

Making Jersey a dementia friendly island

Dementia Jersey We are learning about dementia

Dementia Jersey

Towards a dementia friendly Jersey

Our strategy for 2023 - 2025

www.dementia.je

We are Dementia Jersey, the only local charity for people with dementia and those who care for them.





We want a step change in the way people with dementia and their families are supported in Jersey

People with dementia and their carers have a right to live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality.

Whilst it is estimated that approximately 1,600 people in Jersey live with dementia it is said that for each person with dementia seven other people- be it as spouse, partner, carer, family and friends- are affected and also need advice and support.

We also have an ageing population in Jersey and the biggest non-modifiable risk factor in developing dementia is age. In fact 1 in 5 people on the island are now aged 65 and over and the Government reports dementia is the fastest growing disease on the island and that cases will double by 2036.

We urgently need to set in motion a step change now in the way people with dementia and their families are supported in Jersey.

To achieve this our bold strategy will set us on an ambitious growth path in the next three years and beyond.

It aims to ensure the following outcomes:

- People with dementia feel supported and understood.
- Carers feel equipped to support those they care for.
- Healthcare professionals have the systems in place and the knowledge they need to care for people with dementia.
- A Jersey Dementia Strategy is agreed and implemented.
- Islanders understand dementia.

There are many battles to be fought to achieve these outcomes and people with dementia tell us that public services aren't currently meeting their needs and they regularly encounter negative attitudes about dementia.

To achieve this over the next three years we plan to significantly grow the charity to keep pace with demand and increase our influence where it matters. We will work in partnership with Government to take forward the Jersey Dementia Strategy and put in motion plans to improve services, systems and processes. In particular championing a person-centred approach which prioritises mutual respect and understanding to reach positive outcomes.

We will offer more flexible support to people with dementia and those who care for them from a new Support Hub. We will build on our hugely popular programme of therapeutic events, roll out a first class certification programme for businesses to grow their understanding of dementia, deliver more awareness sessions to schools and much needed training and support for carers; all so we can reach more of the estimated 1,600 people with dementia in Jersey and their families.

Join us on our journey.

Claudine Snape, CEO





Our Vision

Jersey is a dementia friendly island

We will work together with others to create an island where those affected by dementia are supported, accepted and able to live well without stigma.

Our Mission

We support people affected by dementia and improve understanding and awareness of dementia throughout Jersey.

Our Beliefs

- People with dementia should be treated with dignity and respect.
- Every person, of any age, with any physical or mental health conditions, has an equal right to the best health and social care services available to meet their needs.
- A person centred approach should be used to make sure everyone gets the best care and support for their situation.
- People with dementia have a right to be heard and included in all decisions that affect them and those who care for them.
- Helping, caring for and protecting people is everyone's business and is at the heart of a strong island community.

Our Values

Expertise

We use research and the lived experience of people with dementia to guide our work.

Choice

We support people with dementia and those who care for them to make informed choices about the best approach to meet their needs.

Kindness and compassion

We are kind and compassionate in all we do for others and in our support for staff and volunteers.

Challenge

We will stand up for people with dementia to get the best outcomes possible.

History of support

Previously a branch of the UK Alzheimer's Society, Jersey Alzheimer's Association was formed in April 2010 when the Jersey branch closed because of the implementation of the new 'Locality Management' structure which meant that all Jersey services were to be run from Hampshire. We changed our name to Dementia Jersey in 2021 as we wanted to make it clearer that we support people living with all types of dementia not just that caused by Alzheimer's disease.

From these small beginnings in 2010 with only two members of staff, we've grown into a leading charity in Jersey, proving a lifeline for islanders with dementia and their families. We are a full member of Alzheimer's Europe, an organisation which has independent members from 34 different countries.

In 2022 we had 6,500 attendances to our services. We provide expert support on dementia, raise awareness and campaign to improve services for people with dementia and those who care for them. We are here whenever we are needed, providing support and guidance from pre-diagnosis until the end of the journey, no matter what the level or type of dementia.



Our ambition

By 2030 Jersey will be a dementia friendly island

Stigma and discrimination heighten the already significant psychological, social, emotional and financial impacts that dementia has on individuals, their carers, families and communities.

Together we can take action to reduce stigma and move towards a dementia friendly island, making sure that people with dementia have the understanding and support they need to live well with dementia for longer at home.

Increasing public awareness, acceptance and understanding of dementia and making our environment and services dementia friendly will enable people with dementia to participate in the community and maximize their autonomy through improved social participation.

Our ambition is part of the World Health Organisation's Global Action Plan on the public health response to dementia 2017–2025 which has a focus on dementia inclusive societies to ensure quality of life and dignity for people with dementia, their carers and families.





What we will do

To make sure we can achieve our ambition we will work in three areas:

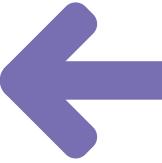
- We will offer advice and support to people with dementia and those who care for them.
- We will influence professional practice and seek to improve services.
- We will educate people to understand more about dementia and remove the stigma.

These are areas where we know we can make the biggest difference, and where not taking action would have serious consequences for people with dementia.

What we won't do

We invest our limited valuable resources in support that makes a unique difference to the lives of people with dementia and their carers. To avoid duplicating the work of other organisations and spreading our resources too thinly there are some things we won't do, including:

- We will not fund medical research into cures for dementia.
- We will not provide personal care for people with dementia.
- We will not provide training for professionals, but will advocate for the need for this to be provided by others.



Advice and support to people with dementia and their carers

The Problem

- The number of people with dementia is set to more than double within a generation.
- There is limited support available to people with dementia and their families following discharge from the Memory Assessment Service.
- In particular there are very few opportunities to attend activities designed for people with dementia and their carers on the island and none for people with mild cognitive impairment, which can be a precursor to dementia.
- There is no other organisation on the island offering tailored support and training for carers of people with dementia.
- However, we know that cognitive stimulation can delay the onset of symptoms, enabling people with dementia to live well for longer at home.
- Regular therapeutic activities can also have a transformative effect on people with dementia, improving the quality of life for them and their carers.

What we will do

We will make sure that people with dementia and those who care for them get the advice and support they need to improve their quality of life.

We will:

- Introduce a Support Hub which provides confidential support from dementia advisers via bookable appointments, drop in visits or by telephone, online and text. Our group of advisers help families navigate and access the services that support their desired outcomes, connecting them to local groups and services that will promote their physical, mental and emotional well-being.
- Continue to expand our therapeutic activities for people with dementia and their carers to meet demand and ensure maximum accessibility for clients with different interests. In particular we will focus on expanding our support for men with dementia, male carers and volunteers who are currently underrepresented. Current popular activities include art, music, swimming, Pétanque, coffee mornings and puzzles/games and a walking group.
- Grow our community of volunteers, introducing a variety of ways people can get involved and that they have the support they need.
- Continue to grow the Meeting Place Project, which is aimed at supporting people with a recent diagnosis with a mixture of weekly cognitive therapy, group work and movement.

The number of people with dementia is set to more than double within a generation



What we will do

We will make sure that people with dementia and those how care for them get the advice and support they need to improve their quality of life.

We will:

- Working in partnership with the Memory Assessment Service, scope the needs of people with younger onset dementia in Jersey with a view to developing a tailored support offer.
- Work with the Memory Assessment Service to scope the needs of people with mild cognitive impairment. In particular scope a) the number of people affected;
 b) whether tailored support would be beneficial; c) whether Dementia Jersey is in a position to offer any services.

How we will measure success

• We will track how many people we reach through our work and evolve the tools we use to understand our impact and the outcomes from our work.

It is estimated that 1,600 people in Jersey are currently living with dementia



Influencing professional practice and improving island-wide services

The Problem

- There is a range in the quality of services.
- People with dementia have reported a lack of understanding of dementia by key health professionals who support them in hospital.
- There is a high percentage of people with dementia stuck in discharge at hospital (known as bed blocking) which is not good for them or the general health system on the Island.
- Severe lack of availability of care staff or nursing beds in care homes.
- Low levels of support available for carers.
- Lack of dedicated support for people with younger onset dementia.

What we will do

We will use our expertise to influence professional practice in order to improve island-wide services in the following ways.

We will:

- Work in partnership with the Government of Jersey to create and implement the Jersey Dementia Strategy and budget. The strategy will outline approaches to tackle the known challenges negatively affecting the quality of life of islanders with dementia.
- Continue to evolve the Lived Experience Advisory Panel which is a group of people with dementia and carers who comment on issues relating to their experiences on a monthly basis and whose recommendations will be shared widely to influence improvements (and followed up).
- Work with a range of partners and working groups to influence work to improve professional services, training and policies affecting people with dementia and those who care for them.
- Organise a series of talks on best practice dementia diagnosis and care from leading experts from around Europe, to coinside with Dementia Awareness Week in May each year.

People with dementia think many health professionals who support them in hospital don't understand their needs

How we will monitor progress

The following factors will be monitored to help our understanding of progress towards desired outcomes:

- Hospital admissions for people with dementia.
- Average length of stay in hospital for people with dementia.
- The number of nursing beds available in care homes for people with dementia.
- The availability of care staff.
- Availability of training on dementia available to healthcare professionals.
- The delivery of clearly defined care and support pathways.

How we will measure success

Success in this area is ultimately the delivery of the Jersey Dementia Strategy and buy-in from Government teams to implement it but is defined by progress towards achieving the following outcomes:

- People with dementia feel supported and understood.
- Carers feel equipped to support those they care for.
- Healthcare professionals have the systems in place and the knowledge they need to care for people with dementia.

We will also track sentiment through an annual survey of people with dementia and their carers and we will work with partners to seek out ways to track sentiment with healthcare professionals.





Educating islanders to understand more about dementia and remove the stigma

The Problem

- Dementia is the most feared health condition for people over the age of 55.
- There is general confusion about what dementia means and whether it is a disease like Alzheimer's (it is not).
- There are also a number of common myths that dementia:
- It is purely genetic (it is not).
- It only affects older adults (there are a small number of adults who develop younger onset dementia).
- It mainly affects memory (dementia is a degenerative disease that leads to death).
- Many islanders aren't aware of the approaches which are fundamental to making people with dementia feel understood and supported.

What we will do

- Expand our free introduction to dementia session called 'Dementia Friends', with the ambition that all schools become dementia friendly.
- Roll out a new chargeable Dementia Friendly Businesses Scheme which offers certification to organisations who provide services to people who may have dementia.
- Evolve the training that we offer to carers to complement the information resources available and will make sure training is practical and meets the 'real world' challenges carers face on a regular basis.
- Pioneer a new approach to risk reduction through working with partners to create a long running campaign focused on 'Brain Health.'

How we will measure success

- We will track our impact on attitudes of those who receive our training.
- We will work with partners to establish ways to track islander's understanding of dementia.

Many islanders aren't aware of the approaches which are fundamental to making people with dementia feel understood and supported



Making it happen

To help achieve our ambition of a dementia friendly island we have prioritised the following areas:

Our People

- We will continue to evolve and grow staff and volunteer resources in areas where we need it to meet demand and invest in learning and development so we have the breadth of skills and knowledge we need, for example in younger onset dementia.
- We will actively listen to our volunteers, and make sure everyone finds a way to get involved that excites and inspires them.

Our Services

- We will invest in the technology needed to simplify the experience of accessing our services for our supporters.
- We will continue to evolve the Support Hub to meet the needs of our clients.
- We will actively listen to the Lived Experience Advisory Panel's recommendations and make sure that they are disseminated widely and acted upon.

Our Facilities

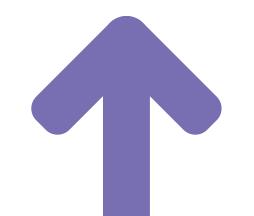
- We have outgrown our current premises and will continue actively looking for new premises which meet our needs.
- We will be an exemplar for dementia friendly environments in our new premises.
- We will take seriously our wider social responsibility and reduce our environmental impact wherever possible.

Our Funding

• We will pilot new fundraising approaches, in particular to build the number of regular givers, to create a more sustainable footing for the charity.

Our Profile

- We will develop targeted, integrated campaigns that raise awareness and inspire change, so that those who would most benefit are aware of the support we offer.
- We cannot create a dementia friendly island alone and promise to build new partnerships and inspire ambassadors to amplify our message. This work also includes working in partnership with people with dementia and their carers, to better understand their needs in order to advocate for them and improve services.
- We will maximise the opportunity of co-authoring the Jersey Dementia Strategy to raise our profile and forge new relationships with healthcare professionals.





Meet Ann Morel. Ann joined our art exploration group in 2021 which helped reignite her passion for drawing and Ann has since joined some of our other activities, including a morning coffee and chat and a project helping people with a recent diagnosis of dementia.

Ann was diagnosed with Frontal Temporal Dementia in 2019, although symptoms first started in 2015. Ann experienced difficulty with speech and headaches, and while previously Ann loved to draw and created some amazing art, when the headaches started, she sadly stopped drawing.

Throughout the journey to diagnosis, Ann's husband Frank began to notice things weren't quite right at home, and he noticed Ann was losing her confidence. While they were relieved to have a diagnosis, this left Ann feeling frightened to leave the house, further affecting her confidence with speaking, answering the phone and most of all, affecting her passion to draw. Since joining Dementia Jersey activities, Ann has been able to socialise with other people with dementia and take part in brain stimulating activities paired with speech therapy. As a result, she started to answer the phone again, was less frightened to go out and has started creating art at home again. This transformation to her confidence levels was one of the positive changes that have helped both her and Frank.

We are delighted to have been able to support Ann and Frank through this journey and help reignite Ann's creative spark.



"As a carer, life has got a lot easier thanks to Dementia Jersey. It's great because I can leave Ann to get on with art and chat away without a worry. It's taken a lot of stress off. We've had a lot of practical and emotional support from Dementia Jersey. You feel like if you have a problem, you can talk through it with their staff and find a solution." – Frank

Ways you can support us

Our running costs are over £600,000 per annum. We therefore rely on the support and generosity of the public and the business community. All money raised in Jersey is spent in Jersey.

Donate Online

Make a donation online via our website: www.dementia.je

Donate by cheque

Please make cheques payable to 'Dementia Jersey' and send to our address below.

Fundraise

Raise money through a challenge event by walking, cycling, abseiling, trekking or skydiving for Dementia Jersey. Or pick a challenge of your own. Contact Nadine for more information. Email: nadine@dementia.je

Charity of the Year Partnerships

Choose us as your business's charity of the year. Contact Nadine for more information. Email: nadine@dementia.je

Volunteer

Consider volunteering at our events, for more information please contact Contact Susie for more information. Email: susie@dementia.je

Contact us

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