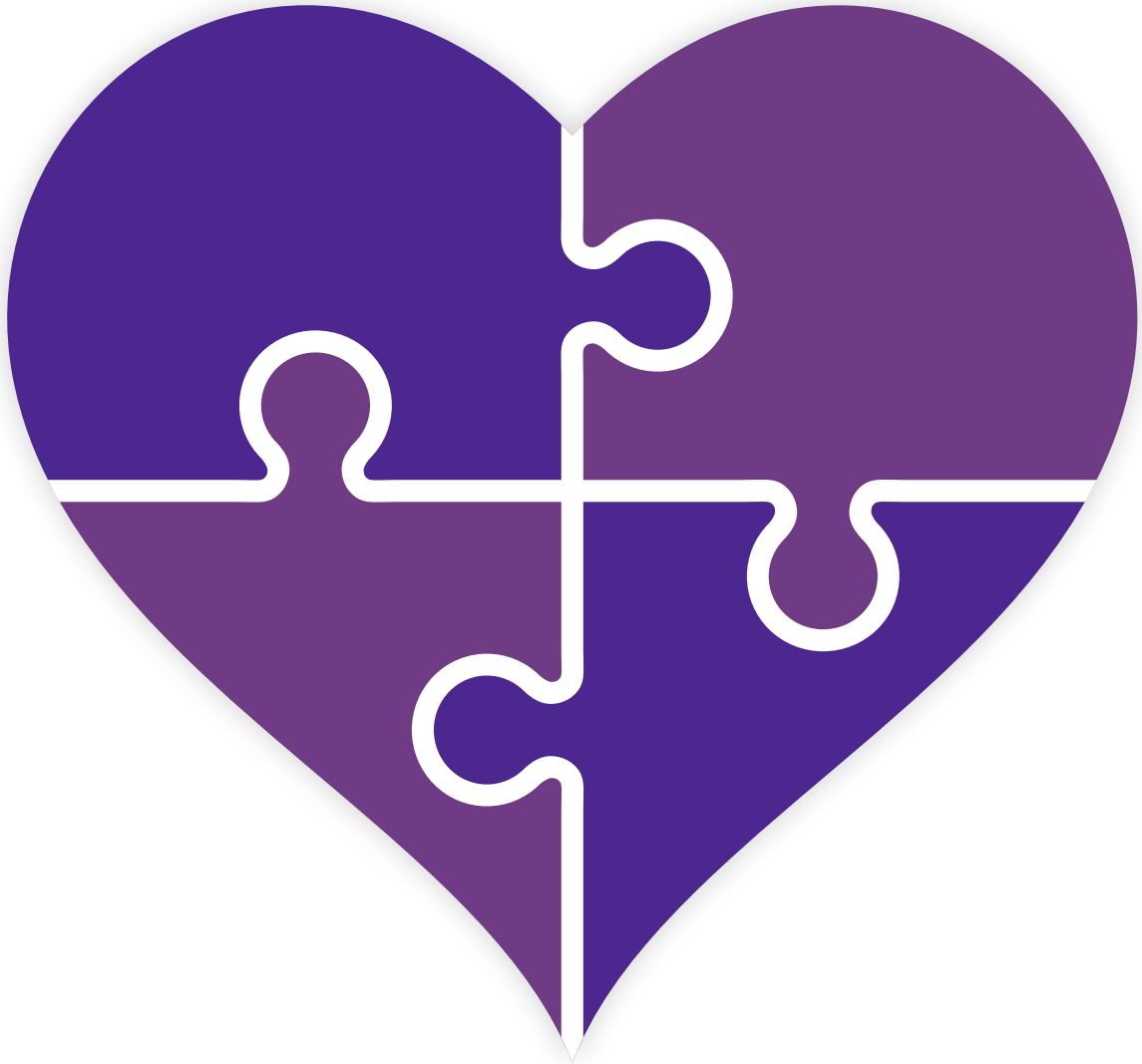




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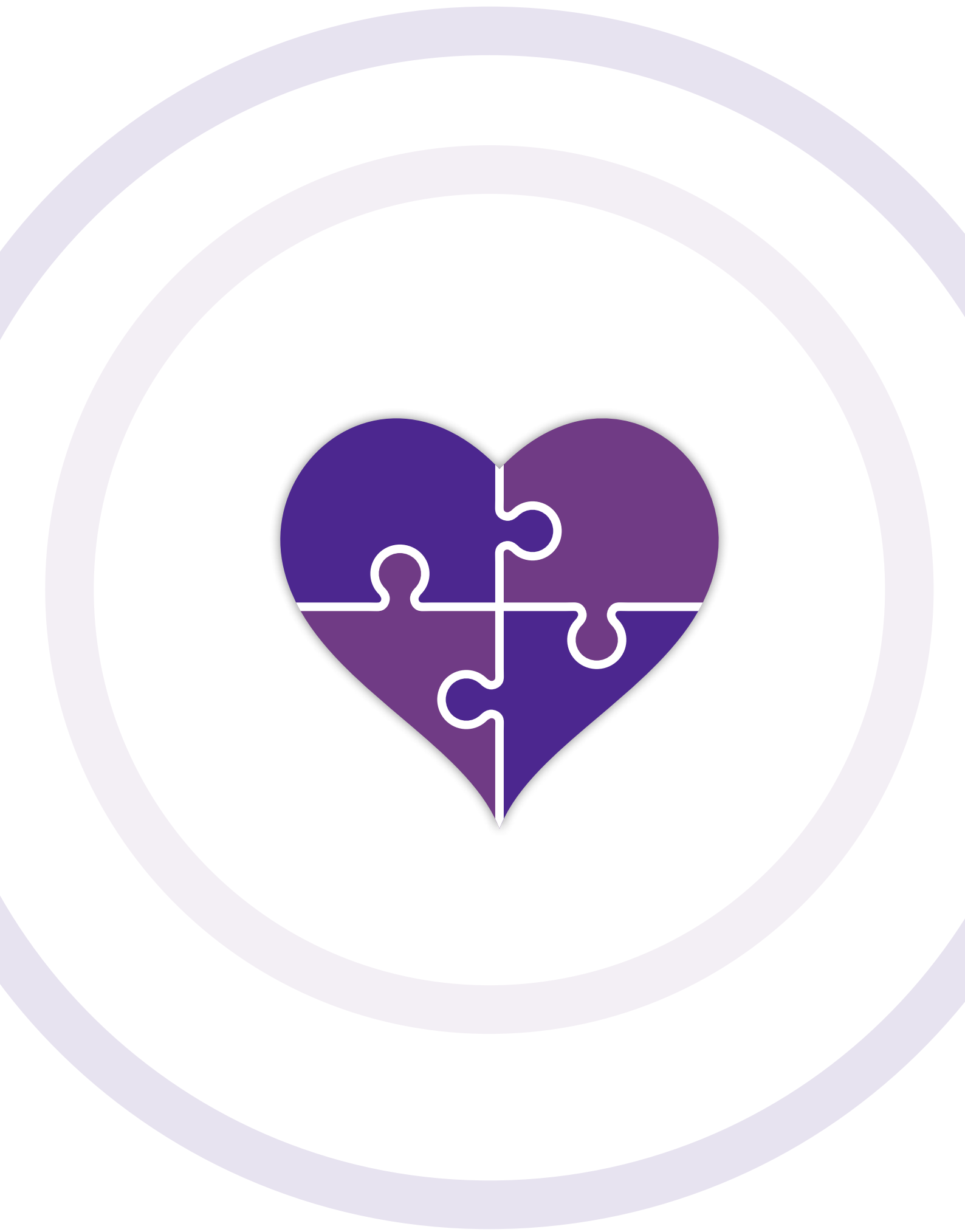
HM Government of Gibraltar



Gibraltar National Dementia Strategy

2023 - 2028





Ministerial Foreword

As Minister for Health and Care, I am delighted to endorse this Strategy. The aim of this strategy is to facilitate an improvement in the quality of life of those living with dementia and their families and carers by strengthening existing services using an integrated and focused approach

We want to build on partnership working between all agencies so that the person living with dementia becomes central to everything we do. This will achieve the best possible outcomes at all stages of the dementia journey for the person living with dementia, their families, their carers and the Gibraltar community.

The strategy is based on the previous Gibraltar National Dementia Strategy (2018 -2021) combining best practice from around the world which aims to meet the needs of the people of Gibraltar.

The strategy has been developed as a result of a multi-agency stakeholder approach involving the Gibraltar Health Authority (GHA), including the Elderly Residential Services (ERS), the Care Agency, the Gibraltar Alzheimer's and Dementia Society as the representation of people living with dementia and the Gibraltar Housing Department. We have also sought the views of people living with dementia in conjunction with their families/carers, as this is their strategy, and we are determined that they have a voice in how we take this agenda forward.

Our vision is to create a Dementia Friendly Country, where people with dementia are valued and able to live well at every stage of their dementia journey. This strategy will raise awareness and understanding of dementia, facilitating an early diagnosis so that people living with dementia, and their families and carers, can be supported to live and die well with dementia, anywhere in Gibraltar. As Minister for Health and Care I give my full support to the National Dementia Steering Group in delivering this most important agenda.



Albert Isola
Minister for Health and Care



Director General Foreword

Dementia is now the 7th leading cause of death globally and it is important to recognise that it is not a disease limited to the older generation. In 2015, Gibraltar launched its first Dementia Strategy, the strategy focused on five key objectives including:

- Making Gibraltar a dementia friendly community
- Improve communication with individuals living with dementia and their families and ensuring that information provided was user friendly.
- Creating greater awareness among our community about dementia and services available to support, not only the individuals with the disease but also their families and friends.
- Promoting greater working relationships with partner agencies and other organisations in delivering the strategies agenda. Ensuring the services provided were in accordance with the needs of the people who use these services.

To achieve the above, the following services have been developed:

- The opening of Bella Vista Day Centre in 2017
- The opening of Hillside Residential Home in 2017
- The introduction of the memory clinic pathway, using evidence-based protocols and tools that are aligned to the level of clinical need that a person with a potential dementia is presenting with, in the community.
- The staff who delivered the above, must be congratulated for all their hard work and dedication to this care group.

However, it is now time to move forward and take further steps to ensure that Gibraltar continues to become a dementia friendly country, recognising the rights of people to feel valued and live well with dementia at every stage of their illness, wherever they live in the community and that choices are available as to how and where people receive care and support.

The 2023-2028 strategy has four key objectives:

1. Continuing to raise awareness and understanding.
2. Support early diagnosis.
3. Promote living well with dementia.
4. Providing leadership that will enable this strategy to be delivered but also to continue to ensure that the services in Gibraltar are up to date, in line with best practice and that patients and their families are at the heart of all our decision-making processes.



As Chair of the Gibraltar National Dementia Steering Group, I would like to thank the GHA, ERS and our key partners including the Care Agency, Housing Department, Voluntary Organisations particularly GADS (Gibraltar Alzheimer's and Dementia Society), for their input and support in developing this document. But also, the people who use our services and their carers to help us understand what it is like to live with dementia. In this way, I believe the strategy reflects the needs of the service user. I would also like to thank our staff who work so hard to serve the needs of people with dementia and their caregivers.

As Director General, I am proud to be associated with the development of this strategy and am delighted that a Multi-Agency Steering Group continues to oversee its implementation.



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Executive Summary

The aim of this 5-year strategy is to facilitate an improvement in the quality of life of those living with dementia by strengthening existing services using an integrated and focused approach.

The strategy objectives

The strategy has been divided into 4 key objectives:

Key Objective 1: Raising awareness and understanding

Improving awareness and understanding will inform individuals and their families about the importance of early diagnosis and promote the prevention of dementia. Raising both awareness and understanding will encourage behaviour change in terms of seeking help and provision whilst reducing stigma.

Key Objective 2: Early diagnosis and support

All people living with dementia in Gibraltar need to have access to robust pathways of care that deliver an early diagnosis which enables treatment and support to be available as soon as possible whilst calibrated to meet changing needs. We also need to ensure that there is easy access into the system at a very early stage with signposts along the journey that allows and encourages people and their carers easy access to help when in need.

Key Objective 3: Living well with dementia

People living with dementia need to be supported to live at home for as long as they choose to. This will involve having access to flexible and reliable services, ranging from early intervention to specialist home care services available twenty-four hours a day seven days a week. To achieve this, we need for organisations involved in delivering services and their staff, to work and think differently so that the person living with dementia becomes the focus of what we do.

Key Objective 4: Leadership and governance

To achieve our vision, we need to have the right Leadership in place across all relevant organisations so that Dementia Services are given priority. In addition, it is essential that there is a Dementia Coordinator position established to lead on the implementation of this strategy and will be held to account by all of the stakeholders for performance managing the roll-out of the strategy's key objectives.

Implementation

The strategy will be modelled over a 5-year period and underpinned by an action plan including a financial/workforce plan with key priorities set for each year to ensure objectives are achieved and that any financial challenges are addressed as part of the annual budget setting processes by all organisations involved. The Dementia Coordinator will be responsible for overseeing this piece of work with support from the National Dementia Steering Group (see Appendix 3 for membership).



1. Introduction

The aim of this strategy is to facilitate an improvement in the quality of life of those living with dementia by strengthening existing services using an integrated and focused approach. This will achieve the best possible outcomes at all stages of the dementia journey for the person living with dementia, their families, their carers and the Gibraltar community.

The strategy is based on the ethos of ‘nothing about us without us’ (Williams, 2011) and ‘see the person, not the dementia’ (Alzheimer Society of Ireland, 2022). It is based on the UK Department of Health ‘Living well with dementia: A National Dementia strategy’ (DoH, 2009), the ‘Dementia Action Plan for Wales 2018 - 2022’, the Dementia Framework for the Bailiwick of Guernsey (2017) and the World Health Organisation (WHO) ‘Global action plan on the public health response to dementia 2017 – 2025.

The strategy has been created as a result of collaboration between all major stakeholders in Gibraltar; GHA (including ERS), the Care Agency, the Gibraltar Housing Department, Gibraltar Alzheimer’s and Dementia Society, but above all people and their families/carers who use the current services, thereby giving them an equal voice in planning the future dementia service for Gibraltar.

This strategy is based on listening to people with dementia and as well as their families and carers, putting them at the heart of how we make decisions. We commit to working in partnership with all people, their families/carers affected by dementia, making sure they are involved in setting our priorities and the approach we take so that we can deliver our strategy/services in accordance with their needs.

Over the last 3 years (2019-2022), we have been met with unprecedented times due to the worldwide pandemic in COVID-19. The effects of this pandemic, on people living with dementia and their families has been significant. The support services to those people in our community will take some time to recover and we have yet to know the full impact. We must also acknowledge the effect on the development of the current strategy whilst the focus of the health services, and their strategic partners, was on saving lives and rolling out a major Covid 19 vaccination programme.

This strategy has 4 key objectives aimed at improving the quality of life for people living with dementia:

- 1. Raising awareness and understanding** to ensure better knowledge about dementia and removing the associated stigma.
- 2. Early diagnosis and support** to ensure that people with dementia get the necessary support and treatment as early as possible.
- 3. Living well with dementia** to develop the necessary services to meet the needs of people living with dementia in the community.
- 4. Leadership and Governance** to ensure we have the right people in the right place/position with the right skill set to implement this strategy.

2. Background



2.1 Dementia worldwide

Dementia is not a normal part of ageing. It is an umbrella term which is used to describe the loss of memory and thinking ability caused by various diseases which damage the brain (Alzheimer Europe, 2022).

Currently more than 55 million people live with dementia worldwide and there are approximately 10 million new cases each year (WHO, 2022). Alzheimer's is the most common cause of dementia, however there are many different types of dementia which are all progressive and life-limiting. Dementia is currently the seventh leading cause of death and one of the leading causes of disability and dependency among older people

worldwide (WHO, 2022). It was the leading cause of death in the UK in 2018, accounting for 12.7% of all deaths registered (Office of National Statistics, 2021). There is currently no cure for dementia; this is predominantly because dementia is caused by more than one disease, consequently, there is unlikely to be a single cure for dementia (NHS, 2021). Dementia does not affect just older people, approximately 9% of all cases are classed as young-onset dementia (WHO, 2022). According to Alzheimer's Disease International (2022) up to three quarters of those with dementia worldwide have not received a diagnosis.

Dementia symptoms can vary from person to person and typical symptoms include memory loss, disorientation, and problems with activities of daily living (Alzheimer's Europe, 2022). There is often a lack of awareness and understanding of dementia which results in stigma along with

barriers to diagnosis and care (WHO, 2022). A diagnosis of dementia is life-changing but with the right help and support we can ensure that the person does not become the illness and can live well within the community they choose to live in.

2.2 Considering dementia as a disability

When using the term disability, dementia is not often included. Dementia, in the earlier stages is not an obvious disability as many people can cope until they face complex situations such as banking, shopping, using a bus, finding their way around, not recognising a loved one or cooking a meal. The standard paradigm of dementia is based on medical and clinical language viewing dementia as a neuro-degenerative condition, which it is. However, although this view is important for diagnosis and research it means that many socio-psychological factors could be overlooked (Kitwood, 1997). By considering dementia as a disability, our way of thinking about the condition is challenged. It recognises that people with dementia have a range of impairments which can face disabling barriers from attitudinal, social, and psychological to environmental and physical. Therefore, our response cannot be just medical, it requires society to realise that as a community we must do something and that as a community we need to take ownership, enabling the abilities of people with dementia, not creating further disability. The Gibraltar Government is currently working towards ensuring that the UN Convention on the Rights of Persons with Disabilities is extended to Gibraltar.

2.3 Dementia in Gibraltar

In 2014, 328 people with a diagnosis of dementia were living in Gibraltar. This rose to 424 people by 2018, an increase of 29%. Currently 366 people are living with dementia in Gibraltar, 185 live in the community and 181 in residential care. Up to 82 people currently use the Bella Vista day care centre. However, the figures surrounding the actual number of people

living with dementia in Gibraltar are likely to be inaccurate due to the impact of the COVID 19 pandemic (Alzheimer's Society, 2020; NHS Digital, 2022).

Gibraltar has an ageing population (HM Government of Gibraltar, 2012), according to last Census of Gibraltar (2012) the largest increase with respect to the Usually-Resident population over the previous 40 years relates to the "80 and over" age group. This group increased by +310.9% (+1,054 persons). Additionally, an increase of +94.3% (+1,869 persons) was seen in persons aged 65 - 79 over the same period. It is therefore likely a further increase in these age groups will be found in the 2022 Census, mirroring the European trend of an ageing population and resulting in a significant need of investment to support this care group from a health and social care position.

According to Alzheimer's Europe (2019) the average predicted prevalence for dementia per population is:

- 1.73% in 2018 (557 people based on 32,194)
- 2% in 2025 (644 people based on 32,194)
- 3.28% in 2050 (1056 people based on 32,194)

Noting the figures broken down by country into the UK and Spain, the UK prevalence is slightly lower, whilst the Spanish prevalence is higher.

Based on Gibraltar population figures (which are likely to be higher) and using the current trends, it is estimated that by 2025, 644 people will be living with dementia in Gibraltar. A 76% increase on our current numbers.

By 2050, it is estimated that there will be 1056 people (a 188% increase) living with dementia in Gibraltar. This appears to follow the UK trend where it is estimated that the cost of dementia is expected to double by 2050 (Alzheimer's Research UK, 2021)

While these figures seem high, up to three quarters of people world-wide have not received a formal dementia diagnosis (Alzheimer's disease International, 2022).

2.4 Lifestyle choices in Gibraltar

Although there is currently no cure for dementia, it is believed that up to 40% of dementia could be prevented (Livingston et al. 2020). Experts agree that what is good for the heart is also good for the brain (NHS, 2020). Key lifestyle choices which are known to have an impact on dementia include smoking, diet, activity and alcohol consumption.

According to a lifestyle survey carried out in Gibraltar in 2021 (Public Health Gibraltar):

- 47.1% of people do little or no exercise per week in their daily routine.
- 82% of adults do not eat at least 5 portions of fruit and vegetables per day.
- 23.5% of adults currently smoke and 3% use e-cigarettes or vape
- 1 in 3 adults drink one or more alcoholic drink per week and 3.5% drink 6 alcoholic drinks more than 3 times per week.

These results show that there is scope to improve the lifestyle choices within the local community.



3. Progress and achievements of the current strategy (2015-2022)

In order to move forward with this updated strategy, it is vital to reflect on the significant successful achievements since the National Dementia Vision and Strategy for Gibraltar (2015) was implemented.

The following have been achieved so far:

1. The opening of the Bella Vista Day Centre and the continued success of the Waterport Day Centre in providing a social, stimulating environment promoting the wellbeing of our service users living with dementia in the community.
2. Relocation of Joint Memory Clinic to Bella Vista Day Centre providing easier access and pathways for an earlier diagnosis and management of dementia.
3. The opening of the Hillsides Residential Care Home with an additional 8 respite beds for the community.
4. The inauguration of the John Mackintosh Home in 2015 has been followed by an increase in its capacity. A further refurbishment to the building in 2018 allowed for an additional 18 beds, in a dementia friendly environment.
5. The integration of Health, Elderly and Social care.
6. The introduction of Care Agency hospital-based and mental health link social workers to assist with discharge planning.
7. The introduction of legislation to support the community, such as, the Lasting Powers of Attorney and Capacity Act (2018) and the Mental Health Act (2016).
8. Additional focus on dementia training for all staff in public and private service providers, involved in the Dementia Journey.
9. Initiatives have been taken in raising public awareness: Dementia Friends; International Dementia and Alzheimer's awareness month; Memory walks; University lectures; Awareness drop-in sessions.
10. Enhanced palliative and end of life care for those living with dementia with the support of palliative care and hospice nurses, and packages of care to support those living in the community.
11. Easier access to medical care for ERS residents and Bella Vista service users.
12. Improvement of Allied Health Professional services in Elderly Residential Services namely Speech and Language Therapy, Occupational Therapy and Physiotherapy.
13. Increased community collaboration and education through the first Dementia Conference in Gibraltar.

4. Purpose and scope of the Strategy 2023-2028

The purpose of this updated strategy is to:

- Build on the achievements to date.
 - Provide a framework for which our strategic partners, and other local services in our community, can deliver quality improvements to services for people living with dementia.
 - To provide guidance and support for the local community for the planning, development and monitoring of services.
 - To provide a guide to inform expectations of the high-quality health and social care services which can be expected by those living with dementia in Gibraltar.
- To be able to live at home for as long as possible.
 - To be cared for by people I am able to communicate with.
 - To be able to access a GP easily when I need to and have them understand me.
 - The ability to access suitable residential care if I can no longer remain at home.
 - Increased care and support as the condition progresses.
 - To remain independent for as long as possible
 - To be supported to remain independent outside of our home, within our community.
 - To be treated with dignity and respect
 - Value the input of my family who know me the best
 - Most importantly, to be recognised as a real person and not just someone with a diagnosis of dementia.

4.1 Methodology

This strategy was developed through the collaboration of GHA including the ERS, the Care Agency, the Housing Department and Gibraltar Alzheimer's and Dementia Society giving an equal voice to those living with dementia. It is a strategy developed from a vision created in 2015, which will continue to evolve and develop based on the requirements and recommendations of those living with dementia in Gibraltar. 'Nothing about us without us' must be the driving force behind this and any future strategies.

4.2 What do people living with dementia in Gibraltar want?

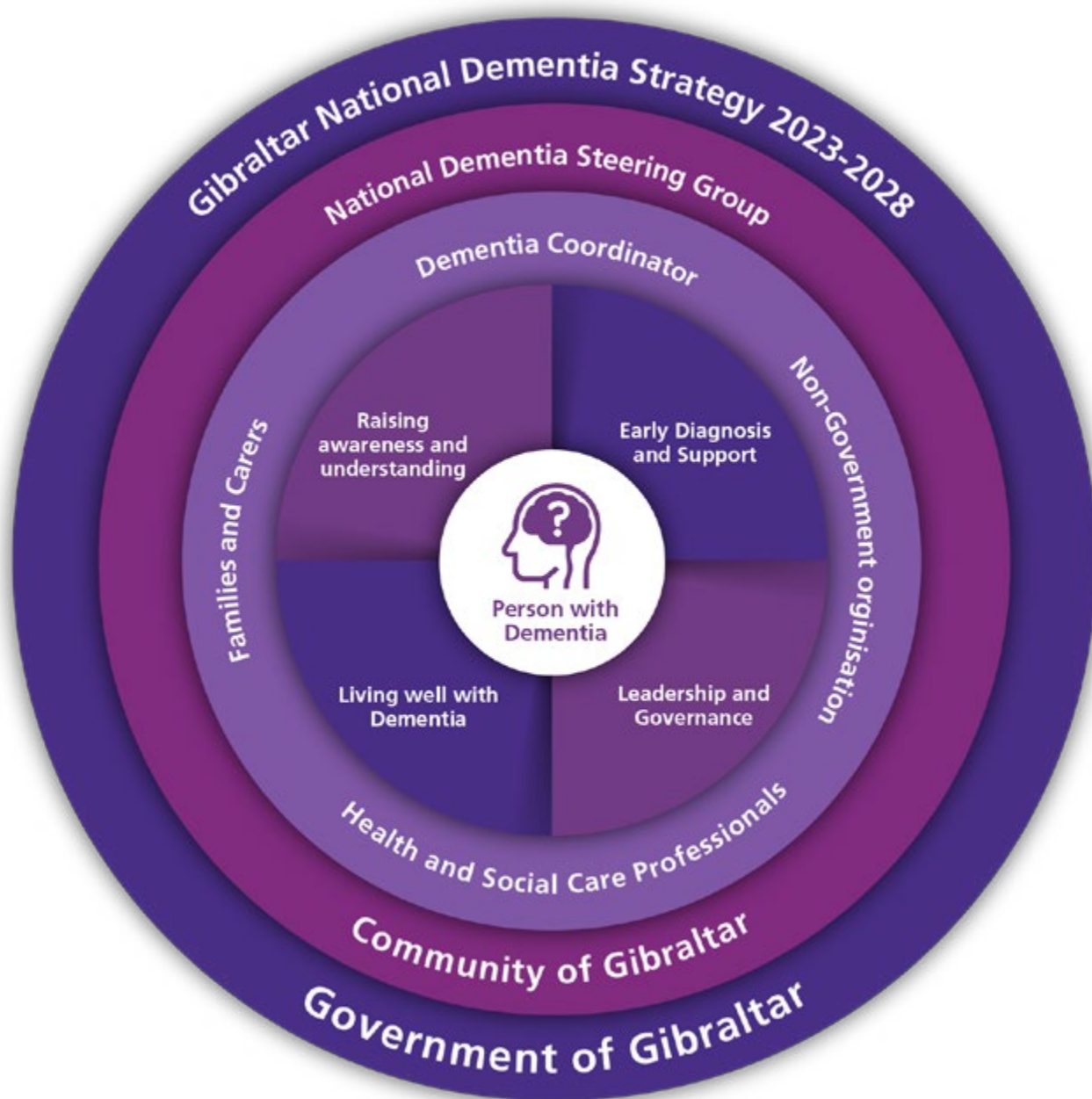
From our research and the listening exercise, which were held when developing this strategy, the following are the key issues that people living with dementia, their families/carers and staff involved in this care group want us to address:

4.3 Ambition

The focus of this strategy will be working in partnership with people living with dementia and their loved ones. Primarily the focus will be on establishing leadership and governance to ensure ownership by all relevant organisations and a commitment to its implementation.

Once we have awareness and understanding within our community, people (including patients and their families/carers) will be able to seek and be supported in achieving an early diagnosis and

in turn this will allow the focus to be on enabling people to live well with dementia throughout their journey and in the place of their choice. This will all be achieved by utilising a Gibraltar Dementia Partnership Framework as a visual representation of the strategy encompassing all aspects with one logo placing the person living with dementia at the centre of everything and working in partnership with them to enable them to live well with dementia.



Gibraltar Dementia partnership framework

5. The Vision for Services for Dementia in Gibraltar

The vision of the Government of Gibraltar is that Gibraltar will be a dementia friendly country recognising the rights of people to feel valued and live well with dementia at every stage of their illness, wherever they are in our community.

The vision is to raise awareness so that people are empowered, supported and able to get an early diagnosis so that they can live their dementia journey, as they choose, from diagnosis to end of life whether it be at home, in the community or in a hospital or care home.

6. Our Mission

In line with our strategy, our mission is to provide a multidisciplinary, participatory approach that will support and facilitate the awareness and understanding of dementia, enabling an early diagnosis so that people can be supported to live and die well with dementia, anywhere in Gibraltar.



7. Core Values



The National Dementia Strategy for Gibraltar is committed to the Gibraltar Health Authority Values found in its constitution:

Working together

Excellence

Compassion

Accountability

Respect

Equality

8. The 6 C's of Dementia Care

The 6 C's (Appendix 1) are a set of values which were drawn up by NHS England Chief Nursing Officer Jane Cummings and launched in December 2012.

These values are required by all staff who come in contact with members of the public within the scope of this strategy. These have been adapted so that they not only apply to health and social care staff but also to staff working in other areas of our community.

Care

Compassion

Competence

Communication

Courage

Commitment



(NHS England, 2015)

9. Key objective 1: Raising awareness and understanding

“ *I feel valued and included in my community. I am aware of the signs and symptoms of dementia and I know where to go for help, if I choose to.* ”

The objective is to improve public and professional awareness and understanding of dementia in Gibraltar. Improving awareness and understanding will inform individuals and their families about the importance of early diagnosis and promote the prevention of dementia. Raising both awareness and understanding will encourage behaviour change in terms of seeking help and provision whilst reducing stigma.

9.1 Prevention

There is increasing evidence that there are steps people can take to reduce their risk of developing certain forms of dementia or at least to delay their onset. It is important to improve awareness among the public that simple changes to lifestyle can reduce the risk of dementia.

9.2 Awareness Campaign

We will launch a public relations campaign to bring to the attention of the public the aims and objectives of our strategy and how they can help with its implementation.

9.3 Dementia friendly community

We need to ensure that Gibraltar is a dementia friendly community. This is a place where everyone in the community, from government, to shops, to public transport, all have an understanding and an awareness of dementia (Alzheimer's Society, 2022). This will enable people to understand the challenges faced by those living with dementia and how they can make small changes that could help. People living with dementia have a lot to offer their community and can continue to have an active role if they receive the appropriate community support.

9.4 Education and Training

“ Only when you understand yourself can you then look after someone to the best of your ability ”

People with dementia, their families and carers, have the right to be supported and cared for by a workforce, whether it is at the Primary Care Centre, St Bernard's Hospital or one of our care homes, which has the knowledge and skills to offer high quality dementia care and support.

All public-sector counters, offices and subcontracted services must also have the

knowledge and skills to support people living with dementia to retain their ability to function independently where possible in the community.

Families and carers must also have access to training which enables them to support people with dementia to live well. This must include information and advice about looking after themselves.

OUTCOME

People living in Gibraltar will understand the challenges faced by people living with dementia and the actions they are required to take to be able to support them in their local community. People will also be aware of the early signs of dementia, and the importance of getting an early diagnosis.



'See the Person' Dementia Conference, Gibraltar 2019.



10. Key Objective 2: Early Diagnosis and Support

“ I have a timely diagnosis and access to information which enables me to make decisions about my care and support... ”

Key objective:

All people living with dementia in Gibraltar need to have access to robust pathways of care that deliver an early diagnosis which enables treatment and support to be available as soon as possible whilst calibrated to meet changing needs. We also need to ensure that there is easy access into the system at a very early stage with signposts along the journey that allows and encourages people and their carers easy access to help when in need.

10.1 Early diagnosis

All people who suspect a diagnosis of dementia should have access to a dementia care pathway starting at the Primary Care Centre. GPs will work alongside mental health teams and the Care Agency and know how to spot the first signs of dementia, and rule out other conditions that may have similar symptoms. This will facilitate referral to the Memory Clinic to gain a specialist assessment leading to a prompt accurate diagnosis. Dementia screening/referrals will also be added to GP Targets.



10.2 Access to information

People diagnosed with dementia and their families and carers need access to high quality easily accessible information about dementia and the services available at the time of diagnosis and throughout their dementia journey. This will require a collaborative multi-agency approach throughout Gibraltar.

10.3 Access to health and social care support

People living with dementia need to have a single-point access to someone who can help them, and their families and carers, throughout their journey with regards to finding the correct:

- Information
- Care
- Support
- Advice

“*I worry that if I forget something, is this the start of dementia for me as it is in my family*”



10.4 Championing Peer support

Gibraltar is unique in its close-knit community and its ability to help and support each other. There is an opportunity to develop local peer support networks, involving the Gibraltar Alzheimer's and Dementia Society and any other

Non-Governmental Organisations, to provide practical and emotional support whilst reducing social isolation. Talking to other people living with dementia and exchanging practical advice and emotional support would be beneficial.

“

The diagnosis of dementia for my wife lead to me losing my friends as I couldn't maintain a balance between caring for my wife and maintaining my social contacts

”



OUTCOME

People living in Gibraltar will understand the challenges faced by people living with dementia and the actions they are required to take to be able to support them in their local community. People will also be aware of the early signs of dementia, and the importance of getting an early diagnosis.

11. Key Objective 3: Living well with dementia

“Dementia is life-changing not life-ending. I know I will be helped to live my life as I choose for as long as possible and I will be involved in the decisions to be cared for as I choose, when I can no longer make those decisions for myself”

Key objective:

People living with dementia need to be supported to live at home for as long as they choose to. This will involve having access to flexible and reliable services, ranging from early intervention to specialist home care services available twenty-four hours a day seven days a week. To achieve this, we need for organisations involved in delivering services and their staff to work and think differently so that the person living with dementia becomes the focus of what we do.

11.1 Living at home

Services must be developed to support people who want to stay in their homes for as long as possible. Services need to be flexible to be able to respond to individuals needs rather than people adapting to the services in place. The services must support groups with specific needs (Appendix 2). A multi-disciplinary approach must be taken to delay loss of skills and maintain life roles for longer. Consideration must also be given to assistive technology and environmental adaptations to maintain independence, safety and wellbeing.

“Sometimes, the help we needed was for shopping or cleaning, but this was not available as part of the package”

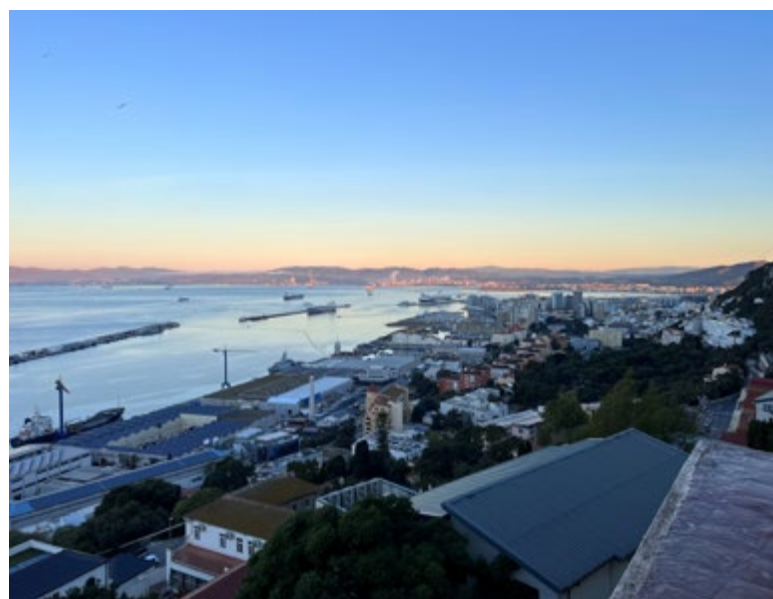
11.2 Support for families and carers

“
...it's like when you are in an aeroplane and you are told to put on your oxygen mask before those who need your help...
the oxygen mask is there for those who have dementia, but we forget the mask for the carers who need it first, to ensure that they can continue to provide the assistance their family member requires
”

In order to live at home for as long as possible, people with dementia are often dependent on the support of families and carers. It is important that there is support for the family member or carer to help prevent crisis and maintain their own physical and mental well-being as well as that of the person they are caring for. Respite and domiciliary services need to be available to provide relief for families and carers with a means of delaying or avoiding admission to long term care. A study of people living with dementia in Gibraltar (Samtani, 2022) identified that carers who felt more supported had a greater ability to cope with their situation and were less likely to consider long-term care. The same study identified a lack of services directed towards the psychological and social needs of the caregiver.

11.3 Advanced Care planning

Dementia is often not recognised as a terminal diagnosis. This can lead to poor access to care, inconsistent quality of care and inadequate pain management. We need to establish a system in which advanced care planning including living wills and power of attorney, is offered to people living with dementia at the early stage of their condition, whilst they can still make these decisions for themselves. This will support people living with dementia to make their own decisions about their future care and support.



11.4 Individualised care for people with dementia in Hospitals

Hospitals are challenging environments for people living with dementia. Ward layouts, signage, noise and the general number of people make

for an unsettling environment. The introduction of Dementia Friends Champions in each of the wards and departments will help raise awareness and enable individualised care and approaches for those living with dementia to meet their needs in addition to their reason for admission to hospital.

“*The staff were nice, but they didn't understand the needs of my mum with dementia*”

11.5 Living well with dementia in Care Homes

Gibraltar is unique in its size and has the ability for the community, primary and secondary care to work closely together. It is important that our care homes have staff with the appropriate skills, knowledge and environments suited to meet the

needs of those living with dementia. Care homes should champion the use of non-pharmacological management approaches and the use of life-story work to find personalised strategies to support responsive behaviours (Dupuis et al. 2012).

“*Doing small jobs each day helps, as mum thinks she is at work*”

11.6 Safeguarding

Our vision is for individuals to be at the centre of decisions about them and to be supported to have choice and control over their lives. It is also important to recognise that people with dementia may be at risk of abuse and neglect. We need to follow the safeguarding principles forming part of Gibraltar Multi-agency Adult Safeguarding Procedures to ensure that people living with dementia are empowered to make decisions, ensuring we are preventing abuse whilst using proportionate measures. We need to work in partnership to identify and respond to those in need of protection and ensure that lines of accountability are clearly defined and understood.

In some situations, decisions or actions need to be taken by a person who is totally independent from the person's personal circumstances and sometimes the involvement of an independent advocate is required by law. The Lasting Powers of Attorney and Capacity Act (2018) provides a statutory framework for people who lack the capacity to make specific decisions, at certain points of time, for themselves. The Act also makes provisions for when people who have capacity want to prepare for a time when they may lack capacity in the future. It sets out who can take decisions, in which situations and how they should go about this.



11.7 Dying well with dementia

Everyone has the right to good end of life care where they are treated as an individual, with dignity and respect, without pain and other

symptoms, in familiar surroundings and with their close family and friends. We need to ensure that the options and access to palliative care and end of life care is the same for a person living with dementia as it is for anybody else in Gibraltar.

OUTCOME

People with dementia, their families and carers, receive person-centred care in the place of their choice with support that adapts as the needs of an individual change.

12. Key Objective 4: Leadership and Governance

Key objective:

To achieve our vision, we need to have the right Leadership in place across all relevant organisations so that Dementia Services are given priority. In addition, it is essential that there is a Dementia Coordinator position established to lead on the implementation of this strategy and who will be held to account by all of the stakeholders for performance managing the roll-out of the strategy's key objectives.

12.1 National Dementia Steering Group

To ensure support for the implementation of the strategy, a National Dementia Steering Group (Appendix 3) will coordinate the efforts of the relevant Government departments, to deliver services to people living with dementia.

The function of this steering group is to ensure the strategy is achieved by working together towards meeting its goals and objectives. This steering group will work closely with service users and their representatives and report to the relevant boards/committee structure within their organisations. An annual review will also take place on how well the objectives of this strategy have been implemented.

“
Someone to share the journey with us, who we can approach for advice at any stage
”

12.2 Dementia Coordinator

A Dementia Coordinator will be appointed and become a focal point with which to interact with government departments, charities, voluntary organisations and the community. The Dementia Coordinator will make a significant difference in guiding people living with dementia and their families/main carers through the Dementia Journey. They will lead the strategy and facilitate a two-way process, enabling people with dementia to contribute directly to the policymaking and strategies. They will link with the community by signposting and facilitating the required health and social care input through the dementia journey. The Dementia Coordinator will be held to account by the National Dementia Steering Group for the implementation of all plans/ actions approved. They will also provide regular performance reports to all the organisations involved in the implementation of this strategy. As this will be a significant piece of work, organisations will be expected to provide the necessary support in resources to assist the Dementia Coordinator to successfully manage this initiative.

12.3 A centralised register of people diagnosed with dementia

A centralised register will be kept of all people diagnosed with dementia. This will enable us to study the prevalence locally and tailor funding and resources appropriately. It is also vital that organisations use this information to inform their yearly budget negotiations with government.

12.4 A centralised database of services

A centralised database of services will be compiled to identify the collection of services already available and identify different services which may be required as the strategy progresses.

OUTCOME

Gibraltar, as a community, will have the knowledge and skills to help identify people with dementia and to feel confident and competent in supporting the person with dementia to live their lives as they choose.



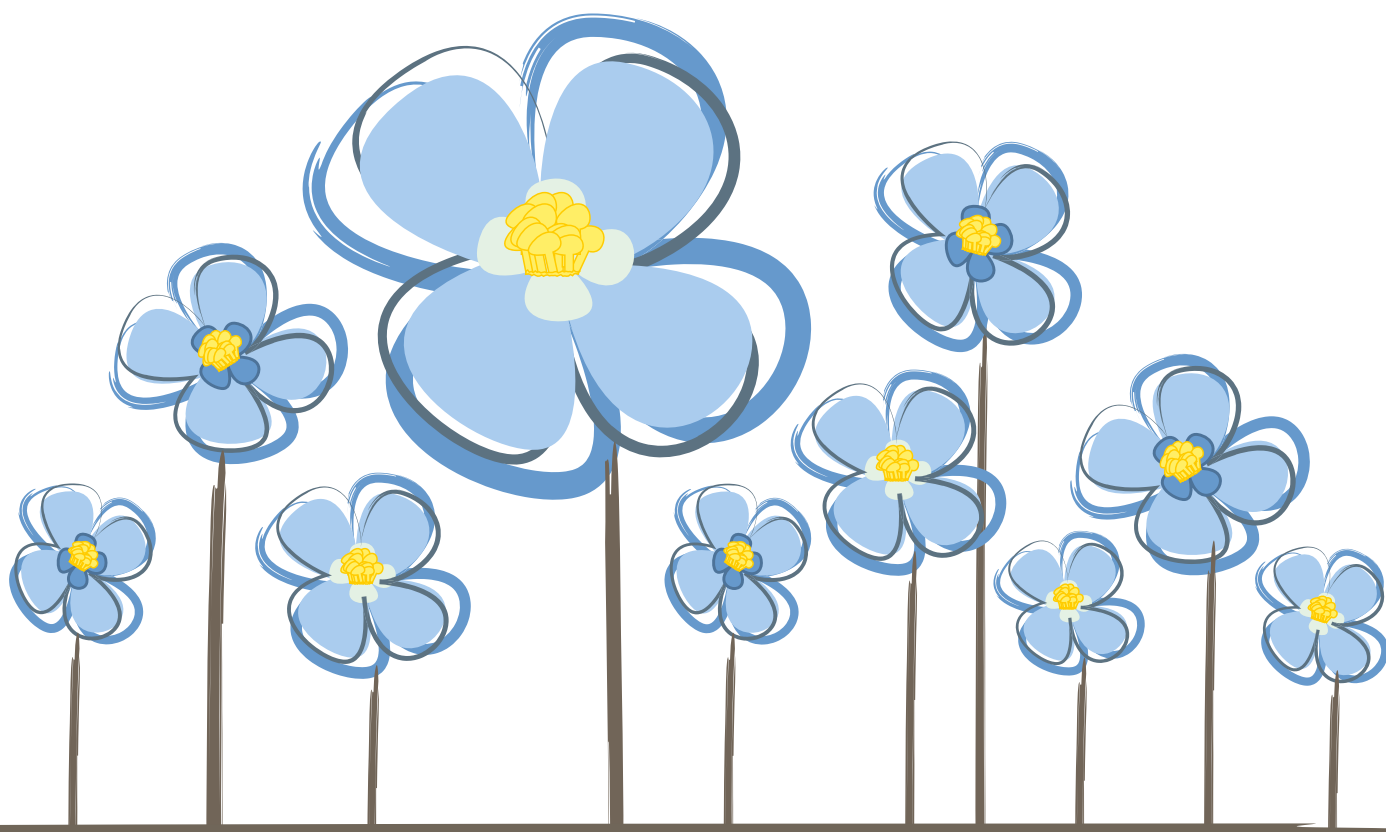
13. Achieving the objectives

These objectives are covered by an action plan with key priorities (Appendix 4) which will be modelled over the next 5 years. The pace of implementation may vary as the strategy develops in real time.

The objectives allow for some fluidity so that as we raise awareness and understanding any other factors or issues that may be identified as a result, can be prioritised and addressed. The needs of people living with dementia are vast and unique and as a 'one size fits all' plan of care is not possible; the same flexibility must be applied to the strategy.



Dementia
“Forget me not”



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15. Authors and stakeholder acknowledgments

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- **Gibraltar Health Authority**
- **The Care Agency**
- **Gibraltar Alzheimer's and Dementia Society**
- **Gibraltar Housing Department**

Appendix 1: The 6 C's OF Dementia Care

(Adapted from NHS England, 2015)

Care

Care is feeling concern or interest about something important. It is our core business and that of our organisations; to help people as individuals and improve the well-being of the whole community.

Caring defines us and our work. People receiving assistance expect it to be right for them consistently throughout every stage of their life.

Compassion

Compassion is how care is given through relationships based on empathy, respect and dignity. It can also be described as intelligent kindness and is demonstrated by a wish to help other people.

Competence

Competence is the ability to understand the needs of an individual living in our community.

It is also about having the expertise and knowledge to deliver an effective service well based on research and evidence.

Communication

Communication is central to facilitating daily interactions with people living with dementia. Effective communication is made up of many different aspects. It is essential that the communication is effective for 'No decision about me, without me'.

Communication is the key to a good quality of life for people living with dementia.

Courage

Courage enables us to do the right thing for the people we care for, to speak up when we have concerns.

It means we have the personal strength and vision to innovate and to embrace new ways of working. It means we are willing to deal with difficult situations.

Commitment

A commitment to our community is the cornerstone of what we do. We need to build on our commitment to improve the experience of people living in our community.

As a community we need to take action to make this vision and strategy a reality for all who live with dementia in Gibraltar.

Appendix 2: Meeting the needs of specific groups

(Adapted from NHS England, 2015)

To ensure the different needs of our community in Gibraltar are fully understood and recognising the 'one size does not fit all' approach; the following themes and actions have been identified as groups to be considered across the implementation of the strategy.

Young onset dementia

Younger people living with dementia often have different needs. They and their partners are more likely to:

- Be in work at the time of the diagnosis and to have financial commitments.
- Have caring responsibilities for children and their own parents.
- Be more active, stronger and fitter than much older people.

Services need to address the specific needs of younger people with dementia in Gibraltar and their families and ensure that they are aware of the help that is available. Employers need to have access to the right information in order to be able to support their employees. We need to be able to ensure they are providing local age-appropriate and meaningful support, whether that is in a person's home or through day, respite or residential care.

Learning disabilities and dementia

People with learning disabilities have a higher risk of developing dementia compared to the general population. For people with Down's syndrome, it is predicted that 1 in 3 people over the age of 50 will develop dementia. If people already have difficulties in processing information or short-term memory problems this can make diagnosis more difficult. Symptoms affecting personality, emotion or behaviour may show before any change in language ability or memory (White, 2015). Communication difficulties, and an increased potential for sensory impairment, may make it more difficult for a person with learning disabilities to describe their experience of symptoms.

Sensory impairment and dementia

A number of people with dementia will have some form of sensory impairment (such as sight loss, hearing loss or both). As this can create additional difficulties with communication, we need to enable equal access for people with a sensory impairment to all dementia related services and support.

Lesbian, gay, bisexual or transgender (LGBT) people with dementia

Older LGBT people are more likely to be single and to live on their own, and are less likely to have children or regular family support. Some LGBT people feel that services are not sensitive to their needs and individuals can sometimes feel out of place in traditional support groups.

Knapp et al. (2007) reported that many older transgender people (aged 60 and over) are concerned that they may develop dementia and need intimate care, which may result in being treated in ways not fitting with their gender identity.

People with dementia from Black, Asian and Minority Ethnic (BAME)

We need to ensure that people from BAME groups within our community can access appropriate services easily. There is known stigma connected with dementia and diagnosis in some cultures and communities, which can lead to reluctance to access services. Equally, services that are not designed to meet cultural or religious needs can unintentionally exclude people and their families and carers from accessing support.

The language needs of people living with dementia may change as the condition progresses, and services need to be aware of and able to respond to a person's language and communication needs. Services should ensure that care, support and treatment provided is culturally acceptable and that staff receive the appropriate training. We need to ensure that a person is asked about their individual culture during contact and that equity of access is available.

Language provision

For people living with dementia, receiving care and support in their first or preferred language is a matter of clinical need. As their condition progresses, people with dementia may understand or be able to communicate in their first language only.

We need to actively offer services through the medium of the appropriate language, rather than expect patients to have to ask for them.

Appendix 3: The National Dementia Steering Group

The National Dementia Steering Group will comprise of the following representatives:

- Director General
- Dementia Co-ordinator
- Head of Older Person Services
- Divisional Nurse Lead (older persons)
- Divisional Medical Lead (older persons)
- Care Agency CEO
- GHA Medical Director
- Principal Housing Officer
- Housing Manager
- GHA Primary Care Divisional lead
- GHA Director of Nursing Services
- Gibraltar Alzheimer's and Dementia Society
- Patients Voice representatives

Representatives from the following organisations may also be required to attend:

- RGP
- Tourism
- Environment
- Transport
- Aviation
- Port
- Culture
- Gibraltar Court Services
- Sports & Leisure
- Education
- Small Businesses
- Any other organisations identified

All the above will be interested partners that we will meet with on a regular basis but do not need to be on the National Dementia Steering Group.

Appendix 4: Key priorities

Short-term priorities over the next 12 months (2023 – 2024) are:

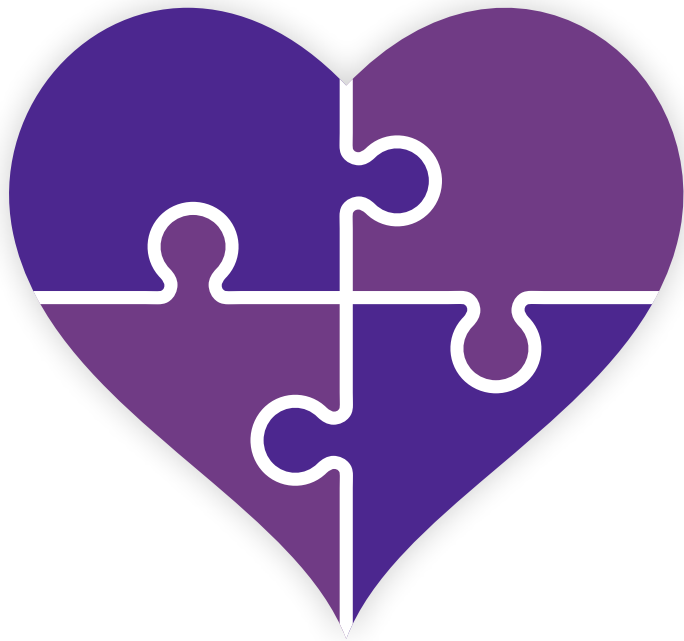
- Conduct an exercise to establish the current services that are available to people living with dementia and create a database with the information.
- Identify what we currently spend on services provided and how this is distributed.
- Establish an awareness programme for health and social care professionals.
- Establish a central community hub where people with dementia and their families can meet and share their experiences and seek support.
- Establish a prevention awareness campaign in partnership with Public Health.
- Review the current training provided in health and social care.. Following this update the mandatory training program to ensure an appropriate balance between online and face to face training.
- Ensure that it is a contract requirement that all service providers are trained to support people living with dementia.
- Work with the wards in St Bernard's Hospital which have the highest number of people living with dementia to ensure that a good hospital experience is received.
- Meet regularly with people living with dementia to identify where needs are not being met.
- Introduce a Dementia Passport for people to record information that they want others to know about them.
- Coordinate quarterly meetings of the National Dementia Steering Group.
- Maintain the centralised register of people with a diagnosis of dementia, incorporating data to support forward planning and predictions.

Our medium-term priorities over the next 3 years (2023 – 2026) are:

- Establish an awareness programme for the community of Gibraltar. Increase the number of people in Gibraltar who can recognise dementia through expanding initiatives such as dementia friends and dementia supportive communities/organisations.
- Increase awareness surrounding the needs of specific groups within the local community.
- Monitor the number of people with a dementia diagnosis and compare with the expected prevalence.
- Work with the GHA across all sites to ensure people living dementia receive a good experience.
- Develop dementia friendly wards and introduce dementia champions on each ward.
- Address the needs identified by people living with dementia in Gibraltar.
- Work in partnership with the Housing Department to enable people with dementia to remain at home for longer.
- Introduce a single access point for health and social care for those who have a dementia diagnosis.
- Raise awareness around advanced care planning.
- Establish a palliative care pathway aimed at creating an individualised end of life care pathway.
- Provide people living with dementia and their carers, good-quality information on the illness and on the services available, both at diagnosis and throughout the course of their care.
- Have a comprehensive care pathway for any person with dementia, from suspected dementia to end of life.
- Engage with young people in schools, clubs and youth organisations to increase their awareness and understanding at the earliest possible age.

Our long-term priorities over the next 3 – 5 years (2026 – 2028) are:

- Ensure that the short-term and medium-term priorities have been implemented.
- Continually review the strategy to ensure the follow-on strategy is relevant.
- Identify potential areas where assistive technology can be used to help people with dementia remain living at home if they choose to.
- Aim to make Gibraltar a Dementia-Friendly Community, where people with dementia are understood, respected and supported.



MINISTRY OF HEALTH
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