

The travails of dementia policy development in a small island state: perspectives from Malta

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Abstract

Malta, the smallest country in the European Union, is experiencing a demographic transition where the share of individuals aged 65-plus currently makes up 16.3% of the total population. This figure is projected to reach 31.2% by 2060. While the opportunity to grow older indicates social success, it creates important challenges at both the personal and political economy levels. As a result of this increase in the number of older persons, age-related neurodegenerative disorders, including the most common forms of dementia, are expected to rise proportionately. This will pose significant societal demands as most dementia care is provided informally by family members living in the community. Furthermore, recent studies have shown that there is considerable lack of awareness and professional training that is seriously undermining timely diagnosis and management. As a result, Malta opted to take a holistic approach towards dementia care by recently launching a long-term strategy focusing on increasing awareness, providing the best services leading to high quality dementia care, and fostering dementia training to healthcare professionals in order to be better equipped to support individuals with dementia. It is a vision that promotes excellence, and effectively reflects the current and future needs of these individuals, their relatives and caregivers.

Introduction

Dementia is a group of brain disorders characterized by progressive deterioration of cognitive function. It is the most common neurological disorder in old age and a major predictor of morbidity and mortality in the elderly. The most common form of dementia is Alzheimer's disease (AD). Other types include vascular dementia, dementia with Lewy bodies, fronto-temporal dementia and dementia secondary to disease [1].

Dementia affects individuals in different ways depending on the type and stage of disease progression [2]. Early-stage dementia is often missed or misdiagnosed due to lack of awareness that often leads to the belief that the observed symptoms are a direct consequence 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 subsequent stages, 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 [2]. The amount of informal caring for an individual with dementia is also related to the severity of the condition with half of the caregivers spending more than ten hours a day in caring for an individual with late-stage dementia compared to 20% for early-stage dementia [3]. For most progressive dementias, no cure exists that stops or reverses the observed brain cell death. Treatments available to date are mostly approved for AD and are intended to delay the decline in cognitive symptoms for a limited amount of time [4]. Treatment for the common changes in behaviour depends on the presenting symptoms which vary from one individual to another. These are usually the most challenging and distressing characteristic of the disease process and include agitation, anxiety, verbal and nonverbal aggression, hallucinations, delusions and sleep disturbances [5].

According to Alzheimer's Disease International, the total number of people with dementia worldwide is projected to almost double every twenty years reaching 75.6 million in 2030 and 135.5 million in 2050 [6]. Much of this increase is attributed to low- and middle-income countries, and driven by population growth and demographic ageing [7]. The global societal costs of dementia are enormous as the total estimated worldwide expenditure for the year 2010 was calculated to reach US\$604 billion, equivalent to 1% of the world's gross domestic product [8]. The cost of care provided by families (informal care) together with societal care (care provided by professional personnel in home

settings) contribute to 42% of the costs worldwide, while direct medical care accounts to 16% of the overall costs. Interestingly, low-income countries account to around 1% of the global dementia costs whereas high-income countries account to 89% [8].

In the recent years, the European Union (EU) has devoted particular attention to the medical, social and financial aspects of dementia. Research on neurodegenerative disorders has been strengthened as part of the Health Theme within FP7 (2007-2013) with special reference to brain research and particular emphasis placed on translational research and the development of new drugs. The Public Health Programme also supported the European Collaboration on Dementia (EuroCoDe) project coordinated by Alzheimer Europe in order to achieve a comprehensive overview of the present situation in terms of prevalence, diagnosis, treatment, and socio-economic costs of AD in EU-member states. Results from this project indicated that 7.3 million individuals live with dementia in the European Union [9]. In January 2011, the European Parliament adopted a resolution calling for dementia to be made an EU health priority and urging member states to develop dedicated national plans and strategies with the aim of addressing the social and health consequences, as well as services and support for affected individuals and their family members. Taking action against dementia through various intervention streams such as strengthening capacity, leadership, governance, risk reduction, public awareness and facilitating technological and social innovations was one of the main recommendations put forward by the World Health Organization (WHO) in its first Ministerial Conference on Global Action Against Dementia organized at the beginning of 2015. The latter was an aftermath of the progress made since the 2013 G8 Dementia Summit which called WHO and the Organization for Economic Co-operation and Development (OECD) to identify dementia as an increasing threat to global health and support countries to strengthen health and social care systems to improve care and services for people with dementia.

As a consequence of the need to address the challenge of dementia, Malta embarked on a nationwide consultation process, starting in 2009, with the aim of developing a holistic approach towards dementia care through a policy document that focuses on a number of intervention streams including an increase in awareness and understanding of dementia, workforce development, providing the best services leading to high quality dementia care, and fostering dementia training to healthcare professionals in order to be better equipped to support individuals with dementia. The policy document was published and officially launched at the beginning of April 2015 making Malta the 21st country to have a national dementia plan worldwide.

Malta: demography and healthcare system

The Maltese archipelago (315 km²) consists of three main islands: Malta, Gozo and Comino. It is located in the centre of the Mediterranean Sea with Sicily 93 km to the north and northern Africa 288 km to the south. The latest available data show that the total population of Malta in 2013 was estimated at 425,384 of which just over half were females [10].

Malta scores high on the Human Development Index with a life expectancy of 79.2 years for males and 83.6 years for females (Table 1). Circulatory diseases are the leading cause of death accounting to 40% of all deaths followed by 27% for neoplasms [10]. Diabetes is highly prevalent in Malta, a pattern shared with other Mediterranean countries.

Health care in Malta is provided through two systems: statutory and private. Health care in the public sector is highly centralized and regulated. The government delivers primary health care through a number of health centres that offer a full range of preventive, curative and rehabilitative services. In secondary and tertiary care, specialized ambulatory care is provided in public outpatient clinics and health centres. The ministry responsible for health finances, regulates and acts as service provider for public hospitals. A number of private hospitals are also available. In 2013, there were 422 physicians, 741 nurses and midwives, and 245 pharmacists per 100,000 population [10].

In the recent years, medicines and medical devices have been the fastest-growing component of public health care expenditure in Malta, the latter totaling 8.6% of the national gross domestic product in 2010. This is mostly due to ever-increasing medical care needs and the advent of new generations of drugs and products. The government supplies medicines listed in the hospital drug formulary free of charge to all in-patients in public hospitals. Other individuals entitled to free medication include pink and yellow card holders. Pink card holders (also referred to as Schedule II patients) benefit under the Medical Aids Grant of the Malta Social Security Act and entitlement is based on the total household income. Yellow card holders (also referred to as Schedule V patients) are individuals with a specific chronic condition listed in the Fifth Schedule of the Social Security Act. Dementia was included as one of the conditions in this list in 2012 with the subsequent introduction of the acetylcholinesterase inhibitor donepezil in the drug formulary.

Table 1. Life expectancy (LE), healthy life expectancy (HLE) and years lived with disability (YD) at birth based on mortality in Malta in 2005 and 2010 according to gender. Adapted from [11]

		LE	HLE	YD
Men	2005	77.2	68.6	8.6
	2010	79.2	70.2	9.0
Women	2005	81.4	70.4	11.0
	2010	83.6	71.6	12.0

Malta: an ageing population

Current projections indicate that Malta will be one of the fastest ageing countries in the European Union. The Economic Policy Commission's Ageing Report 2012 shows that the economic repercussions of this increase are also intensifying due to the interplay of longevity and shrinking of the labour force [12]. The effective economic age-dependency ratio in Malta is projected to increase by 47% from 2010 to 2060, reaching 85%. The share of the population aged 65-plus in Malta is set to increase by 16.1% between 2010 and 2060, to reach 31.2%. The share of the population aged 80-plus population in relation to the population aged 15-64 will increase by 7.9%. This will result in an increase of the old-age dependency ratio from 24.1% in 2010 to 60.9% in 2060 [12].

The healthy life expectancy, based on mortality and morbidity combined data, shows an increase of 0.7 years for Maltese men aged 65 between 2005 and 2010. During the same period, an increase in healthy life expectancy of 0.9 years was observed for Maltese women at the age of 65, which in 2010 stood at 71.6 years and was the highest healthy life expectancy of women at birth in the EU. Healthy life expectancy of the Maltese men is ranked second highest. In 2011 healthy life expectancy at birth of women and men stood at 70.7 years and 70.3 years respectively, while its analogue at the age of 65 stood at 11 years for women and 11.8 years for men. This means that those men, who survive till the age of 65, have actually more healthy years of life than women at the age of 65. Considering men's overall shorter expectation of life, this makes a significant relative impact [11].

The United Nations probabilistic population projections, the 2010 revision based on the probabilistic projections of total fertility and life expectancy at birth, provide a range of values for the Maltese population between 2010 and 2060 [13]. From the data, it looks evident that there is much less uncertainty in the 65-plus projections where the absolute gap is less wide. This is due to the high life expectancy levels already achieved and no influence of fertility changes in these projected cohorts [11]. While the population aged 65-plus is projected to grow, the total population is declining rapidly from 2030 onwards. This results in an increase in the share of persons aged 65-plus in the total population, which reaches 37% in 2060. This is of particular significance in dementia where increased age is the most important non-modifiable risk factor.

Dementia in Malta

The first study to determine the prevalence rates of dementia in the Maltese Islands was published in 2007 [14]. Using the European Community Concerted Action on the Epidemiology and Prevention of Dementia (EURODEM) data methodology, it reported that in 2050, the number of individuals with dementia would reach 6,369, accounting to 2% of the Maltese population. This data was revised in another study published in 2012 [15] using the latest prevalence rates as reviewed by the EuroCoDe project (Table 2). The results showed that the estimated number of individuals with dementia in the Maltese Islands in 2010 was 5,198; a significant increase from the previous predicted data. Likewise, the number of dementia individuals over the age 60 in 2030 is projected to be close to 10,000 or 2.3% of the total population. Thus the 2% estimate will be reached in 2025, twenty-five years prior to what was previously reported. This discrepancy between the two prevalence set of data originates mostly from the oldest-old age groups, the latter being underreported in previous estimation studies. The significant increase reaching 3.6% of the Maltese population over the next fifty years will invariably put greater demands on the already stretched national health care services resulting in considerable socioeconomic consequences.

Table 2. *Estimated number of gender-specific dementia cases in the Maltese Islands according to age groups using EuroCoDe data for the years ranging from 2010 to 2060. Data shown as M/F (M: males; F: females)*

Age groups	Year						
	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	1154/1681	946/1380	1306/1784
>85	483/1399	619/1812	750/2248	1164/3021	2012/4806	2337/5400	2356/5368
Total IWD	5198	6071	7175	9881	12372	12957	14037
% of the population	1.24	1.47	1.73	2.37	3.04	3.26	3.62

State-run services for individuals with dementia and their caregivers are limited and currently not meeting the demands of the ever increasing number of diagnosed dementia cases. There are only two specially designed dementia wards, both manned by healthcare staff specifically trained in person-centred dementia care. Located within the premises of the largest long-term residential care facility in Malta is the dementia activity centre which was launched in 2007 and provides an opportunity of social interaction for residents and non-residents with dementia. Rehabilitation services, a Memory Clinic, respite care and a Dementia Helpline are also offered by staff comprising interdisciplinary healthcare professionals. With few exceptions, none of the privately owned residential homes are dedicated to solely cater for the needs of individuals with dementia. In late 2012, in conjunction with the introduction of donepezil in the government formulary list, there was the setting up of dementia clinics in the community intended to offer support to the already existing Memory Clinic and the Cognitive Behavioural Disorders Clinic within the Neurology Department. Although free drug entitlement is only authorized by consultant geriatricians, neurologists and psychiatrists in patients with a Mini Mental State Examination score ranging from 13-26, all treatment options are available as an out-of-pocket expense from community pharmacies following prescription by any medical practitioner. To date, no protocol exists on the use of medication to control the behavioural and psychological symptoms of dementia (BPSD) experienced by the majority of these individuals. Interestingly, these drugs are rarely used in Malta among in-patients with dementia [16].

Dementia awareness and support in the community mostly comes from the Malta Dementia Society. This non-governmental, non-profit organization was launched in 2004 with the aim of increasing awareness on dementia care and management in the Maltese Islands through the organization of talks and seminars for individuals with dementia, their caregivers and healthcare professionals. Another important aim of the society is that of collaborating with the central health and social care authorities to improve and design new services that enhance the quality of life of individuals with dementia. As previously highlighted, most of the dementia care is provided by family members in the community. A study on the organization of dementia care in the Maltese Islands found significant difficulties in providing care for a relative with dementia [17]. Of particular interest is the fact that families have developed a rotating care pattern to accommodate individual family member's social and working life while still maintaining responsibility. Caregivers views of formal services were dismissive as to their lack of suitability for their or relatives' needs. This research continues to emphasize the need of expanding support services for people with dementia and their carers in the community.

Dementia policy development in Malta

Given the huge burden of dementia, the challenges facing governments worldwide are considerable. In these last few years, there has been an increase in recognizing the extent of this problem and the need to take action. Apart from Malta, only a few countries have dementia plans and policies in action that address the key medical, social

and financial aspects that dementia pose on the society in general [7]. Priority areas for action common to these plans include increase in dementia awareness, access to social and health care, training of the workforce, support to informal caregivers, ethical and legal issues and enhancing research into prevention and treatment [7]. In the beginning of 2009, the Malta Department of Health through its Parliamentary Secretariat for the Elderly and Community Care launched the National Dementia Strategy Group with the aim of identifying a number of recommendations that would provide a strategic framework in order to deliver quality improvements in local dementia services and address any local shortfalls in dementia care [18]. This group was composed of an interdisciplinary team coming from the medical and allied health care professions together with representatives of the society. The work undertaken included (a) detailed analysis of services that are available to individuals with dementia and their caregivers, (b) consultation process with stakeholders working in the field of dementia management and care including professional bodies, and (c) questionnaire designed for the public in order to obtain information regarding the various aspects of informal dementia care. The findings together with the recommendations were presented to the health authorities in January of 2010.

Analysis of the dementia situation in Malta reported considerable lack of support at all levels of dementia care together with a dearth of healthcare staff professionally trained in dementia patient-centred care. Services available were not tailored for the needs of these individuals, their family members and caregivers especially if the person with dementia is still relatively young. Professional training at undergraduate and postgraduate level mostly focused on the medical model with very limited emphasis on social models of care. Basic awareness among the general population was found to be lacking with most individuals adopting a wait-and-see approach towards seeking professional advice [18].

The consultation process involved professional and nonprofessional stakeholders and included contact groups coming from the education sector (including academic bodies representing tertiary education), medical and allied healthcare representatives, acute and long-term health and social service providers and the community. The general public was invited to participate by sending feedback via a specifically drawn-up anonymous questionnaire that was available online and composed of twenty-five multiple choice questions analyzing the various aspects of dementia care within the community setup (Table 3). The topics focused on awareness and training, early intervention, government-supported structures and services, community support and end-of-life issues. A total of 613 completed questionnaires were analyzed as part of the report. Respondents were in the majority females and consisted of healthcare professionals, main carers, family members with no main caring role, individuals with dementia and other members of the public. The age of participants ranged between 30 and 70 years [18].

With respect to awareness and training, results demonstrated that dementia is not considered as a taboo subject among dementia caregivers, relatives and healthcare professionals even though the same categories pointed towards significant lack of public awareness. Issues hindering individuals suspecting dementia from seeking professional assistance included the belief that the symptoms will resolve with time, the presence of stigma that may lead to social discrimination and the assurance that such symptoms are part of the normal ageing process. Only a third of the respondents pointed out that healthcare professionals have the necessary training and skills in dementia care highlighting the need to enhance training in the various aspects of dementia management and care, possibly adopting a multidisciplinary approach that embraces both the medical and the social model.

In the majority of European countries, dementia is not diagnosed early in the diseases process and a significant time lag exists between observing the first symptoms and diagnosis. This is mostly due to lack of training among medical professionals necessary to identify the initial symptoms of dementia. During the stakeholders meetings, dementia caregivers expressed their concerns on the lack of advice and appropriate information at the point of diagnosis. Data from the public questionnaire exercise indicated a significant degree of reluctance to seek medical assistance following the appearance of the first dementia symptoms with a third waiting for more than six months before asking for advice. Stakeholders' intervention on issues relating to the availability of state-run services denoted a significant lack of basic infrastructure that provides adequate support to individuals with dementia. The number of purposely-built dementia units did not meet the demand and more community services were required to limit early admission to long-term nursing care. Furthermore, carers and healthcare professionals working with individuals with dementia pointed towards the need to be supported at all levels to prevent physical and psychological burnout.

The significant majority of individuals who participated in the questionnaire agreed on the importance of respite care provision. Even though the dementia activity centre was offering assistance in terms of providing respite to carers and a socially engaging environment to individuals with dementia, the service was relatively unpopular. Studies show that most individuals with dementia live within the community [17]. This is of great significance in a small country like Malta in which senior citizens continue to live within the family structure. Due to the progressive nature of the most common forms of dementia, affected individuals can still remain active, especially in the early stages of the disease. Recommendations by stakeholders included the provision of good-quality community services that would defer institutionalization, psychological support for informal carers in coping with stress of continuous care, dementia-designed home care services, financial assistance in purchasing assistive technology

and an increase in the carer's pension as dementia costs are significantly higher compared to other medical conditions.

Table 3. Percentage response from different categories of respondents (all categories, n=613) to a sample of questions on various aspects of dementia (n/a: no answer). Adapted from [18]

		yes	no	don't know	n/a
Is there enough awareness on dementia?	carer/relative	24.7	69.0	5.8	0.6
	individual with dementia	17.7	64.7	17.7	0.0
	healthcare professional	19.1	77.9	2.2	0.9
	others	26.7	51.8	19.9	1.6
Is there enough information on services that are available for individuals with dementia?	carer/relative	23.0	64.4	11.5	1.2
	individual with dementia	23.5	47.1	23.5	5.9
	healthcare professional	17.3	71.4	9.5	1.7
	others	18.3	55.0	22.0	4.7
Do healthcare professionals have the necessary skills in dementia management?	carer/relative	44.8	25.9	25.3	4.0
	individual with dementia	47.1	17.7	29.4	5.9
	healthcare professional	30.3	49.8	12.1	7.8
	others	34.6	20.9	34.6	10.0
Do you consider community care as important?	all categories	88.4	1.0	3.1	7.5
Do you consider respite care as important?	all categories	85.6	0.3	5.4	8.6
Does dementia impact on family finances?	all categories	77.5	3.1	4.7	14.6

As expected, the majority of participants to the questionnaire considered community and respite care as important. Furthermore, caring for an individual with dementia has a significant impact on family finances. Other issues that were explored included palliative care, end-of-life issues and ethical approaches to dementia management and care. Unfortunately, there is a lack of these services all across Europe [19] even though such provision of care is routinely offered to terminally-ill cancer patients and that palliative management preserves the dignity of the individual and supports family members in coping with bereavement. Lack of knowledge in this particular area was felt in the feedback obtained from the public with a significant number of respondents indicating lack of knowledge on such themes. Although dementia raises a number of ethical concerns for individuals with dementia and the society as a whole, such issues have not yet been addressed. The report presented to the health authorities in 2010 included recommendations aimed at:

- (a) Improving awareness of dementia in the community
- (b) Facilitating early diagnosis and intervention
- (c) Providing information at the point of diagnosis and beyond
- (d) Increasing knowledge of services that are already available
- (e) Enhancing the quality of care in acute and long-term settings
- (f) Strengthen community support services
- (g) Providing end-of-life support services
- (h) Adopting an ethical approach in dementia management and care.

Although the national dementia strategy has been launched only recently, positive initiatives in these last years comprised the availability of one anti-dementia medication for free by the government, collection of data on the number of dementia cases, increased awareness through the publication of a number of information booklets and training sessions on dementia care to healthcare professionals and support staff working with individuals with dementia in long-term residential/nursing homes. In 2013, the Maltese government appointed a National Focal Point on Dementia with the aim of advising the local authorities on measurements that need to be adopted in order to improve the quality of lives of individuals with dementia, their caregivers and family members. This included the drafting of a dementia strategy for the Maltese Islands.

In recent years, a number of research initiatives were conducted in order to explore the level of local professional workforce knowledge on dementia management and care. Education and training of healthcare professionals are major requisites not only in enhancing awareness, timely diagnosis and service delivery but also in reaching the critical mass necessary to effectively implement the recommendations laid down in the policy document. Most often, knowledge on dementia at undergraduate level is variable, fragmented and lacks focus on the social issues involved in the various stages of disease progression. The old medical model is too restricted to respond effectively to the multifaceted and diverse nature of the condition.

The knowledge and attitudes of nursing students towards dementia has recently been investigated [20]. Because of the upward shift in the number of individuals with dementia, a significant portion of nursing students will come into direct contact with these individuals during their clinical placement and succeeding graduation. Apart from textbook knowledge, nursing professionals need to internalize positive attitudes towards individuals with dementia in order to lessen the negative stereotypes associated with this particular condition. The overall findings show that nursing students in Malta had adequate knowledge of dementia (Table 4) even though they lack information on dementia risk factors and caregiving issues. A positive relationship was reported between perceived satisfaction of their experience during clinical placement and attitude. The students' age was found to be an important factor on the degree of dementia knowledge and attitude scores with older students obtaining the highest values. In conclusion, this study highlighted the need for a better theoretical and experiential preparation in dementia care for Maltese nursing students. This can be achieved by introducing more training that focuses on learning needs possibly through the use of predefined case scenarios and role playing.

Table 4. Mean Alzheimer's Disease Knowledge Scale (ADKS) and Dementia Attitude Scale (DAS) scores according to year of study among Maltese nursing students (n=280, 61.3% response rate)

Mean scores	First year	Second year	Third year	All participants
ADKS (Maximum score: 30)	18.35	19.88	20.18	19.36
DAS (7-point Likert scale)	101.18	105.98	102.30	103.51

Research on dementia in primary care is limited even though general practitioners (GPs) act as first point of contact for individuals suspecting memory problems and thus have an important role in ensuring timely diagnosis. Notwithstanding the considerable drive in promoting educational programmes aimed at primary care levels, dementia remains largely under diagnosed [21] even though there is a consensus among healthcare professionals that early diagnosis is beneficial to the patient and helps in delaying institutionalization. Lack of training in recognizing the initial signs of dementia is one of the underlying factors as well as the confounding symptomatic profile. GPs are also not comfortable with disclosing dementia citing concerns that include erroneous diagnosis and psychological distress. Similar trends were also observed in a study investigating practices in diagnosis, disclosure and pharmacotherapeutic management of dementia among Maltese GPs [22]. In the majority of cases, participating practitioners felt that they do not have enough training and skills in diagnosing dementia even though most of them correctly recognized that memory and behavioural difficulties are important symptomatic signs that accompany the condition. This may have led to a number of practitioners adopting a wait-and-see approach to diagnosis with a consequent delay in early management options. Therapeutic nihilism was observed in those GPs with fifteen years or more experience in general practice thus creating a niche whereby individuals with dementia are getting undiagnosed and unmanaged. In contrast with other countries, referral to dementia specialists was considered only by a very small number of Maltese GPs presumably leading to a lower catchment rate compared to geriatricians,

neurologists and psychiatrists. Dementia disclosure is uncommon with local GPs and when it occurs, the patient is rarely consulted. Preferences of drug interventions shifted depending on the level of cognitive deficit and years of working experience in primary practice. The general use of medication to control the behavioural symptoms of dementia was found to be low and varied depending on disease progression (Table 5). The overall picture obtained through this study was that GPs need more training on managing dementia in the community. Given its unique geographical characteristics with close-knit communities, GPs working in Malta are in direct and constant close contact with their patients and thus may act as role players in providing improved quality care to affected individuals and their carers [22]. A need is also felt in providing continuing educational programmes in order for these professionals to be in a better position to face the growing number and increased needs of individuals with dementia in primary care.

Table 5. *General practitioners (GPs) (n=193, 54.2% response rate) responses on Alzheimer's disease (AD) pharmacotherapy (AChEIs: acetylcholinesterase inhibitors). Supplements included ginkgo-containing agents, nootropics and vitamin E*

	Percentage of GPs
Mild AD	
AChEIs	47.7
Benzodiazepines	0.0
All-class antidepressants	4.1
All-class antipsychotics	0.5
Memantine	3.1
Supplements	36.3
No response	8.3
Moderate AD	
AChEIs	64.2
Benzodiazepines	0.0
All-class antidepressants	3.1
All-class antipsychotics	1.0
Memantine	11.4
Supplements	10.4
No response	9.8
Severe AD	
AChEIs	40.4
Benzodiazepines	3.6
All-class antidepressants	2.6
All class antipsychotics	3.6
Memantine	31.1
Supplements	4.1
No response	14.5

What drug treatment would you consider as first choice?

Empowering change

In April of 2015, Malta officially launched its national dementia strategy entitled 'Empowering change: a national strategy for dementia in the Maltese Islands (2015-2023)'. It 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 policy document also 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 (Table 6). These include an increase in awareness and understanding of dementia, the provision of timely diagnosis, the availability of a trained workforce, improving dementia management and 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 encompasses 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.

Table 6. *Streams of actions, objectives and main recommendations of the National Strategy for Dementia in the Maltese islands (2015-2023)*

Actions	Objectives	Main recommendations
Increase awareness and understanding of dementia	Changing the perception of dementia Encourage help seeking Provide guidance	Continuing information campaigns Appointing Dementia Activists Online guide on dementia caregiving Promote the work of civil society organizations Strengthening of the Dementia Helpline
Timely diagnosis and intervention	Improve diagnosis at an early stage Provide information on available services upon diagnosis Timely access to care	Promote the value of early diagnosis in primary care Enhance training in dementia diagnosis, disclosure and management to primary care physicians Setting up of Dementia Intervention Teams Development and distribution of information at the point of diagnosis and beyond
Workforce development	Ensure health and social care professionals working with individuals with dementia receive specialized training	Provision of dementia patient-centred care training to the workforce Supporting information technology platforms that facilitate online training Continuous professional development programmes
Improving dementia management and care	Availability of all dementia medications on the drug formulary Improve care delivery Provide community support Implementation of dementia-friendly measures	Full access to medication and regular review Establishing training opportunities in non-pharmacological methods Ensure individuals with dementia have a care plan Involvement of all stakeholders in decision taking Increase respite facilities Implementation of dementia-friendly design Availability of palliative care support Ensuring the necessary quality standards in residential/nursing settings
Ethical approach to care	Promote an ethical approach to dementia management and care	Provision of training in ethical decision taking, respect for personhood and wellbeing Promoting the use of advanced directives Provision of psychological support services Adoption of the 'partners in care' approach Monitoring of abuse

Research	Promote and foster research in the field of dementia	Ensure that dementia becomes a national research priority Facilitate access to clinical trials Enhanced participation in European and pan-European research projects on dementia
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Implementation of this policy document is scheduled to start in 2015 and run till 2023. Due to the challenging nature of dementia, this exercise will entail substantial investment in human, financial, technical and infrastructural resources. However, the gradual delivery of the objectives 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 aims to create a system whereby all individuals with dementia have access to the care and support they require.

The objectives laid down will also 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 [23], the implementation strategy will also strive to provide a gender dimension in its 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, the implementation exercise 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 results achieved are regularly communicated to the general public in an efficient and comprehensible manner.

Conclusion

There is little doubt that dementia will pose one of the greatest societal and health challenges that must be addressed nationally as well as at personal and family level. In general, there is a significant lack of awareness, training and support services in many aspects of dementia management and care in Malta. This is to be expected, considering that meaningful discussion on dementia at a national level kicked off only in these last few years. The huge costs of the disease will challenge health systems worldwide with the predicted increase in the prevalence rates in line with an ageing population. Dementia is also overwhelming for family carers who often feel that they are left to fend on their own due to the lack of adequate support that promotes independence and wellbeing. Community support is needed to enable informal carers to continue in their caring role for as long as possible and should involve respite services and financial support. Moreover, training for healthcare professionals should be expanded and include multidisciplinary educational programmes focusing on patient-centred dementia management and care. The organization of effective campaigns that enhance public understanding of dementia will not only reduce misconceptions, stigma and discrimination but will invariably aid in timely diagnosis and help seeking. Political commitment is needed to generate and implement policies that work for these individuals and for those who care for them. The launch of a national dementia strategy aimed at holistically addressing important issues relating to increase in awareness, enhanced training for informal carers and healthcare professionals, and provision of the much required services at community level will undoubtedly have a positive impact on the quality of life of individuals with dementia in Malta.

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