

Chapter 16

Initial management following a diagnosis of dementia

Claire Webster

Key points

- Increased education about dementia will have a significant positive impact on the quality of life of people who have been diagnosed with dementia as well as their carers.
- The World Alzheimer Report survey suggests that the greatest difficulties encountered upon receiving the diagnosis of dementia were lack of adequate information (54%), access to specialised tests (28%), financial constraints (25%) and access to healthcare services (21%).
- People with dementia and carers should be provided with information about the type of dementia they face and potential changes in decision-making capacity.



General background

The previous chapter highlighted how the diagnosis of dementia presents challenges for clinicians as well as the person living with dementia and their family members, whether it was the evolution of the condition through its various stages or the initiation of a care management plan. This chapter takes on a different perspective. It is a testimonial written by one of this World Alzheimer Report

authors, a former carer who accompanied her mother through the diagnosis process, and in doing so, discovered a lack in essential support mechanisms of information and guidance. This not only impacted her mother but also how she as a carer navigated the healthcare system to deal with these obstacles. The ensuing consequences and lessons learned led her onto a path of carer advocate.

Survey results

The 1,111 multidisciplinary clinicians who responded to this survey indicated the frequency with which they provide information or make suggestions about specific issues. Most contact a family member of the person with dementia when one was not present at the diagnostic assessment (66%). Relatively few will contact their employer if needed (11%), and many refer to specialised services for mood and/or behavioural support (40%).

Among the 2,327 persons with dementia and carers who completed the survey, only 45% indicated that they were given adequate information about dementia and its initial management, 26% were given a booklet, and 32% were

provided advice on nutrition and exercise. Among those who replied that they had difficulties with some aspects of the diagnosis, the lack of adequate information was the main issue (54%), ahead of access to specialised tests (28%), financial constraints (25%) and access to healthcare services (21%). The average satisfaction level for the diagnostic process overall was 3.17 where 0 is not favourable and 5 is excellent.

Some questions were common in both the clinicians and people with dementia and carers surveys with differences in some areas reported in Table 1.

What are the most common initial management recommendations you make immediately after disclosing a diagnosis of dementia?

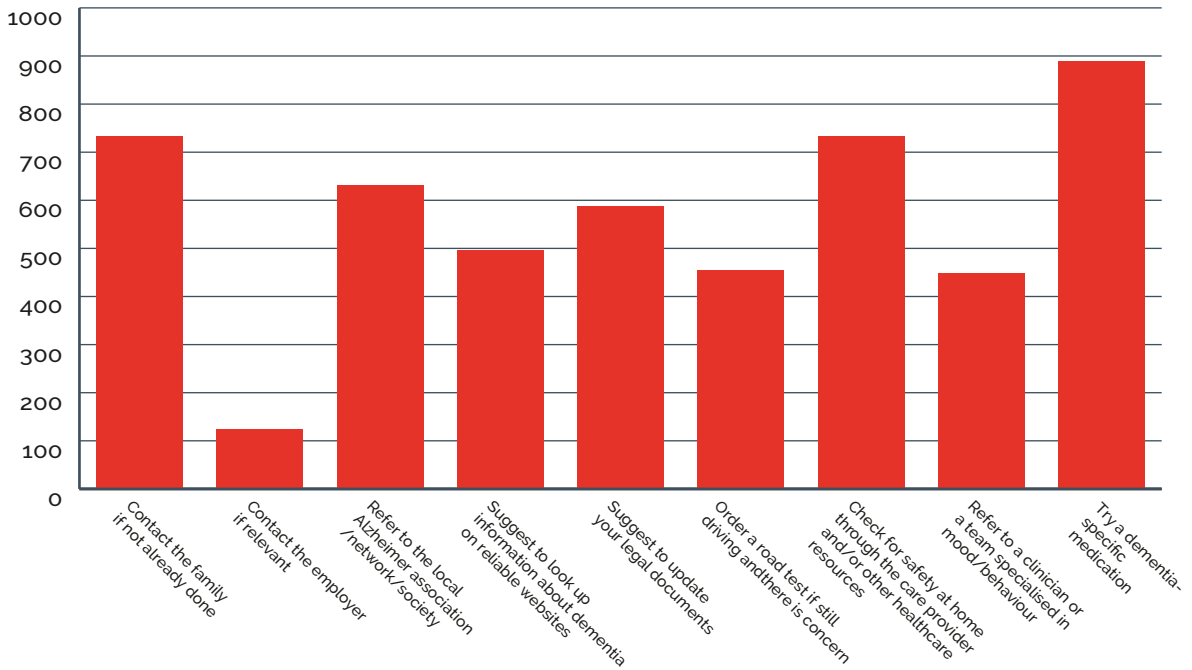


Chart 1. Clinician responses (multiple answers selected).

What difficulties were encountered as part of receiving the diagnosis of dementia?

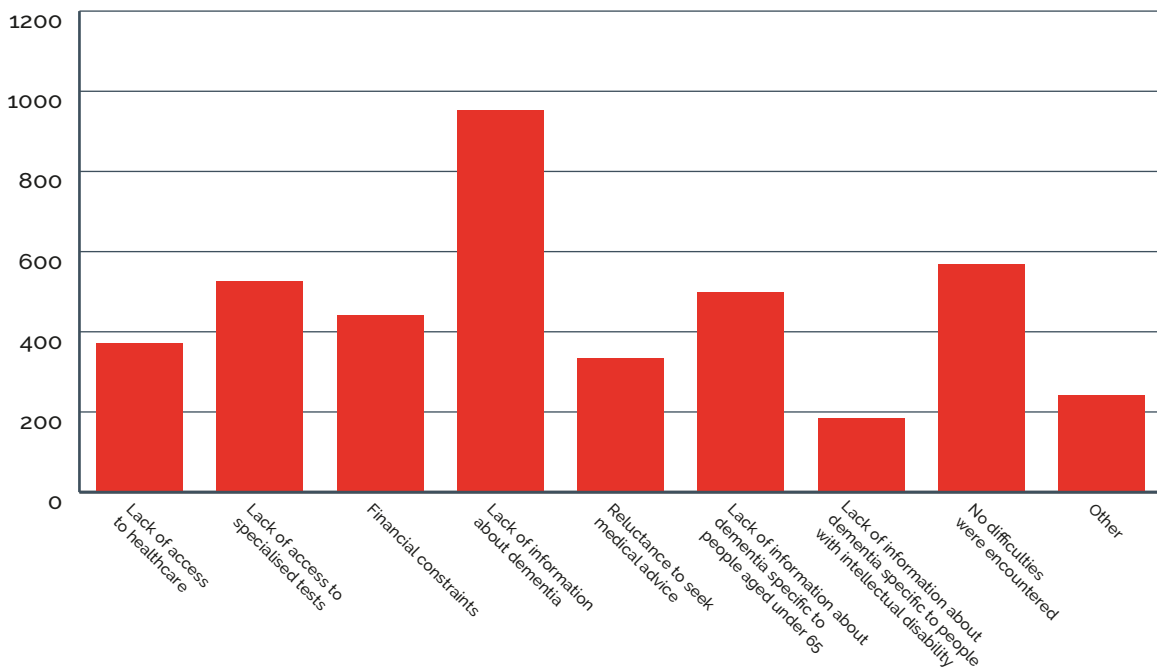


Chart 2. People with dementia and carer responses (multiple answers selected).

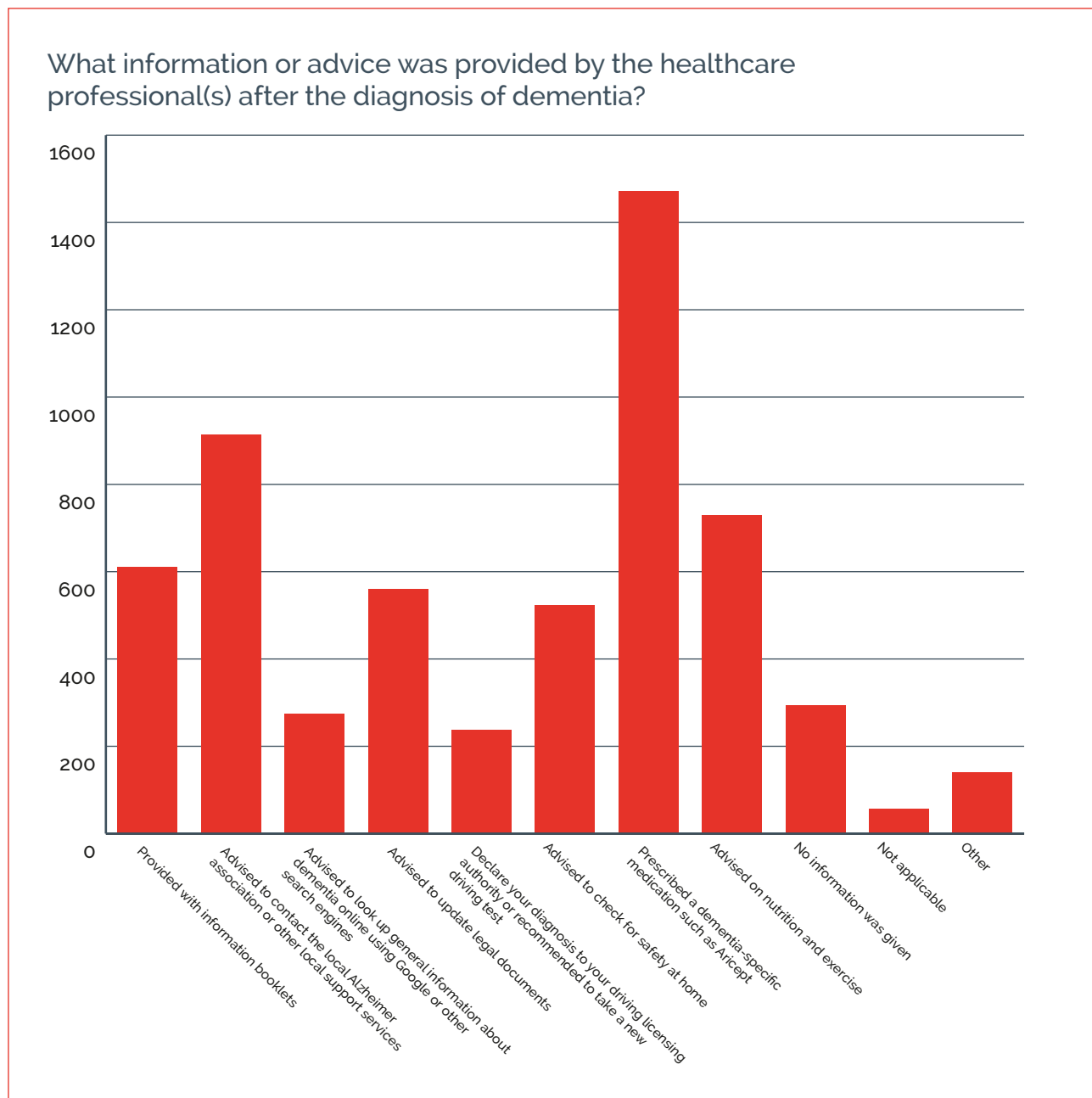


Chart 3. People with dementia and carer responses (multiple answers selected).

Table 1. Selection of survey responses

	Clinicians	People with dementia & carers
Refer to local Alzheimer association or support network	57%	39%
Look up information about dementia on websites	44%	12%
Advice to update legal documents	53%	24%
Advice to assess driving abilities	41%	10%
Advice to assess safety at home by a health professional	65%	22%
Initiate anti-dementia drug treatment	80%	65%

Expert essay

Navigating the journey of dementia after a diagnosis – a prescription of education and support

Claire Webster

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Accept, educate, plan ahead navigate, advocate

There are guiding principles that I wish I had known during my mother's Alzheimer's disease diagnosis in September, 2006. She was 74 years old when I took her to the neurologist after consulting with our family physician about her unusual behaviour and significant personality changes following the death of my father in 2005. My mother had been a physically active, independent, and outgoing woman, but over an 18-month period, had become socially withdrawn and impatient, suffering severe mood swings ranging from bouts of anger to depression. She had increasing difficulty managing her finances and preparing meals for herself. She developed a fear of stairs and had zero tolerance for loud noise, often putting her hands over her ears while rocking back and forth in distress. My mother became obsessed with the next-door neighbour, convinced she was operating a cocaine lab (which was definitely not the case). I also noticed that her car had numerous dents and marks that indicated a series of accidents, and that her summer tyres had not been rotated for the winter months.

A few symptoms had begun to appear a year prior to my father's passing. He would often point these out, but I refused to acknowledge them as anything more than her experiencing carer stress. When the symptoms began to worsen after my father's death, I thought my mother was suffering from depression and grief. She'd been his primary carer for over 30 years. My concerns intensified when I realised that she was no longer able to manage her finances and pay for household expenses. She began donating money to the same charity multiple times a year and having unjustified, random expenses. She was often confused, had difficulty finding her words and started to use odd and inappropriate language in the presence of my young children, often screaming at them for no reason. She had also been hoarding hundreds of empty plastic fruit containers that I found in her kitchen cabinets as well as keeping expired food in the refrigerator.



Me and my mother, Vieno Leskinen, Montreal, Quebec, Canada, April 2015.

I decided it was time for her see a doctor. I didn't know who to consult as her symptoms were more behavioural than physical. Against her will, and in full denial of anything being wrong, I made an appointment with her family doctor, who then referred us to a neurologist. He asked us a series of questions about my mother's cognitive and physical well-being while she sat beside me, in great frustration, refusing to accept or admit to any of the information that was being shared. Her medical history included high cholesterol and a minor stroke at the age of 68. There was a history of cardiac issues in her family and she herself would suffer a heart attack three years post diagnosis a few hours following hip replacement surgery.

The neurologist performed the MoCA (Montreal Cognitive Assessment Test). She scored 17/30. The neurologist then informed us that she had Alzheimer's disease, and upon learning that she was still driving, immediately called the driver's licencing bureau, and without any warning, had her driver's licence cancelled while we were still sitting in his office.

In shock, and completely unaware about anything related to dementia, I asked the doctor if he could explain what Alzheimer's disease was, how to manage it, what to expect and if my mother could still live on her own. The doctor answered, 'No, she cannot live on her own; there is information about the disease on the internet. Good luck Mrs. Webster.' That was it. Nothing else. We left the doctor's office without any information or guidance about the symptoms of the disease, how to plan for the future, the importance of accessing support services from the community or any other information about what the next steps should be. I was totally unfamiliar with the symptoms, expectations and challenges that she, and inevitably I, would face in caring for her. I was instantly compelled to educate myself on the disease.

I was her only child, and at the time of her diagnosis I was 38 years old and raising a family of three young children while holding down a full-time job managing a company with my husband. Over the next few years, with multiple responsibilities caring for both my family and my mother, not to mention facing other personal challenges, I would get caught up in a cyclone of caregiving. When the air settled, I had severe burnout and post-traumatic stress disorder. The lack of a 'prescription of care' (namely being provided information and guidance), from the neurologist or any other healthcare professional with whom I met, would have a significant impact on my mother's quality of care and safety over the coming years, as well as having a ripple effect on my own mental and physical health. My young children would witness not only the decline of their grandmother, but also the unravelling of their mother.



A lack of education about a dementia diagnosis will have a significant impact on the quality of care as well as safety of the individual and their carer(s).

I spent the majority of my carer years in a state of anger and denial. I was angry at the disease for robbing my mother of what should have been her golden years. I was angry at the disease for the carer burden placed on me during a time when my three young children needed me the most. I was in denial of how much I truly needed support and refused to ask for it. I developed coping mechanisms to deal with my stress, namely alcohol. It became both a dependence and a demon which I fortunately conquered and recovered from four years after my mother's death in 2016.

My mother's Alzheimer's disease diagnosis was the beginning of one of the most challenging periods of my life, but would also become the driving force behind my passion for educating and advocating for others. I would devote the rest of my life to improving the way carers are treated in our healthcare system and become a 'Carer Crusader'. Alzheimer's disease taught me about the power of human resilience. I witnessed it in my mother, as well as have come to recognise it in myself. I would not have been able to navigate this journey without the tremendous support and patience of my husband and three children. For that, I am forever grateful.

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The importance of education and support

Over the past 15 years, I've met with hundreds of carers with their own stories to tell. Across all these different lives, I realised that the threads that bind us are also the threads that can derail us. Dementia is complex and the medical community doesn't always provide enough of the necessary information, nor stress the importance of seeking out community support services, two essential components needed to help us take the best possible care of the person living with dementia. It is what I, and all the families I work with, strive for.

How can we accomplish this?

Accept the diagnosis

This is the first step to ensure that the person with dementia receives the best care possible. Many people with dementia experience anosognosia, or the inability to recognise that something is medically wrong. Given that, it falls to the carer to accept the situation and push through the shockwaves this diagnosis represents. Only by learning to adapt to all the cognitive and physical changes brought on by this condition will a carer be able to manage effectively. Likewise, learning to adjust your approach and behaviour when something doesn't work is just as important. In my experience, acceptance of all things dementia is the gateway to best care practices.

'Many thanks, but I'm not there yet'. I cannot tell you how many times I have used these very words or heard them from other carers over the years. We dismiss any attempt to enter our world though we desperately want help yet also feel overwhelmed with all the tasks at hand. Add in an unjustified sense of guilt and you have one solid barrier of resistance. Why is it that family carers sometimes feel that they do not have the right to ask for support when caring for their loved one, and more importantly, why do they feel

that they do not have the right to a life of their own? That is, until a crisis occurs that profoundly impacts on their own health and causes a ripple effect on everyone around them, including the person with dementia.

Accept support

Caring for someone with dementia is very demanding and you cannot do it alone. In order to prevent carer burnout, it is extremely important to identify other family members, friends, community and/or public and private resources to help with household chores, caregiving tasks, transportation as well as mental health support and respite care. Seek out the necessary support services following the diagnosis in order to know what are your available options and prepare accordingly.

Educate yourself

Knowledge is your most powerful resource. Understanding as much as possible about dementia, how it progresses, recognising and managing challenging behaviour and how to plan for the future, prepares both the person with dementia and their carer for the journey. Again, this deliberate exploration equips you with the necessary tools to provide the best care possible. Learn all you can about the support services in your community that can assist both the carer and the person living with dementia. Whether it's your first, second or fifth medical appointment, arrive with a list of prepared questions or concerns you want to address. Your healthcare professional can also point you in the right direction regarding services and facilities that can assist you.

Plan

It is important to understand the evolution of dementia and the care that will be required across the stages. Planning for the future is an important part of the process in order to make decisions concerning health and personal care, living arrangements, finances as well as legal and estate planning. The progressive nature of the condition may make it difficult for the person living with dementia to express their needs and make independent choices. Given that, while still feasible to do with the person living with dementia, you may wish to meet with family members, financial and legal experts to arrange for a notarised mandate and power of attorney. These documents would authorise carers to lawfully make decisions on their behalf if they no longer can.

The COVID-19 pandemic has been a huge lesson for us all in the matter of 'expect the unexpected'. Life can get interrupted in ways we could never see coming. Therefore, prepare yourself by having both a Plan A and a Plan B in place.

Navigate

In addition to becoming as well informed as possible about dementia, it is equally important to know about all the support services available to you, be it community organisations, public healthcare/government agencies, private home care agencies, or public and private long-term care residences. Experience has taught me that learning how to navigate and access these programmes can be a lengthy process, especially if high demand results in waiting lists. Being better informed and starting the process early in the diagnosis will lead to better results.

Strategies I found helpful:

- Educate yourself on the disease – why is the person with dementia doing what they are doing?
- Pick your battles – If what they are doing is not hurting them or others, let them be. What we may find to be unusual behaviour, may be very comforting to an individual with dementia.
- Be a detective and not a judge – take the time necessary to investigate what is happening in the surroundings that could be causing anger, anxiety or discomfort. As people living with dementia lose their ability to communicate with words, they may have a difficult time expressing their emotional and physical needs.
- Join their journey – carers often become frustrated with the person living with dementia as they feel that the stories that they are telling may be over exaggerated and/or repeated multiple times. To avoid conflict, it is best to join their journey and

engage in recollections of events provided that the stories are not distressing. Should the need arise to validate their version of events, be mindful of how you communicate. Avoid using sentences such as 'That's not true! Why can't you remember? I told you many times before!' Instead, use words such as 'I'm sorry that you feel that way. Help me understand why you feel like that happened. It sounds like...It seems as if...'

- Carers should ask themselves how their own mood, patience and energy levels are in order not to transfer their own frustrations onto the person that they are caring for, which can result in confrontation. Caring for a person with dementia requires a tremendous amount of patience and energy and it is therefore very important that carers make their own health and wellbeing a priority.

Advocate

As a former carer, the role of advocate was one of my most important. This safeguarded my mother's wellbeing and dignity throughout the remainder of her life. As the condition progresses, and if the person with dementia begins to lose their ability to communicate effectively and speak up for themselves, it is imperative that their carers assume this responsibility. Essentially, you become their voice. This role necessitates a tremendous amount of dedication and commitment as you will be making difficult life decisions on their behalf. These include the type of care they need, living arrangements, as well as legal, financial, and medical decisions. I often use the term 'tough love' with the families that I counsel to describe those hard decisions.

Safety

As dementia advances, a person's vision, mobility and cognitive decline may have a direct impact on their activities of daily living such as driving, managing personal finances, cooking, eating, bathing, grooming, dressing, sleeping as well as other aspects of their day-to-day life. Keeping the person safe thus becomes a priority to prevent falls, injuries, and significant financial mistakes. Certain rooms in the home have higher risks than others, such as the kitchen, bathroom, and stairs. Meet with an occupational therapist or a specialist who can properly assess the environment to ensure a safe home, outdoor space or work environment. The topics of driving and managing personal finances are delicate as they symbolise the person's sense of independence. When these tasks become compromised as a result of the progression of the illness, it is very important to involve the guidance and expertise of the medical doctor to assist with implementing the necessary next steps to ensure the safety of the individual.

The importance of self-care

A person receiving a dementia diagnosis needs to continue to live as healthy a lifestyle as possible, as well as embrace everything that they can still do. Establishing a regular exercise routine, healthy eating plan and quality time spent with friends, family and colleagues is important to maintaining a balanced life.

Concurrently, carers need to find ways to preserve their energy to fulfil their day-to-day tasks. That means becoming more protective of 'me time' and personal commitments as well as surrounding themselves with people and projects that add positivity to their lives. Learning to say no and becoming selective of where, how, and with whom they invest their time is key.

Becoming an advocate for change

In addition to becoming a Certified Dementia Care Consultant, one of my greatest accomplishments is having founded McGill University's Dementia Education Programⁱ in 2017. The programme works in collaboration with several McGill University partners, including the Division of Geriatric Medicine, the Research Centre for Studies in Aging, the Steinberg Centre for Simulation and Interactive Learning, and the Faculty of Medicine and Health Sciences. I am collaborating with a team of dedicated multidisciplinary healthcare professionals to develop programmes that educate and support family carers, along with healthcare professionals and medical students of the future, with a focus on patient-centred care.

ⁱ This program includes in-class workshops, public education seminars and webinars. A free webcast and podcast series, McGill Cares, a Dementia Companion Guide for people living with dementia and their carers, and a Dementia Activity Booklet are available at www.mcgill.ca/dementia.

Conclusions

Alzheimer's disease and other types of dementia have no cure yet. As the population ages and more people are diagnosed, we need to ensure that the general public becomes better educated about dementia. This starts with health and social care systems that must also be agents of change in their own right. This system is multi-layered and complex. Having a foundation built on informed, reliable and support-driven information and guidance is a priority that demands attention and action.

The 2022 World Alzheimer Report will be dedicated to the journey following diagnosis, a natural next step to this report and looking at best practice models globally, barriers and facilitators, research and innovation.