REACHING NEW HEIGHTS

NATIONAL DEMENTIA STRATEGY

FOR THE **MALTESE ISLANDS**

2024-2031

Dementia Care Directorate

Anzjanità Attiva u Kura fil-Komunità
Active Ageing & Community Care

GOVERNMENT OF MALTA
MINISTRY FOR HEALTH
AND ACTIVE AGEING

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Foreword

Hon. Dr Jo Etienne Abela MD FRCS FEBS MPhil
Minister for Health and Active Ageing

There is no doubt that the incidence of the various forms of dementia is on the rise internationally. This is a reality that paradoxically is twinned with the very significant improvement in life expectancy across nations. Sadly, the advances in medical care and curative treatments for myriad conditions that we have witnessed these past few decades, do not match the curative options for dementia. By stealth, dementia robs the individual of cherished memories, relationships, and one's own identity. It is no co-incidence that in the world-famous Harry Potter series, J.K. Rowling used the word "dementia" to coin a new term for a set magical villians which do just that. It is heart-wrenching to see loved ones, friends, acquaintances, and patients slide down the dementia slope. Although there is significant heterogeneity and wide variation in the rate of progression of this condition, it is small wonder that most of us feel powerless in the face of what is perceived to be inexorable. The very few medications that exist have been around for many years and their efficacy is rather modest at best and negligible at worst.

These truths should not dishearten the reader. If anything, humans have excelled at so many endeavours that I refuse to believe that there is no light at the end of the tunnel. Back in the year 2000, when scientists unravelled the human genome, many of us made optimistic forecasts - a solution to every medical disorder known to man appeared to be just around the corner. Of course everyone knows now that it did not quite happen. It would be foolish to think that a cure for dementia is within easy reach. Nonetheless, when I look at the steady improvement in curative treatment options for common deleterious conditions such as breast and colon cancer, I see the results of bright minds, hard work, concerted efforts and huge multi-centre trials. In essence the vast sums of money thrown at these conditions are reaping dividends. This is why I think that researchers, governments and large corporations the world-over are duty-bound to collaborate with just this one end in mind - to beat dementia! I am most certain that a major break-through in this aspect of healthcare will scoop not a few Nobel Prizes.

In the meantime, we are obliged to offer best standard available care by adhering to modern guidelines, follow adapted protocols and of course doing the sensible thing - treat persons living with dementia as well as we would treat our loved ones, our relatives. The aim of this revamped strategy is not to confine our operations but rather, to heighten awareness and knowledge, to overthrow the notion of ageism and the stigma attached to it, to attract and retain a dedicated workforce, to promote a healthy and active lifestyle and to stimulate research.

My heart-felt congratulations and gratitiude to the team involved in producing this strategy and all those who contributed before, during and after the official public consultation process. Indeed this document bears special significance as one of the authors is a person who is herself living with and adapting to the condition. As such, at least in this country of ours, this strategy must surely rank amongst the landmark works in this field.

Foreword

Hon. Dr Malcolm Paul Agius Galea
Parliamentary Secretary for Active Ageing

It brings me great honour to share with you some thoughts on the National Dementia Strategy for the coming seven years, in my first weeks upon taking office. As our society continues to evolve into one with an increasingly ageing population, our health services need to adapt accordingly. Aside from a direct link to age, dementia and its subsets are also on the rise in developed countries for a plethora of reasons, including greater exposure to cerebrovascular risk factors, such as hypertension, diabetes, obesity, smoking and drinking. Dementia not only affects individuals but reverberates through families, communities, and the very fabric of our social structure. I am also sensitive to the profound economic implications of the increasing prevalence of dementia both in terms of healthcare expenditures and also lost productivity, which underscore the urgency of developing a robust and inclusive strategy.

This strategy is thereby a comprehensive plan which continues to build upon the previous strategy to address the challenges of dementia in our country. It also provides the framework for the delivery of quality improvements in local dementia services and addresses health inequalities in this field. This strategy brings about more than a crucial and gradual quality upgrade in the continuously expanding healthcare system of our country. Above all, it is another step forward in supporting the well-being of our nation. This document is a clear example of how all of our policy and collective decisions are to be based on a person-centred approach, as we aim at improving the quality of life of persons living with these conditions, and their families.

Indeed, a striking element of this strategy is that it is built on empathy. The medical sector often places huge emphasis on medicine, technology, research and infrastructure, all elements which are critical and which we will continue investing in, and yet at times these render the services provided less personalised, less understanding and even unwelcoming. However, as a family doctor, I have witnessed firsthand the importance of reaching out to people, young and old, parents, partners and children of individuals affected by dementia, understanding them and providing them with empathy and support, as a complementary therapy to all other treatments. This strategy is not merely a document; it is a commitment to fostering a society that values and supports individuals living with dementia. It draws on rigorous research, analysis, and a deep understanding of the human experience. The findings presented here provide a foundation for policies that go beyond immediate care, aiming to create an environment that promotes early detection, innovative treatments, and, ultimately, the well-being of those affected.

I hereby wish to congratulate the Honourable Minister Jo Etienne Abela, who has spearheaded this document, and the team at the Dementia Care Directorate, who have worked tirelessly to bring forth a well-researched strategy. I also acknowledge and thank the invaluable input from experts, caregivers, and those living with dementia. Their stories and experiences have illuminated the path forward, guiding the development of a framework that is both compassionate and pragmatic. It will be my mission to facilitate and support in any way possible the implementation of this Strategy in its entirety.

This dementia strategy is a continuation of the Maltese Islands' first national strategy – *Empowering Change (2015-2023)* and it builds on the sound progress made during its implementation.

Acknowledgments

This strategy document would have not been possible without the contribution of several individuals who provided their expert opinions and technical input in the development phases. Special thanks to the team at the Dementia Care Directorate who spearheaded the compilation of the strategy together with the input of the Strategy Advisory Group. The Strategy Advisory Group met several times to discuss the strategy's vision, action areas and objectives and gave their invaluable expert recommendations on each proposal presented in this document. For the first time for the Maltese Islands, the Strategy Advisory Group included a person living with early-onset dementia, who was able to give a unique, first hand perspective of the challenges persons with dementia experience. The Strategy Advisory Group consisted of the following members.

Mr Alex Gobey – *Director – Dementia Care Directorate*

Prof Godfrey Laferla – *Commissioner for the Elderly*

Ms Stephanie Kent – *Assistant Director – Dementia Care Directorate*

Dr Mark Vassallo – *Consultant Geriatrician*

Dr Anthony Scerri – *Malta Dementia Society*

Dr Alexia Mercieca – *Architect*

Ms Rita Vella – *Person living with early on-set dementia*

Ms Rosylnn Vella – *Informal Caregiver*

We are grateful to the valuable contributions presented by the Minister for Health and Active Ageing, Dr Jo Etienne Abela, Permanent Secretary, Ministry for Health and Active Ageing, Ms Christine Schembri and Chief Executive Officer Active Ageing & Community Care, Dr Renzo De Gabriele. Their expert opinions, initiative and support made this strategy document possible.

Glossary

Advance care planning
A process of reflecting on personal values and having discussions with a substitute decision maker about the care that the person with dementia would want to receive should he/she become unable to make decisions.

Activities of daily living (ADLs)
Activities of daily living (ADLs) include eating, bathing, grooming, dressing and going to the toilet. People with dementia may need aid to perform these tasks. Questions about ADLs help decide what type of care a person needs.

Acute care (hospital care)
Acute care refers to when a person receives care in a medical setting such as a hospital, intensive care unit or emergency department.

Alzheimer's disease
Alzheimer's is a type of dementia that causes problems with memory, thinking and behaviour. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks.

Assessment
Refers to an assessment of a person's mental status, a test of a person's ability to think, feel and react to others. A doctor usually performs a mental status assessment.

Assistive technology
An umbrella term used to describe any device or system that allows individuals to perform tasks they would otherwise be unable to do on their own. Assistive technologies can increase the ease and safety with which daily tasks are performed.

Behaviours
Dementia can cause a person to act in different and unpredictable ways. Some individuals with dementia can exhibit behaviours such as agitation, repetition, hallucinations and suspicion.

Caregiver
Anyone who provides care to a person with dementia. Caregivers can be family members, friends or paid professional caregivers. Caregivers may provide full- or part-time help to the person with dementia.

Dementia
Dementia is not a specific disease. It's an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities. Alzheimer's disease is the most common type of dementia.

Dementia Activity Centres (DACs)
Dementia Activity Centres (DACs) offer people with dementia the opportunity to be social and to participate in activities in a safe environment.

Early-onset dementia
Early-onset dementia affects people younger than age 65. Many people with early-onset dementia are in their 40s and 50s. They have families, careers or are even caregivers themselves when they receive a diagnosis.

Evidence-based
The thorough, clear and careful use of existing evidence, for example in developing guidelines, implementing interventions, and making decisions about the types of care and therapies that an individual receives.

Long-term care facility
A long-term care facility is a residential or nursing home.

Palliative care
Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.

Personal care
People with dementia may need help with personal care activities, including grooming, bathing and dressing.

Person-centred care
An approach to the planning and delivery of health care founded on mutually beneficial partnerships among care providers and the people receiving care. Person-centred care is respectful of, and responsive to, the preferences, needs and values of the care recipient.

Risk factors
Factors associated with an increased chance of developing dementia; they include lifestyle, social, economic, biological, behavioural and environmental influences.

Support groups
A group of persons living with dementia or caregivers who connect to share experiences, provide support and give advice. Support groups can meet face-to-face with a support group leader or meet online.

Executive Summary

The term "dementia" refers to a multitude of illnesses marked by a steady decline in cognitive abilities, such as memory, judgement, communication, and behaviour changes severe enough to affect day-to-day functioning. As the population ages, the number of persons with dementia will rise dramatically. In the Maltese Islands, studies are indicating that by the year 2050, 3% of the population will be living with a form of dementia. It is evident from research that this condition is emotionally and financially taxing for those who have it, as well as their family members and caregivers. This dementia strategy is a continuation of the Maltese Islands' first national strategy – Empowering Change (2015-2023) and it builds on the sound progress made during its implementation. A review of the objectives implemented was carried out and new evidence-based practices were sought, so that the objectives brought forward in this strategy are what Malta needs in the next seven years to reach new heights in this care sector. Reference is made in this policy to specific groups of persons with dementia who the Strategy Advisory Group considered needing special attention due to differences among communities present in our society. Special attention was also placed on initiatives to reduce the risk of the condition as indicated by the latest research in the area. The strategy is entitled ‘Reaching New Heights’ since this national strategy aims to significantly improve the quality of services and the quality of life of persons living with the condition in the Maltese islands. This strategy aims to achieve this by working on the following action areas:

Awareness and understanding of dementia

A dementia-friendly society is ideal to create inclusivity and accessibility in community settings that maximise the opportunities for health, involvement, and security for everyone. This will safeguard the quality of life and dignity for people with dementia, their caregivers, and families.

Timely diagnosis

An early diagnosis opens up the possibility of future care and treatment alternatives. Making advance care planning, while one is still able to make important decisions about care and support requirements, as well as decisions about money and legal matters, is extremely advantageous. Utilising cutting-edge diagnostic methods will enable individuals to obtain pertinent information, advice, and guidance as soon as possible. This strategy will put forward objectives to help the population achieve an early diagnosis.

Reducing the risk

The latest research is indicating that the risk of cognitive decline and dementia can be reduced by taking precautionary measures, such as increasing physical activity, preventing and reducing obesity, promoting balanced and healthy diets, quitting smoking and alcohol use, encouraging social engagement, promoting cognitively stimulating activities, preventing and managing diabetes, hypertension, and depression. Initiatives highlighting these new developments, throughout the life course will help the population reduce the risk of developing the condition.

Living well with dementia

As the condition progresses, there are a number of different ways to promote wellness and coping strategies that can be helpful so that the person adapts to the changes that are happening. Throughout this journey, there are opportunities to find services that best suit the person’s requirements and plan support so that the family is able to live well with the condition. The strategy puts forward an approach that is positive and empowering, focused on helping persons with dementia and their families to live well with the condition.

Workforce development

The development and training of a workforce with the capacity and competencies to provide high-quality services and support to the growing population of dementia patients, as well as to successfully address the complex and progressive effects of dementia at all levels of society, are issues of growing public health importance. The strategy puts forward initiatives and objectives on how the nation can develop a workforce which is capable of providing quality services for persons with dementia.

Research & information systems

Data from systematic, routine population-level monitoring of a core set of dementia indicators is needed to support evidence-based choices to improve services and evaluate progress in the implementation of the national dementia strategy.

Dementia management & care

Throughout the dementia journey, integrated, culturally appropriate, person-centred care can ensure that the preferences of persons with dementia are met and their autonomy is respected. Seamless integrated care across settings is the main goal in management and care, and this will significantly improve the quality of life of individuals affected by the condition.

This national strategy on dementia will be implemented in the next seven years and the government will be creating an Inter-Ministerial Committee, led by the Ministry for Health and Active Ageing, that will coordinate and oversee its implementation. This will ensure that the actions outlined in the seven sections of the policy are implemented in an effective and efficient manner. It will also ensure that people with dementia, caregivers, and family members are included in the implementation process by evaluating priorities and establishing a plan of action, timeframes, and key players.

Dementia

Dementia is a syndrome that affects the brain and is usually progressive in nature. According to the World Health Organization (WHO, 2023), dementia is a condition that can be caused by a number of diseases which over time destroy nerve cells and damage the brain, typically leading to deterioration in cognitive function beyond what might be expected from the usual consequences of biological ageing. Dementia is an umbrella term for several diseases affecting memory, other cognitive abilities and behaviour that interfere significantly with a person's ability to maintain their activities of daily living. Although age is the strongest known risk factor for dementia, it is not a normal part of ageing.

In addition to cognitive symptoms, individuals with dementia may also develop behavioural and psychological symptoms such as disinhibited behaviour, delusions, hallucinations, verbal and physical aggression, agitation, anxiety, and depression. 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. Dementia is a major cause of disability and dependency among older adults worldwide, having a significant impact not only on individuals but also on their caregivers, families, communities and societies. According to the World Health Organization (WHO), dementia accounts for 11.9% of the years lived with disability due to a noncommunicable disease (WHO, 2018).

Furthermore, dementia does not just affect the elderly, with early onset dementia (the development of symptoms before the age of 65) accounting for up to 9% of cases (ADI & WHO, 2018). The study by Loy CT et al., (2014) has shown a link between the onset of cognitive impairment and lifestyle-related risk factors common to other noncommunicable illnesses. Physical inactivity, obesity, unbalanced diets, cigarette use, and problematic alcohol use, as well as diabetes mellitus and mid-life hypertension, are all risk factors. Midlife depression, poor educational achievement, social isolation, and cognitive inactivity are other potentially modifiable risk factors for dementia. Furthermore, there are non-modifiable genetic risk factors that raise a person's likelihood of getting dementia.

Types of dementia

There are various types of Dementia with Alzheimer's disease (AD) accounting for approximately 70% 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. It is not uncommon for various types of dementia to co-exist (mixed dementia), especially in the late stages of the condition. According to the World Health Organisation (WHO, 2023), dementia is currently the seventh leading cause of death and one of the major global causes of disability and dependency among older people, with more women than men being affected (Prince et al., 2015).

Modifiable risk factors

According to the 2017 Lancet Commission on dementia prevention, intervention, and care, there are nine potentially modifiable risk factors for dementia: low level of education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, and low social contact. New evidence from the latest report (Lancet, 2020) supports adding three modifiable risk factors - excessive alcohol consumption, head injury, and air pollution. There is no single specific activity that can protect against dementia. However, it is recommended to keep cognitively, physically, and socially active in midlife and later life. Using hearing aids appears to reduce the excess risk of hearing loss, thus potentially reducing the dementia risk. Sustained exercise in midlife, and possibly later in life, protects from dementia, perhaps through decreasing obesity, diabetes, and cardiovascular risk. Depression might be a risk for dementia, but in later life, dementia might cause depression. Although behaviour change is difficult and some associations might not be purely causal, individuals have a huge potential to reduce their dementia risk.

The progressive nature of the condition

Every person with dementia experiences the disease differently, but people tend to experience a similar trajectory from the beginning of the illness to its end. The precise number of stages of the condition is somewhat arbitrary. Most experts use a simple three-phase model (mild, moderate and advanced), while others have found a granular breakdown to be a more useful aid to understanding the progression of the illness. 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 characterized by total dependence. Memory impairment becomes severe and affected individuals are unable to recognize familiar faces and objects. There is an increased need for 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.

TABLE 1: MALTESE POPULATION AGE AND GENDER

Source: National Statistics Office (2023)

60+	**MALE:** 60,906 **FEMALE:** 68,024 **TOTAL:** 128,930	**24.8%** of the Maltese population
60-69	**MALE:** 29,927 **FEMALE:** 29,799 **TOTAL:** 59,726	**11.5%** of the Maltese population
65+	**MALE:** 45,137 **FEMALE:** 52,505 **TOTAL:** 97,642	**18.8%** of the Maltese population
70-79	**MALE:** 22,776 **FEMALE:** 24,958 **TOTAL:** 47,734	**9.2%** of the Maltese population
80+	**MALE:** 8,203 **FEMALE:** 13.267 **TOTAL:** 21,470	**4.1%** of the Maltese population
80-89	**MALE:** 7,267 **FEMALE:** 10,993 **TOTAL:** 18,260	**3.5%** of the Maltese population
90+	**MALE:** 936 **FEMALE:** 2,274 **TOTAL:** 3,210	**0.6%** of the Maltese population

Malta's ageing demographic

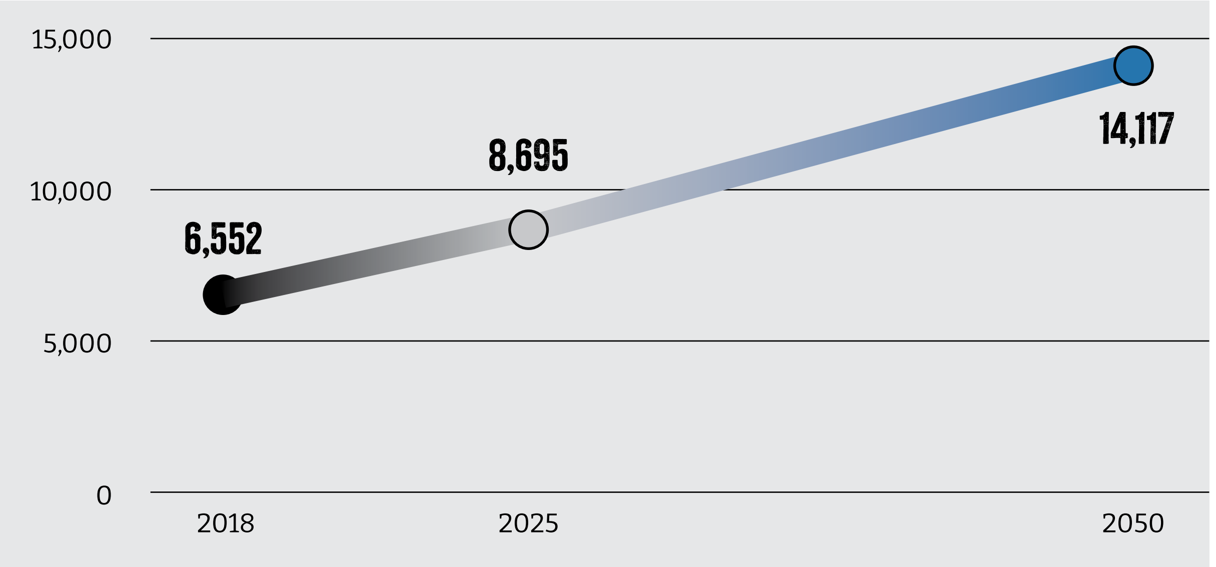
According to National Statistics Office latest census (NSO, 2023), the resident population in Malta was 519,562. The population has more than doubled over a century and grown by more than 100,000 over the past 10 years. The same report states that the population aged 65 years and above in Malta was 18.8%. Over the last 50 years, the Maltese population aged 65 years and above grew substantially from 9.3 to 18.8%, rising at an increasing annual rate that reached a maximum of 4.47% in 2009 and then decreased to 1.39% in 2022.

The primary non-modifiable risk factor for dementia is age. As life expectancy and population ageing continue to increase in Europe, the likelihood of people developing the condition also increases. Over the last three decades, several studies have been conducted at a European level to estimate the prevalence of dementia. These include the EURODEM study (updated in 2000), the European Collaboration on Dementia (EuroCoDe; 2006-2008) and the first EU Joint Action on Dementia - ALCOVE (2011-2013). Table 2 shows the estimated prevalence of dementia in different European Union countries, including Malta, in 2018 and 2050.

Dementia in the Maltese Islands

The overall number of people with dementia in Malta is expected to more than double from 6,552 in 2018 to 14,117 in 2050. This represents an increase from 1.38% of the population in 2018 to 3.31% in 2050 (Scerri & Scerri, 2012). The increase is due to a significant rise in the number of people aged over 75 and particularly those over 85 years, which is expected to more than triple between 2018 and 2050.

GRAPH 1: THE NUMBER OF PEOPLE WITH DEMENTIA IN MALTA FROM 2018 TO 2050



Source: Scerri & Scerri (2012)

TABLE 2: ESTIMATED PREVALENCE OF DEMENTIA IN DIFFERENT EUROPEAN UNION COUNTRIES, IN 2018 AND 2050.

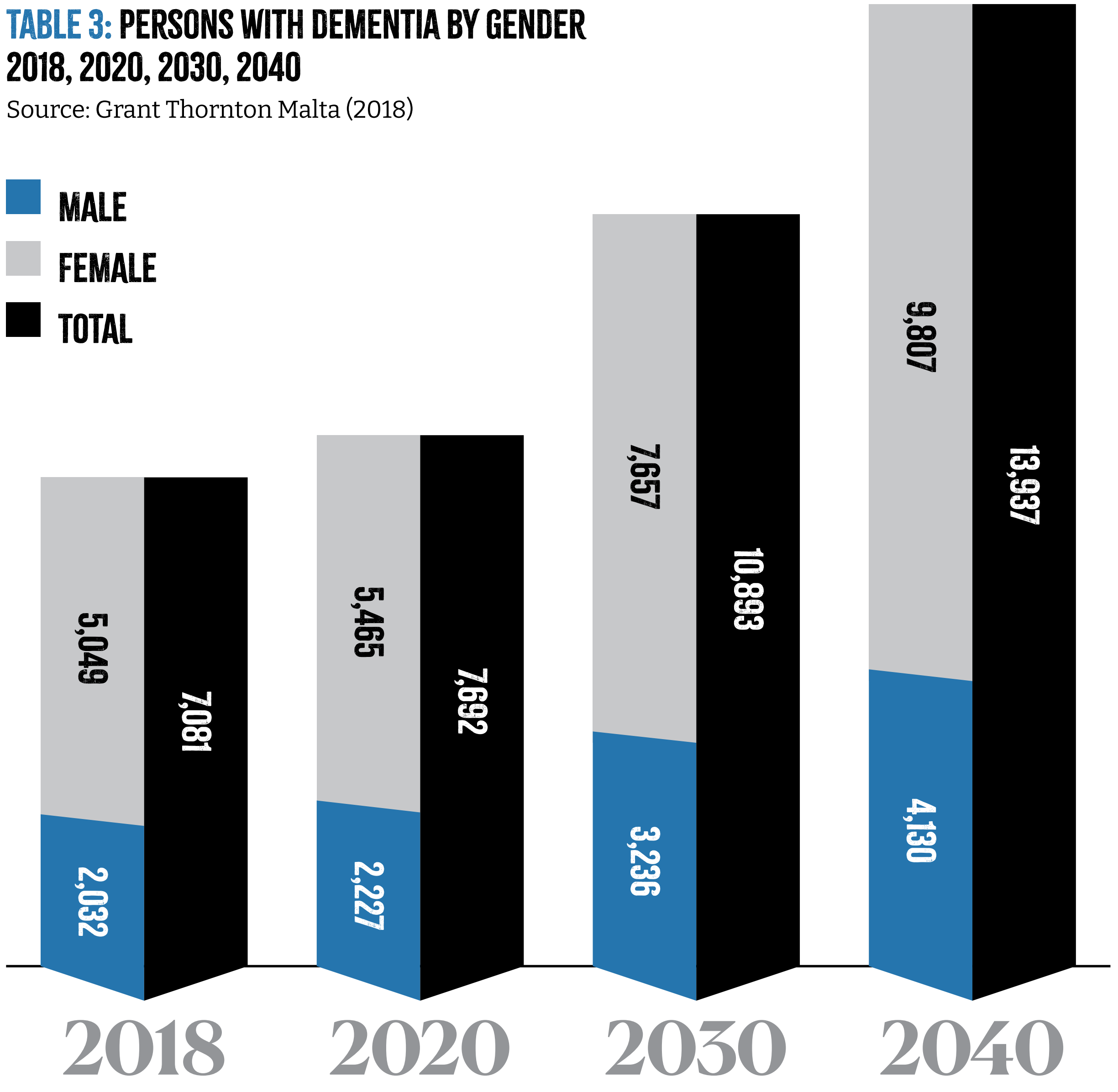
Country	Men	Women	Total	% of the population in 2018	% of the population in 2050
Austria	46,537	100,263	146,801	1.66	3.18
Belgium	61,173	131,753	192,926	1.69	2.95
Bulgaria	34,290	74,594	108,884	1.54	2.47
Croatia	19,535	46,341	65,876	1.60	3.06
Cyprus	3,744	6,345	10,088	1.17	2.44
Czech Republic	46,338	103,295	149,633	1.41	2.65
Denmark	30,228	57,148	87,377	1.51	2.65
Estonia	5,375	17,567	22,942	1.74	3.06
Finland	29,980	65,856	95,836	1.74	3.13
France	374,260	853,298	1,227,558	1.83	3.31
Germany	511,050	1,074,115	1,585,166	1.91	3.43
Greece	75,538	138,141	213,678	1.99	3.95
Hungary	39,876	105,812	145,688	1.49	2.64
Ireland	18,900	33,836	52,736	1.09	2.49
Italy	402,965	876,402	1,279,366	2.12	4.13
Latvia	7,712	26,035	33,747	1.74	3.17
Lithuania	11,783	37,174	48,957	1.74	3.67
Luxembourg	2,479	5,060	7,539	1.25	2.44
Malta	**2,242**	**4,309**	**6,552**	**1.38**	**3.31**
Netherlands	87,292	169,239	256,532	1.49	3.15
Poland	147,733	377,351	525,084	1.38	3.23
Portugal	59,989	133,527	193,516	1.88	3.82
Romania	87,514	192,093	279,607	1.43	2.56
Slovakia	18,101	44,394	62,495	1.15	2.59
Slovenia	10,061	24,076	34,137	1.65	3.40
Spain	271,984	580,758	852,741	1.83	3.99
Sweden	58,222	110,021	168,243	1.66	2.63
United Kingdom	356,741	674,656	1,031,396	1.56	2.67

Source: Alzheimer's Europe (2019)

These estimates were revised in a more recent study by Grant Thornton Malta (2018), which included updated forecasts for the number of people with dementia in the years 2020, 2030, and 2040. The table below gives a summary of these updated findings.

TABLE 3: PERSONS WITH DEMENTIA BY GENDER 2018, 2020, 2030, 2040

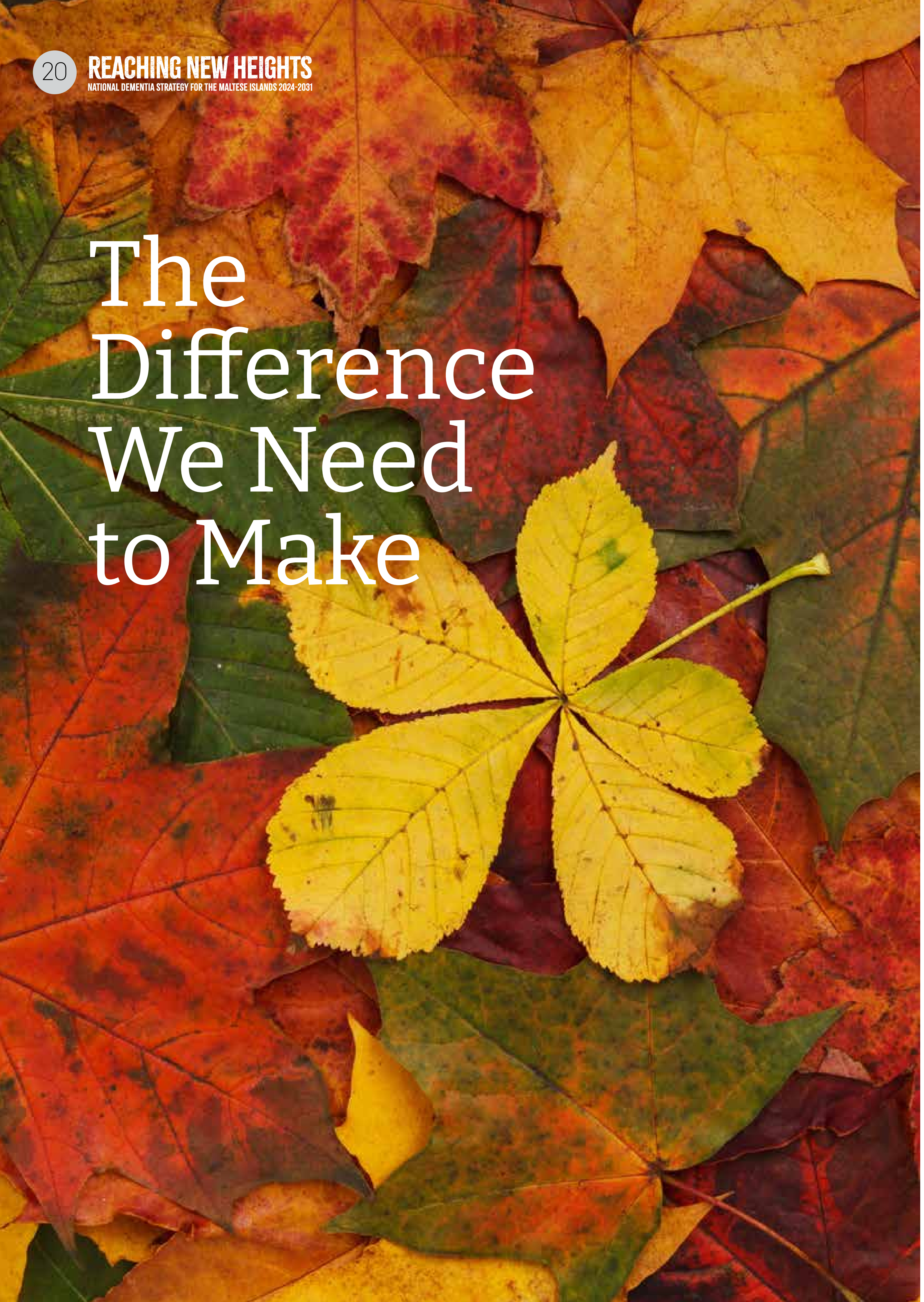
Source: Grant Thornton Malta (2018)



The cost of dementia

The huge costs of dementia worldwide place enormous strains on care systems and families alike. Although most people with dementia live in low- and middle-income countries, the highest total and per-person costs are seen in high-income countries. According to Wimo A et al., (2023), in 2019, the annual global societal costs of dementia were estimated at US $1,313.4 billion for 55.2 million people with dementia, corresponding to US $23,796 per person with dementia. When analysed, the total costs were directed towards 16% medical costs ($213.2 billion), 34% ($448.7 billion) direct to social sector costs (including long-term care), and 50% were directed to informal care ($651.4 billion). Locally, no studies are available to measure the cost of the condition, although it is clear that long-term care and treatment expenses are significant on the country and on the individuals living with the condition and their families.

Without a doubt, dementia also has a cost on the quality of life of the individual directly affected by the condition and those family members and caregivers. Caring for someone with dementia can have emotional, physical, and financial effects on caregivers. Some of the effects include caregiver stress and anxiety, depression, loneliness, lack of self-care, increased mortality, chronic stress, burnout, increased stress levels, financial complications, and rewards of caregiving. Caring for a person with dementia is particularly challenging, causing more severe negative health effects than other types of caregiving. Caregiving often results in chronic stress, which comprises the caregiver's physical and psychological health (Si-Sheng Huang, 2022). A local study by Muscat and Scerri (2018) revealed that depression and burden experienced by informal primary caregivers of individuals with dementia are strongly associated with age, cognitive impairment, and activities of daily living scores of the care recipients. The study also found that dysfunctional coping strategies are related to emotional distress, low quality of life, and burden experienced by caregivers.



The Difference We Need to Make

Why do we need a National Strategy on Dementia?

In terms of policy and practise, dementia is becoming a more significant issue that necessitates national plans and strategies that address the social and health effects of the disease as well as resources and support for those who have dementia and their families. Given that Malta is becoming an increasing ageing population, the Maltese Government acknowledges that dementia and its associated illnesses are a top priority for action. Since a considerable fraction of people with dementia are sent to acute hospital care, residential, long-term nursing, and community care services, dementia has tremendous health, social, and economic relevance to our nation. A national policy on dementia demands further improvement in quality standards currently in place for the care of those with dementia and the support of caregivers to consider and implement strategies that facilitate a healthy, independent, and secure lifestyle for all stakeholders involved.

People with dementia have complex needs that are multifaceted and multifactorial in nature. Recognizing and addressing these needs requires coordinated efforts across all levels of government – local, national, and public sectors. Creating a National Strategy is an opportunity to collaborate with stakeholders and set priorities for the years ahead. According to WHO (2018), producing a dementia strategy signals a political commitment to identify and address dementia as a priority and helps identify system inefficiencies, rationalize service delivery, and optimize the use of available resources.

In 2050, the number of people with dementia in Malta and Gozo are expected to increase to 12,955 (3.26% of the population) according to estimates by Scerri and Scerri (2012). Increased demand for health care services will be inevitable, with significant socioeconomic repercussions. Dementia care and management should be one of the top health priorities in the Maltese islands to meet these current and future issues.

This plan spans over the period of the next seven years. It lays out a vision for how people with dementia might live their lives as well as the necessary societal, policy, and service adjustments needed to facilitate this. The policy identifies priority areas which will help people with the condition and those who help them advance through dementia, as stated by persons living with dementia and their families, as well as what they desire and expect. Seven years is a significant long period of time and, while improvements will be noticeable in a shorter period, we are realistic about the amount of time that social transformation will take, because we believe this shift will be cumulative and incremental and will take time to implement and apply in our society.

Where are we now?

Malta has been at the forefront in dementia and active ageing policies (Formosa & Scerri, 2020). In 2010, the Malta Dementia Strategy Group worked on recommendations for a dementia strategy which were presented to the health authorities of the time and in 2015 the then Parliamentary Secretary for Rights of Persons with Disabilities and Active Ageing published Malta's first national dementia strategy entitled: Empowering Change – A National Strategy for Dementia in the Maltese Islands 2015-2023 (Scerri, 2015).

This strategy is a continuation of the national strategy for Malta and Gozo, which sets a solid initial framework of services and care. Since 2015, a myriad of services and initiatives took place to improve the lives of those living with the condition. Primary examples of these developments were the establishment of the National Dementia Helpline (1771), the formation of the Dementia Intervention Team, the increase in the number of Dementia Activity Centres and recently, the establishment of the Dementia Care Directorate. This strategy acknowledges the work carried out in the first strategy and reflects on the way forward for the coming seven years, based on the latest evidence-based practice and challenges expected.

This second strategy for dementia in the Maltese Islands will put a special emphasis on the prevention of the condition, will emphasize a human rights approach to dementia care, and will additionally place special attention to the needs of specific groups of persons in our society. This will ensure that we continue building on the solid foundations laid down in the first strategy, and progressively build on this solid structure, to improve the lives of those persons living with dementia.

Guiding Principles

This strategy is based on several guiding principles which are at the centre of every objective recommended in this document.

Participation

Everyone has a right to take part in choices that will have an impact on them. Participation must be active, cost-free, and purposeful, while also taking accessibility concerns into consideration, such as having access to information in a format and language that is understandable.

Accountability

Comprehensive human rights standards monitoring is necessary for accountability. To protect human rights, there must be the proper laws, policies, administrative processes, and redress mechanisms for accountability to be effective.

Equity

According to a human rights-based perspective, prejudice in all its manifestations must be outlawed, stopped, and eradicated. Additionally, individuals who are most at risk and experience the greatest obstacles to exercising their rights must be given priority.

Empowerment

People should be adequately supported in exercising their rights to participate in the formation of laws and regulations that have an impact on their daily life. Where required, people should be allowed to assert their rights.

Legality

All legally recognised and mandated human rights must be upheld, respected, and realised. A strategy based on human rights must acknowledge rights as legally enforceable entitlements and be connected to both domestic and international human rights legislation.

The Strategy's Vision

That in Malta and Gozo, dementia is prevented and people with dementia and their caregivers live well and receive the care and support they need to fulfil their full potential with dignity, respect, autonomy, and equality.

The Challenges this Strategy Needs to Address

There are seven main challenges that we must address over the course of this strategy:

1. We must continue to increase awareness and understanding of the condition, across all settings and across the life course.

2. There is growing evidence that we can reduce the risk of developing dementia by controlling modifiable risk factors. This strategy will be highlighting the need to work on prevention and risk reduction to reduce and delay the number of persons who develop the condition.

3. We must continue to strive towards timely diagnosis which breaks the news in a person-centred approach, offers the needed information and post diagnostic care.

4. In the absence of a cure, persons with dementia must be encouraged to live well with the condition through empowerment and person-centred care. Continue building on the progress made around the provision of support after diagnosis and throughout the course of the illness, we must consistently ensure that support is truly person-centred and flexible to take account of individual needs and circumstances.

5. We must continue to educate our workforce in dementia care to provide the best possible care across different settings.

6. Ensure to provide person-centred, coordinated, and flexible support for people living with dementia and their caregivers across a range of settings, including residential and community settings. This support should be consistently available to every person living with dementia and their caregivers. This means we should continue to embrace the process of redesign and transformation of services. More care should be delivered in our communities, but we must also ensure that palliative and end-of-life care services for people with dementia are flexible and responsive to individual needs.

7. We must invest in local research on the condition to base decisions according to the best evidence available. Collaboration with research entities is needed to highlight areas which are a priority to our country.

Aim of the National Strategy for Dementia (2024-2031)

The main goal of the National Strategy for Dementia is to improve the quality of life of people with dementia, their caregivers, and their families. Working on the following strategic objectives will help achieve this ambitious goal. The following action areas will directly act on the challenges Malta and Gozo are currently facing in the field of dementia care:

1. Awareness and Understanding of Dementia

2. Reducing the Risk

3. Timely Diagnosis

4. Living well with Dementia

5. Workforce Development

6. Dementia Management and Care

7. Research & Information Systems

How this Strategy was created

The first National Strategy on Dementia in Malta came to an end in 2023, and immediately preparatory work initiated to pave the way forward towards the next strategy. The newly established Dementia Care Directorate (DCD) within Active Ageing and Community Care, played a leading role in the preparation of this strategy and instantly liaised with the Ministry for Health and Active Ageing and other main stakeholders to establish the strategy for the next seven years.

A review of the progress made during the first Dementia Strategy for the Maltese Islands was carried out to identify the areas where significant progress was made and identify any gaps which needed to be prioritized in the next strategy. Research was done on the most recent recommendations, guidelines, and developments in dementia care in different nations which are considered to be at the forefront of progress in this sector.

Role of Dementia Care Directorate

In 2023, the Dementia Care Directorate (DCD) was established to provide leadership for the implementation of the National Dementia Strategy, so that people with dementia can live well, have services and support delivered in the best possible way, and improve their wellbeing and dignity. The DCD aims to collaboratively work with NGOS/Private/Voluntary services to ensure the effective implementation of the National Dementia Strategy. This creates an interconnected approach to the identification of programme solutions, service delivery, education, and public information.

The DCD played a pivotal role in the creation of this strategy as it aimed to influence policy and practice in dementia care in the Maltese Islands. This was carried out through advocating the need for the next strategy as well as actively working on the strategy and chairing the Dementia Strategy Advisory Group. The DCD was also instrumental in facilitating an evidence-based, progressive approach to the development and provision of dementia and support services.

Dementia Strategy Advisory Group

During the analysis of the previous strategy's implementation, discussions were held with the Ministry for Health and Active Ageing, and it was decided that a Dementia Strategy Advisory Group would be created to obtain their expert opinion on the first draft of the policy. Discussions with this group ensured that the objectives and measures recommended in the strategy were based on the expertise and experiences of representatives of the main stakeholders directly affected in the strategy. The Strategy Advisory Group was made up of key participants who represent the main stakeholders in connection with the strategy. The group was made of experts who work in the field of dementia care, representatives from non-governmental organizations, caregivers of persons with dementia, and persons living with dementia. The inclusion of persons with dementia in the strategy's creation is a first for the Maltese Islands. The inclusion of a person living with the condition brought a new perspective to the formation of the strategy. This highlighted the need to focus on a more person-centred approach which guided the Strategy Advisory Group towards an improved humanist strategy. The Strategy's Advisory Group met a number of times to discuss the strategy with the DCD and gave feedback on priorities which needed to be highlighted. The contributions of the Strategy Advisory Group were instrumental towards creating a holistic and effective strategy which truly puts forward the needs of the people directly affected by this condition.

A qualitative interview with a member of the Strategy Advisory Group who is living with early onset dementia was later carried out to acquire a more in-depth insight to this unique perspective. Throughout the document a series of quotes and excerpts from the perspective of a person dealing with early onset dementia will be shared, to help the reader understand this perspective.

Lived Experience of Early Onset Dementia

Ms Rita Vella shared her experiences with life after a dementia diagnosis and how she felt that her life had changed afterwards. Throughout this document she describes the emotions experienced after her diagnosis and how this impacted her day-to-day life.

> **"I am 54 years old. I am the youngest of a family of 9 children. My mum had dementia in the later stages of her life. My son has passed away due to his brain injury during birth. Since then, my life changed to the better as through him I have been able to help other people in need and give support whenever it is needed.**
>
> **I always loved being around people. I still remember myself waving the passers-by while my mum carried me in the pushchair, while going to visit my grandma. I had the opportunity to travel in faraway places mostly with my family members and went to various interesting faraway places around the world.**
>
> **Currently I work within the public service and part of my job is to coordinate important events and administration.**
>
> **I was also involved with voluntary work with persons with disability and attended EU programmes for youths to expand their opportunities and to feel independent. I was also involved in a committee in my local council where we used to carry out activities for youths involving sports.**
>
> **I consider myself lucky for having a strong support system from family, great friends, and colleagues. They have all been very supportive since I received the sad news regarding my dementia."**

Author Ms Rita Vella

Meeting the needs of specific groups

There is a growing need that we acknowledge and dedicate special attention to specific groups of persons living with dementia in our communities. Policies in dementia care need to be sensitive to the differences exhibited by specific groups in our society. This policy recognizes the fact that "one size does not fit all", and the following specific groups will be highlighted so that they are acknowledged and given the due consideration in dementia care policy. Wright and O'Connor (2018) pointed out that Malta's first National Strategy (2015) had an absence of attention towards the needs of, and implications for, ethnic minorities, LGBTIQ+ people or other marginalized groups, such as those living with learning disabilities and rare types of dementia.

People increasingly adapt to each other's cultures, values, differences, and traditions as our society grows more diverse. We need to minimise structural barriers to participation, diagnosis, treatment, support, and care, regardless of ethnicity, race, sex, gender reassignment, sexual orientation, additional disability, or neurodivergence. This policy is conscious of these differences and will remain sensitive and understanding to them throughout the policy's lifespan.

Early on-set dementia

Persons with early on-set dementia have particular needs. They are more likely to:

- be employed and have financial obligations at the time of the diagnosis.
- be more active, stronger, and fit than others who are considerably older.
- be in charge of taking care of their own parents and children.

The needs of younger persons with dementia and their families must be addressed specifically, and services must make sure that they are aware of the resources available to them. To help employees, employers should have access to the appropriate information. They must be able to show how they are offering local, age-appropriate, and substantial assistance, whether in the form of day-care, respite care, or residential care in the person's home.

Learning disabilities and dementia

Compared to the general population, those with learning difficulties are more likely to acquire dementia. One in three adults with Down's syndrome who reach the age of 50 are expected to acquire dementia (Alzheimer's Disease Association, 2023). It may be more difficult to diagnose someone if they already have issues with short-term memory or information processing. A person with learning impairments may find it more challenging to express their experience of symptoms due to communication issues and a higher risk of sensory impairment. This means that increased care and sensitivity needs to be present when diagnosing and treating individuals with learning disabilities and probable dementia.

LGBTIQ+ persons with dementia

Older LGBTIQ+ individuals are more likely to be unmarried and live alone and have less children and family support (Vella C., 2019). Some LGBTIQ+ persons believe that services are insensitive to their needs, and members of conventional support groups can experience a sense of alienation. A recent study by Vella C. (2019) identified gaps in Maltese policy that would better assist older lesbian and gay people to age in a secure environment free from prejudice and mistreatment. The results also revealed ways in which service provision can be enhanced with increased awareness of the LGBTIQ+ community. Services should ensure that employees are aware and appropriately trained to deliver care and support that is sensitive and acceptable to a person's sexuality and gender identity.

Migrants living with dementia

Migrants living in the Maltese Islands who develop forms of dementia need to have easy access to the right services. In some cultures and societies, there is a stigma associated with dementia diagnoses that can make people reluctant to seek out help. Services that are not created to satisfy cultural or religious requirements may unintentionally prevent individuals, as well as their families and caregivers, from receiving assistance. Services must be aware of and prepared to address a person's language and communication requirements since the language needs of persons living with dementia may alter as the illness worsens. Services should make sure that the care, support, and treatment given is acceptable from a cultural perspective and that the employees are properly trained.

Action Area 1

Awareness and Understanding of Dementia

There are obstacles to diagnosis and care because of the widespread assumption that dementia is an unavoidable aspect of ageing rather than a disease process. Lack of understanding also breeds stigma and discrimination, as well as a dread of dementia. In addition, both in the community and in care facilities, people with dementia at times do not get their human rights respected.

Programmes promoting dementia awareness will:

- promote a thorough understanding of dementia and its various subtypes as clinical diseases.
- lessen stigma and discrimination associated with the condition.
- inform people about the human rights of people with dementia and the Convention on the Rights of Persons with Disabilities.
- improve the general population's capacity to recognize early symptoms and signs of dementia.
- increase public awareness of risk factors associated with dementia.

To ensure the quality of life and dignity for individuals with dementia, their caregivers, and families, a dementia-friendly society is ideal to foster inclusiveness and accessibility in community settings that maximizes chances for health, participation, and security for everyone.

Enhanced health and social outcomes that reflect the preferences and wishes of people with dementia can be promoted by dementia-awareness campaigns and dementia-friendly programmes that are tailored to the cultural contexts and specific needs of a community. These initiatives can also improve the quality of life for people with dementia, their caregivers, and the larger community. Knowledge on services available for persons with dementia and their caregivers is also essential. A study by Spiteri C. & Scerri C. (2020) indicated that although informal caregivers used and were satisfied with the provision of various services that were available, a number of dementia-specific services were still considered to be underutilised. This indicates that there is room for further improvement when it comes to awareness of services. It is critical that dementia care practice and policy development acknowledge the importance of creating awareness on the condition and relevant services available, since this is an essential component towards enhancing the quality of dementia care in the Maltese Islands.

Rationale

People with dementia will be able to participate in society and optimize their autonomy through enhanced social involvement if there is a greater knowledge, acceptance, and public awareness of dementia and its associated services.

Action Area 1: Objectives

	Measure	**Stakeholders**	**Timeframe**
1.1	Organise national dementia awareness initiatives that are community and culturally specific to Malta and Gozo in partnership with persons living with dementia, their caregivers, the organisations that represent them, the media, and other pertinent stakeholders.	*Ministry for Health and Active Ageing, Non-governmental organizations, and Dementia Care Directorate.*	Within 7 years
1.2	Ensure that the public has access to up-to-date information on dementia using different types of media.	*Ministry for Health and Active Ageing, Non-governmental organizations, and Dementia Care Directorate.*	Within 7 years
1.3	Collaborate with governmental and non-governmental organizations to make changes to the built and social environments, such as the provision of amenities, goods, and services, to make them more age- and dementia-friendly and to promote respect and acceptance in a way that satisfies the needs of those who have dementia and those who care for them, enabling participation, safety, and inclusion.	*Ministry for Health and Active Ageing, Ministry for National Heritage, The Arts and Local Government, Non-governmental organizations, and Dementia Care Directorate.*	Within 7 years
1.4	Actively encourage educational settings to create awareness on dementia, using appropriate material for school children.	*Ministry for Health and Active Ageing, Ministry of Education, Non-governmental organizations, and Dementia Care Directorate.*	Within 5 years
1.5	Provide programmes that are tailored to the Maltese context to promote dementia-friendly behaviours in the public and private sectors, and that are informed by the experiences of persons with dementia and those who care for them.	*Ministry for Health and Active Ageing, Ministry for National Heritage, The Arts and Local Government, Non-governmental organizations, and Dementia Care Directorate.*	Within 5 years
1.6	Work in partnership to promote and support the work of non-government organisations working in the field of dementia.	*Ministry for Health and Active Ageing, Non-governmental organizations, and Dementia Care Directorate.*	Within 5 years

To ensure the quality of life and dignity for individuals with dementia, their caregivers, and families, a dementia-friendly society is ideal to foster inclusiveness and accessibility in community settings that maximizes chances for health, participation, and security for everyone.

Action Area 2

Reducing the Risk

Growing evidence points to a connection between dementia and risk factors connected to lifestyle. Physical inactivity, obesity, an imbalanced diet, cigarette use, alcohol abuse, diabetes mellitus, and mid-life hypertension are some of these risk factors. In addition, added risk factors for dementia that may be controllable have been identified, which include social isolation, lack of education, cognitive inactivity, and midlife depression. Individuals and populations can be better equipped to make healthier decisions and adopt lifestyle habits that promote good health by reducing their exposure to these potentially modifiable risk factors, starting in childhood, and continuing throughout the life course.

There is growing understanding that the following actions are protective and can lower the risk of cognitive decline and dementia: increasing physical activity, preventing and reducing obesity, promoting balanced and healthy diets, quitting smoking and alcohol use, encouraging social engagement, promoting cognitively stimulating activities, preventing and managing diabetes, hypertension (especially in midlife), and depression.

When recommending the adoption of healthy lifestyle choices, clinicians should clarify that the healthiest of lifestyles cannot, unfortunately, guarantee that someone will not experience cognitive impairment or dementia, but research is indicating that positive life-style choices significantly reduce the risk.

Rationale

The risk of developing dementia can be decreased, and its progression delayed by enhancing the ability of health and social care professionals to educate the public about and proactively manage modifiable risk factors for dementia. This needs to be carried out through evidence-based, multisectoral, gender- and culturally appropriate interventions.

Action Area 2: Objectives

	Measure	**Stakeholders**	**Timeframe**
2.1	Ensure that evidence-based risk reduction strategies are included in relevant public health promotion policies and programmes.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 5 years
2.2	Ensure that the general population is aware of the measures they can take to reduce the risk of dementia.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 5 years
2.3	Ensure that people with dementia receive advice about changes that they can make to increase their general health and wellbeing.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 5 years
2.4	Create, provide, and spread training and interventions that are supported by evidence for health professionals, to improve knowledge and practices of staff, and proactively manage modifiable dementia risk factors in their practice. As new scientific data becomes available, these treatments need to be regularly updated.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 7 years

Action Area 3

Timely Diagnosis

"...I have been diagnosed with dementia approximately a few months ago. I had felt a hunch that something changed in my life. One day, while driving my car, I found myself in a place far away from my actual destination. This made me realize that I should seek professional help. After many tests etc. I was told by the consultants that I had dementia and that there is nothing they can do to make it better."
Author Ms Rita Vella

Responses to a diagnosis of dementia can range from shock and extreme sadness to rage and despair because it is a disorder that dramatically alters one's quality of life. But it can also be a relief for a lot of persons. A diagnosis might offer long-needed explanations for deteriorating memory, communication issues, and behavioural abnormalities.

Future care and treatment options are made possible by an early diagnosis. Making plans for the future, while one is still able to make critical choices about care and support needs, as well as choices regarding money and legal issues, are beneficial. The use of novel diagnostic techniques will allow persons to receive relevant knowledge, counsel, and direction as early as possible. The study by Frisoni GB et al. (2017) highlighted the need to develop diagnostic algorithms comprising combinations of biomarkers, and the development of clinical guidelines for the use of biomarkers in qualified memory clinics to achieve timely and accurate diagnoses.

A significant study on the advantages of early diagnosis reveals that receiving a diagnosis is frequently met with extreme shock, along with sentiments of shock, rage, loss, and grief (ADI 2011). However, once the initial shock has subsided, a diagnosis is frequently seen as a "positive event" by persons who have dementia and their loved ones. The way a person with dementia is informed of their diagnosis and the quality of care offered to them and their families after the diagnosis are crucial factors in determining how they will react. In Malta and Gozo, primary care physicians act as a first point of contact for individuals suspecting memory loss. However, they frequently miss the early signs of dementia, robbing their patients of an accurate diagnosis. One of the underlying causes of this is a lack of training in early symptom recognition, both throughout their undergraduate medical education and throughout their professional careers. Time restrictions, reluctance to recognize and report dementia, treatment nihilism, and the inadequacy of existing diagnostic methods are among other factors (Scerri, 2018).

It is therefore critical that a dementia diagnosis is delivered to the patient and their family in a constructive manner, with time set aside to address any concerns and offer comfort and support. The person is more likely to feel more in charge and empowered to make choices when the news of the diagnosis is delivered in an appropriate manner. A person exhibiting symptoms of dementia may actually have a treatable condition, and a person with dementia can only obtain the appropriate care and support after a diagnosis, therefore the advantages of an early diagnosis greatly outweigh these anxieties.

Rationale

Achieving an early diagnosis can help people with dementia to have access to relevant information, resources, and support, make the most of their abilities and potentially benefit from drug and non-drug treatment options. An early diagnosis gives professionals the opportunity to explain to family and friends the changes that are happening and will occur in their life.

Action Area 3: Objectives

	Measure	Stakeholders	Timeframe
3.1	Ensure that as many people as possible receive a diagnosis early in the disease's progression.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 7 years
3.2	Work with stakeholders to identify and utilize the most robust clinically validated dementia assessment tool/s for the local context.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 5 years
3.3	Create a single procedure incorporating best practise recommendations for diagnosing and classifying dementia.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 5 years
3.4	Ensure that every person diagnosed with dementia will receive a tailored information pack in an accessible format, including digital options, and should be offered access to post diagnostic support.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 5 years
3.5	Develop the knowledge and abilities of general and specialised professionals involved in the diagnostic process to provide evidence-based, culturally acceptable, and human rights-oriented health and social care.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 7 years
3.6	Develop and make accessible to professionals, diagnostic pathways to help facilitate the diagnosis of dementia and its main subcategories.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 2 years

Making plans for the future, while one is still able to make critical choices about care and support needs, as well as choices regarding money and legal issues, are beneficial.

Action Area 4

Living well with Dementia

When a diagnosis causes life changes, a range of distinct emotions, including sadness and loss, as well as adjustments to relationships, roles, and perspectives on life, might be felt. Changes in cognition, memory, and functioning, among other symptoms, may appear, and these changes can have a variety of effects on a person's life and wellness.

There are various ways to encourage wellbeing along the path, and coping mechanisms can be useful during times of transition. When we reflect on our lives, we can see how we have developed as individuals and adapted to changes we have encountered. This occurs gradually, just like the changes seen during the course of dementia.

Relationship dynamics, changes in responsibilities within relationships, and even the loss of relationships are some of the most frequent parts of life that may be influenced by a dementia diagnosis. Finding solutions to improve the welfare and quality of life for everyone affected by dementia is essential to living well with the disease. It recognises that despite the changes taking place, positive feelings and experiences in life are still possible.

Knowing how to use the healthcare system and support systems, which can be difficult and stressful, is another aspect of living well with dementia. Finding services that best suit your requirements, planning support, and being aware of the resources available, can all enhance the overall experience of living with dementia.

An approach that is positive and empowering, focused on helping persons with dementia live well with the condition, has been adopted by several European countries. However, it is evident that persons with dementia require the right kind of support if they are to have fulfilling lives. This necessitates a comprehensive strategy that considers public policies, social and health systems, and the larger society. Living well has different connotations for different people, so it's important to use a holistic approach while evaluating the individual's requirements and determining the variables that affect their wellbeing. This will result in more tailored, highly effective interventions and assistance to help people "live better" with dementia.

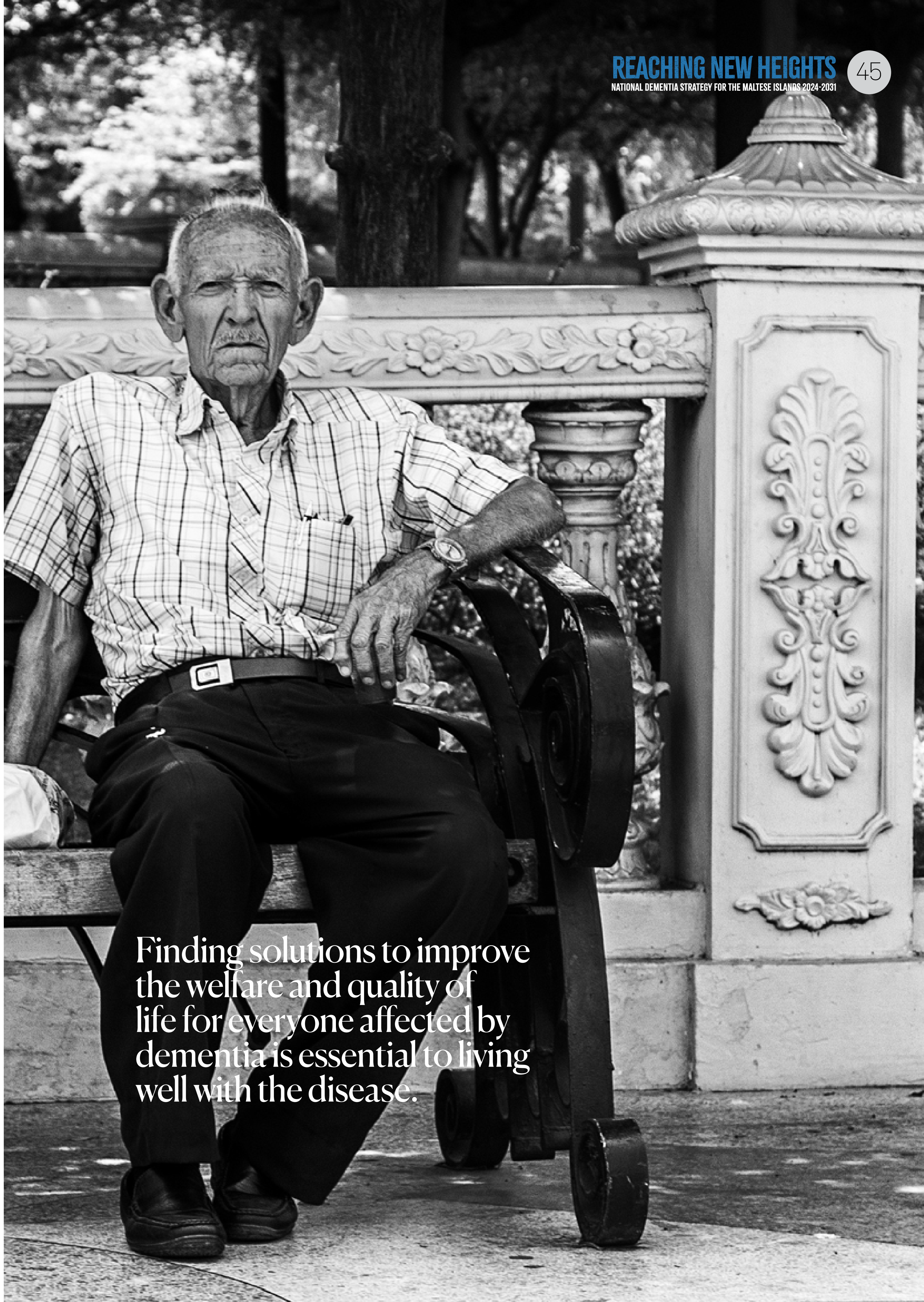
> **"I live on my own, but my family and friends keep me in check. I cook, do the laundry, clean the house, take care of my pet who I love to bits. He truly protects me when he feels that mummy is not feeling well. I love music as it calms me down. I constantly work to gain more positive attributes in order to make my life more serene and be an instrument of great joy to others."**
>
> Author Ms Rita Vella

Rationale

Viewing dementia as a condition that people manage and live with, may reduce stigma and promote a more positive sense of identity.

Action Area 4: Objectives

	Measure	Stakeholders	Timeframe
4.1	Make sure that all persons diagnosed with dementia have access to person-centred and coordinated care guided by the Dementia Intervention Team.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 2 years
4.2	Ensure that day care services for persons with dementia are available and accessible.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 5 years
4.3	Follow the latest evidence-based developments in the pharmacological and non-pharmacological treatment of dementia and consider their implementation in the local context.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 7 years
4.4	Explore the use of technology to support independent living in the community and in residential settings.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 7 years
4.5	Assist in the creation of support networks to help individuals with dementia and their caregivers to have peer support.	*Ministry for Health and Active Ageing, Dementia Care Directorate and non-governmental organizations.*	Within 5 years
4.6	Work towards the development of advanced care planning.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 7 years
4.7	Work towards establishing continued post-diagnostic care when a person with dementia transitions from the community to residential settings	*Ministry for Health and Active Ageing and Dementia Care Directorate*	Within 7 years



Finding solutions to improve the welfare and quality of life for everyone affected by dementia is essential to living well with the disease.

Action Area 5

Work Force Development

Concerns of growing public health importance include creating a public health agenda to prepare the workforce with the capability and skills to deliver high-quality services and support to the expanding population of people with dementia, and to successfully deal with the complex and progressive effects of dementia at all levels of society.

The expansion of the dementia care workforce is having difficulties in terms of hiring, retaining, career promotion, legislation, and training. In terms of curricula and opportunities for practical experience, dementia care is likewise underrepresented in clinical training. There is a demand for geriatric and dementia education across a wide range of occupations, and yet dementia-specific training requirements are lacking and uneven.

Unless workforce issues in dementia care are resolved, our national capability to provide equitable access and non-discriminatory health services to these vulnerable and underserved populations will become even more constrained. The journal Public Health Nursing (Epps F, Alexander K, Brewster GS, et al., 2020) reported on the public health crisis of dementia and vulnerability, emphasizing the value of population-specific education. According to one study, such education “can help ensure future public health programs and policies adequately allocate resources.” A local study by Sacasan N. & Scerri C. (2020) identified a lack of in-depth knowledge among allied health professionals. Scerri C. (2021) found that participants in postgraduate training programmes enhanced the students’ knowledge and attitudes towards individuals with dementia. This continues to highlight the need of enhancing dementia training programmes through undergraduate curriculum development and continuous professional programmes for skills updating.

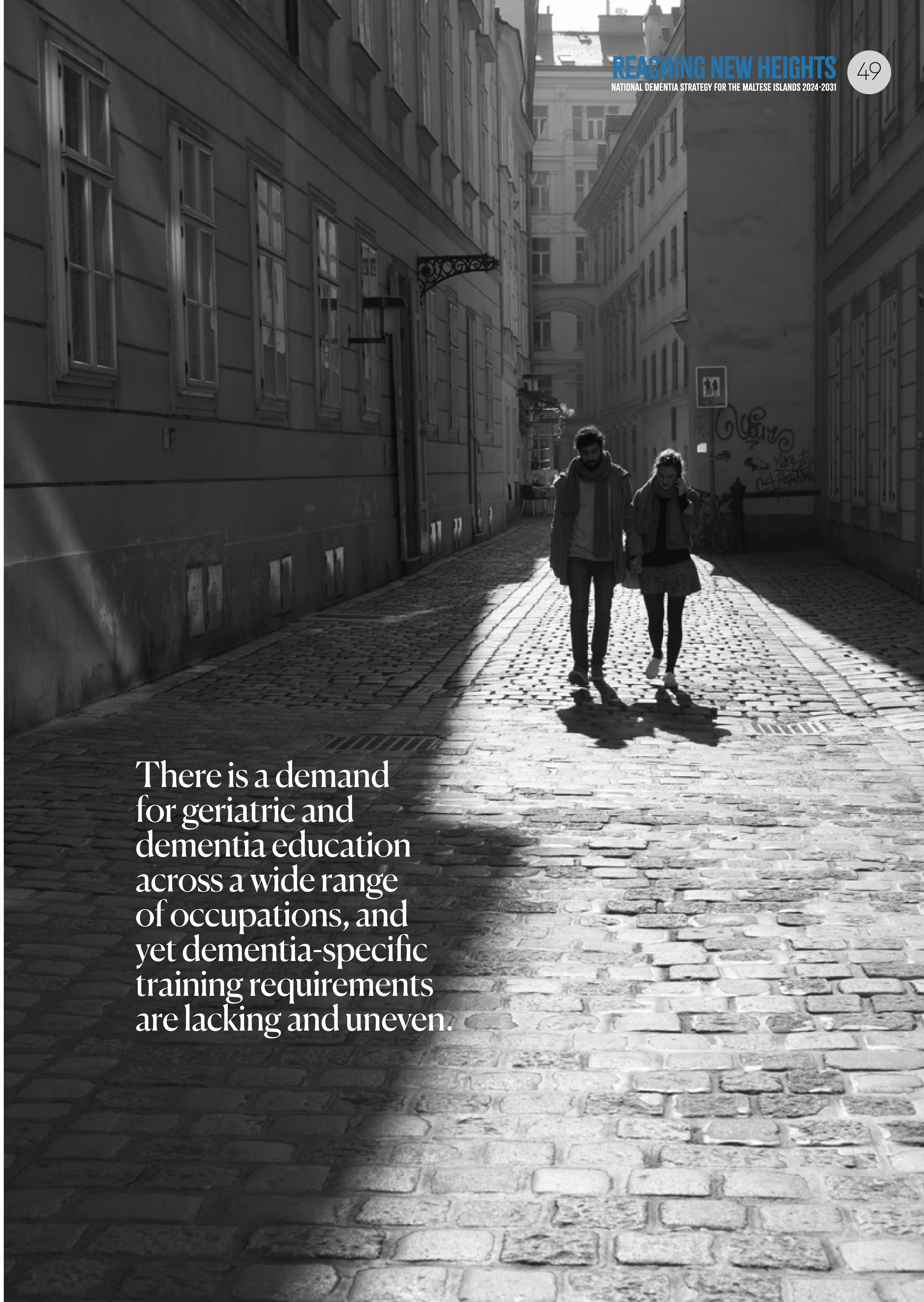
By adopting the following key actions, the nation can work towards achieving the ideals and expectations of providing equitable, ethical, effective, and robust care to people living with dementia, their families, and the community at large, all while reducing personal strain and public health costs.

Rationale

The increasing number of individuals with dementia, necessitates the need to improve education, training, and organizational support for direct care workers. A dementia-capable workforce will address the need for highly competent workers who can deliver quality and comprehensive person-centred care to people living with dementia.

Action Area 5: Objectives

	Measure	**Stakeholders**	**Timeframe**
5.1	Make sure that clinicians undergo the training needed to be proficient in dementia diagnosis and care.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 5 years
5.2	Caregivers of persons with dementia will be offered an assessment of their own needs. Thereafter, a support plan will be developed with the caregivers to identify appropriate support and training needs.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 2 years
5.3	Employees working in dementia day centres will be provided with up-to-date and advanced training on dementia care.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 2 years
5.4	Training programmes for health care and social care employees will be provided so that they can better identify and reduce stress and burn-out of caregivers. This will result in caregivers being empowered to continue performing their caring duties.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 5 years



There is a demand for geriatric and dementia education across a wide range of occupations, and yet dementia-specific training requirements are lacking and uneven.

Action Area 6

Dementia Management & Care

Persons living with dementia ought to have the freedom to live in their neighbourhood and get care that adheres to their preferences and wishes. They require integrated, person-centred, accessible, affordable health and social care, including long-term care, so that they are enabled to maintain a level of functional capacity consistent with their basic rights, fundamental freedoms, and human dignity. From the time of diagnosis through to the end of life and into the stages of mourning, family and caregivers play a vital part of the continuum of care for people with dementia. Holistic services need to offer advance care planning, assistance, as well as physical, emotional, and spiritual support for persons with dementia and their caregivers.

From the onset of dementia symptoms to the end of life, it is essential that care providers, multiple sectors, paid and unpaid caregivers, collaborate actively to provide a continuum of care. This continuum of care should take place across all environments where individuals with dementia reside, including their homes, the community, nursing homes, hospitals, and hospices. All settings must provide integrated, evidence-based, person-centred care. Scerri A., Innes A. & Scerri C. (2020) in their study identified a number of organizational challenges that have a direct impact on the quality of care of patients with dementia in long term care residential facilities. The study suggested several solutions such as realigning the available policies, improving training and care coordination, redesigning the ward environment, and changing leadership styles. Another local study by Scerri A., Innes A., & Scerri C. (2020) found that basic needs such as toileting, feeding, drinking, continence and comfort were not always met in acute ward settings. Moreover, the largest gap between met and unmet needs was found in persons with dementia who were either under constant observation or unable to communicate. Too much emphasis was perceived and observed to be given on what employees considered as safety needs at the expense of other needs. Policies need to acknowledge these limitations and plan how services across the dementia journey improve to provide person-centred care.

> **"...since diagnosis, I have become extremely sad. My *joie de vivre* has been shattered. I cry everyday even though I am trying to get over this but sometimes I feel that I have become a waste of space. I had another big shock when I was told to stop driving. On the other hand, I go out with friends and family. The weekends tend to be full of activities, and it helps me to decrease my anxiety."**

Author Ms Rita Vella

Rationale

The needs and preferences of people with dementia can be met and their autonomy can be respected through integrated, culturally appropriate, person-centred, community-based health, psychosocial, long-term care, and support. The input of families and caregivers is essential for best practises.

Action Area 6: Objectives

	Measure	**Stakeholders**	**Timeframe**
6.1	Review integrated care pathways for appropriate geriatric, neurological, and psychiatric specialty services.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 5 years
6.2	Remove any age limitations when it comes to accessing dementia care services.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 2 years
6.3	Work towards establishing services specialised in dementia management and care in the community, acute rehabilitation, and long-term care residential settings.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 7 years
6.4	Involve caregivers in the planning of care, with attention being given to the wishes and preferences of people with dementia and their families.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 2 years
6.5	Increase the number of beds in long-term settings which can provide care to persons with dementia.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 5 years
6.6	Ensure that structures being built over the coming years to cater for an ageing population, incorporate dementia-friendly designs.	*Ministry for Health and Active Ageing, Older Persons Standards Authority and Dementia Care Directorate.*	Within 7 years
6.7	Ensure that long-term care settings for persons with dementia have appropriate guidelines which safeguard and provide the best quality of life possible. These guidelines also need to be enforced by the competent authorities.	*Ministry for Health and Active Ageing, Older Persons Standards Authority and Dementia Care Directorate.*	Within 5 years
6.8	Recognize and implement palliative care/end of life approaches for persons with dementia in the advanced phases of the condition across all settings.	*Ministry for Health and Active Ageing and Dementia Care Directorate.*	Within 7 years

From the onset of dementia symptoms to the end of life, it is essential that care providers, multiple sectors, paid and unpaid caregivers, collaborate actively to provide a continuum of care.

Action Area 7

Research & Information Systems

Research and innovation are essential. If the incidence of dementia is to decrease, and the lives of those with dementia are to be improved, it is crucial that infrastructures for supporting dementia research and innovation are bolstered.

Additionally, it is crucial that systems are in place to support the proper recruitment of persons with dementia, their families, and caregivers into research projects. Due to lower success rates, longer development times, and lower trial enrolment rates, research and development expenses for dementia are higher than those for other treatment fields. This disparity inhibits investment in this field.

In addition to research for treatment for dementia, there is a need for research in the fields of social science, public health, and implementation research for prevention, risk reduction, diagnosis, treatment, and care.

Innovative health technologies are increasingly being pursued, in dementia prevention, risk reduction, early detection, treatment, care, and support. To facilitate and assist the daily lives of individuals with dementia and their caregivers, these innovations strive to increase knowledge, skills, and coping strategies. They also specifically address identified requirements in a fact-based, age, gender, and culturally sensitive manner.

The data required to inform evidence-based decisions to enhance services and track advancement in the implementation of the national dementia policy, needs to be provided by systematic, regular population-level monitoring of a core set of dementia indicators. The functional trajectories of those with dementia, their caregivers, and their families can be improved by developing and/or upgrading information systems for dementia. To share health and administrative data from each encounter that a person with dementia has with the health and social care system, routine data collecting, recording, linking, and disaggregation must be significantly improved while still adhering to regulatory frameworks.

The strategy recommends that formal channels for communication and collaboration, such as the setting up of advisory boards or committees are sought. These will bring together representatives from various stakeholder groups. Such advisory boards or committees need to include key stakeholder such as the Directorate of Dementia Care, the University of Malta and other stakeholders that can contribute to the forum.

Rationale

Systematic monitoring and evaluation of the use of health and social care systems can provide the best evidence currently available for policy development and service delivery. Progress towards better dementia prevention, diagnosis, treatment, and care can be increased by effectively implementing dementia research in accordance with recognised research goals and social and technological developments.

Action Area 7: Objectives

	Measure	**Stakeholders**	**Timeframe**
7.1	Encourage and support epidemiological studies on dementia management and treatment in various care settings. These need to use inclusive research methodology that includes the person with dementia, their caregivers, and family members.	*Ministry for Health and Active Ageing, Dementia Care Directorate, University of Malta.*	Within 7 years
7.2	Create a group of interdisciplinary dementia specialists to discuss and exchange new research findings and practice-relevant information.	*Ministry for Health and Active Ageing, Dementia Care Directorate, University of Malta.*	Within 5 years
7.3	Develop and encourage multisectoral cooperation and partnerships with other nations at the national and international levels in the fight against dementia.	*Ministry for Health and Active Ageing, Dementia Care Directorate, University of Malta.*	Within 7 years
7.4	Design and conduct research to evaluate the unmet requirements of community-dwelling older persons with dementia, their caregivers, and family members, in cooperation with all the relevant stakeholders.	*Ministry for Health and Active Ageing, Dementia Care Directorate, University of Malta.*	Within 7 years
7.5	Create research projects on behavioural and psychological symptoms of dementia to develop treatments based of evidence-based practice.	*Ministry for Health and Active Ageing, Dementia Care Directorate, University of Malta.*	Within 7 years
7.6	Work towards establishing a dementia register which is accurate and up to date, to improve availability of high-quality, multisectoral data on dementia.	*Ministry for Health and Active Ageing, Ministry of Health and Dementia Care Directorate.*	Within 7 years

In addition to research for treatment for dementia, there is a need for research in the fields of social science, public health, and implementation research for prevention, risk reduction, diagnosis, treatment, and care.

Planning the way forward

This National Dementia Strategy will be implemented gradually over the course of seven years with the goal of addressing the societal, policy, and service changes required to enhance the quality of life for persons who are living with the condition. It offers a comprehensive framework for dementia-related activities across the Maltese Islands, and it may be customised by various communities, organisations, and local governments to meet their particular needs. It is encouraged for individual organisations to bear this in mind as they approach their work on dementia.

As the strategy approaches implementation, it is crucial to maintain communication and involvement with all stakeholders. Understanding how to provide dementia tools and assistance that are both culturally sensitive and appropriate depends on the success of this participation. In fact, every Maltese citizen can take action to reduce the chances of developing dementia through healthy habits described in the strategy and this leads us to achieve a central goal related to the prevention of the condition, which is key to this strategy's success.

In view of the multifaceted nature of the National Dementia Strategy Policy, aside from the Ministry for Health and Active Ageing, other Ministries and Parliamentary Secretariats must take the initiative to implement the National Dementia Strategy Policy's goals, objectives, and recommendations.

The Ministry for Health and Active Ageing will undoubtedly lead the implementation of the recommendations in this document, but due to the national imperative of the strategic policy, various Ministries are required to secure the necessary funding and personnel for initiatives that fall under their respective purviews. In addition, assistance from the European Union is anticipated to increase national budgetary resources as well.

It is advisable that the government creates an Inter-Ministerial Committee, headed by the Ministry for Health and Active Ageing, whose responsibility will be to direct the process of implementing the suggestions within a reasonable timeframe. To ensure that the actions outlined in the seven sections of the policy are carried out effectively and efficiently, this Inter-Ministerial Committee will coordinate and oversee the implementation process. It will also ensure that people with dementia, caregivers, and family members are included in the implementation process by evaluating priorities, and establishing a plan of action, timeframes, and key players. Progress of the strategy's implementation will be monitored closely by the committee and new evidence-based developments in the field, which might occur in this 7-year period, can be implemented after discussions with stakeholders.

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Notes

REACHING NEW HEIGHTS

NATIONAL DEMENTIA STRATEGY
FOR THE MALTESE ISLANDS
2024-2031

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Dementia Care Directorate

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