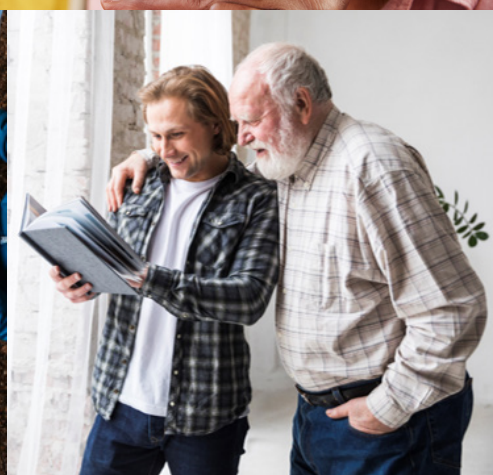


# Living with Dementia in Devon: A Carer's Guide





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In 2009, Jim Delves and David Light, both carers themselves of someone living with dementia, wrote the original, very popular, Dementia Carers' Pathway. In 2019, they gave the rights to Devon County Council and Torbay and South Devon NHS Foundation Trust with the proviso that the guide be suitably updated in a paper version. Sue Younger-Ross, the Joint Commissioner for Carers, allocated this task to Devon Carers.

A working party was set up which included Carer Ambassadors with lived experience of caring for someone living with dementia.

We worked in a co-productive way throughout, collecting frequently asked questions from carers for someone living with dementia from across Devon and requesting answers from appropriate professionals. We have included our own experience as carers, advice and stories from carers across Devon, and signposting to relevant and up-to-date advice readily available to carers who do not have access to the internet.

We have brought the results into a book that we hope will be easily understood by all carers, especially in times of stress when they need guidance most. Following the NICE guidelines on social and community support for carers, the presentation uses colour, diagrams, small chunks of information and Plain English.

We all hope that this updated book will provide guidance to support carers and families in situations which arise along their journeys, just as Jim and David's original version did for many throughout Devon and beyond.

On behalf of the working group

**June Wildman, Carer Ambassador, Devon County Council**

# Introduction



The original Devon 'Dementia Carers' Pathways' booklet was conceived in 2009 by me and David Light. I had earlier, (in 2002), lost my wife, Ingrid, to dementia and David's wife, Pam, was in an advanced stage of dementia.

As former and current carers we were able to understand and share the experiences of stress we had encountered in our caring roles. We realised that information to help carers although available was scattered and difficult to find.

In a voluntary capacity, David and I determined to help those carers who followed us. Over a period of nine months we compiled a directory of local services, bringing them under one cover. We wrote short guides to help

carers understand and deal with the problems that may be encountered when caring for someone with dementia and included these in the booklet. Together we organised the printing of the booklets and personally funded the first print run.

The publication was well received at Devon County Council and was taken up by other counties in the South West of England. Over the following nine years approximately 40,000 copies have been published.

In March of 2019, following a short illness, David sadly passed away. Both David and I had previously agreed that the task of updating and producing the Dementia Carers Pathways booklet was now a little too much to maintain for two elderly pensioners.

We were honoured and delighted when both Torbay NHS Care Trust and Devon County Council said they wished to continue publication of the booklet and agreed to set up a committee to update and revise it.

We can be sure that the new version, perhaps changed in title and presentation will embody the spirit and aims of the original production.

Thank you to everyone who, either in the past, or yet to come, helped David and me.

## **Jim Delves**

This foreword was written by Jim in March 2020. In late April 2020, Jim unexpectedly died in hospital after a very short illness. This was very sad and a great shock to his wife Dionne and to all who knew and worked with him.

He did so much to help those living with dementia and their carers in Devon working with NHS in Torbay and with Devon County Council. Jim was also instrumental in setting up Devon Memory Café Consortium which liaises with statutory bodies on behalf of all the 60 or so Memory Cafés throughout the geographical County of Devon.

It is fitting that this new edition of the Pathway be dedicated to his memory - and also to the memory of David Light. Their spirits will continue to help all families living with dementia.

## **June Wildman**

**Chairman, Devon Memory Café Consortium**



# How To Use This Guide

This guide focuses on information specifically for carers of people living with a dementia.

Where information is relevant to all carers, we have added a brief note and signposted readers to other sources.

The guide is designed for you as a carer to dip into at a time of need in your journey to find out what there is out there to help you in Devon.

Explanations of abbreviations are included in the text.

We have used colour coding to make things a little easier:

**Carers' questions are in green text**

**Carers' quotes and stories are in pink text**



Advice

**Information boxes are blue**

You will find a list of further information and contacts at the back of the guide. At the time of publication, this information was correct.

**DISCLAIMER:** *This booklet has been produced in a collaboration mainly between carers and Devon Carers, who provide Carers Support Services in Devon, and Torbay Carers' Services. The information in it, advice and tips, are what carers themselves have said are most important to have. Those who have worked on this have taken care to ensure to the best of their ability that the information in it is accurate and up to date. However, Devon County Council and the NHS in Devon take no responsibility for the accuracy of the information in it, or of external written or online information referenced in the document, or for any harm resulting from use of the document and its advice, and carers should check information, particularly about the law, services or benefits, before relying on it.*

# Section One: Understanding More About Dementia

## What is dementia?

The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language.

These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour.

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. Alzheimer's disease is the most common cause of dementia, but not the only one. The specific symptoms that someone with dementia experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia.

Source: <https://www.alzheimers.org.uk/about-dementia/types-dementia/what-dementia>

## Is dementia hereditary?

Hereditary dementia is very rare. The most common risk factor for Alzheimer's disease is age. You can help prevent the onset and slow down symptoms by following the guidance on page 7.

## Is there a genetic test for Alzheimer's disease?

If you have several close relatives who have developed Alzheimer's, you can ask your GP for a referral for genetic testing.

## What can I expect as the condition progresses?

Dementia is a terminal illness. Progression will depend on many things such as the person's general health, other conditions, how these impact on the person and how these are managed.

## How long will the person I care for live?

No one can tell you exactly how the dementia will progress as everyone is unique. Because there are so many variables, professionals will not wish to give a precise idea of how long the person with the dementia will live. Nor will they want to give you unrealistic expectations. However, there are changes in the person's physical and cognitive abilities that will indicate that the person is coming to the end of their life. Most people will gradually lose consciousness and die peacefully in their sleep. Your GP, District Nurse or Admiral Nurse where available will be able to advise you. The Alzheimer's Society gives these indicators that a person may be nearing the end of their life:

The person is eating less and is having trouble swallowing, their speech is limited to single words and these do not always make sense, they are physically frail and stay in bed for longer periods, they have become incontinent and they have recurring infections.

Here are some publications that may help:

**Dementia UK: Understanding Dying.** Everyone will experience dying in their unique way. The booklet explains how families and friends can help the person practically and emotionally. Their booklet *Grief, bereavement and loss* looks at carers' feelings in anticipatory grief (before the person has died) and after the death. It recognises physical and social changes you may feel and has advice on what can help.

**Alzheimer's Society:** fact sheet 531 End of Life Care and fact sheet 507 Grief, Loss and Bereavement.

## How do I prevent early symptoms getting worse?

**The advice given below is also good for maintaining carers' health**

Nothing is guaranteed to prevent illness and there is nothing found so far to prevent the progression of dementia. However, keeping healthy will support the immune system. This will protect from minor illnesses and speed the recovery rate. Eating well and exercise will protect against major illnesses such as heart conditions and diabetes. Remaining social will protect against loneliness and having to watch day-time TV!

**Eat well:** A balanced diet with low salt, foods rich in unsaturated fats such as fish or olive oil, plenty of fruit and vegetables, vitamin E and antioxidants will help slow cognitive (brain) decline.

**Keep physically active:** What is good for the heart is good for the brain. Cardiovascular exercise particularly helps maintain the front part of your brain where the decision-making and reasoning happens. Cardiovascular is anything that raises your heart rate such as brisk walking, Zumba or dancing.

Gentle, weight-bearing exercise can improve strength and balance so reduce the risk of falls. Try Tai Chi or aqua-aerobics. Even short periods of standing can help. Try incorporating movement into everyday life, such as stair climbing, light housework and gardening.



**“Older adults should participate in daily physical activity to gain health benefits. Some physical activity is better than none: even light activity brings some health benefits compared to being inactive.” (Chief Medical Officer Guidelines 2019)**

**Keep mentally active:** People with a dementia should be encouraged to keep up with the hobbies and activities they enjoy and to keep socially involved. As the dementia progresses, activities may need to be adapted for the person's abilities. For example, crosswords and games which require planning (e.g. chess, scrabble) or activities which require new learning may become difficult. Conversations that use opinions and long-term memories or singing together may still be pleasurable and stimulating.

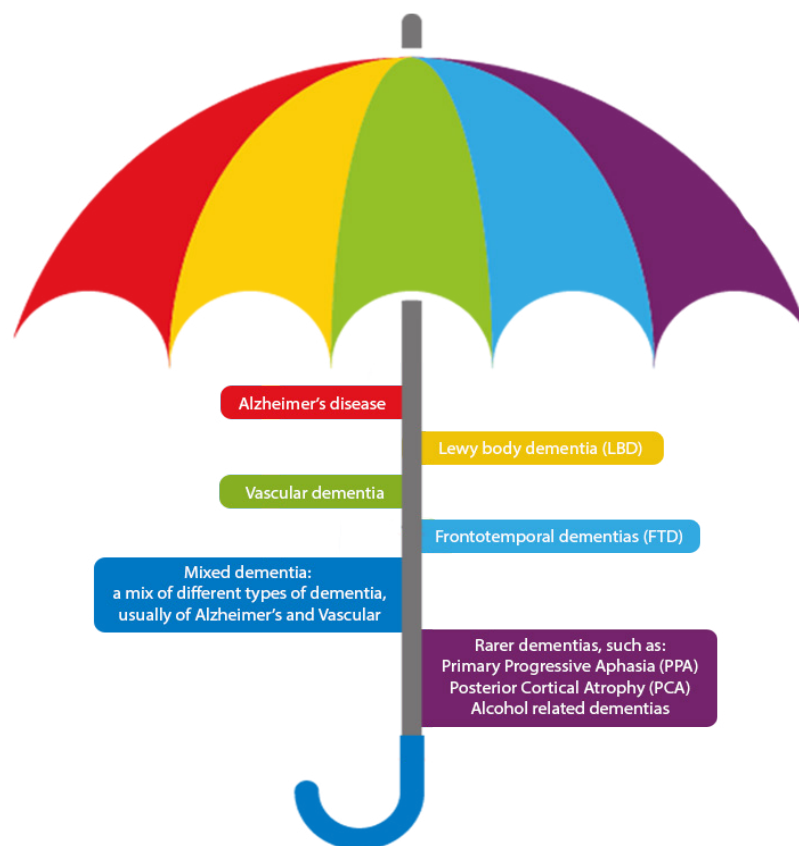
**Keep stress levels low:** Excessive stress can reduce memory capacity (we know this from trying to remember where we put our car keys when we are late). It can also interfere with sleep, leading to people being more irritable and less inclined to be social or active. Physical activity and getting outdoors is known to reduce stress. Using enjoyable mental activities can be a distraction from stress.

*"I so wish I had been better educated about my husband's condition."*

*Carer's story: Don't cry over spilt milk : "One afternoon I returned home to my husband who had dementia. He had helped himself to a glass of red wine, which we normally had with our evening meal. On entering the lounge, I found him sitting quietly in 'my chair' which was nearest the door, surrounded by red stains on the pale fawn carpet and chair. Immediately, I panicked – blood! What had he done to himself? After the relief of finding it was red wine, I felt angry and wanted to shout. I needed someone inside my head to tell me 'he is safe and well – he didn't mean to spill it or even realize that he had – and we still love each other.' Life is too short to worry about stained furnishings. Enjoy being together while you have time."*

## What's the difference between dementia and Alzheimer's?

'Dementia' is the umbrella term for a group of symptoms which affect the brain. There are over 200 identified diseases under this description. Here are the more common ones:



## I have noticed some changes – might these be dementia?

Dementia is not a normal part of ageing. It is true that the risk of developing dementia is generally higher the older we get, but it is also true that the majority of older people (65+) do not get dementia.

Carers often look back to small changes in their relative or friend's behaviour which happened several years before any diagnosis of dementia occurred and which they assumed were normal signs of ageing.

Here are some changes that might indicate a dementia. There may be reasons other than dementia and the changes might be reversible. The sooner you take your concerns to the doctor (General Practitioner, GP), the quicker the person you support can receive advice and treatment.



The signs described here are not necessarily due to dementia. There are a number of things that can cause these “early signs”:

- **Stress**
- **Dehydration**
- **Social isolation or loneliness**
- **Loss of hearing**
- **Side effects of medication**
- **Delirium**
- **Depression**



**The Alzheimer’s Society advises: “Not all of these changes may be present, and the degree of change will vary from person to person.”**

## What are the different types of dementia?

### Is Alzheimer’s just about loss of memory?

Type of dementia	Possible early signs
<b>Alzheimer’s</b>	Short-term memory loss. Confusion. Disorientation in familiar places. Problems carrying out usual everyday tasks. Changes to communication abilities.
<b>Vascular dementia</b>	Slower than usual thought and difficulties with concentration and planning. Changes in mood. Changes can be mistaken for depression. Symptoms may come on suddenly, perhaps after a stroke.
<b>Mixed dementia</b>	This is the term used when a person has more than one type of dementia, usually Alzheimer’s and Vascular. Usually looks like one type first, and often diagnosed as Alzheimer’s.
<b>Lewy body dementia</b>	Changes in thinking speed. Difficulties judging distance or depth. Changes in concentration throughout the day and from day to day. There may be some movement changes (shuffling, tremors) but these may develop later. Hallucinations may come later: seeing, hearing and smelling things that are not there.
<b>Frontotemporal dementia (FTD)</b>	Changes in mood or behaviour such as: Being insensitive or rude and a loss of inhibitions. Losing interest in people and things and in motivation. Compulsive eating or drinking. Forgetting the meaning of everyday words. Automatically repeating what other people have said. The person themselves may be unaware of these changes.
<b>Primary Progressive Aphasia</b>	Difficulties with word finding such as struggling to name objects. Difficulty understanding speech and the person may use grammar incorrectly.
<b>Alcohol-related dementia</b>	Socially inappropriate behaviour. Impulsive and may lack control of feelings. Lack of sensitivity to people’s feelings. Problems with attention, reasoning, judgement and decision-making.

## Young-onset dementia



Young Dementia UK gives this advice:

“Dementia is considered ‘young onset’ when it affects people under 65 years of age. It is also referred to as ‘early onset’ or ‘working age’ dementia.

However, age is less important than the impact of the dementia.

Dementia is life-changing at any age. The impact of the condition pre-65 may be having to give up work, financial concerns, supporting a young family, having unfulfilled ambitions, for example, looking forward to an active retirement.

Further information on young-onset dementia and links to Devon support groups can be found in the Information and Contacts Section.

The Alzheimer’s Society have a booklet:  
**Young-onset dementia: understanding your diagnosis.**

## Pain and dementia

Because of communication difficulties, pain might be missed or misinterpreted in someone with a dementia. The person may express pain by:

- **Changes in behaviour or mood:** fidgeting, bracing, rubbing, reacting with distress during personal care, low mood.
- **Facial expressions:** frowning, grimacing.
- **Sound:** increase or change in calling out.
- **Changes in sleep patterns or appetite.**
- **Changes in physical state:** temperature, flushing/pale, swelling.

When you ask someone what is wrong, they may struggle to express themselves clearly. Try using simple questions such as “does it hurt here?”.

Common causes of pain: constipation, gum disease, arthritis, lack of movement/poor position.

**Speak to your GP about the best course of treatment. It might be helpful to take a diary of such things as when the person appears to be in pain – times of day and what you think might have brought it on.**

# Section Two: Looking After You

## Am I a carer?

You are reading this because you (or someone you know) is caring for someone who has dementia and who could have difficulty managing without your support.

A carer can be an adult, young person or child. The care given is unpaid (although some carers may be eligible for Carers' Allowance).

Becoming a carer can creep up on you – starting with a little help with everyday tasks such as shopping, housework or managing medication. As the person's condition progresses, you may take on more roles such as supporting the person's emotional needs, washing and dressing, or helping them keep in touch with friends and family. You may find increasingly that this support takes up more of your time and energy.

It is important to keep a balance between caring and your own needs: to keep what you see as a worthwhile life. This balance and what is considered to be worthwhile will be different for everyone.

*“My husband and I moved to Honiton three years ago and within six months he was diagnosed with vascular dementia. He was a diabetic on insulin, recovering from a broken hip and a heart attack. He no longer wanted to go out and didn't want me to either. My daughter said I needed support. I saw an advert in the local paper for Honiton Carers and plucked up enough courage to go to a meeting. Win was so welcoming and put me at ease. At first, I used to stay for only half an hour as I didn't like leaving my husband for long. Now the family try to cover, so I can stay for the whole meeting and go on the outings. I have learned a lot from the meetings and look forward to them. I also find I am more able to cope with each day.”*

## I don't want to be a carer

You may not see yourself as a carer. It can be difficult to see caring separately from your relationship with the person you care for, whether you are a parent, child, sibling, partner or friend.

It's likely that most of us will have caring responsibilities at some time in our lives. We may see caring as a privilege, something we take on willingly for someone we love, or we may not feel prepared to take on the role of “carer”. In their 2019 report, Carers UK found that mixed with willingness were practical, financial, physical and emotional challenges.

The 2014 Care Act offers unpaid carers an assessment of need in their own right, whether or not the person they are caring for acknowledges their support. The assessment does not assume you want to continue caring. If you don't feel willing, or you might be willing with some support, here is the opportunity to talk about it without judgement.

**If you think you are caring for someone or about to start caring, you can contact your local carers' association for support. See information and contacts.**



## What training do I need as a carer?

The progress of a dementia will bring changes to the person's abilities and perhaps to their behaviour and personality. This will impact on you as the carer in the kind of support you might need to give. It may change your relationship and make more demands on your time, energy and patience. There are a number of things that can build your resilience to help you cope:

- **Knowing where to find timely and appropriate support.**
- **Feeling able to ask for support.**
- **Having some knowledge and understanding about the nature of the dementia and its impact.**
- **Coming to terms with the diagnosis of dementia and living with the new "normal" on a daily basis.**
- **Getting ready for the future – sorting finances, Power of Attorney and so on.**
- **Having belief in your own ability to cope.**
- **Getting a balance that feels right to you of time spent caring and doing other things for yourself ("me time").**
- **Having a positive outlook and bringing a sense of humour to caring.**
- **Looking after your own health and wellbeing.**

Devon Carers and Torbay Carers run courses and carers' groups to help you develop your resilience. The Alzheimer's Society offer a 5 week education programme for people with dementia and their carers, called Memory Matters; they also have a team of experienced Dementia Advisers. You may have an Admiral Nurse in your area for support. Ask your carers' organisation about the HOPE project.

Many people already have resilience qualities and just need a bit of help to apply them to caring for someone with dementia. For other people, building resilience takes more time. Having a dementia is a new aspect of life for both of you. Be kind to yourself and aim for a life that you see as worthwhile.

Think of resilience as your ability to "bounce back" from the stresses that caring for someone with a dementia brings. This does not mean back to how you were before the dementia, but to a life that you consider to be worthwhile.



## How do I manage the changes in our relationship?

Dementia is a progressive condition meaning that the person you care for will change over time. It is normal for those around to feel a range of emotions, such as anger, grief, guilt and resentment, all of which can affect relationships.

Enjoy the time you spend together. There are many ways that you can remain connected with the person so that your relationship, although different, still brings you both happiness and comfort.

Explore what you both can still do together. Your local surgery, hospital or library can help you link into dementia-friendly activities or groups such as Memory Cafés. Your local community rehabilitation team and leisure centres can advise you on appropriate exercise classes.

On a daily basis you could try looking at holiday photographs, listening to music, going for walks, having a picnic, going on local coach trips or watching a favourite film.

Try to make your outings fun, safe and have a meaning such as a trip down memory lane. If the first time does not go as planned try again but stay nearer to home and choose a different time of day. While out, be clear, brief and practical about what is happening:

- **We are going into the supermarket and then we are having lunch.**
- **We will walk to that lighthouse and back and then have a coffee.**

### Can we still have sex?

Talking about sex and intimacy can be difficult and intimacy means different things to different people. It is important to find someone you can trust if you want to talk about the changes in your relationship.

Changes you might experience are one person having more of an interest in sex than the other, reduced ability to consent to sexual activity, the person not able to recognize their partner and in some cases the person transferring their affection to others.

**Ring Dementia UK and ask for their leaflet: Sex, intimacy and dementia.**

### How do I get a break?

Caring for someone 24/7 is exhausting. As a carer, you must pay attention to your own needs for rest, interests and other responsibilities.

Sometimes a break can just mean being able to go to the toilet on your own. There are tips elsewhere in this guide for short breaks in and out of the house.

Here we mean getting longer breaks of half a day or more where someone else is paid to take responsibility for the person you care for. Health and Social Care Services call this replacement care. You might also know this as respite.

Arranging replacement care is done through an assessment of need. If the person with the dementia has mental capacity, an assessment and replacement care has to be with their agreement. This can potentially cause problems for their carer if the person has no insight into their condition, or where they refuse to have anyone to care for them. As their carer, you can ask for a carers assessment to help identify your needs. Social Care workers can support you to find ways around ensuring the person is safe whilst you have a break. This might be by using telecare or by introducing paid care gradually. For example, by arranging for "cleaners" who will also provide company and safety; encouraging the use of short-term residential care by describing it as a holiday; advising you on the range of replacement care in your area; arranging for you to attend day care opportunities with the person you care for until they feel safe to stay alone.

**For further information see section Seven: Finance, Benefits and Legal Support.**

## How do I explain dementia to children?

Children may become distressed at seeing the changes in the person with the dementia and concerned at tensions in the family. This may affect their sleep and their schoolwork. It is important that their teachers are aware so that appropriate support can be offered. What will help is listening to children's concerns and questions, talking as honestly as you can, involving them and focusing on the person's remaining abilities.

- **Dementia UK provides a series of short films and books to explain dementia to children.**
- **The Alzheimer's Society has a book "It's me Grandma, it's me" and fact sheet 515: Explaining Dementia to children and young people.**
- **Barchester Health Care have two books for children whose grandparents with dementia have moved into residential care.**
- **Young Dementia UK has a number of books to explain dementia to children of all ages.**
- **Ask at your local library to find out what books they have about dementia.**

## How do I deal with repetition?

If the person has short-term memory loss and does not recall the answer you gave to their question, you may have to exercise patience and repeat yourself.



Try this:

- **Keep in mind that from the person's point of view, this is the first time they have asked. Saying "I have just told you", will make no sense.**
- **Challenge yourself to give a different answer each time – how many variations on "It's Tuesday", can you find?**
- **"What are we doing today?" Ask the person what they think.**
- **If you feel your patience running out, excuse yourself to a different room or divert the person's attention with an activity or a cup of tea.**



*Carer's story: "We learned to 'love the repetition'. No matter how many times we had heard it before, if Dad was telling a story, then we enjoyed it. His face would beam with delight as he recalled memories from his childhood and youth; the people and places that had meant so much to him. He was sharing his life with us, he could still tell us about it, he was happy and there was our joy."*



# Section Three: Getting Support

## Where can I take my concerns? What happens after diagnosis?

### GP Support

- If you are concerned about your own memory or the memory of someone you care for, the first person to speak to is the GP.
- As part of this appointment, the GP will complete a physical and mental health assessment to rule out other illnesses/factors which may affect your memory. They will also complete a blood test and a brief memory assessment.
- If your GP suspects you have dementia they will either provide a diagnosis or refer you to Devon Memory Services for further assessment.

### Older People's Mental Health

- The Older People's Mental Health Service includes both Devon Memory Services and local community Older People's Mental Health Teams (OPMH).
- You will be offered either an appointment with Devon Memory Service to be seen at a local Memory Clinic or an appointment with the Community Mental Health Team at their clinic or your home.
- You can approach the Devon and Torbay Dementia Adviser Service (See Information and Contacts).

### Other Agencies

#### **Following your diagnosis, you may be signposted to a number of services for support including:**

- Adult and Community Services in Devon and Adult Social Care in Torbay for help with assessing and funding care and support.
- Devon Carers or Torbay Carers for help and support for carers, including dementia training courses.
- Alzheimer's Society who offer support alongside the Older People's Mental Health Team as well as home visits, telephone support and courses. The Alzheimer's Society will work together and individually with people with dementia and their carers.
- Admiral Nurses offer practical and emotional support to people with dementia and their carers in some parts of Devon.
- Community support such as Memory Cafés across Devon and Torbay.

## How do we prepare for a visit to the doctor?

Spend some time with the person you care for before their appointment to write a list of the things you are both concerned about. This list could include what you have noticed, when the changes began, how frequently they occur and the impact they have on you both. Your list may be different from that of the person you are caring for, so you may need to be assertive (clear and sensitive) to ensure the GP gets an accurate picture.

Put together a list of the person's past and current medical history. Take information about all medication the person is taking (prescription and non-prescription). Tell the GP if other family members have a history of dementia or other significant conditions.

## What if the person I support does not share my concerns?

Experiencing changes in memory can be very frightening and some people may not want to investigate the cause.

It is quite common for someone with a dementia to deny that they are experiencing issues with their memory or other aspects of cognition (such as planning, decision-making, managing finances, following conversations).

Denial may be due to fear about what a diagnosis might mean for the future. Some people may have a lack of insight, meaning that due to the nature of the damage to their brain they are unable to recognize changes in their own behaviour and personality.

Continued denial can cause problems for the person's future support. They may refuse to accept help, there could be delays in starting or stopping medication or they may continue to drive, despite it not being safe for them to do so.

If the person cannot be convinced to see their GP, wait until there is an appointment that they would attend anyway, such as a medication review, well man/well woman clinic or routine test (e.g. diabetes/prostate health).

You can write to their GP beforehand so that appropriate questions can be asked to check your concerns. Try to go with the person to their appointment for emotional support and to sensitively add any useful information that the person may not recall or be reluctant to share which could help with a diagnosis.

You can seek advice from other agencies such as the Alzheimer's Society, Dementia UK or local carers' support groups, with or without the agreement of the person you are concerned about.

## What if the doctor says there is nothing wrong, what can I do next?

Be as specific as possible about what you have noticed to help the GP understand and acknowledge there has been a change. Your GP will be able to diagnose, refer or offer appropriate further advice or suggest that you revisit in a few months' time.

Having the appointment may be worrying for both of you. Try to focus on the benefits of having a diagnosis – being able to get the right treatment and support as soon as possible. You can ask for a double appointment, so you do not feel rushed.

## Is there no cure?

There are no drug treatments that can cure a dementia. However, there are medicines for Alzheimer's disease and some other dementias that can ease symptoms for a while. For some people medication can slow down the progression and make the best of the person as they are.

## What medication can be taken and what are the side effects?

Discuss the possibility of medication with your GP at the earliest opportunity. They will advise you of possible side effects. Take time to read the Patient Safety Leaflet that comes with the medication. Contact your GP or pharmacist (or 111 out of hours) if you are concerned about side effects.

Mention any medication the person is taking to workers from health or social care. Care agency workers may be trained to administer medication and will need to record what has been given, when and by whom.

If the person you care for declines to take medication, do not be tempted to hide it in their food without first discussing it with the GP, Pharmacist or Older People's Mental Health Team who may be able to offer alternatives.

**For more information see the Alzheimer's Society fact sheets for medication – 407 and 408**

## When should I ask for support?

There are a range of professionals who can provide you with support and expert advice. As early as possible arrange for the person with dementia that you care for to consent to have their medical information shared with you to ensure you are able to speak on their behalf and prevent missed appointments. It is important to do this early on when they are able to consent. Most surgeries have a form that can be completed.

The people and organizations that can offer help will differ depending upon the person's dementia diagnosis. Do not be afraid to ask for support and advice early on. A lot of support can be accessed via your General Practitioner, so it is important to ensure your GP is aware that you are a carer.

## How do health, social care and other organisations such as the Alzheimer's Society and Admiral Nurses work together?

Social care and NHS health provision in Devon are moving towards a more joined-up system of working. At present, Torbay has a fully integrated system.

These are the health and social care professionals who could be part of your support.

### **Devon Partnership Trust (DPT) and the Older People's Mental Health Team (OPMHT):**

DPT is the organization that runs Memory Clinics and the OPMHT for older adults (65+). This includes support for mental health (e.g. depression, psychosis), alcohol problems and dementia. A referral is through your GP.



The OPMHT add support that cannot be given by the GP or other services. It is usually a time-limited service and focuses on support such as:

- **Advice on specialist medications.**
- **Assessment and treatment for mental health issues such as depression and anxiety.**
- **Support and information for families and carers, for example, on behavioural changes due to a mental health issue or a dementia.**

The OPMHT work in partnership with the Alzheimer's Society at follow-up appointments at the memory clinics.

**The Alzheimer's Society** offer a 5-week Memory Matters course across Devon, including Torbay. The person with the dementia and their family/friend are invited together. Memory Matters is an opportunity to learn more about dementia, coping strategies, aspects of healthy living and to discuss experiences with others.

The Alzheimer's Society website has a wealth of up-to-date information on many aspects of dementia. You can view and download this for free. If you do not have access to the internet, you can ring them to talk through your concerns. Information can be posted or brought to you by one of their support workers.

Across Devon, the Alzheimer's Society are working closely with DPT to offer personalized and face-to-face support for the person with the dementia and their carers. Their support and information is open to anyone with a diagnosis of dementia and is not restricted to a diagnosis of Alzheimer's.

**Admiral Nurses** provide specialist dementia support. Their numbers are growing across Devon, but they are not present in every locality. Ask your GP about a referral. The unique perspective Admiral Nurses can bring is to support the family with emotions such as guilt and grief, managing the changes in abilities and behaviour that dementia can bring, through to end-of-life and support in bereavement. They can provide practical support, such as teaching families to do the personal care they might not have had to do before and navigating health and social care systems.

### **Is there an Admiral Nurse in each hospital?**

For an up to date list of Admiral Nurses in Devon, ring Dementia UK helpline, see information and contacts. Remember, even if the person you support does not want a diagnosis, you can still use the Alzheimer's Society and Dementia UK online information. You can still be supported by Devon Carers or Torbay Carers.

### **What do social care teams offer and how do I contact them?**

Everyone who thinks they require help to remain independent has a right for a free assessment of need. A copy of the assessment is sent to the person. If the person has eligible needs, a support plan will be created for them.

Social care is means tested. Care Direct, or Adult Social Care in Torbay, will carry out an assessment of the person's assets, savings and capital plus their income (including any welfare benefits to which they are entitled) to work out if they are eligible for a contribution from the Local Authority towards their care. If people choose not to have a financial assessment, they are liable to pay the full cost of care.

For further information see section Seven: Finance, Benefits and Legal Support.

## Occupational Therapy:

### What is this service and how do I get it?

An Occupational Therapist (OT) has specific knowledge and training to help people be as independent as possible in their daily living. An OT can advise you and the person you care for on gadgets and technology which might support a person to live safely in their home. For example, medication alerts, ways to see who is at the door, falls alarms and gas safety cut-off switches. This advice is free. OTs work in hospitals and as part of community teams.

You can ring for advice through Care Direct, Adult Social Care or the Independent Living Service (see Information and Contacts)

### What systems are in place when a person living with dementia has a hospital stay?

- **This is Me:** This is Me is a simple leaflet for anyone who has a dementia or a delirium. It can be taken to hospital or to a care home or given to anyone who will be planning or giving care. It can be used to record important information about the person that they might not be able to tell others. For example: people who are important to them, preferences and routines. This is Me can help overcome communication difficulties and reduce distress for the person and their carers. A copy can be sent to you from the Alzheimer's Society.
- **John's Campaign:** This is an initiative started by carers and running at all the main hospitals in Devon and Torbay. When someone with a dementia is admitted to hospital, as a carer you should be asked whether you want to stay with the person and how you would like to be involved in caring throughout their stay while making sure you get adequate rest.

### How does hospital discharge work?

When in the hospital, ask for the leaflet for patients and families which explains how discharge works. Discharge may work differently depending on whether the person you support has mental capacity and whether you have Lasting Power of Attorney for Health and Welfare. The ward staff will explain this and what services can be offered to you.

*"It has given me confidence knowing an after-care package is available."*

# Section Four: Managing The Changes Dementia Can Bring

## How do I manage changes in eating and drinking?

Eating and drinking difficulties can sometimes be a challenge as the disease progresses. Poor nutritional intake and lack of fluids could increase confusion and lead to other health problems.

*Carer's story: "My husband stopped eating and drinking much a couple of times during the later stages of his dementia, when he was in a care home. He loved his wine so I persuaded the home to lay a table for the two of us in his room, complete with tablecloth and wine glasses. I used to fill our wine glasses with apple juice from a wine bottle, hold mine up and say 'cheers'. He would do the same and always drain the glass and then would eat a mouthful. This was repeated throughout the meal . . . he never realized!"*

For some people, eating too much is the issue. People might want to eat more sweet foods than usual. This could be due to a loss of the sense of smell, loss of inhibitions about regulating food or the need for high energy foods.



### Ideas to try:

- **Taste may change. Try more flavour in foods and different food to the usual to find what the person now prefers.**
- **Sometimes smaller, frequent meals and finger snacks are more appropriate than bigger meals and try a smaller plate.**
- **Try a plain coloured plate. This can help people see the food more easily.**
- **Minimize distractions and make the meal a social occasion – eating and drinking together might encourage the person.**

Managing these changes can be distressing for you both. The NHS has this advice:



### Ideas to try:

- **Substituting healthier sweet foods such as jelly, grapes and chopped up apples, sweeteners in tea.**
- **Set out a small number of biscuits or sweets in a fancy bowl to give the message that this is the portion.**
- **Sensitively remove plates or packets of biscuits and cake out of sight rather than get into a discussion about "eating too many".**

Ring the Alzheimer's Society and ask for fact sheet 511 Eating and Drinking or Dementia UK: Eating and Drinking for a Person with Dementia. If difficulties persist or if swallowing appears to be a problem, consult your GP.

## What is Delirium?

A sudden change in a person's mental state is known as delirium. It can lead to increased confusion and disorientation which can last for a few days, weeks or even months. People report feeling irritable, slow and sleepy or agitated and restless, having vivid dreams, worried that people are trying to harm them, seeing and hearing things that are not there, finding it hard to follow what is being said and to speak.

People with a dementia are at higher risk of developing a delirium, particularly if they develop an infection or become dehydrated or constipated, are in pain or nearing the end of their life.

It is different from dementia. For someone with a delirium, the symptoms come on over a matter of a few hours or days. The symptoms of dementia come on slowly over a period of months or even years.

Delirium is a treatable condition. Recovery can be helped by reassurance, avoiding too much stimulation and change and keeping the person hydrated.

Dementia UK has a leaflet: **Delirium (confusion) Understanding changes in behaviour in dementia.**

## Does dementia cause UTIs?

It is not uncommon for people with a dementia to have problems with continence (urine or bowels). Reasons for this can be:

- **Urinary tract infections (UTIs). These are common in older people and are not brought on by a dementia.**
- **Constipation, which puts pressure on the bladder.**
- **Side effects of some medications.**



- **Keep in mind that it is not the person's fault. Be understanding.**
- **Make the toilet easy to find: keep the door open and the light on. People with a dementia can become disorientated even in their own home.**
- **Watch for signs that the person needs the loo: fidgeting, pulling at their clothes, etc.**
- **Help the person prevent constipation by being active, drinking water regularly and eating a varied diet.**

If you are having problems, ask your GP. They may give you an appointment at the continence clinic which can advise on health and equipment such as pads and waterproof sheets.

Alzheimer's Society fact sheet: 502 Continence and using the toilet  
Dementia UK leaflet: Continence



## What is sundowning and how long does it last?

Sundowning is a term used for changes in behaviour that occur in the evening, around dusk. A person might become increasingly anxious or agitated at this time. They might pace, become confused or be certain they have to pick up the children or go home (even if they are at home). There are several reasons why sundowning might occur: tiredness, the effect of the dementia to disrupt the person's natural body clock (circadian rhythms), low lighting and increased shadows.

Sundowning generally occurs in "mid stage" dementia and fades as the condition progresses. Not all people with a dementia experience sundowning.



### Try this:

**Distractions:** get busy with an evening activity, for example, go for a walk or go shopping, do light housework, make a drink or have a snack.

**Reassurance:** ask the person what is wrong and manage any causes for their distress, talk soothingly, hold the person's hand.

**Close the curtains and put the lights on before dusk and cover any mirrors.**

**Limit daytime napping and caffeinated drinks.**

*Carer's story: "I met my dear wife, Jean, during my National Service. She was the second of nine children. We were married in 1957 and started our married life near Chatham where I worked as a marine engineer in the Dockyard. My parents, six brothers and most of my friends lived nearby and our house was full of visitors, laughter and delicious smells, as Jean was a marvellous cook. Our children were born there too.*

*In 1984, the dockyard closed and we were moved to Devonport, Plymouth. My brother and family and many of our work colleagues also moved, so again we always seemed to have company, which Jean thrived on! Our grown-up children had settled in Swindon, so a few years after our retirement we moved there. We loved it, helping to mind their children and quickly making new friends. After a few years, our children moved to Devon. A few years later, Jean was diagnosed with dementia and our daughter persuaded us to move to Honiton for extra support. The support for carers is wonderful and I have been offered help and advice from so many organizations and I can't thank everyone enough. Jean is often confused and does not believe I am her husband. She believes her parents are still alive and she wants to go home to them. She thinks we have visitors most of the time. I love her dearly, although at times, I must confess I need to remember our marriage vows, 'For better or worse' and 'In sickness and in health'.*

*I suppose it's a mixture of love and duty. Evenings are the worst (I think it's called sundowning). She is sure she is in the wrong house and that I am back home looking after our children. She wants to go home and pleads for our phone number so that she can tell me where she is and to come and get her. She packs her bags and, as you can imagine, is very distressed in thinking she has abandoned her children. I try to comfort her, hug her, show her round our bungalow, show her our furniture, photos of me and our family, but all to no avail. My daughter who is used to dealing with people with dementia can't convince her and has to give up. That's when I feel most helpless."*

See Dementia UK leaflet on Sundowning. If it persists, contact your GP.

## How do I adjust?

Caring can have a big impact on your mental and physical health and wellbeing. Look after yourself well so that you can continue to care for the person with dementia. Attend to your own health needs such as GP appointments. Listen to your body. If you have a niggling twinge, a worrying lump, a persistent cough or changes to your bowel movements, do not put it off. See your GP.

Caring can be emotionally draining. We all have good and bad days but if you are tired all the time, tearful, angry, feeling constantly low or feeling not good enough you may need to consider asking for help. Sort out your sleep pattern, get outside more and make opportunity to take time out for yourself. Seek help from your carers' support group. If this does not work and your mood remains low, seek professional help from your GP.

**Devon Partnership Trust (DPT) provides useful self-help guides on how to manage anxiety, depression and low mood. Ring DPT main office to ask for them to be posted to you: 01392 208866**

In order to develop your resilience and ability to cope, educate yourself on what to expect in the future and make plans for when these changes occur. This may include making the home more dementia-friendly, organizing replacement care or building up a network of support around you. Being prepared often reduces some of the anxieties you may be feeling.



Try this: Consider making a list to answer the following questions:

- **What situations make me feel that I am coping?**
- **What things make me feel good about myself?**
- **What circumstances do I find difficult and what helped me cope last time?**
- **What happens when I start to feel overwhelmed; are there any particular personality, mood or behaviour changes that occur?**
- **Who can I contact to get help when things are too much?**

After doing this you should have a clearer picture of what you need to do to ensure that you stay well, how you best deal with challenges and difficulties and, when things are getting too much, where to seek help.

## My partner is speaking a foreign language

The person's communication will change as their dementia progresses. The nature of the change will depend on the type of dementia.

The Alzheimer's Society, Dementia UK and Devon Carers have excellent information on how carers and families can adjust their communication to include the person with the dementia.

You may find the person you care for is starting to lose some language abilities. Common changes include: Not being able to find the name for familiar objects, starting a sentence then forgetting and changing to another topic, talking about things that didn't happen or didn't happen in quite the way they are retelling it.

This happens to all of us at one time or another, so we have some understanding of the annoyance and possible embarrassment felt.

The person may literally be speaking another language if they are bilingual and they revert to their 'mother tongue' (their childhood language) as the dementia progresses. This can feel frustrating and isolating if you are not familiar with it. Try to find other people who can speak that language to help with communication needs.



#### Try this:

- **Give the person time and your attention.**
- **Reassure the person that what they are saying is important and you will help.**
- **If the person starts to get frustrated, make suggestions based on things such as the first sound they are making, what can be seen, what they often say or what you were talking about. Then check out if you are right.**
- **Decide whether it is useful to correct the person – does it matter if the story is not accurate? If it does, tactfully give your version: "I thought that we....., but I could be wrong". If this causes anxiety or aggression, stop.**

### My partner no longer recognizes me

Difficulty with recognizing people is more common in Alzheimer's than in other dementias. It can be upsetting for the family when it happens.

It may be caused by the loss of recent memories, meaning that the person expects to see a younger you. It may be caused by damage to a particular part of the brain so that the person cannot recognize faces. It may be due to infection, constipation or medication changes, so it is worth checking with the GP. Dementia UK have a useful leaflet: "Things to try when someone with dementia stops recognizing you."



#### Try this:

- **Gently tell the person your name.**
- **Wear aftershave or perfume that the person associates with you.**
- **Have photos of you when you were all younger as well as you all now.**
- **Find other ways to reconnect such as touch, playing familiar music, going for a walk and chatting about the things you see, doing some simple activities together such as drawing, gardening and singing.**

**Dementia UK says:**

**Remember: not being recognized does not mean you are totally forgotten.**

## My mother does not trust me

Dementia UK advises: For some people living with a dementia, their brain misinterprets the information from their senses. A common belief is that someone is stealing from them. It might not be true, but to the person experiencing this belief it is real and trying to explain that it is not real may increase their distress.

They suggest: do not challenge the person, acknowledge their distress, help them look for “lost items”, distract them to something they enjoy, speak to the GP to rule out possibilities of other health issues. Check the person’s claims, they could be right – someone may be taking advantage of their vulnerability, especially if they live alone.

For more information ask Dementia UK for their leaflets False beliefs and delusions in dementia and Changes in perception and hallucinations in dementia

## I don't have any private time, my partner follows me around

*“I feel like I have a ball and chain attached to me; my husband follows me everywhere and gets very anxious if I am out of sight.”*

Living with a dementia can make the person feel insecure and anxious. Nothing makes sense any more. The person may be looking for reassurance from someone they recognize and trust.

It may also be due to short-term memory loss – even if you have said where you are going and when you will be back, they may have forgotten that and come looking for you. Following may be accompanied by asking questions for reassurance: “When can we go home?” (even if they are home) and asking about dead relatives: “When is mum coming?”. “Home” may mean where they felt secure in the past.



### Try this:

- **Remain calm. Listen to the person’s concerns and ask how you can help.**
- **For question about dead relatives, gently divert by talking about that person’s qualities (your mum, what a cake maker! what’s her favourite song?) or talk about houses they used to live in. When they are calm, change the subject with the offer of tea/activity or going to another room. Telling the person their relative has died usually causes more distress as they will have forgotten this and will quickly forget it again.**
- **If you want to read or do a crossword, read a few bits aloud before the person asks you any questions. This may be enough to let them know you are there and for them to feel secure and acknowledged.**
- **Have the radio/music on.**
- **Arrange for the person to go out regularly with someone they trust, such as a day service or friend/relative. If you know you have a break coming, you can be more tolerant.**





- **If you arrange for a friend, neighbour or paid care worker to stay in your home, agree what they should say if the person you care for asks where you are and when you will be back. Be vague about the time, for example, “she has gone shopping and will be back by lunchtime/teatime”. The reason must be plausible and not raise the person’s anxieties.**
- **Go for a brisk walk with the person so that they might have a nap on returning, although no napping after 3pm, otherwise the person may not sleep at night.**

## **All he wants to do is sleep**

Sleeping more is a feature of later stage dementia. This might be because the person is having to make so much effort to understand what is going on and to do simple daily tasks.

A lot of people with a dementia have difficulties sleeping at night and can be drowsy during the day. Difficulties can be not sleeping or only having light sleep. People with dementia with Lewy bodies can be drowsy in the day, despite having adequate sleep at night. As with everyone, not having adequate sleep can lead to feeling agitated during the day and having problems concentrating or with mobility.



### **Try this:**

- **Keep your times of sleep and getting up the same as always, if possible.**
- **Keep a bedtime routine to signal it is time for sleep: keep the room dark and cool (you can leave night lights on in the hall to light the way to the toilet).**
- **Keep active during the day, particularly going outside.**
- **Try to keep naps to mornings or just after lunch – no later.**
- **Reduce drinks from early evening.**
- **Consult your GP if difficulties continue.**

*Carer's story: "My darling 88-year-old mother was in a rotten mood. She hadn't wanted any breakfast, she was uncomfortable, the wind was blowing in the wrong direction, she was tired and generally irritable. I was on general alert, as this usually signalled a mood when she would attempt to demonstrate that she was quite capable of looking after herself – thank you very much! In the recent past, although unsteady on her feet, through her drive and resourcefulness she had unscrewed grab handles, moved heavy furniture, found and climbed a step ladder to wind a clock and indulged her lifelong passion for bonfires. An already difficult morning became more stressful when I could not find my reading glasses. I began searching discreetly in her general direction. I had learned that asking a direct question: 'Have you seen my glasses?' could send mother into a stew and she would become confused and distressed. A 'wuzzling' technique, where I mutter about what I am doing and 'wondering' what she might be thinking or feeling usually produced much better results. I began wuzzling 'I don't know, I can't seem to find my glasses – they have disappeared. I've looked in all the usual places. I really must look at the post. Perhaps I left them in your room. I wonder if they could have got mixed up with yours,' and so on. During this process I paid attention to her reactions, hoping for a clue if she had any information which could help me track down the missing spectacles. Instantly, she brightened up! The more I searched, the happier she became. She watched me hunting high and low. She began offering helpful suggestions and watched me disappear, then return empty-handed. I looked under her bed; I searched the windowsills behind the curtains; I prodded behind chests of drawers and behind the television. With every new idea she was more delighted. It became a game of hide and seek. In the space of ten minutes, we had both shifted mood and were smiling, playful and eager. We stopped for coffee, when she announced she was eager for an early lunch, and after a blissful nap, she woke refreshed and content with the world. Eventually I found my glasses, but ever since, I have become more and more disorganized, and the more things I 'lose', the happier my mother becomes."*



# Section Five: Staying Active, Keeping Connected

## How do I find out what is available in my area?

Devon Carers and Torbay Carers, Age UK, Age Concern, the Alzheimer's Society and Admiral Nurses will have information about what is available locally. Also, look out for posters in your area (library and GP surgery), articles in local newspapers and ask other carers. Several companies provide paid day opportunities. Here are some low-cost and charitable groups:

**Carers' and peer support groups:** These groups offer support in a safe environment to enable the carers to engage with other carers in similar circumstances. They also offer training, support and information and referral to other appropriate organisations.

**Age UK and Age Concern:** Depending where you live in Devon (including Torbay), you may be supported by Age UK or by Age Concern.

Age UK in Devon supports older people (50+) with information and advice, including welfare and benefits help, groups and activities such as seated yoga, walking basketball and lunch clubs and a paid enabling and home care service.

There are some specialist services for people living with a dementia, for example, Reminder Finder groups. These provide fun and stimulating activities to keep people using their remaining abilities and enjoy a social session.

**Dementia Action Alliances:** work locally to reduce the stigma and misconceptions of dementia and to make the local community dementia-friendly. Look out for posters in your area.

**Memory Cafés:** Memory Cafés provide a warm welcome and comfortable environment for people with dementia and their carers to meet with others in a relaxed social setting.

A Memory Café is beneficial for those living with dementia, it is also beneficial for their caregivers: a way to enjoy activities together as a break from the normal routine. They are places to meet and talk to other people experiencing the same challenges and joys, to share experiences and obtain information, guidance and training.

Individual Memory Cafés focus on different aspects for a unique experience. You may find some are activities-based, while others focus on education.

Details of Memory Cafés throughout Devon, including Torbay and Plymouth are available on the Devon Memory Café Consortium website.

Find out what's on in your area contact your local carers organisation for their magazine.

## What if the person I care for is not a joiner and doesn't want to join groups?

Keeping socially connected, using remaining abilities and keeping active are all ways to slow down the progression of dementia. As a carer, it is important that you too keep up with friends, hobbies and remain active.

Invite friends and neighbours in for coffee. This will be company for both of you and possibly lead to the person you care for being comfortable having someone else staying with them while you go out.

Use the Attendance Allowance to pay for someone to stay with the person with dementia while you rest or go out, for example using Time for You or paid agency staff. Ask friends or relatives to take the person out for short periods such as for a drive, walk or to a hobby they enjoy.

Even if the person with dementia is self-funding, Social Care and Occupational Therapy (OT) advice is free. OTs can advise on safety in the home so you feel confident to leave the person for short periods of time.

Some groups are smaller and quieter than others. It can be daunting going to a group where you know no one: go with another couple or arrange that you can stay with the person, at least for a while.

Remember, you can use any group or activity if the person with the dementia feels comfortable and enjoys it: you are not restricted to dementia-specific activities.

## What are the best ways to occupy someone with dementia?

In the early stages you can probably just carry on as normal.

If the person's short-term memory is affected, you may notice they are having trouble following conversations and the plot of TV programmes. Change to programmes where it is not necessary to follow the plot such as well know musicals; animal documentaries, sport and variety shows.

*Carer's story: "When my husband was first diagnosed with dementia, he always got very anxious when I left him and wanted to know exactly when I would be back. If I was a bit late, he was beside himself. So, I took to adding on an hour and writing this time down on a piece of paper which I stuck to the front door. He was always surprised I was back early!"*

It is vital for carers to have breaks to rest and do the things they want to do. From early on, set a routine so the person gets used to you going out. Keep going to your activities and meeting your friends.

Libraries will lend talking books, low-piece jigsaws and other activities so you don't have to buy them yourself. Pottering in the garden or home gives the person a feeling of being valued. You could allocate a patch of garden for weeding. You may have to finish jobs yourself or re-wash the dishes at a discreet time, but most importantly, you will have given the person a sense of purpose.

As the dementia progresses you could create "rummage boxes": containers of things



for the person to do such as pairing socks, sorting nuts and bolts, sanding wood; Lego, adult colouring books, folding the washing, winding wool – or whatever you think will interest the person. People retain their sense of self. Ask for their advice and opinions.

**As a carer, you don't have to be occupying the person all the time. Dementia is tiring for both of you. 10 minutes quality time together, followed by half an hour of TV, silence or sleep is fine.**

## Does music help?

Music can reach parts of the brain in a way other forms of communication cannot. We all have our favourite music and music we like to hear to match our mood. Obviously, you don't have to join a group to enjoy music. Try starting a favourite song to encourage the person to join in or putting on a tune and dancing or doing gentle exercise. Music can bring back personal memories for you both. Don't be afraid of bringing back sadder times – music can help us cry, which is sometimes beneficial. Singing can also lighten the mood – try singing while doing less enjoyable tasks such as personal care.

Music support available in Devon and Torbay includes:

- **Singing for the Brain and Play list for Life (contact the Alzheimer's Society).**
- **Singing to Remember in Tiverton and other similar groups across Devon. Look out for posters locally, in your local paper and from Devon or Torbay Carers.**
- **Purple Angel MP3 Players, available at the RD&E and across Torbay. Contact Torbay Carers.**
- **Join a choir or attend your local church.**
- **Dementia UK have a leaflet which gives tips on using music.**

## Going on holiday?

If you feel that you still want to travel abroad or in this country, the Alzheimer's Society provides a useful guide, or you can ask Devon Carers for their information sheet. Be prepared for the person with dementia to be disorientated and possibly want to go home. As the person's dementia progresses it will become increasingly difficult to leave familiar surroundings and routines.



When going out or travelling, plan ahead. Create a simple check list such as identification and alert cards, medication, any special equipment for eating and drinking, spare clothing/shoes, mobile phone (charged!). Plan toilet and rest opportunities and ensure a toilet opportunity before you leave. Buy a Radar key so you have more options for toilets (ask Care Direct/Adult Social Care for details).

## Managing family relationships

The Alzheimer's Society has an information booklet called "Your Relationships" as part of their Living with Dementia series.

Sometimes families can disagree between themselves and conflicts can arise. At these points a family meeting is often helpful. The Devon and Torbay Dementia Adviser Service may be able to support you with setting up a family meeting.

Staying in contact with family and friends gives you opportunity to talk to people about what you are going through and to get some vital help. Be clear about the help you need and the needs of the person with dementia. Friends and family often want to support you but will need you to guide them.



# Section Six: Staying Safe

## What to do if the person is lost/or has left the house

Getting outdoors is important for our wellbeing. However, dementia can impair a person's sense of where they are and of their own safety. If a person may be at risk if they leave without a carer's knowledge, there are a number of things that can help the person stay safe.



- **Cover external doors with a curtain and leave internal doors that they can go through open and well lit.**
- **Ensure the person has access to the outside such as an enclosed garden or a regular time that they can be accompanied out.**
- **Keep to a routine walk so the person may be able to follow it if they go out alone.**
- **Fit a door exit sensor to alert the carer when an external door has been opened.**
- **Encourage the person to carry personal ID with them at all times (such as an ID bracelet or in their wallet) or a tracker.**
- **Encourage the person to carry a simple mobile phone at all times and ensure it is charged and switched on.**

## The Herbert Protocol

The Herbert Protocol encourages carers of adults living with dementia to collate information on those who are vulnerable onto a form that can be given to the police if the person goes missing.

The form includes information on medication, mobile numbers, and previous homes as well as a recent photograph. If the person goes missing and you have conducted a search of your house and nearby surroundings, call 999 and tell the police that you have a Herbert Protocol person profile form.

Keeping a completed form saves the worry of trying to recall the information during the stressful time of someone going missing. It also saves time for the police, allowing the search to start sooner. For more information and a copy of the form visit <https://www.devon-cornwall.police.uk/missingherbert>

If you do not have access to a printer, ask a family member or your local carers organisation to help.

## How do we keep safe from scams?

Scammers prey particularly on the elderly, people living alone, and people living with dementia and have many approaches and tricks they try. Information for protecting yourself and family is widely available from the following organizations: Utility companies (water, electric, BT etc), banks, building societies, the police, Age UK, Citizens Advice, Trading Standards and Dementia UK. See More Information and Contacts page for details.

*Carers tip: "When the carer goes out, set the answerphone to cut in on two rings. This makes it difficult for anyone else to answer."*



Here is some advice to prevent unwanted callers:

- **If someone you are unsure about calls, it is best to say, “No, thank you”, shut the door, or put down the telephone.**
- **Discourage unwanted callers by placing a ‘no cold caller’ sticker (available through the Trading Standards Service, or the police) on the front door, as well as a ‘no adverts’ sticker on the letter box in an attempt to stop junk mail. Perhaps a trusted neighbour can keep a look out for visitors.**
- **Use a lock and chain on the front door to prevent someone gaining access, and as a reminder to the person inside to be careful.**
- **Blocking systems are available to stop unwanted telephone calls.**
- **Check the post each day with the person with dementia looking out for unwanted mail or suspicious items.**
- **Shred personal and confidential information.**

If goods are bought/services ordered through the internet or post, there is a cooling-off period of 14 days in which to return/cancel them: it is important to act as quickly as possible.

Regularly gauge the person with dementia’s ability to manage finances appropriately. With their permission it may be helpful to check bank statements to ensure there are no irregularities. Talk with them about setting up third party authority on their account to help manage their financial affairs. To set this up you will need to visit the local branch with the person and take ID for both of you. Consider Lasting Power of Attorney for Property and Financial affairs. It is essential the person with dementia appoints someone they trust absolutely. Sadly, financial abuse is often carried out by a family member.

**For concerns about an existing Lasting Power of Attorney, contact the Office of the Public Guardian. Alternatively, speak to Age UK, Dementia UK or the charity, Action on Elder Abuse. All details are in Information and Contacts.**

## **What to do if the person hits you**

Being hit or threatened can come as a shock. Carers may be tempted to think that they should say nothing because it is part of the dementia or that they should be able to cope. It is important to consider the impact of a behaviour, not just the possible cause. Domestic violence may seem a harsh description of what is happening. However, if the change in behaviour is not addressed, abuse and violence may escalate.

Firstly: make yourself safe. Leave the room or even the house and find a place of safety such as the car or at the neighbours. If you cannot leave the house, find a room you can lock, remembering to take your phone with you. If you cannot get out of the room, get something between you such as a table or chair. Do not try to reason with the person



at this point. If they are angry, they are unlikely to hear you or be able to reason. If you feel you are in danger, phone 999. When the threat is over and the person is calm, they may be apologetic and be able to talk about it. Or, they may have forgotten about it. You can be comforting, but do not make any promises that you might not be able to keep (such as not telling anyone).

**Tell someone you trust. This might be your GP or carers' organisation. You can contact Splitz (domestic abuse organization) who can give you advice on keeping safe.**



# Section Seven: Finance, Benefits And Legal Support

## Am I entitled to benefits and financial support?

Having a diagnosis of dementia is helpful when making benefit applications for you and the person you care for:

- **Attendance Allowance (or PIP if the person is under state retirement age)**
- **Carers' Allowance (and how this works with Universal Credit)**
- **Pension Credits**
- **Council Tax reduction**

Due to the complexities of the benefits system, we would encourage carers without access to the internet to seek advice from their local Age UK or Citizens' Advice.

## What am I entitled to if I am self-funding?

The Care Act 2014 entitles you to an assessment in your capacity as a carer. The person you care for is entitled to an assessment of their needs. Assessments and support planning are free, as is occupational therapy advice if this is assessed as necessary to meet your needs. Contact Care Direct for Devon or Adult Social Care for Torbay (see Information and Contacts)

Devon County Council and Adult Social Care in Torbay have fact sheets on paying for care at home and residential care – see Information and Contacts.

## What is Continuing Health Care (CHC)

Devon County Council describes CHC as:

"...the name given to a package of care that is arranged and funded solely by the NHS for individuals who are not in hospital who have complex ongoing healthcare needs."

The NHS states: "A diagnosis of dementia doesn't necessarily mean you will qualify for NHS continuing health care. This depends on how complex and severe your needs are. To qualify for NHS continuing health care, you need to be assessed by a team of health care professionals."

For more information contact the Clinical Commissioning Group (CCG) for Devon. You can also contact Beacon for up to 90 minutes of free advice. See Information and Contacts.

## How can I help my relative maintain their rights?

Having a diagnosis of a dementia can feel devastating. There may be an assumption by the person and by people around them that they now need to stop many of the activities which they enjoy and which maintain their independence.

For the carer, there may be a tension between supporting the person to carry on with their life, at the same time watching to ensure their safety and dignity.

Here are some common challenges:

## Driving

While driving is not a human right, here in Devon we would probably agree that it is very important to our independence and keeping in touch with friends and family. We can understand the frustration and anger of being told you can no longer drive. Once a person has a diagnosis of dementia, they must tell their insurance provider and the DVLA.

The carer or the person with the dementia should talk to their GP, who can advise on whether the person needs to give up now or can continue for a while.

The problem may not be with the physical demands of driving, but with poor “visio-spatial” awareness (meaning where objects are in relation to us) or a slowness in decision-making.

Carers, family members or friends may find the following suggestions useful:

- **Try to acknowledge how difficult the decision may be for the person by listening to their concerns.**
- **Encourage the person to take charge of their new transport arrangements, so that they regain a sense of control. Use any PIP or mobility allowance for transport.**
- **Ask the doctor to tell the person they need to stop driving. People may take the decision better from someone they see as in authority.**
- **Share your concerns with other carers and carer support professionals. They will understand the difficulties and may have ideas to help ease the situation.**

Ask the Alzheimer’s Society for their booklet: Living with Dementia, Driving.

## Legal

The Alzheimer’s Society and Age UK are good sources of information on many aspects of the legal rights of the person with a dementia and how carers can support these rights.

### Employment

### Safeguarding including Liberty

### LGBT+ rights

### Voting

### Safeguards

### Paying for Support

### Consent

### Mental Health Act

### Benefits

**Mental Capacity Act 2005:** protects and supports people who are not in a position to make decisions for themselves, and outlines who can and should make decisions on their behalf. The Mental Capacity Act covers decisions such as finances, housing, future care and consenting to sexual relations.

**Liberty Safeguards:** An assessment will take place if a person with dementia is in a care home, hospital setting or the community and it is felt that they are being, or will be, deprived of their liberty. It becomes relevant to carers when considering the use of

tracking aids or locking doors for safety. Your Social Care team can advise on managing these situations.

**Care Needs Assessment:** Local authorities have a duty to assess the care needs of a person with a dementia to help them remain as independent as possible. The assessment is free.

## How can we prepare for the time when person with the dementia loses their capacity to make decisions?

There are a number of things you can do to prepare for the progression of dementia:



### Try This:

**As early as possible, start the conversation about future planning. Most of us make wills, look into setting up Lasting Power of Attorney as well. It might help if you both set them up to ease any feelings of pessimism. Future planning includes financial planning, medical treatment planning and funeral planning.**

Having a dementia usually means that the person will eventually lose their capacity to make informed decisions. Start the conversations about future planning as early as possible so that you have peace of mind.

Talk about your feelings and concerns to people you trust. Sometimes you don't need advice, just someone to listen. Use your Alzheimer's Society, Dementia UK (Admiral Nurse) and carer's organisation contacts as well as family and friends.

Dying Matters can be contacted by phone on freephone 0800 21 4466 or 020 7520 8200 and leave your contact details. [www.dyingmatters.org](http://www.dyingmatters.org)

Talk about Dying with People Affected by Dementia – or ask your carers organisation to print and post it to you.



# Information And Contacts

Contact information is correct at time of publication, for opening times please contact the organisation.

## Information about aspects of dementia:

**Alzheimer's Society Dementia Connect support line:** 0333 150 3456 for help and support.

To contact the **Devon and Torbay Dementia Adviser Service** or to book onto a Memory Matters programme please contact us on 0300 123 2029

**Dementia UK:** The Admiral Nurse Dementia Helpline is for anyone with a question or concern about dementia. Call the Dementia Helpline in confidence and for free on 0800 888 6678.

**Rare Dementia Support:** 07388 220355 or 07341 776317 who will refer your enquiry to the most appropriate team member. Ask for Devon-based support groups.

**Lewy Body Society UK:** contact 01942 914000 for information.

**Young Dementia UK:** contact them at PO Box 315, Witney, Oxfordshire, OX28 1ZN requesting information/support on the following:

- Young onset dementia symptoms/diagnosis
- Young onset dementia following a diagnosis
- Support services/groups in your local area
- Residential care/accommodation for younger people

For non-support related enquiries, telephone 01993 776295.

**Age UK:** Age UK National advice line 0800 055 6112, this is free to call 8am-7pm 365 days a year.

Age UK Devon offers a range of support, activities and events across Devon – for more information contact 0333 241 2340

Age UK Torbay offers a range of support, activities and events across Torbay – for more information contact 01803 555181

**Age Concern:** Age Concern offer similar services as Age UK:

Age Concern Exmouth: contact them on 01395 271242 or visit at 1 Rolle Street, Exmouth, EX8 1HL

Age Concern Crediton and District: contact them on 01363 775008 or visit at The Lady Mills Centre, Deep Lane, Crediton, EX17 2BX

Age Concern Barnstaple and District: contact them on 01271 324488 or visit at 1 Litchdon Street, Barnstaple, EX32 8ND

## Adult Social Care

**Care Direct:** Devon County Council's social care helpline – the service is for carers of people living in Devon. Contact 0345 155 1007

**Community Customer Services Centre:** For carers of people living in Torbay: 01803 219700

## Carers' Support organisations

**Devon Carers:** 03456 434 435

**Torbay Carers Service:** contact Signposts for Carers on 01803 666620

## Support for people at risk of domestic violence

**SPLITZ Support Service:** 0345 155 1074 (not Torbay)

**Torbay Domestic Abuse Service:** 0800 916 1474

## Lesbian, Gay, Bisexual and Trans (LGBT+) contacts:

**Alzheimer's Society Dementia Connect Support line:** 0333 150 3456 for help and support and to request their fact sheet.

## Black, Asian and Minority Ethnic (BAME) contacts:

**The Alzheimer's Society and Dementia UK services are open to all.**

**Hikmat:** 01392 757220 Enabling and supporting ethnic minority families across Devon. Their support includes working with carers.

## Finance and rights

**Citizens Advice Devon:** Free, confidential and impartial advice 03444 111444

**Devon and Torbay Trading Standards** Call the Citizen's Advice Consumer Helpline: 0808 223 1133. Post: Devon, Somerset and Torbay Trading Standards, County Hall, Topsham Road, Exeter, Devon EX2 4QD.

**Action on Elder Abuse helpline:** 080 8808 8141

**Office of the Public Guardian** provides free booklets on Lasting Power of Attorney, Enduring Power of Attorney and Deputyship: PO Box 16185 Birmingham B2 2WH, 0300 456 0300 (customer services, 9am to 5pm weekdays)

**Court of Protection:** a specialist court for all issues relating to people who lack

capacity to make specific decisions: PO Box 70185 First Avenue House, 42–49 High Holborn, London WC1A 9JA, 0300 456 4600

## **Feedback about adult social care (care homes, care agencies and Devon County Council (DCC) Adult Social Care teams)**

Feedback can include compliments and suggestions as well as complaints

**DCC Social Care Customer Relations Team:** 0800 212 783

If you have a query about care provided or funded by a particular hospital or Health Care Trust, you can contact your local **Patient Advice and Liaison Service (PALS)**

## **Continuing Health Care (CHC) contacts:**

**Beacon** provide an information and advice service with up to 90 minutes of free advice from trained staff. Information and advice in excess of 90 minutes will be charged. 0345 548 0300

**Devon and Torbay Clinical Commissioning Groups:** NHS Devon Clinical Commissioning Group, County Hall, Topsham Road Exeter, Devon EX2 4QD 01392 205 205

## **Here are some publications that may help**

Carer UK offers information as your caring role changes or ends  
<https://www.carersuk.org/help-and-advice/practical-support/when-caring-ends-life-after-caring>

**Dementia UK: Understanding Dying.** Everyone will experience dying in their unique way. The booklet explains how families and friends can help the person practically and emotionally. Their booklet Grief, Bereavement and Loss looks at carers' feelings in anticipatory grief (before the person has died) and after the death. It recognises physical and social changes you may feel and has advice on what can help.

**Marie Curie: Caring for Someone with a terminal illness:** <https://www.mariecurie.org.uk/help/support/being-there>

**Alzheimer's Society:** fact sheet 531 End of Life Care and fact sheet 507 Grief, Loss and Bereavement.

**Information on managing grief from Hospiscare:** <https://www.hospiscare.co.uk/caring-for-your-friends-family>

**Dying Matters, further resources on many aspects of dying and bereavement:** <https://www.dyingmatters.org/page/resources-talking-about-death-and-dying>

**Power of Attorney:** <https://www.alzheimers.org.uk/get-support/legal-financial/lasting-power-attorney>