



EMPOWERING CHANGE

A National Strategy for Dementia in the Maltese Islands

2015-2023



PARLIAMENTARY SECRETARIAT
FOR RIGHTS OF PERSONS WITH DISABILITY
AND ACTIVE AGEING

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A National Strategy for Dementia in the Maltese Islands
2015-2023

Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing

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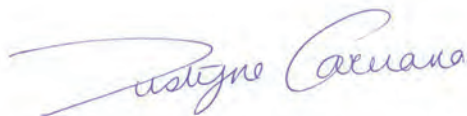
PARLIAMENTARY SECRETARY'S FOREWORD

Dementia constitutes an increasingly important issue in policy and practice, one that demands national plans and strategies that address the social and health consequences, as well as services and support for individuals with dementia and their families. The Maltese government concedes that dementia and other related disorders constitute a priority for action in the context of the ageing of the local population. Dementia has significant health, social and economic significance to our country, since a high proportion of individuals with dementia are referred to acute hospital care, residential, long-term nursing and community care services. The nation's social and health care policy takes into account the potential consequences of the increase of dementia for the financial sustainability of both the health and social protection systems. Presently, one also locates strong inter-ministerial dialogues and collaboration that evaluated existing quality criteria for the care of individuals with dementia and the support of carers, so as to consider and implement strategies that facilitate healthy, independent and secure living for all concerned parties.

The National Strategy for Dementia acts as a national voice for people living with dementia and their caregivers and family members. It underlies the Government's commitment to gain a better understanding of the impact of dementia on the Maltese population, and its pledge for immediate action in capacity building in dementia management and care services. There is no doubt as regards the timeliness of this strategy as it recognises the urgent

need for public, non-governmental, and private bodies, alike to turn the tide of dementia by aiming to minimise the impact of dementia and other related disorders. The Strategy is intrinsically proactive, as it points towards the importance of a multidisciplinary approach which can improve knowledge, diagnosis, treatment, prevention, and social research into the welfare of individuals with dementia and their families and carers. I believe that increasing awareness and timely diagnosis together with the delivery of support services by a trained workforce and specifically earmarked for these individuals will have a profound positive effect on their quality of life.

The series of objectives and recommendations included in the National Strategy for Dementia will surely bring us closer to improved levels of care for individuals with dementia, their caregivers and family members. Furthermore, such proposals will stimulate discussion on what constitutes good and ethical practice in dementia management, alternative care practices ranging from novel welfare services to innovative assistive technologies, and purposeful training and research programmes in the dementia field. It remains that there are enormous challenges for the Government in ensuring that persons with dementia are not admitted to acute care unnecessarily or in care homes prematurely, that persons with dementia are enabled to age-in-place as long as possible, and if admitted to hospital, they are in receipt of effective, person-centred and dignified care. However, there is no doubt that the focus on timely diagnosis and personalised care in the herein Strategy will instigate a process of transformation of care across all sectors in the expectation of a growing number of persons with dementia.



Justyne Caruana

Parliamentary Secretary for Rights of Persons with Disability and Active Ageing



AUTHOR'S FOREWORD

One of the most important challenges facing the Maltese society is the increasing population of senior adults. This is the inevitable consequence of living a healthier life which, coupled with advances in medical care, increases life expectancy. As a result, neurodegenerative diseases normally associated with old age, such as many forms of dementia, will also increase. This will bring about a significant demand not only on health and social care services but also on society as a whole as most of the care for individuals with dementia is provided by family members who act as main caregivers. It is therefore clear that the devastating impact of dementia cannot be ignored and the costs of not facing the dementia challenge will be considerably high both in human and financial terms.

This strategy highlights various measures that need to be implemented in order to enhance the quality of life of individuals with dementia, their caregivers and family members. The multifaceted nature of dementia necessitates a multidisciplinary approach to dementia management and care. The vision of this strategy is for people in various sectors of society to come together and create a system whereby individuals with dementia have access to the support and care they require. Dementia also has a profound effect on relatives and caregivers and thus the content of this document aims to address their needs as part of the holistic approach to dementia care.

The strategy outlines a number of actions that are necessary in the different

priority areas of dementia management and care. These include an increase in awareness and understanding of dementia, the provision of timely diagnosis, the availability of a trained workforce, improving community and hospital care, promoting an ethical approach to dementia care as well as strengthening research in this field. It is also the result of a wide consultation exercise with the general public and stakeholders representing various sectors of dementia management and care. This ensures that the National Strategy for Dementia is a living document which encompass a strong commitment from all those involved in order to empower change and make a true difference in the lives of people living with dementia.

I am grateful to all those who gave their support and provided feedback to the consultation document. Special thanks go to Kathleen England for her contribution in an earlier draft of this document.

A handwritten signature in black ink, appearing to read 'Charles Scerri', with a horizontal line underneath.

Charles Scerri PhD
National Focal Point on Dementia
January 2015

EXECUTIVE SUMMARY

Dementia is a term describing a number of conditions characterised by progressive deterioration in mental functions including memory, judgement, communication skills and behavioural changes serious enough to interfere with daily life. Although dementia becomes increasingly more prevalent in the senior adult population, early onset dementia may occur and is frequently misdiagnosed. In the Maltese Islands, 6,071 individuals will have dementia in 2015, a figure equivalent to approximately 1.5 per cent of the general population. As the population ages, the number of individuals with dementia will increase significantly such that by the year 2030, it is projected that 9,883 individuals will be affected. It is well recognised that dementia presents a psychological and financial challenge both to those with the condition as well as their caregivers and family members. This strategy aims to implement a number of measures in the various areas of dementia management and care with the overarching aim of:

Enhancing the quality of life for individuals with dementia, their caregivers and family members

This strategy is a continuation of previous work carried out by the Malta Dementia Strategy Group on recommendations for a dementia strategy in the Maltese Islands presented to the authorities of Health in January 2010. It is also a reflection of the latest developments in the field of dementia management and care.

The key objectives presented in this strategy include:

Increasing awareness and understanding of dementia

One fundamental aspect of this strategy is that of increasing awareness and understanding of dementia among the general public and healthcare professionals in order to reduce stigma and misconceptions about the condition. Information campaigns will be launched that will seek to provide information about dementia, measures that aid

prevention, the importance of timely diagnosis and services that are available in the community and elsewhere. It also aims to provide adequate knowledge on dementia to non-professional sectors of the population including service providers that come into direct contact with individuals with dementia.

Timely diagnosis and intervention

Early symptom recognition and interventions through appropriate referral pathways together with the necessary pharmacological and psychosocial support offer the best possible management and care for individuals with dementia. This strategy also encourages the development of advanced care directives.

Workforce development

Good quality care will be ensured through the provision of training and educational programmes for staff working with individuals with dementia, giving particular importance to challenging behaviour and palliative care. Caregivers and family members who are responsible for the daily care of individuals with dementia will also be provided with adequate training in order to offer the best quality care and help them cope with new challenges.

Improving dementia management and care

A holistic approach in service provision for individuals with dementia, their caregivers and family members will be adopted. Apart from providing all pharmacotherapeutic options to Alzheimer's disease patients, individuals receiving a diagnosis of dementia will have care plans developed by a multidisciplinary team specialised in dementia management and care. These will address activities that maximise independent living, adapt and develop skills, and minimise the need for support. This, together with a rehabilitation service for those with other comorbidities, will seek to better equip the patient to return to the community. The strategy also aims to strengthen community care for individuals with dementia and their families so that services are closer to the people who need them. The individual with dementia as well as the caregiver and family members need to be viewed as a single unit requiring appropriate care and support. The proposed creation of a Dementia Intervention Team will serve as a single point

of referral for individuals with dementia and their caregivers and will help in providing the most appropriate support according to the family's needs. Provision of different forms of respite services and the availability of outreach support are being seen as central in achieving quality care in the community. The following strategy also aims to create extra dementia units in community care homes. Regular monitoring of homes in order to ensure high standards of care and the gradual incorporation of dementia-friendly measures are also addressed.

Ethical approach to dementia management and care

This strategy aims to promote an ethical approach to dementia management and care and provide individuals with dementia and their caregivers with the necessary psychological support needed in making important decisions regarding their health and welfare.

Research

Information regarding epidemiology of dementia in the Maltese Islands, patterns of detection and diagnosis, and delivery of care are needed for proper planning and allocation of health and social care resources and for outcome evaluation. Since delivery of care is context specific, the strategy aims to promote and support epidemiological research in the field of dementia in different local care settings. Other research initiatives in the dementia field, through the collaboration with other research entities, will be strongly encouraged.

Implementation and delivery

The implementation of the objectives laid down in this strategy document is planned over the next nine years (2015-2023). The strategy entails not only substantial human and financial investment but also joint planning between different government entities, health and social care staff, individuals with dementia, their families and caregivers with the overall aim of improving the quality of life of those affected by dementia in the Maltese Islands.

1

DEMENTIA

- 1.1 Defining dementia
- 1.2 Types of dementia
- 1.3 Dementia risk and protective factors
- 1.4 Stages of dementia
- 1.5 Demography of the population of the Maltese Islands
- 1.6 The burden of dementia
- 1.7 Financial impact of dementia
- 1.8 The perspective of the individual with dementia and the caregiver
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1.1 DEFINING DEMENTIA

Dementia is a syndrome due to illness of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement (World Health Organisation, 2012). These symptoms of cognitive function are mostly the result of structural and chemical changes that occur in the brain leading to considerable cell death. It is a progressive illness with patients becoming more in need of help and support in performing everyday activities. Individuals with dementia may also develop behavioural and psychological symptoms including disinhibited behavior, delusions and hallucinations, verbal and physical aggression, agitation, anxiety and depression (Carson et al., 2006). Although different individuals experience dementia differently, understanding how the disease progresses is crucial in planning and providing the right amount of care as well as helping caregivers and patients to foresee the changes that will occur with time.

1.2 TYPES OF DEMENTIA

There are various types of dementia with Alzheimer's disease (AD) accounting to approximately 70 per cent of all dementia cases. Other common forms of dementia include vascular dementia, Lewy-body dementia, frontotemporal dementia and dementia secondary to disease including other neurodegenerative conditions such as Parkinson's disease, Huntington's disease and amyotrophic lateral sclerosis (Table 1.1). It is not uncommon that various types of dementia co-exist (mixed dementia), especially in the late stages of the condition. According to the World Health Organisation's (WHO) Global Burden of Disease Report, dementia contributes to 11.2 per cent of years lived with disability in people aged 60 years and over (World Health Organisation, 2008). This is due to the fact that dementia has a disproportionate impact on independent living in the older adult population.

| Dementia subtype | Early, characteristic symptoms | Proportion of dementia cases |
|-------------------------------|---|------------------------------|
| Alzheimer’s disease (AD) | Impaired memory, apathy, depression, loss of activities of daily living (ADL), gradual progression | 70% |
| Vascular dementia (VaD) | Similar to AD, but memory less affected, mood fluctuations more prominent, physical frailty, stepwise progression | 20-30% |
| Lewy-body dementia (LBD) | Marked fluctuations in cognitive ability, visual hallucinations, Parkinsonism (tremor and rigidity) | <5% |
| Frontotemporal dementia (FTD) | Personality and mood changes, disinhibition, language difficulties | 5-10% |

Table 1.1. Characteristics of dementia subtypes

1.3 DEMENTIA RISK AND PROTECTIVE FACTORS

Age remains the most important non-modifiable risk factor in developing dementia (Figure 1.1). Although it is possible to have dementia early on in life, the risk increases exponentially with advancing age (Alzheimer Europe, 2009). Women are more likely to develop Alzheimer’s disease whilst men are more prone to vascular dementia. Having a first degree relative increases the risk slightly compared to absent family history. Cardiovascular morbidities such as high blood pressure especially in mid-life, hypercholesterolaemia, diabetes and obesity are major risk factors, as is stroke. Recent studies have also suggested that a link exists between depression and dementia even though the exact cause is not yet known (Kessing, 2012). Repeated head trauma may trigger processes in the brain that results in dementia pugilistica, a form of the condition usually found in individuals practicing sport where head injury is likely. Conversely, active engagement in mental, physical



and social activities may act as protective factors and delay the onset of the most common forms of dementia. A healthy and balanced diet low in saturated fat reduces the likelihood of developing dementia as it reduces the risk of heart disease and stroke.

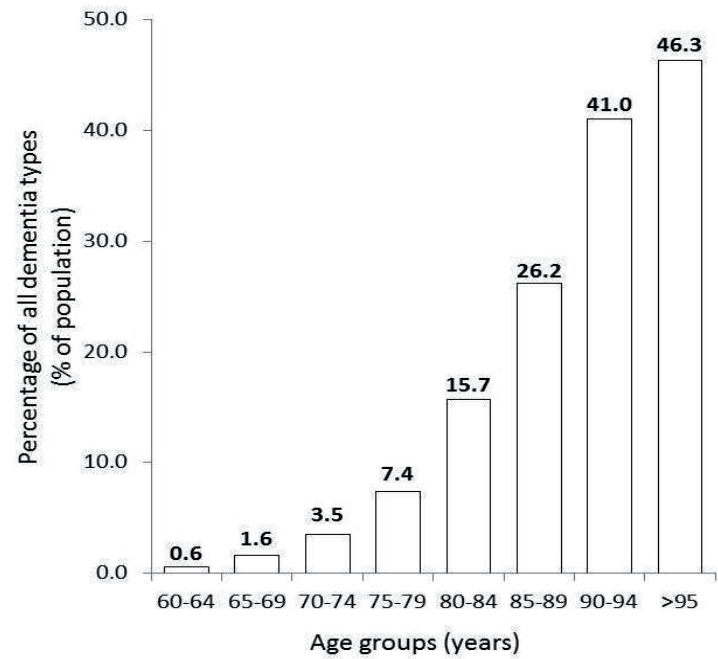


Figure 1.1. European prevalence rates of dementia by age group (Alzheimer Europe, 2009)

Mutations in several genes have been shown to cause AD, but these genetic forms account for less than 5 per cent of all cases (Van der Flier and Scheltens, 2005). Early-onset dementia (EOD, less than 65 years at onset) is a relatively uncommon and frequently misdiagnosed condition. One reason for misdiagnosis is that EOD has a more varied differential diagnosis than late-onset dementia (Mendez, 2006).

Individuals with EOD face multiple challenges as they are more likely to be in employment at the time of diagnosis, have dependent children and partner or have financial commitments that need to be met. Family members, especially children, need to know how dementia will affect their relative and specialized advice and information should be available. Young people who are also at risk of developing dementia include those with Down’s syndrome and other learning disabilities (Krinsky-McHale and Silverman, 2013).

1.4 STAGES OF DEMENTIA

Dementia affects individuals in different ways depending on the stage of disease progression. The latter is normally divided into early (mild), middle (moderate) and late (severe) stages. These can vary as significant inter-subject variability exists in the symptomatic profile. Early stage dementia is often missed or misdiagnosed as lack of awareness often leads to the belief that the observed symptoms are part of the normal ageing process. Common signs at this stage include impairment of short-term memory, difficulty in verbal communication and decision making, difficulty in carrying out complex activities of daily living (ADL) and changes in mood and behaviour including depression and anxiety. As the disease progresses to its moderate stage, individuals become more forgetful, have increased difficulty in communication, are unable to perform basic ADL and live independently, and may display inappropriate behaviour such as wandering, hallucinations and disinhibition. Late stage dementia is characterised by total dependence. Memory impairment becomes severe and affected individuals are unable to recognise familiar faces and objects. There is an increased need of assisted care due to difficulty in swallowing and incontinence. In most cases, individuals with late stage dementia become immobile and behavioural changes may include nonverbal aggression. The median survival time varies considerably in between affected individuals and can be influenced by early diagnosis. The amount of informal caring for an individual with dementia is also related to the severity of the condition. In a study by Alzheimer Europe, it was reported that the number of hours per day in caring for an individual with dementia is directly related to the stage of disease progression (Alzheimer Europe, 2006).

1.5 DEMOGRAPHY OF THE POPULATION OF THE MALTESE ISLANDS

The total population in the Maltese Islands at the end of 2012 stood at 421,364 with 72,278 or 17.2 per cent of the population aged 65 years and over (based on 2011 Census). This percentage is expected to grow as the older adult population increases, while the younger age groups decrease in number due to a reduction in the birth rate (Figure 1.2).

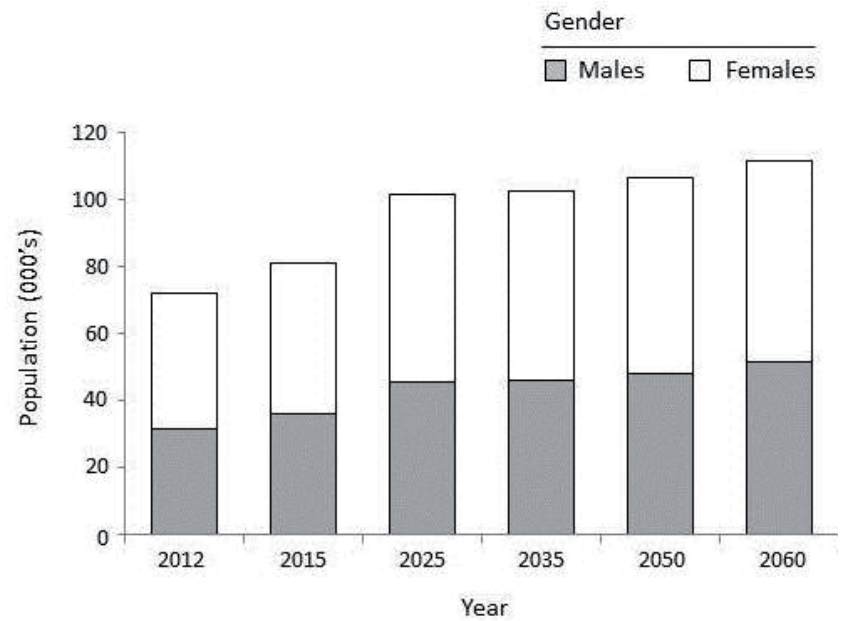


Figure 1.2. Current and projected population of individuals aged 65 years and over according to gender in the Maltese Islands till 2060

The distribution of the Maltese population in the coming years will see a significant shift in the old-age dependency ratio by the year 2060. Every individual above the age of 65 had the support of 4.2 persons in the workforce in 2011. This will go down to 2.6 persons in 2025 and 1.8 persons in 2060 (Figure 1.3).

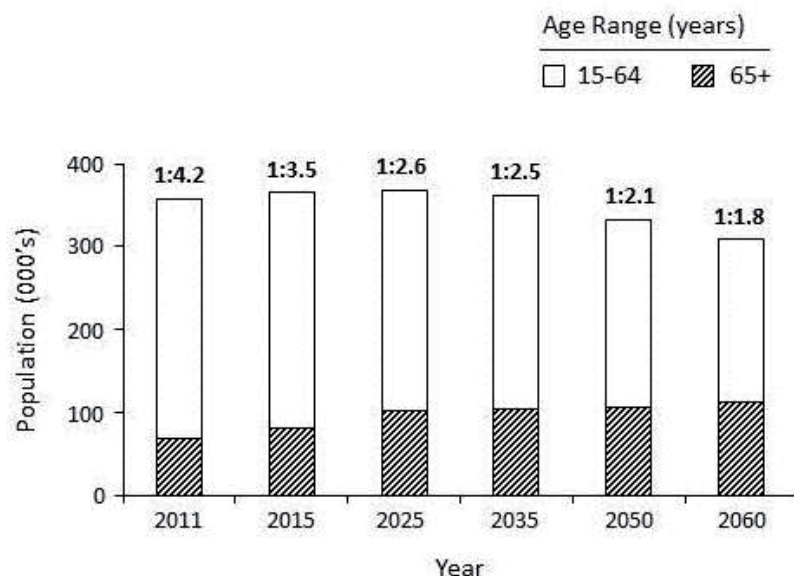


Figure 1.3. Distribution of the total Maltese population according to age brackets (bold figures atop the bars denote the old-age dependency ratios)

1.6 THE BURDEN OF DEMENTIA

According to Alzheimer's Disease International (ADI), there were an estimated 44.4 million people living with dementia worldwide in 2013, increasing to 75.6 million in 2030 and reaching 135.5 million by 2050 (Alzheimer's Disease International, 2013). Approximately 62 per cent of individuals with dementia live in low- and middle-income countries, a figure that will exceed 70 per cent by 2050.

| Countries | Age Group | EuroCoDe | | | |
|----------------|-----------|-----------|-----------|-----------|--------------------------|
| | | Total | Males | Females | As % of total population |
| EU-27 | | 7,302,318 | 2,357,843 | 4,944,476 | |
| Belgium | 30-95+ | 163,511 | 52,684 | 110,827 | 1.56 |
| Bulgaria | 30-95+ | 99,291 | 35,674 | 63,617 | 1.29 |
| Czech Republic | 30-95+ | 123,194 | 38,938 | 84,257 | 1.20 |
| Denmark | 30-95+ | 78,744 | 25,946 | 52,798 | 1.45 |
| Germany | 30-95+ | 1,368,330 | 418,037 | 950,293 | 1.66 |
| Estonia | 30-95+ | 17,825 | 4,528 | 13,296 | 1.33 |
| Ireland (2002) | 30-95+ | 37,417 | 12,946 | 24,471 | 0.96 |
| Greece | 30-95+ | 159,275 | 63,818 | 95,457 | 1.43 |
| Spain | 30-95+ | 690,992 | 233,210 | 457,782 | 1.57 |
| France | 30-95+ | 974,391 | 307,270 | 667,121 | 1.60 |
| Italy (2004) | 30-95+ | 1,012,819 | 325,390 | 687,429 | 1.74 |
| Cyprus | 30-95+ | 8,024 | 3,098 | 4,926 | 1.04 |
| Latvia | 30-95+ | 29,846 | 7,443 | 22,403 | 1.30 |
| Lithuania | 30-95+ | 40,619 | 11,194 | 29,425 | 1.20 |
| Luxembourg | 30-95+ | 5,814 | 1,829 | 3,985 | 1.23 |
| Hungary | 30-95+ | 131,995 | 39,696 | 92,300 | 1.31 |
| Malta | 30-95+ | 4,524 | 1,612 | 2,912 | 1.11 |
| Netherlands | 30-95+ | 210,666 | 68,099 | 142,567 | 1.29 |
| Austria | 30-95+ | 126,296 | 37,961 | 88,335 | 1.52 |
| Poland | 30-95+ | 391,344 | 123,101 | 268,242 | 1.03 |
| Portugal | 30-95+ | 153,386 | 52,761 | 100,625 | 1.45 |
| Romania | 30-95+ | 227,036 | 81,150 | 145,885 | 1.05 |
| Slovenia | 30-95+ | 25,380 | 7,451 | 17,929 | 1.26 |
| Slovakia | 30-95+ | 51,622 | 16,286 | 35,336 | 0.96 |
| Finland | 30-95+ | 77,516 | 23,306 | 54,210 | 1.47 |
| Sweden | 30-95+ | 161,327 | 54,198 | 107,129 | 1.78 |
| United Kingdom | 30-95+ | 931,134 | 310,217 | 620,918 | 1.54 |
| Turkey (2000) | 30-95+ | 253,367 | 102,744 | 150,623 | 0.37 |
| Iceland | 30-95+ | 3,319 | 1,242 | 2,077 | 1.09 |
| Norway | 30-95+ | 71,447 | 23,233 | 48,213 | 1.53 |
| Switzerland | 30-95+ | 125,614 | 40,582 | 85,032 | 1.68 |
| Grand Total | | 7,756,065 | 2,525,644 | 5,230,420 | |

Table 1.2. Total number of dementia cases in Europe (Alzheimer Europe, 2009)

In Europe, the best available estimates indicate that, in 2009, approximately 8 million individuals in the EU-27 member states between the ages of 30 and 99 years had dementia (Table 1.2). The overall figure is expected to exceed 20 million by 2050 (Alzheimer Europe, 2009).

Locally, the number of individuals with dementia in 2010 was estimated at 5,198, equivalent to 1.24 per cent of the general population (Scerri and Scerri, 2012). This estimate was derived by applying age-specific prevalence rates of dementia as indicated in the EuroCoDe study (Alzheimer Europe, 2009) to the Maltese population. The figure is projected to reach 3.62 per cent by the year 2060 (Table 1.3).

| | Year | | | | | | |
|------------------------|----------|----------|----------|-----------|----------|----------|-----------|
| Age groups | 2010 | 2015 | 2020 | 2030 | 2040 | 2050 | 2060 |
| 60-64 | 30/139 | 27/124 | 27/127 | 21/100 | 27/123 | 29/127 | 25/105 |
| 65-69 | 179/154 | 240/201 | 223/186 | 217/177 | 198/164 | 234/193 | 246/185 |
| 70-74 | 242/346 | 246/344 | 381/513 | 376/493 | 292/391 | 382/488 | 419/507 |
| 75-79 | 367/577 | 419/601 | 446/616 | 671/871 | 677/847 | 639/800 | 777/959 |
| 80-84 | 448/834 | 493/945 | 620/1038 | 1100/1672 | 154/1681 | 946/1380 | 1306/1784 |
| ≥85 | 483/1399 | 619/1812 | 750/2248 | 1164/3021 | 012/4806 | 337/5400 | 2356/5368 |
| Total IWD | 5198 | 6071 | 7175 | 9881 | 12372 | 12957 | 14037 |
| Per cent of population | 1.24 | 1.47 | 1.73 | 2.37 | 3.04 | 3.26 | 3.62 |

Table 1.3. Estimated number of gender-specific dementia cases in the Maltese Islands according to age group using EuroCoDe data for the years 2010 to 2060 based on the National Statistics Office (for the year 2010) and EUROSTAT (for the years 2015-2060) demographic projections. Data shown as M (males)/F (females), IWD: individuals with dementia. Adapted from Scerri and Scerri, 2012.



In the below 60 years age group, the number of individuals with dementia was estimated to be 204 in 2015. This figure will drop to 150 individuals in the year 2050 with the main contributing factor being the projected decline in the number of births (Abela et al., 2007).

1.7 FINANCIAL IMPACT OF DEMENTIA

The global societal costs of dementia are enormous as the total worldwide expenditure for the year 2010 was estimated at €424 billion, equivalent to 1 per cent of the world's Gross Domestic Product (GDP). This figure varies from 0.24 per cent in low-income countries to 0.35 per cent in low-middle income countries, 0.5 per cent in high-middle income countries, and 1.24 per cent in high-income countries (Alzheimer's Disease International, 2010). The cost of care provided by families (informal care) together with societal care (care provided by professional personnel in home settings) contribute to 42 per cent of the costs worldwide, while direct medical care accounts to 16 per cent of the overall costs. Low-income countries account to around 1 per cent of the global dementia costs whereas high-income countries account to 89 per cent. In a study assessing the worldwide societal costs for dementia for 2009, the cost for Malta was estimated at a range of €63.1 - €96.2 million (Wimo et al., 2010). This includes both informal care (basic activities of daily living and instrumental activities of daily living) as well as direct medical and social care costs.

1.8 THE PERSPECTIVE OF THE INDIVIDUAL WITH DEMENTIA AND THE CAREGIVER

A diagnosis of dementia has a significant social, psychological and financial impact on the individual. Disease progression varies between subjects and although a number of drugs are present that slow down the cognitive decline, no cure is currently available. With time, the affected individual gradually loses mental function and thus autonomous capacity, becoming more dependent on others for personal care. Professional advice should be sought at an early stage to help the individual with dementia in planning for future personal, financial and legal issues. Activities of daily living will become progressively impaired together with loss of communication skills, changes in mood and behaviour leading to increased agitation, confusion, anxiety and aggression. These disturbances in behaviour are the usual trigger for hospitalisation and need for admission in nursing care homes.

Most of the care for individuals with dementia occurs at home (Bosanquet et al., 1997) (Figure 1.4) with relatives acting as the main caregivers (Innes et al., 2011). The major burden of support for individuals with dementia usually falls on one person (in most cases the spouse) who takes on the role of the main domestic caregiver and, as a result, often experiences considerable hardship in terms of the physical and emotional burden. Interestingly, gender-specific differences exist in the provision of dementia care with women mostly affected in terms of number of caregivers and level of caregiver stress. According to Alzheimer Europe (2006), almost half of the caregivers spend more than 10 hours per day caring for an individual with late stage dementia (Figure 1.5).

There is evidence that keeping an individual with dementia in the community is closely related to the degree of family support and that institutionalisation may have more to do with the attitudes and wellbeing of the caregiver than the impairment of the individual with dementia (Morris et al., 1988). The functional decline is accompanied by a number of behavioural problems that make caring particularly challenging. These impairments can contribute substantially to the psychological and physical morbidity of the caregiver (Hilgeman et al., 2007). Lack of information and support services within the community also contributes towards an enhanced burden of care provision.

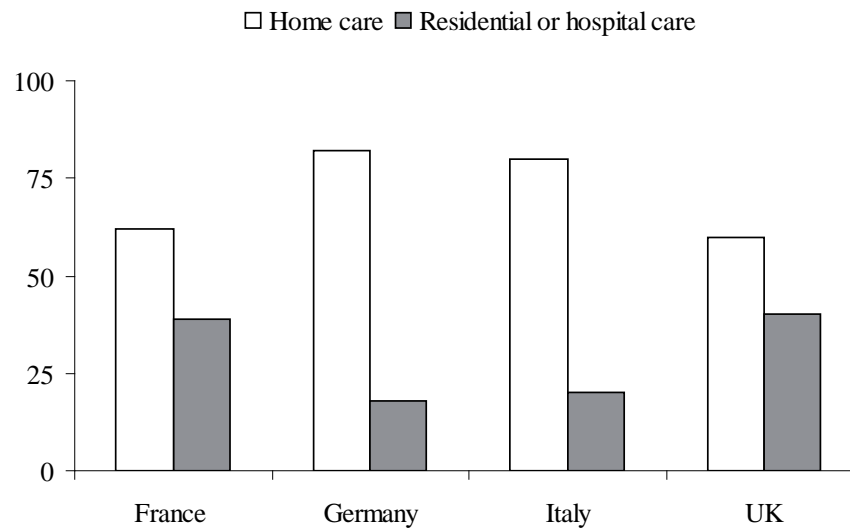


Figure 1.4. Percentages of patients (vertical axis) in home care versus residential or hospital care in selected countries (Bosanquet et al., 1997).

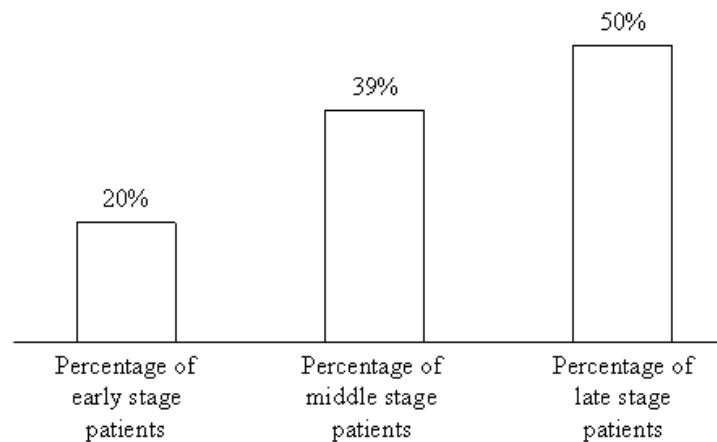


Figure 1.5. Percentage of caregivers spending more than 10 hours every day in caring for an individual with dementia (adapted from Alzheimer Europe, 2006).

Several studies have demonstrated significant effects in reducing caregiver burden, lowering caregiver depression, and delaying institutionalization of care recipients through either targeted interventions that treat a specific caregiver problem, such as depression, or broad-based multi-component interventions that include counseling, case management, and telephone support (Brodaty et al., 2003).

1.9 REFERENCES

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2

PURPOSE FOR A NATIONAL STRATEGY FOR DEMENTIA

- 2.1 Preamble
- 2.2 The European dimension
- 2.3 The Malta Dementia Strategy Group
- 2.4 Aim of the National Strategy for Dementia (2015-2023)
- 2.5 References





2.1 PREAMBLE

As the number of individuals with dementia will continue to increase, the government has decided to implement a number of holistic measures in order to improve the quality of life of individuals with dementia and those who care for them. It is no longer acceptable that dementia is regarded as an inevitable consequence of ageing and that nothing can be done in terms of healthcare and support options. The purpose of these measures is also that of offering the best possible advice to stakeholders in the field of dementia management and care.

The strategy acknowledges the fact that significant measures have already been adopted in providing medical and social support to individuals with dementia but also that a great deal remains to be done in the field of dementia care. It is envisaged that this strategy will be the start of a sustained commitment in this very important sector that is accentuated by the demographic ageing of the population. It is a comprehensive strategy, which provides direction in the various areas of dementia management and care utilising a more person-centred approach (Kitwood, 1997). The latter include principles that assert:

- (i) The human value of people with dementia, regardless of age or cognitive impairment, and those who care for them,
- (ii) The individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia,
- (iii) The importance of the perspective of the person with dementia,
- (iv) The importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being.

This strategy aims to work at all levels of care for individuals with dementia, their families and caregivers. Actions to increase and improve awareness and training, community care, hospital care, and palliative care services are included. The purpose is to have a positive and significant impact on the patient, their family and ultimately on society in general. The support provided must be equitably accessible and of a consistently high quality.

2.2 THE EUROPEAN DIMENSION

In recent years, the European Union has devoted more attention to the medical, social and economic aspects of dementia and urged its member states to develop plans and make dementia a top health and social priority. The White Paper 'Together for Health: A Strategic Approach for the EU 2008-2013' identified a better understanding of neurodegenerative conditions, such as Alzheimer's disease, as an important need to be addressed in the context of demographic ageing. The European Pact on Mental Health, adopted in 2008, has mental health in older people as one of its four main priority themes.

During the French EU Presidency (July–December 2008), the European Council adopted the 'Council Conclusions on Public Health Strategies to Combat Neurodegenerative Diseases Associated with Ageing and in Particular Alzheimer's Disease' in order for member states to recognise that dementia disorders constitute a priority for action in the context of the shift in the ageing EU population. Following this, in July 2009, the European Commission adopted the 'Communication from the Commission COM (2009) 380/4 to the European Parliament and the Council on a European initiative on Alzheimer's disease and other dementias'. This communication highlights the EU support to member states in national efforts in areas of prevention, including measures to promote mental well-being, support early diagnosis, coordinating research across Europe, spreading best practices for treatment and care and developing a common approach to ethical issues such as rights, autonomy and dignity of individuals with dementia. At the same time, the Commission adopted a proposal addressed to the European Council 'Proposal for a Council Recommendation on measures to combat neurodegenerative diseases, in particular Alzheimer's disease, through joint programming of research activities'. This proposal invites member states to work towards a common vision of how research cooperation and coordination at European level can help in understanding, detecting and

prevent neurodegenerative diseases, in particular Alzheimer's disease, and develop a strategic research agenda in order to establish medium and long-term research needs and objectives. In February of 2009, The European Parliament adopted the Written Declaration 80/2008 on the priorities in the fight against Alzheimer's disease, in which members of the European Parliament called on the European Commission and the Member States to recognise Alzheimer's disease as a European public health priority and to develop a European Action Plan.

Research in neurodegenerative diseases, including Alzheimer's disease, was augmented in 2010 when the European Commission contributed close to €2 million in supporting the work of the Joint Programming initiative on Neurodegenerative Diseases (JPND) with the ultimate goal of accelerating the progress in understanding the causes of these debilitating conditions, leading to early diagnosis, the development of new treatments and prevention, and the provision of more effective medical and social care in order to enhance the quality of life for patients and caregivers.

In 2011, the European Parliament adopted a motion for a resolution on a European initiative to combat Alzheimer's disease and other neurodegenerative diseases. This called member states to make dementia a priority, raise awareness about dementia across the EU, increase cooperation between countries in research, care and prevention of Alzheimer's disease and other dementias, setup specialists centres and improve the skills of healthcare professionals, and develop action plans aimed at improving the well-being and quality of life of people with dementia and their families.

In March of 2013, the results of the Alzheimer Cooperative Valuation in Europe (ALCOVE) project were presented. This network was composed of 19 European Member States (including Malta) and 30 European partners. Recommendations for policy makers included ways in better understanding of the prevalence and demographic data about dementia, the need to improve the quality and timeliness of the diagnosis of dementia, improving the care of people experiencing challenging behaviour, ethical and legal issues related to advanced directives, and competency assessment in the context of dementia.

| Country | STATUS |
|-----------------------------------|--------|
| Austria | G |
| Belgium | Y |
| Bulgaria | O |
| Croatia | NP |
| Cyprus | G |
| Czech Republic | G |
| Denmark | Y |
| Estonia | NI |
| Finland | Y |
| France | Y |
| Germany | NP |
| Greece | O |
| Hungary | NI |
| Ireland | G |
| Italy | G |
| Latvia | NI |
| Lithuania | NI |
| Luxembourg | Y |
| Malta | G |
| Netherlands | Y |
| Norway | Y |
| Poland | NP |
| Portugal | G |
| Romania | NP |
| Slovakia | NI |
| Slovenia | G |
| Spain | O |
| Sweden | Y |
| Switzerland | Y |
| Turkey | NP |
| United Kingdom (England) | Y |
| United Kingdom (Northern Ireland) | Y |
| United Kingdom (Scotland) | Y |
| United Kingdom (Wales) | Y |

Table 2.1. National Dementia Plans in Europe (28 EU Countries plus Norway, Switzerland and Turkey). Legend: Y-Yes, G-Government committed to develop a dementia strategy, O-Other political support to develop a dementia strategy, NP-No political support, NI-No information (Alzheimer Europe, 2013).

Other ongoing EU initiatives that have an impact on dementia issues include the European Innovation Partnership on Active and Healthy Ageing (as part of its EU Horizon 2020 and Innovation Union strategies), Age-friendly communities in Europe (with the goal of fostering the implementation of innovative local action for better age-friendly environments), and the European Joint Action on Mental Health (aims at building a framework for action in mental health policy at the European level).

Besides Malta, various other European countries felt the need to develop a national plan on dementia. Countries that already have a dementia strategy include Belgium, Denmark, Finland, France, Luxembourg, the Netherlands, Norway, Sweden, Switzerland and the United Kingdom (Table 2.1).



2.3 THE MALTA DEMENTIA STRATEGY GROUP

The strategy highlighted in this document adds on previous work conducted by the Malta Dementia Strategy Group launched in May of 2009 by the Parliamentary Secretariat for the Elderly and Community Care. Preparatory work undertaken by this multidisciplinary group included a field analysis of dementia services available in the Maltese Islands, a consultative exercise involving stakeholders providing local dementia services, training and support, and feedback from the general public through a specifically designed questionnaire that was available online (www.dementia.gov.mt) together with its dissemination in printed form to all government elderly homes and members of the Malta Dementia Society. A total of 613 completed questionnaires were received from different categories of respondents including caregivers, individuals with dementia, healthcare professionals, relatives and other interested parties (Figure 2.1). The majority of the respondents were females (71.5 per cent) and above the age of 50 years (55.3 per cent). The complete results were collated, analysed and presented in the document *Inspiring New Frontiers: Recommendations for a Dementia Strategy in the Maltese Islands* in January 2010 (Scerri, 2010, 2012).

□ Carers ■ Individuals with dementia □ Healthcare professionals ▨ Relatives ■ Others

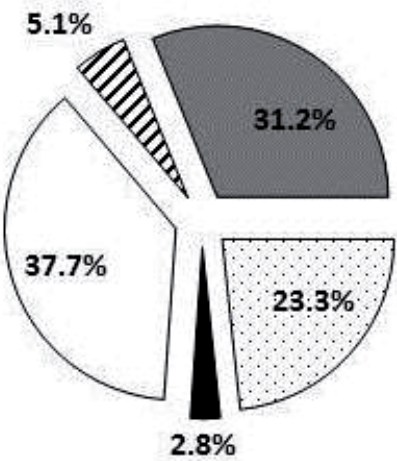


Figure 2.1. Distribution of categories of questionnaire respondents as a percentage ($n=613$)



2.4 AIM OF THE NATIONAL STRATEGY FOR DEMENTIA (2015-2023)

The overarching aim of the National Strategy for Dementia is to *enhance the quality of life of individuals with dementia, their caregivers and family members*. This will be achieved through the following strands of intervention:

- (i) Increasing awareness and understanding of dementia
- (ii) Improving timely diagnosis and early intervention
- (iii) Development of a workforce specialised in patient-centred dementia care
- (iv) Improving treatment and care via:
 - (a) The provision of good quality information at the point of diagnosis for both individuals with dementia and their caregivers
 - (b) Facilitating easy access to appropriate support, advice and care for individuals with dementia and their caregivers
 - (c) The provision of dementia medication, non-pharmacological interventions and assistive/information technologies
 - (d) The improvement in quality of care across all healthcare services for individuals with dementia
 - (e) The improvement of community services that reliably offer support to individuals with dementia, their caregivers and family members
 - (f) The provision of specialised long-term and palliative care
- (v) Promoting the best ethical approaches to dementia management and care
- (vi) Promoting and fostering research in the dementia field

2.5 REFERENCES

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3

INCREASING AWARENESS AND UNDERSTANDING OF DEMENTIA

- 3.1 Preamble
- 3.2 A case for change
- 3.3 Strategy objective
- 3.4 Objective delivery
- 3.5 References





3.1 PREAMBLE

There is a general understanding that increasing awareness and knowledge would decrease the fear and stigma associated with dementia, both among the general public and healthcare professionals. People need information and guidance in order to be aware of risk and protective factors, able to recognise the early symptoms of dementia and seek advice from professionals who will help them in the diagnosis and management of the condition. Good-quality information also needs to be readily accessible for individuals with dementia and caregivers regarding healthcare and support services that are available.

Increasing awareness should also reduce the widespread misconception that the symptoms of dementia are a direct consequence of old age, leading in unwillingness to seek professional assistance. The false belief that nothing can be done also contributes to adopting a wait-and-see approach or inaction. Although there are no proven measures that can avoid dementia, minimising or management of risk factors such as cardiovascular disease, diabetes, high cholesterol levels and obesity can help in prevention. Furthermore, increasing physical activity has beneficial effects on cognitive function and may reduce the incidence of dementia (Lövdén et al., 2013).

Enhancing dementia knowledge is fundamental in developing dementia-friendly communities in which individuals with dementia are welcomed to continue participating in daily life. These individuals and their caregivers and family members need to have their voice heard and be directly involved in the planning of services and policies that affect their lives. Empowering individuals with dementia will not only help in challenging stigma but will also encourage social inclusion and integration.

Currently, at community level, the enhancement of dementia knowledge and understanding is mostly carried out by the Malta Dementia Society. This non-governmental non-profit organisation provides training and support to individuals with dementia and their caregivers, and to healthcare professionals working in the field. The Malta

Dementia Society provides information about dementia through its website (www.maltadementiasociety.org.mt), Facebook page (<https://www.facebook.com/groups/maltadementiasociety>) and via the organisation of educational seminars and training programmes. In collaboration with the government, the society also operates a Dementia Helpline and published, in recent years, three information booklets aimed at increasing awareness: *Patient-Centred Dementia Care: The Right Approach to Help a Person with Dementia* in 2006 (Secretariat for Elderly and Community Care, 2006), *In-Nannu Nesa x'Jisimini* (Grandpa forgot my name) in 2009 (Zahra, 2009) and *X'hin Hu? Fatti Dwar id-Dimensja* (What time is it? Facts about Dementia) in 2013 (Scerri and Zahra, 2013).

There is therefore a need to setup educational campaigns to develop a better understanding of dementia among the public and healthcare professionals. The message needs to be a positive one and should include information about the condition as well as support services that are available. Promoting messages on changes in lifestyle and eating habits should also be encouraged (possibly through collaborations with other national health promotion initiatives).

3.2 A CASE FOR CHANGE

Previous results by the Malta Dementia Strategy Group have indicated that there is an information gap on dementia amongst the general public (Scerri, 2010). A significant number of public questionnaire respondents listed social stigma as being prevalent with 38 per cent still considering dementia a taboo subject. The majority of participants (67 per cent) felt that awareness on dementia is lacking (Figure 3.1) and that not enough information is provided to individuals with dementia and their caregivers regarding services that are available (63 per cent). In general, common misconceptions among respondents included the belief that symptoms of dementia are the consequence of old age and that these symptoms are transient.

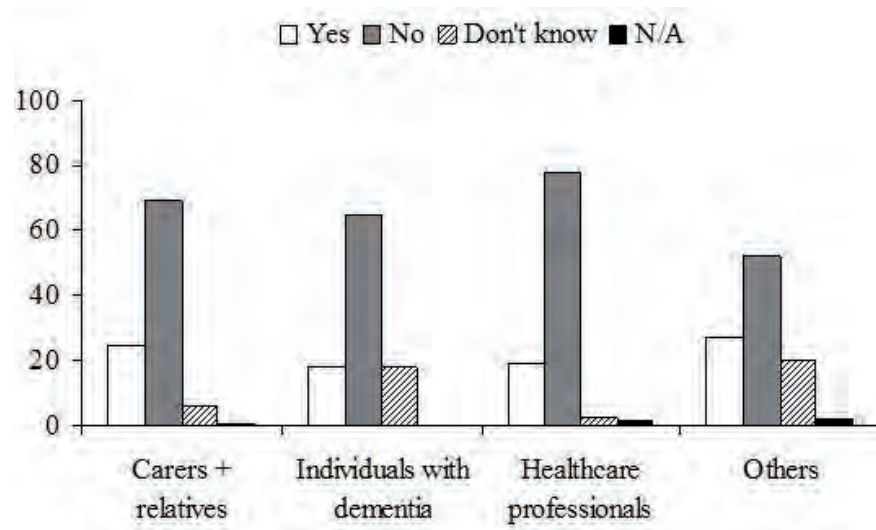


Figure 3.1. Percentage of respondents (vertical axis) indicating the level of awareness on dementia according to category

3.3 STRATEGY OBJECTIVE

The main objective is *to increase awareness and understanding of dementia among the public and healthcare professionals* through:

- (i) changing the perception of dementia, thus reducing stigma and discrimination
- (ii) encourage help-seeking and timely diagnosis whilst promoting information on dementia risk and protective factors
- (iii) providing guidance for individuals with dementia and their caregivers on the availability of support services

3.4 OBJECTIVE DELIVERY

- a. Develop continuing information campaigns targeting different cohorts (e.g. children, senior adults, healthcare professionals) using various media channels. This will involve the Health Promotion Unit as well as the Malta Dementia Society, local councils, parish groups and other relevant stakeholders. The educational campaigns will seek to provide information about the condition, risk factors and preventive measures, the value of early diagnosis and the availability of support services. The participation of individuals with dementia in these campaigns will be strongly encouraged. The ultimate aim is create dementia-friendly communities.
- b. Develop an updated directory of available dementia services to be distributed amongst healthcare professionals, individuals with dementia, their caregivers and family members.
- c. Identify and appoint a number of Dementia Activists with the remit of promoting dementia awareness in schools and the community.
- d. Develop an online guide to dementia caregivers and family members.

- e. Develop information material that specifically targets young individuals with dementia and their family members (including children).
- f. Work in partnership to promote and support the work of the Malta Dementia Society and other non-government organisations working in the field of dementia.
- g. Develop specific, continuing information sessions targeting persons working in the community who may come into direct contact with individuals with dementia. These may include the police, transport and other public service providers, primary healthcare professionals and education/cultural organisations. The private sector should also be encouraged to promote dementia-friendly attitudes.
- h. Strengthening the Dementia Helpline in order to be a point of reference for the community as well as providing information about service availability.

3.5 REFERENCES

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4

TIMELY DIAGNOSIS AND INTERVENTION

- 4.1 Preamble
- 4.2 A case for change
- 4.3 Strategy objective
- 4.4 Objective delivery
- 4.5 References





4.1 PREAMBLE

The majority of individuals with dementia are not diagnosed early in the disease process and as a result, diagnosis is often made when the disease has reached a stage that has a significant negative impact on the health and cognitive function of the individual. Timely diagnosis does not only enhance the quality of life and dignity of the individual but also limits institutionalisation.

The benefits of timely diagnosis include identification of treatable physical and psychiatric causes, treatment of co-morbid conditions, initiation of psychosocial support, and instigation of pharmacological symptomatic treatments (Burns and Iliffe, 2009). The accurate differential diagnosis of dementia subtypes has become increasingly important with the advent of licensed treatments for Alzheimer's disease and the recognition of the potentially serious side effects of antipsychotics in people with Lewy-body and other dementias (National Institute for Health and Clinical Excellence, 2011). It is therefore of utmost importance that diagnosis is made by a specialist in the field of dementia. Timely diagnosis also depends on the detection of symptoms by the relevant practitioner. Primary care is often the point of first medical contact and hence the cornerstone of ensuring early detection, timely intervention, and effective ongoing management (Downs et al., 2006). However, early recognition of symptoms by general practitioners is not always easy due to the insidious and variable onset of the syndrome. It is therefore essential that general practitioners are better trained in identifying the symptoms of dementia early on in the disease process and on criteria for referral to specialised medical services. As part of their assessment, formal cognitive testing should be undertaken using a standardised instrument. Unfortunately, there is a marked reluctance on the part of the primary care provider to be directly involved in the diagnosis of dementia for reasons that include: the belief that nothing can be done for dementia, risk avoidance, concerns about competency, and concerns about the availability of resources (Iliffe et al., 2006).

Early intervention and timely diagnosis is the optimal strategy, not only because the patient's level of function will be preserved for longer, but also because it helps patients and caregivers to cope better within their communities.



Community-dwelling individuals with dementia incur less societal cost than those who require long-term institutional placement (Leifer, 2003). Early intervention is also important as it allows the individual with dementia to plan ahead and make personal choices for the future. Advance care directives are statements which enable a person to determine in advance what his or her wishes are with regards to their treatment and care in the event that they become unable to communicate their requests. Financial decision making can also be planned in advance, including the appointment a responsible person (powers of attorney). The development of advance care directives are of particular importance for individuals with dementia because nearly all dementias are progressive. It fosters autonomous decision making when someone has lost decisional capacity.

Access to timely diagnosis in young patients with dementia should also be given priority. Dementia in young people poses a diagnostic challenge and may present with a wide variety of subtle behavioural, cognitive, psychiatric, or neurological symptoms. These individuals have special requirements, and specialist multidisciplinary services should be developed, allied to existing dementia services, to meet their special needs for assessment, diagnosis and care (Van der Flier and Scheltens, 2005).

4.2 A CASE FOR CHANGE

Currently only a small proportion of individuals with dementia receive a formal diagnosis. In the various consultation meetings with stakeholders held by the Malta Dementia Strategy Group, it was evident that timely diagnosis and intervention in dementia needs to be improved (Scerri, 2010). Lack of professional advice and targeted information at the point of diagnosis was also pointed out. Furthermore, a recent study in Malta reported that general practitioners do not have enough knowledge and training in the various aspects of dementia care, including diagnosis, disclosure and pharmacotherapeutic management of Alzheimer's disease, and that referral to specialist care is extremely low (Caruana-Pulpan and Scerri, 2014). In November of 2012, the Department of Health authorised that the prescription of donepezil, the only treatment for Alzheimer's disease to be included in the Government Formulary List to date, can only be effected by specialists namely consultant geriatricians, neurologists and psychiatrists.

Feedback from the public questionnaire showed that 92 per cent of the respondents felt that early diagnosis is important even though 30 per cent indicated that they waited for more than six months prior to seeking medical assistance on the appearance of the first symptoms (Figure 4.1). Healthcare professional respondents denoted there is considerable lack of information about the various aspects of dementia and services that are available (Figure 4.2) (Scerri, 2012).

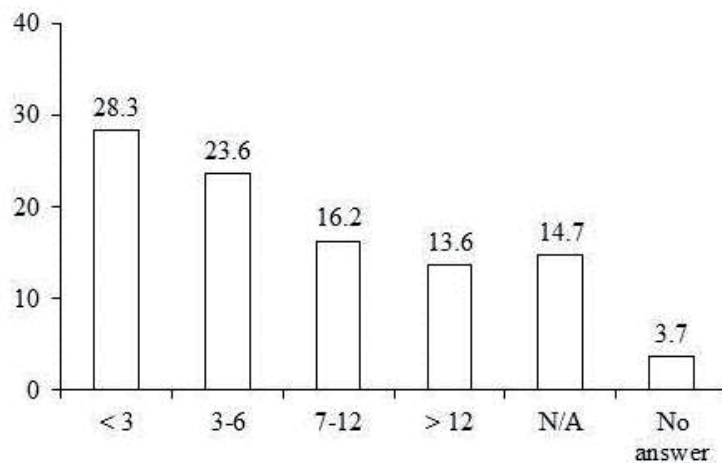


Figure 4.1. Percentage of respondents (atop of bars) among individuals with dementia/caregivers/relatives categories indicating the number of months (horizontal axis) in waiting prior to seeking medical assistance (N/A: not applicable) (adapted from Scerri, 2010)

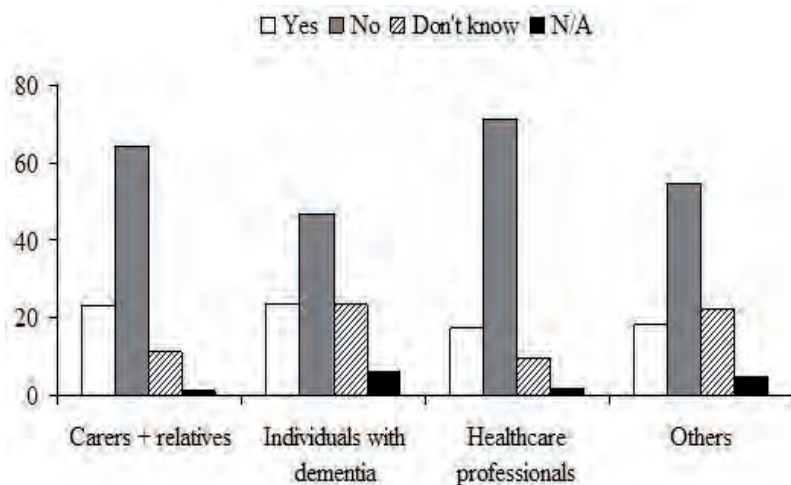


Figure 4.2. Percentage of participants (vertical axis) according to category, indicating whether there is enough information on the services that are available to individuals with dementia and their caregivers (N/A: not applicable) (Scerri, 2012)



4.3 STRATEGY OBJECTIVE

The main objective is to *improve timely diagnosis, early intervention and guidance to individuals with dementia and their caregivers* through:

- (i) ensuring that as many individuals as possible are diagnosed at an early stage in disease progression
- (ii) provision of updated information on dementia and support services available both to the individual with dementia and the caregivers
- (iii) ensuring timely accessibility to the required care and support services

4.4 OBJECTIVE DELIVERY

- a. Promote the value of early diagnosis and intervention in primary care.
- b. Provide opportunities for training to general practitioners in diagnosis, referral, disclosure and management of dementia.
- c. With the aid of experts in the field, develop and distribute information about dementia at the point of diagnosis and throughout the course of disease progression.
- d. Facilitate and draw up referral pathways to relevant specialist services in areas of geriatrics, neurology and psychiatry (including old-age psychiatry).
- e. Draw up a consistent and single protocol for dementia diagnosis and type using international best practice guidelines.
- f. Decrease waiting times for appointments with specialists for individuals suspecting cognitive impairment through the recruitment of additional specialists.
- g. Provide support to individuals with dementia and their caregivers immediately following diagnosis. A new multidisciplinary team, the Dementia Intervention Team, managed by a Dementia Coordinator will be set up to aid individuals with dementia and their relatives by providing information and care coordination (including psychological counseling) throughout the disease progress.
- h. Support and liaison with local non-government organizations in order to provide community and peer support to individuals with dementia, their caregivers and family members.
- i. Work towards the development of advance care directives.
- j. Provide support to young people with dementia, who although much smaller in number, have needs that may be different from those with late onset dementia.

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5

WORKFORCE DEVELOPMENT

- 5.1 Preamble
- 5.2 A case for change
- 5.3 Strategy objective
- 5.4 Objective delivery
- 5.5 References





5.1 PREAMBLE

Training of healthcare professionals in the various aspects of dementia diagnosis, management and care are major requisites in developing an able workforce and acts as an important tool in increasing awareness and quality of life. There is growing evidence that, even among those healthcare professionals working in specialist dementia services, the proportion of staff receiving dementia care training is low (All-Party Parliamentary Group on Dementia, 2009). This continues to highlight the need of delivering high quality training, assessment and supervision through teaching methods and innovative techniques using an interdisciplinary approach. Ultimately, good quality service care is ensured through professionally qualified staff, who meet the individual service user with respect and dignity, and who use their knowledge to provide the best possible care for the patient.

Having a trained workforce is fundamental to accomplish the aims of this strategy. Health and social care managers should ensure that all staff working with older adults in the health, social care and voluntary sectors have access to dementia-care training (skills development) that is consistent with their roles and responsibilities (Beer et al., 2009). Furthermore, an integrated care program having trained multidisciplinary teams both in the hospitals as well as in the community will ensure that individuals with dementia are being offered the best possible care. A collaborative approach between various professionals (including clinical dementia specialists, nurses, psychologists, occupational therapists, speech language pathologists and other allied health professionals) forming the multidisciplinary team will result in significant improvement in the quality of care and in behavioural and psychological symptoms of dementia among primary care patients and their caregivers (Callahan et al., 2006). Consequently, investing and recruitment of qualified health and social care service personnel is one of the largest challenges of this strategy. A 'needs analysis' is necessary to identify the gaps in health/social care professionals both in terms of numbers as well as necessary width and depth of expertise in the various fields of dementia care.

Training of caregivers is also an important aspect of this strategy. An intensive intervention programme for

caregivers of individuals with dementia early in the course of the patient's illness has the potential to delay institutionalisation and reduce the psychological morbidity of the caregiver without increasing the use of health services (Chiu et al., 2013). Family caregivers who are responsible for the daily care of individuals with dementia need to know how to deal with symptoms like memory loss, difficulties in activities of daily living and challenging behaviour.

5.2 A CASE FOR CHANGE

Dementia is a condition which has both medical and social facets. Formal training at undergraduate level is variable and most of the time inadequate and fragmented (Scerri, 2010). In the main, the focus tends to be on the disease model, lacking particular attention on social issues that affect both the individual with dementia and the caregiver. There is also a lack of communication between the medical and social care curricula. Modules on dementia care do not form an integral part in training for doctors, nurses, allied health professionals and other health and social care staff. Although a number of faculties at the University of Malta already offer courses in dementia, the person-centred model of care is rarely adopted.

Training of healthcare professionals is limited, and not meeting the needs. Educational courses for healthcare professionals are infrequently organized by both the Department of Health and the Malta Dementia Society. In 2010, the Rehabilitation Hospital Karin Grech, in collaboration with Mater Dei Hospital and the Malta Dementia Society, organized a number of information sessions which were well-attended. Provided with adequate resources, this program could be extended to run on a regular basis for staff working in hospitals and care homes. In 2013, the first international conference on dementia was held in Malta to which over a hundred local delegates, mostly healthcare professionals, attended.

At community level, the Malta Dementia Society provides most of the informal training to individuals with dementia and their caregivers in order to help them cope with new challenges, maximize independent living,

enhance their quality of life and delay institutionalisation. Limited caregiver training is also carried out at the Rehabilitation Hospital Karin Grech as well as initiatives being undertaken in the private sector.

Feedback from the public questionnaire indicated that only 36 per cent of the overall respondents considered healthcare professionals as having the necessary skills in dementia management and care (Figure 5.1) (Scerri, 2012). This was also demonstrated in a number of research studies carried out locally in which various healthcare professionals categories were found to lack the necessary knowledge on various aspects of dementia diagnosis, management and care (Caruana-Pulpan and Scerri, 2014; Scerri, 2011; Scerri and Scerri, 2012; Zerafa, 2012).

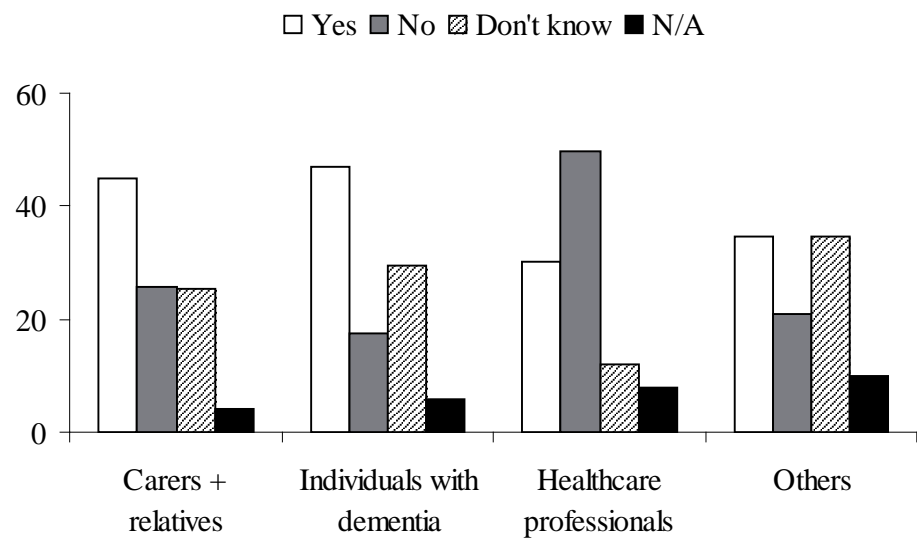


Figure 5.1. Percentage response (vertical axis) from different categories of the Maltese public, indicating whether healthcare professionals have the necessary skills in dementia management and care (N/A: not applicable) (Scerri, 2012)



5.3 STRATEGY OBJECTIVE

The main objective is to *deliver high-quality dementia care by a trained workforce* through:

- (i) ensuring that health and social care staff involved in the direct care and management of individuals with dementia and their caregivers have the necessary qualifications, skills, training and continuous professional development to provide and sustain high-quality dementia care
- (ii) recruitment of trained staff to work in the various areas of dementia management and care

5.4 OBJECTIVE DELIVERY

- a. In collaboration with the University of Malta and the Malta College of Arts, Science and Technology (MCAST), develop study units on the medical, social, psychological and economic aspects of dementia for students undergoing health and social care training programmes. An interdisciplinary team approach will be fostered and emphasised using appropriate teaching methodologies.
- b. Provide patient-centred dementia care training to all healthcare professionals caring for individuals with dementia. This will include continuous professional development programmes for skills updating.
- c. Provide a training programme for caregivers. This may form part of a yearly programme organised by professionals in the dementia field. Various aspects of dementia care including patient-caregiver relationship, stress management and communication will be included.
- d. Support accredited information technology platforms that facilitate online dementia training for healthcare professionals and caregivers.
- e. Provide training opportunities in the optimal delivery of palliative care to health and social care professionals working with individuals with dementia.
- f. Ensure that curricula at all levels of training are coherent in order to develop a well-trained multidisciplinary workforce.
- g. Ensure that all dementia training programmes delivered outside the University of Malta and the Malta College of Arts, Science and Technology (MCAST) (and other recognized institutions) are fully accredited and classified within the Malta Qualification Framework.
- h. Perform a 'need analysis' exercise in order to identify gaps in health/social care professionals both in terms of numbers as well as depth of dementia knowledge and expertise.

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6

IMPROVING DEMENTIA MANAGEMENT AND CARE

- 6.1 Pharmacological and non-pharmacological interventions
- 6.2 Healthcare services
- 6.3 Community care services
- 6.4 Long-term and palliative care
- 6.5 References





6.1 PHARMACOLOGICAL AND NON-PHARMACOLOGICAL INTERVENTIONS

6.1.1 PREAMBLE

Since there is no cure for the most common forms of dementia, the primary goal of pharmacotherapeutic interventions is to delay the progression of cognitive symptoms (Rabins and Black, 2007). Pharmacotherapy should be part of a holistic approach to dementia management that should encompass a well-established diagnosis, education of individuals with dementia, their caregivers and family members as well as various forms of support for both the patient and the caregiver.

Currently, the approved treatments for Alzheimer's disease (AD) consist of the acetylcholinesterase inhibitors (AChEIs) rivastigmine, donepezil and galantamine and the N-methyl-D-aspartate (NMDA) receptor antagonist, memantine, which have modest symptomatic but not curative effects (Atri et al., 2008). Rivastigmine capsules and solution are also indicated in the symptomatic treatment of mild-to-moderately severe dementia in patients with idiopathic Parkinson's disease (European Medicines Agency, 2012). According to the National Institute for Health and Clinical Excellence (2011a), AChEIs are recommended for mild-to-moderate AD whereas memantine is recommended for moderate-to-severe AD.

AChEIs have been shown to offer benefits to patients with AD in cognitive function, activities of daily living (ADL) and behaviour. Individuals with AD participating in short-term clinical trials and longer-term studies show transient improvement and stabilization or reduced deterioration on measures of cognition, behaviour and ADL (Birks, 2006). Memantine slowed the rate of cognitive and functional decline in patients with moderate-to-severe AD (Reisberg et al., 2006). Treatment benefits obtained may translate into an improved quality of life for the individual with dementia as well as reduced demands on caregiver time and delayed nursing home placement. Recent studies suggest that treatment with memantine and AChEIs combination therapy in moderate-to-severe

AD produces consistent benefits that appear to increase over time, and that are beyond those of AChEIs treatment alone (Gauthier and Molinuevo, 2013).

The National Institute of Health and Clinical Excellence (2011a) recommends that:

- a. AChEIs and memantine treatment is only initiated by specialists in the care of individuals with dementia.
- b. Treatment should be continued only when it is considered to be having a worthwhile effect on cognitive, global, functional or behavioural symptoms.
- c. Patients who continue on treatment should be reviewed regularly using cognitive, global, functional and behavioural assessment. Treatment should be reviewed by an appropriate specialist team, unless there are locally agreed protocols for shared care. Caregivers' views on the patient's condition at follow-up should be sought.
- d. AChEIs treatment should normally be started with the drug with the lowest acquisition cost. However, an alternative AChEI could be prescribed if it is considered appropriate when taking into account adverse event profile, expectations about adherence, medical comorbidity, possibility of drug interactions and dosing profile.

Behavioural and Psychological Symptoms of Dementia (BPSD) represent a heterogeneous group of non-cognitive symptoms and behaviours occurring in individuals with dementia (Cerejeira et al., 2012). The treatment of such symptoms has traditionally been led by institutional policies of control and containment, consisting of combinations of medication, environmental and mechanical restraints (Stokes, 2000). However, such approaches are increasingly being challenged both on ethical grounds and for their evidence base (Andrews, 2006). The use of antipsychotics may have serious negative side effects like extrapyramidal symptoms and increased risk of stroke (Mittal et al., 2011) and the use of restraints may result in decreased functional status and quality of life (Ballard

et al., 2009). Various studies have shown that staff education as well as psychological and psychosocial interventions may help in managing behavioural problems and reducing the use of antipsychotic medication (Zwijssen et al., 2011).

In recent years, non-pharmacological interventions in dementia (such as multisensory approaches, reminiscence therapy, music and art therapy, activity therapy and aromatherapy) have received increased attention. The advantages are that, compared to pharmacotherapeutic measures, they avoid potential side-effects, drug-drug interactions and masking of behavior that may serve as a signal for need. Taken as a whole, studies show evidence for small but consistent effects of such an approach in improving cognition in individuals with dementia and in reducing antipsychotic medication (Richter et al., 2012).



6.1.2 A CASE FOR CHANGE

In recent years, medicines and medical devices has been one of the fastest growing components of public health expenditure in the Maltese Islands. The government supplies medicines free of charge to all in-patients in government hospitals as well as to individuals listed as Schedule II patients (Pink Card holders) and Schedule V patients (Yellow Card holders). In the latter, free medicines are available to individuals with a chronic medical condition listed under the Fifth Schedule of the Social Security Act. In 2011, dementia was listed among these conditions and in November of 2012, donepezil was included in the Government Formulary List (Department of Health Circular 455/2012). This was in conjunction with the setting up of dementia clinics in the community intended to offer support to the already existing Memory Clinic at the Rehabilitation Hospital Karin Grech and the Cognitive Behavioural Disorders Clinic within the Neurology Department at Mater Dei Hospital. Although free donepezil entitlement is only authorized by consultant geriatricians, neurologists and psychiatrists in patients with a Mini Mental State Examination (MMSE) score ranging from 13-26, all treatment options are available as an out-of-pocket expense from community pharmacies following prescription by any registered medical doctor. To date, no protocol exists on the use of medication to control the BPSD experienced by the majority of these individuals even though such drugs have been associated with 1,600 additional deaths each year in the UK among individuals with dementia ((Department of Health (UK), 2009)). Furthermore, non-pharmacological interventions are rarely adopted.

6.1.3 STRATEGY OBJECTIVE

The main objective is to *provide the necessary pharmacological and non-pharmacological treatment to individuals with dementia to improve their symptomatic profile and the quality of life.*

6.1.4 OBJECTIVE DELIVERY

- a. Include all approved medications for the symptomatic treatment of Alzheimer's disease in the Government Formulary List as recommended by international evidence and following appropriate consultation with relevant stakeholders.
- b. Ensure that individuals with dementia on such medication are reviewed regularly (every six months) using cognitive screening measures such as the MMSE as well as other appropriate tools for global, functional and behavioural assessment.
- c. Promote emerging technologies that support self-independence of individuals with dementia.
- d. Ensure that the caregiver view on the patient's condition is sought.
- e. Develop educational interventions to assist caregivers and healthcare staff in the management of challenging behaviour.
- f. Regulate the use of antipsychotics in individuals with dementia, through policies whereby justification of starting antipsychotics needs to be clearly documented as well as regular follow up of individuals with dementia on antipsychotics to review the need for continuation of pharmacotherapy. Individuals with dementia, their caregivers as well as healthcare professionals (including general practitioners) need to be aware of the potential risks of treatment.
- g. Develop training opportunities (including continuing education programmes for general practitioners) in non-pharmacological approaches to dementia management and care.
- h. Establish research initiatives in non-pharmacological interventions aimed at cognitive stimulation and behavioural management.

6.2 HEALTHCARE SERVICES

6.2.1 PREAMBLE

In the Maltese Islands, a significant number of hospital beds are occupied by older adults with or without cognitive impairment. In most cases, general hospitals are not equipped to provide adequate care to individuals with dementia. Healthcare staff are not trained sufficiently and often do not have enough contact time to take care of individuals with dementia appropriately according to their special needs. Furthermore, there is an increase in morbidity and mortality for any physical illness treated in hospital and complicated by dementia. Length of stay is also prolonged for any physical illness combined with dementia. Poor uncoordinated hospital care contributes to increased rates of nursing home admissions (Leung and Todd, 2010).

Presently any medical firm at Mater Dei Hospital (MDH) may request review of individuals with dementia or other altered cognitive state depending on presentation, by a geriatrician, neurologist or psychiatrist. Individuals with symptoms suggestive of dementia are also seen at Psychiatric, Neurology or Medical out-patients at MDH, the Dementia Clinics in the community and the Memory Clinic or Geriatric Clinics at Rehabilitation Hospital Karin Grech (RHKG). The objective of the latter is to provide specialised hospital based services for the frail and ill older adults whose medical problems are complicated by functional and social factors and who need to be rehabilitated prior to continue living in the community. This rehabilitation hospital provides a range of services for individuals with dementia including:

Memory Clinic

The Memory Clinic is a specialised out-patient clinic for people aged 60 years and above, who have symptoms such as increasing forgetfulness and/or confusion that may possibly indicate the onset of dementia. The clinic is run by a team of professionals who carry out a thorough assessment of the patient's condition, functional status and living situation. If diagnosis of dementia is confirmed, further information about the condition including treatment options and support services will be provided.

General Geriatrics Clinic

Patients with a diagnosis of dementia are also attended to at the general geriatrics out-patient clinics at the RHKG since cognitive impairment commonly exists concurrently with other co-morbid illnesses in older people.

Dementia Rehabilitation Program

A Dementia Rehabilitation Program is currently being offered after the patient is assessed at the Memory Clinic. Further assessments are carried out by occupational therapists and speech language pathologists. Functional ability, cognitive, domestic, language and swallowing assessments are carried out according to need.

Memory Classes

Memory Classes take the form of parallel sessions both for the individual with dementia and for caregivers and relatives.

Geriatric Rehabilitation Wards

These rehabilitation wards located within RHKG offer inpatient care to persons including those with dementia following an acute hospital stay. In 2010, the average age of patients in these wards was 79.2 years and average length of stay was 40.5 days (Annual Reports of Government Departments, 2010).

St. Vincent de Paul Residence (SVPR) is the largest state-owned long-term care residence in the Maltese Islands providing a range of services, including medical and nursing care, physiotherapy and occupational therapy, dental and ophthalmic care, podology and speech therapy. Specifically designed wards (in Pope John Paul II block) with the aim of caring for individuals with dementia have recently been added. An Activity Centre (Paul Cuschieri Activity Centre) is also located on the grounds of SVPR acting as a specialized Day Centre for individuals with dementia and provides respite for caregivers and family members. This service was launched in July 2007 and provides an opportunity for participation and social interaction to SVPR residents and to individuals with dementia living in the community.

6.2.2 A CASE FOR CHANGE

Individuals with dementia often need help with basic functions such as feeding and may not be able to communicate their needs. All hospital staff coming in contact with individuals with dementia needs to be trained in order to provide the best possible quality care. Prolonged length of stay might be reduced when the social model of dementia care is applied. Acute hospitals should ensure that all people with suspected or known dementia using inpatient services are assessed by a liaison service that specialises in dementia management (National Institute for Health and Clinical Excellence, 2011b).

While services for individuals with dementia exist at the RHKG, additional specialist dementia services in the community are needed. According to international guidelines, memory assessment services (which may be provided by a memory assessment clinic or by community mental health teams) should be the single point of referral for all people with a possible diagnosis of dementia (National Institute for Health and Clinical Excellence, 2011b).

Feedback from the public questionnaire showed that only 21 per cent of individuals received initial dementia diagnosis at MDH (Figure 6.1). Although the Memory Clinic has been running for more than a decade, only 42 per cent of respondents comprising individuals with dementia, caregivers and relatives reported using this service (Figure 6.2). The Activity Centre at SVPR was utilized by only 22 per cent of individuals with dementia, their caregivers or relatives, with the unavailability of transport being the most cited motive (Figure 6.3). About 10 per cent of respondents indicated that they were unaware that an activity centre for individuals with dementia exists (Scerri, 2010).

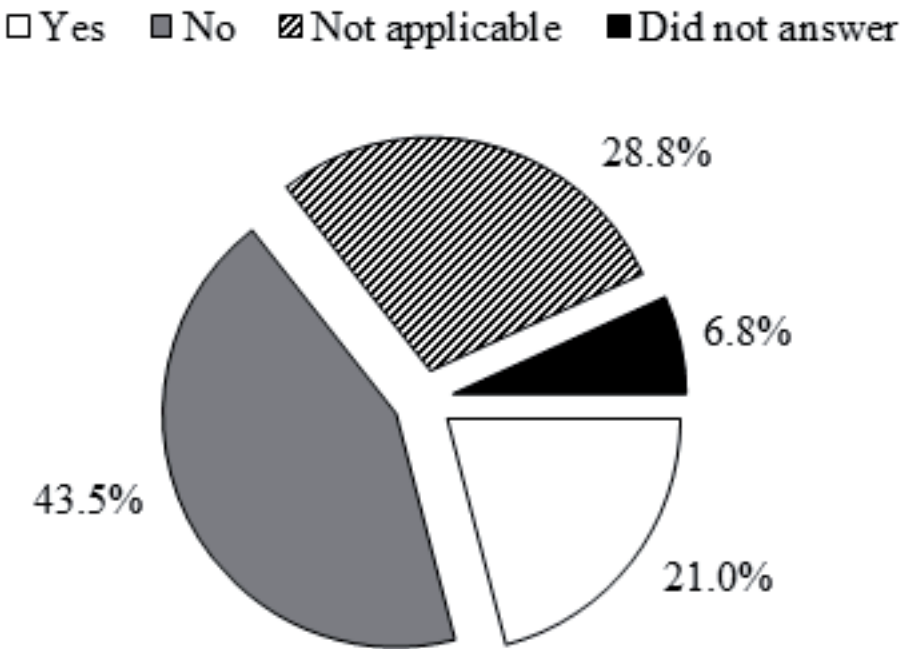


Figure 6.1. Percentage of respondents in the caregivers, relatives and individuals with dementia categories indicating attendance to Mater Dei Hospital as an out-patient for initial diagnosis of dementia (adapted from Scerri, 2010)

□ Yes ■ No ▨ Not applicable ■ Did not answer

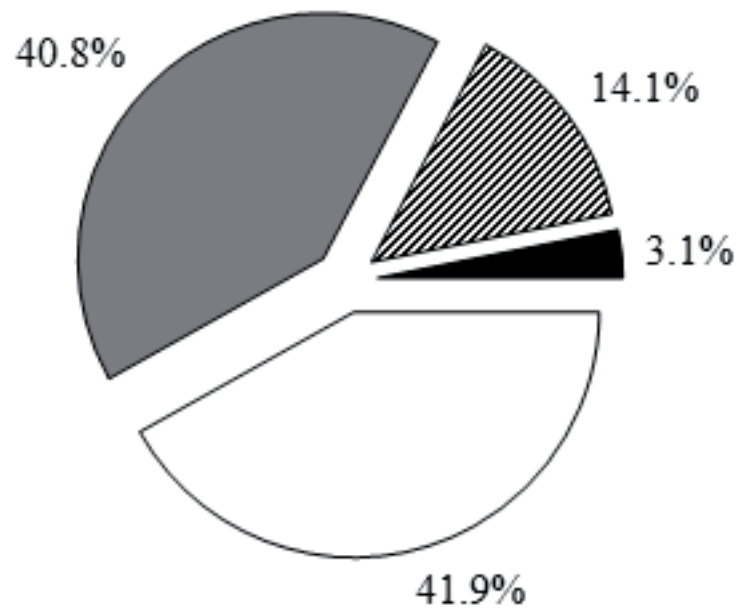


Figure 6.2. Percentage of respondents in the caregivers, relatives and individuals with dementia categories reporting the use of the Memory Clinic (adapted from Scerri, 2010)

□ Yes ■ No ▨ Never heard of it ▩ Not applicable ■ Did not answer

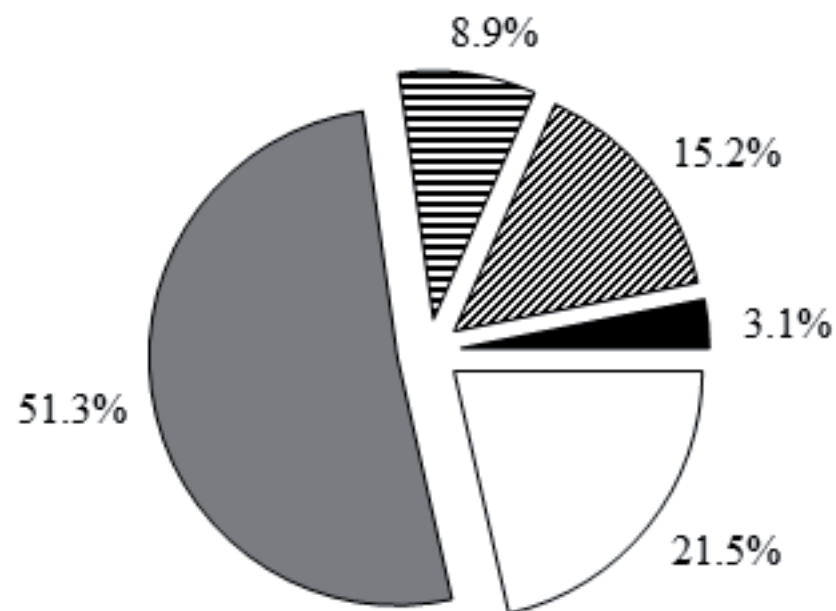


Figure 6.3. Percentage of respondents among in the caregivers, relatives and individuals with dementia categories reporting the use of the Activity Centre at St. Vincent de Paul Residence (adapted from Scerri, 2010)



6.2.3 STRATEGY OBJECTIVE

The main objective is to *provide high-quality healthcare services for individuals with dementia* through:

- (i) improving the delivery of care for individuals with dementia in all healthcare services
- (ii) develop a care pathway for each patient diagnosed with dementia
- (iii) ensure that specialist dementia services for assessing individuals with dementia are available
- (iv) strengthening and further developing the rehabilitation and other care services for individuals with dementia
- (v) ensure that healthcare services have the necessary standards of care including dementia-friendly environments according to international practices and guidelines

6.2.4 OBJECTIVE DELIVERY

- a. Provide training opportunities for healthcare professionals working in acute and long-term settings in order to provide the best quality care to individuals with dementia.
- b. Set up a liaison service that specialises in providing a rapid high-quality assessment of individuals presenting dementia symptoms in acute general hospitals. This service will work closely with the Dementia Intervention Team (see also Section 6.3.4).
- c. Ensure that all individuals with dementia have a care plan developed during their hospital stay after consultation with specialists in this field (and using the 'partners in care' approach). Individual care plans will address activities of daily living that maximise engagement in meaningful occupation, promote independent activity, enhance function, adapt and develop skills, and minimise the need for support.
- d. Offer rehabilitation services to people with mild-to-moderate dementia following a stay in acute hospital if there is a need for it. This service will seek to equip the patient to return to the community. Assessment of needs of caregivers will also be undertaken. Individuals with severe dementia may need more specialist services to meet their physical, psychological and mental health needs.
- e. Develop a series of recommendations that would enhance good quality patient-centred dementia management and care (including dementia-friendly design) in long-term nursing and residential care settings.
- f. Ensure that current and future edifices intended to accommodate senior adults adopt a dementia-friendly design.
- g. Strengthen human resource capacity of the Memory Classes.
- h. Remove any age limits for the access of all services for individuals with dementia and make sure that the needs of individuals with early onset dementia are met.

6.3 COMMUNITY CARE SERVICES

6.3.1 PREAMBLE

The majority of individuals with dementia in the Maltese Islands lives within the community and most are willing to continue doing so for as long as possible. This is of particular importance in a small country in which a significant number of older adults continue to live with the family. Providing the right support, individuals with dementia can remain active within the community, especially in the earlier stages of the condition. As the disease progresses, more services should be available both to the patient and the family caregivers thus delaying institutionalisation. Current and projected services should ensure that they are reliable, flexible and have a holistic approach in which decisions about dementia management and care are taken by healthcare professions, the patient and the family. Care in the community may also be enhanced by the use of new assistive technologies as there is evidence that the use of such technology enables individuals with dementia to remain independent for longer and increase safety (Buettner and Burgener, 2010).

Respite services have been seen as central to achieve care in the community and limiting the costs of long-term care (Social Care Institute for Excellence and National Institute for Health and Clinical Excellence, 2007). Various models of respite care and short breaks are available and can be used effectively (Report for the National Health Research Service Delivery and Organisation Programme, 2009). While respite aims to give the caregivers and family members a break, it is also essential that any form of respite care provides a positive meaningful experience to the individual with dementia. This continues to highlight the importance of having a trained workforce and will also encourage the use of such service. Respite provision needs to be flexible in order to meet the varied individual preferences.

There is evidence that with appropriate intervention and comprehensive caregiver support, institutionalisation is delayed. As family members and informal caregivers provide invaluable support to individuals with dementia, this

strategy should ensure that their needs are included in a holistic approach to dementia management and care. The individual with dementia as well as the family and caregiver needs to be viewed as a single unit requiring appropriate support. Care plans for caregivers should include a range of interventions according to individual needs and psychological support should be available in order to assist family members in coping with their situation. As caregivers often have to leave or reduce their gainful employment in order to take care of a relative with dementia, introducing flexi-time and teleworking may help the caregiver continue working. This is important both from a financial point of view as well as for respite purposes.

The development of integrated services with a single point of referral for persons with dementia and their caregivers and family members will help to provide the most appropriate support according to their needs. There is also the need for more care workers in the community adequately trained in dementia care to support both the individual with dementia and the caregivers.

The voluntary sector also plays an important role in providing assistance to individuals with dementia and their caregivers within the community. A study aimed at identifying the relationship between unmet needs, social networks and quality of life of patients living with dementia at home found that the most frequent unmet needs were daytime activities, company and help with psychological distress (Miranda-Castillo et al., 2010). Care of home-based individuals with dementia by trained part-time volunteers is seen as a future-oriented, easily accessible and financially affordable means of relieving the burden of dementia on family carers. Support networks such as those provided by local non-governmental organisations are also of significant benefit as they provide the right setting for advice seeking and knowledge sharing.

6.3.2 A CASE FOR CHANGE

Currently, most of the available support for individuals with dementia and their caregivers in the community is provided by the Malta Dementia Society and its Support Group which regularly organise talks and discussion groups about the various aspects of dementia care in the community. Such gatherings do not only provide factual information but also act as a platform in which caregivers' voice their concerns and share experiences. Of particular benefit are the outings that are routinely organized by the Malta Dementia Society Support Group (launched in 2013) in which individuals with dementia and their families meet in *Dementia Cafés*, a place for individuals with dementia, their partners, families and friends to meet up in an informal setting.

Experiences of dementia caregivers were recently explored in a study carried out in Malta using semi-structured interviews. The findings showed that, in most cases, female members of the family were entrusted with the delivery of the care to the individual with dementia. Rotating care among family members is sometimes described as another way with which families cope with the demands and obligations to provide care (Innes et al., 2011). Often caregivers do not have time for themselves, do not follow up their own health, have to stop work and become socially isolated. Currently, institutionally-based respite care is being offered at SVPR. Respite is also indirectly offered at the Day Centre located at SVPR. Unfortunately, it's too small a service to meet the demand and the nonavailability of transportation is a problem.

Feedback from the stakeholders' consultation process (Scerri, 2010)

indicated that respite care should be readily available, easy accessible and dementia-specific as this does not only reduce caregiver burnout but will delay institutionalisation of the individual with dementia. Furthermore, psychological support should also be available to assist family members in coping with continuous dementia care. Easily accessible community day care centres offering dementia-specific care and managed by a trained workforce should increase in number to meet current and future demands. Since dementia contributes to, and is exacerbated by, occupational deprivation, the concept of independent living and engagement in meaningful occupation (being self-care, productivity or leisure) will be emphasised.

Results from the consultative questionnaire (Scerri, 2010) showed that most respondents do not make use of community services offered by the government (mostly due to lack of knowledge) even though the majority consider care in the community (Figure 6.4) and respite care (Figure 6.5) as important.

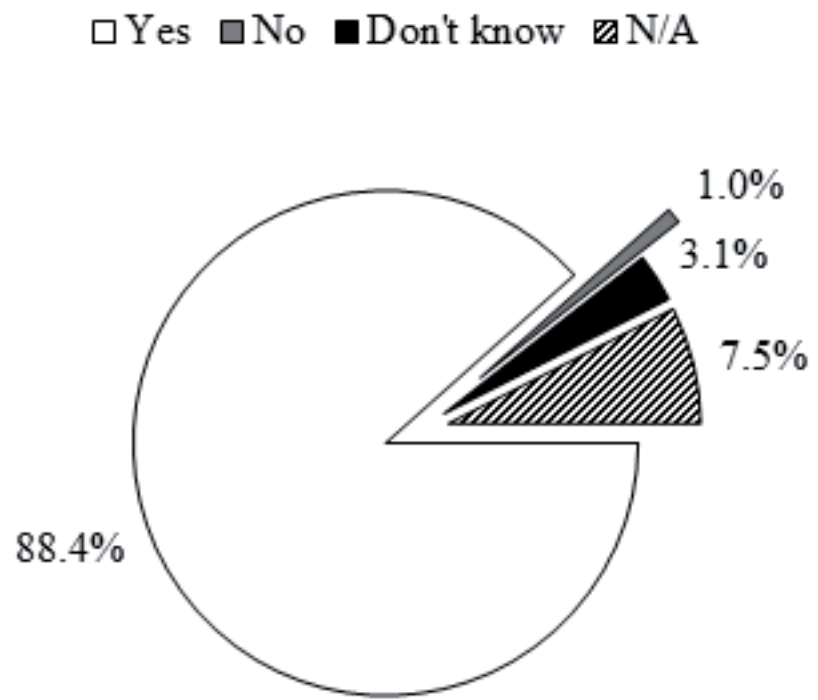


Figure 6.4. Percentage of respondents indicating the importance of community care (adapted from Scerri, 2010)

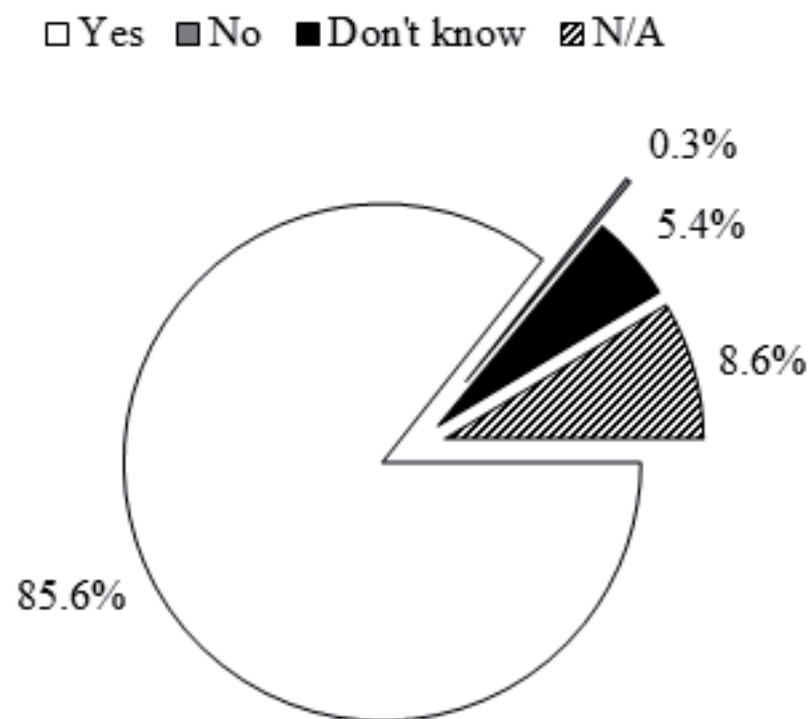


Figure 6.5. Percentage of respondents indicating the importance of respite care (adapted from Scerri, 2010)

Individuals with dementia, caregivers and relatives also indicated that services mostly needed in the community include home help, the availability of dementia-specific activity (day) centres and residential care (Figure 6.6). The results from the questionnaire also highlighted the significant financial impact that dementia care has on the family (Figure 6.7).

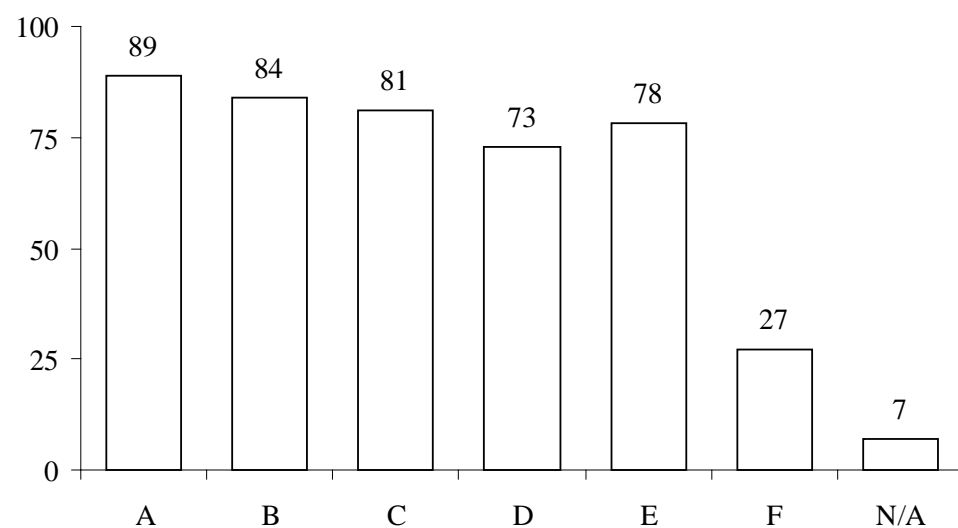


Figure 6.6. Percentage of participants (vertical axis) in the caregivers, relatives and individuals with dementia categories (actual values atop of the bars), indicating support services that need enhancing (A: home help, B: activity centres, C: residential care, D: local dementia societies, E: rehabilitation and respite care, F: others, N/A: no answer) (adapted from Scerri, 2010)

□ Yes ■ No ■ Don't know ▨ Not applicable ▩ N/A

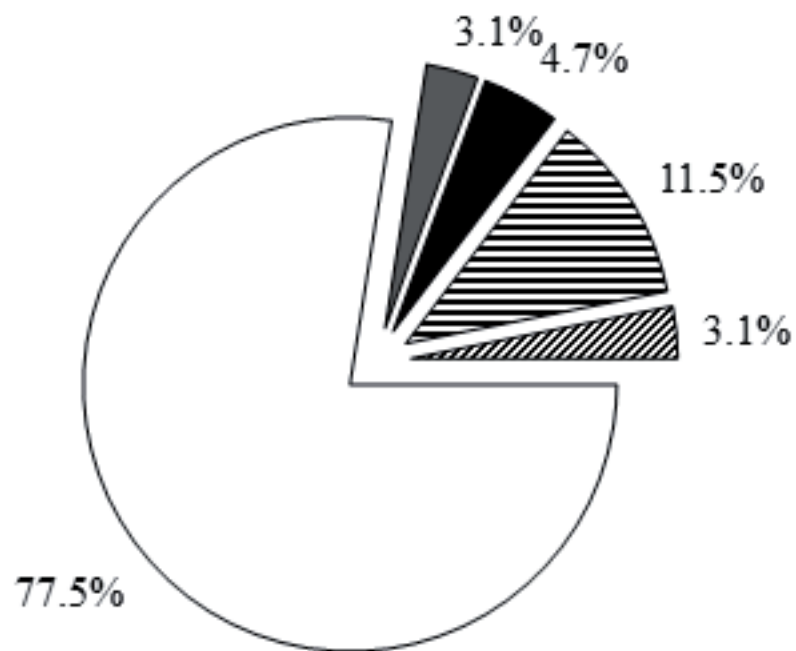


Figure 6.7. Percentage of participants indicating dementia as having a significant impact on family finances (adapted from Scerri, 2010)

6.3.3 STRATEGY OBJECTIVE

The main objective is to *develop community care services that meet the needs of individuals with dementia, their caregivers and family members* through:

- (i) providing easy access to a range of community services
- (ii) ensuring that dementia services strive to integrate individuals with dementia within the community
- (iii) providing the necessary support through a holistic approach with the aim of improving the quality of life

6.3.4 OBJECTIVE DELIVERY

- a. Increase in the number of Day Centres specialising in dementia management and care. Such service should to be managed by adequately trained staff.
- b. Extend the operating hours of the Day Centre at SVPR thereby increasing flexibility for individuals with dementia and their caregivers.
- c. Make appropriate transport service available for individuals with dementia making use of the Day Centres.
- d. Provide training to staff working in community Day Centres in order to be able to deal with behavioural and physical needs of individuals with dementia as well creating an activity program suitable for these patients.
- e. Develop a multi-disciplinary Dementia Intervention Team (coordinated by a Dementia Care Coordinator)

which will serve as a point of reference and community support for individuals with dementia, their caregivers and family members in order for the family to easily access services according to their needs. Services for dementia will be integrated and work together to provide a holistic package of care to persons with dementia and their families.

- f. Provide additional support to the Dementia Helpline as this serves as an important source of information and support to individuals with dementia and their caregivers.
- g. Provide outreach support programmes that include both specialised home help for individuals with dementia as well as respite service in the community. This will require training of a team of certified care-workers and coordinated by the Dementia Intervention Team. Different forms of respite care will become available to accommodate patients' needs.
- h. Increase the number of beds dedicated to institutional community respite for persons with dementia thereby increasing availability.
- i. Develop night-time shelters in a number of localities that specifically cater for individuals with dementia and their caregivers.
- j. Ensure that existing community services (and the development of new ones) housing individuals with dementia adequately cater for their needs. This includes trained staff and a dementia-friendly approach both in service delivery and design.
- k. Assist in the setting up a voluntary service for older adults in the community with the aim of providing companionship to individuals with dementia as well as the elderly in general and providing some respite to caregivers. This service can also be operated in collaboration with the private sector.
- l. Assist in the creation of a network to help individuals with dementia and their caregivers in having peer support. This may be achieved by boosting non-government organisations working in this field, possibly through service level agreements.

- m. Provide financial assistance to purchase/rent new assistive/information technology with the aim of increasing autonomy and quality of life.
- n. Provide financial assistance for infrastructural modifications that may be necessary within the patient's residence with the aim of enhancing safety and quality of life of the individual with dementia, their caregivers and family members.
- o. Provide support to caregivers to continue working whilst providing care. The caregiver pension should also reflect the specific and significant financial needs of dementia care.
- p. Community support services offered by the government should take into consideration the special needs of individuals with dementia and those who care for them in the community. This includes housing options.
- q. Develop a basic dementia training programme for first-contact community support personnel (local council workers, the police force, the army, transport staff, the church etc.) in order to better assist individuals with dementia in the community.
- r. Introduce the Dementia Caregiver Card in order to (i) facilitate caregivers of individuals with dementia to accompany their relative requiring the use of out-patient services at Mater Dei Hospital, and (ii) offer the possibility of extended visiting hours for caregivers of individuals with dementia staying at Mater Dei Hospital.

6.4 LONG-TERM AND PALLIATIVE CARE

6.4.1 PREAMBLE

6.4.1.1 LONG-TERM CARE

The best community and domiciliary services cannot, and should not, be expected to support all individuals with dementia at home indefinitely. However, the transition to a residential or nursing home setting may cause anxiety for both the individual with dementia and the caregiver. Clinical and psychological interventions that better prepare the patient and caregiver for a placement transition may be of great benefit to these individuals.

St. Vincent de Paul Residence (SVPR) is a long-stay residential care complex providing medical and nursing care as well as social and psychological support for older adults. During 2010 the John Paul II block was opened with its new dementia-friendly features, modern furniture and equipment, and specific dementia wards for both males and female residents. However the demand for residential beds is always increasing and there is a waiting time associated with admission to SVPR. Although a number other government homes provide long-stay care for older adults, these do not have specific dementia-friendly wards even though a number of services are provided for individuals with dementia including occupational therapy, speech therapy and physiotherapy.

A number of homes in the private sector cater for assisted living and nursing care. However few have specific units tailored for individuals with dementia. Some of these homes also offer respite and day care services. New initiatives within the private sector are also being developed that assist individuals with dementia in their daily lives including the provision of a safe environment, colour coding, signage and regular cognitive therapy sessions.

While there needs to be an increase in the number of beds in residential care which cater for individuals with dementia, homes for older adults which are already in place need to incorporate dementia-friendly measures and quality of care improvement through training of staff as well as implementation of services which assist individuals with dementia in their daily lives. The Directorate for Health Care Services Standards (DHCSS) who is responsible for the establishment and monitoring of standards in the primary, secondary and tertiary care sectors has continued to invest in close collaborative links with geriatricians to address the sensitive issue of dementia care and how standards will need to be applied (Annual Reports of Government Departments, 2010). A more qualitative approach to the assessment of care homes is needed and should include interviews with patients and their families to report their level of satisfaction with the care being provided. Consequently, legislation and policies are required that establish and safeguard standards of care for elderly homes with particular focus on those accommodating individuals with dementia.



6.4.1.2 PALLIATIVE CARE

As dementia progresses towards the later stages, its management should follow a palliative care approach (Lussier et al., 2011). The challenging features of palliative care for individuals with dementia are found in connection with the use of antibiotics, antipsychotics, and other medications, as well as in decisions about whether the person is in pain or in distress, or whether artificial feeding should be contemplated or not, and the use of advance care directives (Küpper and Hughes, 2011). Currently, individuals with dementia receive poorer end-of-life care than those who are cognitively intact in terms of provision of palliative care.

Dementia care should incorporate a palliative care approach from the time of diagnosis until death. The aim should be to support the quality of life of individuals with dementia and to enable them to die with dignity and in the place of their choosing, while also supporting caregivers during their bereavement, which may both anticipate and follow death (National Institute for Health and Clinical Excellence, 2011b). Specialised dementia hospice units tend to limit medical interventions, including both tube feeding and cardiopulmonary resuscitation, which inflict discomfort and do not provide unequivocal benefit. Such units make the control of symptoms a priority. Furthermore, liaison with professional dementia teams could assist formal and informal caregivers in the community as well as nursing homes and hospitals to provide adequate palliative care. This should be complemented with adequate training of professionals and caregivers involved.

6.4.2 A CASE FOR CHANGE

All across Europe there is a lack of palliative care services for individuals with dementia nearing the final stages of life. Although these services are offered to terminally-ill cancer patients, dementia patients are left out probably due to the fact that this condition is not perceived as incurable. It is therefore important that such services are available to end-stage dementia patients. Palliative care also preserves the dignity of the patient, thus maximizing the quality of life by providing the best level of comfort. It also offers a support system for family members of the

patient to cope with their own bereavement.

Feedback from stakeholders consultation exercise indicated a lack of residential homes that incorporate dementia-friendly measures and the need for such homes to be routinely assessed for their standards and quality of care, and level of staff training. Almost 40 per cent of respondents to the public questionnaire were concerned about end-of-life issues (Figure 6.8). Currently, no hospice care delivery exists locally for individuals with dementia and there is a lack of knowledge about this topic among individuals that are directly involved in dementia care.

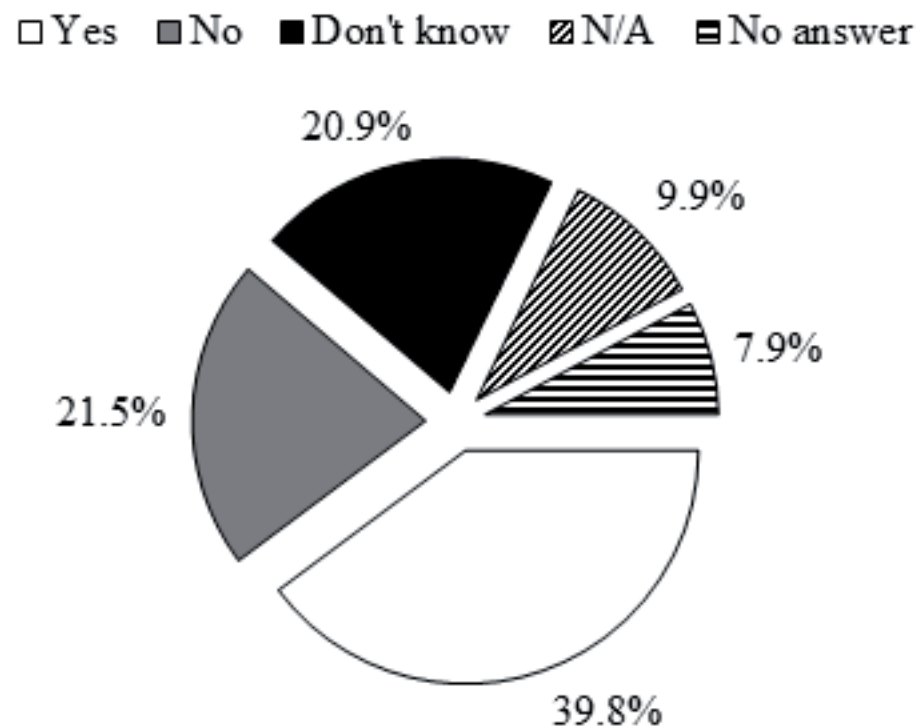


Figure 6.8. Percentage of respondents indicating their concern with end-of-life issues (including palliative care) (adapted from Scerri, 2010)



6.4.3 STRATEGY OBJECTIVE

The main objective is to *provide patient-centred dementia long-term and palliative care* through:

- (i) providing high quality care to individuals with dementia in residential and/or nursing homes
- (ii) adopting legislation on standards of care in homes accommodating older adults including those housing individuals with dementia
- (iii) adopting policies that limit the use of restraint
- (iv) implementation of dementia-friendly measures (including dementia-friendly design) in all elderly homes
- (v) providing end-of-life and palliative care and support to individuals with dementia, their caregivers and family members

6.4.4 OBJECTIVE DELIVERY

- a. Develop new long-term housing units for individuals with dementia. Homes managed by private entities should be encouraged to also provide specific dementia-friendly units.
- b. Adapt care/nursing homes for older people so as to provide a safe physical environment for patients with dementia. This should include a secure open space area (preferably a dementia-friendly garden).
- c. Develop programmes of purposeful and therapeutic activities that keep the individual with dementia active and engaged in meaningful occupation. This can be developed in collaboration with the Active Ageing Unit and in accordance with the recently launched National Strategic Policy for Active Ageing.
- d. Provide training to personnel as well as increasing the number of recruited and retained staff in order to provide high quality dementia care.
- e. Provide palliative and end-of-life care to individuals with advanced stage dementia, including having adequate pain relief as well as psychological support to caregivers and family members.
- f. Devise a number of recommendations for pain assessment in nonverbal individuals with dementia who are unable to self-report.
- g. Ensure that government and privately run care and nursing homes accommodating individuals with dementia have the necessary quality standards and managed by staff adequately trained in dementia management and care. Regular monitoring ensures that such standards are kept and dementia-friendly measures incorporated. A team of experts in various aspects of dementia management and care should act as a consultative entity to the monitoring process.



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7

ETHICAL APPROACH TO DEMENTIA MANAGEMENT AND CARE

- 7.1 Preamble
- 7.2 Strategy objective
- 7.3 Objective delivery
- 7.4 References





7.1 PREAMBLE

Individuals with dementia, and those who care for them, face difficult ethical decisions in all stages of the disease process (Nuffield Council on Bioethics, 2009). It starts from the stigma associated with the diagnosis of dementia, to the quality of care provided in residential and nursing establishments, the availability of support services available in the community, and the later stages of the disease when the individual becomes totally dependent on formal and informal care.

An individual with dementia continues to be a person of worth and dignity, and deserves the same respect as any other human being (Alzheimer's Disease International, 2008). Informing patients with dementia of their diagnosis is difficult and is fraught with ethical concerns. Only the minority of physicians disclose dementia diagnosis to their patients (Caruana-Pulpan and Scerri, 2014). Furthermore, family members often ask physicians not to inform the patient about the diagnosis or else use vague terminology (Phillips et al., 2012). However, individuals with dementia should have the opportunity to make informed decisions about their care and treatment in partnership with their health and social care professionals (National Institute for Health and Clinical Excellence, 2011). Health and social care professionals should always seek valid consent from individuals with dementia. This should entail informing the individual of options, checking whether the individual understands, that there is no coercion and that he or she continues to consent over time (National Institute for Health and Clinical Excellence, 2011). As dementia progresses, decisions will need to be taken more by the caregiver and family members on behalf of the patient. The availability of advanced care directives in the setting of late stages of dementia (as highlighted in Chapter 4) helps in ensuring that decision taking respects the communicated wishes of the patient.

Individuals with dementia may be subjected to a greater risk of physical abuse than individuals without cognitive impairment. Abuse can also be psychological, financial, sexual, or by neglect (Cooper et al., 2009). In addition, due to the presence of behavioural and psychological symptoms, individuals with dementia can direct verbal or physical abuse toward those who care for them. Any policy for safeguarding vulnerable adults must consider

strategies directed towards families who provide the majority of care for senior adults, rather than exclusively formal caregivers. Challenging behavior negatively affects caregivers, increases financial burden, and may have negative consequences for individuals with dementia themselves including institutionalisation, injuries to self and others, and decreased quality of care through the use of physical and chemical restraint (Kunik et al., 2010). Studies show that quality of life for individuals with dementia was better in care facilities that used a specialised staff approach, trained more staff in domains central to dementia care, and encouraged activity participation. Better resident-staff communication was related to higher quality of life as observed and reported by care providers (Zimmerman et al., 2013).

As dementia progresses, there is increased dependency on others due to impairment of memory, confusion, problems with speech and understanding, and changes in personality and/or behavioural disorders. Currently there is no specific legislation in Malta offering legal protection to individuals with dementia. The definition of mental disorder within the Malta Mental Health Act (2012) does not apply in all cases and levels of dementia. The Commissioner for Mental Health recognizes that there is a gap in the available legislation and his Office has initiated a reflection debate involving various stakeholders as to whether the need for protection in individuals with dementia could be better safeguarded through generic mental capacity legislation (personal communication).



7.2 STRATEGY OBJECTIVE

The main objective is to *promote an ethical approach to dementia management and care* through:

- (i) ensuring an ethical approach in caring for individuals with dementia
- (ii) ensuring that the necessary structures are in place to safeguard individuals with dementia, their caregivers and family members

7.3 OBJECTIVE DELIVERY

- a. Provide access to appropriate education and support in ethical decision making to those directly involved in caring for individuals with dementia.
- b. Provide access to appropriate training programmes to healthcare professionals in dementia disclosure, respect for personhood and wellbeing. A 'partners in care' approach would also be encouraged.
- c. Provide individuals with dementia with the necessary psychological support needed in making important decisions regarding their health and welfare as well as dealing with financial and legal issues at an early stage of dementia.
- d. Develop a working partnership, in collaboration with non-governmental organisations and other stakeholders operating in the field, to assess and address abuse in individuals with dementia, their caregivers and family members. This should lead to a number of recommendations with the aim of eliminating such abuse.

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8

RESEARCH

- 8.1 Preamble
- 8.2 A case for change
- 8.3 Strategy objective
- 8.4 Objective delivery
- 8.5 References



8.1 PREAMBLE

In order to face the ever increasing challenges posed by dementia, more funding for research in this area needs to be committed. Research is not only necessary in finding ways of developing new treatment options but is also important in discovering innovative methods of improving management and care for individuals with dementia, their caregivers and family members. Research is thus required to address the obstacles to the timely recognition of dementia syndromes in primary care, the support for people with dementia and their families following diagnosis, caregiver strain, what factors predict the transfer of individuals with dementia to institutional care, interventions to manage challenging behaviour and the therapeutic options available to clinicians which are currently and insufficiently evaluated (Iliffe et al., 2011).

Currently, global research in Alzheimer's disease and other dementias only receives minimal funding compared to other disorders, even though the change in the number of deaths due to Alzheimer's disease between the year 2000 and 2010 increased by 68 per cent (US data: Alzheimer Association, 2014). In December 2013, during the G8 summit on dementia, participating countries agreed on the need to significantly increase the amount devoted on dementia research, develop an international action plan for research and encourage information sharing ((Department of Health (UK), 2013)).

8.2 A CASE FOR CHANGE

The proportion of individuals aged 65 years and over in the Maltese Islands is expected to increase significantly in the coming decades reaching 31.2 per cent by the year 2060 (European Commission, 2012). Senior adults aged 75 years and older, the majority of whom live in the community, constitute a segment of the population that is vulnerable to loss of autonomy. Indeed, many community dwelling older adults have difficulty performing activities of daily living autonomously. The extent of unmet need, or the extent to which needed assistance is unavailable or insufficient, is an important issue in public policy and financing of health and support services. Furthermore, there is a dearth of data on the cognitive status of older adults within healthcare settings and residential care. Thus, a strategy on dementia cannot be complete without incorporating the findings of the Needs Assessment of the Elderly in Malta ((Department of Health (Malta), 2012a)). This will ensure a more coordinated and consistent way of assessing, planning and delivering services. This will help policy makers in identify gaps for which policies can then be tailored in an attempt to address the needs of cognitively impaired adults. Research initiatives would also be needed to study innovative ways with which the measures included in this strategy document will be effectively monitored and implemented.

Currently, the University of Malta is the main establishment where research on various aspects of dementia is carried out, mostly on an individual basis and as part of undergraduate or postgraduate training programmes. In the last few years, data on dementia prevalence rates (Abela et al., 2007; Scerri and Scerri, 2012a), organisation of dementia care by families (Innes et al., 2011), pharmacotherapeutic aspects of dementia care (Scerri et al., 2010), and undergraduate and practicing healthcare professionals' knowledge of dementia (Caruana-Pulpan and Scerri, 2014; Scerri and Scerri, 2012b) were published. Funding for such research is minimal and mostly takes the form of annual research grants. In 2013, the Alzheimer's disease Research Group (ADRG) was launched by the University of Malta (Department of Pathology) with the aim of promoting and facilitating research and scientific collaboration in the diverse disciplines in Alzheimer's disease and related dementias (Scerri et al., 2013).

Dementia is a disease that fulfills most of the parameters proposed by the Centres for Disease Control and Prevention in order to assess the importance and need for an epidemiological surveillance system in terms of public health: frequency and severity, differences and dissimilarities amongst population groups, high cost, potential of primary and secondary prevention, and public interest (Centers for Disease Control and Prevention, 2001). Epidemiological research and surveillance is an essential instrument for planning, managing and distributing community health resources, for following up the natural history of chronic diseases and for assessing the impact of prevention programmes. The creation of a population-based dementia register provides the necessary information about various aspects of the impact of dementia on the healthcare system through information gathering concerning incidence and prevalence rates of dementia, usage of resources, patterns of detection, referral, diagnosis and treatment. This information would pilot current and future planning and allocation of health and social care funds and for outcome evaluation.

With the aim of instituting a dementia registry in Malta, the Department of Health, through the publication of DH Circular 455/2012, instructed consultant geriatricians, neurologists and psychiatrists to complete a Dementia Register Form (D1) for individuals prescribed anti-dementia medication included in the Government Formulary List. A different Dementia Register Form (D2) would need to be completed by the consultant physician for individuals not applying for medication ((Department of Health (Malta), 2012b)).

8.3 STRATEGY OBJECTIVE

The main objective is to *promote and foster research in the field of dementia*

8.4 OBJECTIVE DELIVERY

- a. Promote and support epidemiological research in the field of dementia management and care in different care settings. An inclusive model of research involving the individual with dementia, their caregiver and family members should be sought.
- b. In collaboration with the Active Ageing Unit, design and carry out research to assess the unmet needs of community dwelling older adults with dementia, their caregivers and family members.
- c. Collaborate with the University of Malta and other research based local entities (including the Malta Council for Science and Technology) to give dementia priority in the research field.
- d. Facilitate access for individuals with dementia to participate in clinical trials when and if available.
- e. Through an identified group of multidisciplinary experts in dementia, keep abreast with evolving evidence to inform practice.
- f. Increase involvement and participation in EU projects related to dementia research.

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9

STRATEGY IMPLEMENTATION AND DELIVERY

- 9.1 Preamble
- 9.2 Strategy objective
- 9.3 National Dementia Strategy Implementation Board





9.1 PREAMBLE

Implementation of the National Strategy for Dementia is scheduled to start in 2015 and run till 2023. Due to the challenging nature of dementia, this exercise entails substantial investment in human, financial, technical and infrastructural resources. However, the delivery of the objectives laid down in this document is projected to have a considerable positive impact on the quality of life of individuals with dementia, their family members and caregivers. The latter are carrying an enormous burden and thus require more solidarity from the government and society in general. Implementation of the measures set out in the strategy aims to create a system whereby all individuals with dementia have access to the care and support they require.

The objectives laid down in the strategy will need the extension of a trained workforce in order to deliver new and improved services. It will also require joint planning and working between health and social care staff, policy makers, individuals with dementia, their families and caregivers. Continuous assessment of the outcomes, including real-life experiences of individuals with dementia, will ensure that the objectives set out in this document are met. Assessment should also seek the views of caregivers and healthcare staff. Since important gender differences exist across various aspects of dementia, with women mostly affected both in prevalence and caregiving, the implementation strategy will also strive to provide a gender dimension in its objectives and deliverables.

During the implementation process, a number of gaps may become apparent. Interim evaluations are thus necessary to gather new information and assess the usefulness of different projects being proposed in the various areas of dementia care. This will aid in further detailed planning of long-term objectives. Moreover, implementation of the outlined objectives is expected to reveal other important needs that will require assessment and further plans to adequately address them. A national team will be needed to coordinate and oversee the implementation process. Individuals with dementia, their family members, caregivers and policy makers all expect to see progress in a cost-effective way. It is therefore important that the whole implementation exercise is regularly communicated to the general public in an efficient and comprehensible manner.

Implementation of the National Strategy for Dementia will be a staged process. Currently, the majority of individuals with dementia lives in the community and in need of tailored services delivered by health and social care staff adequately skilled in dementia management and care. Urgent priorities include increase in awareness and workforce development. The latter will be expected to have a positive spill-over effect on timely diagnosis. Core-training to non-professional staff in dementia care should ensure a better quality of life for individuals with dementia in residential care. The introduction of the remaining pharmacological interventions onto the Government Formulary List should also be considered at this stage. Medium and long-term actions would include the strengthening of undergraduate curricula reflecting a multidisciplinary approach, gradual implementation of non-pharmacological interventions, strengthening long-term and palliative care, adoption of dementia-friendly measures, strengthening dementia research and the gradual adoption of an ethical approach to dementia care. These actions would also need to be well documented through both qualitative and quantitative measures via the commissioning of appropriate research to elucidate and gain the required knowledge to evaluate and enable ongoing projects.

9.2 STRATEGY OBJECTIVE

The main objective is to *implement the National Strategy for Dementia (2015-2023)*

9.3 NATIONAL DEMENTIA STRATEGY IMPLEMENTATION BOARD

A National Dementia Strategy Implementation Board with the objective of planning and steering the implementation of the strategy will be set up. Its terms of reference will include:

- a. Coordination of the implementation process by assessing priorities and determine a plan of action, timeframes and key players.
- b. Ensure that the actions laid down in the various chapters of this document are carried out effectively and in a timely fashion.
- c. Ensure that individuals living with dementia and their caregivers and family members are directly involved during the various stages of the implementation process.
- d. Monitor performance and achievements to ensure that the needs of individuals with dementia, their caregivers and family members are effectively met.
- e. Monitor the expenditure from a budget allocated to the implementation of the strategy.

The National Dementia Strategy Implementation Board will work on behalf of the Parliamentary Secretariat for the Rights of Persons with Disability and Active Ageing and in collaboration with other governmental entities. Due to the complex and diverse nature of dementia, representatives from other ministries (including those of Health, Family and Social Solidarity, and Education) together with other relevant stakeholders should be part of this Board.



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Empowering Change – a National Strategy for Dementia in the Maltese Islands 2015-2023



PARLIAMENTARY SECRETARIAT
FOR RIGHTS OF PERSONS WITH DISABILITY
AND ACTIVE AGEING
PALAZZO FERRERIA, REPUBLIC STREET, VALLETTA, MALTA