetitive activities that increase in difficulty
- Ensure the **environment** makes the patient feel safe and comfortable.

The most important message regarding rehabilitation after a hip fracture is that all patients who were able to get out of bed before their fracture, regardless of whether they live with dementia, should have opportunities to access rehabilitation to help them recover.

Early post-operative rehabilitation

We know that early surgery followed by early rehabilitation improve both recovery and survival after a hip fracture, including for those living with dementia. Early rehabilitation focuses on familiar activities such as walking, getting out of bed, and rising from a chair. People living with dementia frequently miss rehabilitation because clinicians do not adapt how they provide care to suit individual needs;[10] therapists have reported that they lack training to work well with people living with dementia.[11] One way of adapting care is to focus on activities the person wants to do; one physiotherapist described how, when working with a person living with dementia, it is important to be led by what the person wants to do: "We could walk him [patient living with dementia] between two of us if he wanted to go to the toilet... but if you were just getting him to walk, he wouldn't necessarily want to do it."[10]

People with and without dementia who are helped to get out of bed within a day after surgery and can bear weight on both legs spend less time in the hospital and are more likely to be walking and doing well a month later, especially those who were moving better before their fracture.[12,13] Despite this, people with dementia are less often provided the opportunity to get moving early after surgery.

Community rehabilitation after hospital discharge

Most people with dementia who experience a hip fracture and participate in community rehabilitation live at home supported by family members or other care providers. Family and other home care providers are important members of the rehabilitation team as they encourage the person to be active and to do their exercises at home,[14] which improves recovery. In a programme in Denmark, people living with dementia who are recovering from a hip fracture are offered rehabilitation in their own homes or at an outpatient centre. They receive three months of individualised balance and progressive strengthening exercises (e.g. leg-press or using elastic bands to increase strength) that focus on regaining the ability to do common daily activities such as climbing stairs, rising from a chair, and walking. We find that focusing on the individual's activities of interest motivates and engages them to participate in their physically demanding rehabilitation sessions actively. A staff member observed that "the physiotherapist pushes to see how many repetitions the individual can do, and they are easily motivated to do more – it almost seems as if there is some kind of competitive instinct or other motivation driving them to perform more exercises." These comments are from people with dementia participating in the programme:

> *"Well, coming out here [to the health centre] to train, that has definitely given a bit more quality of life."*
>
> *Man aged 92*

> *"If I sit down in a chair, then nothing gets done… No, I'm very determined that it must succeed and that I can manage on my own as much as possible, right."*
>
> *Woman aged 75*

> *"Well, I'll admit that at first, I was very sceptical about it… but, uh, that has changed…. I've come to accept that it's probably necessary, and I have to listen a little to what is being said…. When you've been excluded from being able to do it…. and then you can do it again, then you kind of – I don't know if you can – appreciate a bit more that you actually can do that, right…. it gives a sense of satisfaction in everyday life…. that you can do some of the things you could do before, right."*
>
> *Man aged 77*

Rehabilitation for residents in permanent long-term care settings

People living in nursing homes who are older than 85 with advanced dementia and little verbal communication can still improve their mobility when rehabilitation is individualised to each person's ability.[15,16] A 10-week programme performed in the nursing home, involving three physiotherapy sessions per week, improved people's walking and mobility. One year later, most continued to walk and perform their daily tasks of getting in and out of bed and rising from a chair with modest support for safety.[15] They were also more positive about their quality of life. One person who initially responded to the therapist's arrival by saying "Bed" actively participated in the programme, and after a few weeks would say "Walk, Lunch, Bed" when the therapist arrived.

When nursing home staff see people recover the ability to walk, it reminds them that they need to get residents up and encourage mobility.[17] One staff member said: "Their [physiotherapists'] work reminded me, I think we should do our bed mobility… so it's a good reminder of a couple more things we should be doing." Another said: "You're going to make these patients nice and limber, and strong; getting them dressed or getting them to the bathroom, and doing transfers, it makes it so much easier."

Investing in rehabilitation is also economically worthwhile.[18] Overall cost to the healthcare system is higher for people who do not receive rehabilitation because they are more likely to be readmitted to the hospital and experience complications associated with spending prolonged periods in bed in the first year after hip fracture.

Conclusion

- People with hip fractures who were able to move out of bed before their fracture should be offered rehabilitation opportunities across all healthcare settings and/or in their homes, regardless of whether they have dementia.
- Increased education and practical training are needed to improve health practitioners' competence and confidence to work successfully with people living with dementia after any fragility fracture, including hip fracture.[2,11] Practitioners need to learn how to adapt rehabilitation approaches to engage people living with dementia rather than expecting people living with dementia to adapt to approaches used with people who do not have dementia.[9] This is key to success.
- Family members[19] and nursing home staff[20] also need practical education and to understand the goals of rehabilitation. They are important members of the rehabilitation team and can help their family members or residents safely and actively engage in their recovery.

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Case studies

Developing a system of learning to become a skilled cognitive rehabilitation practitioner

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The effectiveness of cognitive rehabilitation (CR) depends largely on the knowledge and skills of the CR practitioner. To ensure that care providers are effective practitioners, they will need skills in addition to their generic professional skills. Therefore, the health or social care system in which they work must be ready to provide them with the necessary support for learning and development.

We first developed a training course for cognitive rehabilitation practitioners as part of our work on the Goal-oriented cognitive Rehabilitation for Early-stage Alzheimer's and related demenTias (GREAT CR) research programme. We wanted to skill up the ten therapists who worked with participants in the GREAT randomised controlled trial of CR;[1] these were nine occupational therapists and one nurse. The foundation-level course we developed was delivered in person over two days. In addition to their good generic professional skills and knowledge, the therapists also needed to know how to:

- Set SMART goals with the participants and identify how participants perceived these as important to their wellbeing
- Measure the current level of goal attainment and identify incremental stages of progress with attainment to evaluate the impact of cognitive rehabilitation
- Understand how cognitive impairment affects functional ability, and specifically the current level of goal attainment
- Select the cognitive rehabilitation techniques that would address the functional challenges and be achievable for the participant and in line with their lived experience
- Try introducing restorative approaches first before relying on compensatory ones
- Apply restorative techniques to support the person to maximise the use of compensatory strategies, for example, using a rhyme to encourage checking the calendar for the day's activities: "My breakfast waits, but first check my dates"
- Develop a rehabilitation plan with the participant and provide information to their carer where relevant
- Use learning methods that can embed the cognitive rehabilitation techniques into the participant's everyday activities
- Support the carer to enable the participant to practise between sessions with the CR practitioner
- Support the participant and the carer to recognise and utilise transferable skills and apply strategies learned in working on one personal goal to another goal
- Plan with the person and carer how to maintain the rehabilitation achievements

After the research trial, we worked on implementing cognitive rehabilitation into existing health and social care services in England.[2] As the two trainers, we worked with 15 organisations and trained 41 practitioners of mixed skills and roles. They were mainly occupational therapists (OTs), but also included OT assistants. While most were working in community-based services, we also worked in several residential care homes, and so the practitioners included senior carers and activities coordinators. The work was disrupted by the COVID-19 pandemic, and as face-to-face training was not possible, we amended the original two-day foundation-level training course to deliver it remotely. This online course consisted of:

- Pre-course reading and eight hours of trainer-led online learning in two parts of four hours each
- Two quizzes to consolidate learning, one quiz after each part of the training
- Three monthly one-hour sessions of online supervision from one of the trainers to support the application of cognitive rehabilitation in clinical practice

The availability of sufficient practitioners with the skills and experience to provide CR is essential to future implementation. To achieve larger numbers of trained practitioners, the online foundation-level training course was further adapted into an e-learning format, incorporating educational videos prepared in collaboration with NHS Education for Scotland, and made available to NHS practitioners in England via the NHS Learning Hub[3] and to others via the internet.[4]

The experience of teaching the online trainer-led course emphasised to us the importance of interactive learning, and so the e-learning course was developed with that knowledge in mind, incorporating quizzes and interactive exercises. To assess and consolidate learning, an end-of-course quiz was included. Upon completion of the course, delegates can access related materials such as a practitioner handbook and a handbook on addressing rehabilitation goals, begin to practise cognitive rehabilitation, and become members of the CR community of practice by joining the ReableDem[5] LinkedIn group. This approach helps to ensure that cognitive rehabilitation is embedded into practice without diluting the evidence-based approaches to delivering it. Ideally, the course would include application of a pass mark based on the quizzes and certification of the CR practitioner, although this would require dedicated resources to administer and monitor. This option was not available to us when developing the course.

Our aim is to provide advanced-level training for practitioners who have gained sufficient experience at the foundation level. This will enable them to support others in delivering the intervention, allowing for a gradual withdrawal of the trainer or external supervisor, and promoting sustainability. We delivered an advanced-level course to a group of 10 CR practitioners in April 2021. This was a one-day in-person event with the opportunity to hear evidence updates, refresh skills, share experience of delivering cognitive rehabilitation and build links with other CR practitioners in a community of practice. A train-the-trainer course is also envisaged for the future.

Whilst e-learning does not allow people to benefit from the opportunity to learn from others through discussion, it offers a more flexible way of learning that fits with different ways of working and geographical dispersal, and it also provides consistency in teaching methods. An e-learning course can be accessed from anywhere in the world, although it would need to be adapted for cultural and language differences. To evaluate the uptake and effectiveness of the e-learning course, future iterations should incorporate analytics capabilities. This would require a learning management capability within the training tool.

The inclusion of cognitive rehabilitation training and practice delivery objectives in the strategic plans of health and social care organisations would ensure that providers focus on workforce learning needs and on optimising cognitive rehabilitation practice and rehabilitation outcomes for their service users who are living with dementia.

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Introducing cognitive rehabilitation in Norway

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In Norway, health and social care services are publicly funded, with only a small out-of-pocket fee for some services. Most municipalities have organised memory teams,[1,2] which are multidisciplinary dementia resource teams. The teams assist GPs in diagnostic assessment of persons suspected of having dementia and are case managers for people with dementia and their family carers throughout the course of the condition. Further, many municipalities offer reablement through rehabilitation teams.[3,4] These teams traditionally provide rehabilitation after injuries, functional decline, or somatic disease, and although people with dementia are not excluded from the service, they usually do not get the reablement service for challenges caused by dementia.

The Norwegian National Centre on Ageing and Health received funding from the Foundation Dam, in cooperation with the Norwegian Brain Council, for a pilot implementing cognitive rehabilitation (CR) based on evidence from the GREAT CR research programme.[5,6] Six CR practitioners from memory teams in four municipalities, three registered nurses, and three occupational therapists were trained in CR using the English-language e-learning course (see the case study on page 95) and a translated version of the accompanying practitioner handbook.[7] While testing the method, they received monthly supervision from the UK and met weekly in a digital Norwegian-language discussion group.

The CR practitioners identified potential clients for the intervention from their caseloads. As case managers, the CR practitioners already knew the resources, challenges, and needs of their clients, which made it easier to identify people with dementia who could benefit from CR. It also provided CR practitioners with a good starting point for discussing appropriate or relevant goals with the client.

The clients chose goals such as using travel apps on their smartphones, cooking, and using technology and household appliances. More than half of the clients had a family carer to support them in the rehabilitation process. The CR practitioners visited weekly to support the process for an average of six weeks. Adjustments were often necessary during the rehabilitation process, and it usually took a few weeks to see progress, but eventually, most participants fully or partially reached their goals.

The CR practitioners found the CR approach useful and person centred. It helped raise their awareness about focusing on what the person could still do, and how. It was rewarding to work on maintaining independence and not just firefighting when crises arose. Tailored learning techniques were used in addition to or instead of assistive technology, and people with dementia were able to overcome activity challenges, as Samuel's experience shows.

Samuel decided he wanted to learn how to use his smartphone better, specifically managing his contacts and using the travel app from the local bus company. By breaking down the activity and learning it step by step, Samuel was able to learn each part without making mistakes. Having the activity demonstrated rather than explained made learning easier, as did learning by doing the activity himself. The practitioner gradually reduced supervision and prompts until Samuel did not need any. Written instructions, developed collaboratively by Samuel and the practitioner, served as a 'backup' resource should he forget steps or otherwise need it. With his contacts correctly saved on his phone, Samuel readily knew who had texted and called him, making him more confident in texting or calling back. Being able to use the travel app gave Samuel the opportunity to travel by bus on his own, as he no longer needed help to purchase a ticket.

Sometimes, the improved functioning gained through CR resulted in reduced needs for services. Even if services will eventually have to be reintroduced, CR can postpone service needs and make people with dementia more independent for longer, as Martin's example shows.

Martin received help from home-based services to heat his dinner in the microwave every afternoon. He had had this microwave for several years, but never had the confidence to use it himself. He made it his goal to heat his dinner independently. Following a six-week CR intervention where the CR practitioner tailored several learning techniques, labelled the microwave and made a step-by-step introduction in cooperation with Martin, he was able to heat his dinner independently. The number of visits from home-based services was reduced, and four months later, Martin still did not require any help with heating his dinner.

Informal carers often support people with dementia in the rehabilitation process. Improved independence in the person with dementia also had positive effects for the carers and on the relationship between the person and the carer, as Elsie's example shows.

Elsie's goal was to keep track of her appointments using a digital calendar. She had struggled with this for a long time, worrying about missing out on appointments. She often called her daughter several times during the day to ask what day it was and whether she had any appointments. Through CR, Elsie learned to use the calendar, something which gave her more confidence and a feeling of being in charge of her own time. Her daughter told the CR practitioner that her mother started calling her just to chat, not because she needed help or reminders.

Sometimes the person's network was involved in implementing the strategies, which added to the effects of CR. Even when goals were not reached, the person and the healthcare staff had still learned useful strategies and approaches to coping in everyday life with dementia.

> **"Even when goals were not reached, the person and the healthcare staff had still learned useful strategies and approaches to coping in everyday life with dementia."**

Trondheim municipality, which took part in the pilot, is now planning a project implementing CR in its 12 municipal reablement teams. This is a different setting from the memory teams, but these rehabilitation teams already have competence in rehabilitation and use a similar structure in their work to that used in CR. Through this, cognitive rehabilitation will be offered in line with other more traditional rehabilitation approaches in Trondheim, giving people with dementia the same opportunity for rehabilitation as the general population.

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Identifying a novel pathway for the implementation of cognitive rehabilitation in Ireland

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The national Model of Care (MoC) for Dementia in Ireland, published in 2023, identifies cognitive rehabilitation (CR) as an intervention to be offered in post-diagnostic support pathways that ideally follow diagnosis.[1] This MoC, which details actionable steps required for the roll out of our National Dementia Strategy,[2] describes targets and practice recommendations relating to treatment, care and support for those living with dementia. Despite the prioritisation of access to timely evidence-based supports for those with dementia, a treatment gap exists where early interventions do not routinely follow diagnosis.[3] In our experience, limited staffing and time are among the key challenges to making CR more accessible.

The CR-Ireland project

We designed the 'CR-Ireland' project, with funding from The Alzheimer Society of Ireland, to offer an innovative solution to address inadequate staff resourcing for cognitive rehabilitation in Irish memory services. We created a new service model to deliver community-based CR through supervised placements for early career psychologists. In Ireland, many master 's-level and doctoral-level trainee psychologists are required to complete supervised clinical placements as part of their training. Often, the demand for placements in older adult services is unmet. We tapped into this unmet need by creating a supervised work placement model for behavioural psychology trainees, with a pilot site at the Regional Specialist Memory Clinic (RSMC) at Tallaght University Hospital, Dublin. People living with dementia and their families contributed to the project design, procedures and ethical considerations.

Eleven trainee psychologists, referred to as 'placement practitioners', were recruited in waves to these supervised clinical placements. Training included the nine-module CR eLearning programme[4] described on page 95 and hosted on the eLearning platform of the Dementia Services Information and Development Centre (DSIDC). Training also included dementia education, behavioural training, statutory health service training required by the pilot site (e.g., data protection and safeguarding), and a meeting with Public and Patient Involvement (PPI) contributors with experience of cognitive rehabilitation.

Potential participants with dementia were identified by the neuropsychology team at the RSMC. We recruited 38 participants between the ages of 60 and 83, of whom 27 completed the cognitive rehabilitation sessions. Most had diagnoses of Alzheimer's disease with typical memory-related challenges, two had young-onset dementia, one had Lewy body dementia, and one had posterior cortical atrophy. Efforts to include participants with rare dementia or atypical presentations proved challenging on a practical level, but our expectation is that, with experience, this will become more feasible.

Placement practitioners delivered CR over about six to eight weeks in participants' homes, with one participant opting to work with the practitioner at the clinic. Intervention delivery was supported by weekly or fortnightly individual clinical supervision and periodic group supervision, provided by three members of the project team who were either clinical neuropsychologists or behavioural psychologists. As we expected, practitioners required support with translating their learning about cognitive rehabilitation into practice, how to identify and set clear CR goals, and how to put specific CR-related techniques and strategies into action. We learned that supervision of the relational side of the work was also necessary. Themes that arose in supervision included adjusting to visiting a participant's home, understanding the lived reality of dementia, responding flexibly to changing needs and abilities of participants, managing the practitioner's own emotional responses to the work, and issues around ending visits in a supportive way. Participants and their families required accessible information about the nature of the programme, support with realistic expectations, and an opportunity to feed back their experiences.

Goals were set using the Bangor Goal-Setting Interview[5] (described on page 30). The types of goals identified included everyday tasks like making tea, using the television remote control, or preparing to leave the house; enjoyable activities like reading the newspaper, completing crossword puzzles, engaging in art, or playing music; and activities to promote social contact, like learning to use a mobile phone. Memory rehabilitation goals were also common, such as face-name or story recall. The practitioners were encouraged to operationally define goals in measurable terms and incorporate strategies like task analysis, shaping, chaining, spaced retrieval, prompting and fading, and environmental modification. They were also asked to monitor progress at each session and adapt their intervention strategies as needed.

Recommendations and implications

Placement students required varied but generally high levels of support during training and early supervision stages; this had resource implications for supervisors. Future projects should consider supervision resourcing from the outset. If possible, recruitment of second-year master's or doctoral students who have experience working with vulnerable groups would be preferable. If that is not possible, additional training and supervision would likely be required. We found that when students had the skills to quickly build a rapport with participants, the participants tended to engage better and make faster progress. Student recruitment, therefore, requires careful consideration. For our participants, we learned that people who benefitted most from cognitive rehabilitation tended to have relatively milder cognitive challenges and generally good mobility and were motivated to work with the practitioners. Family support was also important; families should be willing to support the person to be independent. Setting clear expectations with carers at the outset was helpful.

The CR-Ireland project provides further evidence of the effectiveness of cognitive rehabilitation; our case data has been positive and supports previous research findings. Beyond this, our ongoing work aims to evaluate the feasibility and acceptability of this supervised placement model in the Irish context. Should this be successful, placement opportunities may be expanded to include other suitable disciplines. A key sign of success for us will be the maintenance of placements going forward. We expect our evaluation to provide a roadmap for the scaling up of this service model. By providing a 'toolkit' to other memory services based on our learning, we hope that other sites will incorporate timely access to cognitive rehabilitation into their post-diagnostic support pathways, in line with the MoC recommendations. The CR-Ireland project has the potential to significantly impact wider dementia-care service provision by identifying ways to bridge the gap between policy and practice.

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Implementing cognitive rehabilitation in a community organisation

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Not-for-profit organisations often provide valuable support in their communities where there are gaps in statutory services. This case study describes how our not-for-profit organisation, known as Partners in Dementia, uses CR to support people with dementia.

The City of York's Dementia Strategy 2022–2027

Our organisation aims to provide services that are useful to local people affected by dementia. Here in the city of York (UK) where our organisation is based, we have a local dementia strategy. It recommends that services supporting people with dementia after they are diagnosed should be based on good evidence of effectiveness. The strategy goes on to say that services must 'include support to maintain inclusion, occupation, identity and social relationships'. Cognitive rehabilitation meets the criteria in York's Dementia Strategy and aims to support inclusion, occupation, identity, and social relationships. The strategy emphasises how support must make use of the existing abilities and skills of people with dementia and be 'delivered in a way which is considerate of their individuality'. CR makes use of the skills and abilities of the person with dementia and is person centred.[1-3]

Our CR pilot project

In 2023–2024, our organisation worked with 18 people with dementia and their care partners in a CR pilot project. In the project, participants with dementia were motivated to increase their independence, keep physically active, manage difficulties, and remain socially connected. In terms of how cognitive rehabilitation affected participants' functioning, at the start, participants rated their functioning in relation to their goals as 2.67/10 on average. After the CR sessions, this increased to 7.5/10. These figures demonstrate that in our project, CR was effective in helping people with dementia to significantly improve their functioning in relation to their specific personal goals.

For Mike, one of the programme's participants, rehabilitation goals focused on walking and getting out into nature.

Brenda describes her experience of CR

A couple of years after being diagnosed with dementia, Justin from Partners in Dementia was introduced to me, and we embarked together on a cognitive rehabilitation journey. I felt listened to and excited about being independent – the repetition made me aware of what was to come next. Justin's rehabilitation therapy awakened my memory of how to use public transport. It gave me the confidence to leave the house safely with the items I needed and walk to the bus stop feeling confident. It also gave me confidence in walking in my village as I recognised landmarks and a set routine for walking. Ten months after being introduced to CR, it is still useful: The best thing, I know it seems trivial, but it's not – before I go out, I need my diary, purse, phone, and keys.

Other outcomes for people with dementia in our CR project were things like increased confidence and applying cognitive rehabilitation learning to other goals without the CR practitioner. For instance, we learnt to play Rummikub using the CR approach. We practised in the same way for weeks on end, which also helped my social networks. Friendship, meeting new people, and making friends are so important.

Community organisations and CR

Cognitive rehabilitation is a very practical and accessible way of working for practitioners and can be delivered by a variety of staff.[4] However, we have found it important for CR staff to have supervision with experienced practitioners so that they are supported to gain confidence and skills as they learn. Funding cognitive rehabilitation poses its own challenges for community organisations. Funding options could include contracts, fundraising, grants, or private payments. We have found that although CR is similar in cost to traditional home care services for the period it is actively delivered – usually about six to eight weeks – there is currently not the widespread understanding that people with dementia can be supported to function at a significantly higher level than they often do. Dementia is not talked about enough, which would help with understanding cognitive rehabilitation, and people need to be encouraged to talk about dementia.

Our future with CR

Our organisation developed a CR steering group involving people with dementia, their care partners, researchers, and professionals to try to progress with cognitive rehabilitation. It was not always an easy process. As one person commented:

> *I was upset some of the professionals hadn't turned up. Shows how important this is to them. A lot of them, it seemed to me, were not interested in hearing the stories we had to tell. They were not prepared to put in any effort at all … I came out of that so frustrated. I felt as though I'd been offered a cherry and they took it away.*

We eventually agreed in the CR steering group to apply for another grant to try to help increase cognitive rehabilitation provision in and around York. We are really pleased to have received funding again from the National Lottery Community Fund, this time to provide three years of ongoing CR services to 108 people with dementia. We will work towards a sustainable funding model and potentially see whether CR can delay transitions into a care home by six months, as identified in research[5]. In the UK, a six-month saving on care home fees is equivalent to £31,330 per person for people who pay for their own care and £19,630 for the Local Authority (York), which pays less for care home places than self-funders. These potential savings have 'practical implications for the care system as associated savings could be used to at least partially fund staff training and provide time for CR'.[4]

We think what we have taken on is like standing on the edge of a thick wood, and you know that what you want is somewhere in the forest, but you don't know where exactly. We are trying to find a path with different people, and somehow it is coming together.

See our organisation's webpage on cognitive rehabilitation with a link to our Journal of Dementia Care article:[6] https://www.partnersindementia.org/doing-this-doing-that/.

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Cognitive rehabilitation in a clinical psychology practice and in a UK memory service

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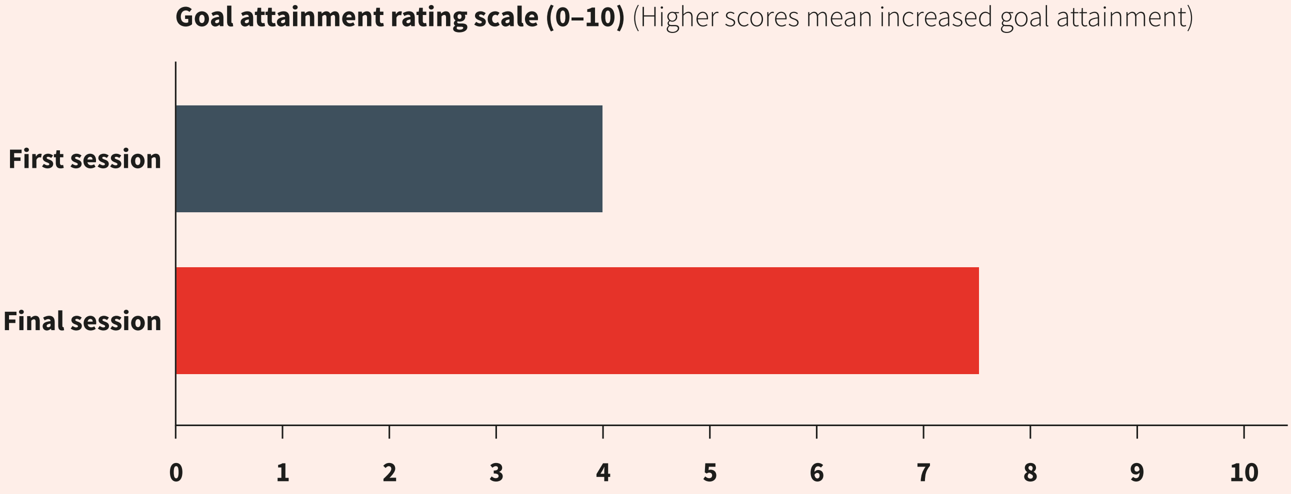
As a clinical psychologist working in specialist mental health services for older people and focusing on dementia assessment and treatment as part of a memory service, I have a great deal of experience in neuropsychological assessment and formulation. With this professional background, I have always found it difficult to understand why people with cognitive disabilities due to head injuries or stroke have access to rehabilitative approaches based on detailed assessment of their strengths and difficulties, while people with a dementia diagnosis do not. There is plenty of evidence from clinical practice and research to support the notion that rehabilitation and new learning are possible and effective in dementia. My service was part of the GREAT research trial that demonstrated we could enable people to achieve realistic goals through cognitive rehabilitation[1] (CR) and subsequent implementation work.[2]

In recent years in the UK, memory services have been under pressure to provide ever greater numbers of dementia diagnoses. This has diverted limited resources away from post-diagnostic support and reduced the availability of specialist professionals, which has made it difficult to offer CR as part of our service. To combat this, we have looked at how to make cognitive rehabilitation available and useful to people with dementia in ways that require less staff time.

The online resource My Life, My Goals[4] offers one way of making CR more widely available. Memory services in the National Health Service (NHS) Trust where I work have adopted several ways of improving accessibility and use of this online resource. They include the link in the post-assessment letter confirming the diagnosis, display posters and leaflets about it in the clinic waiting area, and showcase it in the two-hour post-diagnostic workshop offered to all patients.

For people with dementia who would like to find out more, the clinical psychology service offers a three-session introduction to cognitive rehabilitation and the online resource. This is led by an assistant psychologist or occupational therapist, who supports the participants in identifying their goals and the strategies they can use to work towards achieving them. The first 10 people to participate in this programme told us they liked it and found it useful. The ratings they made before and after working on their goals showed an improvement similar to what we saw in the research studies.[1,2] Figure 1 shows the average ratings of how well they were doing in relation to their goal before working on the goal (in gray) and how these improved after working on the goal (in red).

Figure 1. Average performance before and after working on the goal



> **"I have always found it difficult to understand why people with cognitive disabilities due to head injuries or stroke have access to rehabilitative approaches based on detailed assessment of their strengths and difficulties, while people with a dementia diagnosis do not."**

Although the sessions are only offered to participants who have at least basic computer skills and internet access, several participants have had difficulties with the technology that prevented them from continuing. We offered them printed versions, but they found these less engaging and said it was harder to navigate to the required section. There is clearly potential to improve on these aspects. However, all are encouraged by the idea that they can learn, adapt, and use strategies.

Developing dementia is stressful and can lead to mental health issues, in particular depression and anxiety, often requiring referral for psychological therapies. The diagnostic process adds a period of uncertainty to the dominant narrative of inexorable decline, loss of independence and institutionalisation, which is particularly strong among older people. There is a range of post-diagnostic group programmes to help people adjust to living with the diagnosis.[5] Given the underlying message of cognitive rehabilitation is one of hope, of the possibility of coping, working towards goals, and improving independence and quality of life, its inclusion in post-diagnostic therapeutic work is particularly helpful in alleviating depression and anxiety.

As part of my post-diagnostic support practice, I work with more junior staff, including undergraduate students on placements, assistant psychologists, and trainee clinical psychologists to offer elements of CR, guided by the My Life, My Goals resource,[4] and life story work that includes compiling a timeline and photo album with the person with dementia. These staff receive a basic training session and monthly supervision of their clinical work, and deliver two to four CR-based sessions, often as part of wider therapeutic work undertaken by more experienced psychologists. In my own clinical practice, I often combine cognitive rehabilitation with other therapeutic models and interventions, as the following two examples illustrate.

CR combines particularly well with a framework of cognitive behaviour therapy (CBT) for depression and anxiety.[6] Using CR methods, I encourage clients to develop, for example:

- Written materials for anxiety management, relaxation, or breathing exercises
- Reminders of reconsidered catastrophising thoughts or negative beliefs
- Cue cards for specific issues, codesigned or written by the person themselves
- A list of items to take when going out, placed at the front door
- Graded hierarchies of goals to overcome anxieties or build up activity.

I met Daniel, a 79-year-old former insurance clerk and environmental activist, after COVID-19 restrictions were eased and mainly worked with him online. He had been diagnosed with Alzheimer's Disease some 18 months prior, becoming anxious, depressed, and increasingly isolated. He held catastrophic beliefs about dementia, and following repeated experiences of leaving keys, money, etc., at home, he had stopped going out. Examples of people living positively with dementia taken from the Living with Dementia Toolkit[7] and online contact with UK dementia activists helped to change his beliefs about rapid decline. Learning about CR gave him hope that he might be able to learn ways of coping and increased his motivation to re-engage with previous activities, which in turn improved his mood. Cognitive rehabilitation was also helpful in negotiating graded exposure goals with him to gradually increase his levels of activity and the distance from home he felt able to venture. What he found most helpful was having a list of all the objects he would need to take with him pinned to his door to check before going out, and writing down and practising how he might tell others of his dementia diagnosis. Once he found that he could go out without disastrous consequences and that others responded helpfully when hearing about his dementia, his anxiety and depression resolved.

When the person's greatest fear is forgetting their own history and identity, I combine CR with life story work[8] and support the person to compile a timeline, a life story book, or a piece of autobiographical writing that can be used both to deepen memory and as a memory aid. Cindy, a 76-year-old retired nurse with a diagnosis of Lewy body dementia, was referred with her husband because of conflicts that arose when she did not recognise him, wanted to pick up her now adult children from school, or saw children moving around the house. Cindy had good language and communication skills and much insight into living with dementia. She described episodes of completely losing her orientation like this: 'I am finding myself at the bottom of the ladder and have to work my way all the way up again'. At these times, she might feel she had children who needed her care, and her husband did not look like the young man she expected to see, leaving her afraid and desperate. Our agreed goal was to find ways of orienting herself again more quickly and reliably. Working with a student on placement, a book of key moments in her life was compiled, and a poster format family tree with pictures of her family was created and hung up in the hallway. In addition, she wrote humorous notes to herself about the length of her marriage and her age. The process of discussing these goals and devising the strategies resulted in fewer episodes of conflict, and the couple was able to use the materials so successfully that no further episodes occurred.

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Function-focused care in nursing homes in the USA

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The majority of residents in nursing homes have functional impairment and need help with three or more activities of daily living (e.g., bathing, dressing, walking).[1] These abilities tend to decline over time, particularly for residents living with dementia. The decline is due to the inability to remember how to perform the activities, staff taking over care and thus the resident losing the opportunity and ability to perform the task, lack of motivation to complete the activity, lack of resources to help with performing the activity (e.g., assistive devices or staff to encourage resident participation), and fear of falls among staff and residents. In addition, these residents have multiple chronic conditions and tend to be sedentary, which also contributes to functional decline beyond what is expected from dementia progression.

To prevent further functional decline, we developed a four-step, theory-based approach referred to as Function-Focused Care (FFC).[2] FFC is a philosophy of care that helps staff evaluate the older adult's underlying capability regarding function and physical activity and uses the information to engage the resident in their highest level of function and physical activity. The advantage of FFC is that it is incorporated into routine care and does not require staff to do additional tasks such as providing an exercise programme. Examples of FFC interactions include using verbal cues during bathing so the resident living with dementia performs the tasks rather than the care worker bathing the resident, going to an exercise class, having the resident participate in bed mobility versus just pulling him or her up in the bed, role modelling dressing or brushing teeth so the resident copies the behaviour, or hand-over-hand or hand-under-hand eating so the resident at least gets some range of motion with care worker support. Residents living with advanced dementia may particularly misinterpret touch provided during routine care provided by staff, and may resist the care and can become verbally or physically aggressive towards care staff.[3] Utilising an FFC approach that actively engages the resident living with dementia in their own care may result in a decrease in resistance and rejection of care.

Implementing an FFC approach to care is done using a four-step process guided by a champion within the community or home. The steps are described in Table 1: (1) Environment and policy assessment; (2) Education of staff, families, and residents; (3) Establishing FFC goals; and (4) Motivating and mentoring.

Table 1. Description of the four steps in Function-Focused Care

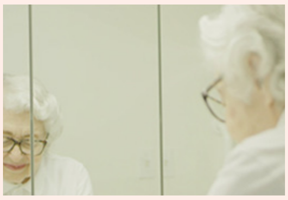
Step	Activities involved
(1) Environment and policy	Assessments are conducted to determine whether changes are needed in the environment or policies to optimise opportunities for physical activity among residents. Changes can include ensuring there are appropriate chairs in each room for residents to sit in and that hallways have clear, pleasant, and open areas for residents to walk outside their rooms.
(2) Education of staff, families, and residents	Education of staff (done based on preferences for face-to-face or online education) about the benefit of all types of physical activity for residents with dementia and ways to evaluate resident capability and motivate the resident to participate in physical activity; education for residents and families about the benefits of physical activity during hospitalisations.
(3) Establishing person-centred FFC goals	The facilitator works with staff and residents to evaluate the residents' underlying physical capability using an established measure[4] and develop FFC goals (e.g., resident to wash upper body with verbal cues; resident to sit up at bedside for one hour daily).
(4) Mentoring and motivating the staff, residents, and families	Mentoring and motivating are done using the four approaches recommended within social cognitive theory that strengthen self-efficacy and outcome expectations (e.g., getting residents to perform and experience the activity; verbal encouragement; role modelling; and highlighting the pleasant and addressing any unpleasant sensations associated with the activity). In addition, fun activities such as contests were provided (e.g., a contest for the most innovative approach to motivating a resident to walk over a holiday such as Halloween or Christmas).

The champion might be a nurse, a direct care worker, or a family member or friend in the home setting. The champion should also identify a team composed of leadership in the community or home to help develop FFC goals, help with resource allocation, integration of activities, and to participate in the critically important ongoing motivation of the resident and all caregivers as described below. Resources for the implementation of an FFC approach are provided at www.functionfocusedcare.org. Examples of video coaching resources for FFC are shown below.

FFC is well suited for residents living with dementia as it is based on the residents' underlying capabilities, both cognitive and functional. Individualised FCC goals are adjusted to fit the resident's abilities. For example, a resident who can only cognitively follow a visual versus a verbal cue would have a goal to participate in eating, hygiene, bathing, and dressing with the caregiver providing visual cues for each activity. A resident with advanced end-stage dementia who is unable to follow either verbal or visual cues to perform an activity may have FFC goals that include hand-over-hand or hand-under-hand eating and bathing so that the resident at least is doing the range of motion involved with these tasks.

Optimising function and physical activity by using an FFC approach with residents living with dementia has the advantage of changing how care is provided. The goal should be that care is provided *with*, rather than *to,* the resident, and that physical activity with a focus on completing functional tasks is incorporated into all care interactions. In so doing, it will help the resident living with dementia to maintain and optimise function and physical activity at his or her highest level. Furthermore, staff also note that the use of an FFC approach saves them time as it results in residents maintaining function, such as the ability to stand and transfer, and decreases the extra time needed in caregiving when there is resistance to care.

Video coaching resources for Function-Focused Care

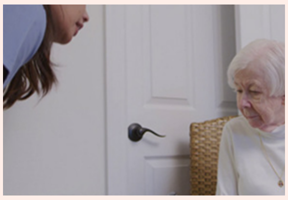

Promoting Independence

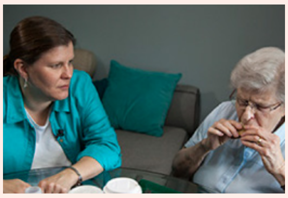

Tips for Bathing


Toileting


Going Outside


Tips for Dressing and Toileting


Tips for Oral Care


Eating


Dressing

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Section 4:

System readiness for rehabilitation

Organist Wayne de la Cruz playing the Hammond B2 organ at a club in San Francisco., California, USA, in October 2018. (Photo courtesy of Alex Kornhuber)

Section overview

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> *When you hear the word rehabilitation, you might picture someone learning to walk again after an injury, or maybe an intense gym routine with a personal trainer yammering motivational quotes in your ear. But dementia rehabilitation? That one doesn't get nearly enough airtime – and it should, because it's not about trying to "fix" someone's memory or turn back the clock, and more about helping people to live well, in the here and now, on their terms, in spite of their dementia diagnosis.*[1]
>
> *Dave Carpenter, Member of Dementia Alliance International*

Awareness of dementia rehabilitation is growing as an emerging way of working with people with dementia. Progress in ways to ensure that rehabilitation is offered as part of post-diagnostic dementia care services is also growing, albeit slowly, and with unequal representation globally. Far more projects and programmes address dementia rehabilitation in higher-income countries than lower- and middle-income countries. While acknowledging the present-day imbalance, this report hopes to encourage more countries to incorporate tenets of rehabilitation into their dementia care pathway. Box 1 details varying approaches used to gather information and evidence for this report.

The prevailing lack of routine rehabilitation services across countries of all income levels has been corroborated through these sources. We have observed that few services for people with dementia offer rehabilitation, few rehabilitation services accept people with dementia, and general rehabilitation services for physical problems are not well-equipped to provide rehabilitation for people with dementia. Often, people with dementia are explicitly excluded from rehabilitation. It is time to question the reasons why this occurs and to challenge this exclusion.

Notably, the scale and depth of the rehabilitation access issue and the potential solutions for it differ across income levels, influenced by each country's access capacity and capability for the delivery of post-diagnostic dementia care services broadly, as well as the availability of existing rehabilitation services for other health conditions. For example, introducing a new dementia rehabilitation service in countries with no post-diagnostic dementia care in place or no systemwide rehabilitation services for any health conditions would require substantially different system-, workforce-, and societal-level changes from instances where countries have some level of post-diagnostic dementia care and systemwide rehabilitation services for other health conditions. Specialised rehabilitation services (e.g., rehabilitation hospitals, outreach rehabilitation

Box 1. Multiple sources of information and evidence

- Published research and international reports, including Cochrane systematic reviews.
- A recent mapping of post-diagnosis dementia care in the Western Pacific region.[2]
- ÍvDementia and rehabilitation experts invited for expert essays in this report from Australia, Canada, the Netherlands, Switzerland, the UK, and the USA; as well as case studies from Norway and Ireland.
- Outreach to 50 experts in dementia care from 23 countries across Africa, the Middle East, Asia, and Latin America, with a particular focus on countries where there is no published work on dementia rehabilitation (20 lower- or middle-income countries). The aim was to identify routinely provided rehabilitation services for people living with dementia across all regions.*

**Only six responses met the definition and criteria for rehabilitation outlined in this report. Four responses concerned the availability of non-pharmacological therapies offered as group services without any specific reference to individualised rehabilitation plans (e.g., music therapy, reminiscence therapy, cognition-oriented therapies, and art therapy). Those interventions are recognised as part of good dementia care and have been covered elsewhere, including in the World Alzheimer Report 2022.*

services, and individual rehabilitation specialist services by allied health professionals) are an established part of the healthcare system in most high- and upper-middle-income countries, and the benefits are well understood, although this approach and understanding rarely extend to people with dementia. Non-specialised rehabilitation services (e.g., social care, residential care, and home services) may be more accessible for people with dementia, but are unlikely to be equipped with a skilled workforce and resources to meet their needs for rehabilitation.

A starting point should be developing or adapting a rehabilitation model tailored to the specific context of health, social, and long-term care systems. It is critical to invest in knowledge mobilisation and implementation research that focuses on effective ways to adopt and sustain rehabilitation models or programmes in various care settings and contexts. We also acknowledge the need to build more evidence on effective rehabilitation models for different types of dementia, in particular, rare types of dementia, and outcome measures that can reliably and authentically determine the effect of rehabilitation, considering the unique goals of individuals and costs.

Case studies: examples of hope

As exemplified in the case studies of six countries in this section (page 129), while access to rehabilitation tailored to the needs of people with dementia is limited chiefly to local contexts, there are clear pathways through which rehabilitation can be put in place as a routine service after the diagnosis of dementia. Japan and Malta lead this field, providing multidisciplinary and tailored dementia rehabilitation programmes integrated into mainstream geriatric or rehabilitation services. South Korea has 256 government-funded Dementia Relief Centres nationwide, providing support and services for various non-pharmacological interventions for people with dementia. One of the centres has begun a combination of individualised rehabilitation training and home-based rehabilitation for people with the early stages of dementia and their carers. In Brazil, while there is limited access to specialised dementia services, mostly concentrated in major urban areas, occupational therapist-led rehabilitation has been offered through university research programmes, relying on students and volunteer professionals. In Indonesia, ADI member association Alzheimer Indonesia (ALZI) provides multidisciplinary home-based rehabilitation in the Greater Jakarta area. The case study from Togo is uniquely positioned in that their rehabilitation programme in a private clinic setting illustrates how programmes can lay the groundwork for dementia rehabilitation development in other countries in a similar position.

The case studies in this section demonstrate how successfully rehabilitation can be offered in various care settings, leading to improved functioning and wellbeing of those people with dementia when they have access to rehabilitation. They also highlight common issues and challenges concerning education and training needs, recruitment and retention of skilled practitioners, as well as the availability of dementia rehabilitation services to a broader population. Nevertheless, they serve as powerful examples of how targeted efforts can act as building blocks for establishing dementia rehabilitation services across diverse world regions.

Access to rehabilitation: system readiness

Throughout this report, we have discussed good evidence for dementia rehabilitation in improving the individual's functioning and explained what rehabilitation entails, how it works, and how it can be implemented. While there is limited data about the cost of rehabilitation for people living with dementia or evidence for cost effectiveness, Claire Hulme and Daim Syukriyah argue that there is an economic case to be made for dementia rehabilitation – including due to its potential for delaying or preventing residential or care home admission, and reducing use of hospital and long-term care services and loss of income. Acknowledging varying levels of limitations in the application of the cost-effectiveness framework in dementia rehabilitation, they argue for an alternative approach to economic evaluation, for example, examining cost consequences or cost savings, along with relationships between direct effects and subsequent, longer-term impacts of dementia rehabilitation. In their essay (page 113), they call for further research to be conducted into the economics of dementia rehabilitation.

There seem to be unnecessary delays in the provision of rehabilitation in the form of routine services and programmes, or models of care integrated into the health and long-term care systems, where people with dementia can access timely and appropriate rehabilitation. This lack of progress in dementia rehabilitation is part of broader issues in limited access to post-diagnostic dementia care and, therefore, shares similar action priorities to post-diagnostic dementia care recommended in the World Alzheimer Report 2022.[5] Notable priorities include access to personalised rehabilitation plans, support for carers, coordinated and accessible care, workforce education and training, and challenging stigma and raising awareness.[3,4,6] As pointed out by Michele Callisaya and colleagues (page 118), the workforce issues are compounded by varying layers of complexity, such as practitioners' negative attitudes and lack of understanding about dementia and the role of rehabilitation, insufficient knowledge and skill in preparation for dementia care and rehabilitation at the professional educational level, and a limited number of skilled rehabilitation practitioners available. They emphasise the importance of approaching dementia rehabilitation workforce issues in a multipronged way, targeting not only improved and quality education and training but also organisational and system support to promote a positive learning culture.

Access to care also needs to be recognised as reflecting multiple dimensions, including **availability** of services and skilled workforce, **accessibility** of the service location,

accommodation of individual needs and preferences in service arrangements, **affordability** concerning the capacity to pay through adequate insurance or subsidy, and **acceptability** regarding the cultural, social, and value alignment.[7]

The question is therefore: how do we ensure that systems of care across health, social, and long-term care are ready for rehabilitation? This involves having the appropriate and adequate infrastructure and resources (e.g., physical facilities, technical and technological resources, skilled workforce), leadership, policies and procedures, including governance, strategic directions and regulatory frameworks at local and national levels, and operational resources such as funding, as well as data monitoring and evaluation systems and mechanisms.

Launched in 2017, the WHO Rehabilitation 2030 initiative stipulates the importance of access to rehabilitation incorporated into universal health coverage, which "means that all people have access to the full range of health services they need – including rehabilitation – without experiencing financial hardship."[8] The WHO's ten priority areas for action to scale up rehabilitation, shown in Box 2, offer much-needed global guidance.

Box 2. The ten priority areas for action to scale up rehabilitation, as identified by the World Health Organization

1. Creating strong leadership and political support
2. Strengthening rehabilitation planning and implementation
3. Improving integration of rehabilitation into the health sector
4. Incorporating rehabilitation in universal health coverage
5. Building comprehensive rehabilitation service delivery models
6. Developing a strong multidisciplinary rehabilitation workforce
7. Expanding financing for rehabilitation through appropriate mechanisms
8. Collecting information relevant to rehabilitation
9. Building research capacity and expanding the availability of robust evidence
10. Establishing and strengthening networks and partnerships in rehabilitation

Antony Duttine provides an overview of rehabilitation in relation to the six building blocks of the ten priority areas, the implications for rehabilitation in the context of dementia care, and the specific Rehabilitation 2030 tool or product that relates to the building block (page 122).

Access to rehabilitation: societal and social readiness

Successful implementation of rehabilitation as a routine service relies on both system and societal readiness that supports change, individual, organisational, and political leadership, and sound evidence. We hear consistently about society's negative attitudes towards dementia, a known barrier to access to timely services, and the real and potential impact on the individual's decision to use post-diagnostic dementia care services, including rehabilitation. The 2024 World Alzheimer Report on attitudes to dementia[9] paints a disconcerting picture of the lack of progress, and even regression, in the way the public and health and care practitioners perceive, understand, and think about dementia and care, and behave towards people with dementia:

> *…nearly 80% of the general public and, more worryingly, 65% of health and care professionals, still believe that dementia is a normal part of ageing. This is a concerning increase from our 2019 survey numbers, as we know that this lack of understanding can delay diagnosis and access to treatment and support.*[9]

There needs to be a strategic plan for addressing change in the way society perceives dementia, focusing more on what the person can do and less about what they cannot, to create awareness of the role of rehabilitation in enabling and empowering the person so that they can live with a sense of independence as long and as well as possible. It is useful to refer to recent guidance by the WHO, in which community engagement is identified as a key system enabler, along with other system enablers or building blocks mentioned earlier:

> *[Community engagement and social participation] involves … communication and engagement between the community and the public sector to inform, influence, motivate and engage populations on health issues. This involves building an environment where well informed citizens are able to take decisions and responsibilities regarding their own health.*[10]

The message here is that societal readiness for change in dementia care cannot be fully left to those who govern or policymakers; citizens and others involved in dementia care need the opportunity to participate in the creation of the solution, but also need the will to take action. One of the barriers to the implementation of rehabilitation is the reluctance of people living with dementia and their families to accept, or even contemplate, rehabilitation. This is particularly common in the early stages of dementia, when the optimal effect of rehabilitation can be gained, as they believe that they do not need any form of rehabilitation at that stage or that rehabilitation will not help the person to live well. Sometimes, people with dementia and their families may want to be part of a rehabilitation programme because they expect it to be a support service where someone is doing things for them, rather than a therapeutic approach to care that enables the person's functioning and independence.[11] In those scenarios, providing information or public education about rehabilitation can be one of the many layers of strategies to reach the desired outcome – routine access to rehabilitation – but it alone cannot be a solution. Participatory approaches to change and community mobilisation, where citizens are empowered and given the opportunity to work together, create much more tangible solutions for a complex agenda, such as implementing rehabilitation. Marc Stears offers a unique perspective on the importance of societal and political drivers for change, while putting the ownership of the change on society at large, not just governments. He discusses key action points to be considered for the change in dementia rehabilitation to occur, highlighting that there is certainly a hope, but also practical pathways to realise this change (page 127).

Strengthening system and societal readiness: key messages

- Rehabilitation has much to offer people with dementia and their families, but few are able to access it. We must address inequality and inequity in dementia rehabilitation. Society is still too ready to assume that nothing can be done when it comes to dementia, or that the sheer scale of need is simply overwhelming. On the contrary, **as we have shown in this report, a great deal can be done from a rehabilitation perspective**.
- Dementia is a complex condition and there will not likely be one simple method to 'cure' it; rather, a gradual evolution of progress towards disease modification, eventually resulting in dementia becoming viewed as a long-term condition to be managed. Combining rehabilitation with disease-modifying treatments could optimise their benefits, and **making rehabilitation widely available could go some way towards mitigating the inevitable inequalities in access to such treatments**.
- Resources are always a concern, but **rehabilitation can be provided at relatively modest cost when it is integrated into existing systems of care**. It does not usually require expensive equipment, technology, or large hospital premises, for example. Investing in enabling people to function optimally should, in turn, reduce dependence and the need for support services.
- There can be an assumption that what is needed is simply to provide good care and support quality of life and wellbeing, for example, by offering curated group activities. In this case, the potential for optimising functioning on an individual basis is missed. There is a great deal more that can be done if we focus on functioning and apply a rehabilitative approach. **We can and should be more ambitious.**
- Societal readiness for change in dementia care cannot be fully left to those who govern or policymakers; **citizens and others involved in dementia care need the opportunity to participate in the creation of the solution, but also be willing and interested in enacting change**.

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Expert essays

Making the economic case for rehabilitation in dementia

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Rehabilitation is a key strategy for promoting wellbeing.[1] Evidence shows that it may benefit any person with a long-lasting disability arising from any cause, and may do so at any stage of the condition, at any age, and may be delivered in any setting.[2] In this essay, we will consider the context of rehabilitation in relation to economics, which is an important factor for governments as they make choices around which programmes, services, and treatments to fund and to what extent.

Globally, we have an ageing population that is set to grow exponentially, with a concurrent increase in demand for health, social, and long-term care services, and an impact on the availability of informal care, which accounts for half the costs associated with dementia. These factors together point to an economic case for rehabilitation as a key strategy in order to optimise the functional ability of people living with dementia and help promote their independence for as long as possible. However, few services for people with dementia offer rehabilitation, few rehabilitation services accept people with dementia, and general rehabilitation services for physical problems are not well equipped to provide rehabilitation for people with dementia. On the demand side, barriers to rehabilitation include a lack of knowledge about options, challenges with transport and geographical location, the cost of the service (the user's willingness and ability to pay), and difficulty navigating the health and care systems.[3] A gap exists between individual needs and access to services, particularly in countries with more limited resources.

Cost of dementia

Dementia represents an increasing economic burden. Globally, there are around 55 million people with dementia, with associated costs estimated at around US$1.3 trillion.[4,5] Just under two thirds of people with dementia live in lower- and middle-income countries, yet around three-quarters of global costs of dementia occur in higher-income countries.[5] The number of people with dementia is set to increase as life expectancy rises, with the largest increases predicted in the Middle East, North Africa, and eastern sub-Saharan Africa.[6,7] By 2030, dementia costs are estimated to rise to $2.8 trillion.[4]

The costs associated with dementia fall onto the health and social care sectors, the individual living with dementia, and family and friends. Healthcare costs include diagnosis, management and treatment in hospital, primary care, or community settings. Social and long-term care covers a range of services, including social workers, home care, day care, and long-term institutional care in residential or nursing care facilities. As health and social care budgets become increasingly stretched, choices must be made around which programmes, services, and treatments to offer and to what extent.

> **"As health and social care budgets become increasingly stretched, choices must be made around which programmes, services, and treatments to offer and to what extent."**

The costs to the person living with dementia can include funding their own care, for example, residential care or nursing home care. For those who are working, the onset of dementia may result in lost income. The costs to family and friends relate to unpaid or informal caregiving and, potentially, losses from income resulting from their caregiving responsibilities. Informal care costs make up around half of the total global costs of dementia, with around a third attributed to the social sector and the remainder to the medical or health sector.[5,6] These combined factors point to the need to find solutions that help reduce the economic burden of dementia.

Rehabilitation evidence

Rehabilitation can provide one such solution. Rehabilitation is designed to optimise functioning, enabling individuals to be as independent as possible, to participate in education, work, leisure, and meaningful life roles,[1] which in turn can reduce demands on informal care and formal care services. At least one in three people globally will need rehabilitation for an illness or injury at some point in their lives.[8] Yet typically the need for rehabilitation is largely unmet, particularly in lower- and middle-income countries, where more than half of people do not receive the rehabilitation services they require.[1] This is despite the fact that rehabilitation is an investment that can provide cost benefits for both the individuals and society.[1] Rehabilitation makes a difference to people's independence and ability to function. This has broader significance, for example, by enabling individuals to engage in or return to work and employment, or to remain independent at home, minimising the need for financial or caregiver support.

There is a body of evidence showing the cost effectiveness of rehabilitation across many disease areas.[9,10,11] Formal evidence regarding the cost effectiveness of rehabilitation for people living with dementia is more limited. Yet rehabilitation has the potential to be low cost, given the number of sessions and cost of delivery can be modest. Rehabilitation costs are mainly driven by the cost of staff delivering the intervention, together with often less substantial costs such as training and travel expenses.[12,13] If the approach is integrated into mainstream services, particularly at the primary healthcare level, it could further reduce cost and improve access, equity, and timeliness.[1]

Current evidence on costs and cost effectiveness of rehabilitation and dementia

Cost-effectiveness analysis compares the costs and outcomes associated with competing programmes or services to assess the value. It calculates the differences in costs between the programmes or services of interest. For rehabilitation, these costs can include delivery of the rehabilitation programme, concurrent and subsequent health and social care use, and costs to family and friends. The difference in outcomes between the interventions of interest is also calculated. This could be, for example, change in functioning. Cost-utility analysis is a specific type of cost-effectiveness analysis that uses quality-adjusted life years (QALYs) or disability-adjusted life years (DALYs) as a measurement of the burden of disease. QALYs are based on the quality of years of life over the study period, whilst DALYs are based on years of healthy life lost due to disability. The differences between costs and outcomes are then combined to produce an incremental cost-effectiveness ratio (ICER).

Within the economic literature in dementia, focus lies on assessing the cost effectiveness of specific rehabilitation interventions for particular groups, typically as part of clinical trials. The number of cost-effectiveness or cost-utility studies of rehabilitation for people living with dementia is small,[14,15] and typically focus on those with mild or moderate dementia.

The Australian study of an Interdisciplinary Home-bAsed Reablement Programme (I-HARP) on improving functional independence of people living with dementia conducted a cost-effectiveness study alongside a trial.[16] They reported lower costs for the intervention group over 12 months, but a high degree of uncertainty around estimates of how much better I-HARP is in terms of quality of life (QALYs) and cost, which meant there was no clear conclusion about cost effectiveness. However, the overall average health-related costs per person for people with mild dementia were substantially less in the intervention group ($A 6,836.59) than in the control group ($A 13,934.57), with a significant saving from delayed or prevented care home admissions.

> **"If [rehabilitation] is integrated into mainstream services, particularly at the primary healthcare level, it could further reduce cost and improve access, equity, and timeliness."**

Paterson[17] undertook a trial-based cost-effectiveness analysis of hearing and vision rehabilitation for people with dementia in five European countries (SENSE-Cog). Unfortunately, only a small number of participants were randomised to receive the intervention, and, due to the pandemic, some participants saw part of the support either not fully delivered or not delivered at all. The trial also saw a differential dropout or loss to follow-up by treatment group. Together, this meant the results were not robust.

Other, non-trial-based evaluations tend to be more exploratory. For example, Fischer and colleagues[18] undertook a proof-of-concept cost-utility analysis comparing standard pharmacological treatment with combined cognitive rehabilitation in early dementia. Whilst the sample size was small (only 17 patients in total) the results were promising, suggesting that cognitive rehabilitation could be efficient for the patient and cost-saving for the health insurance system.

Within the trial-based economic evaluations,[16, 17, 19] the authors often report uncertainty in their results. The difficulty in drawing conclusions from the results of many of the analyses reflects challenges within the evaluations. Use of trial-based economic evaluation (cost-effectiveness or cost-utility analysis) has limitations that are particularly pertinent to rehabilitation interventions. These include duration of the trial and time horizon for the economic evaluation (which may not fully reflect the cost benefits of, for example, remaining in their own home for longer), restricted generalisability to different settings or countries, and failure to incorporate all relevant evidence.[20] Trials tend to have restricted inclusion and exclusion criteria, and delivering the intervention may be more costly in the trial than in a 'real-world' setting.

There is high variability in the assessment of outcomes and, in some cases, criticism over the use of inappropriate and inadequate endpoints.[21,22] The primary outcomes of rehabilitation in dementia are functional outcomes, but there are questions over whether the right outcome measures are being used to capture the outcomes effectively and translate them into economic terms, and it has been argued that QALYs and ICERS may not be appropriate metrics. In their cost–utility study comparing the UK implementation of COTiD with treatment as usual in dementia using the data from the VALID trial, Wenborn and colleagues[19] chose not to report the ICER given the small mean QALYs gained (0.00664, 95% CI –0.00404).

Current evidence on cost savings or cost consequences of rehabilitation and dementia

In addition to cost-effectiveness analyses, there are a small number of cost analyses of rehabilitation for people with dementia. Cost analyses typically consider resources used over a period of time in addition to the delivery of the intervention. Cost savings can accrue from changes in the resources used by individuals subsequent to, or even concurrently with, their rehabilitation. Within economic studies, and in studies of rehabilitation programmes and services more widely, an area of particular interest is the potential for delayed or prevented residential or care home admission and reduced use of hospital and long-term care services.[16,23,24] For example, Amieva and colleagues[23] compared cognitive rehabilitation to a control group for people with mild to moderate dementia and found a reduction in costs resulting from a six-month delay in institutionalisation at 24-month follow-up, reflecting the slower functional decline in the cognitive rehabilitation group. Similarly, whilst a Cochrane review of enhanced rehabilitation and care models for adults with dementia following hip fracture surgery did not find any cost-effectiveness analyses, there was evidence to suggest that those exposed to an enhanced interdisciplinary rehabilitation and care model both in hospital and at home had a reduced length of hospital stay, decreased risk of institutional placement at three months, better functioning in activities of daily living (ADL), and greater probability of regaining pre-fracture walking capability, compared to those who had usual care.[25] These findings have been found in other studies with older people. For example, Beaupre and colleagues'[26] study of an outreach rehabilitation programme for nursing home residents reported cost savings as a result of lower hospital readmissions in the rehabilitation group. Indeed, the use of long-term institutional care represents a substantial resource and cost to health and care systems and, in many cases, to the individual and their family, illustrating the potential for rehabilitation to affect substantial cost savings in addition to the core purpose of optimising functioning and enabling individuals to be as independent as possible.

Economic evidence from LMICs

It is of note that within the small evidence base of economic studies for rehabilitation with people living with dementia, there is a dearth of evidence from lower- and middle-income countries, which might be explained by almost all dementia care being provided by family and friends in many lower- and middle-income countries.[6] Indeed, access to rehabilitation worldwide is generally limited, giving little opportunity to examine the economic aspects. People with dementia rarely have access to rehabilitation despite evidence that they can benefit from it. In lower- and middle-income countries, barriers to access can include not only lack of resources but also education, leadership/policy, social support, cultural influences, and political issues.[27]

Relative to opportunity – is rehabilitation expensive in the bigger scheme of things?

Whilst health insurance and funding from government and non-governmental organisations (NGOs) can strengthen rehabilitation services, it is important to find practical, low-cost approaches that improve availability and access to rehabilitation.[27]

Community-based rehabilitation can be provided at relatively modest cost. It does not usually require expensive equipment, technology, or large hospital premises. On the supply side, the main cost driver of rehabilitation services is staff time, while a practical issue for personalised home-based rehabilitation could be the cost of home visits, especially in hard-to-reach areas due to distance and travel. One potential solution is the use of digital technologies, where, for example, a model combining visits and telehealth could be applied. Investment in, and availability of, digital technologies to support people living with dementia and their carers has burgeoned over the past decade. Whilst there are still questions over the benefits and drawbacks[28,29] it is an area of great potential. Staff time might also be used more efficiently by building up practitioner expertise over time. For example, offering short training courses for qualified practitioners and eventually incorporating rehabilitation in basic professional training, rather than needing extra training; and/or training 'dementia rehabilitation practitioners' who can work under the guidance of specialists from relevant disciplines to implement rehabilitative approaches.

On the demand side, challenges with geographical distance and transport may also be addressed through the use of digital technology or telehealth, increasing engagement with rehabilitation and other services. Improving access to good information sources and free, available educational tools about rehabilitation principles to people with dementia and family carers is an important step in addressing the lack of knowledge about options.

How do we collect evidence to make an economic case for rehabilitation?

Currently, the evidence base is small. Potential pathways that could help include considering an alternative approach to economic evaluation rather than the cost-effectiveness framework. The cost-consequence approach enables a wide range of costs (or cost savings) and outcomes of rehabilitation for people living with dementia to be captured, including relationships between direct intervention effects and subsequent, longer-term impacts. The approach presents a balance sheet of monetary, quantitative, and descriptive consequences that is useful when there are relationships between intervention effects and subsequent impacts, which can also be compounded by the variety of ways effects are reported.[30] The approach will facilitate a comprehensive assessment and understanding of costs accruing to different sectors within different health and care systems and can reflect the potentially myriad beneficial outcomes. Similarly, more implementation research on models of care that address the need for system change and integration of rehabilitation into existing systems of care will allow a better understanding of the costs of rehabilitation as well as the cost consequences.

Budget impact analyses could usefully be employed to provide comprehensive economic assessment, illustrating expected changes in healthcare system spending following the adoption of rehabilitation services.[31] Social Return on Investment (SROI) estimates can value the impact of health and social care programmes, although their use has been relatively limited.[32] This type of analysis has been used with people living with dementia (see for example, Doungson et al.,[33] who estimate a £0.58–2.33 return for every £1 invested in a home exercise programme for people with early dementia). However, their limited use in general is likely, in part, to be due to methodological weaknesses, including imprecise measures of costs and benefits and potential sources of bias in defining what costs and outcomes are and are not important and measured.[34]

Conclusion

Rehabilitation for people with dementia is a human right as part of post-diagnostic services and support.[35] The value of rehabilitation lies in enabling and empowering the person with dementia, and all people living with dementia can benefit from rehabilitation.[36] The implications of an ageing population for increased demand for health and long-term care services point to an economic case for rehabilitation as a key strategy for promoting wellbeing in people with dementia. The implications of an ageing population for increased demand for health and long-term care services point to an economic case for rehabilitation as a key strategy for promoting wellbeing in people with dementia.

> **"The implications of an ageing population for increased demand for health and long-term care services point to an economic case for rehabilitation as a key strategy for promoting wellbeing in people with dementia."**

Yet there is a gap between needs and access, particularly in countries with limited resources.[36] Globally, the economic climate is particularly stretched and, irrespective of the size of a country or region's health and social care budget, policy choices or decisions will need to be made in how resources or funding are allocated. Community-based rehabilitation can be provided at relatively modest cost with the potential to accrue savings through delayed or prevented residential or care home admission and reduced use of hospital and long-term care services. Current research is limited and focused on costs and cost effectiveness. Alternative economic methods or frameworks should be considered to aid accurate reflections of the economic value of rehabilitation for this population.

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Workforce education and training and the importance of an interdisciplinary approach

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Adequate workforce capacity and capability are essential to ensure that rehabilitation is available to all people with dementia across care settings. Capability includes the necessary knowledge and skills to deliver rehabilitation, as well as the ability to work as part of an interdisciplinary team. This essay outlines current workforce barriers and solutions to support workforce readiness.

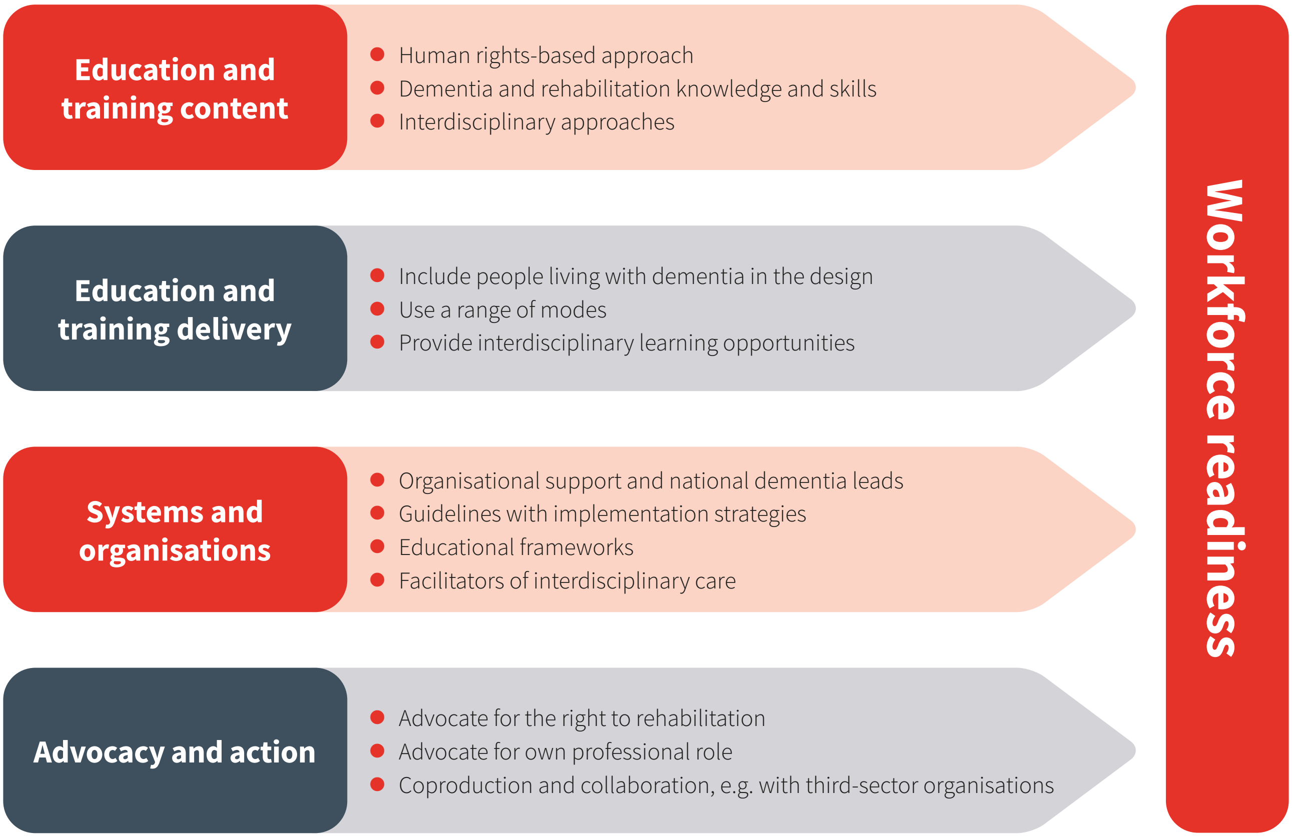
Much needs to change. In many places around the world, dementia care still has a medical-only focus, which may not account for broader participation or rehabilitation goals.[1] Interdisciplinary approaches, where care professionals and informal carers work collaboratively to meet individuals' physical, mental, social, and spiritual wellbeing goals, are needed. To improve access to quality rehabilitation, a number of workforce issues need to be addressed:[1,2]

- The incorrect belief that people living with dementia don't benefit from rehabilitation, and that they cannot engage or participate.
- Low knowledge about dementia in general, and specifically about dementia rehabilitation.
- Limited dementia education in undergraduate courses, with a focus on pathology and symptoms rather than practical strategies.
- Low confidence and skills in rehabilitation, including interdisciplinary care, person-centred goal setting, and coaching.
- Historical separation of dementia and rehabilitation services, with the term 'rehabilitation' associated with sub-acute care and physical interventions.
- Low numbers of health and social care professionals specialising or working in dementia, especially in low- to middle-income countries.
- Dementia workforce burnout.

A multifaceted plan is needed to build workforce readiness, including comprehensive education and training delivered through varied modes. Organisations and systems need to support and promote a positive learning culture, and the workforce will need to know how to address stigma to support people with dementia to access rehabilitation. (Figure 1). We discuss each of these elements below.

> **"Organisations and systems need to support and promote a positive learning culture, and the workforce will need to know how to address stigma to support people with dementia to access rehabilitation."**

Figure 1. Solutions to ensure workforce readiness for dementia rehabilitation



Education and training content

- **A human rights-based approach**: Attitudes must change so that all workers believe and take action to ensure timely and equitable access to rehabilitation services. This includes rehabilitation for both dementia-related disability and comorbidities (e.g., stroke or hip fracture), where people with dementia are often excluded.
- **Rehabilitation essentials:** Roles of team members, effective teamwork skills, person-centred goal setting, motivational coaching, and evidence for different types of therapies.
- **Dementia essentials:** Effective communication, supports for cognition, identifying and addressing unmet needs, assessing and managing pain, addressing behaviours and psychological symptoms, and using a supported decision-making approach.
- **Additional knowledge and skills:** Addressing negative attitudes, practices, and exclusionary environments. Knowledge of dementia-inclusive rehabilitation services and pathways.

Education and training delivery

- **Involving people with dementia and their families** in the codesign of education to reflect their views and needs. Showcasing that people with dementia want and benefit from dementia rehabilitation can have a powerful effect on stigma. For example, Dementia Alliance International is an organisation of people with dementia that promotes the right to rehabilitation.
- **Lectures, tutorials, and online education** can provide foundational knowledge. A face-to-face course on rights-based dementia rehabilitation for allied health professionals (AHP) in Scotland resulted in improved knowledge, attitudes, and practice.[3] Online courses provide an accessible format, particularly for those in rural areas or low-income countries. An interdisciplinary introductory dementia rehabilitation e-course for health professionals in Australia was codesigned with clinicians and people with lived experience.[1] The e-course contains a module on advocacy and action to address stigma and other barriers to rehabilitation. Health professionals' attitudes and confidence in dementia rehabilitation improved, and when combined with a community of practice, health professionals changed service inclusion criteria and practices, increasing the number of dementia rehabilitation referrals.
- **Practical sessions and clinical placements**: Contact with people with dementia can break down stigma. Clinical placements provide 'real-world' learning with supervision, but this needs to be from experienced dementia workers who are skilled and enthusiastic about dementia care.[4] Instead of 'protecting' students from seeing people with

dementia,[4] there is a need to provide students with positive experiences to support their motivations to develop their dementia care skills.[5] The 'Time for Dementia' education programme in the UK provides healthcare students with visits to people with dementia and their families over a two-year period.[6] Evaluations indicate improved knowledge, attitudes, and confidence in delivering person-centred care.[6]

- **Simulation-based learning**, including role play, virtual reality, augmented reality, or immersive experiences, has been trialled to address the difficulty of finding volunteers. Peer simulation or role play can help build empathy and communication skills, but students without sufficient knowledge may have difficulty portraying a person with dementia. An actor may be more authentic, but comes at a greater cost. Virtual or augmented reality can help students and workers experience what it is like to have dementia,[7] and simulation communication experiences like the Dementia Australia 60-minute 'Talk with Ted' AI Avatar enable practice and improvement of communication skills.[8]
- **Learning on the job** can be facilitated by intra- or inter-professional shadowing, joint sessions, buddies, and debriefing sessions.[9] Cognitive or dementia leads in organisations can help create a learning culture (see below for more information). Innovative ways to use tele-mentoring may be areas for exploration where expertise is not readily accessible.
- **Interprofessional learning** allows different professions to learn from and with each other. For example, physiotherapists and nurses can learn communication techniques from speech and language pathologists, nurses can learn the application of cognitive strategies from psychologists and occupational therapists, and AHPs can learn from nurses about addressing clinical issues and medications incorporated into the rehabilitation plan. Networks across settings can also facilitate collaboration, learning and mentorship. In Wales, a national AHP dementia network has broad membership, including non-AHP workforce as partners, community and third sector organisations, and lived experience voices. The network promotes rehabilitation through virtual meetings, a national newsletter, and a members' web platform.[10] Such interprofessional learning can facilitate interdisciplinary teamwork where AHPs and nurses learn and work together to meet people's goals, rather than separately, in silos.[11]

Systems and organisational solutions

- **Standards for dementia rehabilitation education and training** underpin quality curricula. Different tiers of learning allow for different needs and experience, for example, the Australian National Dementia Education and Training Standards Framework, with 14 domains, including Independence and Enablement.[12]
- **Dementia rehabilitation guidelines**, complemented with **quality assurance standards and monitoring systems,** help ensure that rehabilitation is delivered effectively. The Wales Dementia Care Pathway of Standards[13] covers both workforce education and access to dementia rehabilitation. Regular evaluation and feedback help identify areas for improvement, akin to other conditions such as stroke.[14]
- **Incentives and organisational support**: Supportive policies, adequate funding and time are necessary to ensure workforce capacity and capability. Scholarships offered to workers to complete specialist training, with ongoing salary loadings, may help. Other incentives include professional development points and time in working hours to complete education. Leaders can foster a positive learning culture and help set up mentorship and supervision programmes. Burnout can be common in dementia care, and leaders need to factor in support to ensure self-care for their workforce. Introducing dementia rehabilitation leads into workplaces or health systems can support the workforce, as well as providing career paths. Examples include the Allied Health Dementia Leads in Scotland and Wales who advocate for and influence proactive care across each country.[10,15]
- **Facilitating interdisciplinary care** through shared objectives, regular communication, and clear leadership is needed. Shared electronic records, goals and care plans, allocating a key contact person, regular case conferences, and colocating teams in the same physical workspace are additional facilitators. Many health and care services have rehabilitation programmes for other neurological conditions, and dementia programmes could be added. Alternatively, existing cognitive clinics could be extended to provide ongoing rehabilitation and follow-up assessments.
- **Lower- to middle-income countries** may have a workforce less equipped to deliver rehabilitation, due to workforce shortages for both dementia care and rehabilitation.[16,17] Implementation will need to consider specific country health and cultural contexts, as has been done to plan for Cognitive Stimulation Therapy in India, Brazil, and Tanzania. In Tanzania, strategies included dementia awareness programmes, screening for dementia in different settings, a train-the-trainer model, task-shifting, and creating dementia-friendly environments.[18] A consideration in lower- to middle-income countries is that dementia care is commonly provided solely by family, often women with little training.[16] For conditions like stroke, where rehabilitation is more common, it is also provided by informal carers, or by task-shifting to other professions.[17] If used, task-shifting should be a planned and resourced strategy. A further consideration is stigma. In Kilifi County in Kenya, some individuals believe dementia is associated with witchcraft, leading to neglect or even deadly violence.[19] However, anti-stigma interventions, such as those delivered in rural Kenya that involved face-to-face training and virtual 'social contract' videos, improve knowledge and attitudes of the general public.[20]

Conclusion

Key recommendations to promote a strong, informed workforce that can meet demand for dementia rehabilitation include:

- Human rights-based education and training for all workers, which is codesigned with lived experience, involves interdisciplinary learning and real-life or simulation learning.
- Workforce education incentives and structures to support interdisciplinary learning and teamwork, including dementia leadership roles, regular meetings and opportunities for learning on-the-job through mentors, and clinical networks.
- A planned and resourced task-shifting strategy, where there are fewer workforce resources.
- Clinical guidelines, education standards, audits and feedback to monitor access and quality of dementia rehabilitation.

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System readiness and how we can promote the availability of rehabilitation

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> *Rehabilitation is an essential health service and crucial for achieving universal health coverage.*
>
> *World Health Organization, Rehabilitation 2030*

Rehabilitation is all about facilitating people in doing the things that are important to them when or after they experience illness or injury. For people with dementia and their caregivers, rehabilitation has the power to optimise functioning and wellbeing and enable independence and safe living for as long as possible, adapting to their evolving needs as the condition changes or progresses.[1] Despite clear evidence to suggest that rehabilitation is beneficial for people with dementia, it is reliant on the systems in which it operates to ensure that such services are available, accessible, affordable, acceptable, and quality.

Rehabilitation and health systems: what does this mean?

At its very core, rehabilitation is a health service, though at times it may be provided outside of a specific health setting – such as in schools, community centres, or in people's homes. In an ideal world, rehabilitation would be well integrated into the health system, ensuring that anyone with a rehabilitation need could access the service that best suits their needs, when and where they need it.[2] Often, however, rehabilitation has taken place outside of the health sector, fragmented across different agencies and seen as an 'afterthought' to health planning.

In 2017, the World Health Organization launched an initiative called Rehabilitation 2030[2], a call to action to ensure that rehabilitation is better integrated into health systems and services. When health strategies are considered, rehabilitation should be embedded within these strategies; when staffing levels are reviewed, they should be done keeping in mind the numbers needed in the rehabilitation workforce; when budgets are prioritised, the one in every three people with a rehabilitation need must be seen as a priority too; and when health conditions like dementia are discussed, rehabilitation needs to be embedded within the care pathway. This year, the Rehabilitation 2030 footprint is likely to pass 80 countries that have, since 2017, undertaken a piece of work relating to strengthening their rehabilitation sector under the initiative's auspices (This includes a number of countries whose rehabilitation activities have been in relation to response to acute emergencies). By 2030, we hope to have reached 100 countries from a mixture of high-, middle-, and lower-income contexts.

Rehabilitation 2030 frames much of its approach around the six building blocks for a health system.[3,4] A series of practical tools and products was developed by the WHO as part of Rehabilitation 2030 to support countries in strengthening rehabilitation related to these blocks. Below is an overview of rehabilitation in relation to the six building blocks, the implications for rehabilitation in the context of dementia care, and the specific Rehabilitation 2030 tool or product that relates to the building block.

Leadership and governance

> *"Leadership and governance involves ensuring strategic policy frameworks exist and are combined with effective oversight, coalition-building, the provision of appropriate regulations and incentives, attention to system-design, and accountability."*[3]

For rehabilitation, that means strong leadership and engagement at high levels of planning and oversight, ensuring that rehabilitation is integrated as a core component of universal health coverage and national health strategies and plans; is regularly monitored, evolved and coordinated; and fosters strong coalitions with key stakeholders. It is crucial that the health sector play a driving role in governance for rehabilitation.

In dementia care, strong governance and leadership for rehabilitation can mean fostering interdisciplinary collaboration, investing in workforce training, and developing policies that prioritise person-centred approaches. Rehabilitation leaders must ensure they are engaging regularly with the dementia community, and conversely, leaders of the dementia community must push and advocate for rehabilitation as a core component of dementia care.

Key Rehabilitation 2030 tools:

- **Rehabilitation in Health Systems.**[5] *This document provides recommendations for Member States and other relevant stakeholders to strengthen and expand the availability of quality rehabilitation services.*
- **Rehabilitation in Health Systems: A Guide for Action**.[6] *This tool allows countries to undertake a broad evaluation of their rehabilitation sectors to understand their current status in terms of the six building blocks.*

Healthcare financing

> *"A good health financing system raises adequate funds for health, in ways that ensure people can use needed services, and are protected from financial catastrophe or impoverishment associated with having to pay for them"*[3]

For rehabilitation, this means considering and ensuring that health coverage and financial protection for the population include rehabilitation. This may be through national or subnational health budgets, social health insurance, private health insurance, or various other financial mechanisms.[7] Strategic purchasing, pooled funding, and inclusion of rehabilitation in health insurance benefit packages are key to expanding access.

In dementia care, people may often require long-term, multidisciplinary support that can be financially catastrophic for the individual or their families if there is not adequate public investment. Ensuring that rehabilitation is included in any health benefits packages that are developed or existing in relation to dementia will be an important step to providing access and care.

Key Rehabilitation 2030 tool:

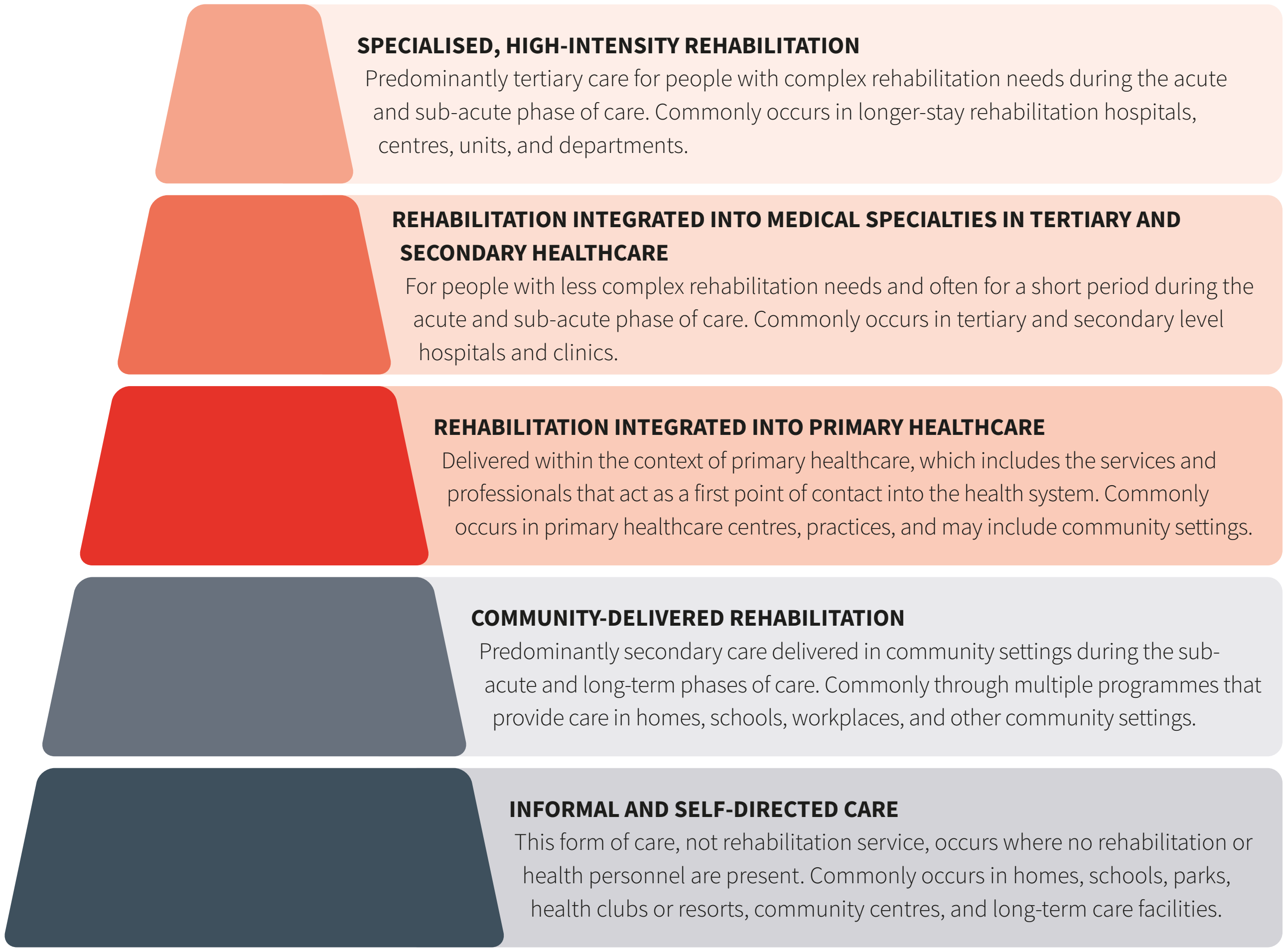
- **Rehabilitation in health financing: opportunities on the way to universal health coverage.**[7] *This document considers current practices for financing rehabilitation services, frames major challenges and opportunities, and offers guidance to decision-makers engaged in strengthening rehabilitation within health systems.*

Service delivery

> *"Good health services are those which deliver effective, safe, quality personal and non-personal health interventions to those who need them, when and where needed, with minimum waste of resources."*[3]

For rehabilitation, this means ensuring that individuals receive timely, coordinated, and person-centred care, considering the most efficient and effective service models at every level of the health system. Figure 1 shows how the WHO envisages rehabilitation across the health framework.[6] It shows that rehabilitation is relevant and should be available at all levels, but that most rehabilitative care, particularly that which is not highly complex, can be provided in primary, community, or informal settings if the competencies and services are available.

Figure 1. Rehabilitation in the health framework



SPECIALISED, HIGH-INTENSITY REHABILITATION
Predominantly tertiary care for people with complex rehabilitation needs during the acute and sub-acute phase of care. Commonly occurs in longer-stay rehabilitation hospitals, centres, units, and departments.

REHABILITATION INTEGRATED INTO MEDICAL SPECIALTIES IN TERTIARY AND SECONDARY HEALTHCARE
For people with less complex rehabilitation needs and often for a short period during the acute and sub-acute phase of care. Commonly occurs in tertiary and secondary level hospitals and clinics.

REHABILITATION INTEGRATED INTO PRIMARY HEALTHCARE
Delivered within the context of primary healthcare, which includes the services and professionals that act as a first point of contact into the health system. Commonly occurs in primary healthcare centres, practices, and may include community settings.

COMMUNITY-DELIVERED REHABILITATION
Predominantly secondary care delivered in community settings during the sub-acute and long-term phases of care. Commonly through multiple programmes that provide care in homes, schools, workplaces, and other community settings.

INFORMAL AND SELF-DIRECTED CARE
This form of care, not rehabilitation service, occurs where no rehabilitation or health personnel are present. Commonly occurs in homes, schools, parks, health clubs or resorts, community centres, and long-term care facilities.

In dementia care, this may involve ensuring good integration and coordination of rehabilitation across both health and non-health settings. People with dementia may navigate frequently between different health and non-health services and often experience fragmentation of care. Furthermore, many people with dementia may have other comorbidities and rehabilitative needs, such as musculoskeletal or cardiovascular health issues. When planning health services, it is particularly crucial to take into consideration people with dementia and the fundamental need for seamless, coordinated, and well-communicated care between providers.

Key Rehabilitation 2030 tool:

- **Package of Interventions for Rehabilitation.**[8] *This includes a module on neurological conditions that has a specific chapter on dementia, along with 19 other health conditions.*

Note: A *Basic Package of Interventions for Rehabilitation*, which provides non-complex rehabilitation approaches designed to be delivered by general (i.e., non-rehabilitation) health professionals in primary care settings, is under development and due to be launched by the end of 2025.

Health workforce

> *"A well-performing health workforce is one that works in ways that are responsive, fair and efficient to achieve the best health outcomes possible, given available resources and circumstances (i.e., there are sufficient staff, fairly distributed; they are competent, responsive and productive)."*[3]

For rehabilitation, building and maintaining a multidisciplinary rehabilitation workforce that includes a range of capable and competent professional groups is fundamental to ensuring the delivery of quality rehabilitation care.

For dementia care, professionals may require specific competencies to address the cognitive, functional, and psychosocial challenges associated with dementia, and to deliver person-centred, individually tailored rehabilitation interventions. Furthermore, strengthening workforce capacity, especially among non-rehabilitation professionals in primary and community care settings, is essential to ensure early intervention and continuity of care.

Key Rehabilitation 2030 tools:

- **Guide for Rehabilitation Workforce Evaluation (GROWE).**[9] *GROWE applies a labour market and competency analysis approach to capture the state of the rehabilitation workforce and better understand the problems and opportunities that the system and workers are facing.*
- **Rehabilitation Competency Framework (RCF).**[10] *The RCF can be used to align the rehabilitation workforce with population needs through supporting competency-based education and training and regulatory standards.*

Health products and technologies

> *"A well-functioning health system ensures equitable access to essential medical products, vaccines and technologies of assured quality, safety, efficacy and cost-effectiveness, and their scientifically sound and cost-effective use."*[3]

For rehabilitation, this often relates to assistive technology and assistive products, which include external devices, equipment, instruments, or software that are used to support mobility, vision, hearing, cognition, and communication to maintain and improve individual functioning. It also considers the consumables and equipment that may be used in rehabilitation sessions or activities.

In dementia care, examples of assistive products may include devices such as memory aids, mobility devices, communication tools, and home-based monitoring systems that promote independence and safety. Assuring access to important devices and home adaptations is critical for maximising independence and functioning for people living with dementia.

Key Rehabilitation 2030 tool:

- The main work on assistive technology is conducted under the **WHO GATE initiative**, which has developed a range of tools and products in this field.[11]

Health information systems

> *"A well-functioning health information system is one that ensures the production, analysis, dissemination and use of reliable and timely information on health determinants, health system performance and health status"*[3]

For rehabilitation, this means that health information systems must capture comprehensive, timely, and disaggregated data on rehabilitation, including key indicators such as needs, service utilisation, outcomes, and workforce capacity. The capacity to capture such data, as well as the skills to appropriately analyse and use it, help make strategic enhancements to services and approaches in order to improve the rehabilitation system.

For dementia care, this may include tracking cognitive and functional assessments, rehabilitation plans, caregiver support needs, and the use of assistive technologies. Integrated digital platforms can facilitate continuity of care across settings, support clinical decision-making, and enable early identification of rehabilitation needs. Moreover, data systems should be interoperable, privacy-compliant, and designed to inform policy and resource allocation.

Key Rehabilitation 2030 tool:

- **Routine health information systems – rehabilitation toolkit**[12]

Promoting availability for rehabilitation: implications for dementia and beyond

What we have found while carrying out national assessments and developing subsequent plans across the world over the past six years is that there is huge variability in health system readiness for rehabilitation. Some countries show a remarkable level of progress, while others are at the very beginning of their journey and have barely one or two rehabilitation professionals for huge populations.[13]

The key question is therefore: Where do the dementia and rehabilitation sectors go from here? It is clear that for people living with dementia, their families, and caregivers, a stronger health system with more availability of rehabilitation services will allow for better and earlier access to the right rehabilitation services that are needed. Three important areas for immediate action can be highlighted:

1) Ensure that actions to strengthen rehabilitation include dementia

Where countries are working on strengthening their rehabilitation sector, whether through the tools and products of Rehabilitation 2030 or by other means, it is important that the voice of dementia is heard and represented. Whether looking at workforce competencies, financing, or national rehabilitation planning, the needs of people with dementia (as well as those with other health conditions) must be factored in.

2) Ensure that actions to strengthen dementia include rehabilitation

On a similar vein, where actions are being taken – whether large or small – to make improvements in dementia care, rehabilitation should be considered. Rehabilitation leaders – whether in ministries of health, academia, professional organisations, or others – should be asked to provide input into strategic decision-making on dementia. This is particularly important when care pathways, clinical guidance, or health benefits packages for dementia are being reviewed and updated.

3) Bring more awareness of rehabilitation for dementia

Given that rehabilitation has not historically been a core part of the care pathway for dementia, all countries can do more to raise awareness of its value and importance. This can be done in many ways – from public communications and awareness raising to health worker training, from including the voices of people with dementia to the opinions of clinical leaders in the field. We have learned from other sectors that advancing one step at a time, changing one mind at a time, eventually leads to rehabilitation being seen not as a "nice to have" but as a "need to have."

> **"Advancing one step at a time, changing one mind at a time, eventually leads to rehabilitation being seen not as a 'nice to have' but as a 'need to have.'"**

Work is being done around the world right now to strengthen rehabilitation services. Work is being done around the world right now to strengthen dementia care. It is beyond time for these two areas to begin to strengthen in harmony.

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Changing culture and attitudes across levels at a moment of great flux

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Is it possible to change people's minds about an issue as fundamental as dementia rehabilitation? If so, how can we do it? What would a practical campaign for service change and policy advocacy actually look like? In this essay, I draw upon both the academic literature in political science and some personal experience in leading policy change to try to answer these fundamental questions in a way that I hope will be directly useful to those committed to change.

What moment are we living in?

We are living in a period of great social and political tumult across the world. This can bring enormous insecurity to people, as ideas and institutions that were once taken as unquestioned fundamentals are challenged and reshaped, often by malign political forces. We have witnessed this at a global level with the unpicking of the international institutional order that used to govern trade and security, and at a national level, with challenges to once strongly held assumptions about the ways in which we debate key political issues, including those related to race and gender. But anxiety-producing though this moment of flux undoubtedly is, it also presents an opportunity for those committed to social and attitudinal change to open up new ways of thinking and attempt to reject previously exclusionary or damaging patterns of thought and action. At moments like these, policymakers and those in other positions of authority are forced to think anew, to question the *status quo* and to consider the possibilities offered by new perspectives, even those which might be deeply at odds with their prior commitments.

This is the vital context within which the debate about rehabilitation currently occurs. As the authors of this report have written, rehabilitation offers a wholly new way of thinking about the disabilities that currently result from dementia. For them, it means enabling people experiencing disability to be as independent as they can be and wish to be, to have as much control as possible over daily life, to have opportunities to engage in meaningful roles and activities, and to integrate the changes they experience into a coherent and enduring sense of identity.

To achieve this, we must shift the way in which core health, social, and long-term care services work in older age, build the requisite capacity in the care workforce, create the right metrics of assessment and interventions to encourage care-providing organisations to innovate in the desired way and, of course, provide the necessary funding such a transformation will require, at least in the short term. Most of all, however, we will need to change the attitudes and expectations of the broader public and of key decision-makers, because without their willing engagement in change, it is always exceptionally hard to alter long-established practices of service provision and policy support.

Political scientists have written for many years about the "stickiness" of such provision, with otherwise well-intentioned service providers and policymakers unwilling to challenge the fundamentals of existing practice, even when provided with strong evidence about the advantages of doing so. Through a process known as "path dependence", both service providers and policymakers see the returns to their activity and investments as dependent on keeping moving within the same paradigm that they are used to, or along the same general direction, worrying that any change in course will be extremely costly, either in terms of financial resource or time and effort. These actors have a tendency to switch only at particular moments in time, which the literature describes as "critical junctures", when wholly new ways of thinking about problems and evaluating solutions allow for an openness to alternative concrete proposals.[1]

It is usually beyond the agency of any particular group to create such a "critical juncture"; these are the product of larger social, economic, and political trends. Thus, the context is generally taken by political scientists to be more important than the individual efforts of any particular group in determining whether any effort at a significant change will succeed. That is why our moment in time, however, might be seen as a particularly opportune one to be advocating for a change as potentially far-reaching as a move to thinking about rehabilitation and reablement in dementia care. We clearly live at a moment when significant rethinking is already occurring across a range of public service and public policy concerns, pushed there by a distinctly unstable social, political, and economic context. The question for those with an interest in advancing this particular agenda, then, is how to make the most of this opportunity and potentially lead the change.

What will it take to lead change?

The answer to that question has three core parts. First, it is important to note that **the conventional ways of calling for change are less likely to succeed in moments of flux than they are at moments of relative stability**. To put that another way, many of us have gotten used to making arguments for the redesign of services that reinforce, rather than challenge, key elements of the status quo. These include making conventional financial return-on-investment arguments, pointing to the views of established experts, lobbying through existing policy channels at a national or subnational level, or drawing on conventional coalitions of public support, including the perspectives of well-respected professional advocacy groups or non-governmental organisations. These so-called "insider" tactics remain potentially useful and important, of course, and no sensible social change strategy should overlook them entirely, but there is good reason to believe that they are unlikely to be enough to secure the kind of far-reaching service and policy change that rehabilitation requires, especially at a moment of general instability.[2]

If those conventional tactics are unlikely to be enough, it is, of course, necessary to look for less conventional ones. That observation leads, in turn, to the second reflection: **it will be important to draw new people into any potential group calling for change**. This is in order to generate both new and innovative ideas through new talent and to create broader, cross-cutting coalitions arguing in favour of change. When policymakers see that the coalition calling for change has shifted, then their calculations as to whether the coalition needs to be heeded or not often change, too. This is especially true, of course, if the new coalition involves people who have become significantly more influential or powerful at a particular moment in time, as a result of some development often entirely unrelated to the specific issue at hand. In the UK at the moment, for example, the views of a small group of the electorate who live in a particularly tightly contested group of electoral constituencies, known as the "Red Wall", have an enormous sway on the views of both government and opposition parties. Given this, a key consideration for anyone interested in advancing the idea of rehabilitation is: *who* is arguing for this change, who has not done so before, and why will their views be taken especially seriously by the decision-makers whose minds need to be changed? For a fascinating example, see Han.[3]

Vital though this issue is, **it is not only who argues for change that matters, but how they do so. The specific kinds of arguments that they make will need to find a willing audience.** The ideas deployed will need to resonate with some broader social trends. Political strategists and leaders of social change organisations often call this "speaking to the moment"; proving, in other words, that this is a shift whose time has come, one that goes with an emerging grain and not against it. It is here, I believe, that those calling for a move to rehabilitation have the greatest cause for optimism. The very core of the argument for rehabilitation, as I understand it, is shared with a whole host of other issues and organisations.

That core itself is composed of two passionate beliefs. First, that all people, no matter who they are, where they are from, or what intense challenges they face, have the right to expect that they can direct their own lives rather than have them directed for them by someone else. We have left behind the era in which a standard set of normative assumptions about what life should look like and who we should seek to be were established and set in advance. We now live at a time when people think of themselves as what the philosopher Joseph Raz once called "*at least the part-authors of their own lives*".[4] Any idea which speaks to that concern is thus likely to find an eager audience. Second, the key areas of life that we ought to be able to direct ourselves as far as possible are the *everyday* areas of life, and not some grand objective. There is a widespread sense that the areas of life that matter most to people are the most basic and fundamental concerns of daily life: having contact with family and friends, being able to choose what your own daily living space looks like, and being able to do some everyday things that bring even momentary joy and a sense of fulfilment.[5] Any proposed service or policy innovation that speaks directly to these everyday concerns, therefore, is more likely to have success than innovations that do not.

Concluding thoughts

Challenging social attitudes and transforming key service provision and policy preferences is never easy. As the authors of this report suggest, *"perhaps society is still too ready to assume that, when it comes to dementia, nothing can be done"*. But there is no reason to give up. Thanks both to the labours of political scientists and the efforts of actual change-makers, we do know quite a lot about when and how change occurs. Critical junctures allow new ideas to take hold, as long as those ideas are advocated for in fresh new ways, by groups of people who are broader or different from usual, deploying arguments whose time is widely considered to have come. The key, of course, is that once we have that knowledge, we need to act upon it. And that will take the efforts of us all.

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Case studies

Homelearn programme: improving the daily function of people living with dementia in South Korea

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Since the implementation of the 'National Responsibility for Dementia' policy in 2017, 256 Dementia Relief Centres have been established nationwide in South Korea, providing support and services for brain health and various non-pharmacological interventions for people with dementia. The centres offer cognitive rehabilitation for individuals with a diagnosis of dementia, cognitive enhancement for those with mild cognitive impairment, and dementia prevention group programmes for seniors.[1] However, based on the concept of ageing in place, it was recognised that personalised interventions are necessary for people with dementia who have unique challenges, leading to the development of the 'Homelearn' programme.[2-4]

How the Homelearn programme works

The programme provides one-on-one individualised training and home-based rehabilitation for people with early-stage dementia experiencing difficulties in performing activities of daily living (ADL). To receive support, individuals need to be registered at the Nowon-gu Dementia Relief Centre. Family carers and home care workers of those eligible participants are also involved in the programme. The programme is led by occupational therapists employed by the Centre. Key components include:

- After an initial assessment and consultation, individualised ADL training goals are set, and one-on-one basic training is provided at the centre.
- This centre-based training is delivered by occupational therapists over two months (eight weekly sessions of 1–1.5 hours), covering cognition, depression, falls risk, nutrition, daily living activities, and home environment.
- Family members or care workers of participants are also educated to ensure that the training can be maintained at home even after the programme is completed.
- Following a personalised rehabilitation plan, individual home visits are provided once a week for a total of eight sessions over two months.

Training for Activities of Daily Living (ADL). This photo shows a cognitive activity to promote self-recognition in a patient who had difficulty recognising their own face and body prior to personal hygiene training.

Key principles of the programme

- The Person-Environment-Occupation (P-E-O) model: The programme is personalised to each participant's cognitive abilities, personality, history, and family and physical environment.
- Intrinsic motivation enhancement: Cognitive and emotional changes make it difficult to foster motivation, directly affecting therapy participation and outcomes.
- Carer awareness improvement: Carers often underestimate the importance of ADL training, which impacts programme effectiveness, highlighting the need for education and support. During the initial consultation session with the carer, they often respond, "Even if my parent has difficulties with

day-to-day activities, it doesn't matter because I can just do things for them. I would rather you focus on behavioural and cognitive programmes." Such responses highlight the importance of including carers in the programme.

Programme evaluation

To date, a total of 58 participants have received the programme. The programme started on a small scale and efforts are being made to increase the number of participants each year. Pre- and post-evaluations have shown notable improvements in cognitive function, performance in ADL, and reduced depression levels among participants. Carers have reported positive changes, for example:

"After receiving the Homelearn programme, my husband began to engage in activities independently, and this experience became a motivation for him to try on his own, which was truly wonderful. I observed a significant change, and it brought me great comfort as well."

Unique aspects of the programme

This is the first one-on-one personalised rehabilitation programme for people living with dementia in South Korea, now established as an ADL training centre. The centre has developed various resources such as ADL programme guides, sticker books, and cognitive/ADL training manuals. After the completion of the programme, participants are provided with an ADL Safety Kit, which includes eight essential items to enhance home safety. These measures aim to strengthen the safety of the person in their home, ensuring a secure and supportive environment even after the programme has concluded. By providing education to family carers and care workers, the rehabilitation plan initiated by occupational therapists during the eight-session programme is expected to be maintained continuously.

Factors that support or impede rehabilitation efforts

Services are free for all Nowon-gu residents and provided regardless of their education level, income, or living status. However, there have been challenges in scaling up the programme, largely due to workforce and financial limitations, as well as a lack of recognition about the need for individualised rehabilitation for people with dementia:

- Individualised rehabilitation after a dementia diagnosis requires a specialist's referral and is offered in the clinic at the person's own expense. Individualised therapies are accessed by those with financial means. A personalised programme by an occupational therapist at a Dementia Relief Centre is rare.
- The concept of individualised dementia rehabilitation is not widely accepted due to limited targets and group-oriented services for people with dementia. Generally, group-oriented programmes are favoured over individualised ones. Dementia Relief Centres are no exception and focus primarily on group-based programmes to meet the target performance indicator (i.e., the total number of service recipients) set by the national dementia management system. As a result, there is a shortage of dedicated personnel to implement individualised, person-centred programmes.

Lessons learned and actions to avoid or attempt in the future

- **Including carers to ensure sustainability**: Dementia rehabilitation is often perceived to be limited to cognitive activities and therapies such as practising number calculation, recall therapy, music and art therapies. Supporting daily activities is seen as the carer's role, which creates undue pressure in recruiting participants for the Homelearn programme. Improving carers' awareness and knowledge about the importance of the person's functional independence and self-care ability should be included in the rehabilitation programme in advance for successful recruitment of participants, as well as for the continuation of both training and in-home activities.
- **Expanding capacity and capability through community collaboration**: Due to potentially costly home modifications that require a separate budget, individualised rehabilitation, such as the Homelearn programme, is limited. Collaboration with other local community organisations (e.g., local community and senior citizen welfare centres, and social welfare teams in the district office) with similar interests and goals is recommended.
- **Training and education for specialised personnel**: Addressing the complex needs (clinical, social, and environmental) of people living with dementia requires specialist skills and knowledge. The need for regular and ongoing clinical supervision has been identified.
- **Development of daily functional assessment tools and resources**: There is a need for more rigorous assessment tools to measure individual outcomes and treatment manuals that support individualised approaches.

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Karin Grech Rehabilitation Hospital: providing interdisciplinary rehabilitation in Malta

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The Maltese Islands are an archipelago located in the central Mediterranean Sea. With a growing ageing population, this island nation faces increasing demand for specialised rehabilitation services, particularly for older adults and persons living with dementia. Established in June 2007, Karin Grech Rehabilitation Hospital (KGH) in Pietà serves as the nation's primary facility dedicated to comprehensive rehabilitation. Operating under the Ministry for Health, KGH provides nationwide services, emphasising sustainable, interdisciplinary care aimed at maximising individual potential and optimising outcomes.[1]

KGH operates a 293-bed facility and is the only rehabilitation hospital on the island. Patients are typically referred from Mater Dei Hospital, Malta's main acute care hospital, once they are deemed medically stable. The average inpatient stay is approximately four weeks, though this varies according to individual needs. Following discharge, patients may continue their rehabilitation through the hospital's Day Hospital or Outpatient Services.[2] Moreover, the Day Hospital also provides an opportunity for conducting a comprehensive geriatric assessment (CGA), which contributes to the identification and management of biopsychosocial needs of older persons living in the community.

KGH offers a wide range of inpatient and outpatient services. The hospital also provides several specialised rehabilitation programmes tailored to the diverse needs of its patients. Its neurological rehabilitation programme addresses a broad range of conditions, including stroke, traumatic brain injury, spinal cord lesions, multiple sclerosis, Parkinson's disease, and other neurodegenerative disorders such as dementia and Alzheimer's disease.[3] The main reasons for their admission to hospital are for other conditions such as falls and fractures, chest infections, chronic heart failure, and deterioration in mobility. The time for transfer is around 20 days from the date of admission to the acute care hospital, where the initial management (such as any acute interventions or surgery) and assessment for rehabilitation potential is carried out prior to transfer for rehabilitation.

There are currently 150 geriatric rehabilitation beds at KGH, and regular cognitive testing as part of a comprehensive geriatrics assessment shows that as many as 40% of beds are occupied by persons living with dementia. Persons living with dementia benefit from personalised rehabilitation plans developed following a comprehensive assessment using the Interprofessional Clinical Documentation (IPCD) system. Individualised goals are established by an interdisciplinary team, which meets weekly in case conferences led by a geriatrician or rehabilitation specialist. These goals are based on the specific needs of both the patient and their family. Multidisciplinary team reviews and meetings serve to improve communication across teams, support continuity of care, and enhance discharge outcomes. Training sessions for carers of persons living with dementia are regularly offered as part of the outpatient service provision.[4] Moreover, home visits are carried out by the rehabilitation team, who may suggest changes to the home environment and how to apply to community services, thereby facilitating the transfer from hospital to community care.

KGH plays a critical role in the identification of cognitive impairment or dementia in newly admitted patients. Many individuals referred for rehabilitation may not have a prior formal diagnosis of dementia. Through structured clinical assessments, the hospital often identifies undiagnosed dementia, which allows for appropriate referrals, tailored interventions, and future care planning. This highlights the importance of having skilled healthcare professionals capable of detecting cognitive decline as part of the routine admission process.

> **"Through structured clinical assessments, the hospital often identifies undiagnosed dementia, which allows for appropriate referrals, tailored interventions, and future care planning. This highlights the importance of having skilled healthcare professionals capable of detecting cognitive decline as part of the routine admission process."**

Persons with dementia or cognitive impairment admitted to the hospital typically present with multiple comorbidities, including musculoskeletal injuries, neurological conditions, or general decline following acute medical conditions. Recent hospitalisation often leads to physical deconditioning and a decline in both physical and cognitive function. Rehabilitation aims to restore functional ability and enhance quality of life by enabling patients to regain independence in daily activities. A more holistic and specialised geriatric approach is adopted in these cases, incorporating medical, functional, psychological, and social dimensions of care, which is essential in managing the complex needs of this population.

However, challenges persist in adapting rehabilitation programmes to the unique needs of persons with dementia. Negative staff attitudes can sometimes result in therapeutic nihilism – the belief that little or nothing can be done to meaningfully help people with dementia. While dementia care training is regularly provided to healthcare professionals and care staff, high staff turnover and reliance on temporary staffing pools limit continuity of care. Additionally, the physical environment of a traditional rehabilitation hospital may not be ideally suited to the needs of persons living with dementia.[5]

Karin Grech Rehabilitation Hospital provides a holistic, interdisciplinary approach to rehabilitation, particularly for older adults, many of whom have cognitive impairment or dementia. By focusing on personalised care plans and actively involving patients and their families in the rehabilitation process, KGH seeks to maximise individual potential and improve quality of life. Continued investment in staff training, systematic cognitive assessment, and improvements to the physical infrastructure could further enhance its effectiveness and impact.

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Rehabilitation in dementia: a person-centred occupational therapy approach in the Brazilian context

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Brazil has one of the world's largest universal health systems, the Sistema Único de Saúde (SUS), serving a rapidly ageing population.[1,2] SUS is committed to improving diagnosis and care for persons with dementia and their families[3], especially in primary care.[4] However, access to specialised dementia services remains limited and is often concentrated in major urban areas, generally delivered in large hospitals or in university-affiliated centres. University extension and outreach programmes play a key role by offering professional training, health education, and free services aligned with SUS. These programmes are typically driven by postgraduate research and depend on volunteer professionals and students providing multimodal approaches.

In these settings, psychotherapy, cognitive stimulation therapy, older adults' groups, carers' groups, and occupational therapy interventions are provided. Occupational therapy interventions are based on person-centred rehabilitation plans that take into account functional abilities and the person's social and cultural context to enhance engagement and achieve rehabilitation goals. They begin with individual sessions and then include group-based interventions. To maximise limited resources, especially in lower- and middle-income settings, group-based interventions are crucial for expanding access and impact.

Mr. John's rehabilitation journey

Mr John (pseudonym) is a 77-year-old married man with children and grandchildren, now retired. He completed primary school, and was the family provider throughout his life, working as a religious leader and manual labourer. He has had worsening memory and problem-solving skills over the past two years, which have affected his ability to carry out daily tasks. After a thorough evaluation, he was diagnosed with probable dementia due to Alzheimer's disease. He began treatment with medication and received a personalised care plan focused on his specific needs.

Assessment and planning

Concerning his rehabilitation, his abilities were assessed using frameworks from the World Health Organization and the American Occupational Therapy Association to understand how his cognitive impairments, surroundings, and daily activities interact.[5,6] The rehabilitation plan was tailored to Mr John's needs, focusing on his daily activities, personal history, routines, abilities, and environment. The broad aims of rehabilitation were improving independence in daily tasks, maintaining social participation, and reconnecting with valued life roles, particularly those tied to spirituality and family. Specific goals focused on personal care, especially shaving. The rehabilitation started with individual sessions. Later, group activities for both him and his wife, Mary (pseudonym), were added.

Individual sessions

In the individual sessions, the main goal was to help Mr John stay as independent as possible in daily tasks and remain socially active. Activities were designed to support his overall thinking abilities and specific skills, such as paying attention, remembering past events and facts, using language, spatial orientation, and solving problems. Strategies included using spoken and visual reminders, tools to help with time and place orientation, adapted games as shown below, organising his environment, and therapeutic activities connected to his interests, such as reading Bible passages and remembering important moments from his life.

Mr John participated in therapy activities that simulated real-life tasks related to daily living, such as shopping, using the phone, and organising household routines. These activities aimed to promote the highest level of independence, help him stay independent, and connect to meaningful roles he once valued, like his involvement in religious activities. To support this, strategies included breaking tasks into smaller steps, using helpful tools, and adapting the environment to his needs while

Development of adapted games, verbal and visual cues, and spatial orientation.

acknowledging that he still needed some help. For example, Mr John had difficulty following the steps in the right order when shaving, but with guidance, he was able to shave himself again.

Another goal was to promote Mr John's rehabilitation in daily tasks like sweeping, tidying up the house, and taking care of the yard and plants. He was interested in and motivated to do these activities, but had trouble planning and organising what to do first and how to follow through, so he needed some practical support to complete them. Mary was letting him do these tasks in his own way, but when she saw they were not done properly, she would redo everything herself, which exhausted her physically and emotionally. It also frustrated Mr John, who felt disregarded when his efforts were undone. Mary was instructed to supervise these activities instead of taking over, helping only when really needed, especially with spatial organisation and the steps involved. The goal of the intervention was to keep Mr John actively involved, using strategies and support that matched his current cognitive abilities. This helped him keep a sense of independence while easing Mary's physical and emotional load. The focus was on supporting real-life function, strengthening their family connection, and helping Mr John stay engaged in meaningful everyday activities.

Group therapy

The individual rehabilitation sessions were augmented by group therapy sessions held every two weeks with the aim of supporting Mr John's social life and communication skills. These group activities were carefully planned to gradually become more challenging, follow a predictable structure to reduce confusion and anxiety, and be personally meaningful. Activities included group reading of religious texts, guided discussions, and creative ways to express feelings and memories through art and the sharing of personal stories. Mr John's participation helped him reconnect with his role as a spiritual guide and improve his interaction with others, a major goal defined in his collaborative assessment.

At the same time, his wife, Mary, joined a biweekly support group for carers. These meetings focused on her wellbeing, helping her manage stress, organise caregiving routines, and access community resources. Topics also included understanding dementia, taking care of herself, and dealing with the emotional challenges of caregiving. The sessions recognised how social and cultural factors, especially the common role of women as caregivers in Brazil, affect the caregiving experience.

Outcomes

After the initial rehabilitation period, Mr John became more engaged in daily activities, responded better to his surroundings, and adapted more easily to changes in routine. Spirituality returned as a key part of his life through Bible reading and sharing religious reflections. In the group sessions, he became more talkative, expressed emotions more freely, and enjoyed sharing his personal stories. Mary also felt less stressed, learned new ways to manage her daily tasks, and, for the first time, recognised the importance of caring for her own wellbeing and making time for leisure. The principles of rehabilitation-focused care[7] can be observed in Mr John's rehabilitation journey: it considered how much independence he wished to have; it promoted as much control as possible over his daily life; it promoted opportunities to engage in meaningful roles and activities; and it enabled him to integrate the changes that he and Mary experienced into a coherent and enduring sense of identity.

Concluding comments

Over the past eight years, this extension and outreach programme has provided care and support for people living with dementia and their carers. In University Extension and Outreach Programmes, these multimodal person-centred and rehabilitation approaches rely on postgraduate research and the support of volunteer professionals. Nevertheless, adequate funding is still needed to retain qualified staff, expand these initiatives to other centres, and strengthen integration with referral and counter-referral systems between primary and specialised care.

Acknowledgments

These interventions were made possible through the efforts of the PROEPSI I UFMG and Cog-Aging Teams, with the support of Prof. Edgar Nunes de Moraes (NUGG-UFMG), Prof. Marco Aurélio Romano-Silva (CTMM / INCT-Neurotec-R), and University Hospital of the Federal University of Minas Gerais (HC-UFMG) / EBSERH.

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Nationwide intensive rehabilitation for people living with dementia in geriatric health facilities in Japan

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In Japan, Long-Term Care Insurance (LTCI) was introduced in 2000 in response to a rapidly ageing society and increasing health and care needs of older people. At that time, pharmacological therapies for people with dementia were neither common nor covered by LTCI. Rehabilitation or any form of non-pharmacological interventions, such as exercise, music, and art interventions, were implemented only at some advanced geriatric care facilities, and the implementation of rehabilitation services was not systemwide. When older people with dementia are hospitalised, their physical and cognitive functions often decline further, which may become challenging for family and informal carers, making it difficult for the person to return home after discharge. In recognition of these issues, intensive rehabilitation for people living with dementia[1] has been introduced in more than 1,421 Geriatric Health Facilities (GHFs) since mid-2000.[2]

Programme details

Upon admission to the GHF, the attending doctor will determine whether the person should receive either intensive rehabilitation for older people with and without any cognitive impairment or intensive rehabilitation for people with cognitive impairment only. Typically, intensive rehabilitation is offered for people in the early (mild) stages of dementia and mild cognitive impairment, where the focus is on improving activities of daily living. For those people in the moderate or advanced stages of dementia who may experience neuropsychiatric symptoms (e.g., agitation, aggression, and depression), a wide range of non-pharmacological (cognitive and psychosocial) interventions is offered.[3]

In both programmes, residents are individually assessed by the rehabilitation team using the Comprehensive Geriatric Assessment framework, which includes the resident's personal values, physical and mental conditions, hobbies, job, family relations, type of dementia, and other health conditions. The rehabilitation team – consisting of a doctor, a psychologist, a physical therapist, an occupational therapist, and a nurse – develops the rehabilitation plan and offers one-on-one, tailor-made rehabilitation. The basic format is one-on-one sessions lasting 20 minutes, two or three times a week for up to six months. These may include occupational therapy and physiotherapy, involve preferred activities and exercise, and draw on additional non-pharmacological interventions such as music therapy and life review. The programmes have led to improvements in residents' cognition, motivation, and daily function as well as a reduction in neuropsychiatric symptoms.

The programmes are underpinned by several core principles:

1. The resident is treated with respect as an individual and placed at the centre of rehabilitation through attentive listening and understanding of their life history, hobbies, preferences, strengths, and limitations.
2. The rehabilitation plan requires that the resident can easily participate, taking into consideration their personality, motivation, and "willingness to participate".
3. The rehabilitation plan needs to be flexible and responsive to any changes to the resident's abilities and motivation.
4. The goal of the intensive rehabilitation programme is for residents to have improved independence and be able to return to their own home.

Example

Ms Aiko is in her 70s, lives with her husband, and was diagnosed with dementia. She had a hip fracture after a fall and was admitted to the hospital for surgery. During hospitalisation, she developed delirium and showed symptoms of depression. As her husband could not take care of her at home alone, she was admitted to a GHF for rehabilitation. She was initially unwilling to participate in rehabilitation, but started responding to the therapist, who was able to build rapport and learned that she enjoyed knitting. The therapist then began using knitting as part of her rehabilitation. Gradually, her conversation increased, and she actively participated in physical rehabilitation such as gait training and group exercises. She eventually returned home in good health.

Challenges experienced

Staff turnover at GHFs is high, and improvements in working conditions and pay are necessary. The rehabilitation programmes rely on LTCI. However, it is estimated that over several million people in Japan have no access to LTCI despite having dementia. In communities, building new facilities is limited, and therefore repurposing existing buildings, such as farms or temples or collaborating with non-profit organisations, has been suggested as a potential solution.

Acknowledgements

Dr Kenji Toba and Dr Masahiro Akishita are acknowledged for their valuable feedback and review of this case study.

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A trusted, community-based cognitive rehabilitation and dementia care service supporting families and people living with dementia in Indonesia

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People living with dementia face both psychological and physical challenges. Alzheimer Indonesia (ALZI), a non-profit organisation committed to improving the quality of life for people with dementia (PWD), their families, and caregivers in Indonesia, seeks to address a critical and often overlooked need: dementia care that is personal, flexible, and home-based.

Since 2020, ALZI has developed the ALZI Care Navigation programme (NARAZI; Indonesian: Navigasi Perawatan ALZI), a service that combines online and offline consultations with therapy through home visits conducted by the multidisciplinary NARAZI team. While the online services are available to Indonesian families both within the country and abroad, the offline/home-visit services are currently limited to the Greater Jakarta area (Jabodetabek), with plans for future expansion.

This programme is more than a technical solution; it is a person- and community-centred approach that places people living with dementia at the heart of every care decision. This principle aligns with the WHO's recommendation to promote community-based rehabilitation that upholds personal autonomy and the right to a meaningful life within familiar surroundings[1].

One of the beneficiaries of this programme is Mr Y, a man in his 80s living with his family in Jakarta. After being diagnosed with mild dementia, his wife reached out to ALZI when she noticed that he had begun getting lost on familiar walks around the neighbourhood. Since then, Mr Y has participated in cognitive-based physiotherapy sessions twice a week, along with daily exercises involving his family members.

The approach is deeply personalised: activities such as walking while counting, recognising directions, and placing objects based on instructions are designed to stimulate memory while maintaining muscle strength and balance. Over time, Mr Y has shown measurable improvement; he remains able to care for himself with minimal assistance and has not experienced significant cognitive decline.

The Alzheimer Indonesia (ALZI) team conducts a home visit, providing personalised support and care for a person living with dementia and their family caregivers.

A similar story comes from Mrs X, an older adult with limited mobility who uses a walker. Through regular visits from physiotherapists and the support of her family, she is still able to perform some daily tasks, maintain joint flexibility, and preserve muscle strength. For her, simple freedoms such as choosing her own clothes, deciding on daily meals, or sitting on the front porch each morning are priceless expressions of quality of life.

Behind these individual successes lies a consistent and engaging strategy. Exercises are delivered repetitively, enhanced with visual and auditory cues to aid comprehension and participation. Crucially, family members are not merely present; they are empowered as active partners in the rehabilitation journey.

Each care plan is personalised, with clearly defined goals tailored to the individual needs of the person living with dementia. These goals typically include:

- Improving balance and mobility to reduce the risk of falls
- Maintaining a routine of meaningful daily activities
- Stimulating cognitive functions through integrated physical movement

While promising, this approach is not without challenges. Families often struggle to maintain consistency due to work commitments and limited time. The number of professionals trained in dementia-centred rehabilitation remains low, and the current focus on the Jabodetabek region limits the programme's reach to other areas in Indonesia.

As the programme evolves, ALZI continues to refine its approach based on ongoing feedback from families and caregivers. Regular monitoring and follow-up ensure that care plans remain relevant and adaptable to each individual's condition and progression. Beyond clinical outcomes, the programme fosters emotional resilience among families, strengthens intergenerational bonds, and reduces stigma around dementia within the community. This is a testimonial from Mr Y's family member regarding the ALZI NARAZI programme:

> *We have trusted the ALZI NARAZI Home Visit Programme since March 17, 2022. More than 114 cognitive rehabilitation sessions have been conducted over the past three years with support from the NARAZI team. These home-based sessions have significantly boosted my husband's enthusiasm and strength in performing daily activities, including exercises that activate both physical and cognitive functions. Routine home visits have not only spared us from the stress of traffic but also improved his mood, as he can exercise comfortably in a familiar environment. The strong bond developed between my husband and the NARAZI team has brought him great joy.*

This home-based model, grounded in empathy and local relevance, holds strong potential for replication in other regions across Indonesia and similar low- and middle-income settings. By investing in family empowerment and community-led care, we lay the foundation for a more inclusive and responsive dementia care ecosystem. Through a compassionate, person-centred care and community-based approach, we help preserve the meaning in their lives, one small step, one exercise, one memory at a time.

Acknowledgements

Thanks to the NARAZI team – DY Suharya, Asmara Pusparani, Ajat Sudrajat, Mush'ab Faza, Lelly Milawati, Tuty Sunardi, Ratu Tita Quritama Putri, and Julitta Fitrin Elyanarih.

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Paving the way: cognitive rehabilitation for people living with dementia and mild cognitive impairment in Togo

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Sub-Saharan Africa is experiencing a rapid demographic transition with older adults forming a growing proportion of the population, leading to associated increases in cognitive decline and dementia.[1] In Togo, a country in West Africa, we are witnessing a growing number of older adults seeking help for cognitive decline, highlighting an increasing recognition of Alzheimer's disease and related dementias (ADRD) as a significant public health concern.

In 2019, 12,196 cases of dementia were reported in Togo, a country with a total population of more than 8 million people. Projections predict a significant increase to about 55,318 cases by 2050, representing a substantial rise of 354%.[2] These figures highlight the urgent need for the implementation of comprehensive health strategies and resources to manage the anticipated rise in dementia cases and support affected individuals and their caregivers effectively.

The Ahonhon cognitive rehabilitation programme

The Ahonhon Cognitive Rehabilitation programme – a recent initiative by the Ahonhon Neuroscience Research Centre and its Memory and Trauma Centre, based in the country's capital, Lomé – aims to fill that gap. The term "Ahonhon" means "brain" in éwé, a language spoken in Togo. Initially focused on patients recovering from traumatic brain injury and stroke, the programme has expanded to include individuals with mild cognitive impairment (MCI) and dementia, specifically targeting those in the mild to moderate stages.

Our cognitive rehabilitation programme, delivered through a multidisciplinary team approach that includes a clinical neuropsychologist, a physician, a nurse, and a social worker, is designed to enhance memory and executive functions in individuals living with dementia or mild cognitive impairment. The programme begins with a comprehensive assessment to determine the type of memory and executive function difficulties and the level of advancement. This assessment includes neuropsychological testing, self-report measures, and behavioural rating scales. For memory, the goal is to ascertain the person's level of awareness of their memory difficulties, the capacity to use written versus electronic memory supports, and how the difficulties affect their daily life. For executive function, the focus is on identifying the type of difficulty, its impact on daily life, and determining the prerequisites for intervention.

A key focus of our programme is improving prospective memory (the cognitive ability to remember to perform an intended action at a specific point in the future) and recall for everyday tasks[3]. We achieve this through a combination of internalised strategies, such as visual imagery and association techniques, and external memory compensations like the "Ahonhon book" (Figure 1). This is a cognitive companion tool locally designed by our team and based on our Ahonhon healthy aging model (and used as a manual for our rehabilitation programme, which helps users remember future actions, store and retrieve important information, and report details from events or activities.

We also employ strategies including errorless learning, chaining, and spaced retrieval, which help minimise errors, break tasks into manageable steps, and reinforce information through repeated practice. Our memory strategy training incorporates a variety of techniques to enhance recall and orientation. These include visual-verbal associations, the visual peg method, the

Figure 1. The Ahonhon book

method of loci, and organisational techniques such as first letter mnemonics, semantic clustering, PQRST (Preview, Question, Read, State, Test), humour, and storytelling.

In addition to memory rehabilitation, we focus on the rehabilitation of executive functions through metacognitive strategy training. This training incorporates protocols for problem-solving and goal management, emphasising their application to everyday situations and functional activities. By teaching individuals living with dementia to become aware of their cognitive processes, set realistic goals, and develop systematic approaches to problem-solving, we aim to enhance their ability to manage daily tasks and improve overall functionality.

Our cognitive rehabilitation efforts for individuals living with dementia are supported by factors such as strong family and social support and a multidisciplinary approach, while factors such as societal misconceptions and cultural superstitions about dementia impede rehabilitation efforts. The programme also includes dementia education sessions given to families and caregivers, which have received positive feedback. One family carer said:

> *We should have come to you earlier, doctor. For a long time, we thought what was happening to our mother was just a normal part of ageing. We even laughed when she forgot where she put things.*

Lessons learned

Cognitive rehabilitation is currently offered within the private health system in Togo. We hope to see this care for people living with mild cognitive impairment and dementia become more accessible across the country. Available funding, supportive government policies, investment in dementia training, public-private partnerships, public awareness campaigns, and expanded health insurance coverage can make this a reality.

Although we are at the very beginning of our programme, it is deeply fulfilling to see the positive impact our support is having on families caring for their loved ones living with mild cognitive impairment and dementia.

One key lesson learned so far is the importance of early intervention and continuous support. Our future efforts should focus on expanding services to underserved areas and advocating for policy changes to ensure equitable access to care and increased awareness. As one participant in the programme said:

> *Doctor, you should speak more about this to raise awareness among the population. Many people are caring for loved ones with dementia and do not really know how to provide proper care.*

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Conclusion

Dementia rehabilitation may be underutilised and overlooked as a legitimate post-diagnostic intervention, but as demonstrated throughout this report, it is well worth exploring and investing in.

People living with dementia face many hurdles – from obtaining an accurate diagnosis to having access to adequate treatment, care, and support as their condition progresses. The prevailing belief far too often remains that nothing can be done – that someone living with dementia must passively accept loss of function and autonomy from the day of their diagnosis onward.

But as diagnostic techniques improve, a growing number of people are being diagnosed with dementia earlier in the progression of the condition, increasingly, when they are still of working age or early in their retirement years. To tell someone to give up on life at this stage – or at any point – is not only cruel, but counterproductive and, ultimately, costly.

Rehabilitation is not a magic wand that erases all symptoms of dementia. What it does provide, however, is tools to build upon existing strengths and to manage symptoms with a degree of agency and dignity far too often denied to those living with the condition. These intangibles are priceless for the individual and their loved ones, empowering them to implement strategies to prolong independence, carry out meaningful life activities for as long as possible, and provide them with a sense of purpose that bears a real impact on morale and overall wellbeing.

Barriers still exist to making rehabilitation a more mainstream approach to dementia. Lack of awareness remains a significant obstacle, as is inadequate health system readiness to implement such a degree of precision care at a broader scale. In countries where dementia treatment and care are hard to come by, pushing for rehabilitation may feel like putting the cart before the horse. But while this report outlines rehabilitation best practices, the practical guidelines found in these pages should encourage the reader to think about how these may be applied with their patients or loved ones. There is no one-size-fits-all rehabilitation plan; the adaptability model at its heart should be seen as encouraging, allowing individuals to tailor their goals and strategies to the motivations and means available to them. Rehabilitation can be implemented via a whole team of allied healthcare professionals – or it can be devised by a person living with dementia and carried out with the help of their informal support system.

You will have read first-person anecdotes in this report about the impact of rehabilitation on people living with dementia and their carers. To expand the benefits of dementia rehabilitation, we need more advocates, researchers, health and care professionals, and governments to engage with and invest in rehabilitation, thereby gathering more real-world data to build an ever more compelling case and reach more people who may benefit from it.

Living well, with purpose and dignity, should not be a luxury for people living with dementia, but a basic right. In the continued absence of a cure, rehabilitation is an avenue we have a collective duty to pursue.

> **"Rehabilitation is not a magic wand that erases all symptoms of dementia. What it does provide, however, is tools to build upon existing strengths and to manage symptoms with a degree of agency and dignity far too often denied to those living with the condition."**

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