

dementia

Care



The Orders of
St John
Care Trust



Each circle represents 1,000 people currently diagnosed with dementia in the UK

Dementia care

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There are now nearly 944,000 people living within the United Kingdom with a diagnosis of dementia.

This publication has been produced to explore dementia in more detail and raise awareness of the support available to those facing the difficult decision of choosing care.

Some people who receive a diagnosis of dementia can live independently at home with support from a relative, friend or paid carer and may never need to move into a residential care setting. But for those who do, we at The Orders of St John Care Trust (OSJCT) want to make sure that the experience is as close as possible to the care the person would have received at home.

OSJCT is committed to providing high quality, person centred care for older people from all sections of the community, irrespective of race or religion. Our dementia specialists have an expert understanding of the best way to support people who are living with the many different types of dementia.

What is dementia?

Dementia is a broad umbrella term used to describe a range of progressive neurological disorders.

There are many different forms of dementia and some people may present with a combination of types. Regardless of which is diagnosed, each person will experience their dementia in their own unique way.

Dementia symptoms are caused when the brain is damaged by diseases, such as Alzheimer's disease, which is the most common irreversible type of dementia. Prevention of Alzheimer's disease is not presently possible, however there are known risk factors that contribute towards developing the disease, such as advancing age.

Vascular dementia is the second most common form of dementia, where blockages or interruptions of

blood flow within the brain cause multiple strokes. Vascular dementia is often related to high blood pressure, high cholesterol, heart disease and diabetes; treating these conditions can slow down the progress of vascular dementia.

Other irreversible medical conditions that can cause dementia include Parkinson's disease, Huntington's disease, Frontotemporal dementia, or Creutzfeldt-Jakob disease.

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Each person will experience their dementia in their own unique way.



Dealing with new challenges around the house

For those who are living at home and plan to remain at home it is important to consider and prepare for some of the challenges you may have in the future.

Dementia has a number of symptoms: memory problems, physical difficulties and simple changes in what makes you feel safe and secure. With this comes increasing problems that can make simple things one has been doing for years become more and more difficult. Whilst living alone is harder with dementia, there are several things you can do to reduce the challenges you face.

Forgetting where to store things

It's easy to understand why people with dementia might get confused about where things belong – imagine going to a complete stranger's kitchen and trying to put away all the things in their dishwasher. Whilst putting socks in the wrong drawer might not pose a major health risk, it can be extremely disruptive and make life increasingly difficult for people living with dementia and for those living with them. This problem can be solved easily by the use of clear labels or signage to make it obvious where everything belongs. If possible, use open fronted cupboards or shelves that are easy to see. Grouping things together can also help – for example, in the kitchen, why not put the teaspoon, mugs and teabags together so that it is easier to make a cup of tea.

Forgetting how to use items

If your loved one has an item such as an iron or a kettle that they've had for years then it may still be easy to operate, but newer items can look like the most complicated of gadgets. It can be extremely upsetting to realise suddenly that they are unable to operate an iron, a washing machine or even a home phone.

Not having the strength

Cooking can become more challenging, with heavy saucepans and even the kettle. Carrying piles of washing down the stairs may not be as easy as it

once was, since the person living with dementia may experience difficulties with balance. Using knives and even scissors requires precision that may not be there anymore, and whilst opening jars and tins sometimes can be challenging for the best of us it may pose more of a challenge for those older in age. There are several tools and gadgets that are ergonomically designed and can be used to help with dexterity problems, tools that make opening cans with ring pulls easier, kettle tipplers, cooking baskets and plate holders are all available, however learning to use these new tools can be difficult.



5 things you should know about dementia

Dementia is something that affects families all over the UK, and the number of families is expected to rise over the next few years. By 2040, more than 1.4 million people will have been diagnosed with the condition, which can have a considerable impact on the lives of the individuals and their families.

1. Nearly half of people with dementia go undiagnosed

The symptoms of dementia can often be mistaken for other conditions, especially in young people because it is often thought to be something that only affects the elderly. The term dementia describes a wide range of symptoms that steadily worsen over time, but early intervention can ensure people get the support that they need to plan and prepare for the future.

As dementia is caused by damage to the brain, it's not possible to reverse the effects, however, there are a number of treatments that can slow down the disease progression. Healthy lifestyle and keeping active can reduce the risk of developing dementia.

2. You can still lead a full life with dementia

Dementia care has come a long way in the past few years and there are a variety of treatment options available for those who want support. This involves medication to slow the progression of symptoms, lifestyle changes and help or advice for family members.

People living with the condition can live active and independent lives for a long time but knowing what support and dementia care is available.

3. Younger people can be diagnosed with dementia

Although most people with dementia are older (over 65), more than 40,000 individuals have an early-onset version of the condition. This is usually caused by Alzheimer's disease but is often misdiagnosed as something else like mental health problems because of their age.

4. It's more than just memory loss

People often think dementia is just about memory loss, which can lead to misunderstandings about what is 'just old age' and what may be more serious. The symptoms a person experiences depends on what part of the brain is affected by the condition but there are a few that are common:

- Day-to-day memory loss
- Problems concentrating or planning
- Difficulty keeping up with conversations or finding the right word
- Problems judging distances
- Becoming confused about the day/ date or about where they are
- Sudden mood changes



Experiencing one or more of the above symptoms doesn't mean you have dementia but it's best to consult a doctor as it may be a sign of something else. Depression, chest and urinary tract infections, vitamin and thyroid deficiencies and brain tumours can all cause similar problems.

5. You're not alone

It can be difficult discussing this sort of topic with a loved one, especially if they have been experiencing changes in mood or dislike visiting the doctor. There are lots of charities like the Alzheimer's Society that can help you talk to your relative about dementia and encourage them to see their GP. Reaching out to these support networks can make all the difference should you get a dementia diagnosis as they can advise you on the best type of care and treatment to get. Here at OSJCT our homes run regular events across Gloucestershire that offer support and guidance in many forms. You will read more about these later on in this booklet.

Holidays for those living with dementia



Visit www.osjct.co.uk/respite or
pop in and meet us to learn more.

One size doesn't fit all for a holiday, that's why there are so many different holiday options to choose from.

When planning a holiday with or for someone who is living with dementia, there are extra factors to consider in addition to interests, personal preferences and budget. For example, it's important to think about how a person's dementia affects daily activities and any additional requirements they might have. How will they react to unfamiliar surroundings? Would it be better to find accommodation that is smaller in size in order to minimise confusion? These are the types of questions to consider when choosing a trip for those living with dementia.

Advice for staying with relatives

Travelling to familiar places such as the home of a relative is often the best option for a trip away, especially those in the later stages of the illness. This is because it offers the most comfort, reducing anxiety and confusion. When planning a trip to stay with relatives or a family holiday, it's important to speak openly about what to expect and what each family member can do to make the trip a success. If a person has a usual carer then consider whether they too need a break.

How to stay safe

Staying safe when travelling relies upon good preparation and foresight. Ensure that the carer has a bag of essentials with them at all times to include medications, a change of clothes, water, snacks and a travel itinerary. Create an itinerary with information about the destination and your activities and distribute these to emergency contacts back at home. It's a good idea for the person with dementia to wear an identification bracelet and carry contact information, as wandering can be triggered by a change in environment.

When staying in a hotel or similar serviced accommodation, it's often a good idea to inform the staff in advance of any specific needs so they can be well prepared – never be afraid to ask for assistance.

Consider a respite care break

Sometimes, travelling abroad or staying with relatives is not an option. In such situations, one of the best alternatives to consider is respite care. Respite care is a short-term break in a residential home, allowing for carers and those living with dementia to rejuvenate their batteries. Caring is rewarding, yet demanding, and all carers need some time to themselves to ensure they do their best job possible of caring for an older person.

Take a day of relaxation, for all of you

Day care services often provide significant benefits; from providing a day of practical support for people who are caring for or have a relative or friend living with them, a day to help relieve isolation and loneliness of those living on their own and also for those being cared for; it can provide a safe environment to relax and enjoy different activities or to pursue a hobby.

A little relaxation... and fun!

Day centres and day care services can be wholly tailored around you, what you would like to do and what you enjoy. A few activities that are on offer include:



Quizzes
and Bingo



Arts and
crafts



Exercise
sessions



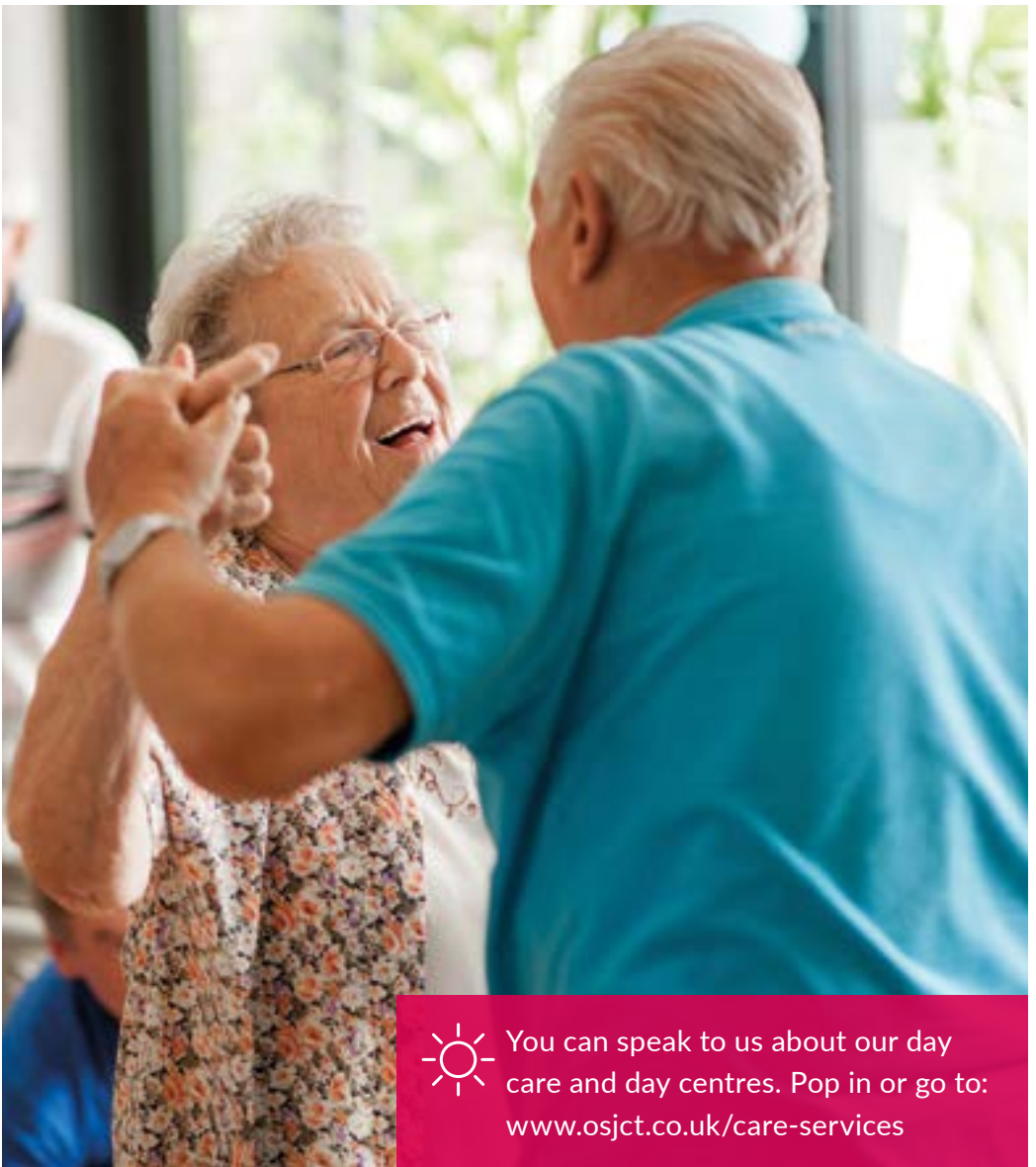
Singing
and music
sessions



Day trips

If you choose to attend one of our day care centres, you will also be served a hot lunch and refreshments throughout the day. In many care homes, you can also be allocated a room for the day to relax in, between activities or you may also be able to use the facilities, such as assisted bathing, hairdressing or foot care.

For a person looking after someone with dementia, a day of practical support has been proven to have significant benefits for all; whether you are looking for an opportunity to socialise and meet others, get a little help or just have a bit of a break to nip out to run errands. Day services offer a little respite and the peace of mind that your relative is well looked after. Additionally, this time can also mean that you can receive help and advice from trained staff and volunteers, should you feel this is something that would be of benefit.



You can speak to us about our day care and day centres. Pop in or go to: www.osjct.co.uk/care-services

No commitment required...

You don't have to make a big commitment – many day centres are very flexible, and you can vary times from week to week or month to month. Day centre and day care services are

available for all older people – as a one off or on a regular basis and ultimately to provide a warm and comfortable environment committed to providing the best of care and care services.

Our commitment to those with dementia

The OSJCT team have worked hard to develop a unique Framework for Dementia care, implemented in all our homes and schemes that specialise in dementia care.

The Dementia Care Framework draws on learnings from OSJCT with input from colleagues, volunteers and families, collaborating partners and published best practice. The Framework provides guidance for our employees, detailing the knowledge and skills that they should aspire to achieve in relation to their specific role.

The Framework has been designed to recognise the existence of various sector specific standards; the principles of the National Dementia Declaration, The National Dementia Strategy and NICE Dementia Quality Standards, which describe what good dementia care should look like.

We understand that living with dementia brings its own challenges and each person's experience is unique. However, we are committed to ensuring that everyone can still enjoy an independent and fulfilling life.

Our dementia specialist care homes offer care in safe, supportive, specially designed environments that maximise a person's independence and enhance their well-being. Residents have the opportunity to move around safely and enjoy their home to the full, utilising themed destination areas, the use of colour contrast and appropriate signage that is worded and pictorially illustrated.

Additionally, OSJCT are proud to be one of the few care providers to employ our own Admiral Nurses, supported by Dementia UK who are specifically trained to support people living with dementia, their friends, families and carers.



We love speaking to people so pop in and have a coffee and a chat with us at any of our homes at any time.

We focus on what people can do rather than what they can't, providing what is needed at that moment in time.

Living at OSJCT

The importance of providing a well-designed environment for people living with dementia is well supported by research literature. Evidence suggests that quality of life for older people is influenced by the environment in which they live, with good design increasingly recognised as an important aid in the care of people living with dementia.

Here at OSJCT we design our new homes into small households to ensure the environment is familiar and cosy and so as people see the same individuals most days just like in a traditional home. The use of colour and other visual cues, with signage and tactile decoration helps residents to find their way around the home.

Reinforced by various studies suggesting a small 'home like' environment is beneficial for

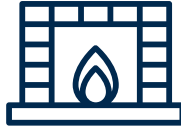
older people living with dementia, the 'household' model developed for OSJCT new build OSJCT's new care homes incorporates these design features.

A maximum size of 16 was established for the new household model. However, a central domestic kitchen allows the household to be broken down further into two smaller households of eight people – creating a small and homelike care setting. The kitchen is designed to create a safe environment to actively encourage resident participation in activities of daily living such as baking, cooking, washing-up, etc. In addition to en-suite bedrooms and other ancillary areas, each household has its own dining room, lounge and separate sitting room. Residents are also provided with direct barrier free access to a safe and secure garden on the ground floor and external balconies on upper floors.

Features included in homes designed for dementia care:



Small households



Familiar, domestic, homely in style



Plenty of scope for ordinary activities (e.g. kitchens, washing lines, garden sheds, etc)



Unobtrusive concern for safety



Different rooms for different functions



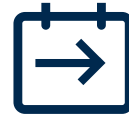
Age appropriate furniture and fittings



Safe and secure outside space



Single rooms big enough for lots of personal belongings



Good signage and multiple cues where possible (i.e. sight, sound)



Use of objects rather than colour for orientation



Enhancement of visual access



Controlled stimuli, especially noise

Why not visit one of our homes to see these principles in action. The Lakes, South Cerney is a fantastic example.



Evidence suggests that quality of life for older people is influenced by the environment in which they live, with good design increasingly recognised as an important aid in the care of people living with dementia.



With advancing dementia, people may encounter difficulties in retrieving a mental image of a place they cannot see. Therefore, the household design adopts the concept of 'total visual access'. For example, the dining room and lounge is designed with a combination of solid walls, half-height walls and timber screening, providing maximum visual access into the rooms whilst maintaining both privacy and the mitigation of noise transfer.

The small-scale environment not only encourages residents with limited mobility to walk and maintain independence, but also assists with orientation.

Careful consideration is given to the interior design, with the inclusion of themed areas and variances in décor further assisting orientation and way-finding.

In our older homes, we have adapted and refurbished different areas in specific themes, for example an old-fashioned tea room, an indoor potting shed or a beach scene. This not only provides greater variety but also helps bring back fond memories. The use of colour and other visual cues, with signage and tactile decoration helps residents to find their way around the home.

Therapeutic Approaches to Care

Moving to a new home can be quite a big change for someone of any age but particularly for people living with dementia.

We support individuals in keeping their identity and interests, by helping to continue with daily living skills such as baking, sandwich making and household skills such as dusting and polishing; enabling people to be the “domestic goddess” that they may have always been.

We use objects of attachment such as dolls, blankets, soft toys and other items. Attachment Therapy is another way for us to help provide comfort to people living with dementia. Research identifies that people living with dementia can gain great comfort from the use of dolls and soft toys.

We have visiting Therapy Dogs in most of our homes; some centres have their own pets such as dogs, cats, rabbits and chickens. There may also be an option for people to bring their own pet to come and live with them.

To make a smoother transition and help people feel more comfortable in their new environment we've created an approach to help the care team get to know people better based on the principles of Life Story work from Dementia UK.

- Life Story work is an on-going activity where we work together to review and evaluate an individual's past life events, developing a biography for that person. The life stories shape the care provision to provide person-centred, individualised care.
- We use it to help develop an understanding of a person's past experiences and how they coped with changes in their life.
- Life Story work is a shared activity between the person, their family and care home employees as appropriate.

To find out more about
Life Story work visit
www.dementiauk.org



Life Story Work

Our life experiences shape us as individuals and this helps others to understand who we are as a person.

People living with dementia sometimes need help to communicate important aspects of who they are and what they like. It is important to understand what interests them, what their hobbies are and what is important to them. The greatest benefit of life story is that it can lift a person's mood – enabling them to talk about the 'good old days' and share their experiences of growing up, working, holidays and family get-togethers.

At OSJCT, Life Story work is an activity in which the person living with dementia is supported by the care

team and family members to gather and review their past life events and build a personal biography. It is used to help the person understand their past experiences and how they have coped with events in their life. It can help people living with dementia share their stories and enhance their sense of identity. This is especially useful when they are having difficulty in sharing this information themselves. Life Story work can help encourage better communication and an understanding of the person's needs and wishes. This will inform their care and ensure that it is provided in a positive and person-centered way. It will also help the person develop closer relationships with family carers and the care team through sharing stories.



The support network at OSJCT

All of our employees – from carers to cooks – have dementia specific training, to help them understand the needs of a person living with dementia. This means our teams are well equipped to understand and support people's individual situations.

The majority of homes has a Dementia Lead whose responsibility it is to make sure everyone is up to date with the latest learning on dementia and are always championing the best quality care. They attend special workshops and share learnings with colleagues, in order to maintain best practice.

Our care is centred around each individual, and their unique likes and dislikes. We do this by finding out people's life story and individually

tailoring care plans. This also means we really get to know everyone so we can chat and help them feel reassured.

Everyone can still enjoy their favourite interests and social activities. Wherever possible, we encourage reminiscence to relive happy memories and events.

Some of our homes specialise in caring for people with the advanced stages of dementia, where we employ managers with a special interest and expertise in this area to help enhance people's lives.

Pop in for a tea and a chat at any of our homes. The kettle is always on and time will always be made for you.



Admiral Nurse Service

At OSJCT we have Admiral Nurses who are trained by Dementia UK and who are Registered Nurses that specialise in dementia care and are supported by Dementia UK. The role has four main functions:

- Nursing interventions to support families and carers based on specialist assessment and complex problem-solving skills
- Emotional support through reflective support and practice
- Dementia specific training and education
- Consultancy work with other health and social care professionals

The Admiral Nursing Service aims to support and empower families of people living or employees working in an OSJCT care setting by providing:

- Emotional support through the transitional process of entering long term care
- Emotional and educational support around disease progression
- Expert guidance throughout the journey of dementia

The community-based Admiral Nurses support family carers in the community by providing:

- Clinical and emotional support to families living with dementia
- Expert guidance and practical solutions to support the person with dementia
- One-to-one work with informal carers
- Advice on communication skills and techniques
- Signposting to other services
- Liaison between health and social care professionals
- Facilitation of Memory Cafés
- Advice and support with finances and benefits available

The Admiral Nurse Service operates an open referral system and welcomes discussions with and referrals from Home Managers, Care Home employees, Operational Teams, Care Quality Team and external professionals.

The community-based Admiral Nurses operate an open referral system and welcome referrals from healthcare professionals and self-referrals from family carers.



Dementia Leads

Dementia Leads support residents with dementia, care teams and relatives by:

- Role modelling care and leading by example
- Having a positive attitude
- Being motivated and proactive
- Having good values and passion for improving life for residents with dementia
- Being assertive and acting as an advocate for people who may be unable to speak up for themselves
- Having an open mind, respecting people's choices and values
- Implement best practice techniques
- Being excellent communicators
- Being involved in influencing positive change
- Having empathy and understanding
- Attending quarterly county meetings facilitated by the Admiral Nurses
- Having opportunities to develop knowledge and skills

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