States of Guernsey
Adult Community Services

Dementia Framework for the Bailiwick of Guernsey

Part of the States of Guernsey Disability and Inclusion Strategy

February 2017

Contents

Table of Contents

Introduction

The Supported Living and Ageing Well Strategy (SLAWS) [1], and the former Policy Council [2] have clearly identified that increased life expectancy is one of the biggest challenges facing Guernsey in the years ahead. It has been estimated that the number of people aged over 85yrs in Guernsey is expected to triple by 2050. This is a worldwide trend and as people live longer this will lead to an increase in the numbers of people developing dementia.

Dementia has significant health, social and economic significance to Guernsey, since a high proportion of individuals with dementia are users of acute hospital, community care and long-term residential and nursing placements [3]. It is estimated that the health and social care costs for dementia in the U.K. almost match the combined costs of treating cancer, heart disease and stroke [4]. The Bailiwick of Guernsey therefore needs to plan to meet the growing need for support that people with dementia will require within our healthcare services.

Dementia however, is not a disease of one person; it has a huge impact on family caregivers; emotionally, physically and financially. Carers shoulder a huge cost of care for the taxpayer and as such need to be supported in their roles if we are to avoid premature and costly admission of people with dementia to long term care.

It must also be acknowledged that people with dementia are not just users of medical services; like anybody else they need to use shops, hairdressers, banks, post offices, buses, the theatre, airlines and the pub. The Guernsey community in general should be prepared to adapt to meet this need and to promote inclusivity.

This document sets out 6 key principles which are consistent with U.K. and global government policy [6], [11], [47], [68] in relation to dementia and which aim to enhance the good work that is already underway around dementia care in Guernsey.

Paul Corcoran. RMN, B.A. (Hons)
December 2016

How to use this document

This report proposes 6 key person centred areas of practice (below) where Guernsey has an opportunity to make positive changes in relation to dementia care. People are at the heart of our community and the six key principles are focussed around the person with dementia as illustrated in the diagram below. The report can be read in its entirety; however, reading to the end of chapter 6 **(page 49)** will give the reader an overview of the 6 key areas where we have opportunity to make positive changes in Guernsey in future.

The 6 key principles are evidence-based and linked to best practice guidelines, government policy and service developments within in dementia care across the U.K. and worldwide:

The full report goes on to provide further detail on individual issues related to dementia care within the Bailiwick with links to referenced articles and reports.

However you choose to read the report it is hoped that it will stimulate questions, comments and debate on how Guernsey can improve and further develop its dementia services.

Abbreviations occurring within the document include:

OACMHT – Older Adult Community Mental Health Team

The Older Adult Community Mental Health Team (OACMHT) is a community based multi-disciplinary team that offers mental health assessment and support to islanders who are generally aged over 65. The team also provides support to people under the age of 65 where dementia is the primary diagnosis. The team consists of 2 psychiatrists, mental health nurses, an occupational therapist, support workers and team secretaries with plans for access to specialist social worker input.

DFG – Dementia Friendly Guernsey

A volunteer group consisting of professionals, voluntary sector groups, douzaineers, members of the public and people with dementia and their carers. The group are striving to raise awareness about dementia and hope to make Guernsey a more dementia-friendly community. The group hopes to foster more joined-up working between community organisations and promote inclusivity for people with dementia.

HSC – Guernsey's Health and Social Care Committee.

A Principal Committee of the States of Guernsey with responsibility for:

1. Adult social care
2. The welfare and protection of children, young people and their families
3. The prevention, diagnosis and treatment of acute and chronic diseases or conditions
4. Mental health
5. Care of the elderly
6. Health promotion
7. Environmental health
8. Public health

Where does the Framework fit in?

This framework is developed as part of Guernsey's Disability and Inclusion Strategy [17] under the Social Policy tier of The States Strategic Plan 2013-2017. The ageing population is a key priority within the Social Policy Plans as the prevalence of disability is known to increase with age [3], [5]. The Framework also fits in with the States' Public Service Reform Framework which examines how the public sector can work differently and engage closer with voluntary and private sector agencies [76]. It will also dovetail with similar Frameworks being developed for people with autism and learning disabilities.

The Dementia Framework will overlap and embrace many of the principles of the Supported Living and Ageing Well Strategy (SLAWS) [1], and The Mental Health and Wellbeing Strategy [18]. One of the priorities of SLAWS is to examine how The Bailiwick of Guernsey will continue to fund the cost of supporting an ageing population with increasing health and social care needs and this will impact on people with dementia.

The fairly recent introduction of Guernsey's Mental Health Law (2010) [69] has significantly improved the rights of people who require treatment and support as a result of mental health issues. The law however does not particularly make reference to people who may lack capacity due to dementia. The Bailiwick of Guernsey is currently working on drafting a Mental Capacity law which will further protect and empower individuals who may lack the mental capacity to make their own decisions about their care and treatment. The law should allow persons to appoint a trusted person to make a decision on their behalf should they lack capacity in the future; an important aspect of planning for the future following a diagnosis of dementia.

Ethos

This framework views dementia as a disability. A condition that people can continue to live well with if the correct support is in place. This framework therefore strives to embrace the underpinning principles of the Disability and Inclusion Strategy, which are:

- **Respect**. People with dementia and their carers are treated with dignity and respect.
- **Non-discrimination**. A person with dementia and their carer must never be treated worse than others, excluded from or denied access to goods, services or social life on the basis of their disability or because they provide care for a disabled person.
- **Participation and inclusion**. A person with dementia and their carers should be supported to have full and effective participation and inclusion in society.
- **Acceptance**. We should accept that dementia is part of human diversity and humanity.
- **Equality of opportunity**. The Bailiwick of Guernsey should take positive action to ensure barriers are removed because of one's diagnosis. Society should be willing to give extra support to the person with dementia rather than deny them opportunities because of their condition.
- **Accessibility** People with dementia, their carers and families will have access to competent, affordable, timely care and support services, including respite. This also means being able to access their physical environment, having access to transportation and good quality information about services.
- **Quality of care**. A collaborative approach is adopted between services and a knowledgeable and skilled workforce is developed and maintained to provide quality care.

Overall aims

The purpose of the framework is:

- To ultimately help create a better quality of life for people with dementia and their carers in The Bailiwick of Guernsey.
- To increase public and professional awareness of dementia and help reduce stigma.
- To help make it easier for people with dementia, their carers and professionals to access help, support and information about local dementia services.
- To help inform local government ministers and commissioners in relation to dementia policy and practice worldwide and to help influence future service development.

Process

Part 1:

- Identify key themes and best-practice guidelines emerging from established dementia strategies and policy across the world but particularly within the UK.

Part 2:

- Consult with key stakeholders, including people with dementia and carers in Guernsey, about their experiences, thoughts and ideas around dementia care provision locally.
- Highlight current service provision, identify any shortfalls and map proposed future demand.
- Publish a document which can serve as a guide to inform commissioners and help guide future service development.

Part 3

- Dementia Framework report to The Committee *for* Health and Social Care for approval
- Dementia Framework report to the Disability and Inclusion Strategy Project Board following approval from HSC
- Establish implementation steering groups to ensure delivery

Consultation groups have already included:

- People with dementia and their carers
- Older Adult Community Mental Health Team
- Dementia Friendly Guernsey Committee
- Ageing Well in the Bailiwick Committee
- Senior Nurse Forums
- Voluntary sector groups
- Church and pastoral care groups
- Jersey Older Adult Mental Health services
- Guernsey Care Home Managers Association
- Inspector of care homes in The Bailiwick of Guernsey
- Community Social Workers
- Carer groups
- Guernsey Alzheimer's Association
- Alzheimer's Society (Guernsey)
- Alderney public meetings
- Alderney school
- Scouting groups
- Community Services Team leaders

Dementia

The term dementia can be a confusing and frightening one for many people. It is now, more than cancer, considered to be the condition that people aged over 55yrs in the UK are most frightened of developing. [6].

Dementia is not one single disease; it is an umbrella term used to describe a group of over 90 different diseases that affect the brain and which cause progressive cognitive decline. It is beyond the scope of this report to go into detail on the various types as there is so much information available through organisations like the Alzheimer's Society www.alzheimers.org.uk.

Dementia is progressive which means the symptoms gradually get worse over time. The rate of progression varies depending on various factors including the type of dementia, the age of onset and the person's co-existing physical health conditions. Dementia is a diagnosable condition and should not be considered to be a part of normal ageing.

The most common symptoms of dementia include:

- Memory loss
- Speech, language and communication difficulties
- Difficulty planning and organising daily tasks
- Disorientation to time and place
- The symptoms can make the person feels anxious, frightened or depressed.
- In this report dementia should be differentiated from acquired brain injuries such as stroke, hypoxic brain damage or injury as a result of trauma.

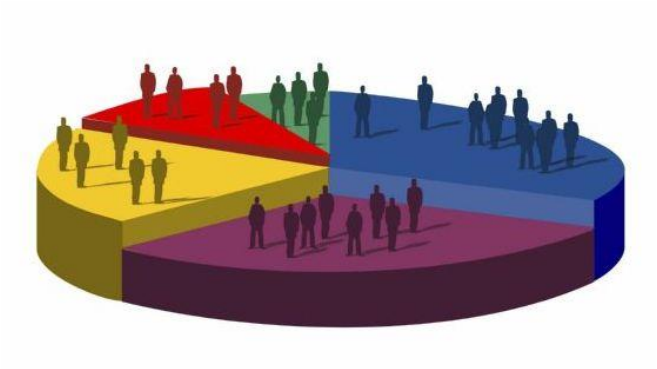
Whilst many people can live fulfilling lives with dementia with the right support, the condition can increase the person's vulnerability in relation to areas such as:

- Maintaining adequate hydration and nutrition

- Fire safety
- Getting lost
- Managing finances and exploitation
- Driving
- Physical abuse
- Sexual abuse
- Neglect

People with dementia need complex plans of support to minimise such risks and to support carers in managing these risks.

More detail on the various types of dementias and the symptoms can be found in the main report (page 50) or from:
https://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200120



Demographics

Guernsey's ageing population presents many challenges for the government and community. One of the most significant of these is the predicted increase in the numbers of people now and in the future who will be affected by dementia. In 2015 the average life expectancy in Guernsey was 82.47 years, ranking it tenth highest in the world [83]. Whilst this means that many people will be living healthy lives into older age, it also means that we will see a high proportion of people develop dementia.

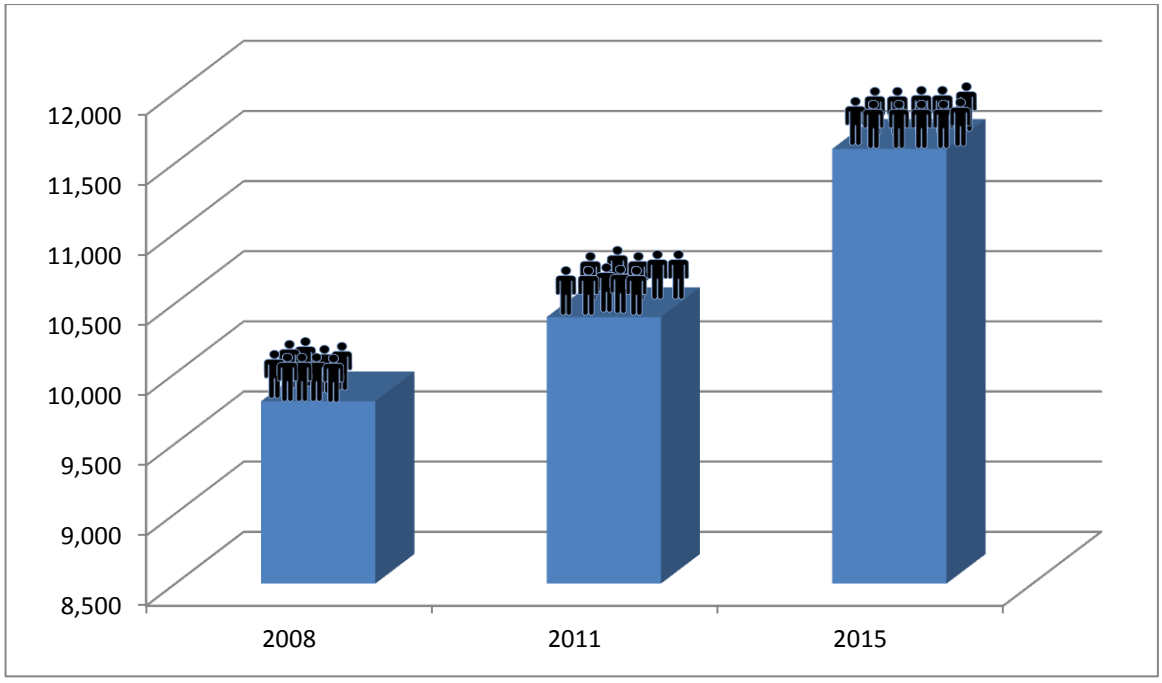
Worldwide, there was an estimated 46.8 million people living with dementia in 2015. This number will almost double every 20 years, reaching 74.7 million in 2030 and 131.5 million in

2050 [68]. This equates to one new case developing every seven seconds. No country is adequately prepared to deal with a crisis of this magnitude.
In the UK there are about 850,000 people with dementia and this number is set to rise to 1 million within 10 years [3].

Guernsey's population trends clearly demonstrate that this ageing demographic is no different for the island (**Chart 1)**. This has seen Guernsey's over 65's population increase from approximately 9,800 to 11,700 between 2008 and 2015. This may be partly accounted for by the post WW2 'baby boom' so this trend may plateau over time, however as life expectancy increases the ratio of older people to working-age population is likely to rise accordingly.

SLAWS [1] has predicted that the number of people aged 85yrs and over in the Bailiwick of The Bailiwick of Guernsey will more than triple by 2050. This is the age range where the prevalence of dementia is most common; 1 in 3 people of this age group will develop dementia.

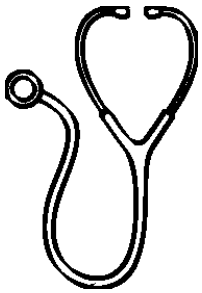
Chart 1: Over 65yr growth demographic in Guernsey



Research undertaken by Guernsey's Public Health department [9] estimates the numbers of people with dementia in Guernsey to be approximately 1,250. The figures for Alderney equates to about 68 people, based on the same calculation. These figures fit fairly closely with the worldwide incidence [36] which estimates that one in nine (11%) of individuals aged 65 years or

older will have dementia. This number is significantly more than the approximately 700 reported in the last full census in 2001 and numbers are clearly growing.
Whilst The Bailiwick of Guernsey's dementia support services have grown and developed since 2001, the island is once again feeling the strain of this changing worldwide demographic and services need to develop and be prepared to meet this need. Alderney' s needs should also be considered as their infrastructure, particularly in relation to social care and support services has not developed in line with the services in Guernsey.

In the past 15 years there has been a huge shift in the way that people view dementia. Much has been learnt about better interventions, wellbeing markers and person-centred approaches to care. Most dementia strategies advocate that early diagnosis, giving clear information and providing carer support can prolong the length of time that people remain in their own homes and subsequently improve people's wellbeing. Whilst long-term residential and nursing care will always be necessary as an option in dementia, it is expensive and there has been an over-reliance on this in the past in The Bailiwick of Guernsey. There are many community-based support services that should be implemented in the first instance and this is where HSC should take a strategic view on prioritizing implementation of the framework.



Dementia diagnostic rates

In 2015, Guernsey's OACMHT received about 110 referrals from GP's to the memory clinic service requesting specific assessments for suspected dementia. This referral rate is growing, with about 3-4 new memory clinic referrals now being received weekly (approx. 180 per year). The team receives many more referrals for older adult mental health issues apart from dementia. Approximately 70% of people referred to the memory clinic receive a diagnosis of dementia (Alzheimer's, mixed dementia or vascular types).

- Approximately 15% tend to have Mild Cognitive Impairment (MCI) and are offered follow up to monitor their situation. Some of these people will go on to develop dementia.
- The remaining 15% tend to present with other issues which may include:
    - Physical health issues impacting on memory
    - Depression or mood disorders
    - Transient amnesic issues
    - Lifestyle issues (alcohol etc.)

Those diagnosed through the memory clinic pathway will not account for all of the people that develop dementia in The Bailiwick of Guernsey every year. There are some that may be diagnosed by their GP and many others that develop dementia whilst in long term care settings who might never come into contact with secondary care or specialist services.

1. Raising Awareness

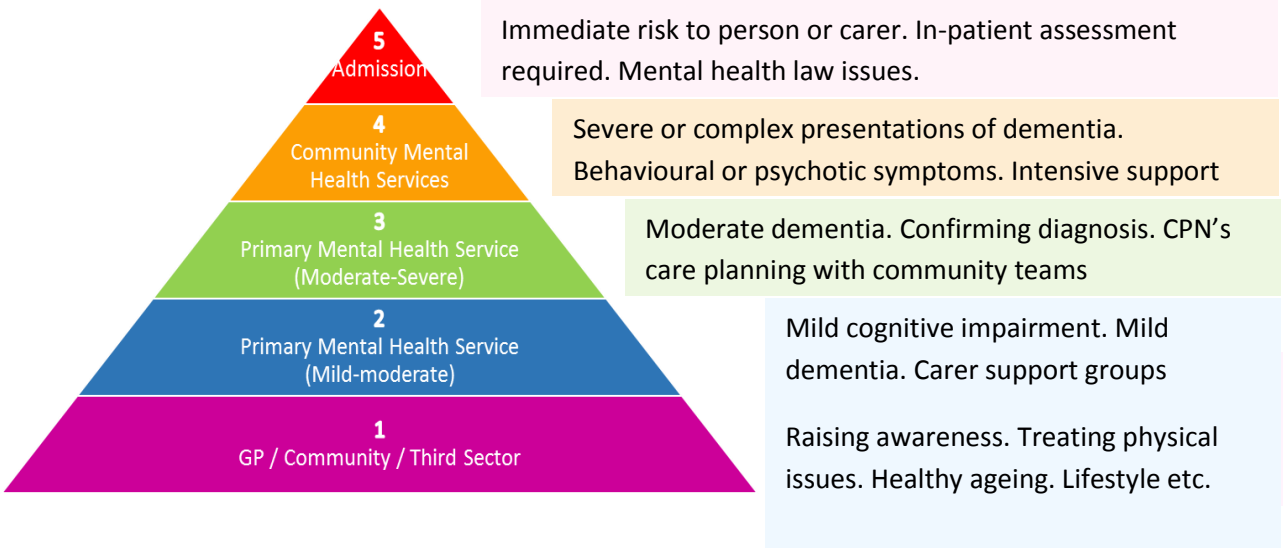
A key recommendation of the first U.K. National Dementia Strategy, 2009 [6] was to promote and raise awareness of dementia and to reduce stigma associated with the condition. This was further reiterated in March 2012 in the subsequent Prime Minister's challenge on dementia [11] and again in the latest government report Dementia 2020 [47]. Raising awareness about the condition can only be beneficial towards changing attitudes about a condition that is sometimes hidden away and stigmatized.

There are already some exciting initiatives underway in an effort to make The Bailiwick of Guernsey a more dementia-friendly environment and islands where people with dementia will feel more supported and understood.

Raising awareness also entails promoting campaigns informing the public about the risk factors associated with developing dementia (particularly vascular types). There are significant opportunities for The Bailiwick of Guernsey to make strong links between healthy lifestyles in younger life, (diet, exercise, alcohol, smoking, mental health) healthy ageing (maintaining physical activity, keeping socially connected, lifestyle etc.) and reducing dementia risk and incidence in future.

Much of this work does not require highly specialised professionals. A five-tiered model is used across the UK as a framework to illustrate the delivery of mental health services; from those people experiencing mild to moderate symptoms, to those with the most serious difficulties. It is a system of delivering services so that a range of options is available and access to the different levels is assessed according to need. The least resource-intensive services are delivered to individuals by community-based organisations with a focus on prevention and early intervention type services. The 2012 Mental Health and Wellbeing Strategy for The Bailiwick of Guernsey [18] supports the principles of this stepped approach to accessing mental health services generally. A similar approach could be adopted for specialist dementia support in Guernsey **(chart 2)**.

Chart 2:



In terms of awareness-raising campaigns for dementia, these would sit towards the base (level 1 and 2). Working within a model such as this would allow for costly resources to be allocated towards specialist interventions like Memory Clinic (level 3), CPN's and specialist community support (level 4) and in-patient assessment (level 5).

Best Practice Statement 1.1	**Public and political awareness of dementia will be increased.**
Benefits of raising awareness.	Increased political awareness will encourage current service provision to be considered at a strategic level by the States of Guernsey. Increased public awareness may enable people with dementia to talk about their condition and perhaps find it easier to seek help and support. People with dementia will feel able to engage more in their own community and stigma may be reduced. Healthy ageing campaigns may encourage people to take more responsibility for general health issues which can impact on cognitive function. Voluntary sector may be encouraged to develop further and consolidate behind specific campaigns in the promotion of dementia awareness. Secondary care (HSC) can better focus on complex case work.
What's happening in The Bailiwick of Guernsey in relation to raising awareness about dementia?	**Dementia Friendly Guernsey** (DFG) http://dementiafriendly.org.gg/ committee has drawn together a committee of volunteers, established charities, professionals, private sector representatives, and people with dementia in an effort to raise awareness about the condition in Guernsey. The group officially launched in early 2017 and has begun to roll out training to key individuals in an effort to make Guernsey a more dementia-friendly community. The launch was supported by the Chairman of the UK Alzheimer's Society, Mr. Jeremy Hughes (MBE). The Disability and Inclusion Strategy has recognised dementia as a disability; a condition that means people with dementia may need more support to manage their day to day lives. www.signpost.gg is now live. A Guide to information, support and services for disabled people and carers' in The Bailiwick of Guernsey. Guernsey Disability Alliance have recognised and promoted awareness of dementia as a hidden disability through a film about the condition as experienced by a local Guernsey couple http://matter.gg/our-stories/hidden-disabilities/dementia/

What's happening in The Bailiwick of Guernsey in relation to raising awareness about dementia?	How Guernsey and Alderney provides services for people with dementia now and in the future is recognised as a priority area within SLAWS [1]. Consultation on this Framework has helped promote discussion around the topic of dementia. HSC professionals deliver occasional dementia awareness talks to various groups and associations. Press articles, radio specials and awareness campaigns on dementia usually held around dementia awareness week in May. Milly's Foundation in Alderney used funding to arrange professional Dementia Awareness training during the first ever Dementia Awareness week in Alderney in 2016. Increasing influence within the media from groups such as Guernsey Alzheimer's Association and Alzheimer's Society (Guernsey) and DFG. Information about local dementia services on www.gov.gg website has been updated and will raise awareness of support available. The Guernsey Health Promotion unit run various campaigns that focus on healthy lifestyles and the impact of diet and alcohol which can impact on stroke reduction and vascular dementia risk factors. Ageing Well in the Bailiwick committee have drawn together a wide range of stakeholders and are having significant influence in raising the profile of dementia care provision locally.
What do we need and how do we achieve this?	Use this document to consult further with key stakeholder groups. **Responsibility: HSC through 2017** There is an opportunity to further develop and encourage our voluntary sector to promote awareness-raising. Jersey Alzheimer's Association http://www.jerseyalzheimers.com undertake a wide programme of awareness-raising which involves delivering talks and training to schools, colleges, the business sector and care home providers. **Responsibility: Voluntary sector groups** Healthy lifestyle campaigns should continue to focus on healthy ageing from a young age to raise awareness around smoking, exercise, weight, diet, blood pressure, social contact and education. **Responsibility: Health Promotion, Public health, schools**

	The role of the **Admiral Nurse** or **Dementia Advisor** [81] [82] [89] has been shown to be of significant benefit in bridging the gap between specialist services and the 3rd sector. They can provide a key role in signposting families towards services and helping to develop educational and awareness sessions for carers and the public. **Responsibility: HSC to consider the development of such a role**
Risks and barriers	Clearer lines of responsibility need to be established as to who should be primarily responsible for awareness-raising programmes. Increasing clinical caseloads mean that HSC professionals are increasingly focused on the "core business" of managing complex cases. No current provision for dementia advisor type role that might bridge gap with voluntary sector and help develop awareness programmes. Voluntary sector in dementia care still not as developed as some regions in UK where paid staff undertake campaigns of awareness raising.

Best Practice Statement 1.2	**The Bailiwick of Guernsey can work towards being a dementia friendly community**
Benefits of this happening.	People with dementia will feel able to engage more easily in their own community and this could reduce isolation and loneliness and promote wellbeing. [80] Stigma can be reduced as inclusivity is promoted. Carer strain can be reduced as people continue to access their own environment for longer and maintain independence. Demands on social care budgets can be reduced as people with dementia remain independent for longer.
What's happening in The Bailiwick of Guernsey in relation to dementia friendly communities?	Dementia Friendly Guernsey (DFG) http://dementiafriendly.org.gg/ committee has drawn together a committee of volunteers, established charities, professionals, private sector representatives, and people with dementia in an effort to raise awareness about the condition in Guernsey. The group officially launched in early 2017 and has begun to roll out training to key individuals in an effort to make Guernsey a more dementia-friendly community.
What do we need and how do we achieve this?	A programme of dementia awareness training needs to be delivered to various businesses and general public. This will require some "train the trainer" sessions to enable a cohort of volunteers to be trained up.

	Responsibility: DFG, Alzheimer's Society, Volunteers (commencing Feb 2017) Consideration should be given to creating a Dementia Advisor role to bridge the gap between HSC and Voluntary sector. This role would encompass some of the post-diagnostic counselling and signposting to 3rd sector following diagnosis. **Responsibility: HSC as part of Public Service Reform 2015-25** Public-facing businesses that are keen to become more dementia-aware need to commit to making their staff available for training. **Responsibility: Business managers, Voluntary sector** (2017 and ongoing) Consideration given for local Banks and financial institutions to adopt the Dementia Friendly Financial Services Charter. This may help with the often complicated issues around safeguarding people with dementia from potential financial abuse. https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2891
Risks and barriers	The delivery of training to the public in dementia-awareness depends on a small number of volunteers so priority needs to be given to "training the trainers". Commitment needs to be made by volunteers and trainers to keep skills and awareness updated and to make time to deliver sessions.

2. Early Diagnosis

Early or 'timely' diagnosis lies at the heart of many dementia strategies worldwide. Receiving a diagnosis at an early stage allows people to access information, support and treatments so they can be involved in decisions about their care while they still retain capacity. Economic models suggest that the costs associated with an earlier dementia diagnosis are more than offset by the cost savings from the benefits of anti-dementia drugs and caregiver support interventions. These benefits include delayed institutionalisation and enhanced quality of life of people with dementia

and their carers [87]. In Guernsey and Alderney, the majority of people diagnosed with dementia come through the Memory Clinic pathway.

A timely diagnosis of dementia affords families the following benefits:

- Provides a person with dementia with an explanation for their symptoms and allows them time to come to terms with it.
- Enables timely access to anti-dementia medication.
- Allows the person and family to plan for the future and consider financial and legal matters. (e.g. power of attorney)
- Addresses potential safety issues (Driving, fire risks, finance, cooking etc.)
- Enables the person and carer to access community support (occupational therapy, home care, day centres, specialist nurses, respite etc.)
- Enables access to financial support in terms of allowances.
- Enables access to carer support groups within the voluntary sector which provide both educational and peer support for carers.

2.1 Disclosing diagnosis

It is still common for many people to live with dementia for years without ever being given a formal diagnosis. If this were any other condition there would be an outcry, yet with dementia it seems to be somehow acceptable. Whilst government initiatives in the UK are increasing the rates of diagnosis it is estimated that between 30-50% of people still never get formally diagnosed [11].

The reasons for such low rates of disclosure are complex. Many GP's feel they lack confidence in formalising an accurate diagnosis of subtype whilst others feel a degree of apathy about what can be done [31]. Time constraints are also a factor. Sometimes symptoms can mimic the 'normal ageing' process [12] whilst ruling out differential diagnoses can also be difficult. Even specialists can be hesitant about giving a diagnosis to a person for fear it may have a negative impact on the person's wellbeing.

This issue has been discussed at various consultation groups in The Bailiwick of Guernsey as part of this process and the responses generally suggest that service users would like practitioners to be as clear as possible when giving this information whilst bearing in mind the persons own wishes, expectations and mental wellbeing.

Diagnosing dementia however is not an exact science and there are many factors that can prove to be a barrier. In many cases the person may deny symptoms or compensate to cover up shortfalls. Sometimes there can be a reluctance to engage in the assessment procedure and in many cases anxiety has an impact on the results so it calls for experienced practitioners to help attendees to feel at ease and to minimise the chance of 'false positives' occurring. Some people will explicitly ask not to be told and that needs to be respected also.

There are many other 'dementia plus' conditions which are atypical and require detailed investigations, tests and exploring to rule out differential diagnoses. Jersey Memory Clinic has the routine input of a neurologist to explore such cases which at present The Bailiwick of Guernsey does not have.

Guernsey's Memory Clinic, like Jersey, has adapted the clinical pathway to allow for a separate diagnostic consultation with a psychiatrist once all the information has been gathered. This usually occurs alongside a family member with the permission of the service user. The service also extends to Alderney (though the clinical pathway is amended) every 3 weeks with the further option of Tele conferencing links with the psychiatrist as required.

A key issue here may be whether dementia diagnosis could be a task undertaken by GP's in straightforward cases? – a recent review of guidelines [88] suggest that Canada may be unique in asserting that the typical presentations of the most common types of dementia can be accurately diagnosed by primary care. It may be, for that reason, that some of the more innovative approaches to scaling up primary care diagnosis are currently originating from that country.

The diagnosis of dementia, wherever it is given, should be delivered sensitively and at an opportune time for the person whilst balancing the benefits with the risks. [10]

In the UK, there are often long waiting times, sometimes up to 1 year for an initial memory assessment with a specialist [22]. The 2015 UK National Memory Clinic Audit [32] which gathered data from 182 of the 222 UK memory clinic services illustrates a 31% rise in referrals to services from 3 years previous. The following data is useful for comparison.

UK Memory Clinics	Guernsey Memory Clinic
Waiting time from referral to 1st assessment: 5.4 weeks	**Waiting time from referral to 1st assessment:** 18 working days (under 4 weeks)
Waiting time to diagnosis: 14 weeks	**Waiting time to diagnosis:** 40.2 working days (8 weeks approx.)
52% patients received an early diagnosis	Majority of people seen at early stage of condition. Mini-Mental average 25/30. Average ACE-R score 74/100. Range 34-93%
99% clinics can initiate & monitor anti-dementia medication	The clinic can initiate and monitor anti-dementia medication
85% clinics have access to specialist post diagnostic counselling	100% of people receiving a diagnosis offered post-diagnostic counselling
98% clinics have access to education and support for carers	The clinic offers access to education and support groups for carers
68% clinics have access to Cognitive Stimulation Therapy	Cognitive Stimulation Groups have been offered in the past but currently no provision due to demands on the team
63% clinics have access to life story work	100% of assessments incorporate comprehensive life story/history assessment

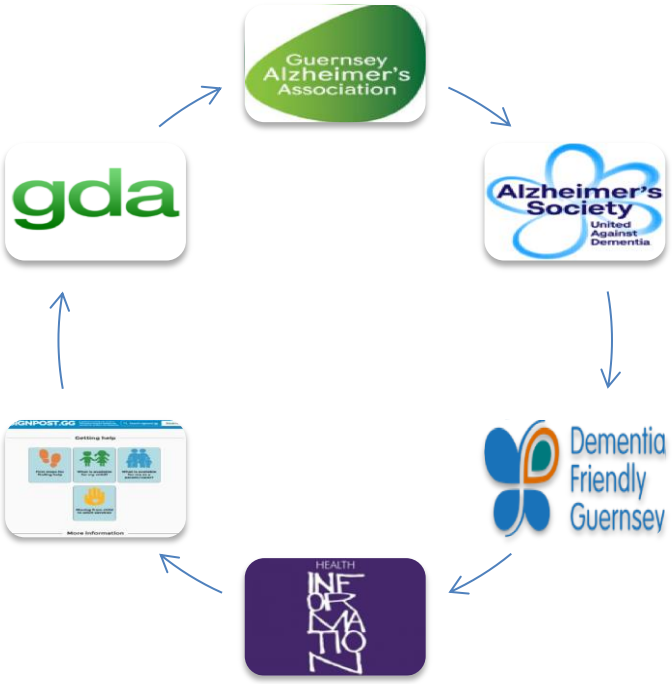
The data demonstrates that, at time of writing, Guernsey compares favourably to similar services in the UK and our waiting times for initial assessment are well within the recommended 6 weeks recommended by the Prime Minister [22]. The service however is struggling to maintain these outcomes.

The clinic is primarily led by a community psychiatric nurse and an associate specialist psychiatrist who also have other generic roles within the team. Recent issues with staffing have seen the clinic lack specialist input from occupational therapy, social work and psychology. Current Staffing establishment within the clinic leaves little room for sickness or holiday cover.

A visit to Jersey services shows that they face similar pressures in regard to their ageing population but they have developed a dedicated memory clinic team. The Memory Clinic team in Jersey is headed by a specialist psychiatrist but also has input from 2 nurses, an Occupational Therapist, a Social worker and a neurologist. Following diagnosis, the team either discharges to the GP or they make a referral to a substantial OACMHT if more specialist interventions are required. The States of Jersey have also committed to investing significant funding and to establish 17 extra full time staff into the Older Adult Community Mental Health team and plans to align them closer with primary care.

Early diagnosis allows people to plan for the future, knowing they have a progressive condition. Further issues, beyond the scope of this report, should also consider legislation in The Bailiwick of Guernsey pertaining to mental capacity. Currently this is being drafted and will address issues such as setting up (EPA) enduring power of attorney and making advance decisions on care interventions in the future.

Support and information for families following diagnosis is provided by both HSC (via Memory Clinic) and voluntary sector groups (below) and is explored in more detail on p 67 which outlines in detail the Memory Clinic process.



Best Practice Statement 2.1	**It should be straightforward and clear for GP's to make a referral for someone they think may have dementia.**
Benefits of achieving this outcome	Good screening from GP's can rule out treatable causes of memory impairment (depression, thyroid function, anaemia, infection etc.) A standardised referral pathway ensures equity of treatment for individuals. Clear referral guidelines may help Memory Clinic become accredited in future.
What's happening in The Bailiwick of Guernsey already?	Referral guidelines for GP's have been established for many years and follow NICE guidelines. Referral standards still vary between GP's and Practices.

What do we need and how do we achieve this?	Re-present referral guidelines to GP's many of whom may have arrived since the original pathway was launched and may not be fully aware of the referral process. **Responsibility: Older Adult CMHT** (mid 2017) GP's also have an important role to play in diagnosing dementia in more straightforward cases whilst still being able to refer the family onwards to access post-diagnostic support from specialist HSC services and voluntary sector groups. A dementia Roadmap may be worth devising to outline the support services available in Guernsey for people with dementia. **Responsibility: GP's, OACMHT, Psychiatrists, voluntary sector groups**
Risks and barriers	Referral standards vary between GP's and incomplete referrals (missing key screening tests and information) delay the process and can delay access to diagnosis, treatment and support. GP's have been reluctant to take on the role of making dementia diagnoses and prefer to refer to Memory Clinic which puts added pressure on a busy service.

Best Practice Statement 2.2	**Once referral is accepted by HSC there should be a clear and timely diagnostic pathway for the patient and carer.**
Benefits of achieving this outcome	A systematic approach provides a service that is comprehensive and equitable and follows NICE guidelines.
What's happening in The Bailiwick of Guernsey already?	The memory clinic service runs within the OACMHT. The service has existed since 2003 when it launched off the back of the Insurance Corporation healthcare bursary. The service has developed over time but has never become a stand-alone service with its own staffing establishment. The diagnostic pathway is comprehensive and primarily run by one nurse who undertakes pre-clinic home visits, cognitive testing, report writing, and 3 post diagnostic follow-ups. Diagnostic clinics are run by the associate specialist psychiatrist. (see p 67) Consultations as part of this Framework have indicated that some families still felt "left in the dark" about where to go for advice following diagnosis. This pathway is available on the States website at: https://www.gov.gg/article/151983/Memory-services

What do we need and how do we achieve this?	It is important that resources are allocated appropriately to Memory clinic to ensure that all those referred receive timely assessment, diagnosis and high quality follow-up care. The service should be run in a multi-disciplinary way with input and consultation from a range of professionals. Consideration should be given to the further development of the Memory Clinic with access to dedicated professional input as required from: Psychiatry CPN's Occupational Therapy Support workers Dementia advisors **Responsibility: HSC to consider how the memory clinic service is developed as part of Public Service Reform 2015-25** Dementia Advisers or Admiral Nurses in the UK provide an invaluable role in post diagnostic dementia support and guidance for families. The development of such a role could improve support for families in The Bailiwick of Guernsey and help prevent early admissions to care. Scotland's Dementia Strategy [89] advocates for support for up to a year following diagnosis and this is often provided by dementia advisors. **Responsibility: Consideration for HSC or jointly with Voluntary sector** Maintain close links with third sector groups to promote post-diagnostic support. **Responsibility HSC and 3rd sector** (in progress)
Risks and barriers	Ageing population could see current service being overwhelmed and waiting lists being generated as the service currently stands. Costs of service development. Recruitment and retention issues.

3. Support for Carers

In this chapter the term ‘carer’ refers to informal or family caregivers (usually spouses, family members or friends who provide regular support for people with dementia and are not paid or employed to do so). Two thirds of people with dementia still live in the community [3] (either in their own home or in the home of a family member) and a large proportion of these people rely on family carers for support.

Dementia care costs the UK economy £26 billion every year, more than the cost of cancer, stroke and heart disease [23] and carers save the taxpayer a further £6 billion per year by supporting

family members to remain in their own homes and preventing premature admission to residential care [84]. Carers will require ongoing support if they are going to continue to shoulder this significant burden of care (and cost) from State provided services.

Informal carers play a vital role in the lives of people with dementia. They frequently assist with such duties as:

- Personal care
- Meal preparation
- Supervision of medications
- Transport issues
- Shopping
- Financial management
- Housework and other activities.
- They are often faced with managing behavioural problems.

Carer strain, depression and burnout is very common and carers often have significant healthcare needs themselves. Anxiety, irritability, sleep disturbances, incontinence, repetitive questioning and hallucinations expressed by the person with dementia have all been reported to be positively associated with increased levels of carer stress when providing care [54], [56], [57]. It is therefore vitally important that carers have access to emotional support which has also been highlighted via the Carers Guernsey working party.

In the U.K. family carers make up about 12% of the workforce and are often aged between 45-64yrs and are often at the peak of their careers. There can therefore be a loss in productivity to the economy if working-age carers have to stop working prematurely to undertake a full time caring role due to inflexible working terms. There is a need for review of employment legislation here in relation to supporting carer's rights.

The Bailiwick of Guernsey needs to improve access to short breaks for carers. The respite service should be able to provide planned breaks for people with dementia within suitable care environments without the risk of the placement breaking down. If family carers have to suffer the worry and stress of not knowing where their loved-one will reside there is a chance they will carry on beyond their capabilities and risk carer burnout.

"Trying to find an appropriate environment for my husband, and not knowing where he would be placed while I took a short break, was so stressful. It almost takes away the benefit of having a break." (Carer, Guernsey)

Providing carer education programmes has been shown to have positive lasting results on caregiver's psychological and general wellbeing and is a cost-effective way of providing support to larger groups as opposed to individual work [72].

One way that this has been implemented in the U.K. is through the development of Admiral Nurses or the more generic Dementia advisor role [81, 82] that can bridge the gap between state provided services and the voluntary sector and whose role focuses very much on carers needs. The funding for such roles however comes from various sources such as the Alzheimer's Society or Dementia U.K. but also through local authorities in the U.K. and Ireland. The development of Admiral Nurses or Dementia Advisors has been shown to promote significant cost savings to Health Trusts like the 2013 project in the Norfolk area has shown [91]:

Savings - Delayed Admission/Admission Avoidance

In Norfolk, a pilot programme of developing three Admiral Nurses demonstrated that £426,601 of savings were made as a result of admission avoidance/delayed admissions to residential /nursing care homes and acute hospital admissions between June 2013 and April 2014. Much of the savings stemmed from education programmes and guiding carers in the early identification of conditions such as chest infections, urinary tract infections and management of non-specific conditions, falls and end of life without the need for admission to hospital.

Best Practice Statement 3.1	**Carers should have access to clear and information about services, benefits and support available.**
Benefits of achieving this outcome	Informed carers know where to seek help and support and can carry on in their caring roles for longer. Reduced risk of carer breakdown and need for potential crisis placements. Family caregivers shoulder a cost from the taxpayer.
What's happening in The Bailiwick	Information related to dementia services currently comes from various sources (Memory Clinic, GP, psychiatrists, Social workers, CPN's, OT's, Support Groups, Health Information exchange http://www.information-

of Guernsey already?	exchange.org/index.php, States of Guernsey website www.gov.gg; www.signpost.gg; Dementia Friendly Guernsey http://dementiafriendly.org.gg/about-dementia/
What do we need and how do we achieve this?	Consider development of printed local dementia services guide for people who are not familiar with using the internet. **Responsibility: Charity or voluntary sector project?** (2017-18). Launch of DFG website will help to guide families to services. **Responsibility: DFG** (Feb 2017). Clear roles to be defined for specialist mental health social worker for older people's mental health particularly in relation to carer support. **Responsibility: HSC Service Managers within Community Services and Services for Older People** Carer assessments as standard when dementia is identified. **Responsibility: All health and social care professionals as well as GP's** Dementia advisors or Admiral Nurses are commonplace throughout the UK. They have a strong focus on carer support. They provide clear information following dementia diagnosis and signposting carers towards services. **Responsibility: HSC to consider as part of Public Service Reform 2015-25** Further development of dementia support workers role. **Responsibility OACMHT** (Ongoing) Better sharing of information and quality assessments between disciplines across electronic healthcare record TRAK will avoid duplication of work and frustration for carers. **Responsibility HSC, IT** (Ongoing)
Risks and barriers	• Staff retention • Cost of publishing information and keeping it updated • Keeping staff and volunteers updated • Electronic Healthcare Record (TRAK) still very difficult to navigate between departments.

Best Practice Statement 3.2	**Carers should have access to practical advice, education and peer support.**
Benefits of	Informed carers can maintain their caring roles for longer. Reduced risk of carer breakdown and needs for crisis placement.

achieving this outcome	Family caregivers shoulder a cost from the taxpayer. Carers learn from each other.
What's happening in The Bailiwick of Guernsey already?	There is an established weekly carer support group run in conjunction with HSC and The Guernsey Alzheimer's Association. The group hosts various speakers including professionals from health, social care, social security and legal backgrounds. Alzheimer's Café is also run by the Guernsey Alzheimer's Society. This forum also provides advice and information for people with dementia and carers through the involvement of guest speakers. Singing for the Brain (Alzheimer's Society). Singing down Memory Lane (Alzheimer's Association). Both groups provide peer support to carers whilst using music as a medium of bringing people together. Informal Church groups run from people's homes provide further support for carers.
What do we need and how do we achieve this?	Carer education sessions could be better attended. There is scope for these forums to be promoted further perhaps via radio (What's on diary), DFG website, www.signpost.gg, . **Responsibility: Voluntary Sector Groups, DFG** Consideration could be given to evening support groups to fit in with working-age carers. **Responsibility: Voluntary sector and HSC clinical staff** There is the potential for the voluntary sector to be further developed in terms of the support they offer. **Responsibility: Voluntary sector groups**
Risks and barriers	Flexibility of volunteers and professionals. Committees of voluntary sector groups are small. Very few staff within the voluntary sector in The Bailiwick of Guernsey are employed by charities; the model of care is very different to what it is in the UK. The Bailiwick of Guernsey very much depends on volunteers to offer their help and support.

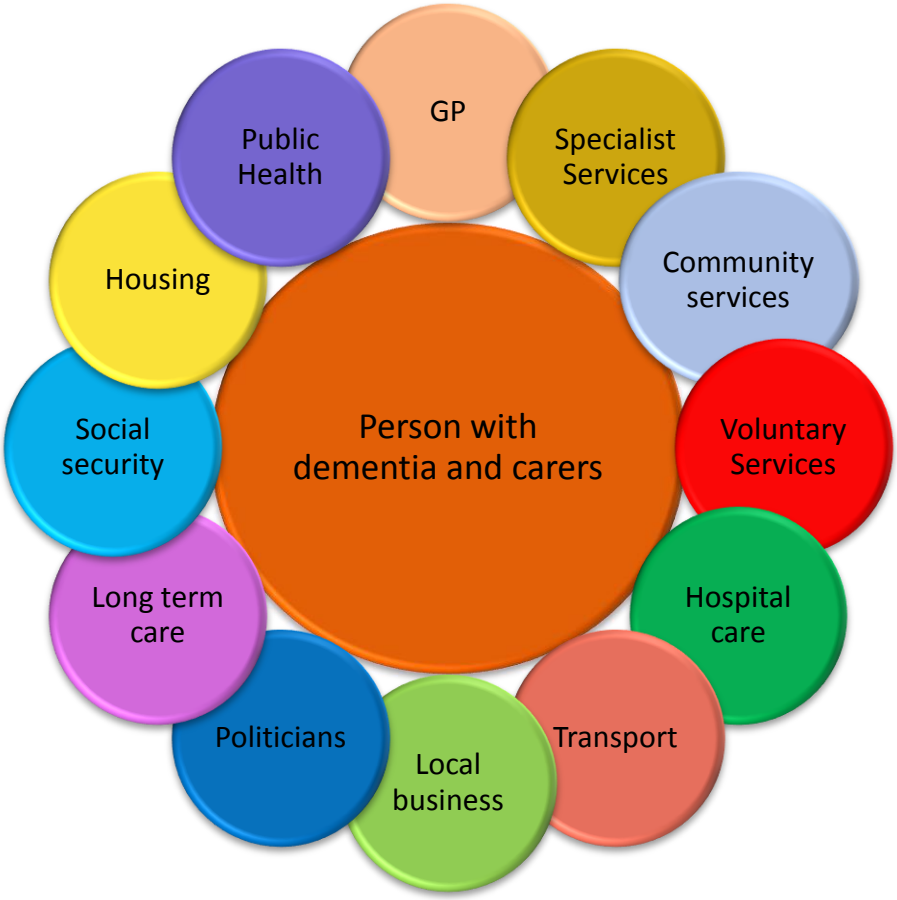
Best Practice Statement 3.3	**There should be easy access to day care and short breaks for carers.**
Benefits of achieving this outcome	Carers who feel supported and who have access to regular breaks can maintain their caring roles for longer. Reduced risk of carer burnout and need for emergency placements.
What's happening in The Bailiwick of Guernsey already?	The Willows Day Centre based at La Nouvelle Maritaine provides Occupational therapy, socialisation and personal care services for people with dementia and people with ongoing physical conditions. The service also serves to provide essential **day care** for carers. Interventions include art projects, music, gardening, visits to local amenities and a bathing service. Duchess of Kent provides two **bookable short break beds** for people with dementia. Carers of people with dementia who require planned short breaks can be waiting "up until the last minute" before they know where a bed will become available. At time of writing there was no provision for **bookable short-break beds** within the private sector care homes. This was trialled in the past but stopped due to the difficulty of managing and administering the bookings and that the beds were often used for crisis placements rather than planned breaks. Some private nursing homes provide private day care to enable carers to take a break or undertake chores. This is paid for by the family as Long term care benefit does not cover this arrangement. Sitting service allows for carers to have a short break from their caring role for up to 2 hours at a time (4 hours weekly). The service is very much dependent on professionals providing their time outside of working hours and is currently stretched. Some sitting provision is also available through the voluntary sector.
What do we need and how do we achieve this?	Provide greater flexibility within the current respite and short break care service model to adequately meet carers' needs. Support innovation in new models of effective respite care (respite at home). These services however are normally provided by private care agencies. **Responsibility: many of the issues related to respite care are being addressed by the SLAWS working parties** Personal care budgets may need to be considered to avoid reliance on people "going in" to residential settings for short breaks. Personal care

	budgets can entice family members to offer up more time into supporting the individual. In Jersey the availability of a direct payment system has encouraged the growth of several professional agencies. These agencies have relieved some of the pressure for long term care beds and from state social services providers. **Responsibility: Ultimately the funding of such a scheme would come under the remit of Social Security** Respite beds for people with dementia are not readily available in EMI registered homes. Funding 1-2 **short break EMI beds** in the community may be worth piloting to gauge the necessity of this service. **Responsibility: HSC, Care Home sector, Social Security** Examine feasibility of expanding sitting service or developing some close partnership working with 3rd sector to develop a bigger pool of people to provide short breaks at home. The role of the 3rd sector in providing direct dementia services is very much in its infancy. **Responsibility: HSC and Voluntary Sector**
Risks and barriers	Funding (although investing in schemes such as personal care budgets may be a cheaper alternative to Residential Care as only the actual care costs would be funded and not the cost of accommodation, utilities or food). Staffing. Training needs. The role of respite care co-ordinator has been lost which saved professionals a lot of valuable time in seeking potential respite beds. Previous attempts at keeping respite beds in community did not last due to the beds often been used in a crisis rather than for planned bookings. Also the home was not an EMI dementia care home.

Best Practice Statement 3.4	**There should be flexibility within terms of employment to allow family carers to undertake their caring role**
Benefits of achieving this outcome	Carers can be supported to remain in paid employment for longer thus continuing to contribute to the economy and maintain their own wellbeing.
What's happening in The Bailiwick	There is no employment legislation that currently recognises the rights of carers officially.

of Guernsey already?	
What do we need and how do we achieve this?	The Bailiwick of Guernsey could consider adopting principles of the Carers Act (2014) to enable employee's the right to request flexible working patterns. Employers should be made more aware of the benefits of allowing flexible working patterns in order to help keep maintain employees in work. **Responsibility: This may happen via the DFG awareness raising sessions across the business sector**
Risks and barriers	Inflexible employers. No legislation in place currently.

4. Integrated community care



The graphic above illustrates what an integrated dementia-friendly community might look like; the person with dementia and their carers at the centre with a close-knit seamless arrangement

of services supporting them. Specialist dementia services (memory clinic, OACMHT, psychiatry) are only a small part of this network. Good dementia care involves the whole community. Unfortunately, services aren't always as joined-up as this but we can strive towards making it. We are fortunate however that The Bailiwick of Guernsey is small enough to allow various departments to liaise between each other quite easily. Innovations within Children's Services in Guernsey demonstrate that their Multi Agency Support Hub (MASH) has proved very successful in bringing agencies together and improved communication relating to vulnerable children http://www.icpc.gg/article/118046/MASH. This also happens less frequently but effectively within the Safeguarding arena for older people.

Co-locating specialist (health) and generic (social) dementia services could improve the integration of dementia care locally.

Whilst all of the components above are important in supporting people with dementia to live as well as possible in their own homes, Community Services tend to provide the bulk of the practical and care support for families at home.

Most people with dementia in The Bailiwick of Guernsey live in their own homes and most families wish to continue to do so for as long as possible. Dementia often impacts on a person's ability to manage self-care tasks like washing and dressing. A high proportion therefore will be in receipt of help and support which is delivered by Community Services through the Home Care teams. The three Community teams, allocated by GP practice groups, provide packages of care which may involve providing help with issues such as

- Washing and dressing
- Preparing meals
- Prompting and administering prescribed medications
- Shopping
- Bathing
- General housework

The nature of dementia means the delivery of daily community care packages for that person is likely to be more complicated and typically takes more time and skill than might be required for a person without cognitive impairment. The person with dementia may struggle to recognise the community worker or understand the purpose of their visit. Community Home Care teams report that they are often constrained by time issues as they are required to provide care to a set

number of people on their rounds. The risk with trying to meet the needs of somebody with dementia in a regular time slot is that the person may become de-skilled if they are unable to take part in the procedure or there is the likelihood that they may feel rushed, pressured or frightened and resist the input, possibly resulting in challenging behavioural issues.

"*We don't always have the luxury of going away and calling back later when a person may be more accepting of the input." (*Community Care worker, Guernsey*)*

The rounds or patches that the care teams cover also change regularly and this complicates matters, as people with dementia struggle with change.

"I notice it with my wife; she definitely declines mentally for a time whenever the girls change their rounds…don't get me wrong, they are all good but they all do things slightly differently and don't always know her little ways" (Husband and carer of a lady with dementia, Guernsey)

There is therefore a recognised training need for all community staff who work with people with dementia. This has been highlighted also in the initial SLAWS report [73]. The issue also exists that the Community Services Teams are based at the old Castel Hospital site whilst the Older Adult CMHT are located at the Oberlands Centre which makes it difficult to discuss and review cases regularly.

As increasing numbers of people are living longer and as dementia becomes more prevalent the need for specialist community support will increase. At present, there are growing waiting lists for any person requiring routine community support (which is new for The Bailiwick of Guernsey).

The Rapid Response service is another valuable resource in preventing hospital admissions (which can be a confusing environment for people with dementia). The delivery of intensive care within the person's own home such as receiving IV antibiotics can prevent costly admissions to hospital and consequently reduce the risk of long term care placements being required.

Other methods of delivering support and care in the community may need to be examined outside of HSC-managed services. The recent introduction of the long-term care benefit scheme in Jersey made provision for funding to be made available for the families to source their own private support and partly fund it with the allowance. This has seen the expansion, development

and regulation of local private care agencies in Jersey who provide daily personal care and live-in care. This system, if explored, may help relieve some of the burden from the public sector and could help reduce the reliance on the long-term care sector.

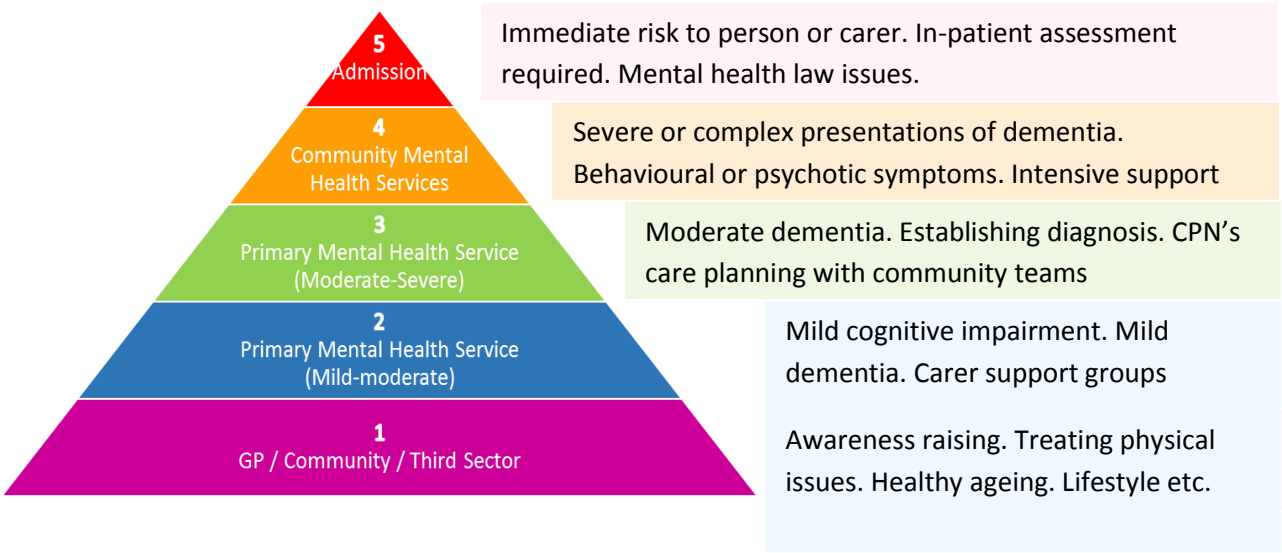
There is only one identified day care service specialising in the community support of people with dementia (The Willows) and this service is running at full capacity. Day centres like The Willows provide essential short breaks for carers who can as a result, engage in a social activity, attend appointments or go shopping which might be difficult if the person they care for was present. The expansion of such services should be given consideration as future demand is likely to increase.

Whilst the lower tiers of support **(chart 2)** are essential in maintaining wellbeing and supporting people with dementia in the community, the need for in-patient and specialised assessment (level 4 and 5) will also be required for some people during their journey of dementia.

Currently HSC have 8 beds within Tautenay ward at the Oberlands Centre which are used for assessment of complex mental health needs of older people. The service is beginning to feel the strain as the ward currently runs at very high occupancy. As people are maintained in the community for longer, when they do require in-patient assessment, they often present with complex needs and co-morbidities meaning admissions can often be protracted until suitable long-term care options emerge. Consideration should be made for expansion of the bed numbers and staffing to meet this growing need.

Within the voluntary sector, Guernsey also has opportunities to further integrate existing agencies to work closer together. This is one of the secondary aims of the DFG project which has already fostered better relationships between the Guernsey Alzheimer's Association and Guernsey Alzheimer's Society. Drawing together agencies should further help develop services, close gaps in service provision and enable easier access to services for people with dementia and their families.

Chart 2:



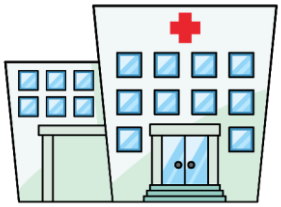
Best Practice Statement 4.1	**People with dementia in receipt of personal care at home should have care provided by adequately trained staff who have enough time to provide person-centred care**
Benefits of achieving this outcome	People with dementia are likely to be more receptive to care when they are familiar with their carers and a consistent approach is adopted. Relationship-centred care maintains people's wellbeing. Having enough time to provide good quality care can maintain people's independence and is less likely to de-skill individuals. This is likely to delay admission to long term care and can save money [84].
What's happening in The Bailiwick of Guernsey already?	Community care teams provide care to an increasing number of people with dementia without any formal structured dementia training. Community teams are feeling the pressure of increased workloads and struggle to find the extra time to give to people with dementia New care staff employed by HSC are required to undertake the Care Certificate [85] which covers basic dementia awareness and person-centred care approaches. Some specific Challenging Behaviour training to be offered across HSC in 2017.
What do we need and how do we achieve this?	Consider offering longer calls to people with dementia or developing a care team who specialise in supporting people with dementia who typically require more time. **Responsibility: HSC Community services, OACMHT**

	Ongoing training issues required in approaches to care. **Responsibility: HSC Practice Development Leads** Consider examining the feasibility of direct payments so families can look at buying in their own care which may in turn prompt the development of private agencies? **Responsibility: HSC, Social security** Closer working between specialist OACMHT and Community teams to review care plans and to offer advice. **Responsibility: HSC** An adequate resource of staff to implement and deliver care packages.
Risks and barriers	**Location:** Community teams and specialist teams are located on different sites. This makes regular liaising between disciplines difficult. Identifying trainers and keeping this updated. Releasing staff for regular training.

Best Practice Statement 4.2	**People with dementia with complex needs in the community will have access to specialist practitioners who can draw up support plans and link families with established support services.**
Benefits of achieving this outcome	Early intervention in cases where people present with complex needs can prevent admission to hospital and delay possible placement into long term care.
What's happening in The Bailiwick of Guernsey already?	OACMHT are currently operating as a Memory Clinic and as a Community Mental Health team and also have a Carer Support and education roles. Whilst the team has grown in recent years The team manage complex caseloads and take on increasing numbers from Memory Clinic.
What do we need and how do we achieve this?	Evidence shows that HSC's current 8 dementia assessment beds are in high use. OACMHT should be considered for further development to address this growing issue in the community. **Responsibility: HSC** Skill mix and specific roles within the OACMHT should be reviewed to reflect ageing population and specialist requirements that people with dementia need throughout their journey. This should include general hospital liaison roles, diagnostics, post diagnostic support, generic mental health support, occupational therapy, carer support, prescribing issues and Social work. **Responsibility: Ongoing as part of skill mix review process**

Risks and barriers	Cost Staffing (Recruitment and retention) Housing licences, population issues

Best Practice Statement 4.3	**People with dementia with complex needs who cannot be supported safely in the community will have access to specialized assessments beds**
Benefits of achieving this outcome	Acute assessment and treatment of complex needs in dementia can prevent further cognitive decline and facilitate successful home discharges. Acute assessment and treatment of complex needs in dementia can maintain current care-home placements and promote continuity of care for the person.
What's happening in The Bailiwick of Guernsey already?	Assessment unit Tautenay ward (8 beds) running at high occupancy. Beds often need to be used on adjoining adult mental health ward.
What do we need and how do we achieve this?	Consider expansion of the current in-patient assessment service in terms of beds and staffing establishment to possibly 12 beds. **Responsibility: HSC Service Managers, Psychiatrists, Team Leaders**
Risks and barriers	Cost Staffing (Recruitment and retention) Housing licences, population issues



5. General Hospital care

SLAWS [1] has already pointed out that 1 in 3 of our older adults who have physical problems will also have co-existing mental health needs and will typically be involved with several support services at the same time. At any one time, a quarter of acute hospital beds are in use by people with dementia [71]. These admissions to hospital are usually precipitated as a result of an injury, infection or another condition related to the person's physical health, rather than as a direct result of their dementia.

Dementia however complicates the picture and can make the treatment of physical health issues more of a challenge for staff. Symptoms of dementia such as memory loss, difficulties with communication, low mood, agitation, disorientation and cognitive issues can make it difficult for staff to deliver good quality care. The extra support that a person with dementia invariably

requires coupled with time pressures and staff training issues present significant challenges for general hospital staff. Early identification of the person with dementia's support needs is essential to that person receiving appropriate care during their visit to hospital.

The Alzheimer's Society [28] has published a recent report which shows huge variation in the standard of dementia care in general hospitals across the UK. Some of the key findings in this report show that:

- People with dementia spend much longer in hospital than over 65 year olds without dementia (5 -7 times longer in the worst performing hospitals)
- Many people with dementia become more confused in hospital
- 60% of the carers surveyed felt the person with dementia wasn't treated with dignity or respect
- There was evidence of poorly co-ordinated discharges of people with dementia
- A high incidence of falls. 50 - 70% of people aged over 65 who had a fall in hospital were people with dementia
- A poor awareness and understanding of dementia care amongst many health professionals.

Care in general hospitals across the UK has come under scrutiny and has been found in some cases to be below minimum standards. The Francis Inquiry into the Mid Staffordshire NHS Foundation Trust 2013 [26] found serious failures in relation to the quality of patient care delivered by that Trust and reported an **"***insidious negative culture involving a tolerance of poor standards and a disengagement from managerial and leadership responsibilities***"**.
The National audit of dementia care in general hospitals [27] built on this Inquiry's findings, recommending that hospitals should have a dementia strategy in order to improve dementia care. They recommend there be

- A dementia champion on the board and a defined process for the board to review the quality of dementia care.
- There should be a clear, personalised dementia care-pathway from admission to discharge with an identified senior clinician to oversee its implementation.
- All staff should be dementia aware; those delivering care should receive dementia training appropriate to their role.

- The hospital environment should be adapted to be dementia-friendly.

The importance of the care environment is further recognised in the Royal College of Nursing's Commitment to the Care of People with Dementia in General Hospitals [30] and although there have been significant improvements in staff training since the publication of the National Dementia Strategy, attention has not always been focused on the impact that the physical environment of care can have on people who are confused.

The RCN has identified 5 key areas for improvement that general hospitals should be striving to improve upon in terms of dementia care.

- Staff need to be informed, skilled and have enough time to care.
- Family carers and friends are seen as partners in care, unless indicated otherwise by the person living with dementia.
- A dementia assessment will be offered to all those at risk, to support early identification and appropriate care.
- Care plans will be person-centred, responsive to individual needs and support nutrition, dignity, comfort, continence, rehabilitation, activity and palliative care.
- Environments will be dementia friendly and support independence and wellbeing.

In general hospital settings delirium is a condition often overlooked and mistaken for dementia. Delirium is an acute neuropsychiatric syndrome; occurring in 11–42% of elderly in-patients [61]. The presence of delirium is associated with prolonged hospital stay, higher rates of institutionalisation and increased mortality [62]. It is also associated with accelerated cognitive decline in those with a pre-existing dementia. Causes are usually physical in nature, including infection and dehydration. The risk of developing delirium is three times higher over age 65, rises rapidly with increasing age, and is five times more common in older people who have dementia. It is associated with increased cognitive decline and increased risk of medical complications including infection, falls, and incontinence.

The condition increases mortality, disability and length of hospital stays. Like many mental health conditions of older people, delirium is often undetected an untreated. It is however both preventable and treatable. The British Geriatric Society and the Royal College of Physicians have produced guidelines for the prevention, diagnosis and management of delirium which can be summarised in the 5 steps below:

Step 1:

Identify all older patients (over 65 years) with cognitive impairment using the MMSE or similar screen on admission to hospital.

Step 2:

Consider delirium in all patients with cognitive impairment and at high risk (severe illness, dementia, fractured neck of femur, visual and hearing impairment).

Step 3:

Identify the cause of delirium and treat underlying cause or causes – consider drugs or drug withdrawal, infection, electrolyte disturbance, dehydration or constipation.

Step 4:

For patients with delirium and patients at high risk of delirium:-

Do

- provide environmental and personal orientation ensure continuity of care
- encourage mobility
- reduce medication but ensure adequate analgesia
- ensure hearing aids and spectacles are available and in good working order
- avoid constipation
- maintain a good sleep pattern
- maintain good fluid intake
- involve relatives and carers (carers leaflet)
- avoid complications (immobility, malnutrition, pressure sores, over sedation, falls, incontinence)
- liaise with Old Age Psychiatry Service

Do not

- catheterise
- use restraint
- sedate routinely
- argue with the patient

Step 5:

Ensure a safe discharge and consider follow up with Old Age Psychiatry Team. Provide family/carer education and support

Best Practice Statement 5.1	**All care staff that might come into contact with people with dementia in hospital should have training in dementia awareness.**
Benefits of achieving this outcome	Understanding of dementia can help all staff adapt their approach to suit the person's need. Person-centred care can help ensure that people's needs are understood and subsequently promote wellbeing and reduce likelihood of behavioural issues.
What's happening in The Bailiwick of Guernsey already?	The Care Values Framework [86] was launched towards the end of 2016 and is based around the six themes of Service Guernsey integrated with 6 key Principles to ensure that there is a focus on the areas that will help us deliver a higher quality of care. The Care Values Framework remains committed to the values of the 6Cs (Care, Compassion, Competence, Courage, Communication and Commitment) and delivering the values of Service Guernsey. The Care Passport is being trialled within PEH which aims at personalising care for people with communication needs (including dementia). The initiative strives to foster stronger relationships with carers and view them as partners in care. Some specific dementia training to be made available to all hospital staff relating to why challenging behaviour might occur in people with dementia. Working groups have been developed as part of the Care Values Frameworks focussing on specific areas of care in hospital. Dementia awareness modules and placements are offered during the pre-registration nurse training courses in Guernsey. Development pathways are being developed across the organization and are a means for care workers to develop their skills in care and progress to Band 4 practitioners and ultimately offer a pathway to nurse training.
What do we need and how do we achieve this?	Dementia training modules to be made available through Institute of Health and Social Care Studies? **Responsibility: Practice development leads and specialist staff. Ongoing** Dementia Friendly Hospitals in the UK have attained certain standards and training to be recognised as such. Training packages such as the Butterfly Scheme [74] can raised awareness and standards in general hospitals and have helped hospitals become more dementia friendly environments. Such schemes require "buying in" to external training but there are many resources available free of charge e.g.

	http://www.dementiaaction.org.uk/joint_work/the_right_care/d_kit/d_kit_downloads. **Responsibility: Opportunity to explore such a project as a jointly funded initiative between HSC and Voluntary sector groups.**
Risks and barriers	Staffing and skill mix needs to be reviewed regularly to ensure care standards can be maintained and that staff can be released for training. Identifying trainers and keeping this updated across the organisation.

Best Practice Statement 5.2	**People with dementia should be recognised as having extra support needs on admission to hospital.**
Benefits of achieving this outcome	Diagnosis of dementia is recognised at admission. Suspected diagnoses are flagged up for follow up and assessment by professionals following discharge. Staff should be aware that people with dementia should be offered extra support with basic essential care such as eating and drinking, mobilising and using the toilet. Reduced likelihood of patients missing out on basic care needs. Faster recovery is promoted. Risk of delirium should be considered as an outcome when physical ill health is combined with dementia. Addressing and investigating underlying physical health issues should be considered a priority when fluctuations occur in the behaviour or cognition of a person with dementia. Admissions are less protracted and there is less chance of a person's skills and abilities deteriorating. Chances of successful discharge home are increased.
What's happening in The Bailiwick of Guernsey already?	Care Passport system has been adopted and should help staff identify any extra support needs a person may have and encourage carers to be more involved in care. This system will be particularly useful for planned admissions like surgery. Care Values Framework should help embed good care practices, drive innovations forward and make staff aware of how to flag up concerns about poor care practices. Disability awareness training available for all staff as e-learning package within States of Guernsey.

What do we need and how do we achieve this?	Dementia Friendly Hospital schemes such as the Butterfly Scheme [74] have raised awareness and standards in general hospitals and have helped hospitals become more dementia friendly environments. Such schemes require "buying in" to external training but there are many resources available free of charge e.g. http://www.dementiaaction.org.uk/joint_work/the_right_care/d_kit/d_kit_downloads. **Responsibility: Opportunity to explore such a project as a jointly funded initiative between HSC and Voluntary sector groups.** Consider investment and training in dementia-friendly hospital design schemes like The Butterfly Scheme [74] **Responsibility: HSC, Acute care managers** Explore whether voluntary sector groups could provide extra support for people with dementia who may have no immediate family? Dementia champions should be developed within the general hospital environment. **Responsibility: HSC**
Risks and barriers	Cost of buying in training. Staff turnover (how often is training repeated?). Staffing establishment and skill mix review to ensure there are enough staff to meet extra needs of those who need extra care and support. Voluntary sector involvement and availability.

6. Improved care in care homes

Up to 80% of the residents in residential and nursing homes have dementia according to Alzheimer's Society figures [29]. This figure has also been echoed locally with many of the private care sector managers reporting that their residents either arrive with dementia already established or they go on to develop it whilst there. This 80% figure is likely to be nearer 100% for those care homes that are recognized as EMI homes (see glossary). It is clear therefore that understanding dementia and the challenges it presents is a key priority for all care home staff.

There are 5 dementia specialist care homes in The Bailiwick of Guernsey. In Alderney both the Mignot Memorial Hospital and the Royal Connaught Care Home regularly support people with dementia. Many other care homes not registered as EMI also care for people with dementia.

There are established local dementia standards that The Bailiwick of Guernsey EMI care homes have to meet in addition to the generic standards for every home. These can be accessed via www.gov.gg. [71]

Some of the key recurring issues identified within the annual inspection reports relate to the difficulty for home managers in accessing specialist dementia training and lack of evidence of person-centred care planning.

As care homes will remain an important component of care within the journey of somebody with dementia, the quality of care within them should be monitored through the evidence of good quality care plans, meaningful activity programmes and life history work.

Good holistic assessments recognise a person's strengths and values and each person is recognised as being individual. Domains which should be assessed on an ongoing basis should include:

- Cognitive health
- Physical health
- Physical functioning
- Sensory capabilities
- Communication abilities
- Personal background
- Cultural preferences
- Spiritual needs and preferences

Dr. David Sheard [25], an expert in dementia care culture within long-term care settings, in a recent keynote speech at Dementia Congress 2016 firmly believes that within the care sector "*we have created an emotionally detached workforce".* His observations are concerning given this is exactly the kind of work that demands profuse emotional engagement especially when trying to engage with people with cognitive impairment where verbal communication takes on less meaning.

Naomi Feil [21] through her pioneering work in Validation therapy reflects this ethos. She reminds us that most "*behaviour*" in dementia is a form of communication and needs to be recognised

and validated. Care workers can sometimes become immune to behaviour as a means of communication and may ignore it or even worse punish it by means of isolating the person or by use of sedating medications. She makes the important observation that even in very late-stage dementia, when spoken word has disappeared and eyesight has diminished, people use their minds' eye to see. People will often use repetitive sounds and rhythms to communicate. *"To survive present day losses, the very old restore the past*". This demanding stage of the illness requires skilled and caring practitioners who need support to deliver good quality care.

Aside from direct patient care there are further challenges facing care home managers in The Bailiwick of Guernsey. These include issues around staffing, housing licenses, population control, accommodation and the cost of living in The Bailiwick of Guernsey. Attracting local staff into care work remains a challenge as pay rates cannot compare with sectors, such as finance, and the work can be emotionally and physically demanding. It is imperative then that Guernsey's housing laws recognise the need for the care home sector to be able to attract unqualified care staff here to the island. There are local initiatives developing however aiming to address the promotional career opportunities for un-qualified care staff and this may make the role more appealing to those considering a career in nursing.

Staffing issues are not unique to The Bailiwick of Guernsey but the issues here make it difficult for managers to retain staff for long periods of time. This continuity of care is very important in dementia care work as relationships between care staff, residents and families take time to develop. High turnover also makes training issues an ongoing priority and challenge for managers.

A large percentage of the care staff working within the care sector come from countries where English is not their first language. Whilst this diversity of culture is enriching, language differences can prove to be another barrier when communicating with people with dementia. This can also make the delivery of training difficult for managers and trainers. Investing in training of key staff members to deliver sessions in different languages should be considered to help translate the ethos of person-centred approaches if language is a barrier.

Best Practice Statement 6.1	**Care home managers in EMI homes need to be responsible for regular training of their staff in person-centred approaches to dementia care.**
Benefits of	Person-centred approaches to care value the person and recognise the life they have led and still lead. Holistic approaches to care can improve

achieving this outcome	wellbeing in people with dementia.
What's happening in The Bailiwick of Guernsey already?	Care managers access training for staff from various sources (VQ units, Institute of Health and Social care, local trainers, privately). Dementia awareness and expertise amongst care home managers is improving especially within EMI settings.
What do we need and how do we achieve this?	Care home managers association could consider bringing in recognised UK speakers to up-skill key staff via workshops. This could enable some staff to become dementia champions within the homes. This could also help engage staff where language is a barrier to training. Encourage EMI dementia care managers to develop their own skills so that they can be mentors to their staff and embed good cultures of care. **Responsibility: Care Home sector**
Risks and barriers	Cost Staff turnover Interest from staff Training delivery

Best Practice Statement 6.2	**Care home managers should be encouraging a culture of activity within their homes as per standard 5 of the local EMI standards**
Benefits of achieving this outcome	Meaningful activity increases wellbeing, activity and gives a sense of purpose to people who reside in care homes.
What's happening in The Bailiwick of Guernsey already?	All the EMI homes as well as many others have established "activity practitioners". A forum for this group of staff has recently been developed so that they can share ideas and good practice.
What do we need and how do we achieve this?	Encourage managers to invest in this important aspect of dementia care. This should include investing in staffing, outings, vehicles, bringing in entertainment, art and craft materials, music etc. **Responsibility: Inspector of Care homes, Care Home managers**
Risks and barriers	Cost

	Staff turnover Training delivery

Best Practice Statement 6.3	**Anti-psychotic medications usage should be reviewed by care home managers and discontinued if possible under the supervision of mental health teams.**
Benefits of achieving this outcome	The use of such medication in the long term has been shown to increase the risk of stroke or death.
What's happening in The Bailiwick of Guernsey already?	Sometimes anti-psychotic medication is prescribed by doctors to treat behavioural and psychotic symptoms in the context of dementia. The problem is that sometimes these medications are left in place long after the presenting problem has resolved.
What do we need and how do we achieve this?	Care home managers should encourage regular medication reviews by GP's or specialist teams. **Responsibility: GP's, care home managers, specialist teams** Offer Newcastle model training which advocates for non-medical approaches in addressing challenging behaviour in dementia **Responsibility: Care homes, Practice development, Institute of health (Currently in progress)** HSC to ratify non-medical prescribing. Nurse specialists may be much better placed than GP's to prescribe and review closely anti-psychotic medications. Non-medical prescribing has been shown to reduce the cost of prescribing by means of closer review and discontinuation of medications. **Currently in progress**
Risks and barriers	Cost Training delivery Motivation from care sector

Key Recommendations

In summary here are the key recommendations under the 6 headings.

Raising Awareness

- Continue to develop the DFG dementia friendly community initiative and deliver training and awareness across the community via the Dementia Friends Champions.
- Link closely with voluntary sector groups to help raise awareness.

Early Diagnosis

- Continue to develop and implement the capacity legislation so that people with an early diagnosis of dementia can plan ahead for the future while they still retain the ability to make decisions.
- GP's to reconsider making diagnoses in more straightforward cases whilst still being able to refer on for specialist support following this.
- Consider development of a dementia guide to help GP's signpost after diagnosis.
- Consider a revision of the diagnostic pathway with a view to becoming an accredited UK service.
- Further improve the availability of post-diagnostic support through a dementia adviser or Admiral Nurse.

Carer Support

- Further promote the development of carer support groups for people with dementia.
- Consider developing the role of Dementia Advisers to provide post-diagnostic care and support.
- Consider developing an Admiral Nurse position.

Integrated Community care

- Consideration to be given to the current location of Community Teams and specialist Older Adult Mental Health teams to foster closer working relationships.
- Training issues for community care staff remains a priority. Consideration given to development of specialist dementia community care teams
- More open and transparent electronic healthcare records between mental health and community teams to truly integrate care.
- Easier access to respite and day care services for people with dementia.
- Decisions to be made on an ageless mental health service to close gaps in provision.

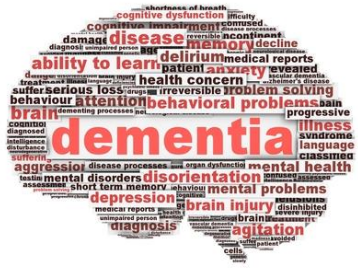
Care in hospital

- Training in dementia care awareness to be rolled out across the organisation.
- Development of dementia friendly wards to promote wellbeing in dementia.

- Encourage engagement of family and carers as partners in care.
- Further encourage use of hospital passport document to promote person-centred care approaches.
- Consider development of hospital liaison psychiatrist role.

Care in Care Homes

- Training in dementia care should be prioritised especially in EMI homes.
- Managers should foster a culture of activity and engagement within homes.
- Monitor use of anti-psychotic use and promote behavioural approaches.
- Specialist nurse-prescribing should be developed to help monitor anti-psychotic use.
- Encourage person-centred care plans and life history work.
- Population and housing issues to be considered to maintain viable workforce.



Types of dementia

Whilst it is helpful to know how dementia can present it's important not to focus too much on symptoms and risk forgetting about the person. Focusing solely on the symptoms of dementia tends to medicalize the condition and can conceptualise it from a purely neurological standpoint. It doesn't recognise the complexity of dementia and tends to neglect the uniqueness of each person and the impact of external factors or the so called social psychology [7].

Alzheimer's disease

The term Alzheimer's disease and dementia are often used interchangeably and can be confusing for people. Alzheimer's is the most common type of dementia and accounts for more than 60% of all dementia cases. This is no different in The Bailiwick of Guernsey and it is the sub-type most often identified via the memory clinic.

The term Alzheimer's disease is named after the German neurologist Alois Alzheimer who in 1906 found, on post mortem examination, particular changes within the brains of his patients and concluded…

"*we are apparently confronted with a distinctive disease process*"[20]

He noted microscopic changes occurring within the brain of the person causing the formation of neurofibrillary tangles and amyloid plaque deposits. The build-up of these plaques and tangles impairs the ability of the neurons to relay messages across the brain. The hippocampus is also affected which is the area of the brain responsible for forming new memories. Over time the brain cells die and the brain typically decreases in size and weight.

The main risk factor associated with Alzheimer's disease is age. After the age of 65 years the likelihood of developing dementia roughly doubles every five years. By the age of 80 years the risk of a person having dementia is about 1 in 5. The likelihood of developing the disease may increase if there is a strong family history of Alzheimer's (e.g. if both parents had the disease, or if many members of one side of the family developed the condition).

Vascular Dementia

The second most common cause is vascular dementia accounting for about 20% of all the dementias. This type of dementia occurs as a result of problems with blood supply to the brain; either the blood supply is interrupted or there are microscopic bleeds as a result of mini strokes or TIA's. Studies have shown that up to half of dementias can be of a mixed type; both Alzheimer's and vascular pathology [19].

There is good evidence to suggest that healthy lifestyles may help reduce the incidence of vascular dementia, and therefore dementia generally. A recent study [38] notes that up to half of dementia cases worldwide are attributable to seven potentially modifiable risk factors — such as diabetes, midlife hypertension, midlife obesity, smoking, depression, cognitive inactivity and physical inactivity. It is estimated that a 10-25 % reduction in all seven risk factors could potentially prevent as many as 1.1-3 million Alzheimer' disease cases worldwide. Risk factors for vascular dementia are the same as those for strokes. The Alzheimer's Society [8] has also published the guideline "*What's good for the heart is good for the head*" which outlines the steps we can take during our lives to reduce vascular risk factors of dementia:

- **Monitoring blood pressure:** Get your blood pressure checked when you visit your GP and follow medical advice to keep it under control.

- **Monitor cholesterol:** Evidence shows that high cholesterol levels in mid-life can increase your risk of dementia later on. Your GP may be able to give you advice on reducing levels if elevated.
- **Avoiding obesity:** Obesity can increase the risk of high blood pressure and diabetes which can increase the risk of dementia. Eating a healthy diet and reducing excess sugar and saturated fats is recommended.
- **Regular exercise:** Try to be physically active for at least 30 minutes, five times a week, with a moderate intensity activity such as brisk walking or cycling. You should be working hard enough to raise your heart rate and break a sweat.
- **Stopping smoking:** Smoking has an extremely harmful effect on the heart, lungs and blood vessels, including the blood vessels in the brain. Research shows that smokers have a 50 per cent greater chance of developing dementia than those who have never smoked, but this risk can be significantly reduced by quitting the habit.
- **Avoiding excess alcohol:** Drinking more than the recommended levels of alcohol increases the risk of developing various forms of dementia, such as Korsakoff's disease and vascular dementia. However, research suggests that light-to-moderate amounts of alcohol may protect the brain against dementia and keep the heart and vascular system healthy.
- **Mental activity:** It is thought that mental activity increases the brain's ability to cope with, and compensate for, physical damage. This would mean a person who often takes part in these activities will be able to tolerate a greater level of cell damage before symptoms of dementia are detected. Taking up new hobbies or learning new skills are great ways to challenge your brain and keep it active. Social activity is also a very good way of keeping the brain active.

Other less common types of dementia include Lewy Body dementia, fronto-temporal dementia and alcohol-related dementias are also seen in The Bailiwick of Guernsey. Some of these dementias tend to occur in younger adults (from 55yrs of age upwards). Providing support for this group of people can provide its own particular challenges as services in The Bailiwick of Guernsey are not necessarily developed to provide support for younger adults. For example, most residential care services tend to focus on the care of older people.

Mild cognitive impairment

Mild cognitive impairment (MCI) is a diagnostic term used when a person's memory problems are in excess of what one might expect for their age, but not severe enough to be called dementia. About 1 in 3 people with this condition may go on to develop dementia, but it cannot yet be predicted with certainty who these people will be. Some people with this condition are identified through the memory clinic. This group of people are usually offered 6 monthly follow up appointments in the memory clinic to monitor changes that may occur.

Younger people and dementia

Whilst dementia mainly affects older people, there is also growing awareness locally of people developing it before the age of 65 yrs. Younger onset dementia typically progresses quickly and can be very difficult for families to cope with. This small group of people are often physically well and active and care may be provided by much younger carers and sometimes children. Furthermore, most residential care environments focus on supporting older people and younger people with dementia will have different needs and require different approaches to care. There is a lack of local provision in the care sector for people with these rarer dementias.

Dementia services in The Bailiwick of Guernsey

Table 4: Dementia services map

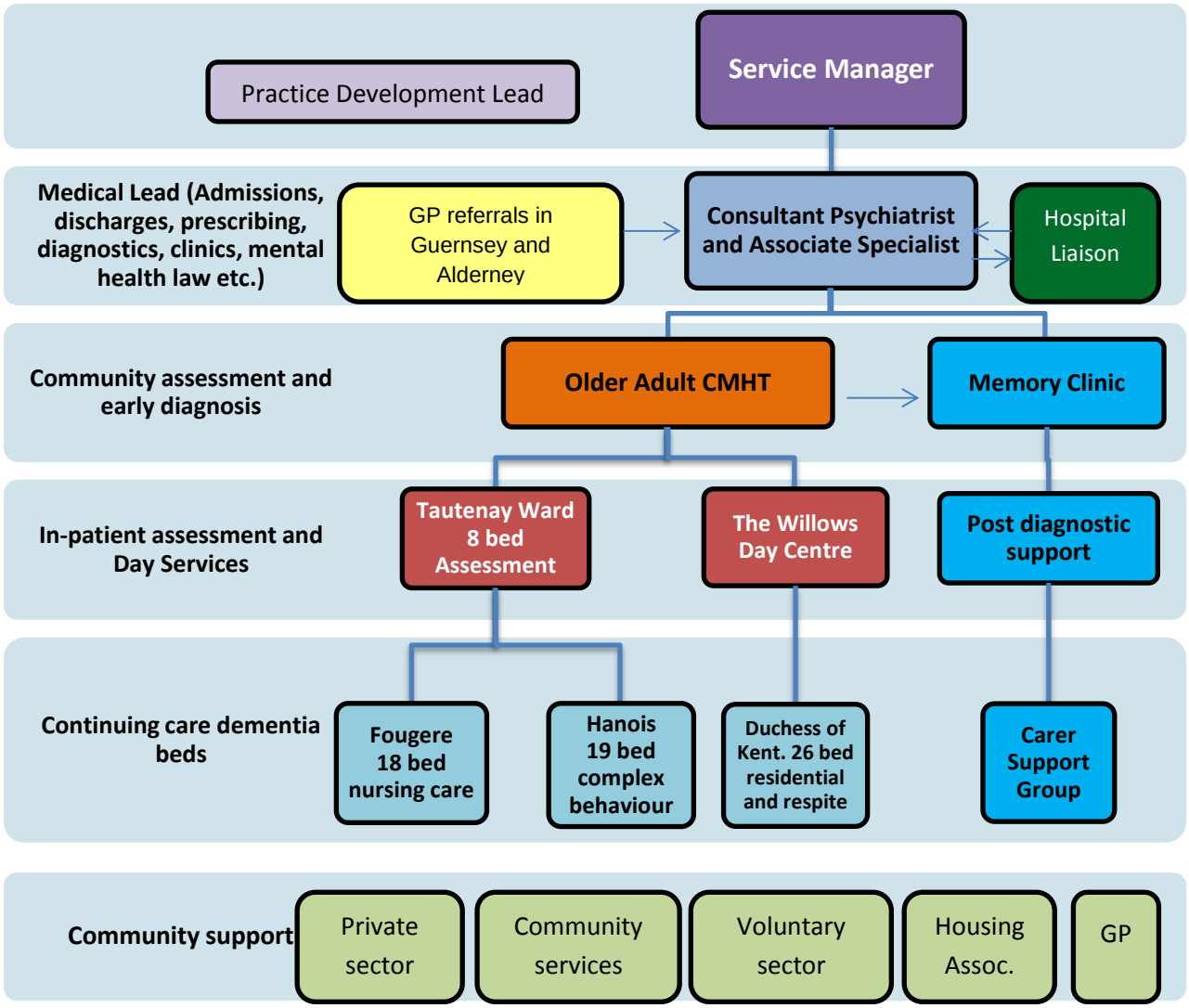


Table 4 above outlines how dementia care support services are set out in The Bailiwick of Guernsey.

The Bailiwick of Guernsey's dementia services are delivered via various agencies. The States of Guernsey, through the Committee for Health and Social Care (HSC), provide services including diagnostic (memory) clinic, community mental health support, in-patient assessment, day

services and long-term continuing care. Ongoing practical home care support is provided by the Community Services team.

Further support for people with dementia is delivered by the private sector, voluntary sector, and by the person's own GP.

Described below is an overview of the main responsibilities of each department.

Older Adult Community Mental Health Team

The Older Adult Community Mental Health Team (OACMHT) is a community based multi-disciplinary team that offers mental health assessment and support to islanders who are generally aged over 65. The team also provides support to people under the age of 65 where dementia is the primary diagnosis. This demarcation by age may change in future (see p 65).

Like many community health teams the ethos is no longer based on a purely medical model of care but values the specialist professional input of all its members. That said, there is some commonality and overlap of roles between team members.

The primary focus of the OACMHT is to support people in the community to live with either acute or enduring mental health conditions. The ethos of the team is to promote wellbeing, prevent deterioration, and to help people remain safely at home for as long as possible. In many cases (such as dementia) the condition is not reversible and so the focus is on adaptation and helping families develop strategies to cope. This may involve providing education about dementia and helping carers understand why some difficult behaviours may occur. At times, medication may be recommended in the short-term treatment of mental health conditions and this requires monitoring by team members.

Much of the work that the OACMHT do is focussed on helping and supporting carers in their role. This involves family carers but also carers and managers supporting people with dementia within residential and nursing home settings. Team members also visit Alderney about every three weeks where they run a clinic in the Mignot Memorial Hospital.

The team help devise personalised care plans in conjunction with the service user and family once their needs have been fully assessed. They undertake risk assessments and also identify the strengths that a person possesses. The team can offer advice and signposting towards local

services. They can also offer advice around medications and will liaise closely with the person's own GP in this regard.

If a person needs practical help with personal care such as washing and dressing, prompting with medications or shopping the team can liaise and refer to the Community Services team to help put this in place although waiting lists are likely. Unfortunately the OACMHT do not currently have the capacity to offer ongoing follow up to people with dementia unless the issues become complex in nature. This is an area where the growth of the voluntary sector may be able to support HSC services.

Referral to the OACMHT is usually via the person's own GP. The team contains professionals from various disciplines listed below. An attempt has been made at briefly summarising the particular roles of the individual members; however there will be many aspects of the roles that will have invariably been missed out. There is also a considerable amount of overlap between roles as team member's work collaboratively to support individuals with mental health needs in the community.

- **1 Consultant Psychiatrist**:
  The consultant psychiatrist is the clinical and medical lead of the multi-disciplinary community team and supports the various members of the team in their roles. The consultant makes decisions regarding the admission and discharge of patients to and from the assessment ward (Tautenay). The consultant psychiatrist maintains medical responsibility and makes clinical decisions about patient's care which includes those in Tautenay ward, the Lighthouse wards and Duchess of Kent. There is also provision for general medical care in these areas from a visiting GP. The consultant also devises treatment plans for people seen at home, out-patient clinics or in residential/nursing homes.

  The consultant undertakes a key role in assessing and admitting patients under the mental health law in association with an approved social worker. The consultant also maintains a liaison role with medical colleagues in the PEH and will offer advice on patients' care where cognitive impairment or functional mental health issues are

suspected. The consultant also has a role in advising on the future development of the older adult mental health services.

- **1 Associate Specialist:**
  The Associate Specialist psychiatrist undertakes a similar medical role to the consultant but offers specialist input within the Memory Clinic pathway where they run a weekly diagnostic clinic. The associate specialist also provides regular support to Alderney through clinics held there.

- **1 Team Manager**
  A Community mental health nurse with responsibility for the daily management and development of the team. The manager also sees some patients in a clinical role and has regular involvement with the memory clinic and runs clinics in Alderney.

- **4 Community Psychiatric Nurses (CPN's)**
  2 of the CPN's have a generic role and are focussed on providing mental health support to service users in the community; their role is varied. They are involved in undertaking first line mental health assessments, cognitive assessments, carer assessments and have responsibility for drawing up care plans and reviewing them. CPN's tend to have involvement with supporting clients with commencement and titration of medication and monitoring effectiveness and concordance.

  2 of the CPN's have a special interest in the Memory Clinic pathway. This early diagnostic pathway involves the completion of detailed assessments of a person's cognitive and functional abilities, their background history, their living situation and the needs of the carer. The process also entails post-diagnostic follow-up visits. They tend to work closely with the associate specialist doctor in helping establish a diagnosis. Delivering this pathway of care takes up most of their time.

  All of the CPN's have involvement in carer education and some in-reach work into the private sector care homes.

- **1 Occupational Therapist**
  The Occupational Therapist (OT) undertakes numerous roles within the team. The OT provides an essential link to the admission ward (Tautenay) and can help facilitate earlier

discharge of clients by offering functional assessments of a person's strengths and needs; they are specialists in planning care and support based on the outcomes.

The OT also plays an important role within Memory Clinic and can add their expertise to the assessment process, particularly around safety and risk assessment in the home which may be of concern due to a person's dementia.

The OT has been instrumental in developing the carer support groups in conjunction with the Alzheimer's Association and has forged valuable links with the Alzheimer's Society and other voluntary sector groups. The OT has also played an important role in developing the role of the support worker within the team.

Further roles of the OT include:

- Providing non-pharmacological management of symptoms, such as behavioural disturbance and depression.
- To complete functional assessments to support diagnosis
- Assisting home carers to work 'with' rather than 'for' people with dementia, thereby reducing dependence.
- Effective and efficient discharge planning.
- Prevention of admission to hospital with effective interventions to manage risk
- Ensuring that developments in tele care and assisted housing are appropriate for people with dementia.
- Providing 'in-reach' services for people in care homes, in order to enable meaningful occupation.
- Home hazard assessments and adapting or modifying the home environment
- Providing advice, support and education to carers.

- **2 Community support workers**

Support worker undertake a variety of important roles in supporting people with dementia in the community. This person can provide intensive support to people who live alone and who may need several daily visits for a period of time. They also provide invaluable practical support to people with dementia such as helping with filling in forms, organising equipment and liaising with the handyman service. The support worker liaises closely with the generic community care team to help facilitate seamless handover of care without too much anxiety for the person.

They also provide essential transport links for people who would otherwise not be able to attend various groups. The roles are still developing and the team are looking at innovative ways of supporting people with dementia.

- **Social Worker**

  The OACMHT have in the past had a dedicated social worker in the team. The post has recently been amended to sit within community services so that the role will be split between Older Adult mental health, community services and one week in four will be assigned to the duty social work team.

  Many of the people supported by the OACMHT will require specific social interventions and practical support. Previously the social worker within older adult mental health supported families to arrange respite, access benefits and advise on long term care placements, and whilst this is important their role is much more complex than this. The absence of a specialist dementia care social worker means that the CPN's and Occupational Therapists have to be much more involved with organising long term placements for families.

  Social workers have a crucial part to play in improving mental health outcomes for service users. They bring a distinctive social and rights-based perspective to their work. Their relationship based skills and their focus on personalisation and recovery, can support people to make positive, self-directed change. A specialist social worker also maintains an important link with our adult social work colleagues.

  Social workers are trained to work in partnership with people who use a range of health and social care services. They involve their families and carers, to optimise involvement and collaborative solutions. They help link services together to provide tighter plans of care and to avoid duplication of work.

  Social workers also manage some of the most challenging and complex risks for individuals and make decisions with and on behalf of people within complicated legal frameworks, balancing and protecting the rights of different parties. This includes, but is not limited to, their vital role as the core of the Approved Mental Health Professional (AMHP) workforce.

  A social worker is required to liaise closely with the consultant psychiatrist when planning to admit persons with dementia who present with complex mental health and social

needs under Guernsey's Mental Health Law (2010) [69]. The SW can also provide advice on legal matters and will be an essential component in the team with the advent of the incoming Capacity Law.

- **Psychologist**

  The OACMHT do not have a dedicated psychologist. Access to psychological interventions (CBT, counselling etc.) for adults aged over 65 yrs. is now offered through the psychological therapies service but waiting lists can be long and age has been a barrier to accessing the service in the past. Primary Care mental health services do not provide a service for adults who are older than 'working age'.
  There is still establishment for the OACMHT to have their own psychologist who the team feel could play an important role in devising behavioural support plans to help educate staff on approaches to care, particularly within the care home sector. This role could be undertaken by any professional with a special interest however. This kind of intervention has shown to be very effective within the Guernsey learning disability services through the development of the positive behavioural support team. Addressing the unmet needs of people with dementia promptly could help avoid unnecessary admissions to hospital which usually results in a decline in wellbeing, orientation and cognitive function.

  Psychologists also play an important role within Memory Clinic services and can deliver specialist psychometric testing and offer detailed analysis of test results.
  The OACMHT have access to a psychology assistant for some clinic sessions.

Tautenay Ward

Tautenay is an 8 bedded assessment unit for older adults with dementia and other mental health issues. It is based at the Oberlands centre. The ward employs registered mental health nurses and healthcare assistants. Clinical care is overseen by the consultant psychiatrist and there is input from a GP with a special interest in dementia for two sessions weekly.

Service users may be admitted here through the consultant on a voluntary basis or formally under the Mental Health law. Following a period of assessment, service users can often return back home with some added support. If discharge home is not possible then a long term care

placement may be explored and arranged. Discharges will be planned with the help of the wider community team. The ward runs at high occupancy.

Duchess of Kent House

The Duchess of Kent House is based within the PEH site. The home offers residential placements supporting older adults with mental health conditions which may mean they need care and support for complex or challenging behaviour. This includes, but is not limited to, dementia. The service is not suitable for those with significant physical or mobility difficulties.

There are 26 beds available, 2 of which are reserved for short-break respite care placements. Respite provides short term accommodation and support for a person or allows the person who cares for them a break, or both. Respite is offered up to 4 weeks per year at no charge to the individual.

Long-term care provided within the Duchess of Kent is mostly funded by The Committee for Health and Social Care however residents pay a fee equivalent to the Long-term Care Insurance co-payment (usually the equivalent of a full Guernsey old-age pension).

Hanois Ward

Hanois is a 20 bedded continuing care ward (currently reduced to 15 beds). This ward is specifically focused on supporting people with complex behaviour associated with mental health conditions, particularly dementia.

Long-term care provided within Hanois ward is mostly funded by The Committee for Health and Social Care however residents pay a fee equivalent to the Long-term Care Insurance co-payment (usually the equivalent of a full Guernsey old-age pension).

Fougere Ward

Fougere is a 20 bedded continuing care ward providing support for people with more advanced dementia and associated nursing care needs.

Long-term care provided within Fougere ward is mostly funded by The Committee for Health and Social Care however residents pay a fee equivalent to the Long-term Care Insurance co-payment (usually the equivalent of a full Guernsey old-age pension).

The Willows

The Willows Day Centre provides specialist day care facilities and programs of care for people with dementia; it is based at La Nouvelle Maritaine. The development saw the merging of two day services, namely The Meadows and St. Luke's day centre which were previously based at The Castel and King Edward 7th Hospitals respectively.

The Willows establishment includes an occupational therapist, nursing staff and healthcare assistants. The Willows focuses on occupation and activity as a therapeutic intervention. The attendees can engage in a range of activity from art, gardening, cooking, singing, quizzes and exercise and it also provides essential social support and engagement. The attendees can also avail of an assisted bath if required which is a much valued service. This service also runs at very high capacity.

Private Sector

There are 5 private dementia-specific care homes in the community. These homes have to meet the standards of care expected of all care homes as well as extra standards particularly related to dementia. The extra standards relate to person centred approaches to care, activity and social engagement and the care environment. Other non-EMI care homes also provide care and support for people with dementia, especially as many residents can develop the condition during the time they live there.

The OACMHT have good working relationships with the private care sector in supporting clients with dementia and other mental health problems. This fits in with one of the principles of SLAWS which emphasises that *'The States of Guernsey should take a strategic role in developing a "care community" working in partnership with the private and third sectors.'*

The Memory Clinic Pathway

The information below is taken from the www.gov.gg memory services page https://www.gov.gg/article/151983/Memory-services. The information is written for the benefit of anyone who may be worried about their memory and is wondering what steps to take.

What should I do if I am worried about my memory?

If the shortfalls in your memory are occurring regularly or if they are interfering with your ability to manage your day-to-day life then they should be explored further. If your memory is causing you to struggle with things you once did well such as:

- Finding the right words
- Managing money
- Keeping appointments
- Shopping
- Cooking
- Managing household chores
- Keeping on top of bills
- Getting lost or disorientated
- Remembering names of close family or friends
- Driving

then you should go and speak to your GP. It may also be helpful to ask a family member or friend to go along with you for support.

What will my doctor do?

- Your GP will ask you some questions about your memory and how this is affecting your daily life. The doctor may also ask you to undertake a brief memory test.

- Your doctor will want to undertake some basic blood tests. This is to find out if there are any treatable conditions that might be affecting your memory. You will probably be asked to have an ECG to check your heart rhythm. You may also be referred for a CT scan to see if there are any changes occurring in the brain that may be affecting your memory.

- Your doctor should also ask you some brief questions about your mood. Depression can have symptoms very similar to dementia. It can slow up your thinking, cause you to forget things and affect your concentration. If depression is a factor then your GP may want to treat this or offer you further support to address the underlying issues.

- Once your doctor has received all the test results he/she may want to treat any medical causes that may be affecting your memory. The GP may then refer you for a more specialised assessment at the Memory Clinic. The doctor will ask your permission for this to occur.

What happens at the Memory Clinic?

- Within about 2-4 weeks of receiving the referral, a member of the Memory Clinic team will arrange to come and see you at home. They will explain the process to you. With your permission they will gather some background information about you and ask you about your daily activities and how your memory is affecting your daily life. You will be asked about your wishes relating to being told a diagnosis if evident at the end of the process. It is your right to be told but also you may choose not to be told and this is also fine.

- Once the team has established an overview of your concerns you will be invited to come along to the Memory Clinic at the hospital usually with a family member. There you will have a more in-depth assessment of your memory. With your permission your family member will also be able to contribute to the discussion.

- Once all the assessment is complete you will be offered an appointment to see a specialist doctor at the PEH who will go through the test results with you and aim to explain the probable cause of your memory problem. They may make a diagnosis (if you

have asked for one) and prescribe some medication to help your memory. If the diagnosis is unclear we usually ask to see you again in about 6 months to monitor your situation.

- If you receive a diagnosis of dementia you will have the opportunity to discuss with the doctor what this means and the implications it may have for you in the future. We usually try to include your family member in these discussions so that they can offer you support and ask any questions they may have.

- If you receive a diagnosis a team member will visit you at home about 2 weeks afterwards. You may have questions you want to ask. You will be provided with information about your diagnosis and offered advice about support groups and practical help if needed. You will be seen again after about 6 and 12 weeks. After 12 weeks you may be discharged from the clinic or offered ongoing support if required.

- Your GP will be provided with a report from the Memory Clinic and if you are prescribed medication it will eventually be added to your normal prescription which you collect from the GP practice.

What help can I get after diagnosis?

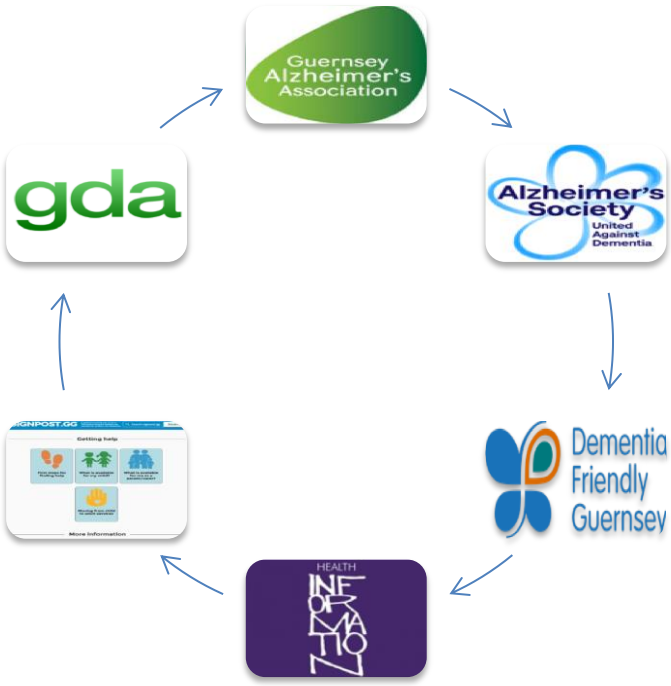
- After you have been diagnosed and given information about your condition you will be given advice about support groups delivered via the voluntary sector and HSC. These groups are also helpful for anyone who supports you. See details below.

- If you need ongoing support or advice you may be allocated to a member of the OACMHT or a social worker. The key worker will be able to advise you on issues around benefits, support networks or about planning ahead for the future.

- Organisations such as the Alzheimer's Society and The Guernsey Alzheimer's Association provide support, information and advice specifically for people with dementia and their carers. The organisations host talks from professionals as well as running peer support and music groups. Sitting services and befriending can also be provided by these organisations.

The Guernsey Alzheimer's Association can sometimes provide financial help via a grant scheme to people in a caring role, if for example a family need to purchase or rent some specialist equipment.

Other smaller organisations that should be recognised include church groups who provide social engagement for people with dementia and pastoral care groups who can provide spiritual support.



Defining disability

As this report is developed under the Disability and Inclusion Strategy it is important at this juncture to understand what is meant by the term disability and why dementia is viewed as a disability. The term itself holds different meanings for different people and for different purposes

and is a complex phenomenon. The World Health Organization body which focuses on disability (ICF) broadly define a disability as:

'….the interaction between individuals with a health condition and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports).' [13]

The definition reflects the idea that the term disability is both a medical and a social construct. For example, whilst a wheelchair user has obvious mobility impairment, the impairment itself may only be a small part of the disability. That person may have all the adaptations they need within their home to remain independent but the disability is often further enhanced as a result of the barriers that person may face in getting about their daily lives, being included in society or maintaining employment. Those barriers may be either structural (buildings, transport, etc.) attitudinal or organizational.

In the case of a wheelchair user the impairment may be fairly obvious but there is a long continuum of disability, some which may not be so obvious.

Consider a person with facial scarring who is asked to move to another part of the organisation as their employer feels that the public wouldn't want to look at them. That person may have engaged professionally and appropriately during all interactions with the public. They may not have acknowledged their condition as a disability. In this case, attitudinal discrimination has created further disability.

Organizational factors can also lead to discrimination when inflexible working patterns or rules limit the ability of a person to manage their role or daily routines. This might occur if a person was penalised for having to adhere to a strict regime of medication or had to access the bathroom frequently for example.

The Disability Needs Survey of Guernsey and Alderney (2012) [5] estimates rates of disability for people with long-term conditions range from 10% for those aged under-16 years to 38% for those aged 67 and over. It is clear therefore that age is a significant determinant of disability.

Older age, in its own right, is also a significant factor linked to discrimination. Experimental evidence suggests that a person's subjective or perceived age changes in response to age-related social cues and information [52, 53]. The studies show that societal attitudes influence adults' susceptibility to ageist stereotypes. It is possible therefore for people to age 'before their time'.

Conversely, a positive societal attitude towards ageing might therefore go some way towards preventing this occurring?

Mental health conditions can also be considered to be hidden disabilities. Such impairments often attract stigma, pre-conceptions and misunderstanding and can further disable people. This can impact significantly on a person's ability to be included in society especially in relation to employment [14, 15]. Such pre-conceived attitudes can actually prevent people with mental health conditions from seeking employment as they often expect to encounter discrimination [16].

Progress has occurred however, and people in The Bailiwick of Guernsey with disabilities and additional needs are having their voices heard through organisations such as The Guernsey Disability Alliance. People with disabilities are being supported in continuing to work, to remain independent and lead fulfilling lives much more than in years gone by. Society is beginning to change both culturally and environmentally to help enable this.

Despite the positive changes there is still a long way to go and as yet there is no specific legislation in place to prevent discrimination against disabled people. This work stream is currently being progressed as a priority by the Committee for Employment & Social Security. For the avoidance of doubt, the definition of disability set out in this Framework and explored in more detail using specific examples should not be taken as an indication of how disability may be defined in local disability discrimination legislation in future.

99% of people live in countries that have signed the UN Convention of the Rights of Persons with Disabilities. The Bailiwick of Guernsey is in the remaining 1% along with Somalia and Kosovo [37]. The Bailiwick of Guernsey does however aim to sign up to the UN Convention on the Rights of Persons with Disabilities which reaffirms that

all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced. [90]

Dementia viewed as a disability

When people think of the term ‘disability’ they could be excused for not placing dementia high on that list. Much of the work championing the rights of people with disability has been conducted around people with a physical, sensory or learning disability. Dementia is not one of the obvious disabilities, and many people with the condition may appear to be coping well until they are faced with complex situations such as managing a transaction in the bank, using the bus, shopping, finding their way home, or preparing a meal.

The standard paradigm of dementia tends to draw heavily on medical and clinical language and views dementia as a progressive neuro-degenerative condition. Whilst the neurological viewpoint remains important, (e.g. when establishing accurate diagnoses or within the field of research) it is both deterministic and pessimistic [7]. If we continue to conceptualise dementia purely from this neurological viewpoint, we risk overlooking the many socio-psychological factors which impact on the person with dementia.

Whilst we know that some abilities for the person with dementia are compromised, many still remain. Viewing dementia as a disability therefore challenges our way of thinking about the condition. It recognises that people with dementia have a range of impairments and, as a result, face a variety of disabling barriers, including attitudinal, social, psychological, architectural, physical and institutional.

Such negative attitudes and stereotypes have been shown to adversely affect the abilities of people with dementia and have led to the marginalisation and exclusion of people with dementia from many areas of society [40] [52] [53].

Negative attitudes can also prevail in the media and press. The language we use about dementia can negatively colour the public’s perception of the condition. Terms such as “sufferer” are used too often and whilst not meant in a negative way it can have negative connotations.

Tom Kitwood in his seminal work ‘*Dementia Reconsidered*’ [7] recognised the influence of interpersonal and social factors (which should be taken to include political and economic structures) on the wellbeing of the person. He referred to them as the ‘social psychology’;

This social psychology relates to the constant interaction of the person with dementia, those supporting them and the physical environment.

Kitwood also noted that when the social psychology around the person with dementia deteriorates it can have devastating effects on their wellbeing. He coined the phrase '*malignant social psychology*' (MSP). When a MSP exists there is evidence of, amongst others, disempowerment, imposition, outpacing and objectification etc. Such attitudes further disable the person with dementia by limiting choice and not recognising the person as being unique. Kitwood noted that often such practice is not even recognised and sometimes can be condoned and operationalized into systems of working. It is often 'low-level' and not explicit but occurs when the person with dementia is not recognised as a full person but rather a 'shell' [66] of their former selves.

"One can only truly be considered a person if they are recognised as such by others" [66].

Such disabling attitudes can also exist in our fast-paced society especially when people with dementia often require more time, understanding and support and may need more help in accessing or making sense of information.

By viewing dementia as a disability we as a society can help shift the mind-set from "*there is nothing you can do*" to one where society and individuals realise we can have a huge impact both positively and negatively on the wellbeing of the person with dementia.
At every stage of the condition society must strive to see the person behind the impairment. Society must endeavour to maximise the abilities of people with dementia and take care not to create further disability.
These sentiments are reflected by the words of people with dementia across the world and also here in Guernsey. A consultation group run by Michael Nicholls from the Alzheimer's Society (Guernsey Branch) in 2015 garnered rich data from people with dementia which indicates how people with dementia perceive themselves and wish to be perceived:

"*I do not want to be defined by the disease*"

"*I don't want to be treated differently"*

"Having a sense of humour is helpful. I can laugh about some things I do"

"I want to make the most of what I've still got"

"Don't forget me. I want to be included like everyone else"

"I want to be able to get on with life and feel useful"

"Some people treat you like a child and I don't like that"

Many other reports elicit similar qualitative data. A 2007 UK inquiry into mental health and wellbeing in later life [41] noted the following remarks from people with dementia:

'Mental illness is still stigmatised whether you are young or old but older people have a double whammy!'

'[When] they know you have Alzheimer's, they just kind of ignore you. You can go to a family affair and everybody is kind of gabbing, gabbing. But they leave you alone because they figure you don't know what is going on... They are frightened; they think you have lost your mind... You are just there and that's it.'

Hearing the voice of people with dementia is important as the services that are delivered need to be focused around their requirements.

Dementia within mental health services

The provision of specialist dementia care within most healthcare services tends to come under the remit of mental health services. This is no different in The Bailiwick of Guernsey.
There has long been debate as to whether dementia should be viewed as a mental health condition at all. The organic nature of the condition differentiates it from functional mental health issues such as depression, anxiety or psychoses etc.
However, given the particular behavioural and psychological challenges that can sometimes occur in the context of dementia, as well as the potential for the co-existence of other functional psychiatric disorders, mental health services are often seen as being best placed to offer this specialist support.

In reality, mental health services may only be involved with a person at particular junctures during the course of the condition. Alongside family carers, many private and voluntary services tend to be involved in providing ongoing support to the person and the family on a regular basis.

The inherent risk with dementia's close connection to mental health services is that behavioural issues can sometimes be too readily attributed to 'the illness' rather than considering why that behaviour may be occurring.

Expressed behaviour in dementia may be a person's only means of communicating a physical need such as pain, hunger, thirst, temperature regulation, needing the toilet etc. Behavioural issues can also occur in dementia as an expression of psychological need such as fear, anxiety or need for attachment, feeling useful or valued [75]. This knowledge is especially important for staff working within long term care settings where dementia can often be more advanced and where special attention needs to be made to connect with people with dementia.

There is a need here for specialist mental health services to work closer with other agencies to offer their expertise to help prevent crises but also to educate care providers on approaches to care that may prevent behavioural issues happening in the first instance.

The specialism of older adult mental health

Whilst Older Adult mental health services see people with a wide variety of mental health problems they tend to see many more people with dementia than general adult services. It is a specialism in its own right.

General adult mental health services focus on supporting adults of working age whose presentation may be acute in nature and cover specialties such as forensic psychiatry, eating disorders and substance abuse. The focus of general adult psychiatry is often built around models of recovery which can differ from the focus given to organic conditions such as dementia which focus more on adaptation.

General adult mental health services are not always equipped to provide ongoing support for people with dementia or significant cognitive impairment. This can be especially evident when admission to assessment wards is necessary. Wards with mixed groups of younger adults and older people often have difficulty providing for the specific needs of both groups.

People with dementia and their carers require specialist approaches to care and from teams who have knowledge of local support services.

The specialism of old age psychiatry (formerly 'psychogeriatrics') was pioneered in the UK. A professional group of general psychiatrists with special interest in disorders of old-age obtained formal speciality status from the Department of Health in 1989 [39].

Old age psychiatry recognises that older people may have particular health and social needs impacting on their mental health, including:

- The co-existence of other medical conditions
- Possibility of cognitive impairment
- Possibility of mobility or sensory limitations
- Frailty
- Nutritional issues
- Social isolation and loneliness
- Loss of role function
- Co-existing functional psychiatric issues
- Likely use of multiple medications for concurrent physical health conditions
- Possible impact of alcohol or substance misuse
- Having ongoing involvement with other community support services
- Long-term care or housing issues
- Capacity and decision-making issues
- Issues occurring within residential or nursing care settings
- Loss and grief issues are common among older adults

As a result of these particular needs Old Age psychiatry services tend to maintain close working relationships with geriatric medicine, private residential and nursing homes, social services and community services [39].

Transitions of care

Like many healthcare services across the UK, The Bailiwick of Guernsey's mental health services are divided into three distinct services, determined primarily by age:

- Child and adolescent mental health services (CAMHS) - Children and young adults up to the age of 18yrs
- Adult Mental Health Services – Adults aged from 18yrs to 65yrs
- Older Adult Mental Health Services – Adults aged 65yrs and upwards

There comes a time, based on age, when people have to move between the above services. The transition from child and adolescent services to adult services is relatively clear. Turning 18 means that a person is no longer recognised as a child because they are no longer the sole

responsibility of his/her parents. An 18yr old can legally buy alcohol, be tried in a magistrate's court, make a will or stand for election.

The transition from adult to 'older adult' is less straightforward. 65 is an arbitrary number that has long been accepted as the marker for older age, although nowadays many would argue against this being the case.
Traditionally, those adults who have been long-term users of mental health services have 'graduated' and transferred to older adult services on reaching their 65th birthday. This protocol has recently been revised to allow service users to stay under the care of their current mental health team for the duration of the particular episode, and this may be well into older age. This continuity of care is important especially where therapeutic relationships have been developed between service-users and practitioners over time and where stability is important in maintaining mental wellbeing.

A person is likely to transfer to older adult services once discharged and re-referred after their 65th birthday irrespective of whether their needs have changed. This system however doesn't necessarily make for good continuity of care nor does it seem person centred. The marker for old age hasn't changed either, despite working age and retirement age being increased within the general population in The Bailiwick of Guernsey.

There are exceptions however within the above parameters. Younger adults (under 65yrs) with a diagnosis of dementia tend to be supported by older adult mental health services who are likely to have more expertise and knowledge of local support services within this particular area.

An ageless mental health service?

The designation of mental health service provision, by age, has for many years been a stumbling block for service users and professionals, and can be a juncture where service users and families can fall through gaps in service. This demarcation by age is not needs-focused and stands in contrast to UK government initiatives dating back to the National Service Framework (NSF) for Older People, 2001 [42].
This publication recommended that NHS services should be provided '*regardless of age, on the basis of need alone'*. The principles were further reiterated in the Department of Health's (2005)

best practice report [43] and by the Royal College of Psychiatrists (2009) and the Joint Commissioning Panel for mental health [77], [44].

Whilst age discrimination has been in decline since the NSF's were published in 2001, the Healthcare Commission (2006) [45] has pointed out that the exception to this is often found when the organisational structure of mental health services results in unequal access to services for older people. Banarjee *et. al*. (2009) [58] also cites 14 separate reports which indicate discrimination and inequality of treatment for older people within mental health services.

Within the field of medicine and nursing, mental health is often referred to as the 'Cinderella service' [59] [67]. In her initial report for the States of Guernsey Policy Council, Phillips [73] stressed,

'*There is a need to put mental health services, particularly dementia care, on a par with physical health services and ensure there is a strong connection between the two.'*

Funding in the UK for mental health services has improved recently however where approximately 13% of the annual health budget is now allocated towards mental health [63]. Much of the increase in investment has been focused around acute mental health, psychological therapies and health promotion. The specialty of older adult mental health and dementia care has not fared as well and has been referred to as the 'Cinderella' of mental health services [60].

Whilst Older Adult community mental health services in The Bailiwick of Guernsey have grown slowly, the development of the service has not matched the scale of development and reorganisation within adult mental health services. This trend appears to be reflected across the UK where a 2009 Department of Health report [46] found that older adult mental health teams tended to employ fewer psychiatrists and nearly half as many psychologists and social workers per case as their adult colleagues.

The development of mental health services for working-age adults in The Bailiwick of Guernsey's should be celebrated. The service development has dovetailed with the development The Mental Health Strategy [18], the implementation of Guernsey's Mental Health Law (2010) and the move into new facilities at Oberlands. This has allowed access to a wider range of services which has seen the rights of service users notably enhanced.

The investment allocated to these services have afforded the people of The Bailiwick of Guernsey more timely access to a range of psychological support provided by psychiatrists, psychologists, therapists and psychological wellbeing practitioners (PWPs); the community and primary care

teams have grown and developed to meet this need. The re-design of services has also framed mental health in a more positive light and helped reduce stigma. This has been helped by aligning some PWP's within primary care GP surgeries and other community centres to provide easier access to the lower level tier of psychological support. More information on the services available to working-age adults can be found via this article: https://www.gov.gg/article/120846/Mental-Health

Access to the Primary Care psychological therapies however has not been straightforward for people over the age of 65yrs in The Bailiwick of Guernsey due to the initial referral criteria set out for the service. The criteria and funding for this service was agreed with Social Security as a means of helping working-age adults return to work and reduce long term absenteeism due to ill health. This is despite the Ageing Well chapter of the Mental Health Strategy [18] recommending Cognitive Behavioural Therapy (CBT) as an effective intervention for older adults and one which should be prescribed more.

There is now some flexibility within the Psychological Therapies Interventions service which gives consideration to the fact that people over 65 may well require psychological input in the absence of any dementia. This approach will need to continue and the protocols to be further clarified given the ageing demographic shown in **Table 2** (p. 11) and the service is likely to need further investment in the service.

There has been some debate over the years about redesigning community mental health services into an 'ageless service'. In theory this should work and would mean that the most qualified team would provide a service regardless of the age of the patient. A system such as this may well help make services more accessible to all and potentially tighten up the gaps that currently exist where age is often a debating point on who should oversee the care of the patient.

As the line marking the start of 'old age' begins to become less distinct and extends toward 69yrs, it would seem pertinent to strive to deliver services based more on the need of the service user and less around age [77]. This ageless system should be explored further so that service users can access the most appropriate support from the right people at the right time.

Forgetfulness vs dementia

We must be careful however when raising awareness that we differentiate between what may be symptoms of dementia and what may be normal forgetfulness. The purpose of this report is not about creating a wave of referrals (to an already stretched service) of people who may be experiencing occasional memory lapses.

We all forget things from time to time, which is unsurprising. Modern day lifestyles are fast-paced and more complicated than they were 20 years ago. The current economic climate, worldwide political tensions & climate change are but a few of the factors that may add further background stress to our daily lives.

Short-term working memory acts like a 'scratch pad' and typically holds about 4-7 pieces of information, for up to a minute. These pieces of information either get wiped to make room for the next piece or they get converted to long term memory.

Long term memory, in comparison, is almost infinite in its capacity. There is a process involved in converting the short term memories to long term. To make something stick we have to recognise it as being important and we must put some effort into remembering. If we haven't concentrated in the first place or if we get distracted during the process then that memory is not encoded and will not be retained.

Nowadays we are bombarded with information from various sources. By virtue of having access to a smartphone we are afforded instant connection to friends, family, work, e-mail, social media, news headlines, calendar, music, sport etc. Whilst much of this is superfluous information many people feel they have to respond to it immediately. It is distracting and it allows us very little 'down-time'. This constant stream of information takes up valuable headspace and makes it almost impossible for the brain to process, filter, encode and file all of it.

Carr (2010) [48] believes that the internet has 'rewired our brains' and affected the way we learn and process information. Whilst he recognises that it has made information more accessible he suggests that it has impaired our ability to read and absorb longer articles. He makes the interesting analogy that the way we absorb information has taken on a 'staccato' quality, and remarks

"Once I was a scuba diver in a sea of words. Now I zip along on the surface like a guy on a Jet Ski".

Henkel (2014) [49] conducted a study in which two groups of participants were asked to view artwork in a gallery. The group who viewed and used their phones to take pictures of the artwork actually recalled less detail than those who just viewed and appreciated the art for what it is. It suggests that we tend to rely on this technology as a means of backing up our memories rather than going through the full process of attaching meaning and absorbing the event. It is some of these intricacies that help embed memories by making links within the brain.

So occasional lapses in memory are not uncommon and do not necessarily indicate the start of dementia. We just need to concentrate on what's important.

Some further information on memory tips have been made available online via:

www.gov.gg/article/151983/Memory-services

Depression

Every year 1 in 4 people will experience a mental health condition [47]. Depression is the most commonly experienced mental health condition and one which can also impact negatively on memory. Depressive symptoms are likely to occur in most of the population at some point in their lives.

Depression should be screened for by GP's prior to a referral to Memory Clinic services.

Depressive cognitions are marked by diminished self-esteem and negative thoughts about the world and self. Those thoughts that do occur are often self-concerned and inward looking and the symptoms (slowness of thought, lethargy, diminished interest, and concentration problems) can easily be mistaken for dementia.

Depression is not a normal part of ageing and shouldn't be dismissed as so. Whilst depression is common across all age groups older people can face some particular issues that can impact negatively on mood, such as:

- Loss of a lifelong partner through bereavement.
- Physical limitations due to health issues.
- Sensory deficits (hearing, eyesight etc.)

- Loneliness and isolation.
- Loss of meaningful role.
- Reduced income which may limit lifestyle.
- Loss of independence (e.g. having to stop driving)
- Negative societal attitudes towards older people.

These issues should be addressed in the first instance. Depression can respond well to a combination of therapy, mental health and social care interventions, lifestyle adjustments and anti-depressant medication.

Physical health issues and memory

As well as depression there are many medical conditions that can impact on memory. These include but are not limited to

- Low thyroid function.
- Anaemia.
- Infection (especially in the elderly)
- Electrolyte imbalance.
- Vitamin deficiency.
- Effects of certain medications.
- Overuse of alcohol.

Such conditions are in many cases quite treatable and memory problems can often resolve once addressed. These conditions are normally screened for by GP's and addressed as part of the recommended work-up prior to referral to memory clinic. This screening is recommended by NICE [50] the organisation responsible for issuing guidance on evidence-based clinical guidelines. Brain scans are not a prerequisite when screening for dementia, especially if a diagnosis of dementia seems clear or is at a moderate to advanced stage. Brain scans are useful however when the diagnosis is unclear or if there has been a sudden change in cognitive or functional ability. They can be helpful in determining subtypes of dementia. They can also be useful in ruling out treatable conditions such as normal pressure hydrocephalus or tumour.

It is important that all potential treatable causes of memory impairment are fully investigated and treated.

Recent developments in dementia services in The Bailiwick of Guernsey

There have been some significant improvements for people with dementia in The Bailiwick of Guernsey.

The Castel Hospital

In December 2015 the Castel Hospital closed its doors to all in-patient care. For many years it was Health and Social Care's (HSC) main provider of long-term dementia care in Guernsey. The building was long past its prime and was earmarked for closure for many years. It was never designed with the delivery of long-term dementia care in mind. The Castel also retained a certain stigma which tended to exist around many older psychiatric hospitals. This was particularly evident when older people attended for clinics; their anxiety about the consultation was clearly exacerbated as a result of the setting alone.
The phasing down of its use had been occurring for many years. Up to 2004 the long-stay residents typically shared 4 or 6-bedded dorms and independent access to the outdoors was difficult without supervision from the 1st and 2nd floor wards. In 2004 the three continuing care wards named after Guernsey bays; Fermain, Cobo and Etoile, moved to purpose-built units at the Corbinnerie on the PEH site and were re-named after Bailiwick lighthouses; Casquets, Hanois and Fougere.

Each resident now has their own single room with en-suite facilities. The buildings benefit from natural light and a sense of space and thoughtful design makes accessing rooms and toilets much easier for residents. Specialist equipment to meet a person's nursing care needs has been incorporated into the design and the units also have access to safe enclosed accessible gardens. Due to a combination of staffing issues and essential maintenance work Casquets ward has recently been 'rested' to in-patient care during the writing of this report.

Memory Clinic

The development of Guernsey's Memory Clinic in 2003 has helped to promote earlier diagnosis of dementia and provide timely access to support and advice. The clinical pathway has been revised as part of this project and a full outline of this can be found in **Section 2** (Early Diagnosis) below or online at https://www.gov.gg/article/151983/Memory-services

Oberlands

Another significant development for mental health services in general has been the opening of the new mental health facility at Oberlands on the PEH site in 2015. This service encompasses new admission and assessment units, for adults (Crevichon) and older adults (Tautenay). The building also houses new offices for CAMHS, Drug and Alcohol teams, Psychological Therapies, Recovery and Wellbeing and Community Mental Health teams. The entrance foyer has a positive and welcoming feel and encompasses Beacons café which supports the employment of service users; enabling people with mental health difficulties to engage in meaningful roles and to facilitate recovery. There is an ethos of inclusiveness about the building.
The Oberlands centre now sees most of Guernsey's dementia and mental health care provided within the Princess Elizabeth Hospital site and should further help the reduction of stigma associated with mental health conditions.

The Willows

The Willows Day centre, which provides specialist day care facilities and programs of care for people with dementia, opened at La Nouvelle Maritaine. This saw the merging of two day services, namely The Meadows and St. Luke's day centre which were previously based at The Castel and King Edward 7th Hospitals respectively. The new facilities are not without their teething problems; however space is at a premium for activity such as group work and gardening. The facility is part of a community centre and supported living complex in the north of the island and has moved away from its previous institutional setting.

Supported Living

Three new supported living complexes have been developed in Guernsey. Rosaire Court was the first to open, followed by the redevelopments of Maison Maritaine and Longue Rue – now

renamed La Nouvelle Maritaine and La Grand Courtil. These developments have significantly changed the model of care previously offered to older people. These facilities now encourage more independence for individuals and care and support is available on-site when needed. Whilst the focus of the supported living complex is not primarily dementia-specific (many of the previous residents with dementia could not make the transition) the staff can provide support for some people with mild dementia.

Private Sector

The private care sector has responded to the growing number of people with dementia. It is estimated that up to 80% of the residents of care homes have a degree of dementia. Four care homes have embraced dementia care as a priority and have been recognised as EMI homes with another due to open. The extra funding they receive enables extra support and activity to be provided for people with dementia. This sector is expected to further expand over the coming years.

Voluntary Sector

Voluntary sector groups have also recognised dementia as a priority and have developed accordingly. Organisations such as Alzheimer's Society, Guernsey Alzheimer's Association and a working group Dementia Friendly Guernsey are all doing good work in raising the profile of dementia in The Bailiwick.

There is the potential for even more growth within the voluntary sector in terms of how they provide support to the families of people with dementia. In the UK such organisations often undertake the delivery of care by bidding for contracts put out to tender by clinical commissioning groups. As well as supporting people with dementia directly, voluntary groups also support carers and provide education, signposting and advice to families. The Older Adult CMHT agreed a handover of responsibility for the administration of the Dementia Carer Support group to the Guernsey Alzheimer's Association; a move which will help foster growth in the voluntary sector and allow clinicians to use their expertise where most needed.

Community Mental Health

The Older Adult Community Mental Health Team (OACMHT) has also adapted the way they provide support. Aside from their more clinical roles, the team has developed carer support in association with the voluntary sector and also run cognitive stimulation groups as well as specific groups for men who are often reluctant engagers.
There is further need for support groups to involve younger people with dementia but at present there is no scope within the team to offer such a group.
There is however a need for the role of a Dementia Advisor to offer ongoing post-diagnostic support. Such roles are commonplace throughout trusts in the UK and in Ireland and are often funded or co-funded by charitable or voluntary organisations. Such services are found to be very helpful in providing the extra information that families need after diagnosis [64].

The development of two support worker positions has enabled the team to provide more intensive social support for clients living in the community.

Consultations

This document has been written in consultation with many key stakeholder groups. It has been clear throughout the process that the subject of dementia is very important to professionals, private agencies, voluntary groups, pastoral care workers and to people with dementia and their carers. People want to understand the best approaches to care and to do it correctly.
Within HSC's Community and Social work department it is reported that community teams and social workers are increasingly providing specialist packages of care to people living with dementia. Common themes emerging include time constraints; staff recruitment/retention; training issues; specialist respite placement issues; specialist long-term care placement issues and limited contact with the specialist teams (partly due to the location of the two teams).

Within the private care sector the main themes emerging centre around the difficulty accessing specialist training in dementia care coupled with high turnover of staff and the difficulty of providing rolling training to meet this need.

The care home managers also report frustration with providing respite services for people with dementia. The planning of which can often be unpredictable, sometimes lacking key information and, by nature of respite being a short break service it can be disorientating and too short in duration to allow the person to settle in to the home environment.
Further concerns are reported about the care homes having too little specialist input from the specialist HSC teams.
Concerns were raised regarding the difficulty in engaging some families in Life History work to provide meaningful information about the residents that they look after. This can then make person-centred care planning difficult.

Consultations with senior nurses from the Princess Elizabeth Hospital also highlighted a demand for more dementia training and this has been echoed by student nurses; with more than one basing their dissertations around dementia care in general hospital environments.

Consulting with voluntary sector groups has shown that there is a strong interest in expanding the role they play including carer support, activity, music groups and education of the public and business sector. This has also been helped by the committee of Dementia Friendly Guernsey which has brought together representatives from The Guernsey Alzheimer's Association and the Alzheimer's Society with a view to making Guernsey more dementia-friendly and aware.
An appendix from Michael Nicholls of the Alzheimer's Society is included in this report which contains a thorough précis of his suggestions of where dementia care could be improved in The Bailiwick of Guernsey.

And of course people with dementia and carers have also had their voices heard and reflected in the report and it is clear that they want more accessible information and education on how to best "live well with dementia" by accessing good quality support and advice and to feel listened to.

References

[1] States of Guernsey Policy Council (2016) *The supported living and ageing well strategy.* Billet d'État III Feb 2016. [Online] Available from http://www.gov.gg/CHttpHandler.ashx?id=99841andp=0

[2] States of Guernsey (2012) *Oxford economics report review of Guernsey's economic profile and assessment of future opportunities.* Policy Council/Commerce and Employment [Online] Available from: http://theoldsite.gov.gg/CHttpHandler.ashx?id=28431andp=0

[3] Alzheimer's Society (2013) *Dementia UK Update*. Alzheimer's Society, London.

[4] Department of Health (2013) *Dementia: A state of the nation report on dementia care and support in England.* [Online] Available from https://www.gov.uk/government/uploads/Dementia.pdf

[5] States of Guernsey (2013) *Disability Needs Survey: Review of prevalence across Guernsey and Alderney*

[6] Department of Health (2009) *Living well with dementia: A National Dementia Strategy*. DH: London

[7] Kitwood, T. (1997) *Dementia reconsidered: the person comes first.* Milton Keynes: Open University Press.

[8] Alzheimer's Society (2010) *How could I reduce my risk of dementia?* [Online] Available from https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2411

[9] HSSD Guernsey (2010) *Guernsey mental health needs assessment.*

[10] Dhedhi, S.A., Swinglehurst, D. and Russell, J. (2014) 'Timely' diagnosis of dementia: what does it mean? A narrative analysis of GP's accounts. *BMJ Open* [Online] Available from http://bmjopen.bmj.com/content/4/3/e004439.full.pdf+html

[11] Department of Health (2012) *Prime minister's challenge on dementia: delivering major improvements in dementia care and research by 2015.* DH: London

[12] Kostopoulou, O., Delaney, B.C. and Munro, C.W. (2008) Diagnostic difficulty and error in primary care – a systematic review. *Family Practice;* **25** 400-13

[12] Phillips, J., Pond, C.D., Patterson, N.E., Howell, C., Shell, A., Stocks, N.P., Goode, S.M. and Marley J.E. (2012) Difficulties in disclosing the diagnosis of dementia: a qualitative study in general practice. *British Journal of General Practice* **62**(601) 546-53

[13] WHO (2002) *Towards a common language for functioning, disability and health: ICF.* Geneva [Online] Available from http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf

[14] Mental Health Foundation (2002) *Out at Work. A survey of the experiences of people with Mental Health Problems within the Workplace*. London: Mental Health Foundation.

[15] Wahl O.F. (1999) Mental health consumers' experience of stigma. *Schizophrenia Bulletin* **25** 467–78

[16] Thornicroft G., Brohan E., Rose D., Sartorius N. and Leese M. (2009) The INDIGO Study Group. Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. *The Lancet* **373** 408–15

[17] States of Guernsey Policy Council (2013) *Disability and Inclusion Strategy.* Billet d'État XXII, November 2013.

[18] Health and Social Services Department (2013) *Mental Health and Wellbeing Strategy.* Billet d'État III,
February 2013.

[19] Bennett, D.A., Schneider, J.A., Buchman, A.S., Mendes de Leon, C., Bienias, J.L. and Wilson, R.S. (2005) The Rush memory and ageing project: study design and baseline characteristics of the study cohort. *Neuroepidemiology*. **25** 163–75

[20] Alzheimer, A. (1907) Uber eine eigenartige Erkanjung der Hirnrinde. *Allgemine zietshrift fur psychiatrie*. 64, 146-48

[21] Feil, N. (2002) *The validation breakthrough.* Health Professionals Press: Baltimore

[22] All party parliamentary group on dementia (2012) *Unlocking diagnosis: The key to improving the lives of people with dementia.*

[23] *Dementia 2014: Opportunity for change*. Alzheimer's Society, (2014)

[24] *The Care Act* (2014) London: The Stationery Office

[25] Sheard, D. (2015) *The feeling of being: The S factor in dementia care*. Keynote speech. Dementia Congress, Telford. November 2015

[26] *Report of the Mid Staffordshire NHS Foundation Trust* (2013) London: The Stationery Office [Online] Available from:
http://webarchive.nationalarchives.gov.uk/http://www.midstaffspublicinquiry.com

[27] Royal college of psychiatrists (2013) *Liaison psychiatry for every acute hospital: Integrated mental and physical healthcare.*
http://www.rcpsych.ac.uk/files/pdfversion/CR183.pdf

[28] Alzheimer's Society (2016) *Fix dementia care: Hospitals.* [Online] Available from
https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2907

[29] Alzheimer's Society [Online] Available from https://www.alzheimers.org.uk/statistics

[30] RCN (2014) *Commitment to the Care of People with Dementia in General Hospitals.* RCN [Online] Available from http://www2.rcn.org.uk/development/practice/dementia

[31] Ahmad, S., Orrell, M., Iliffe, S. and Gracie A. (2010) GPs' attitudes, awareness, and practice regarding early diagnosis of dementia. *British Journal of General Practice* **60**(578) 360-65

[32] Royal College of Psychiatrists (2015) *Second English National Memory Clinics Audit Report.* Department of Health.

[33] Department of Health (1989) *Caring for People: Community Care in the Next Decade and Beyond.* HMSO, London.

[34] Department of Health (1990) *Community Care in the Next Decade and Beyond*. HMSO, London.

[35] Department of Health (1995) *Carers (Recognition and Services) Act 1995: Practice Guidance.* HMSO: London.

[36] Hebert, L.E., Weuve, J., Scherr, P.A. and Evans, D.A. (2013) Alzheimer disease in the United States (2010–2050) estimated using the 2010 census. *Neurology* **80** [19] 1778–83

[37] Guernsey Disability Alliance (2016) Available from http://disabilityalliance.org.gg/disability-strategy/

[38] Barnes, D.E. and Yaffe, K. (2011). The projected effect of risk factor reduction on Alzheimer's disease prevalence. *Lancet Neurology.* **10** 819-828.

[39] Fairbairn, A.F. (2002) 'Principles of service provision in old age psychiatry' In: Jacoby, R. and Oppenheimer, C. (eds) *Psychiatry in the Elderly*

[40] Scholl, J.M. and Sabat, S.R. (2008) Stereotypes, stereotype threat and ageing: implications for the understanding and treatment of people with Alzheimer's disease. *Ageing and Society* **28**: 103 -30

[41] Crown, J. and Lee, M. (2007) *Promoting mental health and wellbeing in later life: A report from the UK inquiry into mental health and wellbeing in later life.* London: Age Concern; Mental Health foundation

[42] Department of Health (2001) *National Service Framework for Older people: Modern Standards and Service Models*. DH

[43] Department of Health Care Services Improvement Partnership (2005) *Everybody's business: integrated Mental health services for older adults: a service development guide* DH 2005

[44] Royal College of Psychiatrists (2009) *Links not boundaries: service transitions for older people growing Older with enduring or relapsing mental illness.* (College report, CR153), London: Royal College of Psychiatrists

[45] Healthcare Commission, Audit Commission and Commission for Social Care Inspection (2006) *Living well In later life: a review of progress against the National Service Framework for Older People* London: Healthcare Commission

[46] Department of Health Care Services Improvement Partnership (2009) *Combined Mapping Framework*. http://www.mhcombinedmap.org/Reports.aspx

[47] The Health and Social Care Information Centre (2009) *Adult psychiatric morbidity in England: results of a household survey. [*Online]Available from http://www.hscic.gov.uk/pubs/psychiatricmorbidity07

[48] Carr, N. (2010) *The shallows: how the internet is changing the way we think, read and remember.* New York: W.W. Norton and co.

[49] Henkel, L.A. (2014) *Point and shoot memories: the influence of taking photos for memory for a museum tour*. Dept of Psychology, Fairfield University, Connecticut

[50] NICE (2012) National Institute for health and Care Excellence. *Dementia: supporting people with dementia and their carers in health and social care.* [Online] Available from: https://www.nice.org.uk/guidance/cg42/chapter/1-guidance#risk-factors-prevention-and-early-identification

[51] Alzheimer's Society (2014) *Intergenerational Schools Project.* [Online] Available from: https://www.alzheimers.org.uk/schools

[52] Stephan, Y., Chalabaev, A., Kotter-Grühn, D. and Jaconelli, A. (2013) Feeling Younger, Being Stronger: An experimental study of subjective age and physical functioning among older adults. *Journal of Gerontology* **68**: 1–7.

[53] Eibach, R.P., Mock, S.E. and Courtney, E.A. (2010) Having a "senior moment": Induced aging phenomenology, subjective age, and susceptibility to ageist stereotypes. *J of Experimental Social Psychology* **46**: 643–49

[54] Buckner, L. and Yeandle, S. (2011) *Valuing Carers*. Carers UK: London.

[55] Hirst, M. (2005) Carer distress: a prospective, population-based study. *Social science and medicine* **61**:697–708.

[56] Neil, W. and Bowie, P. (2008) Carer burden in dementia—assessing the impact of behavioural and psychological symptoms via self-report questionnaire. *Int Journal of Geriatric Psychiatry* **23**: 60–64

[57] Molyneux, G.J., McCarthy, G.M., McEniff, S., Cryan, M. and Conroy, R.M. (2008). Prevalence and predictors of carer burden and depression in carers of patients referred to an old age psychiatry service. *International Psychogeriatrics* **20**: 1193–1202.

[58] Anderson, D., Banerjee, S., Barker, A., Connelly, P., Junaid, O., and Series, H. (2009)

The Need to Tackle Age Discrimination in Mental Health: A Compendium of Evidence. Royal College of Psychiatrists.

[59] All party parliamentary group on mental health (2015) *Parity in progress: inquiry into parity of self-esteem for mental health.* [Online] Available from https://www.mind.org.uk/media/1939983/appg-parity-in-progress-final.pdf

[60] Whelan, P., Andrews, T., Patel, S. and Lewis, A. (2010) Taking the Cinderella speciality to the PROM: developing a patient related outcome measure for an older adult mental health service. *Quality in ageing and older adults*. **11:** (4) 51-55

[61] Siddiqi, N., House, A.O. and Holmes, J.D. (2006) Occurrence and outcome of delirium in medical in-patients: a systematic literature review. *Age and Ageing*. **35**: 350–64.

[62] Witlox, J., Eurelings, L.S., de Jonghe, .JF., Kalisvaart, K.J., Eikelenboom, P., and van Gool, W.A. (2010) Delirium in elderly patients and the risk of post-discharge mortality, institutionalization, and dementia: a meta-analysis. *Journal of the American medical association*. **304**: 443–51

[63] Molloy, E. (2015, October 6th) Mental health is the Cinderella of the HSE and we're all losing out as a result. *The Irish Independent.* [Online] Available from http://www.independent.ie/opinion/comment/mental-health-is-the-cinderella-of-the-hse-and-were-all-losing-out-as-a-result-31585528.html

[64] Alzheimer's Society (2011) *Dementia adviser service: Results of an evaluation of the Alzheimer's Society Pathfinder sites*. [Online] Available from http://dementiapartnerships.com/wp-content/uploads/sites/2/Dementia_Adviser_Evaluation_Report1.pdf

[65] Department of Health (2015) *Prime Minister's challenge on dementia 2020* [Online] available from https://www.gov.uk/government/uploads/system/uploads/attachment_data/pm-dementia2020.pdf

[66] Morton, I. (1999) *Person-centred approaches to dementia care.* Winslow Press

[67] Hardcastle, M., Kennard D., Grandison, S. and Fagin, L. (2007) *Experiences of mental health in-patient Care – narratives from service users, carers and professionals.* London: Routledge

[68] Alzheimer's Disease International (2015) World Alzheimer's Report: The global impact of dementia [Online] Available from https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf

[69] The Mental Health (Bailiwick of Guernsey) Law (2010) http://www.guernseylegalresources.gg/CHttpHandler.ashx?id=79818&p=0

[70] Byrne, G. and Neville, C. (2010) *Community mental health for older people.* Churchill Livingstone

[71] HSSD Guernsey (2007) Guernsey standards for inspection of homes specialising in caring for people with dementia http://theoldsite.gov.gg/CHttpHandler.ashx?id=82310andp=0

[72] Livingston, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., Romeo, R., King, D., Livingston, D., Lewis-Holmes, E., Mummery, C., Walker, Z., Hoe, J., and Cooper, C. (2014) START (Strategies for Relatives) A pragmatic randomised controlled trial to determine the clinical effectiveness and cost-effectiveness of a manual-based coping strategy programme in promoting the mental health of carers of people with dementia. *Health technology assessment* **18**: 61 1-242

[73] Phillips, M (2014) Initial report for the supported living and ageing well strategy SLAWS: A new health and social care system. *States of Guernsey, Policy Council* [Online] Available from: https://www.gov.gg/CHttpHandler.ashx?id=100018andp=0

[74] The Butterfly Scheme (2016) [Online] Available from http://butterflyscheme.org.uk/

[75] Moniz-Cook, E. D., Swift, K., James, I., Malouf, R., De Vugt, M. and Verhey, F. (2012) Functional analysis-based interventions for challenging behavior in dementia. *Cochrane dementia and cognitive improvement group*

[76] States of Guernsey (2015) A framework for public service reform 2015-2025 [Online] Available from https://www.gov.gg/CHttpHandler.ashx?id=97310andp=0

[77] Joint Commissioning Panel for Mental Health (2013) *Guidance for commissioners of older people's mental health services.*

[78] British Geriatrics Society (2006) *Guidelines for the prevention, diagnosis and management of delirium in older people in hospital*

[79] Royal College of Physicians (2006) *The prevention, diagnosis and management of delirium in older people: National Guidelines*

[80] National Institute for Health and Clinical Excellence (2006) *Dementia: a NICE-SCIE guideline on supporting people with dementia and their carers in health and social care. National clinical guideline number 42.* London: NICE

[81] Di Siun, A. (2013) *Briefing paper on dementia advisors (Ireland)* Genio [Online] Available from http://www.genio.ie/system/files/publications/GENIO_DEMENTIA_ADVISORS_BP_NO.2.pdf

[82] Alzheimer's Society (2009) what is a dementia adviser? [Online] http://www.2gether.nhs.uk/files/What_is_a_Dementia_Adviser.pdf

[83] Dementia Action Alliance (2017) http://www.dementiaaction.org.uk/local_alliances/17292_Guernsey

[84] Knapp, M., Kia-Chong, C., Broadbent, M., Chang, C. Fernandez, J., Milea, D., Romeo, R., Lovestone, S., Spencer, M., Thompson, G., Stewart, R. and Hayes, R.D. (2016) Predictors of care

home and hospital admissions and their costs for older people with Alzheimer's disease: findings from a large London case register. *British medical journal.* 10.1136/bmjopen-2016-013591

[85] Skills for Care (2015) Care certificate [Online] http://www.skillsforcare.org.uk/Learning-development/Care-Certificate/Care-Certificate.aspx

[86] HSC Guernsey (2016) Care values framework http://bohweb1.hssd.int.gov.gg/int2/LinkClick.aspx?fileticket=bz73906jngQ%3dandtabid=101andmid=1576

[87] Alzheimer Disease International (2016) *World Alzheimer Report: Improving healthcare for people living with dementia coverage, quality and costs now and In the future*

[88] Aminzadeh, F., Molnar, F.J., Dalziel, W.B., Ayotte, D. A. (2012) Review of Barriers and Enablers to Diagnosis and Management of Persons with Dementia in Primary Care. *Canada Geriatrics Journal* **15**: 85–94.

[89] Scotland's National Dementia Strategy 2013-16 (2013) http://www.gov.scot/Resource/0042/00423472.pdf

[90] United Nations Convention on the Rights of Persons with Disabilities (2008) https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html

[91] Aldridge, Z. & Findlay, N. (2014) Norfolk admiral nurse pilot: evaluation report [Online] http://dementiapartnerships.com/wp-content/uploads/sites/2/IDN412AdmiralNursePilotEvalReport.pdf

Appendix 1 – Alzheimer's Society (Guernsey Branch) Recommendations

Issue	Current situation/Problems	Some possible solutions
Resources	Lack of funding - High quality, person-centred dementia care cannot be provided on a shoe-string	Political pressure to force dementia further up the political agenda and invest in dementia care. Knowledge and education can empower – when people have a better understanding they can begin to see simple, cheap or even free things they can do to make a difference.
Professional bodies	Lack of understanding	Training
Unregulated care sector	Poor practice and standards No requirement for workers to have qualifications or training related to dementia care before starting work with service users	Regulation and implementation of Guernsey Care Standards. The focus of inspections needs to shift to the quality of interactions and obtain evidence of person-centred care. Training
General public	Negative attitudes towards people with dementia Poor understanding of how dementia affects people and how to include people with dementia in their communities Negative attitudes towards ageing	Raise awareness and understanding Funding for an annual Dementia Awareness Campaign Develop Dementia Friendly Communities e.g. through Dementia Friends Dementia Friendly Guernsey (Action Alliance) Intergenerational projects Education in schools
Social isolation	Lack of transport Voluntary Car Service only for medical appointments Stigma Lack of opportunities	A door to door service like Dial-A-Ride Better public transport Extend Voluntary Car Service to include social outings Better inclusion in the community and awareness as above More social groups
Community Services	Waiting lists for a range of community based services due to lack of resources	Investment in services needed to help people continue living at home for as long as possible, maintaining their independence. Long term savings as it will avoid early admittance into more expensive hospital care etc.
Specialist care facilities	Lack of facilities specializing in dementia care People being placed in inappropriate facilities	More services in the community to help people to stay at home for longer New specialist care facilities

	that are not geared up to providing the right care needed Specialist care facilities are very expensive and not affordable to many even with LTCB.	Improve existing facilities
Safeguarding for vulnerable adults	Not in place yet	Urgently needed to protect people and improve care
Service-user involvement	Lack of consultation and involvement	Recognise that this is needed People living with dementia want their voices to be heard See National Dementia Declaration One-to-one support to enable people with dementia to be truly involved
Dementia care pathway	Some GPs slow to investigate and refer OACMHT is under resourced No dedicated team of community carers attached to the team	Needs to be smooth from early recognition and diagnosis, referral to specialists, information provision, emotional and educational support at different stages. WAYM campaign to raise awareness and help GPs to recognize symptoms and have confidence to know when to refer. Dementia Advisors in GP practices? A named person as Key Worker for each service user to accompany them on their journey. A multi-disciplinary team with support staff and care team
Advocacy	No independent advocacy exists	Independent advocacy needs to be made available, free where necessary
Mental Capacity/ Enduring Power of Attorneys	Mental Capacity Act not yet in place and no EPAs	Needs to be introduced urgently
Recruitment and retention of staff	Small market Retention problem Leadership/management skills Undervalued Poor pay Long shifts Unsociable working hours Lack of support and training No requirement for people in leadership to have a qualification that gives even a basic knowledge about dementia	Induction training Dementia Awareness Training CPD Regular team meetings Motivation Opportunities for progression Recognition of their value Better pay and conditions

	and person-centred theory	
Carer needs and assessments	Not always informed about important decisions being made or involved in care planning. No requirement at present to carry out an assessment Carer stress and health.	Recognise the valuable role that carers play – see them as a valuable source of information and support. Involve carers more in care planning. Need to be introduced to provide carers with a full assessment of their needs Informal education Support groups Emotional support Regular breaks Respite An organization like Carers UK
Respite care	Not available in the community Long waiting times where it is available Carers unable to plan ahead as they often do not know till the last minute when the respite will be provided	More respite beds needed Option to have respite provided in a person's own home
Anti-psychotics	Overuse Lack of monitoring and policy	Promote non-pharmacological approaches Monitor use of medication Support to care homes to reduce usage, manage behavior through person-centred approaches.
Lack of statistics	How to plan for services? How many people living with dementia and carers do we have? How to cost?	What do we know already? What projections can we make? States Committees and organizations to keep accurate statistics Share information
PEH	Lack of training for hospital staff Not enough support available on wards Not a dementia friendly environment Patients with dementia accessing AandE kept waiting till last!	Awareness training for staff Trained volunteers to assist with meals, befriending Adopt a scheme such as the Butterfly scheme in England or similar Providing occupation and creating a more relaxing environment, familiar with quiet areas. Improve physical environment such as signage
Integration of care/communication	Lack of integrated services and communication between different agencies and departments involved in providing care Confidentiality can be a barrier sometimes – need for consent to sharing information	Multi-disciplinary and multi-agency approach needed to provide more holistic care with better service user outcomes. Also more cost effective in the long run.

Appendix 2 – Glossary of Terms

2020 vision	Health and Social Care (HSC) '2020 Vision' was debated and approved by the States in May 2011 and set out a framework for future development of the health and social care system in Guernsey and Alderney.
Access	The extent to which people are able to receive the information, service of care they need and are not discouraged from seeking help. Issues involved include distance of travel; physical access (e.g. premises suitable for wheelchairs); communication (e.g. information in Braille/large print and other formats); and the provision of culturally appropriate service.
Accessible housing	Housing which has been specially adapted for someone with mobility problems or sensory impairment.
Active support	A way of delivering care which is intended to: · Provide 'real' activities at home and in the community · Organise support to maximise involvement · Train staff to develop an enabling style of support · Monitor improvements in practice
Activities of Daily Living	Day-to-day tasks associated with the process of performing personal and domestic care, e.g. washing, bathing, dressing, hair and skin care, eating and drinking, and other basic daily tasks, such as cleaning.
Acute Care	Acute care is where people receive specialised support in an emergency or following referral for surgery or medical assessment, complex tests or other things that cannot be done in the community. The term 'acute care' arose when people used to go through the acute or emergency phase of their condition in hospital before moving on to community settings. Now the terms acute care, secondary care and hospital care are sometimes used interchangeably for services that are carried out by specialised staff and equipment. Acute care usually provides treatment for a short period, until the person is well enough to be supported in the community again.
Ageing demographic	Describes the situation in which the proportion of older people in the population is increasing over time.
Ageing Well in the Bailiwick	Ageing Well in the Bailiwick is a group brought together by the Guernsey Community Foundation which consists of representatives from organisations working with older people, from the private, voluntary and public sectors.
Ageism	Where unspoken assumptions and stereotypes based on a person's age are

	used to make judgments about what the person wants or needs without seeing them as individuals with diverse interests.
Aids and Adaptations	Equipment or adjustments to a person's home to enable them to care for themselves and go about their day-to-day lives without support from another person. This may refer to physical adaptations to a property, or the introduction of equipment or assistive technology to support people to live independently.
Allied Health Professionals	Groups of professionals working in Health and Social Care Services, including for example, physiotherapists, occupational therapists and dieticians.
Approved provider	Under the Long-term Care Insurance Law (2002) the Administrator of Social Security may designate: "any provider of long-term care services as an approved care provider" and "any establishment as an approved care establishment" regulations can be made specifying registration process and quality standards to be met by any establishment wishing to be designated as such. This can be a requirement for an approved provider or establishment wishing to receive Long-term Care Benefit on behalf of a resident.
Assessment	The overall process for identifying and recording the health care and social care risks and needs of an individual and evaluating their impact on daily living and quality of life, so that appropriate action can be planned.
Assistive Technology	Technology which can support and enable people to participate – this can include, for example, technology to assist with sensory impairments, such as hearing aids; equipment and adaptations to assist with mobility issues; technology which can assist with communication; technology to help people to remember to take medication; and so on. See also telecare and telehealth.
Avoidable Admission	Admission to hospital that would be unnecessary if alternative services were available.
Baby boomer	Refers to a generation of people born between the end of WWII and the mid-late 1960s.
Care and Support	Any support that a person might need in order to maintain their well-being. Help with transport, housework, paperwork, food preparation, personal care (e.g. bathing, eating or getting out of bed in the morning), help to go out or someone to talk to.
Care community	The network of families, friends, community organisations, not-for-profit and private sector organisations and States-run services which provide care and support to Islanders.

Care continuum	The range of services available which are intended to meet low to high need levels and their connection to each other. For services to be a 'continuum' then a person using services should experience smooth transition as they come into contact with new services which adapt around their changing needs.
Care coordination	Working with an individual to identify what they need, what services are on offer and how best to arrange them to meet the needs of the individual.
Care Package	The particular set of services, which may be provided by different providers, to be delivered to an individual. This might include a timetabled range of visits of different kinds of care professional to an individual throughout the week.
Care Pathway	An outline (usually documented) of what stages of care a person can expect to go through according to the condition that they present with. This will show clearly the different organisations and services an individual will come into contact with, when and how the referrals between the services will work as their conditions progresses.
Care Plan	A personalised care plan outlines the high level needs of an individual and documents the services to be provided, the assessed individuals and their carer(s) participation, the objectives, a review date, and consent from the assessed person to share the plan with the care team.
Care sector	All of the organisations which provide care and support services for the exchange of public, charitable or private funding (whether or not profit based).
Care Settings	The type of place where an individual receives care e.g. hospital, care home, or in their own home.
Carer	A person who cares for or supports, without payment, a family member or friend with a long-term condition.
Carer's Allowance	Carer's Allowance is a weekly benefit intended for anyone who stays home to care for someone who has a disability and needs a lot of attention or supervision by day or night.
Children and Young People's Plan (CYPP)	A plan which is reviewed periodically setting out the objectives and actions required to ensure that there is a holistic and co-ordinated strategy for all children's services in Guernsey. This will enable the States of Guernsey, and its policy and delivery partners in the third sector, to prioritise how resources should be used, and will bring together all the organisations working with young people in schools and in the community, enabling them to work to a common agreed strategy.

Clinical Nurse Specialist	A nurse who is highly trained in a certain area of practice or in supporting people with a particular condition or group of conditions.
Commissioning	A set of procurement processes used to tender or contract for a service provided by a third party. Commissioning tends to take a more outcome-focused approach than other forms of procurement, encouraging providers to innovate in how they deliver those outcomes.
Community Care	Community care services provide health and social care to people in their own homes who have long-term conditions and require regular support (this can be a mix of medical support from nurses, for example managing medication or changing dressings, and social care support to help with personal care, for example, getting out of bed in the morning).
Community Health and Wellbeing Services	A group of services provided by HSC which incorporates community nursing, senior carers, home helps, the shopping service and handy-person service, the health visitor for older people, social workers and occupational therapists.
Community Home	A term given to a group residential homes administered by HSC, typically for individuals with a learning difficulty or learning disability, or people with a mental health problem who need support with activities of daily living.
Community Mental Health Team	Multi-disciplinary team made up of psychiatrists, social workers, community psychiatric nurses, psychologists and therapists. Provides assessment, treatment and care in the community, rather than in hospitals, for people with severe and/or long-term mental health problems.
Community Nursing	Nursing care (i.e. including medication, dressings and other medical tasks over and above help with day-to-day tasks) provided by qualified nursing staff who visit people living in their own homes in the community.
Co-payment	At present, when someone moves into a care home and claims Long-term Care Benefit they are required to pay a 'co-payment' which is a contribution towards the cost of care from their personal finances. See section 7.2.1.
Corporate Housing Programme	The States Corporate Housing Programme (CHP) is an action plan of housing-related projects being carried out by States' Committees, voluntary organisations and the private sector. The CHP is an important part of the Social Policy Plan.
Courtil Jacques	Courtil Jacques is a sheltered housing development which is in proximity to and supported by staff from Le Grand Courtil extra-care housing development in St Martins.
Day Centres and Day Services	Facilities run by social services, health, or a voluntary organisation, that provides care, stimulations and activities. Presently, this is largely for people

	who live on their own or with family in the community. This can be a form of 'short-break' service.
Dementia	Term used for different illnesses that affect the brain and diminish the ability to do everyday tasks. 'Dementia' should be used to describe symptoms, not the condition itself. Symptoms include loss of memory; difficulty in understanding people and find the right words; difficulty in completing simple tasks and solving minor problems; mood changes and emotional upsets.
Demographic	Relating to the make-up of the population. In this context largely to do with the relative size of different age groups within the population.
Dependency	Describes how reliant a person is on someone else for help with activities of daily living or for medical support – low dependency means not very reliant, high dependency means very reliant.
Dependency ratio	The proportion of a population who are economically dependent - those who are eligible for retirement (over pensionable age) and those who are still in compulsory full-time education (children under compulsory school leaving age) - when compared to the number of people who are of working age (i.e. at present this is all those between the ages of 16 and 64 years).
Dignity	Ensuring that a person receives the type of care that makes them feel respected as an individual and help them develop and maintain self-esteem.
Direct Payment	A form of personal budgets where a cash sum is given to a person with care or support needs to arrange their own care and support.
Disability	The UK Disability Discrimination Act 1995 describes disability as 'a physical or mental impairment that has a substantial and long term adverse effect on a person's ability to carry out normal day-to-day activities. Most people and organisations now accept the 'social model of disability': • A fundamental aspect of the social model concerns equality. Equal rights are said to give empowerment, choice and control to make decisions and the opportunity to live life to the fullest. • Disability arises from social or environmental barriers, and is not an inevitable consequence of impairment. • The position of disabled people in society is a human and civil rights issue; and society must be changed to allow full inclusion.
Disability and Inclusion Strategy	In November 2013, the States considered and approved the Disability and Inclusion Strategy109. The Strategy aims to improve the quality of life of disabled Islanders and carers so that they can be actively engaged socially, economically and culturally and that there are improved attitudes towards disabled people.

Disability Needs Survey	A survey undertaken in 2012 to inform the Disability and Inclusion Strategy. Available at: https://www.gov.gg/article/152970/Disability-and-Inclusion-Strategy
Domiciliary Care	Assistance provided to a person in their home, including home care, equipment and adaptation, and meals on wheels. Are generally used to describe visiting services provided to help someone with activities of daily living (bathing, dressing, help with toileting, meal preparation, house cleaning, laundry etc). (See 'Aids and Adaptations').
Duchess of Kent	States-provided residential care for older adults with mental health conditions, particularly dementia.
Elderly Mental Infirmity (EMI)	Elderly Mental Infirmity (EMI) refers to older adults with a mental health condition, usually dementia. It is a category of Long-term Care Benefit which is higher than residential care to account for the extra care-work involved in caring for an individual with more complex support needs associated with dementia.
Enabling environments	Housing, work or other built environments which are designed in such a way as to support people with impairments to be able to function without assistance – for example wheelchair accessible housing.
Enduring care and support needs	Where someone requires care and support on a permanent or ongoing intermittent basis. This is usually due to a long-term condition which could be a physical or learning disability, a mental health condition, dementia, chronic illness, conditions associated with ageing or due to another cause.
'Extra Care' Housing	Independent housing units (flats generally) where an on-site care team provides 24/7 care services to assist with activities of daily living. 'Extra care' housing schemes may also provide outreach care (see outreach services) or support services into the surrounding community and may be a base for community facilities such as restaurants, hairdressers, etc.
Fiscal Framework	The Fiscal Framework is a set of parameters agreed by the States in 2009 to guide future States fiscal policy (i.e. how much tax, borrowing etc. is permissible for the government), committing the States to long-term financial balance and limiting the size of the public sector.
Funding of Long-term Care Working Party	The 'Funding of Long-Term Care Working Party' was formed in mid-2011 to examine the wide ranging and complex issues surrounding the funding of long-term care. It was formed in response to the political concerns about the sustainability of the revenue funding of two 'extra care' housing projects put forward by Housing and HSC in May 20111, which have replaced Longue Rue House and Maison Maritaine residential care homes.
General Revenue	Government income from taxes, charges and other sources. Under the structure of Guernsey's current tax system, this is heavily dependent upon

	income tax.
Le Grand Courtil	Extra-care housing developed by the Guernsey Housing Association, on the site of what was the Housing Department's Longue Rue House residential care home in St Martin's.
The Bailiwick of Guernsey Disability Alliance	The Guernsey Disability Alliance includes representatives from more than 30 local disability charities, plus individual disabled people, their families and the professionals who support them.
The Bailiwick of Guernsey Housing Association	A not-for-profit Housing Association provision social housing for rent and partial-ownership for local Guernsey people.
Handyperson Service	Offered by HSC, this is a service for minor home repairs and adjustments (there is sometimes a charge for this service).
Health	A state of complete physical, social and mental well-being and not merely the absence of disease or infirmity. Health is a resource for everyday life, not the object of living. It is a positive concept emphasising social and personal resources as well as physical capabilities.
Health care	Health care is care associated with treatment and management of long-term conditions via medication, therapy, diagnostics, treatment and so on. This is in contrast to social care which focuses on supporting people to live their day-to-day lives.
Health Information Exchange	A third sector organisation providing information and advice to people about disability and health matters.
Health Visitor for Older People	A community practitioner who helps senior members (over 65s) of the community to lead as healthy a life as possible, both physically and mentally, and to improve the quality of their lives by helping them to maintain their independence and keep safe and well in their own home.
Home Helps	HSC's Home Help Service provides help with domestic jobs such as housework and ironing (there is sometimes a charge for this service).
Housing and Care 21	A national not-for-profit organisation providing housing and care for older people. In Guernsey housing and care 21 operate the extra-care housing in Rosaire Avenue.
Housing Needs Survey	A survey undertaken every five years by Housing to inform policy development in relation to current and future housing needs.
Housing with care	A term used to cover all housing where there is on-site care provision. This includes care homes, but also includes extra-care housing and supported

	housing where a housing development has on-site care staff. The term was proposed by the 2014 UK Commission on Residential Care.
Hospice Care	Hospice care aims to improve the lives of people whose illness may not be curable. It helps people to live as actively as possible after diagnosis to the end of their lives, however long that may be. The caregivers try to control pain and other symptoms so a person can remain as alert and comfortable as possible. The highest value is put on respect and choice. Hospices not only take care of people's physical needs, they consider their emotional, spiritual and social needs too. And they support families and close friends, both during the illness and in bereavement.
'In Reach' Services	Services delivered by a health care or social care professional or team to a location within a community setting. An example would be specialist nurses coming into an extra care scheme to run a falls clinic, or continence advice, or a community nurse (see 'Community Nursing') coming into the scheme to promote flu vaccinations or other health programmes.
Independence	The ability to carry out activities that support one's own lifestyle and to have some control over how and where care and support is received.
Industrial Disablement Benefit	This is a cash benefit payable to a person who has suffered a personal injury caused by an industrial accident, or suffers from a disease prescribed in relation to the person's employment, and has suffered a loss of physical or mental faculty. The amount of benefit payable is fixed by reference to the degree of disablement assessed by a medical board and expressed as a percentage.
Industrial Injury Benefit	This is a cash benefit available to a person who is unable to work through suffering a personal injury caused by an accident at work, or who suffers from a disease prescribed in relation to the person's employment.
Informal care	Care provided by unpaid family members, friends and other informal helpers to individuals with care and support needs.
Integrated Care	Partnerships in which health care and social care staff share information appropriately and work together to ensure that people receive the support and care they need to remain independent in the community.
Integrated Services	Services taking a person-centred approach and seeking to meet a person's social and emotional needs as well as their physical and medical ones.
Intensive outreach	A community outreach service for people with long-term mental health support needs.
Intermediate Care	Care provided to someone when they are at a stage of recovery where they still need health care and support at a level greater than would ordinarily be provided at home but not at an intensive hospital level.

Invalidity Benefit	This benefit is payable to insured persons who for 26 weeks have been entitled to sickness or invalidity benefit and continue to be incapable of work, because of bodily or mental illness or disablement.
Island Development Plan	The Island Development Plan is a Development Plan, prepared by the Committee for Environment and Infrastructure under section 8 of the Land Planning and Development (Guernsey) Law, 2005, which sets out the land planning policies for the whole of Guernsey in a single document.
Key Worker	A named member of a multi-disciplinary team with particular responsibility for co-ordinating care.
Learning Difficulty	Refers to specific learning problems. The umbrella term Specific Learning Disabilities (SpLD) is used to cover a wide variety of difficulties. Many people use it synonymously with dyslexia (a difficulty with words), but it is now generally accepted that dyslexia is only one of a group of difficulties that may include: • Dysgraphia – writing difficulty • Dyspraxia – motor difficulties • **Dyscalculia** – a difficulty performing mathematical calculations • **Attention Deficit Disorder, or Attention Deficit Hyperactive Disorder** (ADD or ADHD) – concentration difficulties with heightened activity levels and impulsiveness • **Asperger's Syndrome and Autism** – emotional behaviour or even social communication difficulties
Learning Disability	Learning Disability is defined as referring to: i. A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; ii. A reduced ability to cope independently (impaired social functioning); iii. Which start before adulthood, with a lasting effect on development. This development encompasses people with a broad range of disabilities. The presence of a low intelligence quotient, for example an IQ below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining need. Many people with learning disabilities also have physical and/or sensory impairments. The definition covers adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average or even above average intelligence – such as people with Asperger's Syndrome. (The above two points refer to DOH (2001) Valuing people: A new strategy for Learning Disability for the 21st Century – A White Paper). To clarify the definition further, it may be helpful to consider those people who would not be included in this definition: i. People who develop an intellectual disability after the age of 18;

	ii. People who suffer brain injury in accidents after the age of 18; iii. People with complex medical conditions which affect their intellectual abilities and which develop after the age of 18 – for example Huntingdon's Chorea, Alzheimer's Disease iv. People with some specific learning difficulties e.g. Dyslexia, Attention Deficit Hyperactivity Disorder.
Lifeline Telephone system	The Lifeline telephone system means help can be summoned in an emergency 24 hours a day by simply pressing a button on a telephone or on a pendant which is worn by the service user. This is arranged via Sure Ltd. to whom a line payment is paid for the service. (This is a form of telecare).
Lifetime Homes standards	'Lifetime Homes' are ordinary homes designed to incorporate design criteria from the outset that can be universally applied to new homes at minimal cost. In the Guernsey context this relates particularly to the need to incorporate design features in all new development, or to design development so that there is the potential to easily adapt it in the future, which can address the requirements of disabled residents or support the changing needs of occupants as they age (taken from the draft Island Development Plan, paragraph 19.9.15)
Lighthouse Wards	The Lighthouse Wards (Hanois, Fougere and Casquets) are on the Princess Elizabeth Hospital site and provide specialist residential placements for people with complex physical needs. Their services are not age-specific but are need-led. One ward is specifically focused on complex behaviour associated with mental health conditions (especially dementia); one ward is for people with both complex behaviour and physical needs; and another is solely for complex physical needs. The current capacity is 53 with 2 short-break care beds.
Long-stay fee	This is a fee charged to people to contribute to their care costs when they are resident in the Lighthouse Wards, Duchess of Kent and Mignot Hospital Continuing Care Ward which is equivalent to the Long-term Care Co-payment.
Long-term care	It is the requirement for care and support by an individual that defines long-term care, not the place or situation where that care and support is provided. Long-term care thus encompasses a wide range of formal services, as well as the care provided by unpaid family members and other informal helpers. It is distinguishable from acute care as it is provided to individuals with enduring needs, including chronic, disabling conditions or impairments, who need support on a permanent or ongoing intermittent basis.
Long Term Conditions	Illnesses which last longer than a year, usually degenerative, causing limitations to one's physical, mental and/or social well-being. Long Term

	Conditions include Diabetes, Chronic Obstructive Pulmonary Disease, Asthma, Arthritis, MS, Parkinson's Disease, Epilepsy, and Mental Health. Multiple Long Term Conditions make care particularly complex, and a small number of individuals and conditions require complex care packages and high levels of health care use (especially hospital care). According to the World Health Organisation, Long Term Conditions will be the leading cause of disability by 2020.
Long-term Care Benefit	Long-term Care Benefit is a weekly benefit which is paid towards the cost of the fees if you are in a private residential home or private nursing home. (NB. "Private" means not run by the States.)
Long-term Care Insurance Fund	Money raised via Social Security Contributions for the purpose of Long-term Care is kept in a Fund which is managed as an investment. This is called the Long-term Care Insurance Fund.
Long-term Care Insurance Scheme	The Long-term Care Insurance Scheme describes the system under which Long-term Care Benefit operates including the benefit payments and fund as prescribed by the Long-term Care Insurance (Guernsey) Law, 2002.
Long-term Hospital Care	Where an individual as acute or complex needs which necessitate a long-term stay in a hospital setting.
Longue-Rue House	The Residential Care Home which was operated by the Housing Department in St Martins which has now been redeveloped into Le Grand Courtil extra-care housing.
Maison Maritaine	The Residential Care Home which was operated by the Housing Department in the Vale which has now been redeveloped into La Nouvelle Maritaine extra-care housing.
Managed Personal Budget	Where a social worker works with the person with care needs to identify what services they want to spend their personal budget on from a 'menu' of approved providers, and then arranges for these services to be paid for from the personal budget without the individual needing to contact care agencies themselves or handle the money.
Meals on Wheels	Deliveries of pre-cooked meals to the homes of people who are housebound and/or are unable to prepare meals and/or cook for themselves. (NB. This could also be the delivery of frozen meals for the individual to prepare themselves, although this service is not available in Guernsey.)
Medical Specialist Group	Provides the emergency and elective specialist medical services for the Bailiwick of Guernsey, Alderney and Herm within the secondary health care framework and in partnership with HSC.
Medical Model of Health	Model or philosophy of health based on the premise that all illness has a biological/physiological cause, and can therefore be cured by medical

	intervention, e.g. drugs, surgery.
Memory Clinic	A clinic to which individuals with memory problems are referred in order to assist with diagnosis.
Mental Health	How an individual thinks, feels, and acts when faced with life's situations. This includes handling stress, relating to other people, and making decisions. A mental health problem is a psychiatric disorder that results in a disruption in a person's thinking, feeling, moods, and ability to relate to others. The more extreme forms can be very disturbing for both the individual concerned and for those around them. However, while mental health problems can lead to considerable disruption and difficulty, many people find ways of managing their needs and are able to lead fulfilling and active lives. Many people with mental health problems will also be supported informally by friends and relatives, or receive treatment with their GP. When an individual has high levels of risk and particularly complex needs, they may be referred to the specialist mental health service provider for assessment, treatment or support. People referred to a specialist mental health service provider may receive an assessment from a psychiatrist, psychologist, mental health nurse, social worker, or occupational therapist and, if they need further treatment or support, they may be offered medication, psychological therapies, occupational therapies or social support.
Mental Health and Wellbeing Strategy	In February 2013, the States of Deliberation approved a report from HSC outlining a Mental Health and Wellbeing Strategy110. The Strategy is intended to promote mental health and wellbeing across the community, support vulnerable people, and ensure that appropriate and effective treatment is provided for those who need it.
Metivier House	A Guernsey Housing Association development of 14 flats of sheltered housing which is supported by staff from Le Grand Courtil extra-care site.
Mignot Memorial Hospital	The hospital in Alderney, which includes a Continuing Care ward for individuals in Alderney with long-term nursing care needs.
Morbidity/Co-morbidity	Applies to illness or disease. The morbidity rate is the incidence of disease in a population over a given period of time. Co-morbidity is where a person has several different long-term conditions at the same time. For example, diabetes and a heart condition.
Multi-Disciplinary Team	A group of people from different disciplines who work together to provide and/or improve care for patients with a particular condition. The composition of multi-disciplinary teams will include people from various disciplines (both healthcare and non-healthcare).

Multi-Disciplinary Assessment	Assessment of an individual's needs that actively involves professionals from different disciplines in collecting and evaluating assessment information.
Needs	What an individual requires to achieve and maintain health and well-being. Areas of needs include: physical, emotional, mental health, spiritual, environmental, social, sexual, financial and cultural.
Needs Assessment	A process by which health care and social care professionals assess and then make conclusions on risks and needs. The assessment sets out what is necessary for an individual to maintain their life at a certain standard.
Needs Assessment Panel	The Needs Assessment Panel is a body of professionals convened by HSC to make decisions on where an individual's needs will be most appropriately met. A certificate confirming the level of need is required from the panel to access most forms of bed-based care.
Night Sitting Service	A carer provides personal care and support services to an individual in their own home over night.
Not-for-profit	An organisation or company which may charge for services but reinvests any surplus revenue to further its purpose rather than distributing profits to shareholders or owners.
Nursing Care	Involves the use of clinical judgement in the provision of care to enable people to improve, maintain, or recover health; to cope with health problems; and to achieve the best possible quality of life, whatever their disease or disability, until death. Nursing includes the promotion of health, prevention of illness, and the care of ill, disabled and dying people.
Nursing Home	Care home that provides nursing care (with, generally, at least one registered nurse on duty).
Occupational Therapy	Occupational therapists work with people who have a physical impairment, a medical condition, a mental health problem or a learning disability. They help people who have difficulties with practical everyday tasks. The aim of occupational therapy is to enable individuals to live as independently as possible – at home, in employment, or in education. Occupational therapists work in health and social care and work closely with health, housing, and educational services. An occupational therapist can help individuals adapt to changes in everyday life caused by disability or illness and to overcome practical problems. Occupational therapists have specialist knowledge and can advise on disability equipment, housing adaptations, and adaptations to the workplace.
Off-Island Placements	Where an individual presents with high-level or specialist needs which cannot be effectively met on-Island, long-term placements are arranged to enable an individual to be appropriately supported elsewhere, mostly in the

	UK.
Older Adult Mental Health Service	A service which supports the mental health needs of people over retirement age, incorporating but not limited to dementia. The service operates a community team, an assessment ward, the Duchess of Kent and Lighthouse Wards.
Older People's Strategy	A strategy which was under development until 2011 which was not presented to the States, but developed into the Supported Living and Ageing Well Strategy.
'Outreach' Services	Describes those services or facilities which are managed within a specific location (for instance an extra care scheme) and delivered from that location into community settings. Outreach Services might also be a specialist care or support service. An example of this kind of Outreach Service might be an Assistive Technology response service where staff based at an extra care scheme respond to community alarms triggered by people who live in the surrounding community.
Palliative Care	Palliative care is the term used to describe the care that is given when cure is not possible. The word comes from the Latin 'palliatus' (covered or hidden with a cloak) and is used to mean 'relieving without curing'. Palliative care is a proactive approach involving a multi-professional team. As well as controlling pain and other distressing symptoms, it applies a holistic approach to meeting the physical, practical, functional, social, emotional, and spiritual needs of patients and carers facing progressive illness and bereavement. Although historically associated with the later stages of cancer, it is now established that palliative care should also be a routine part of end of life care for those living with and dying from a wide variety of non-malignant conditions, such as Dementia, Heart Failure, Huntington's Disease, Motor Neurone Disease, MS, Muscular Dystrophy, Parkinson's Disease, Renal Failure, and Respiratory Failure among others.
Palliative Care team	A multi-disciplinary community team providing palliative care support.
Person Centred Care	Person centred approaches are ways of commissioning, providing, and organising services rooted in listening to what people want, to help them live in their communities as they choose. These approaches work to use resources flexibly, designed around what is important to an individual from their own perspective, and work to remove any cultural and organisational barriers. People are not simply placed in pre-existing services and expected to adjust, rather the service strives to adjust to the person. Health care and social care agencies are increasingly using 'individual' or 'person' or 'citizen' as a term in

	place of traditional, organisational specific terms such as customer, client, service user, and (where appropriate) patient. (NB. HSC has adopted the term 'service users'.
Personal budgets	A way of funding long-term care currently used within the UK. A personal budget is an amount of money set aside to purchase a person's care and support from third-party organisations based on an assessment of their needs.
Personal contributions	In this report, used to describe any case in which an individual is asked to contribute financially towards the cost of their care.
Personal Care	Providing assistance with dressing, feeding, washing and toileting, taking medication, as well as advice, encouragement, and emotional and psychological support.
Personal expenses	Items for which individuals might have to pay when they are living in a residential long-term care setting, for example a ward or care home. This might include hairdressing, gifts, chiropody, incontinence pads, toiletries etc.
Personal Tax Pensions and Benefits Review	A comprehensive review of personal taxes, allowances and benefits undertaken by the Policy and Resources Committee and Social Security and debated by the States in March 2015.
Physiotherapy	Physiotherapy is a science-based healthcare profession which views movement as central to health and well-being. Physiotherapists aim to identify and make the most of movement ability by health promotion, preventative advice, treatment and rehabilitation. Physiotherapists believe it is of vital importance to take note of psychological, cultural and social factors which influence their clients. They try to bring patients into an active role to help make the best use of independence and function.
Positive Behaviour Support Team	A team based in the Learning Disability Service which helps service users and staff to manage and reduce challenging behaviour.
Preventative Services	These services are associated with preventing the onset of situations or conditions that could lead to acute service responses. Services are associated with the promotion of health and the prevention of disease. An example of a preventative health programme would be 'Walk Your Way to Health', a programme offered by the Guernsey Health Promotion Unit.
Primary Care	Health services offered by providers who act as the principal point of consultation for patients within a health care system, e.g. doctors, dentists, pharmacists. These are services which someone can access directly without referral.
Private Nursing	Nursing care and other support services provided by voluntary, charitable

and Domiciliary Care	and not for profit organisations and private businesses (i.e. not by the States).
Provider	Organisations or care staff that supply services.
Public Engagement Steering Group	A group composed of representatives of Ageing Well in the Bailiwick, the Guernsey Disability Alliance and the States Champion for Disabled People who supported the Working Party in the development of the Strategy.
Public Health	The prevention of disease and promotion of health through the development of evidence-based programmes. A directorate of HSC incorporating health promotion.
Rapid response team	A team which provides short-term rapid access to additional support in crisis situations for people or their carers to manage an escalation of need and prevent hospitalisation if possible.
Re-ablement	The active process of regaining skills, confidence, and independence.
Rehabilitation	A multidisciplinary process which supports the individual to achieve their maximum potential to function physically, socially, and psychosocially through support and intervention.
Residential Home	Care home that does not provide nursing care, but provides support with activities of daily living in a group home setting with shared communal facilities.
Respite Care	Short-term care for a person to allow their carer a break from caring to sustain their caring role. This can be in the form of in a care environment (i.e. in a respite home), short breaks, outreach support, or day care. This service can be provided on a planned or emergency basis and should be a positive experience for both parties.
Risk, Risk Assessment	When a holistic assessment is completed, the assessor and the individual consider and evaluate conclusions on the risks and needs. This evaluation also takes full account of the likely outcome if assistance were not to be provided. There are also specialised risk assessments for specific types of risks, i.e. violence and aggression, manual handling. The evaluation of risk focuses on the following aspects that are central to an individual's independence: autonomy and freedom to make choices; health and safety including freedom from harm, abuse and neglect, taking uses of housing circumstances and community safety into account; the ability to manage personal and other daily routines; and the involvement in family and wider community life, including leisure, hobbies, unpaid and paid work, learning and volunteering. Assessors also consider risks faced, not only by the person assessed, but by

	those close to them, such as carers (and to staff and society). They also consider which risks cause serious concern and which may be acceptable or can be viewed as a natural healthy part of independent living.
Sarnia Ward	A ward used for the assessment of older adults presenting with mental health needs.
Secondary Care	Hospital Care resulting from a referral by a health professional in Primary Care.
Senior Carer Service	Home care workers who give help with personal care such as washing and dressing, going to the toilet, and provision of simple meals.
Service charge	The amount an individual is charged in extra-care housing, or other rental accommodation over and above rent for services provided (e.g. cleaning of communal areas).
Service Framework	Evidence-based standards to improve health and social care outcomes, reduce inequalities in health and social well-being and improve service access and delivery. Services frameworks set out standards of care that patients, clients, families and carers can expect to receive.
Service Level Agreement (SLA)	Service level agreements are agreements between the States and organisations that provide services stating what it is expected that the organisation will provide in exchange for funding.
Severe Disability Benefit	Severe Disability Benefit is a weekly benefit intended for adults and children who have a physical or mental disability and need a lot of attention or supervision by day or night. It can be used for a range of purposes including equipment purchase, additional heating, transport, therapy, care and support and more.
Sheltered Housing	Independent housing units (flats, bungalows, houses) that are linked to a community alarm service and with a warden who can help people access support services which enable them to live independently for as long as possible. Generally associated with older people.
Shopping service	A service provided by HSC to assist people with shopping where necessary. There is a minimal charge for this service.
Short-break service	Services which both enable those individuals with care or support needs to spend time with people, be in places or undertake activities that would not otherwise be available to them, and can also enable those who care for others to have a break from caring.
Single Assessment Process	Standardised holistic assessment framework across health care and social care so duplication is minimised and an individual receives timely and proportionate assistance appropriate to their risks and needs. The Single

	Assessment Process aims to put individuals at the centre of their own assessment and subsequent personalised care planning. Originally brought in for older people, it is increasingly being used as the framework for other adult groups.
Sitting service	This service can help carers to have a break from looking after someone at home; day care may be provided for people who live in the community.
SLAWS Working Party	A Working Party formed to progress the Strategy formed of representatives of the Policy and Resources Committee, Social Security, HSC and Housing.
Social Care	Care provided to support an individual's social care needs as opposed to health care needs. Social care comes in many forms. Adults can be supported in the community through home care, sitting, meals, and day services, or through residential home or nursing home care. Children and families are supported at home through a wide range of child protection, social work, early year, and other services. Sometimes fostering, adoption and residential care services may be an option. Social care services are provided for people who need help to live their lives as independently as possible in the community (either at home or in care settings), people who are vulnerable and people who may need protection.
Social housing	Housing provided by the States or third-sector not-for-profit providers to individuals with unmet housing needs. This can include affordable housing, related to the financial ability of individuals to cover their housing costs, but also to specialised housing – such as extra-care housing, which caters to specific needs and access to which is not income-based.
Social model of disability	"The social model of disability identifies systemic barriers, negative attitudes and exclusion by society (purposely or inadvertently) that mean society is the main contributory factor in disabling people i.e. it is the society as a whole that is responsible for creating barriers to full participation of persons with disabilities, and it is the society as a whole that has the responsibility to remove them." (Delia Ferri, 2011).
Social Policy Group	A sub-group of the Policy Council comprising the Chief Minister and Ministers of the Committee for Home Affairs, the Committee for Health and Social Care, the Committee for Education, Sport and Culture, Social Security, and the Policy and Resources Committee.
Social Policy Plan	Part of the States Strategic Plan. The purpose of the Social Policy Plan is to assist the States to develop and deliver services for people to meet their needs for welfare and wellbeing. The areas covered by the Plan include health; social care; benefits; housing; employment; equality; education and security.

Social Security Contributions	The amount individuals and employers pay from their income towards Social Security. This funds contributory benefits including pensions and long-term care benefit. Currently only individuals, and not employers, contribute to the Long-term Care Fund.
Social Services	Personal social services are one of the major public services and describe a wide range of support that help people to carry on in their daily lives. It includes: • Services for children such as adoption, fostering and protection; • Help for people with mental health needs; • Support and care services for older people; • Support for people with a disability and people with learning disabilities. The term social care is increasingly now being used instead of social services. This reflects the greater involvement of the independent sector and voluntary sector in the provision of social care services and the continuing role of the 'statutory' sector as commissioners as well as providers of support and care. Social services functions in many jurisdictions no longer stand alone, but are increasingly combined with housing, education, and health services.
Social Worker	Professionals who are available to provide information about services in Guernsey and to discuss with people which service may be appropriate for their needs, particularly regarding carer support and help to stay living at home. They call upon a range of expertise to assist with complex problems. They also undertake comprehensive assessments for people who require residential home or nursing home care.
Specialised Housing	A land-planning use-class which incorporates care homes and supported housing – any housing where there is on-site care provision.
Specialist Residential Care home	Care home that does not provide nursing care, but provides support with a range of activities of daily living in a group home setting with shared communal facilities providing for individuals with specialist needs e.g. dementia.
States Champion for Disabled People	A Deputy appointed by vote of the Guernsey Disability Alliance to act as a champion for disabled Islanders in the States.
States Strategic Plan	The States Strategic Plan (SSP) is the long-term planning mechanism to enable the States to decide what they want to achieve over the medium- to long-term and how they will manage or influence the use of Island resources to pursue those objectives. The latest version of the States Strategic Plan was considered and approved by the States in March 2013.
"States rates"	An informal term used to refer to care home placements which are the sum of Long-term Care Benefit and the Co-payment and for which no additional top-up fee paid by the individual is required.

States Review Committee	A committee formed by the States to make recommendations on the reform of the machinery of Government. Changes, including the restructuring of departments into new committees, which took place during 2016.
St John Ambulance Subscriptions	An annual subscription scheme to meet the cost of emergency ambulance services.
St Julian's House	Managed by HSC to accommodate and support on a temporary basis vulnerable men and women (max. 32) who would otherwise be homeless, in mostly dormitory-style accommodation.
Strategic Land Use Plan (SLUP)	One of four Island Resource Plans which describe the ways in which the States proposes to manage or influence the use of Island Resources to support the overall Aims and Objectives of the States Strategic Plan. The SLUP sets out a 20-year agenda for land use planning in Guernsey and has been used by the Committee for the Environment and Infrastructure to guide the preparation of the draft Island Development Plan.
Supplementary Benefit	Supplementary Benefit is a cash benefit intended to bring household income up to a level which the States believes is enough to live on. The amount of benefit receivable is calculated on a weekly basis with reference to household income.
Support Services	Support services include services which enable independent living, such as help to arrange shopping; housekeeping; helping to complete benefit claims; providing links to other community or voluntary services like Age Concern, GVS, etc.; providing links to States' services where necessary; arranging social events; help with laundry, meal preparation, etc.
Supported Housing	Independent housing units (flats, bungalows, houses) that are designed to help people with a range of needs to live independently for as long as possible. Generally associated with adults under pensionable age.
Tax burden	The proportion of a person's income that they are paying in tax and social security contributions.
Telecare	A combination of equipment, monitoring and response that can help individuals to care for themselves or call for help. It can include basic community alarm services able to respond in an emergency and provide regular contact by telephone, as well as detectors which detect factors such as falls, fire or gas and trigger a warning to a response centre. Telecare can work in a preventative or monitoring mode, for example, through monitoring signs, which can provide early warning of deterioration, prompting a response from family or professionals. Telecare can also provide safety and security by protecting against bogus callers and burglary.
Telehealth	Telehealth is technology which can support the provision of healthcare

	remotely. For example, it can allow a medical specialist to have a video conference meeting with someone in a remote location, or carry out certain tests from a distance.
Third Sector	Term used to describe the range of groups and organisations including small local community and voluntary groups, registered charities both large and small, foundations, trusts, and the growing number of social enterprises and co-operatives. Third sector organisations share common characteristics in the social, environmental, or cultural objectives they pursue; their independence from government; and in the reinvestment of surpluses for those same objectives. So, as well as including charities and support groups, the third sector also includes not-for-profit housing and care providers.
Third sector compact	An agreement between the States of Guernsey and the Association of Guernsey Charities made in 2014 outlining the ways in which the public and third sectors would work together.
Top-up fee	The amount which a care home might charge over and above the sum of the Long-term Care Benefit and Co-payment. This cost is usually met by the individual from their personal resources.
Transition	Generally refers to the transition from children and young people's to adult services which occurs in late teens or early twenties.
Travel Allowance Grants	A grant given by Social Security to those travelling off-Island for medical assessment and/or treatment to cover the costs of their travel.
Unit cost	The amount it costs per unit of a service delivered, e.g. the cost to provide a bed in a care home per night or an appointment with community services staff.
Unmet Need	Social care needs that are not met because of lack of awareness, because there are not enough resources or because the services are not of a sufficiently high standard.
User Involvement	Involving individuals in the planning and development of the services they use. There is a need for a range of models of involvement, depending on the level of activity that participants wish to commit. What is important is that the choice is there, and that the involvement – or partnership – is real. User involvement should relate clearly to a decision that the organisation plans to make, and is open to influence. It should be made clear what individuals may or may not be able to change.

Vital Signs	Regular performance information and reports regarding safety, service quality, staffing and spend.
Voluntary Car Service	Helps those who need it with transportation to medical appointments (e.g. an older person living in the community who has an appointment with a General Practitioner or with the Medical Specialist Group). This service is provided by volunteer personnel. It is not wheelchair accessible.
Vulnerable Person	An individual who is at risk of abuse or harm due to life circumstances, for example, a homeless person or a frail older person, or personal choice, e.g. an individual may decide to continue with the risk.
Well-being	The state of being healthy, happy, and prospering. An individual's health and well-being is affected by a number of different factors that contribute positively to health and well-being such as: • A balanced diet; • Regular exercise; • Supportive relationships; • Adequate financial resources; • Stimulating work, education, and leisure activity; • Use of health monitoring and illness prevention services (such as screening and vaccination); Use of risk management to protect individuals and promote personal safety.