

DEMENTIA FRIENDLY HAMPSHIRE

2023/24

A practical guide to living with dementia in Hampshire



ABClivein Care Hampshire



ABClivein Care providers who offer excellent quality care to keep you safe and comfortable in your own home. We believe that it's your life and your care, so it must be your way. We see each of our customers as unique, with their own individual lifestyle and needs. We keep you in control and provide you with the care and support that you want, where and when you want it.

The services we offer

The service may be anything from a 30 minute visit to 24-hour care. Our care workers are able to provide you with the following types of care and support:

- Help with personal care and hygiene;
- Help with getting up and going to bed;
- Prompting or giving medicines and collecting or returning medication from pharmacies or dispensing GP surgeries;
- Preparing meals and helping at mealtimes;
- Shopping, laundry and housework;
- Support with social activities such as attending a day centre, visiting friends or family, going to your church or club etc.

We provide care to people over 65 years of age, people 18+ with physical disabilities, people with a sensory loss or impairment, people with dementia, people with learning disabilities or an autistic spectrum disorder, people with mental health problems.

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 CareChoices



Alternative formats

Recite^{me}

This Guide is available electronically at www.carechoices.co.uk/dementia/
The e-book is also Recite Me compatible for those requiring information in the spoken word.



Introduction

According to Alzheimer's Society, around 225,000 people will develop dementia each year; that's one every three minutes. Dementia is a progressive illness. It affects the brain and its symptoms can vary from person to person. No two people experience dementia in the same way.

‘ Don't wait too long to get help. Press for diagnosis, which is key to getting services. Knowledge itself can help you to cope, accept what's happening, and plan for the future. Use the internet and social media to gain information and support from peers. ’

You may have a copy of this Guide because someone close to you has received a diagnosis of dementia. It may be that you have strong feelings that a close relative or friend is starting to demonstrate symptoms of the condition which are affecting their daily life. Whether dementia has been a part of your life for some time or is something relatively new to you, you are likely to be looking for information.

Whatever your situation, this Guide offers practical information for people living with dementia and those supporting someone with dementia. You may be a relative, a friend or a member of the community and, whatever your role in the person with dementia's life, this Guide should help inform you about dementia and living with the condition on a daily basis.

To remain consistent, throughout this Guide we will be referring to 'you' as the person supporting someone with dementia. This is not intended to exclude those living with dementia – the person with dementia should always be at the centre of everything.

DIAGNOSIS

When it comes to a dementia diagnosis, whether it is expected or comes completely out of the blue, it is likely to have a significant impact on the person receiving the diagnosis and those around them. Each person will be different and there is no doubt that there are considerations to be made along the way. Some may even decide they

don't want to pursue a diagnosis.

Early diagnosis can be considered important. It may be key to receiving information and/or support. However, there are many factors that can affect if, or when, a person receives any diagnosis of dementia.

COMMUNICATION

It is unrealistic to think that everybody will come to this publication at the same stage. Although it is hard to come to terms with, the symptoms of dementia will increase over time. By directing the information in this Guide to you, as a family member or close friend, but keeping the person with dementia at the heart of the conversation, we hope to reach everybody.

Communication can feel hard, conversations can be difficult, and people don't always want to open up. This means that people can delay having important conversations about the future. The aim of this Guide is to support

and inform you and your family to talk about important matters when you are all ready, whether that's now or in the future.

It is important to try to talk as much as possible and keep the lines of communication open, with the person with dementia, family members and professionals. By doing this, it is more likely that you will find answers to the questions that you have and ways to manage the ongoing changes that dementia symptoms bring. Repeat appointments with professionals can also allow you all to ask any questions that may arise over time.

SERVICES

Accessing services and support can make a huge difference to people with dementia and their families. In many places, a dementia diagnosis is the starting point for accessing support.

However, it doesn't have to be, and this Guide has comprehensive lists of local services starting on page 66 that can help you to live well with dementia.

PLANNING

It is important to recognise that a diagnosis of dementia does not necessarily mean that an individual can no longer make decisions about their future. People can live well with dementia for a long time. By leading the decision-making process in any way possible, for as long as they are able, it can help their day-to-day life to take shape in the way they want it to and create a

positive plan for their future.

Planning for the future, including the use of life stories, lasting powers of attorney and advanced decisions, often brings reassurance to people who are worried that they may not be able to make such important decisions in the future. It also guarantees that you are not put under

the additional pressure of making a decision on behalf of your loved one and worrying that it may go against what they would have wanted for themselves.

Remembering that a person with dementia is, first and foremost, an individual with their own

unique life experiences, personality and likes and dislikes, is one of the most important aspects of supporting them and planning for the future. This will also shape how the person with dementia would prefer to be cared for as their needs increase, including their end of life and funeral wishes.

CARE AND SUPPORT

This sentiment is echoed in national strategies for dementia, which aim to ensure that people who deliver adult social care services fully understand and meet the needs of the person with dementia and their family. This includes person-centred planning, gathering and recording information and using life stories, along with an ethos centred on really getting to know the person with dementia. This enables them to deliver

relationship-centred care as relationships are a huge part of life and who we are as individuals.

There is also a drive to raise awareness of dementia amongst the wider public, in communities and public services, as well as raising standards and increasing public awareness of excellent dementia care. Raising public awareness starts with each one of us.

LIVING WELL WITH DEMENTIA

This Guide will support you, and the person living with dementia, from diagnosis and daily living, onto care and support through to plans for end of life care. We will also discuss the legal and financial considerations that come with a dementia diagnosis. The resources and information available are vast, and for that reason we are aware that this publication can only take you so far.

Other **useful publications and sources** start on page 66. We have also included further links to websites, videos and blogs, where people share their experiences to help you and the person you support.

Although you may currently feel alone, there is a lot of support and guidance available. Throughout this Guide, we have included real-life examples and stories from people who support someone with dementia. These might be family carers, dedicated dementia nurses or

trained care and support staff. Consider that the information you gather and experiences you have whilst supporting someone with dementia could help someone else. Over time, if you feel able to, consider passing your knowledge forward and sharing your experiences with others.

People live well with dementia for a long time. We hope this Guide offers you the information to support the person in your life to live well with dementia.





What is dementia?

You may be supporting someone living with a formal diagnosis of dementia, or you may be finding changes in someone's ability to recall recent or long-term memory which is affecting their daily life. Whatever your situation, there can be a lot of myths around dementia.

‘I found it helped to read up on my Dad's dementia. It was hard to start with, and frankly quite daunting, but the more I read, the more I realised that everyone's dementia symptoms are different. Of course, some people had difficult stories to share, but it's the same with everything, everyone had a different experience and I prefer to be informed.’

If you think that someone may have dementia, or you or someone close to you has just received a diagnosis of dementia, you are likely to want to know more information. In modern times, it's natural to head to the internet and search 'dementia'. You are likely to find a wide variety of information, covering many different types of dementia. You may find it difficult to sort through everything; you may be overwhelmed by other people's experiences of dementia and its symptoms. If you want to know more about dementia, it's important to look for quality information, and filter through what you read.

Organisations like Alzheimer's Society or Alzheimer's Research UK have a lot of useful publications that can help to inform you. They are written by experts but in an easy-to-digest way. If you're going to start anywhere, this is as good a place as any.

This publication intends to give you an overview of dementia, living with the symptoms of the condition and planning for the future. We're starting with some common examples

of dementia and their symptoms, though it's important to consider that no two people experience dementia in the same way, as the symptoms are different in all people.

Dementia is the name given to describe a variety of conditions, all of which can cause the brain to deteriorate. Many people live well for a long time

and have a good memory, although some people may notice memory changes over time. It should be said that the ageing process can put someone at higher risk of developing certain types of dementia, however, dementia is not a normal part of getting older. Also, it doesn't just affect older people. Whilst dementia is more prevalent in people over 65, it can develop at a younger age.

COMMON TYPES OF DEMENTIA

According to Alzheimer's Society, there are many different types of dementia. Some are very rare, and little is known about them, but some are much more common.

As mentioned above, each type of dementia can be very different, and people can experience different symptoms. Dementia looks different in all people. It is a progressive condition that affects the brain. As a result, this can affect the personality, ability to communicate and, ultimately, the physical and mental abilities of the person with the condition.

Alzheimer's disease

This is the most common form of dementia and the one you may have heard most about. Alzheimer's disease develops 'plaques' and 'tangles' in the brain, as well as depleting the brain of certain chemicals. These physically change the brain and its ability to send and receive signals. As the disease progresses, the chemistry and structure of the brain change. This leads to the deterioration of brain cells and an inability to access what was held by those cells.

Although Alzheimer's disease can affect people differently, there are common examples of symptoms. Although, again, symptoms can be different in different people. Someone with a diagnosis of Alzheimer's disease may become confused or disorientated. The person may struggle to recall a recent memory or people's names. Alzheimer's disease can also affect

the person's mood and may make them angry, upset or frustrated. As the dementia symptoms progress, they can have an impact on the person's ability to communicate. This has been known to lead to people becoming withdrawn or depressed.

Vascular dementia

Vascular dementia is caused when the brain's blood supply is interrupted. The symptoms of vascular dementia can occur suddenly, following a stroke, or over time through a series of smaller strokes or small vessel disease. Not everyone who has had a stroke will go on to develop this type of dementia, but those who have are more at risk.

As with Alzheimer's disease, vascular dementia's symptoms can develop in different ways in different people. However, commonly experienced symptoms can affect a person's concentration, cause confusion or even seizures. Issues with memory aren't always the first symptom of vascular dementia.

Dementia with Lewy bodies

Lewy bodies are small, circular lumps of protein that develop inside brain cells. It is not known what causes them. It is also unclear how they affect the brain and eventually cause dementia symptoms. However, their presence is linked to low levels of important chemical messengers and a loss of connections between nerve cells.

This form of dementia progresses in a similar

way to Parkinson's disease, where people may have similar symptoms, such as muscle rigidity, involuntary shaking and slow movement. Dementia with Lewy bodies may affect memory, but people may also have symptoms including disturbed sleep, issues with attention span or spatial awareness.

Dementia with Lewy Bodies can occur alongside Alzheimer's disease or vascular dementia.

Fronto-temporal dementia

This type of dementia is one of the less common forms. It is caused by damage and shrinking in specific areas of the brain that control behaviour, emotions and language. It may also be called Pick's disease. When nerve cells in these parts of the brain die off, the pathways that connect them change and, over time, the brain tissue shrinks.



This form of dementia is more likely to affect people under the age of 65.

By its nature, people with this type of dementia are likely to experience personality changes. Some symptoms may include unusual behaviour such as aggression or being distracted. People may also develop difficulty with their speech, or experience changes in their ability to hold conversations and/or find the right words.

RARER TYPES OF DEMENTIA

There are many other types of dementia that are much rarer than those mentioned above. Alzheimer's Society has a good explanation of all forms of dementia, including those which are less

common, plus details of where to go for help.

Useful sources begin on page 66.

NEXT STEPS

If your loved one has received a formal diagnosis (discussed more in the next chapter), you may have a name for their type of dementia. This may be the time that you consider searching the internet for more information.

Whatever information you find, a diagnosis doesn't mean that the person will have 'textbook' symptoms, or that the dementia symptoms progress in a common way.

Seeking a diagnosis can be the key to accessing services and support. However, a person has a choice over whether or not to seek a diagnosis. They may not be aware of any symptoms or have

insight into what you consider may be dementia symptoms. This is why it is important to speak to the person and focus on their thoughts, wishes and considerations.

Whether or not the person with dementia has received a formal diagnosis or wants to consider diagnosis now or in the future, there are a number of national and local organisations that can offer support.

The **local organisations** starting on page 66 will give you more information on what's available locally.



Is it dementia? Symptoms and diagnosis

Many people live well for a long time and have a good memory; however, it isn't unusual to notice some memory changes over time. It can be difficult to tell whether memory changes are actually a symptom of dementia or just what some like to call 'senior moments'.

‘ Arrange a follow-up appointment with your GP to cover social services, intervention therapies, and face-to face peer support for both the person diagnosed with dementia and their carer. ’

At some point in their lives, most people have forgotten an appointment, lost their keys or had trouble putting a name to a face. However, if these occasions are becoming more frequent, or it is becoming increasingly difficult to recall certain things, they may be symptoms of an underlying condition, particularly if other changes are happening at the same time.

According to Alzheimer's Society, people with dementia experience the symptoms of the condition in different ways. However, common symptoms can include:

- Memory lapses, such as struggling to remember recent events.
- Difficulty taking in new information.
- Losing the track of conversations or TV programmes.
- Being unable to remember names, people or items.

- Changes in ability to reason or make decisions.
- Changes in personality or behaviour, including becoming angry, frustrated or upset at memory issues.
- Being disorientated in time or place, including changes to spatial awareness.

If you are concerned that someone may be demonstrating the symptoms of dementia, try to keep a note of things that are changing. As mentioned previously, dementia symptoms can be different in different people. It's not always forgetfulness, it may be changes in their personality, a spatial awareness issue, confusion or even being unable to find the right words. This is why jotting down your concerns can help you to see if there is a pattern, or whether they may

suggest specific dementia symptoms. Having this information may help you if you want to search online. It may also form the starting point for any conversations with the person demonstrating the symptoms or to give examples to the GP.

People have differing opinions about getting a dementia diagnosis. Some people are keen to have answers, whereas others feel it may become a label. People have a choice over whether to seek a diagnosis now, in the future or not at all.

Whatever your thoughts, and the thoughts of the person who may have dementia, a formal diagnosis can be the key to accessing professionals, services, support and, where appropriate, treatment if that is what the person wishes.

UNDERSTANDING CHANGES

If someone begins to recognise symptoms that could be related to dementia, the first port of call should be the GP. If it is you who has noticed changes in another person, approach the matter sensitively with them and try to understand their perspective. They may not be aware of any changes, or they may not want to act on anything. You don't want to create a situation where they feel under pressure to see a doctor if they're not ready or don't want to.

In these situations, approach the subject in different ways. Keeping a note and showing them the symptoms or signs written down may be effective. As may a frank or sensitive conversation about your worries. Approach the situation as you would any delicate subject; your intimate knowledge of the person demonstrating dementia symptoms will help with this.

Don't be afraid to share your thoughts with a close family friend or relative who may also know the person well. They may be able to help you

come up with ways to broach the subject or may have noticed symptoms too.

Dementia is not spoken about as much as it should be. Many people don't have conversations early enough. However, if the person demonstrating the dementia symptoms is open to it, it's important to seek assistance from a medical professional as early on as possible.

Early diagnosis is the key to any available treatment, support or services and to enable planning for the future. However, that said, it is not always easy to diagnose in early stages.

When visiting the doctor, respect your relative's privacy. If they don't want you to go along to the appointment, respect that.

You may be able to put down in writing the symptoms that you have noticed, which they can take along, or you may be able to call, write to or email the doctor in advance.

MEDICAL EXPERTISE

There are some medical conditions that can mimic dementia-like symptoms. A doctor would be able to rule out anything else. The GP may undertake blood and urine tests to check whether there is an underlying cause.

There is no single test for diagnosing dementia, but the doctor is likely to ask the person demonstrating dementia symptoms about themselves, talking to you as well if you're at the appointment. This is where any symptoms you have written down can help the doctor to build a bigger picture.

The doctor will also look at your relative's medical history and review any existing conditions or medications. This will help them to identify whether there are other causes that need managing or treating first. The GP may also offer a simple 'pen and paper' test for the person to complete while they're there.

In some cases, the GP may be able to diagnose dementia at this point – especially where symptoms may already be quite advanced. However, they may want to refer on for further tests, or wait until they have the results of any medical tests.

Referrals from the GP may be onto community mental health teams, made up of a number of different specialists, or onto a memory clinic or a memory service – they will be called different things in different areas. These specialist services may undertake more in-depth memory tests to diagnose dementia or be able to signpost to further information and services.

The memory service is designed to give a diagnosis, however, follow-up appointments and further assessments may be needed. The person with dementia should be fully involved, and informed, at every stage and the GP

should also receive details of the assessments and any diagnosis.

The NHS website has a good summary of the types of dementia tests that may be offered in order to receive a diagnosis; visit **www.nhs.uk**

Research by Alzheimer's Society has found that doctors can be reluctant to diagnose dementia because of a lack of support from NHS and social care services. If you feel this is the case, speak to the GP openly and ask for a second opinion, if you feel it necessary.

Services across England to support people living with dementia, their family and carers are many and varied. They may be health, social care, primary care or community services.

In some areas, these different organisations may work well together. However, in other areas they may not be as joined up.

In these cases, you and the person living with dementia may find yourselves answering the same questions, giving the same information and having to make contact with different services and departments. It can be frustrating.

As the level of formal services varies across the country, there is an increasing number of local voluntary services which can offer different types of support.

The **local contacts** starting on page 66 could help you to find services nearby.



DIAGNOSIS

If, or when, a diagnosis of dementia is made, any treatments that are available will be discussed with you and the person with dementia. Any treatments will vary depending on the type of dementia the person has been diagnosed with, and how far the symptoms have progressed.

If the dementia is caused by an underlying medical condition, treating the condition may help. For others, there may be medication available, although this is not always the case and depends on a number of factors.

Dementia is a progressive illness and, although there are treatments, there is no cure. If someone has been diagnosed with dementia, they may be offered medication to help slow the progress of symptoms, depending on the stage and type of dementia. However, medication may not be offered to everyone, as it may not be effective in their specific circumstances.

The NHS website sets out different treatments for dementia. Speak to a medical professional about what may be available for your relative because unfortunately, there may not be a suitable treatment.

At the point of diagnosis, you and the person with dementia should be given information and advice on local services and support groups, details of any benefits that may be available and techniques to help manage symptoms.

Details of **local support services** start on page 66. Information on **benefits** is on page 38 and the chapter on **living with dementia** starts on page 25.

‘What was important to me was to ask my GP what type of dementia my mother had and how it would progress.’

AFTER DIAGNOSIS

Receiving a diagnosis can be a shock for some people. For others, it can help them to finally have answers to symptoms that they have been experiencing. It is important that everyone takes the time to process the news.

As with any diagnosis, you, the person with dementia and their wider family and friends may react in different ways. This is completely natural, and people may need time to process the news.

There should be support available to help at this time and into the future. Take a look at the **local services** starting on page 66.

Some people can feel left on their own after a diagnosis of dementia. This should not happen, but knowing what services are available in the local area, and making contact with them, can

offer support and advice when you need it.

Also, look to set up a good support network of family, friends or people in the wider community, such as neighbours, religious or cultural groups or local support organisations.

It may be important to you or the person diagnosed to discuss the diagnosis with your local faith leader, for example your local vicar, rabbi or imam, to see what support they might be able to offer, both practically and spiritually.

If you are not offered any follow-up appointments with medical professionals, seek advice from local organisations as to what may be available in your area.

See page 66 for information on **local services**. →

➔ Look to see if there are any 'Dementia Friends' sessions in the area if you want to know more about dementia and how to support someone with dementia. Also, more areas are becoming 'Dementia Friendly' where individuals, shops and other organisations undertake dementia training to support people with dementia in their community.

The Social Care Institute for Excellence (SCIE) provides a dementia awareness e-learning course on its website. For more information, visit www.scie.org.uk/e-learning/dementia

Some people may find it rewarding to participate in research studies if they have received a diagnosis of dementia. Join Dementia Research is a website designed to match people who want to be a part of dementia research with studies that would suit them, from questionnaires

through to drug trials.

Visit www.joindementiaresearch.nihr.ac.uk to find out more about what's involved.

The Dementia Engagement Empowerment Project (DEEP) is the UK network of dementia voices. DEEP consists of around 100 groups of people living with dementia seeking to improve the quality of life for people living with dementia. For more information, visit www.dementiavoices.org.uk

Dementia is a progressive condition; this means it is important to think about the future and make plans with the person with dementia, while they are able to share their wishes. This is discussed in more detail in the following chapters, but it is important to note that planning for the future is easier the sooner it is started.

Carer support

Do you look after someone who couldn't manage without your help?

Andover Mind supports unpaid adult carers (including young carers 16+) caring for another adult with any health condition, to maintain their caring role for as long as they are willing and able to do so.

Our carer support advisors offer 1:1 emotional support and peer support groups, providing advice, information, signposting and training.

Dementia advice

There's no need to navigate your dementia journey alone. Our dementia advisors provide one to one support for people living with dementia and their carers, family and friends.

If you have a diagnosis of dementia, mild cognitive impairment, or are concerned about your memory, we are here to help.

Our services are **free** and we accept both professional and self-referrals via our website, by calling **01264 332 297** or email enquiries@andovermind.org.uk

We provide services across Hampshire, but our head office is at Andover Mind, Westbrook Close, South Street, Andover Hampshire, SP10 2BN (open Mon-Fri 9am-4.30pm)



CSDAHampshire



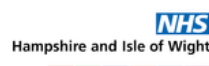
carer_and_dementia_support

andovermind.org.uk (Webchat is available)

Andover Mind: registered charity no. 1039094 registered company no. 2935549



The carer support and dementia advice service for Hampshire is commissioned by:





Planning for the future

There is a running theme through this Guide around the importance of planning when someone has dementia or receives a dementia diagnosis and, wherever possible, to plan early.

‘My husband has chosen a nursing home, so that will negate any guilt on my part if the time comes for placement. Or if I become incapacitated.’

Most people will automatically consider planning for legal and financial considerations – wills, financial affairs, powers of attorney (see page 59). However, just as important is considering the person with dementia’s life history, who they are and what makes them the person they are. This could involve putting together scrapbooks of photographs and stories, anecdotes, details of childhood and adult friends, favourite pets, enjoyable games and hobbies – this information will become invaluable as the dementia symptoms progress.

Whether the person with dementia is a partner, parent, sibling or close friend, whatever your relationship, you are unlikely to know everything about their life. Alzheimer’s Society recommends that people make a life history book; however, it doesn’t have to be a book, it could be a memory box, photo album, digital presentation or video – the choice of format is entirely up to you and your loved one. ➔

➔ Wherever possible, draw on the input of others whilst putting together this life story record. People can find this aspect of reminiscing and planning very helpful and therapeutic, helping them to share stories, connect and enjoy their time learning about each other. Also, different people have different perspectives, stories and insights, which can really enhance the reminiscence and be useful in the future. Not only will everyone enjoy the time spent sharing stories, you will have a lovely keepsake to refer to and which can also be passed onto future generations.

It is also valuable to help support the person with dementia as their symptoms progress. As the condition develops, understanding their life history can help to fill in aspects of what they may be experiencing or trying to communicate. As short-term memories can fade, longer term ones can remain, so having the life story to refer

back to, look through together, or inform is really helpful.

Practically, it can be a useful resource for sharing time together and may bring comfort to all. The information can be condensed for medical professionals and shared with any care or support staff. This will help everyone who may support the person with dementia to gain a good understanding of them as an individual and what makes them who they are.

It will help to build up a picture of their personality, likes and dislikes, routines and how they like to live their life. This can then be central to any personalised care and support plans.

‘ We had a storybook photo album of Mum’s life. She loved it and the staff at the care home loved it, too. ’

WHAT GOES INTO A LIFE STORY RECORD?

A life story record is a unique collection of information, memories and anecdotes about the person with dementia. It could cover all manner of things. However, it is a good idea to start talking with the person about their early life and significant events. Try to keep all conversations positive, but if there are any particularly significant negative life events, record these elsewhere for future reference – but not necessarily as part of the main record.



The following categories are designed to be conversation prompts. Not all need to be discussed, and if the person with dementia isn’t able to recall some or all of them, that’s fine, just concentrate on what they’re able to share and consider coming back to things at another time.

- Place of birth.
- Childhood town.
- Family – parents, siblings, other close relations – names, occupations, interests.
- Childhood friends.
- Pets.
- School life.
- Childhood interests – hobbies, favourite holidays etc.

- Occupations.
- Meeting their partner.
- Getting married.
- Having children.
- Family holidays.
- Significant family memories.

These topics are great to open conversations. From here, you can consider looking through old photos to give context to specific events or memories. Your relative may have special items or possessions that also help to build the picture or stimulate conversations. Try to bring these into the conversation and make a note of the story behind them.

Don't forget the benefits of involving other people in this process for different perspectives, stories or anecdotes.

If compiling a book or folder, you can stick in or add the photographs and write the anecdotes or stories alongside. The items could go into a memory box, or you could take a photo of them to put into the book for future reference, or to keep the connection between the item and the story.

Alzheimer's Society's *Remembering together – making a life history book*, leaflet has a useful suggestion for when there may not be photos or items available. It recommends, 'Photographs and documents may have been lost over time. Think creatively about finding things to use, such as a recent map showing a

place of birth or a modern photo of a school attended. It may be possible to find old photographs and postcards at antique fairs, second-hand book and charity shops or online.' Also, if there is a historical society close to where the person with dementia grew up, they may be able to help.

From this point, you can go on to explore the person with dementia's likes and dislikes, daily routines or habits. Consider the following as a starting point:

- How do they like to be dressed?
- How do they have their hair?
- How do they have their facial hair?
- What do they like to do in the morning?
- What are their favourite meals?
- What foods don't they like?
- Do they listen to the radio or watch TV?
- What's their favourite type of music, programme or song?
- How do they take their tea?
- Do they attend church?
- Do they enjoy gardening?
- Do they enjoy animals? Have any pets?

As the person's dementia symptoms progress, these specifics will assist anyone who may support them in daily life. It will enable people to build a clear understanding of who the person is and what is important to them.

CARE AND SUPPORT PLANNING

The care and support chapter starting on page 45 covers what types of services may be available. However, when engaging with formal care services, planning is, again, essential. You may

want to discuss thoughts and wishes around care and support. Does the person with dementia want to be supported at home for as long as possible? Would they prefer to be supported in a

care home or care home with nursing when their needs reach the level that requires care home support? Conversations around care and support can be difficult; people can have mixed feelings about care homes. As such, planning in advance and discussing care and support options can make decisions easier in the future.

When choosing social care support, any service provider, or the local authority, if it is involved, will undertake an assessment of the person with dementia, looking at any care and support needs they may have. How these needs will be best met should be set out in a care and support plan and could include formal services, or outside activities such as day services or voluntary organisations.

‘Social services is an invaluable resource and isn’t going to take the person with dementia away.’

As part of the assessment and planning process, other professionals involved in the person’s life should be consulted to build a picture of their care and support needs. If you’d like to know more about specific care and support that is available, the Care Choices website could help. It has a wealth of information for people seeking care and support as well as details of local care providers. Visit www.carechoices.co.uk

Once the person’s needs have been assessed and any suitable services have been recommended or engaged, their life story details and personal information will come into their own.

As the symptoms progress, it can become difficult for people with dementia to communicate what they may be experiencing. A good knowledge of their life history and their likes and dislikes can help anyone supporting them to understand what they may be communicating or experiencing. For example, if someone becomes upset at breakfast time and doesn’t want to eat, consider what you’ve

offered them: do they like it? Have you made them coffee when they only drink tea? Do you have Radio 2 on, when they prefer Radio 4? Any of these could have unsettled the person with dementia.

This is why understanding more about who they are can help everyone to understand what they are trying to communicate. This is useful information for any family members, friends and care or support workers – so keep a copy of their life story record in easy reach for consultation, but also as a lovely activity to look through regularly.

LIFE STORIES IN CARE SETTINGS

‘Knowing about a person’s life story is very important to care teams. It enables them to provide person-centred care and helps them to have insight into any particular actions or behaviours a person may have that are sometimes difficult to understand.’

‘A gentleman could not be persuaded to shower. However, when the care team became aware that his wife always used to lay out his clean clothes for him before running his shower, they did the same and it gave him the opportunity to do as much of his own personal care as he could.’

‘A lady would become very unsettled after teatime. Using her life story, the care team found out that she used to work in a pub in the evenings. Once they knew this, they started to invite her to gather up the plates and glasses after teatime and then do the washing up.

‘This fitted with what she had done for years. It helped her to become more settled, perhaps feeling that she had achieved her goal.’

With thanks to an Admiral Nurse at The Orders of St John Care Trust.

OTHER FORMS OF PLANNING

As mentioned at the beginning of this chapter, planning for the future is important. There are specific financial, legal and end of life plans that need to be made. As a person's dementia symptoms progress, they are likely to lose the capacity to make specific, important decisions. That is why these plans need to be in place.

The chapter on **financial and legal planning** explains more on page 59. Making plans for **end of life** including **funeral wishes** is covered in more detail on page 54.

Additional plans that you may like to consider

could be:

- Advance care planning (explained further on page 55).
- Using a support tool such as Alzheimer's Society's *This is me* document. For more information, see page 35 or visit www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me where you can download or order a free copy.
- Contingency planning for your wellbeing, such as arranging appropriate help to support your caring role. This Guide has a chapter on looking after you, beginning on page 37.

IS IT TOO LATE TO PLAN?

In an ideal world, everyone would receive an early diagnosis of dementia, enabling them to plan for the future and set out everything they wish.

However, it is quite likely that the formal diagnosis has come later, if at all, and the person's dementia symptoms have progressed to a point where they aren't able to communicate all of these things as you, or they, would like.

This doesn't mean you can't plan at all. People experience the symptoms of dementia in different ways, at different times. There may be moments when the person is able to recall specific events or stories. At these times, the use

of photographs can help to prompt them. As can involving friends or family members, as they may have a story or event to share.

Alternatively, playing their favourite music may help or singing a favourite song. Looking over and handling cherished items can be useful, as can smells such as a favourite perfume or aftershave, meal or flower.

Putting plans in place will help to ensure that everyone around the person with dementia will know their likes, dislikes, preferences, life history and wishes for the future.

This can be an emotional process and may take time to complete. However, when important decisions need to be made in the future, it will help that you've had the opportunity to make these plans, in whatever way has been possible for you.

“ There may be moments when the person is able to recall specific events or stories. ”

If someone's capacity to make decisions over their **legal, financial and healthcare affairs** changes significantly, the chapter on page 59 covers the available options in more detail.



When a family member has dementia

It's true to say that a diagnosis of dementia isn't just given to the person with dementia, but to their wider family, friends, neighbours and social networks. If the person who is diagnosed with dementia is still working, that also means sharing that diagnosis with their manager and work colleagues.

‘ Don't expect too much of yourself. Try to recognise which jobs have to be done by you and which can be done by someone else, allowing you to be wife/son/husband/daughter – which is your most valuable role. ’

The way in which you, as one of the people around someone with dementia, experience that person's dementia, is always going to be different to the experiences of the diagnosed person. Depending on individual outlooks, a person diagnosed with dementia may learn to live with their symptoms and adapt to their changed life. Other people living with dementia may go into denial, or even shut off from the world around them.

As the symptoms of dementia progress, it can be common for a person with dementia to not be aware of this, or not fully absorb the effect that their symptoms are having on themselves or those around them.

CHANGES TO RELATIONSHIPS

Alongside the different emotions being felt by the person with dementia, and those closest to them, you may find that family dynamics change.

They may become strained or redefined over time.

Whenever a person you care about develops dementia symptoms, there is inevitably going to be an adjustment to this new reality. If the person with dementia used to take charge of certain regular tasks for themselves and/or others, such as cooking, cleaning, shopping, gardening, working, running household finances or caring for other family members, any difficulties they experience with completing these tasks are going to impact upon their life, and yours.

‘ We found that education as to what dementia entails was really important. We learnt that we must help to manage the condition, not the person. That the person with the diagnosis of dementia is the same person after diagnosis as they were before diagnosis. Their symptoms do not immediately become severe just because of a diagnosis of dementia. There are beginning and middle stages long before later stages. ’

It is important to remember that for most people with dementia, changes are gradual. A lot of people live well with dementia for a long time. Gradual changes allow for small adjustments to be made to life and routines, as the weeks, months and years pass. As such, a diagnosis, if received, doesn't mean that life in its current form has to change overnight. However, it is helpful to be prepared for the changes that may come along.

For family and friends, and particularly if you accept the very personal and intimate role as a carer, the changes that dementia brings can often be experienced in very painful and emotional terms.

Common emotions can include denial, fear, a sense of loss and, as the person's dementia symptoms progress, guilt if their needs get to a

point where you can no longer care for them as you would wish to.

This is where the role of Admiral Nurses (specialist dementia nurses) really comes to the fore. Admiral Nurses support the whole family, and many carers report that the support of an Admiral Nurse was an absolute lifeline, helping to prevent carer breakdown. Sadly, Admiral Nursing services aren't available across the whole of England.

Find out if you have a **local Admiral Nursing team** on the **Dementia UK** website, **www.dementiauk.org**

Even if you don't have a local service that can provide face-to-face support, Admiral Nursing Direct is a national telephone helpline staffed by Admiral Nurses. It can be accessed by anyone looking for support and advice relating to dementia.

The **Helpline** is **0800 888 6678** or email **helpline@dementiauk.org** There are **top tips from an Admiral Nurse** on page 36.

The chapter starting on page 37 looks at carers, their rights, needs and support. However, it is worth mentioning now that if you are a carer, you need to look after yourself to enable you to look after the person with dementia. Consider contacting the local authority for an assessment of your needs; you have a right to have your needs assessed and you may be eligible for support. Also explore any benefits like carer's allowance. Local support organisations may be able to help you apply for benefits.

‘ Do not be dragged down by the negative stories out there. Be aware of the likelihood that things could become very difficult, but until they do, enjoy life! Change your mind to the situation. Don't let your mind make it bad before it is. ’

PARTNERS

Alongside aspects of daily living, and changing abilities to complete certain regular tasks, family relationships can also change. If you are the partner of a person with dementia, and perhaps together you had made plans for the future, it's natural to feel a certain sense of loss that these plans may never be able to come to fruition. These feelings can be even more acute if the person with dementia has been diagnosed when they are younger (under 65).

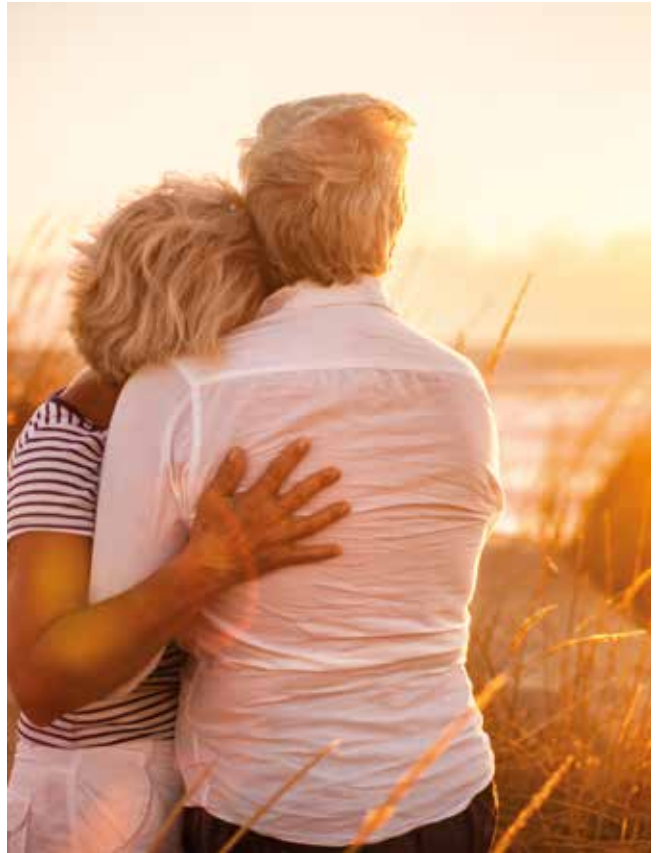
6 Donald had held a high-profile job in the city of London when he was offered early retirement. He and his wife, Sylvia, had planned a future full of activity and adventure, but within a year he had been diagnosed with dementia and this advanced rapidly, leaving Sylvia feeling unable to cope with her emotions of loss and fear. 9

It is worth remembering, however, that there are often many things that a person with dementia can do. With modification, the plans you've made together may still be relevant.

As communities become more dementia-friendly, there is a greater understanding of how to support people with dementia. There are even dementia-friendly holidays and activities available.

As a partner, you may feel that a future as a carer isn't how you expected your relationship to evolve. You might feel unprepared. It's helpful to remember that whatever your future caring role may become, you are still first and foremost a partner. Many people living with dementia actually dislike the term carer, when used to describe their partner.

If your partner's dementia symptoms impact upon their ability to show affection, or maintain an intimate or sexual relationship, it is



understandable that you could feel rejected.

Conversely, sometimes as a person's dementia symptoms progress, they may demonstrate increased levels of sexual desire, or even direct that desire towards someone else.

This can be very upsetting for you, as their partner. However, it is important to recognise that this isn't meant as a gesture to upset you, but a symptom of the dementia that needs as much support as any other symptom.

In every situation, however, drawing on the strength of your relationship, keeping alive memories of how you first became a couple, and supporting your partner to do likewise, can help to strengthen bonds. Some couples report developing an even deeper and more meaningful relationship by working together through the challenges that dementia has brought them.

WHEN A PARENT OR GRANDPARENT HAS DEMENTIA

If the person who has been diagnosed is a parent or grandparent, again a whole new mixture of relationship issues can come to the fore.

For younger children, it can be difficult to understand the changes in a parent or grandparent as the dementia symptoms progress. Alzheimer's Research UK has created a website called 'Dementia Explained' to help young people better understand dementia.

The website **www.alzheimersresearchuk.org/kids/dementia-explained** provides child-friendly dementia information, focusing on the ways people with dementia can change and the effect this can have on families.

By bringing together a range of resources including stories narrated by the broadcaster, Edith Bowman, videos and interactive games, the site allows young people to discover more about the brain, how it is affected by dementia and share their experiences to help others.



‘Beth’s father had vascular dementia for 19 years, beginning when she was around 12. As his dementia progressed, their relationship changed from being a father/daughter relationship to Beth having to take on more responsibility and, in the end, feeling as though she had become a parent to her parent.’

‘Coping with these changes wasn’t easy, but they didn’t happen overnight. The vast majority of the most difficult responsibilities came in the areas of being a next-of-kin and discussing do-not-resuscitate decisions, the latter happening in the last two to three years of her father’s life. Beth also had to take on roles such as advocating for her father and interpreting his needs when he could no longer communicate these clearly.’

‘What she missed as her father’s dementia symptoms progressed was the ability to go to him, as a father, and get his advice and help, as well as sharing any problems she was having. The physical decline he experienced in his later years with dementia was also upsetting to witness. Yet, despite the difficulties, her abiding memories are of the strength of their relationship and the pride she had in being able to help and care for him, as he had helped and cared for her when she was growing up.’

FAMILIES FROM DIFFERENT CULTURES

If the person living with dementia is from a different culture, you and they may have unique experiences.

As the person’s dementia symptoms progress, you may find that they revert back to a native language. They may find comfort in activities or

food from their childhood, or their culture may become increasingly important to them.

You may find that there are culturally specific services in your area, and if looking for formal support, a good provider should always take into account the person’s cultural background. →

➔ However, it is worth considering that some services may not be responsive to the individual needs of a person with dementia who is from a different culture. In these cases, look around for a service that is.

Whatever your connection to the person with dementia, it is likely that there will be gradual changes to your relationship. Being aware of these and adjusting to them with time will help. You may find some changes easier to manage than others, but remember, your response to the changes is natural and there is support out there to help you.

DAVID AND IRENE'S STORY

'When my husband David was diagnosed, he was only 60. He was working as a company director and the first thing I noticed was that he had started scribbling notes down before making phone calls, which he had never done before.

'What shocked me the most was how hard it was to get a diagnosis. David knew it wasn't just 'normal' memory lapses, but we could not get a doctor to acknowledge it might be dementia. It was only out of luck we were put in touch with one of the top dementia doctors in the country, who diagnosed David with semantic dementia.

'If you're not sure, or you think something might be wrong, you have to make sure you push to find out. I think GPs should be more knowledgeable about the microelements of dementia. I also think the information should be more readily available, because having to find out most of the information on my own during the early stages just added to the stress.

'My biggest piece of advice, having gone through this, is that you as a carer or family member have to make sure you look after

yourself and seek respite care and help.

'It got to the point with us that I was getting physically ill every day and eventually I was prescribed anti-depressants just to get through the day because of the stress of looking after David on my own.

'You need to take care of yourself because if your health deteriorates you're less helpful to your loved ones.

'It was only after I first arranged for David to go on an Experience Day at Belong, which is a day for people to go and take part in activities and interact with others who might be going through a similar experience, that I realised how tired I had got.

'I think that is why Belong's Macclesfield village has been such a big help because they first recommended David needed full-time care. When David eventually moved into the village it was such a relief to me, which sounds horrible to say, but the stress was just so overwhelming, and at least I knew David was getting the quality care he needed.

'Belong is quite unique because they employ an Admiral Nurse, who is a specialist dementia care nurse, and that makes everything so much easier for family members because you know your loved one is being treated properly.

'It's only after you get the chance to sit back and reflect that you realise how utterly overwhelming caring for someone in this situation can be. I think people don't like to talk about dementia, it's like the cancer of the 21st century because the word is so daunting, and so many carers carry on struggling.

'My advice is to get help, but more definitely needs to be done to let people know that the help is out there for them.'



Living well with dementia

People can live well with dementia. However, their symptoms can vary from day to day. Understanding the symptoms and how to manage them so you can all live well on a daily basis is important.

‘When Jack needed to take a break, he made sure Mary was happy and comfortable, listening to the radio or watching the birds in the garden, something she enjoyed doing. He then took five minutes to make a cup of tea and read the paper.’

How much a person living with dementia understands about their symptoms and how they are progressing is individual. Some people have more insight than others, and it's important to reflect on these variations, and if their symptoms are particularly challenging, not feel that the person is being deliberately difficult.

As Kerry Kleinbergen, a person who lives with the symptoms of dementia, said in a graphic she created to express how her diagnosis of dementia was affecting her life, ‘The person with dementia is not giving you a hard time. The person with dementia is having a hard time.’

Be mindful that as a person's dementia symptoms progress, their levels of understanding or awareness may decline. As a close relative or carer, you may find yourself having to explain things to them that you hadn't had to explain previously or help them with tasks that they used to do unaided. →

➔ Patience and calmness are important qualities in these situations, and you may want to call upon coping strategies like silent counting in your head or deep breathing techniques, to keep your cool if you need to.

Also, consider if there is anyone you can call upon if you need to, whether that's to come over for a chat or to offer practical support. There is no shame in calling for assistance.

It is vital, whenever you support a person with dementia, to ensure that you don't find yourself taking over from them. It can often seem easier, and quicker, to simply do things for a person.

However, by doing this, you may be contributing to them becoming more disempowered; losing skills and, ultimately, relying on you more than they might otherwise need to.

‘I thought that by helping Dad to drink I was helping him to get in vital fluids that the doctor said he needed. When my sister came around with a pack of straws, Dad was able to drink by himself. I hadn't even thought of it, but it meant he could drink when he wanted, and it was one less thing for me to have to do – although I always kept an eye on how much he was drinking and that he could reach the cup. Sometimes you need someone else's perspective on things because you can't see the wood for the trees.’

Over time there will be some crucial aspects of daily living, like driving a car, crossing the road or operating household appliances that could put



the person in danger as their dementia symptoms progress. These will obviously need to be carefully thought through. In relation to driving, a person who has been diagnosed with dementia has a duty to inform the DVLA, but that doesn't necessarily mean they will have to immediately stop driving.

In terms of household safety, there are technological options that can help to keep a person with dementia safe in the home. These include sensors and simple devices that can prevent overflow situations when using the bath or basin or that indicate when the gas has been left on. It's helpful to look into ways to make your home more dementia-friendly, and there is lots of guidance available.

The chapter on **care and support**, starting on page 45, explains this in more detail.

THE SYMPTOMS OF DEMENTIA AND THE CHANGES THEY BRING

No matter how the person's dementia presents itself, and however frightened or apprehensive you may feel, as a family member you may feel far more empowered, and able to cope, once you have armed yourself with as much information as

you can realistically take in.

If you are the sort of person who thrives on knowledge and takes an approach that 'information is power', you will undoubtedly

benefit from doing as much research and accessing as many support services as possible. These may be online, printed, via helplines, face-to-face or from seeing a dementia adviser, an Admiral Nurse or attending carers' or dementia support groups.

Even if you initially shut off from learning about dementia, over time you may find that you want to know more. It's perfectly okay to decline help and then look for it again at a later date. Everyone has their own way of coping, and you shouldn't feel that any doors to support are permanently shut. Sometimes people decline offers of information because they are fearful of learning about how dementia progresses but informing yourself now may help you to manage better should difficulties arise later on.

It's important to remember that you are experiencing your relative's dementia in your own unique way, which may be different to the views and emotions of other family members. These experiences are tied up with lots of emotional responses and linked to the specific relationship you have with the person with dementia. Sometimes these changes can feel overwhelming.

‘ Don't take anything they may say or do personally. ’

You may feel very isolated and invisible if any help offered by health or social care services is directed at the person living with dementia, rather than anyone asking how you are feeling and if you need any help. However, GPs and local authorities have a duty to consider the needs of family carers and should ask you about your

caring role and any impact it has on you. Even if they don't approach you, you have the right to ask them for an assessment of your own needs (see page 37). If you consider your needs early on and look after yourself, you will be in a better position to look after the person with dementia.

Don't be afraid to admit how you're feeling if you are finding things tough or if you need some extra support. Asking for help isn't a sign of weakness or a reflection of your caring ability. It is an acknowledgement that you are human, and you need to look after yourself too. If you struggle to manage as a carer, it's not only you who will need support, your relative will need to be looked after too. By seeking the support that you need, when you need it, you are caring for yourself as well as the person with dementia.

‘ To manage my caring role, I read what I could, learnt from it, listened to other carers and joined forums. Although this is not always the best thing to do as a huge number of carers just tell their stories: how bad it is/ was for them. But we are managing very well and take a lot of flak for not bleating about the worst of it. ’



MANAGING YOUR FEELINGS

As fulfilling and rewarding as taking on a caring role can be, you may also experience feelings of guilt, anger and loneliness at one time or

another. It is essential that you address your feelings as best you can, so that your own wellbeing is not affected.



→ Keep a diary of your feelings

By keeping a track of your emotions throughout the days and weeks, you may identify certain things that trigger particular feelings. If you know that one type of situation will make you feel a certain way, it may be easier to avoid in the future.

‘Take each day and situation as it comes. Be very patient and look for the positives.’

Talk to people

You may find it easier to talk with friends rather than family members as they're not as emotionally involved in the situation.

‘I practise self-care, talk to a friend or my mentor. I do fun things, such as go to the cinema, go for a walk, meet up with friends.’

Ask for help

If you feel other family members should be helping out more, speak to them as early as possible to avoid tensions later on.

‘Put emotional support for yourself in place. Find out more about dementia, join a support group.’

Let things go

There may be lots of niggles and stresses throughout your day. When you step back from the situation and look at it with a clear head, you may realise that it's not worth causing you additional stress.

‘I cope with tricky situations by biting my tongue and not putting across my point of view. I also avoid trigger subjects.’

DAILY LIVING TECHNIQUES

The book, *Confidence to Care* by Molly Carpenter, published by the home care provider, Home Instead, sets out some techniques to help support the person with dementia, and any specific dementia symptoms, on a daily basis. These are tried and tested but not everybody will feel comfortable applying them all. It is down to personal preference whether you try them.

- **Give simple choices.** By supporting the person with dementia to make simple choices, you are enabling them to have control.
- **Maintain their routine.** Life story records can help you to understand and, therefore, follow your loved one's routine.



- **Be flexible.** If the person with dementia changes their routine or something they usually do, be flexible. Try to adapt to the changes as best you can, as long as the changes aren't causing anyone any harm.
- **Live in their moment.** For example, it can be distressing for someone with dementia who is asking after a deceased parent to be told that the person has passed away. By living in their moment, you can help to reduce any distress that may be caused.
- **Redirect.** Redirection can be a useful tool in changing a mood, topic or subject as well as moving the person from an environment, or situation, that may be distressing or upsetting to them. This could even be changing the subject of a conversation to something familiar and comforting, looking out of the window at birds or traffic outside, opening their life story record or getting out treasured items.

- If something has upset the person you support, and you are unable to calm them down, you may want to **consider taking the blame** and apologising for the situation. It may help to diffuse things – however, this may not be effective in every situation and you may not feel comfortable with this.
- **Take a break.** If you feel that a situation is getting on top of you, try to take a break. If the person you are supporting is comfortable and

safe, take five minutes to yourself. If you find you need someone to help support the person with dementia while you have some time to yourself, don't be afraid to call on a friend or family member, support group or neighbour. Looking after yourself is as important as looking after the person with dementia.

‘I use lots of reassurance, encouragement, distraction techniques.’

KEEPING BUSY – HOBBIES AND PASTIMES

Keeping busy with a variety of activities is considered, by many people, to be vital in slowing down the progression of dementia. Activity and occupation can be anything that the person with dementia and you, as their family member or friend, want it to be. The social care provider, Care UK, has produced a useful guide to dementia-friendly family days out which is available on its website. The National Activity Providers Association has a number of useful publications, including a book of activities, that are available to purchase from its online shop.

A person with dementia may continue to enjoy hobbies and pastimes that have been life-long pleasures, or they may lose interest in these activities. It is important that you, family members or friends don't force the person to do something that they are losing interest in. Although it may be upsetting to see someone you care about discarding something you have previously strongly associated with them, see these changes as a chance to introduce the possibility of other activities that they haven't previously tried.

‘Anything from a cup of tea to walking around the block.’

In these situations, you may find that compiling their life story record or expanding upon it, can be very helpful in bringing your family together in

a new, shared endeavour to create this resource that everyone can benefit from and enjoy.

For more information on this, see the **planning chapter** starting on page 15.

Dementia should never be seen as a barrier to enjoying a particular activity (even if that activity has to be modified) or trying new things. Learning something new, be it a language, musical instrument or technology, can be revitalising for a person with dementia and give you, or other family members, or friends, something to engage in together. It may be that it is something that the person with dementia can be supported with by someone else, while you take a break. You may find befriending services in your local area that could be helpful in these circumstances.

Also, bear in mind that the tasks of daily living are activities in their own right. For example, cooking or folding the laundry. Engaging the person with dementia in these tasks can help to bring you closer together through regularly shared experiences. Using simple prompts, which may just be signs, such as words and pictures, around the home and on cupboard doors to identify what is kept where can help the person with dementia to participate in these activities more independently.

Also consider day services that might be available

in your area. These may be held in community halls or local care homes. They can offer a welcome change of scenery for the person with dementia and you. You may be able to drop them off and take a couple of hours for yourself. They may have a carers' group at the same time where you can relax and have a cup of tea or chat with other people who are caring for someone.

Details of **local services** start on page 66.

Respite care may also be available to you. Respite is another name for a short break, where the person with dementia can be supported either at home or in a care setting, whilst their carer takes a break. It can be invaluable to help carers recharge and do something for themselves.

MY EXPERIENCE OF ALZHEIMER'S BY CAROL BRANDON

'When my lovely, kind, caring soulmate, the man who supported and protected me for all my married life, was diagnosed with Alzheimer's, I had no experience of the disease.

'As we left the hospital, the fear of what was ahead left me with a terrible pain in my heart that made me want to be physically sick. I was so frightened. I had no idea where to turn to for advice and I know he felt just the same.

'My husband is a 'wait and see' person but I knew, from the then only slight change in his personality, that I needed help.

'My first contact was Alzheimer's Society who pointed me to an Alzheimer's café where I could meet people in the same position as myself. From other carers, I heard that some care homes provide day care. I knew this was what we needed for both our sakes. I was spending all day, every day keeping him occupied, taking him out and about and answering repetitive questions.

'I visited the local care homes where day care was provided to see which one would suit my husband's needs. He started at a care centre just one day a week at first, but this was unsuitable as they liked their customers to sit at tables playing cards or dominoes or doing sit-down activities. My husband just wanted to wander around all the time. They said he didn't fit in so he had to leave. The second place was adequate, but not very successful as it was more for the later stages of the disease and although I knew he was safe, he wasn't happy. Then I heard about Hartsholme House, which was quite close, although traffic and train barriers were obstacles. I gave it a try.

'From pulling into the drive, I felt it would be right for him. It was modern and spacious. I was so impressed with my tour around the building and the garden was light and open. Staff were lovely and friendly and just what he needed. This was completely right for him, and he loves it. He wanders around the large garden which is beautifully set out, and even has a chicken coop. He could do crafts, singing and all sorts of activities or he could wander safely around with all the staff there to keep a watchful eye on him.

'There are lounges, sitting rooms and a restaurant. He loves it and calls it his club. He has made many friends among other day care users, residents and, of course, the lovely caring staff, fully qualified to look after this lovely man, who is the most precious thing in my life.

'I feel happy and comfortable, relieved and content when I leave him there because he is safe and caringly looked after. I know that if I needed help at any time, if they could, they would accommodate, help and advise me.

'My husband is safe and happy; I have peace of mind. What more could I ask? It's like a second home to him.'

THERAPIES AND MEDICATION

There are numerous interventions that can come under the banner of therapies – everything from massage, yoga, aromatherapy and physical exercise to music, meditation, blogging and brain training exercises.

There are some fantastic examples of people with dementia who are living well having used various therapeutic strategies, including Chris Roberts. Chris has a blog at **www.mason4233.wordpress.com** and keeps himself active by speaking at public events and training people to become Dementia Friends.

Kate Swaffer is living with dementia in Australia. She uses a variety of different therapies to keep her dementia symptoms in check. On her blog (**www.kateswaffer.com**), Kate discusses the various interventions she uses and looks at therapeutic interventions generally.

A local memory clinic may offer different therapeutic interventions after a diagnosis of dementia – most commonly this is likely to be cognitive behavioural therapy or cognitive stimulation therapy. You may also find different therapy groups in the local area, such as those listed on page 67, which may be specific to helping people with dementia. Although, beware of anything that claims to produce miracle results.

Depending on the type of dementia a person is diagnosed with, they may also be offered different medications to help slow down the progression of symptoms. Currently, there are no pharmacological treatments to prevent or reverse dementia, and you should remember



that any medication a person with dementia may be offered may or may not be effective and could also involve side-effects.

‘ Mum is now in end stage [dementia] and has been symptomatic for up to 20 years but remains in denial. She was always unwilling to confront the issue of her symptoms and antagonistic to receiving any kind of assessment or outside help. Consequently, she was only officially diagnosed very late for legal purposes, to enable me to take charge of her financial affairs; by then she needed residential care. ’

If the person with dementia has other conditions and is already on medications, or has different medications prescribed in the future, check how these are likely to interact with each other. It's also a good idea to request a medication review either from the GP or local pharmacist (or indeed both if you want to get a second opinion). It is important to ensure that the person living with dementia isn't taking any more medication than is necessary and to report any side-effects. If a person is on lots of different medications, it can help to keep a daily record of these with the option to add in comments about any negative effects that occurred after a particular medicine was taken.

PRACTICAL ASPECTS OF LIVING WITH DEMENTIA

Every person approaches supporting someone with dementia, and any potential caring role, in a different way. There is no right or wrong.

In the early days, it might be a case of managing emotional changes, differences in the relationship that you once had. This can be difficult, and you

may develop ways of approaching situations or feel the need to ask for support.

‘ I manage by evolving to the new changes and nuances on a daily basis. I do not dwell on the loss of affection or closeness that we once had. I do not play games as in getting huffy because he won’t hold my hand. I tried that, it had no effect on him and made me feel worse. If I cannot change something, I change my own mind to it. The situation is exactly the same, but mindset is different, therefore whatever ‘it’ is, isn’t so bad. ’

You may find you are very good at providing practical help, like washing and dressing. Maybe your strengths lie in advocating for the person with dementia in meetings or appointments or sitting with them while you share a pastime or hobby.

Different family members may have different strengths and take on different roles too. Don’t be afraid to ask them to assist or be involved.

Over time, if you are supporting someone on your own, you may discover abilities you didn’t think you had and have to overcome difficult challenges.

PERSONAL CARE TASKS

Tommy has a YouTube channel, Tommy on Tour. The issues Tommy describes in an interview on YouTube, namely around caring for a family member of the opposite sex, get to the heart of the dignity and privacy concerns that many carers struggle with.

‘ When caring for his mum, Joan, Tommy struggled with more personal aspects of caring when he needed to help her bathe. ’

At first you may feel very uncomfortable helping with more intimate care – for example, washing, using the toilet or getting dressed – and that is a perfectly normal reaction that many carers report. If the person with dementia is your partner, you may still feel very uncomfortable, not because you aren’t used to seeing them in a state of undress, but because you are helping them with personal care that previously they would have done themselves. If the person is your parent, you may be helping them with intimate aspects of life that you had never considered – even seeing them undressed may make you feel uncomfortable.

Taking your time, acknowledging your feelings and, if necessary, seeking practical or emotional

help from health or social care professionals, is vital if you are struggling with this type of caring.

You may also worry about whether you are offering care and support in the ‘correct’ way. You may be fearful of unintentionally hurting the person living with dementia or doing something that causes additional distress or discomfort. In these circumstances, it can be helpful to look into the possibility of having some training. What provision you have in your local area for family carer training can vary, and many areas still have no official training available for families who are caring for a relative. However, you could be proactive and approach a local care home to see if they would allow you to visit. The person with dementia could be looked after whilst you, as their carer, join in some of the training being given to care staff.



‘Jenny was struggling to get her husband, Michael, in and out of the car until care home staff showed her the techniques they had learnt for helping a person with limited mobility to move from one position to another. That help was invaluable and enabled them to continue to get out and about in their local area.’

In common with many carers, you may find that as a person’s dementia symptoms progress, supporting them with mobility or incontinence are two of the most difficult aspects of caring. Recognising this, and being prepared, may help you to manage. It is also worth bearing in mind that paid care workers are meant to receive specific training in ‘moving and handling’ and supporting a person with incontinence, so don’t feel that you have failed if you don’t know how to approach these challenges. Many of the skills of caring don’t come naturally, and you may find that you will need extra help, either in the form of training, help in sourcing and using equipment, or from professional home care workers who can assist you with difficult tasks.

If you and the person with dementia attend any dementia day services, you may find that the staff there are trained and could give you advice. They may also be able to point you in the right direction of any training or other knowledgeable people.

Adapting the home

Be mindful that there are often things that you can do to modify the home environment to help delay any potential decline in the abilities of the person with dementia. Examples include: using signage or lights to help guide the way to the toilet, ensuring flooring is uniform (differences in floor surfaces can lead to a person with dementia not wanting to enter a room, such as the bathroom or cloakroom). Likewise, maintaining an exercise regime and seeking treatment for any joint problems can help people to remain mobile for longer.

Telecare has greatly evolved in recent years and there is a wide range of devices to support people living with dementia to remain independent at home. Adaptations such as grab rails, step-in showers or step-free access to front doors can enable a person to have more confidence in moving around the home and reduce their risk of falls. See page 45 for more information about assistance with daily living.

There are different approaches on what can help people live well with dementia in their own home. It is worth researching these in more detail and trying some out.

‘I wish I’d received practical advice, such as what equipment was available and how long it would take to come.’

CARING FROM A DISTANCE

There are unique challenges when you care from a distance, as many family members increasingly do if their relative is diagnosed with dementia and living alone in a different part of the country. There are lots of things you can do to help your relative, even if you aren’t with them, including using different technologies to communicate and remind them about certain activities, like taking medication or eating; and adapting their home to help them remain independent for longer. For more information, visit www.connecttosupporthampshire.org.uk/carersupport and select ‘Caring from a distance’.



COMMON CONDITIONS

Dementia rarely exists in isolation, and many people who are living with dementia also live with other conditions such as hypertension (high blood pressure), digestive problems (including irritable bowel syndrome, constipation or diarrhoea), heart problems (including chronic obstructive pulmonary disease), bone, joint and muscle problems (including osteoporosis and arthritis), breathing problems (such as asthma), skin problems (including eczema), learning disabilities and many different cancers. It is known that pain is often poorly understood and treated in people with dementia, and as a person's dementia advances they may find it more difficult to express whether and where they have pain and to request treatment, which can be particularly difficult and upsetting for you too.

Sensory loss

It is also important to be mindful of sensory loss in a person who is living with dementia. The person with dementia may need glasses or hearing aids, which they will need to be assessed for. They may develop different conditions related to their ears or eyes – for example, macular degeneration is a possibility as eyes age. Be mindful that it can be common for people with dementia to find it difficult to adapt to wearing glasses or hearing aids, and some people may even refuse to wear them when, prior to their dementia, they would have always worn them. Speak to a professional if you face this issue and ask if there is anything you can do to help the situation.

Oral health

It's vital too that the dental health of the person with dementia is monitored. Over time it may become more difficult to maintain a good oral hygiene routine, and the expert input of a dentist, who is trained in treating people with dementia, is important to help prevent other health issues developing as a result of tooth decay. If the person with dementia needs to wear dentures, you should be prepared that over time these may become another item that they no longer want to use.

Eating and drinking

People with dementia are also at increased risk of dehydration and malnutrition. They may forget to eat and drink, or their tastes may change. You may find yourself becoming frustrated if the foods and drinks that you are preparing aren't being consumed like they used to be. However, try to experiment with different flavours (sometimes stronger flavours help) or textures of food, introduce more finger food, and in the case of dehydration, try a variety of drinks as well as foods that are high in water, such as some fruits. Their GP can also prescribe food supplements if malnutrition is a concern.

As a person's dementia progresses, they may develop dysphagia (swallowing problems). If you suspect the person with dementia is struggling with their swallowing, you should ask their GP for a referral to a speech and language therapist. The speech and language therapist will carry out an assessment and may recommend that you thicken foods and drinks. A thickener may be prescribed. They may give advice on the best posture for eating and offer strategies with foods and drinks to make them easier and safer to eat, including pureeing food. If the person with dementia is having problems with swallowing, this can lead to an increased risk of chest infections, so it's important to keep a close eye on them to catch any signs of chest problems.

Mobility

If the person with dementia's mobility decreases, they may become more susceptible to pressure ulcers. There are lots of useful products on the market, and if they are becoming even less mobile, you should speak to their GP to get an assessment of their mobility and details of any products that can help to prevent skin damage.

Mental health

It's also important to remember that alongside changes to physical health, a person with dementia

could also have, or develop, mental health issues. Two of the most common examples are depression and delirium. Such conditions need specialist help, medication or other therapeutic interventions. If you are concerned about the mental health of someone with dementia, you should talk to their GP.

Hospital

If the person with dementia needs to go into hospital, you might like to consider completing a document like Alzheimer's Society's *This is me* to help hospital staff know a little more about the person. It is a simplified life story document. There is also a campaign to give carers the right to remain with the person they are caring for when they are in hospital. It's called *John's Campaign – For the right to stay with people with dementia in hospital*, visit www.johnscampaign.org.uk

Flu

Adults over 65 should receive the flu vaccination annually. Those with dementia are at increased risk of having health complications from influenza. Those providing care and support can ask their GP

or pharmacy for a vaccination. This protects you and prevents the virus passing to others, even if you don't show any symptoms.

Incontinence

Incontinence is a frequently reported concern in people with dementia but there are many ways to prevent or reverse it. Incontinence should be properly assessed and reversible causes treated where possible, but while the person is waiting for treatment or waiting for treatment to work, continence products are essential. You can get advice at www.continenceproductadvisor.org/ There is a lot to consider when supporting someone with dementia on a daily basis. You will develop your own routines and techniques but consider that these are likely to have to change over time. Don't feel like you must manage on your own. There are support networks out there, whether that's family and friends, local groups or national organisations, so look after yourself as much as you look after the person you support. For more information, visit www.alzheimers.org.uk (search 'Continence and dementia').

**Want to live
independently
at home?**



Your online one-stop-shop for information, advice and services to help you manage your care, stay independent and connect to your community.

ConnectToSupportHampshire.org.uk

**Connect to
Support
Hampshire**

Top tips from an Admiral Nurse

Admiral Nurse Caroline Clifton works for Belong and supports carers and families of people with dementia. As a specialist mental health nurse, she helps increase understanding of techniques to support people with dementia. Here are her top tips for family members and professionals.

1 If the person with dementia is not a close relative, get to know the person.

- ✓ Know their likes and dislikes.
- ✓ Gather life history.
- ✓ Have three points of conversation.

2 Maintain eye contact and smile.

The person with dementia will notice:

- ✓ Your emotional state.
- ✓ Your body language.
- ✓ Tone of voice.

3 Slow down.

- ✓ Provide support in a relaxed manner.
- ✓ Help the person to do things for themselves.
- ✓ Keep it simple.

4 Introduce yourself every time if they are uncertain of who you are.

- ✓ Tell the person your name.
- ✓ Tell them what you are there for.
- ✓ Refer to the person by their name.

5 Communicate clearly.

- ✓ Talk about one thing at a time.
- ✓ Offer simple choices.
- ✓ Speak clearly in a warm, calm voice.

6 Step into the person's world.

If the person becomes upset:

- ✓ Reassure the person.
- ✓ Acknowledge that you can see the person is upset.
- ✓ Validate what the person is saying or doing.

7 Keep it quiet.

- ✓ Create a relaxed environment.
- ✓ Stop, listen and avoid distraction.
- ✓ Reduce conflicting noises.
- ✓ Avoid crowds and lots of noise.

8 Don't argue or quibble.

- ✓ Go with the flow.
- ✓ Acknowledge and respect what the person is saying and doing.
- ✓ Telling them they are wrong may have a negative effect.

9 Engage and encourage.

- ✓ Get the person started with a meaningful activity.
- ✓ Set up activities to succeed so that there is a positive outcome.
- ✓ Focus on what the person can do.

10 Talk with others.

- ✓ Share your experiences with others.
- ✓ Talk together about what has happened and how you dealt with the situation.
- ✓ Record what has helped and what has not for future reference.

With thanks to Caroline Clifton, Admiral Nurse, Belong.



Looking after you

Carers regularly look after, help or support someone who wouldn't be able to manage everyday life without their help. A carer doesn't have to be living with the person they care for, and the help they give doesn't have to be physical. The carer may be caring for a partner, another relative, a friend or a neighbour.

‘I would have liked to have known what I was entitled to or what was available in my local area – respite care, carers' groups and benefits advice. ’

If you're not sure if you're a carer, consider whether you help with the following tasks:

- Personal care, such as washing and dressing.
- Going to the toilet, or dealing with incontinence.
- Eating or taking medicines.
- Getting about at home or outside.
- Practical help at home, keeping them company.
- Emotional support or communicating.

If you are taking on any of these tasks, it's likely that you are a carer. If you are undertaking a caring role for the person with dementia, ask your GP surgery to register you as a carer. If your GP is different from the GP of the person with dementia, it is worth making both doctors aware of your role. It is important that you look after your health and consider your needs, this will enable you to look after the person with dementia. ➔

➔ You should ask your GP for an assessment of your health and your needs as a carer. This is separate from the assessment the person with dementia may have and is very much an appointment about you and helping you to maintain your health and look after yourself so that you can care effectively.

‘I wish I’d had more regular contact with my GP.’

You may also want to request a carers’ assessment from your local council. This is different from any GP assessment and should look at other aspects of your life including how you can be supported to maintain your caring role. Your assessment may be carried out at the same time as that of the person with dementia. However, they do not have to have an assessment if they don’t want to. Also, if you wish to speak in private about your caring role, this is also completely possible. In those circumstances, you can have an assessment on your own.

A common reason for assessments to happen together is because support for you, as a carer, might be best met by services provided to the person you care for. Respite care and short breaks may be provided to the person you are caring for, but they will enable you to take a break from your caring role.

However it is carried out, it is important to be as open and honest as you can be during your

assessment so that the person carrying out the assessment fully understands your situation.

BENEFITS

There are a number of State benefits that you, and the person living with dementia, may be able to apply for. These could include:

- Attendance Allowance.
- Personal Independence Payments.
- Carer’s Allowance.
- Council Tax reductions.
- Income Support.
- Pension Credit.
- Savings Credit.

It is important to have a full benefit check for both yourself and the person living with dementia. Also, make sure the situation is reviewed occasionally, especially as any dementia symptoms progress. Local support organisations may be able to help you carry out a full benefits check – these may be carer support groups, dementia groups, Age UK or Citizens Advice.

For more information on **local services**, see page 66. Alternatively, **Money Helper** offers free and impartial financial advice. Visit www.moneyhelper.org.uk

CARING WHILST WORKING

If you are in employment, you may want to talk to your employer about your caring responsibilities. As a carer, you may have the right to request flexible working depending on certain criteria; however, it is not guaranteed that you will receive it. Carers UK has useful information on caring whilst in employment. It is under the ‘Help and Advice’ tab on its website.

Deciding to tell your employer that you have caring responsibilities is very personal. You do not need to disclose this information; however, it may help you to access certain legal rights and additional support.

Your company handbook may also contain details of any company policies to support carers.

PRACTICAL SUPPORT

In terms of practical support, national organisations like Alzheimer's Society, Dementia UK, Age UK, Carers Trust and Carers UK all provide carers' services in various forms, including online, leaflets, helplines and face-to-face support groups.

‘The best advice I was given was to look after myself.’

You may also have some independent carers' services in your area (services that aren't linked to a national organisation) – the local sources starting on page 66, an internet search, a leaflet from your GP surgery or an enquiry via your local Citizens Advice should be able to locate these for you. In addition, there is specialist support from Young Dementia UK if the person you are caring for has been diagnosed at a younger age.

Some services may offer forms of training for carers, via workshops or information sessions. It might be worth contacting a local carers' organisation to find out if there's anything available in your area.

A wide range of local information, support and advice can be found on **Connect to Support Hampshire**. Visit www.connecttosupporthampshire.org.uk

In addition, **Andover Mind** is the Hampshire-wide commissioned service to support carers and people living with dementia. Find them on page 66.

‘I would have benefited from finding an online community for me, as a carer. Since I have discovered Twitter and social media I have realised that there is always someone out there to talk to.’

If difficult situations arise, you may benefit from seeking an advocate, either for yourself or the person with dementia, to provide support in meetings and when dealing with professionals.

There is a national 'Carers Week' held every June and a 'Carers Rights Day' in November. You may find that during that time there are events happening in your local area which may be helpful to you.

There is also an annual **National Dementia Carers Day**. Visit www.nationaldementiacarersday.org.uk for information.

Alongside these awareness-raising events, there is an annual Dementia Action Week run by Alzheimer's Society every May and World Alzheimer's Month, co-ordinated by Alzheimer's Disease International, is every September.

During these times, you may find more coverage of dementia in the media, and dementia-specific events being held in your area that could provide useful support and advice.

If you are a young carer, or your children or teenagers are involved in the care of a person with dementia, there are some specific resources that have been made by, and for, younger age groups. The NHS website sets out rights of young carers. Barnardo's and other organisations can support young carers. In Hampshire, search online for the Hampshire Young Carers Alliance.

You may also find yourself in the position of a 'Sandwich Carer', which is the name given to a person who is looking after young children and caring for ageing parents. This can be a delicate balancing act and it's important to seek support to help you. You do not have to undertake everything yourself, in isolation.

SUPPORT

No matter what form your support or caring role takes, you may find you benefit from peer support and mentoring.

Talking to other carers or family members, either through carers' groups, online forums such as Alzheimer's Society's Talking Point or social media may be useful for you in helping you connect with others and get support with any practical or emotional issues that you are experiencing. There are also specific organisations that can help carers, including the Together in Dementia Everyday network.

‘I managed by speaking to people who had cared for a person with dementia. I was assigned a mentor who had been a carer. She taught me coping strategies that included arranging activities that were nourishing and enjoyable. She was my lifeline.’



WHAT IF I CAN'T CARRY ON CARING?

If your caring role begins to feel too much for you, it is best to do something about it as soon as possible. It may help to talk to other family members first and ask for their advice. When alternative care for the person with dementia starts to be discussed, it is likely to provoke an emotional response amongst your family. However, it is important not to feel pressured into something you feel like you can't carry on with.

It is also important to think in advance why, in time, you may no longer be able to care. This can allow contingency plans to be organised and enable you to find some support early on. You should also consider emergency planning for unexpected circumstances like being admitted to hospital. Visit <https://carercentre.com/emergency-planning> for more information.

You may want to contact your local authority to ask them to undertake an assessment of the person with dementia, even if they have been assessed before. Their needs may have changed or increased. The outcome of any new assessment will help to inform your decisions about what to do for the best. The local authority may also offer you

information and advice or direct you to specific services that can support you.

Depending on the circumstances, respite care may be a suitable solution. This gives you as the carer time to yourself, knowing that your loved one is cared for.

Respite can be arranged on a regular basis or just when needed and can last anywhere from a few days to a number of weeks.

For more information on **formal care and support**, see page 46.

The publisher of this Guide also has a website containing information on seeking care and support for a family member and how to cope with the emotional situations that may arise during the process. Visit www.carechoices.co.uk

Caring for someone with dementia can be very rewarding and be a natural part of your relationship. However, don't forget to look after yourself and access any support you may need to carry on caring.



People you may meet

There is a wide range of health and social care services that support people with dementia and their families. For some people, meeting so many new professionals in a short space of time can feel overwhelming, so it may be helpful to know who they are and what they do.

‘ Every day can be different when someone has dementia, don’t assume it will be the same. ’

The professionals may be employed by the NHS or local authority, private businesses or voluntary organisations. Here are details of just some of the professionals you may meet.

GPs

The local GP will probably have been your first point of contact. The GP is the one who may offer a diagnosis of dementia, refer you to a consultant doctor or a memory clinic, or consider your health needs as a carer.

CONSULTANTS

These are doctors who have had extensive training and experience in a particular area.

There are different types of consultants, and who people are referred to will depend on their symptoms and how the services in the local area

are arranged. The consultant may be a:

- **Neurologist** – specialists in disorders of the brain and nervous system.
- **Geriatrician** – specialists in the physical illnesses and disabilities of old age and the care of older people.
- **Psychiatrist** – specialists in diagnosing and

treating a range of mental health conditions.

- **Old age psychiatrist** – psychiatrists who have had further training in the mental health conditions of older people.

The consultant will work with other professionals, including nurses, social workers and occupational therapists.

CLINICAL PSYCHOLOGISTS

Clinical psychologists assess memory, learning abilities and other skills, and can offer support.

They often work with consultants in memory clinics, as part of a team.

NURSES, DISTRICT NURSES OR COMMUNITY MENTAL HEALTH NURSES

Nurses support people in hospital, undertake procedures at the GP surgery or will be based in the community. They may make home visits, or you may meet them in a healthcare setting. They may carry out assessments in the home and offer

treatment, care and support.

They are likely to be able to advise on how people with dementia, and those supporting them, can improve their quality of life and general health.

ADMIRAL NURSES

These are dementia specialist nurses. They are trained to give practical guidance and solutions alongside emotional support to people with dementia, and their family members or carers. They tailor their vast knowledge and understanding of dementia to support the unique needs of each individual and their family. Admiral Nurses can provide the emotional and psychological support that people may need.

Acting as a stepping stone to the different parts of the health and social care system, Admiral Nurses can also help to connect all aspects of

care for people living with dementia and ensure that everybody's needs are being met.

More recently, Admiral Nurses are linking with care organisations and are, themselves, supported in their professional development by Dementia UK.

People living with dementia could be referred to **Admiral Nurses** by their GP or you can find a local team online at **www.dementiauk.org/get-support/find-an-admiral-nurse**

OCCUPATIONAL THERAPISTS (OTs)

Adapting to an individual's changing level of cognitive functioning is essential for maintaining and increasing the wellbeing of a person living with dementia. OTs are specialists in this area

and that provides a foundation for undertaking assessments and intervention covering physical, social and mental health. GPs can refer the person living with dementia to local services.

SPEECH AND LANGUAGE THERAPISTS

These therapists are able to advise on ways of communicating more effectively and on

eating or drinking if the person with dementia is experiencing swallowing difficulties.

CONTINENCE ADVISERS

Some areas may have a continence adviser who can assist with continence issues. They can also give information on useful equipment, ranging

from commodes to incontinence pads. The GP may make a referral to an adviser, or you may be able to get in touch directly.

DIETITIANS

A professionally qualified dietitian can provide advice and guidance about food, nutrition and issues such as a poor appetite, weight loss, weight gain, vitamins and food supplements. Your GP or

consultant can arrange for a referral to a dietitian. Some dietitians may be able to offer home visits (including to care homes), while others may be based at a local health centre or hospital.

CHIROPODISTS

Maintaining mobility is much easier when you have healthy, pain-free feet. NHS chiropody (sometimes known as podiatry) can be accessed

through the GP but there are restrictions on eligibility, so check with the GP first. Alternatively, consider a private chiropodist.

EARS, TEETH AND EYE PROFESSIONALS

Though these things may not be the first issues people think about if living with a diagnosis of dementia, issues with these parts of the body can greatly impact on a person's wellbeing. They can increase levels of confusion, distress or discomfort. It is important to get checked regularly and find

professionals who have an understanding of the specific health considerations of someone with dementia. A referral to an audiologist, dentist or optometrist may be made through the GP. Alternatively, you may already be in touch with these services or find them on the high street.

SOCIAL WORKERS

Sometimes referred to as care managers, social workers have specific training and qualifications. They are usually involved in assessing a person's

social care needs and eligibility for services as well as in planning, co-ordinating and advising on services to meet those needs.

CARE WORKERS

Care workers are formally trained to help with day-to-day activities such as personal care, washing and dressing, housework and emptying

commodes, preparing meals, prompting to take medication at the right times and accompanying people on social activities or to appointments.

www.livingwithdementiatoolkit.org.uk

The Living with Dementia Toolkit for people with dementia and their carers is full of resources to:

- give you **hope** for the future
- **inspire** you through real-life examples
- offer **ideas** to help you live your life as you choose

You'll find lots of resources in these five sections:



Open the camera on your smartphone or tablet. Point it at the QR code (on the right). This will open the **Living with Dementia Toolkit**.





Care and support needs

As a person's dementia symptoms progress, you or they may need some help or support on a daily basis. There are differing levels of support, from simple home aids which help with tasks that are becoming more difficult, through to formal social care support from a home care provider and onto residential care.

‘ I am grateful that mum is well cared-for in a good specialist unit and grateful we could afford to pay for it. It was the only place I saw where I felt comfortable for her to go and there is a huge waiting list. ’

Completing an advance care plan with your loved one can indicate which care and support options may be best. See page 55 for more information.

ASSISTANCE WITH DAILY LIVING

Simple aids and adaptations around the house can make a huge difference to someone's independence. They can be subtle and unobtrusive to help manage everyday tasks. These could include medicine dispensers, cupboard labels or pictures, contrasting coloured crockery or large-handled utensils. There is a wealth of different items.

There is also an increasing number of electronic devices or assistive technology products on the market that can offer support to someone with dementia. These can include sensors that indicate when the gas or water is left on and devices that notify if someone leaves the house. Argenti can offer support with a range of technology enabled care options via Hampshire County Council.

Visit <https://argenti.co.uk/hampshire>



➔ If you're not sure where to start, an occupational therapist may be able to help.

If you're not in touch with the local authority's adult social care department, then you may need to make contact in order to access an occupational therapist.

However, if there is an independent living centre nearby, they may have in-house occupational therapists. Some independent living centres are open to the public, whereas others are run by the

local authority and you may need an appointment.

Contact your local centre for more information. Alternatively, there are a growing number of private occupational therapists. A quick search online may find one local to you.

The **Living Made Easy** website offers help and advice on daily living as well as details on equipment. For more information, visit www.livingmadeeasy.org.uk

GROWING SUPPORT NEEDS

You or another friend or relative may be supporting the person with dementia on a daily basis. However, there is likely to come a time when their needs increase or the person who supports them regularly requires a break. It is at this point that you're likely to come into contact with formal care and support services.

Support can range from home help, assisting around the house with housework, shopping, cooking etc, through to assistance with personal care needs. Personal care can include helping the person with dementia to get dressed, assisting them in having a shower or going to the bathroom, or supporting them to eat or take their medication. See below for more information on the different types of formal care and support.

Depending on your situation, your first step could be visiting Connect to Support Hampshire online to find informal support opportunities. You may want to contact the local authority for an assessment of the person's care needs. This can help to identify what health and social care needs they may have and how to meet them.

Alternatively, you can contact private care and support providers who will also assess your loved one as part of the initial care planning process. Even if you have contacted the local authority, it may be that after an assessment you are advised that you need to contact a private organisation to find suitable support. Either way, it is important that the person with dementia's needs are fully assessed to enable you to find the right support for them.

FORMAL CARE AND SUPPORT

There are various different levels of formal care and support.

Home help

Home help offers support with a range of household jobs, including cooking, shopping, gardening, companionship and help with getting to and from social activities or appointments. Some even undertake small maintenance jobs.

Home help doesn't include personal care. If the person living with dementia doesn't have any specific care needs but would benefit from some additional company or help with small jobs, then home help could be the right choice.

Home care

Home care is also known as domiciliary care. It involves trained care staff assisting the person

with dementia with personal care tasks. These can include: getting up in the morning, washing, showering, bathing and dressing; preparing meals and helping with eating; help with any specific needs, including prompting to take medication; help to get to bed at night and helping with mobility – home care staff have specific training covering moving, handling and the use of hoists.

Care staff can visit your relative's home every day, for as long as is needed to meet their needs. Before a routine is set in place, visits should be arranged between the agency, the person with dementia, you or anyone who may offer regular, unpaid support and anyone else who may be able to advise on your loved one's care and support needs. The visit will look at the person with dementia's specific care needs and how they will best be met with support. A clear care and support plan will then be drafted.

The care plan means everyone knows when visits are to be expected and which tasks the care assistant will undertake. Visits can vary depending on individual needs and care assistants can visit more than once a day if needed. Typically, care services are available from 7.00am until 10.00pm. Night-sitting is also a possibility and can help if your loved one experiences difficulties sleeping at night and the person supporting them at home needs to get a good night's rest.

The hourly rates for this type of service vary depending on the specific services required, the time visits are arranged for and the location. Always ask for a clear breakdown of costs, any additional charges and whether they are reviewed annually before deciding on an agency.

Extra Care (Housing with care)

This is affordable housing offering care and support for people 55+ who may be struggling to live at home but don't need residential care, combining services and independent living. This can promote a person's wellbeing, rejuvenating

independence they may have feared lost. An Adults' Health and Care assessment and a Housing assessment will be required.

18 schemes across Hampshire cater for varying care needs including dementia. Rowan Court in Eastleigh and Matilda Place in Winchester specialise in dementia care. Residents rent their own flats and receive scheduled personal care visits from staff according to specified care plans. On-site staff can also provide emergency care 24 hours a day. Flexible reassessments by Adults' Health and Care facilitate changing needs. There are communal areas, meal provision if required, regular activities and shared facilities such as lounges and gardens. Rowan Court also has a salon. Both schemes offer a safe and supported environment nearby local facilities and Matilda Place will consider residents' pets.

Extra Care can help to delay or prevent admission to a care home. All schemes aim to be a home for life; end of life care can be provided when needed. Further information can be found at **www.hants.gov.uk/extracarehousing**

Personal Assistant (PA)

You can employ a PA to help with care needs by setting the tasks that you would like a PA to help with and picking the days and times you would like support. The Hampshire PA finder can match with a local PA in your area. Visit **www.hampshirepafinder.org.uk/home**

Shared Lives

Shared Lives provides a permanent home, a short stay or day care for eligible people in the home of a Shared Lives carer. Shared Lives carers undertake a thorough assessment process prior to approval. Needs, likes, dislikes and interests are identified so that Shared Lives carers can be carefully matched with eligible people. Short stays can be arranged on a regular or occasional basis. Find out more at **www.hants.gov.uk/sharedlives**



→ Live-in care

If your relative has round-the-clock needs but would like to remain at home, 24-hour live-in care may suit them. Live-in care can be an alternative to a care or nursing home and can be an option for family carers to take a short break. As well as all the tasks you would expect a care assistant to help with, live-in carers can also become great companions and provide assistance with other tasks, including running the household and accompanying them on social activities.

Care homes

Care homes and care homes with nursing offer 24-hour care and support to people who are no longer able to live independently in their own home and require more intensive care than home

care is able to provide.

Care homes offer assistance with personal care needs, whereas nursing homes have registered nurses to undertake any specific nursing needs. The media gives a poor impression of care homes; however, the right care home can make a huge difference to someone's quality of life.

Every care home is different and making the right choice to meet your relative's particular needs, preferences and personality is the most important thing. There are thousands of care homes in England; however, it's important to ensure that the staff in the homes you are looking at have received training in supporting someone with dementia and can meet the person's specific needs.

SPECIALIST DEMENTIA CARE

Relationships are a huge part of life. We all value them, they are important to us and our lives. This means that they are just as important when considering care and support. Whenever you interact with services – health, social care or other support, it's important that they see the person with dementia as a person first and foremost. This is where life story planning can come into play. Basing care and support on good relationships and communication is essential to building person-centred care. This should be a consideration for any care and support services you may consider.

When looking for care for a person with dementia, it can be hard to differentiate those providers who say they support people with dementia from those who have had specialist training in providing care that is tailored to the particular needs of people with the condition. Although every care provider can tick a box to say they support people with dementia, there are several things to look out for to find those providers that go the extra mile.

If you are looking for home care or domiciliary care, speak to the manager, in depth, about how

they support people with dementia and any specific training staff may have. The person with dementia is likely to respond better to someone supporting them if it is the same person each time. This enables them to become accustomed to that person coming into their house.

With this in mind, you may want to ask what happens when the usual care worker is away – will alternative care be arranged? Will you be informed by the agency when somebody else is coming instead? Will that person be known to the person with dementia? Ask whether care workers have to work within strict time constraints, especially where visits are quite short, or do they have any flexibility to stay a little longer, if necessary?

Good-quality care providers will focus on relationships and have an emphasis on person-centred care. Where dementia is concerned, this approach means that all staff will focus on the person as an individual, rather than the condition itself. Although it sounds simple, it means that they will be treated as the person they are, not as a person with dementia.

Staff should engage in conversation with them and get to know their interests, likes and dislikes, even if they cannot communicate their wishes. Staff should also try to accommodate your loved one's daily routines. They should be interested in, and try to learn about, their past and what their life has been like, their childhood, their career, their family etc. This is where the life story record can help.

Ask any care provider if staff have specialist dementia qualifications. Alzheimer's Society, for example, offers a Foundation Certificate in Dementia Awareness. The test is available on its website and it tests care staff on their knowledge of dementia and how people can be supported in a person-centred way.

Care providers and their staff will undertake specific training on aspects of supporting people who receive care and support. Dementia training can be one aspect of this and many training organisations offer this type of course. A good care provider will undertake training in supporting people with dementia and will be able to prove, and be proud of, that fact. Some care providers have developed their own dementia care training, which is accredited, and are likely to have a specific member of staff to take the lead on caring for people with dementia.

All of these aspects point towards a care provider having a true understanding of how to support someone with dementia. However, choosing a care provider is a very personal decision. It includes so much more than these pointers. If you find a good home, or provider, that takes the time to understand the person with dementia, to see them as an individual and provide the very best relationship-centred support, that you feel comfortable and confident with, then follow your gut instinct. If you have the opportunity, trial periods are a good way to see how the person with dementia will feel with the service and you can always change your mind or look for another home or provider if it doesn't work.

When it comes to care homes or care homes with nursing, there are no specific dementia care homes. Care homes and care homes with nursing are regulated by the Care Quality Commission and all are able to say that they support people with dementia. However, there are ways that care homes and care homes with nursing can demonstrate that they focus on dementia care, have training in supporting people with dementia and make their home dementia-friendly.

‘ I wish I'd used residential care two years sooner, but that's said with hindsight, because at the time the right care home didn't exist. ’

The physical appearance of a care home may be an important factor in which home you choose. You might want to consider somewhere that has a homely look, rather than a hotel-style or vice versa. It's important to remember that this is where the person with dementia will be living, and they need to feel comfortable in their surroundings as it will be their home.

Some newer, purpose-built homes have circular corridors or gardens that the people can explore on their own. Some homes have cabinets outside of each person's room, containing an individual's personal items enabling them to recognise their room. Some homes have rummage boxes filled with items to look through; some may be period items, which can be useful for reminiscing.

‘ My mother-in-law, who had dementia, spent the last nine months of her life in a nursing home. The staff, especially the matron in charge and the GP, were very supportive. They took time to talk to us and my mother-in-law and tried hard to take her individual needs and wishes into account. ’

When looking at a care home, it's important to consider what activities are provided. Meaningful activity on a daily basis can really help people to engage and have a good quality of life. →

➔ A good care home or care home with nursing will support people to make their own decisions on a daily basis. This may be as simple as choosing what they'd like to eat or wear that day or helping to perform day-to-day tasks, like laying the table, folding the washing or gardening. This is relationship-centred care with person-centred outcomes – these simple approaches to daily living can help the person with dementia to have control over their life.

There should also be group activities that people can choose to be involved in, from tea dances to exercise. The options are endless and should be developed with the people living there in mind. The National Activity Providers Association (NAPA) supports care teams to enable people to live the life they choose. A project called My Home Life also promotes quality of life and delivers positive change in care homes for older people. Ask any care home you visit if it has heard of NAPA or My Home Life and uses their resources.

Most people want to be fully involved in their loved one's life if they move into a care home. A good home will ensure that the carer and close family are involved as much as possible in the person with dementia's care. If you feel that the home is not involving you as much as you would like, speak to the manager. They should value your input and knowledge of the person with dementia, and should see you as a partner in their care and support.

For more on identifying a care home that has specialist training in caring for people with dementia, visit **www.carechoices.co.uk** which has a wealth of information and the facility to search for care provision in your given area.

SUPPORTING SOMEONE WITH DEMENTIA IN A CARE HOME

'By now, probably all the best dementia care providers rightly emphasise the importance of

knowing the person and their life story.

'When we deliver dementia training to our team members, we often talk about becoming 'dementia detectives', learning to piece together the phrases, signals and behaviour of residents and relate them to important life events and relationships for each individual.

'An ability to read these signals and understand the indicators of wellbeing and tension make it easier for care staff to promote a positive frame of mind and help residents move to a better place if they are distressed. We believe that the person living with dementia is the expert and we need to take our lead from that person.

'Equally important to us though, are all the things we don't know and the appreciation that residents continue to have an emotional life in the present. We believe it is just as important to 'take people as we find them' and not focus exclusively on the past.

'Much of caring is simply about relating to people 'person to person' and reaching out to them in the here and now – a smile, affection and good humour all help to ensure quality of life today and tomorrow. We often describe it as 'a long goodbye, with lots and lots of hellos.'

'Similarly, activities that 'go with the flow' are often the most successful – listening to music, dancing, singing or sharing in simple games.

'As many people have observed, it's often easier for people who haven't known the person with dementia in the past to relate to them today and to 'step into their world'. Our advice to family members and friends is to get to know your new mum or dad and celebrate the wonder of who the person is today.'

With thanks to Belinda Jones, Dementia Champion and Trainer at Belong.

Home 1

Home 2

Home 3

Fees per week

£	
£	
£	

We suggest that you take paper with you when visiting care homes so that you can make notes. You can download and print this checklist at www.carechoices.co.uk/checklists

Design

Are there clear signs throughout the home? ☐ ☐ ☐

Has the home been designed or adapted for people with dementia? ☐ ☐ ☐

Are the home and grounds secure? ☐ ☐ ☐

Are there prompts outside the residents' rooms to help people identify their own? ☐ ☐ ☐

Is the décor familiar to your loved one? ☐ ☐ ☐

Choices

Do residents get choice in terms of what they wear each day? ☐ ☐ ☐

Are residents encouraged to be independent? ☐ ☐ ☐

Can residents decide what to do each day? ☐ ☐ ☐

Can residents have a say in the décor of their room? ☐ ☐ ☐

Activities

Are residents able to join in with household tasks like folding washing? ☐ ☐ ☐

Are there activities on each day? ☐ ☐ ☐

Can residents walk around outside on their own? ☐ ☐ ☐

Are residents sitting in front of the TV or are they active and engaged? ☐ ☐ ☐

Are there rummage boxes around? ☐ ☐ ☐

Health

Can residents get help with eating and drinking? ☐ ☐ ☐

How often does the home review residents' medication? ☐ ☐ ☐

Does the home offer help if a resident needs assistance taking medication? ☐ ☐ ☐

Do GPs visit the home regularly? ☐ ☐ ☐

Staff

Are staff trained to identify when a resident might be unwell? ☐ ☐ ☐

Are staff trained to spot when someone needs to go to the toilet? ☐ ☐ ☐

Do the staff have any dementia specific training/experience? ☐ ☐ ☐

Will your loved one have a member of staff specifically responsible for their care? ☐ ☐ ☐

Approach to care

Does the home follow a specific approach to dementia therapy, for example, validation therapy? ☐ ☐ ☐

Will the home keep you informed about changes to your loved one's care? ☐ ☐ ☐

Does the home have a specific approach to end of life care? ☐ ☐ ☐

Does the home keep up to date with best practice in dementia care? ☐ ☐ ☐

HOSPITAL ADMISSIONS

Hospital visits, planned or unplanned, can be unsettling for a person with dementia. However, if the person with dementia needs treatment in a hospital, there are important things you can do to help make the visit less stressful for you both.

Bear in mind that a hospital stay may cause confusion and disorientation. It is a new environment that is unfamiliar. The person with dementia may not know where they are or be able to comprehend why they are there. They may also suggest that they don't need to be there at all.

This might be upsetting, but at these times it's particularly important to make sure that the staff are fully informed. Ensuring that staff are aware that your relative is living with dementia is vital. The staff will not necessarily know of this and may not be specially trained to care for people who are living with the condition. As such, you may need to stay close by to ensure your loved one's needs and wishes are communicated and they feel comfortable and safe.

If the hospital visit is planned, find out whether the hospital has a dementia champion who you can speak to about supporting the person with dementia. If there is no dementia champion at the hospital, you can arrange to meet with the named nurse. He or she should be able to answer any questions you have and work with you to make sure that the person with dementia is well cared for.

On any visit to the hospital, ensure you fully inform them of your loved one's dementia and if you have put together a life story record, take this with you or use Alzheimer's Society's *This is me* document. If you have pulled out the important issues and have any medical information in there such as advance decisions and specific health and care considerations take a copy of that along too.

This can be kept in their patient file so that anyone who may treat your relative can see it. These documents can be a useful tool for medical staff, who may find it easier to communicate with the person with dementia if they have some background information on their life.

Even if the person you care for has been taken to hospital in an emergency situation, and you have been unable to plan for it, there is plenty you can do. During both planned and unplanned visits, the hospital staff will appreciate any information that you can give them. As the carer of the person with dementia, you are in a position to know what might make them upset. You may also be able to let the nurses know what they can do to help if the person becomes anxious.

You may want to offer to help at mealtimes if your relative needs assistance. Hospital staff may find this useful as mealtimes are often a busy time for them and they may not have the resources readily available to help people who are living with dementia. Try to help keep them hydrated too as some symptoms of dehydration can mimic dementia.

When someone is in hospital, if you (or a friend or relative) are able to visit regularly, it may help to bring comfort to the person with dementia. You will also be able to understand how they are getting on and offer any additional support they may need. It can be a difficult time for all and you may notice a deterioration in their condition. You may also want to push for flexible visiting times, to enable you to stay with the person with dementia to support them should they not settle.

John's Campaign fights for the right to stay with people with dementia in hospital. The campaign calls for the families and carers of people with dementia to have the same rights as the parents of sick children and be allowed to remain with

them in hospital for as many hours as they are needed, and as they are able to give.

John's Campaign has advice for carers if the person they support goes into hospital. It says that as a carer, you should insist that you need to be there for the person with dementia and explain why. Be clear. A carer is different from a visitor. Quite a number of hospitals have policies of allowing carer access outside visiting hours and some hospitals use Carer Passports, but it's not always highlighted. Also, identify yourself

as a carer, as well as the person's child, spouse, companion or best friend. There is often a policy that will cover carers. Be clear that you are there to provide that totally essential nurture and connection back to the outside world.

If you're able and willing to be there, don't let yourself be turned away.

The campaign's website **www.johnscampaign.org.uk** has a list of participating hospitals.

FORMAL CARE OUT OF HOSPITAL

The person with dementia may require formal care services upon discharge from hospital, or existing services may need to be changed or reinstated when the person is ready to be discharged from hospital. You may find the person with dementia is required to stay in hospital for longer than anticipated if services are required and are not in place. You may wish to consider alternative accommodation if returning home is not the right thing for the person with dementia.

You should speak to the hospital discharge team to get an assessment of your relative's needs to assist in getting the relevant support in place as quickly as you can. This is likely to include a number of different professionals including social services staff, occupational therapists and medical specialists. It should result in a care plan being put in place and services being arranged. If the person with dementia is not in need of formal care services, they may be discharged back home and

require a few weeks of support to enable them to get back on their feet. Speak to the hospital or any social worker about the options available; this may be called reablement or intermediate care.

Care Choices, the publisher of this Guide, has a number of other information sources to help with care and support decisions. The Care Choices website has more information on arranging care and support. It covers all aspects of the process in more detail than we can cover here.

Care Choices also publishes regional care and support directories and has comprehensive listings of all care providers in its publications and on its website. These resources enable you to look for care and support providers based on specific requirements. Using the website will result in a tailor-made list of care services matching individual needs and preferences in your chosen locality. Visit **www.carechoices.co.uk**



Formal care and support can play a huge part in the life of a person with dementia and their family. By understanding their needs and enlisting the most appropriate service, people can be supported to live well with dementia in whatever setting is most appropriate for them.



Planning for end of life

Talking about end of life can be difficult. It isn't always easy to face the thought that a loved one will pass away and broaching the subject can be painful. However, openness and positive planning can help everyone prepare and bring comfort as the dementia symptoms progress. This can be achieved by discussing, sharing and understanding the wishes of the person with dementia.

‘ If I could do something differently, I would have found out more about dementia, and discussed and documented end of life wishes, while my mother-in-law still had mental capacity. ’

Dementia is a progressive condition which, unfortunately, doesn't have a cure. It is classed as a terminal illness, which people may not realise or want to accept. Early diagnosis, followed by honest conversations and careful planning, are essential. Although they may not be the easiest of conversations, ultimately, it should help the person with dementia to feel confident that their preferences and concerns around death are known and will be acted upon when the time comes. It can help to reduce anxiety and also give any family carers the confidence to make important decisions when needed, because you have all openly discussed the wishes of the person with dementia.

DISCUSSING END OF LIFE PLANS

People deal with end of life considerations in different ways and there's no right or wrong approach. When someone has a dementia diagnosis, they may immediately wish to get their affairs in order and make plans for their will and estate.

Or they may not want to address these matters straight away. Everyone is different. However, it is important not to leave it too late to have conversations about life and death. Dementia can take away the ability to communicate, so talking sooner rather than later will help everyone.

Whenever you, the person with dementia and any close family members start to get plans in place, it's important that conversations include end of life considerations. These can be difficult and some people, the person with dementia, you, other members of the family or close friends may not want to talk about them. However, as mentioned above, when someone has dementia, it is important to broach these subjects while they are able to share their wishes. They should be at the centre of all conversations and you should consider that plans may change and evolve over time.

It has been said that what we fear most about dying is the associated loss of control. By the person with dementia expressing their wishes for care and support, as the condition progresses towards the end of their life, control can be restored. People should be supported not only to live well with dementia, but to die well too. You must all be supported with accurate information to help the planning process. Alzheimer's Society has factsheets on end of life care when someone has dementia.

‘ We discussed end of life wishes, but we didn't have a realistic view of what advanced dementia would be like. Therefore, we weren't adequately prepared. ’

Try to choose the right place and the right time to start having conversations. It may be that the person with dementia raises the subject, or you may feel the need to instigate initial conversations. Avoid stressful situations and be sensitive to the person with dementia's desire to talk about their future. There's no right or wrong

way to address the topic of dying and end of life, but here are a few sensitive suggestions.

- Find a sensitive time to raise the subject.
- Start with a question such as, 'Do you think we should talk about...?' 'Have you thought about...?'
- Alternatively, start with something direct but reassuring, 'I know this isn't easy to talk about...' or 'We've never talked about this before but...'
- Sometimes people prefer to set out what they don't want such as stating that they wouldn't like to die in hospital. This can open the door to a wider conversation.
- Encourage everyone involved to be totally honest about how they feel from the start. If you're all open, there may be both laughter and tears – don't be afraid of either.
- If the person with dementia is worried about talking about death with those they love, suggest they perhaps talk to someone else like a GP, nurse or friend.
- Don't be so worried about saying the wrong thing that you don't say anything.

ADVANCE CARE PLANNING

During the planning process, the person with dementia may wish to make an advance care plan. This will set out their wishes for their future care, including where they would like to be cared for, any treatment they may, or may not, wish to receive, where they would like to die and if they wish to be resuscitated.

An advance care plan is a discussion between the person with dementia, their family (if they wish) and anyone providing them with care and support. A document can be drafted to be kept by those supporting the person with dementia, health or social care professionals, family members plus any appointed attorney

(for more information on **powers of attorney** see page 60). During this process, it is possible to go on to make specific legal arrangements such as an advance decision.

An advance decision may also be called a living will and enables people to refuse specific types of treatment in the future. This is particularly useful if the person with dementia is no longer able to communicate their wishes. All treatments they would like to refuse, and any specific circumstances, must be detailed

in the document. The document can be legally binding, so it is important to make sure it sets out the person's wishes, and is signed by them and a witness. Speak to a health professional about an advance decision.

The person with dementia must have the mental capacity to make the advance decisions so, as with all aspects of planning, it is better to make these decisions sooner rather than later. For information on **mental capacity**, see page 59.

APPROACHING THE END OF LIFE

As the symptoms of dementia progress, the person with dementia may develop other conditions – see page 34 for more information on health conditions associated with dementia. It's important to be prepared for this.

It is also important to be aware of pre-bereavement, as well as bereavement. Many people grieve together before someone dies and support can help them to deal with this. It is common to experience feelings of bereavement and grief throughout the whole process. If you need help or advice, there are a number of support networks.

Look at the **local services** starting on page 66.

Wherever the person with dementia is being cared for, in their own home, a care home, hospice or hospital, you should be confident that the people caring for them have the necessary training to help make their end of life as comfortable as possible. A good understanding of someone's wishes can help to ensure this happens, as well as to avoid unnecessary hospital admission. Most people would prefer not to die in a hospital and with good planning, everyone involved in the person's care should help to ensure this happens.

Any health and care staff should assess the person with dementia as their needs and symptoms progress. They should also be familiar with the person's specific wishes. Talking about these things whilst the person with dementia still has the capacity can help to ensure this happens.

Health, care and support providers should have their own end of life care policies; ask any professionals about their policy and training on the subject. End of life should be a sympathetic time and care staff, whilst being professional, will also be sympathetic and understanding of the situation and the emotions surrounding it.

You might be offered an Admiral Nurse or a Marie Curie nurse to support you and the person with dementia towards the end of their life. Admiral Nurses are specialist dementia nurses who offer practical and emotional support – not just at the end of life. They can support the person with dementia, you and your wider family. Admiral Nurses are covered in more detail on page 42.

Marie Curie nurses make it possible for people to die at home, comfortably, with their wishes followed and surrounded by their close family and friends. Your GP or district nurse are key to getting a Marie Curie nurse so speak to them directly.

PALLIATIVE CARE

Palliative care focuses on the relief of pain and other symptoms experienced in serious illness. The aim is to improve quality of life, by increasing comfort, promoting dignity and providing a support system to the person with dementia and those close to them.

People with dementia often live for many years after their diagnosis, but it is recommended to make palliative care plans long before entering the end of life phase. Palliative care neither hastens nor prolongs death. It makes the most of life, even when time is limited. It regards

dying as a normal process. Palliative care can be delivered in any setting, including at home, care homes, hospitals and hospices. Hospices provide palliative care services at home, in day care centres or hospice inpatient units. Most people who have inpatient hospice care return home once their needs for care support are addressed.

‘I wish I’d known about palliative care and what it could offer to my mother and myself. If I had, I would have been a stronger advocate for it.’

DYING WITH DIGNITY

Wherever the person with dementia chooses to die, it is of utmost importance that they are treated with compassion, dignity, respect, comfort and support. Even when they are unable to communicate their wishes. As mentioned above, talking about and planning for end of life can help you to ensure that you fully understand their wishes. It may enable them to have the best quality of life possible right up until the end. The death of a loved one is not easy to deal with; however, being safe in the knowledge they are comfortable, cared for and at peace, will bring you comfort.

Ensuring the person with dementia has a good quality of life is important. What makes their quality of life good will be specific to them. However, it is likely to include ensuring they are pain-free and comfortable and that any social, medical, emotional or spiritual needs are respected. They may want to be surrounded by their own possessions, family, pets or familiar music. They may want to be able to see outside, hear the birds or have the radio on. People of faith may want to be visited by their local faith leader. This will be very personal to them and reiterates the importance of planning and understanding what they like, what makes them happy or brings them comfort plus their specific end of life wishes.

However, consider that people’s needs and wishes may change towards the end of their life. If this happens, the person with dementia may not want the things they had discussed when planning their end of life care. Consider their needs regularly and if it is clear that something they have requested distresses them, or if their needs change to the point that you cannot follow their wishes, it is okay to shift from the plans, if needed.

THE IMPORTANCE OF GOOD CARE IN END OF LIFE

‘A care home moved Christmas forward two months for a male resident who loved that time of year and was on an end of life pathway. They decorated his room with tinsel and Christmas lights, dressed up in Christmas jumpers, sang Christmas carols, brought in reindeer to see him, gathered his family and took lots of pictures. He passed away two days later, but he got his wish to see Christmas. His family and the home also have many happy memories of his final few days.’

With thanks to an Admiral Nurse at The Orders of St John Care Trust.

FUNERAL PLANNING

Whilst planning for the future, many people consider writing down their wishes for their funeral. This can help to alleviate pressures on the wider family. You may appreciate knowing your loved one's wishes and that you can make sure these are considered at their funeral. By detailing their wishes, it can

bring comfort to know that you don't need to make all the decisions about the service and know that you are making the right choices. Hospice UK outlines information to help make funeral arrangements easier at www.hospiceuk.org (search 'How to arrange a funeral').

OTHER CONSIDERATIONS

Beyond the subjects mentioned above, there are other considerations that you and your loved one may like to discuss.

- Have either of you considered how funeral costs would be met?
- Will they 'opt out' of organ donation?
- Would they want to leave their brain or body to medical research, e.g. to help with dementia research?
- How would they like to be remembered?
- What would they like people to know before they die?

PRACTICAL HELP

There is a range of organisations that can help you plan the support and care the person with dementia needs towards the end of life, including advising on writing wills and advance decisions and providing advice on the emotional issues surrounding dying. The Dying Matters and NHS websites are useful starting points.

You can also find information about a range of practical services to support people approaching the end of life, their family and their carers on the Dying Matters website.

Life after caring can also seem daunting. If your future has been put on hold whilst you care for someone with dementia, you may feel uncertain about where you go from here. There are lots of resources available to support you as you adjust to your new situation and it can help to talk openly.

Many people grieve while the person is still alive but bear in mind that the grieving process can come out in many ways.

Also, consider that different people deal with death and dying differently, and just because someone isn't grieving in the same way as you, doesn't mean they're not grieving. Counselling and support can be very useful when dealing with the prospect of someone dying. This doesn't have to be towards the end of their life; it can be at diagnosis, after they have passed away or at any stage in between.





Legal and financial affairs

A running theme through this Guide is one of planning; helping the person with dementia to plan their wishes, set out their life history and make a plan for legal and financial considerations before their capacity to do so changes.

‘ You can’t expect the person with dementia to be logical and rational. ’

In an ideal world, the person with dementia received an early diagnosis. In these circumstances plans can be made, involving family and professionals in the discussions. The best approach is considered to be to plan together while you still can, wherever possible enabling the person with dementia to lead the discussions. However, it is quite likely that you’ll be coming to this planning process once symptoms have progressed. Even so, there are mechanisms in place to help the person with dementia to make decisions or to support you to make the right decisions in their best interests. These may be in relation to managing finances, property and welfare.

WHAT IS MENTAL CAPACITY?

Mental capacity is about having the ability to make decisions. This includes being able to understand the decision that needs to be made, and its implications, when it needs to be made. ➔

➔ According to the Mental Health Foundation, for someone to 'lack capacity' – because of an illness or disability such as dementia – they cannot do one or more of the following four things:

- Understand information given to them about a particular decision.
- Retain that information long enough to be able to make the decision.
- Weigh up the information available to make the decision.
- Communicate their decision.

As the dementia symptoms progress, they can affect a person's ability to make certain decisions, although they may have periods when they are able to understand the situation and make the relevant decision.

The Mental Capacity Act 2005 protects people in England and Wales who may lack the capacity to make one or more decisions when the decision needs to be made. One of its main principles is that a person must be assumed to have capacity unless it is established that he/she lacks capacity. Whether someone has capacity is considered on a decision-by-decision basis. For instance, they may lack the capacity to make a decision about travel or selling their home but will be able to decide what they would like for lunch or where, ideally, they would prefer to live. Speak to a professional about the Mental Capacity Act and ensure it is followed if the person with dementia needs to make specific decisions as their symptoms progress.

WHAT HAPPENS IF SOMEONE LACKS CAPACITY?

If the person with dementia has assets of their own, such as property or bank accounts, you may find that as their symptoms progress they will increasingly need assistance with managing their financial affairs. There is no automatic right for someone, even a spouse, to take over managing the finances of another person. The situation can become complicated if the right safeguards aren't in place. Before someone's capacity to make these decisions changes, you and the person living with dementia should consider setting up a power of attorney.

A power of attorney is a document that enables someone to appoint 'attorneys', a trusted friend and/or relative, to manage their financial affairs. This can be if they no longer wish to manage them themselves or if they become incapable of doing so, for example, as the dementia symptoms progress. Usually, at least two people are appointed to act as attorneys and a professional adviser, such as a solicitor, can also act as an attorney.

Pre-2007, someone may have had an Enduring Power of Attorney – this will still be valid if prepared before October 2007. However, if prepared after that time, the document is known as a Lasting Power of Attorney. There are two types, one dealing with welfare decisions and the other dealing with finances.

It is not necessary to have both documents, but it is worth considering whether to empower an attorney to act in best interests with regard to decisions about finances and healthcare.

Powers of attorney must be registered with the Office of the Public Guardian before they can be used.

In a Lasting Power of Attorney, the person with dementia can set out their plans for managing their affairs. If there is more than one attorney appointed, they can decide whether the attorneys can act together, or independently of each other. They can also place restrictions on what attorneys can and can't deal with, should

they wish. If they set no restrictions, then the attorney has the power to access all of the person's financial affairs, including being able to buy and sell any property on their behalf, as long as they are acting in the person's best interests.

If granted attorneyship in relation to health matters, then similarly this person will be able to access the person with dementia's health

records and be involved in decision-making with professionals involved in managing their care. By appointing an attorney, the person with dementia is essentially placing their life in the hands of one or more people, enabling them to help make decisions for them. This is why attorneys should be someone the person with dementia trusts and believes will act in their best interests at all times.

WHEN IS IT TOO LATE TO GET A POWER OF ATTORNEY?

It is important that the person with dementia prepares their power of attorney when they still have the capacity to do so. However advanced a person's dementia symptoms may be, they may still have periods when they can understand the power of attorney. As long as they are able to communicate their understanding, someone may be able to sign on their behalf. It is important to get legal advice on these matters though to

ensure the power of attorney is completed in the best interests of the person with dementia and is legally binding.

In cases where someone's dementia symptoms have progressed to the stage that they are unable to complete a Lasting Power of Attorney, you can apply to the Court of Protection to appoint a deputy.

WHAT IS A DEPUTY?

A deputy can be anyone over the age of 18, including relatives or friends. They have a similar role to that of an attorney and, by way of a court order, they are able to manage the financial affairs of the person with dementia.

To be appointed a deputy, the person needs to submit an application to the Court of Protection

setting out their suitability for the role and information about the person with dementia's financial circumstances. This application will go to a judge who will consider whether the person with dementia lacks capacity to manage their own affairs and, if so, whether it is in their best interests for the applicant to be appointed as their deputy.

MAKING A WILL

If you are the partner or spouse of the person with dementia, you may know if they have made a will; however, that's not always the case. A will is a confidential document setting out someone's wishes around what happens to their money, property and possessions after they die. If someone dies without a will, the law sets out who gets what. Making a will doesn't have to be an expensive process and the Government website

www.gov.uk/make-will has lots of information. People can write their wills themselves; however, it is a legal document, so it is important to seek specialist legal advice.

If the person with dementia wishes to make a new will, or there is no trace of them having a will, you need to find out whether they have 'testamentary capacity' to make a new one. →

➔ If there are concerns that the person with dementia lacks capacity to make a new will, a GP can be asked to assess this. If medical opinion is that the person lacks testamentary capacity, then an application can be made to the Court of Protection for a 'statutory will'. The person making the application does not need to be the deputy or attorney of the person with dementia. A statutory will is essentially a will that is prepared on behalf of the person with dementia with terms that are

believed to be in their best interests. The Court of Protection then considers the will and the wishes and feelings of those people who would otherwise inherit and decides whether to approve the will. This process can be very complex and it is advisable to seek advice from a specialist solicitor to make this type of application in all cases. In many cases, it will be better for all concerned than allowing the person with dementia to die without a will in place.

FURTHER INFORMATION

These are only some of the legal and financial considerations when a person has dementia. There are other considerations if they require formal care or support and how this may be paid for. The Care Choices website, produced by the publisher of this Guide, has more information

on finding care and support and associated considerations. Alternatively, Care Choices publishes a range of care and support guides for different regions; visit **www.carechoices.co.uk** to see if your region is covered, find out more or to search for care providers in your area.

Dementia Action Alliances

DEMENTIA FRIENDLY HAMPSHIRE AND THE HAMPSHIRE DEMENTIA ACTION ALLIANCE

Dementia Friendly Hampshire is a charity working to make Hampshire a better place for people affected by dementia. Our aim is for people to live as well as possible, to continue to be part of their communities and to feel better supported in them.

We can achieve this by increasing understanding and awareness of dementia to reduce stigma. We are developing bespoke materials for different settings, including businesses, which provide greater understanding of the issues their customers/clients may be facing and how they can support them better.

We also help set up local Dementia Action Groups and network with these groups to share good

practice and ideas. We have been working on guides and materials which should support these groups or individuals to make their communities more dementia accessible.

In addition, we:

- Signpost people to advice and information on dementia, through this Guide, our social media, our website and our new newsletters.
- Attend local health and wellbeing events and dementia specific events, such as the East Hants Dementia Festival, Havant Information Fayre, RomDag Information Days and Reminiscence in the Park run by the Bursledon Hamble and Hound Group.

- Work to increase awareness of risk factors associated with dementia.
- Encourage businesses and organisations to become Dementia Friendly and to join their local Action Groups.

One priority is to create opportunities for people to continue to live their lives despite their dementia. It is important that people living with dementia and their carers stay active for as long as possible, retain their social networks and preserve their emotional wellbeing.

Unfortunately, many people affected by dementia experience physical and emotional barriers to getting out and about caused by dementia. We aim to create opportunities to get out where we can provide support to break down these barriers.

We are working with partners to provide accessible sports sessions, dancing and gardening. For example, we partner with Hampshire Cricket providing Memory Days where people living with dementia are supported to watch matches at the Ageas Bowl.

We run supported outings to various venues across Hampshire, helping people affected by dementia. We are continually seeking new partnerships, new ideas and new ways to provide accessible activities, so please challenge us to organise sessions for your favourite hobby. We can't promise we will achieve it, but we can certainly try!



Hampshire Forget-me-nots is a group aimed at anyone in Hampshire affected by dementia; people with a diagnosis, family, friends and the professionals supporting them. The idea is to form a community to which we all belong. A first major activity of the group is the introduction of a regular newsletter. Sign up at <http://eepurl.com/h2uxPn>

Dementia Friendly Hampshire

Tel: **07388 668332**

Email:

jane.ward@dementiafriendlyhampshire.org.uk

Web: **www.dementiafriendlyhampshire.org.uk**

Facebook: **@DF Hampshire**

X (formerly Twitter): **@DFHampshire**

PORTSMOUTH DEMENTIA ACTION ALLIANCE

The Portsmouth Dementia Action Alliance (PDAA) is run by Remind, Portsmouth's local dementia service. Remind is delivered in partnership with

Solent NHS Trust and Rowans Hospice, working together to support people living with dementia and their carers.



➔ We believe that people with a dementia diagnosis can live well and be part of their communities.

We are working with local businesses and services to encourage the people of Portsmouth to have a better understanding and awareness of dementia:

- We provide information on how to access free Dementia Friendly training.
- Portsmouth has Dementia Friendly status. We would like to encourage more organisations and businesses to join the Dementia Action Alliance.
- We share information and updates about the work that is taking place in Portsmouth to bring together a society-wide response to dementia.

Portsmouth Dementia Action Alliance's vision is for information and advice regarding memory

issues and dementia to be easily accessible to all.

For more information, or if your organisation would like to be part of Portsmouth Dementia Action Alliance, contact Remind.

Tel: **0330 332 4030**

Email: **remind@solentmind.org.uk**

Web: **www.solentmind.org.uk/support-for-you/our-services/remind**

“As a Dementia friend, the training really helped my awareness of people who may have a form of dementia, and I can use the insight to help support business decisions and strategies at Gunwharf Quays in the future.”

Jay Wood, Guest Relations Manager at Gunwharf Quays retail outlet.

DEMENTIA FRIENDLY SOUTHAMPTON

Southampton Voluntary Services co-ordinates Dementia Friendly Southampton alongside the programme SO:Linked (**www.solinked.org.uk**).

The city has a range of dementia support services, including Admiral Nursing, memory cafés, Dementia Community Navigators (as part of the SO:Linked service) and is host to many activities across the city including a dementia festival, supported by an active and committed group of residents.

Southampton City Council funds Southampton Voluntary Services to deliver Dementia Friendly Southampton, with the aim of:

- Raising awareness of dementia and reducing associated stigmas across the city.
- Supporting businesses and organisations city-wide to become more dementia friendly.
- Helping to create and support Dementia

Friendly Communities in different areas of Southampton.

- Contributing towards making Southampton a recognised Dementia Friendly City.

Dementia Friendly Southampton's action plan focuses on the following areas:

- Dementia Friendly information sessions to be offered throughout the city to businesses, organisations and community groups.
- Exploring opportunities for high-quality information about the dementia journey alongside local information about services, support groups and care pathways being made available to people affected by dementia, their families and carers.
- Resourcing local groups, through a small grants fund, to deliver community-based initiatives that contribute to a dementia friendly city.

To find out more about dementia support in Southampton, to join Dementia Friendly Southampton Steering Group or to organise a Dementia Friendly Community, contact Dementia Friendly Southampton or SO:Linked.

Web: www.solinked.org.uk/dementia-friendly-southampton



Hampshire County Council

HAMPSHIRE LIBRARIES



Hampshire Libraries can help to support and enhance the lives of people living with dementia and their friends and carers.

Some libraries hold events and drop-ins where you can receive advice and participate in activities. Check the Hampshire Libraries website (www.hants.gov.uk/library) for opening times, activities and events near you. Most staff and volunteers have attended Dementia Awareness sessions and have become Dementia Friends; they can be identified by their Dementia Friends badge.

We have a wide range of materials and resources to help improve wellbeing and to stimulate conversation and memories including a Reminiscence collection (www.hants.gov.uk – search ‘Reminiscence’). Visit www.hants.gov.uk (search ‘Dementia resources’) to view the full range. We also have digital collections of eBooks and eAudiobooks available on BorrowBox. Visit <https://hampshire.borrowbox.com> (search ‘Dementia’).

The Home Library Service helps people who can’t access the library themselves due to ill-health, disability or caring responsibilities. We can arrange for books, audiobooks, and other library materials to be delivered to you or a loved one’s home by one of our friendly volunteers on a monthly basis. This is a free service. For further details, ask at your local library, call **0300 555 1387**, or visit www.hants.gov.uk (search ‘Home library service’).



Dementia support in Hampshire

This list of groups and activities is maintained by Dementia Friendly Hampshire and it endeavours to keep it accurate. Dementia Friendly Hampshire relies on the organisations listed and members of its communities to support this. If you know of any changes to this list, or think there is something missing, email jane.ward@dementiafriendlyhampshire.org.uk

You should contact any group you are thinking of joining in advance to confirm that it is running and to book a place if necessary. If you have a carer, you might like to ask if they can attend too. Transport may be available, and some services have a charge to cover the cost of equipment and or refreshments.

Admiral Nurses – Hampshire

The Royal British Legion works with Dementia UK to provide a service that supports its beneficiaries, which can be the carer or the person with dementia, who have served in the UK Armed Forces. The team also run Veterans' groups in Winchester, Petersfield, Gosport, Portsmouth and Havant. Get in touch for a referral.

Tel: **0808 802 8080**

Email: sphilpott@britishlegion.org.uk

Alzheimer's Society

Information and practical guidance to help people understand dementia, cope with day-to-day challenges and prepare for the future. • Dementia Connect support line:

0333 150 3456

Web: www.alzheimers.org.uk

Forum: forum.alzheimers.org.uk

Caraway

The Caraway Dementia Team offers a growing number of dementia services for families living with dementia in Southampton.

Email: caraway@caraway.uk.com

Web:

www.caraway.uk.com/dementia-services

Carer Support and Dementia Advice Service for Hampshire – Carer Support Service

Offers a range of Hampshire-wide peer support groups, carer clinics and one to one support for all adult carers who care for another adult regardless of their illness, condition or diagnosis, provided by Andover Mind.

Tel: **01264 332297**

Email: enquiries@andovermind.org.uk

Web: www.andovermind.org.uk

Carer Support and Dementia Advice Service for Hampshire – Dementia Advice Service

Offering Hampshire-wide advice, information, signposting and support groups to people with dementia and their families throughout their journey, provided by Andover Mind.

Tel: **01264 332297**

Email: enquiries@andovermind.org.uk

Web: www.andovermind.org.uk

Life and Chimes

Pompey in the Community's 'Life and Chimes' project works with people living with – or at risk of developing – dementia and those who feel socially isolated. The group meet once a week and run visits to local theatres, the cinema, bowling alleys and the dockyard.

Tel: **023 9272 8899**

Email: info@pompeyitc.org.uk

Web: www.pompeyitc.co.uk/life-n-chimes

Memory Assessment and Research Centre (MARC)

A Southampton-based research centre for clinical trials into dementia, mild cognitive impairment and memory problems. One of its beliefs is that everyone can contribute to dementia research by taking part in simple surveys or complex interventional studies. For more information, use the following contact details.

Tel: **023 8047 5206**

Email: marc@southernhealth.nhs.uk

Web: www.southernhealth.nhs.uk (search 'Memory Assessment and Research Centre').

Pazzazz Me Movement and Mobility Classes

Exercise from a seated position or standing with the support of a chair to improve your mobility and fitness. Join a live online class via Zoom or watch a pre-recorded class.

Tel: **07889 419681** • Email: **belinda@pazzazz.me**

Web: **<https://pazzazz.me>**

Specsavers Home Eye Test

You may be eligible for a home eye test if you are living with cognitive impairment or dementia. For more information and to request a home eye test, visit the following website.

Web: **www.specsavers.co.uk/home-eye-tests/eligibility**

The Memory Box Project

National Lottery funded group that aims to stimulate the senses to evoke memories of the past for all those participating in sessions.

Tel: **023 8071 5446**

Email: **erin@wessexheritagetrust.org**

Web: **www.wessexheritagetrust.org/thememory-box-project**

The Memory Choir (TMC)

TMC is a social enterprise with the aim of enhancing the wellbeing of people living with dementia through singing as a group. There are choirs already established in several locations across the county (check in the local listings), with plans to create additional choirs across Hampshire.

Email: **hello@memorychoir.com**



SUPPORT GROUPS, DEMENTIA CAFÉS AND DEMENTIA ACTIVITIES

Basingstoke and Dean

Alzheimer's Society – Singing for the Brain

St Mary's Church, Church Lane, Old Basing RG24 7DJ
Second Friday of month, 10.30am to 12.00pm.

Tel: **0333 150 3456**

Andover Mind – Peer Support Group

Westside Community Centre RG22 6QB
First Friday each month, 11.00am to 12.00pm.
Tel: **01264 332297** (option three).

Email: **enquiries@andovermind.org.uk**

Andover Mind – Young Onset Dementia and Carer Support Group

Dashwood Manor Care Home Café,
Bradley Way RG23 7GF
Third Friday each month, 10.30am to 12.00pm.
Tel: **01264 332297** (option three).
Email: **enquiries@andovermind.org.uk**

Basingstoke Support and Social Group

Basingstoke Discovery Centre,
Potters Walk RG21 7LS
Mondays, 1.30pm to 3.30pm.

Tel: **0344 324 6589**

Email: **support@mydementiasupport.org**

Memory Tree Social Club

United Reform Church,
20 London Street RG21 7NU
Wednesdays, 10.30am to 12.00pm.
Tel: **01256 242152**

Monday Meander at Black Dam Ponds

Accessible supported walks. Meet at the free car park.
Black Dam Ponds, RG21 3QU
Mondays, 10.00am to 10.40am.
Tel: **01256 840660**

Sunflower Café

Old School, London Road, Odiham RG29 1AG
(The Vine Church).
Wednesdays, 2.00pm to 4.00pm.
Email: coordinatorssunflowercafe@yahoo.com

Viabes Memory Support Group

Viabes Community Centre RG22 6QB
Fridays, 10.30am to 12.30pm; and 1.00pm to 3.00pm.
Tel: **01256 473634**
Email: office@viabes.org.uk

East Hampshire

Active Dementia Exercise Group

Winton House, 18 High Street, Petersfield GU32 3JL
First Wednesday each month, 2.30pm to 4.00pm.
Tel: **01730 266046**
Email: infodesk@wintonhousecentre.org.uk

Allotment Group

Wooteys Allotment, Alton.
Tuesdays, 1.00pm to 3.30pm.
Tel: **01420 551455**
Email: dementia_friends@btinternet.com

Alton Memory Choir

Refer to the following contact details.
Tel: **07872 955050**
Email: hello@kimg.co.uk

Alton Memory Lane Café

Alton Community Centre, Amery Street GU34 1HN
Wednesdays, 10.30am to 1.00pm.
Tel: **01420 85057**
Email: dementia_friends@btinternet.com

Andover Mind – Chase Hospital Carer Support Group

Chase Hospital, Conde Way, Bordon GU35 0YZ
Second Monday each month, 2.00pm to 3.30pm.
Tel: **01264 332297** (option three).
Email: enquiries@andovermind.org.uk

Coffee and Catch-up

Edgar Hall, Anstey Park GU34 2NB
Thursdays, 10.30am to 11.00am.
Tel: **01420 551455**
Email: dementia_friends@btinternet.com

Creative and Curious

Edgar Hall, Anstey Park GU34 2NB
Every Monday, 10.30am to 12.30pm
Tel: **01420 551455**
Email: dementia_friends@btinternet.com

Flourish in the Forest

Alice Holt Forest, Bucks Horn Oak, Farnham GU10 4LS
First Saturday each month, 10.00am onwards.
Tel: **01420 551455**
Email: dementia_friends@btinternet.com

Gardening Gang at Town Park

Meet at the sensory garden to help with gardening activities.
Mondays, 2.00pm to 3.30pm.
Tel: **01420 551455**
Email: dementia_friends@btinternet.com

Jeff William's Friendship Group

United Reformed Church, College Street GU31 4AG
First Friday each month, 11.00am to 12.30pm.
Tel: **07966 759929** or **07909 546081**

Kitbags Live On

Activity group for veterans living with dementia.
Petersfield Community Centre, Love Lane, Petersfield GU31 4BW
Third Thursday each month, 1.30pm to 3.30pm.
Tel: **07458 134672**
Email: sphilpott@britishlegion.org.uk

Legions Legends

Royal British Legion, Anstey Park GU34 2RL
Second Thursday each month, 2.00pm to 3.30pm.
Tel: **01420 551455**
Email: dementia_friends@btinternet.com

Let's Get Growing

Sensory Garden, Town Park, Alton.

Sundays, 2.00pm to 6.00pm.

Tel: **01420 551455**

Email: **dementia_friends@btinternet.com**

Love 2 Move

A chair-based movement class for people living with dementia.

Alton Community Centre, Amery Street GU34 1HN

Wednesdays, 2.00pm to 3.30pm.

Tel: **01420 551455**

Email: **dementia_friends@btinternet.com**

Music Session

Edgar Hall, Anstey Park GU34 2NB

Fridays, 11.00am to 12.15pm.

Tel: **01420 551455**

Email: **dementia_friends@btinternet.com**

Pam Robson's Entertainment Group

United Reformed Church,

College Street GU31 4AG

Fourth Friday each month, 11.00am to 12.30pm.

Tel: **01730 892996** or **07966 759929**

Pam Robinson's Music Group

United Reformed Church,

College Street GU31 4AG

Second Thursday each month,

2.00pm to 3.00pm.

Tel: **07966 759929** or **07909 546081**

Petersfield Art and Social Group

Winton House, 18 High Street GU32 3JL

Second Monday each month, 2.00pm to 3.30pm.

Tel: **07539 225144**

Email: **kym@creativemojo.co.uk**

Petersfield Dementia Choir

Petersfield Rugby Club House,

Penns Place GU31 4EP

First, third and fourth Tuesday each month,
10.45am to 12.00pm.

Tel: **07557 914954** or **07775 902298**

Petersfield Memory Café

Winton House, 18 High Street GU32 3JL

Third Wednesday each month, 2.00pm to 3.30pm.

Tel: **01730 266046**

Email: **infodesk@wintonhousecentre.org.uk**

Petersfield Walking Football

Taro Centre, Petersfield GU31 4EX

Second and fourth Monday each month.

Tel: **07966 759929**

Singing for the Mind

The Beehive, Hogmoor Enclosure, Hogmoor Road, Bordon GU35 9HN

Fourth Monday each month, 10.45am to 12.00pm.

Tel: **01420 481716**

Email:

hello@rightathomealtonandbordon.co.uk

Skittles and Sports Talk

Edgar Hall, Anstey Park GU34 2NB

Tuesdays, 9.30am to 10.30am.

Tel: **01420 551455**

Email: **dementia_friends@btinternet.com**

Sunflower Café Bordon

Sacred Heart Catholic Church,

High Street GU35 0AU

Second and fourth Thursday each month,
10.30am to 12.00pm.

Tel: **01420 481716**

Email:

hello@rightathomealtonandbordon.co.uk

Tea Dances in Alton

Royal British Legion, Anstey Park GU34 2RL

Tuesdays monthly, 1.30pm to 3.00pm.

Tel: **01420 551455**

Email: **dementia_friends@btinternet.com**

Walking for Fitness Group

Edgar Hall, Anstey Park GU34 2NB

Tuesdays and Thursdays, 9.30am to 10.30am.

Tel: **01420 551455**

Email: **dementia_friends@btinternet.com**

Eastleigh

Bursledon, Hamble and Hound Memory Café

Netley Court Care Home,
Victoria Road SO31 5DR
Second Wednesday each month, 2.00pm
to 3.30pm.
Tel: **01264 332297** (option three).
Email: enquiries@andovermind.org.uk

Carers' Get Together

Valley Park Community Centre, Pilgrim's Close,
Chandler's Ford SO53 4ST
Fourth Tuesday each month, 4.00pm to 5.30pm.
Tel: **01264 332297** (option three).
Email: enquiries@andovermind.org.uk

Carers' Support Drop-in

Speedwell Court, Mansbridge Road,
West End SO18 3HW
First Wednesday each month, 2.00pm to 3.00pm.
Tel: **07827 318032**
Email: enquiries@andovermind.org.uk

Eastleigh Support and Social Group

St. Swithun Wells Holy Cross Church,
53 Leigh Road SO50 9DF
Fridays, 1.00pm to 3.00pm.
Tel: **0344 324 6589**
Email: support@mydementiasupport.org

Forget-me-not Café

YMCA Café, Whieldon Way SO50 9SB
Last Friday each month, 2.00pm to 3.30pm.
Tel: **023 8235 1520**
Email:
jane.ward@dementiafriendlyhampshire.org.uk

Hamberly Care Homes – Forget-me-not Café

Alston House Care Home,
18-24 Leigh Road SO50 9DF
Second Wednesday each month,
2.30pm to 4.00pm.
Tel: **023 8001 7900**
Email: alston.wl@hamberlycarehomes.co.uk

Inclusive Cinema

The Point, Leigh Road SO50 9DE
Tel: **023 8065 2333**
Email: thepoint@eastleigh.gov.uk
Web: www.thepointeastleigh.co.uk

Horton Heath Memory Choir

The Lapstone, Botley Road,
Horton Heath SO50 7AP
Second, third and fourth Monday each month,
2.00pm to 3.00pm.
Tel: **07872 955050**
Email: hello@king.co.uk

Memory Support Group

The Methodist Church, Winchester Road,
Chandler's Ford SO53 2GJ
Wednesdays, 2.00pm to 4.00pm.
Tel: **023 8026 0128**

MIND Memory Café

Sunnybank House Care Home, Botley Road,
Fair Oak SO50 7AP
Second Monday each month, 2.00pm to 3.30pm.
Tel: **023 8060 3120**
Email: sunnybank.activitie@cinnamoncc.com

Musical Memories Social Afternoon

Snowdrop Place, Pavillion Road, Hedge End SO30
2ZS (Every second Tuesday, 2.00pm to 3.30pm);
Shawford Springs, Otterbourne Road, Winchester
SO21 2RT (Every third Tuesday, 2.00pm to
3.30pm); and Sunnybank House Care Home,
Botley Road, Fair Oak SO50 7AP (Every fourth
Saturday, 2.30pm to 4.00pm).
Tel: **0344 324 6589**
Email: support@mydementiasupport.org

Singing for the Brain

The Community Hub, Brendon Care,
Otterbourne Hill SO21 2FL
Last Thursday each month, 10.30am to 11.30am.
Tel: **01962 736681**
Email: hants@homeinstead.co.uk

Sporting Memories with Southampton FC

Velmore Centre, Falklands Road,
Chandlers Ford SO53 3GY
Mondays, 4.00pm to 6.00pm.
Tel: **01962 676165**

West End Memory Choir

Speedwell Court, Mansbridge Road SO18 3HW
Third Tuesday each month.
Tel: **07872 955050**
Email: **hello@king.co.uk**

Fareham and Gosport

Andover Mind and Fareham College – Six-week Cookery Group

Fareham College, Bishopsfield Road PO14 1NH
Thursdays (term time only), 2.00pm to 4.00pm.
Tel: **01264 332297** (option three).
Email: **enquiries@andovermind.org.uk**

Andover Mind – Tea and Toast Group

Bridgemary, Rowner and Woodcot Community
Association, Wych Lane PO13 0JN
Second and fourth Tuesday each month,
10.00am to 12.00pm
Tel: **01264 332297** (option three).
Email: **enquiries@andovermind.org.uk**

Creative Mojo Art and Social Group

Cams Mill Pub PO16 8AA
Last Monday each month, 2.30pm to 3.45pm.
Tel: **07539 225144**
Email: **kym@creativemojo.co.uk**

Dementia Care Hub Social Group

Titchfield Community Centre, Mill Street,
Titchfield PO14 4AB
Wednesdays, 2.00pm to 4.00pm.
Tel: **07769 009599**
Email: **info@materialcitizenship.com**

Fareham College Memory Café

D Building, Bishopsfield Road PO14 1NH
Fridays (term time only), 10.30am to 11.30am.
Tel: **01329 815167**
Email: **claire.streetjestico@fareham.ac.uk**

Fareham Dementia Café

The Fernes, 6 Samuel Mortimer Close PO15 5NZ
First Friday each month, 11.00am to 1.00pm.
Tel: **01329 443600**

Friends of Fareham Community Hospital Carers' Support Group

The Royal British Legion, 366 Brook Lane,
Salisbury SO31 7DP
Mondays, 10.30am to 12.30pm; and
1.00pm to 3.00pm.
Email: **foffch10@gmail.com**

Gosport Memory Café

St Columba United Reform Church,
Elson Road PO12 4BW
Second Tuesday of each month,
2.00pm to 4.00pm.
Tel: **07568 174861**

Home Instead – Friendship and Memory Café

Lowry Room, Parish Centre, St Faiths Church,
Victoria Square, Lee on Solent PO13 9NF
Last Wednesday each month, 2.00pm to 4.00pm
(except May, July and September).
Tel: **01329 596706**
Email: **john.james@homeinstead.co.uk**

Home Instead – Friendship and Memory Café

Wickham Room, Community Centre, Mill Lane,
Wickham PO17 5AL
Second Wednesday each month,
2.00pm to 4.00pm.
Tel: **01329 596706**
Email: **john.james@homeinstead.co.uk**

Home Instead – Memory Café

Warsash United Reformed Church,
55 Warsash Road, Warsash SO31 9HW
Second and fourth Wednesday each month,
2.00pm to 4.00pm.
Tel: **01489 345879**
Email: **southampton@homeinstead.co.uk**
Web: **www.homeinstead.co.uk/southampton**

Home Instead – Singing to Remember

Warsash United Reformed Church, 55 Warsash Road, Warsash SO31 9HW
Third Wednesday each month, 2.00pm to 4.00pm.
Tel: **01489 345879**
Email: **southampton@homeinstead.co.uk**
Web: **www.homeinstead.co.uk/southampton**

Kitbags Live On – Gosport

Activity group for veterans living with dementia.
Christ Church Centre, Stoke Road PO12 1JQ
Third Wednesday each month, 10.30am to 12.30pm.
Tel: **023 8202 5787**
Email: **sphilpott@britishlegion.org.uk**

Kitbags Live On – Stubbington

Activity group for veterans living with dementia.
Stubbington Baptist Church,
5 Jay Close PO14 3TA
Fourth Wednesday each month,
10.30am to 12.30pm.
Tel: **023 8202 5787**
Email: **sphilpott@britishlegion.org.uk**

Musical Moments Group

Florence Court Care Home, 243 Segensworth Road PO15 5FF
Every fourth Tuesday, 2.00pm to 3.30pm.
Tel: **0344 324 6589**
Email: **support@mydementiasupport.org**

Recapture Life

A group providing Cognitive Stimulation Therapy that supports people living with dementia and allows their carers three hours of respite.
Tel: **07821 666480**
Email: **lesley@recapturelife.co.uk**

Saturday Club Activity Group

For people living with Young Onset Dementia (aged 65 and under).
Second Saturday each month.
Tel: **07870 866114**
Email: **cliff.cropley@hotmail.co.uk**

Singing to Remember

Crofton Community Centre, Stubbington Lane, Stubbington PO14 2PP
First Tuesday each month, 2.00pm to 3.30pm.
Tel: **01329 596706**
Email: **john.james@homeinstead.co.uk**

Support and Social Group

Holy Trinity Church, 132 West Street PO16 0EL
Thursdays, 1.00 pm to 3.00pm.
Tel: **0344 324 6589**
Email: **support@mydementiasupport.org**

Hart and Rushmoor

Aldershot Community Choir

Part of the Dementia Choir Network.
Traction Athletic Club, Weybourne Road GU11 3NE
Mondays, 11.40am to 12.30pm.
Tel: **01420 82705**
Email: **hello@thehappyhealinghut.com**

Aldershot Memory Café

Traction Athletic Club, Weybourne Road GU11 3NE
Mondays, 11.00am to 1.00pm.
Tel: **01420 82705**
Email: **hello@thehappyhealinghut.com**

Alzheimer Café UK

St Peter's Parish Centre, 60 Church Avenue, Farnborough GU14 7AP
Tel: **07938 175002**
Email: **alzheimercafe@hotmail.co.uk**
Web: **www.alzheimercafe.co.uk**

Andover Mind – Peer Support Group

Wellbeing Centre, Farnborough GU14 7QY (first Thursday each month, 11.30am to 1.00pm); and Harlington Centre, Fleet GU51 4BY (last Thursday each month, 12.00pm to 2.00pm).
Tel: **01264 332297** (option three).
Email: **enquiries@andovermind.org.uk**

Bluebell Café

Holdshott Farm, Heckfield, Hook RG27 0JZ
Fridays, 2.00pm to 4.00pm.
Tel: **0118 932 6266**

Daisy Chain Café

Darby Green Centre, Darby Green Road
Yateley GU17 0DT
Mondays, 2.30pm to 4.30pm
(except Bank Holidays).
Tel: **01252 872198**
Email: **daisychaincafe1@gmail.com**

Hartley Wintney Forget Me Not Café

St John's Church, Fleet Road RG27 8ED
Tuesdays, 2.00pm to 4.00pm.
Tel: **0845 519 0855**
Email: **info.hwcaregroup@gmail.com**
Web:
www.hartleywintneyvoluntarycare.org.uk

Hartley Wintney Singing for the Mind

Hartley Wintney Football Club,
Green Lane RG27 8DL
Wednesdays, 1.30pm to 3.00pm.
Tel: **0845 519 0855**
Email: **info.hwcaregroup@gmail.com**

Inclusive Cricket

Farnham Leisure Centre, Dogflud Way,
Farnham GU9 7UD
Wednesdays, 2.00pm to 3.00pm.
Tel: **01252 783426**
Email: **hello@rightathomegf.co.uk**

Love 2 Move

A chair-based movement class for people living
with dementia.
Farnham Memorial Hall, Babbs Mead,
Farnham GU9 7EE
Tuesdays, 10.00am to 11.30am.
Tel: **01252 783426**
Email: **hello@rightathomegf.co.uk**

Memory Lane Singing for the Mind

Catholic Church of our Lady, 32 Kings Road,
Fleet GU51 3ST
Tuesdays, 2.15pm to 3.30pm.
Tel: **01252 614344**
Email: **ptickner97@gmail.com**

Princess Royal Trust for Carers – Carers Hub

Parsonage Farm Nursery and Infant School,
Cherry Tree Close, Cove, Farnborough GU14 9TT
Tel: **01264 835246**
Email: **info@carercentre.com**

Sunflower Café Farnham

Farnham Spire Church, South Street GU9 7QU
Thursdays, 11.00am to 12.30pm.
Tel: **01252 783426**
Email: **hello@rightathomegf.co.uk**

Sunflower Café Odiham

The Old School, 37 London Road RG29 1AJ
Wednesdays, 2.00pm to 4.00pm.
Email: **coordinatorsunflowercafe@yahoo.com**

Havant

Accessible Activities

Walking football, cricket and table tennis.
Horizon Leisure Centre, Civic Centre Way PO9 2AY
Thursdays, 2.00pm to 3.00pm.
Tel: **023 9247 6026**

Andover Mind – Cowplain Carers' Group

Age Concern, Borrow Centre,
London Road PO8 8DB
Third Thursday each month, 1.30pm to 3.30pm.
Tel: **01264 332297** (option three).
Email: **enquiries@andovermind.org.uk**

Andover Mind –Time Together Group

Hayling Island, Community Centre,
Station Road PO11 OHB
Second Wednesday each month,
1.30pm to 3.00pm.
Tel: **01264 332297** (option three).
Email: **enquiries@andovermind.org.uk**

Creative Connections Reminiscence and Poetry

Waterlooville Library, PO7 7DT
Last Friday each month, 2.00pm to 3.15pm.
Tel: **07539 225144**
Email: **creativeconnections2022@gmail.com**

Creative Memory Café

Spring Arts and Heritage Centre,
56 East Street PO9 1BS
One Wednesday each month, 11.00am to
12.30pm; and 2.00pm to 3.30pm.
Tel: **023 9247 2700**
Email: info@thespring.co.uk
Web: www.thespring.co.uk

Creative Mojo Art and Social group – Emsworth

Blooms and Wishes Florist and Café PO10 7PU
Third Wednesday each month, 2.00pm to 3.15pm.
Tel: **07539 225144**
Email: kym@creativemojo.co.uk

Creative Mojo Art and Social group – Waterlooville

Waterlooville Library PO7 7DT
First Thursday each month, 11.00am to 12.15pm.
Tel: **07539 225144**
Email: kym@creativemojo.co.uk

Home Instead Havant – Forget Me Not Cinema

Spring Arts and Heritage Centre,
56 East Street PO9 1BS
First Monday each month.
Tel: **023 9247 2700**
Email: info@thespring.co.uk
Web: www.thespring.co.uk

Just for Carers Group

Waterlooville Library PO7 7DT
First Thursday each month, 11.00am to 12.00pm.
Tel: **07507 968433**

Kim's Café Havant

Supported by Dementia Coaches from Havant
and Waterlooville Primary Care Network.
Pallant Centre PO9 1BE
Third Thursday each month, 11.00am to 12.30pm.
Tel: **07787 112380**
Email: nikki.shepherd2@nhs.net

Kitbags Live On – Havant

Activity group for veterans living with dementia.

Bedhampton Community Centre,
21 Bedhampton Road PO9 3ES
Second Thursday each month, 1.30pm to 3.30pm.
Tel: **023 8202 5787**
Email: sphilpott@britishlegion.org.uk

Love 2 Move

A chair-based movement class for people living
with dementia.
Pallant Centre PO9 1BE
Tuesdays, 2.00pm to 3.30pm.
Tel: **023 9319 0091**

Memory Lane Café

Tesco Community Room, Solent Road PO9 1AF
Last Thursday each month, 1.30pm to 3.30pm.
Tel: **023 9387 8777**
Email: havant@rightathome.co.uk

Recapture Life

A group providing Cognitive Stimulation Therapy
that supports people living with dementia and
allows their carers three hours of respite.
Tel: **07821 666480**
Email: lesley@recapturelife.co.uk

Saturday Club Activity Group

For people living with Young Onset Dementia
(aged 65 and under).
Second Saturday each month.
Tel: **07870 866114**
Email: cliff.cropley@hotmail.co.uk

Singing for the Mind – Emsworth

The Pastoral Centre, 19 High Street PO10 7AQ
Last Wednesday each month, 11.00am
to 12.00pm.
Tel: **023 9387 8777**

Singing for the Mind – Waterlooville

Waterlooville Community Centre,
Maurepas Way PO7 7AY
Second Thursday each month, 1.30pm to 2.30pm.
Tel: **023 9387 8777**

Waterlooville Memory Café

Waterlooville Community Centre,
Maurepas Way PO7 7AY
First and third Monday each month,
2.00pm to 4.00pm.
Tel: **023 9225 6823**

New Forest

Alderholt Café

Evangelical Church Hall, Hillbury Road SP6 3BQ
Third Wednesday each month,
10.30am to 1.00pm.
Tel: **01425 655155**
Email: **office@alderholtchapel.org**

Art Dementia New Forest

Linden House, New Street, Lymington SO41 9BP
(two Mondays each month, 9.45am to 11.45am);
and Milford Community Centre, Sea Road,
Milford on Sea SO41 0PH (two Mondays each
month, 9.45am to 11.45am).
Tel: **01590 679838** or **07855 985375**
Email: **annabelcollenette@mail.com**

Board Games and Ping Pong

Bransgore Village Hall BH24 8BA
First and third Thursday each month,
2.00pm to 3.00pm.
Tel: **07775 908330**
Email: **df.ringwoodandbransgore@gmail.com**

Bransgore Coffee and Company Drop-in

Crown Inn, Ringwood Road, Christchurch BH23
8AA (first Monday each month, 11.30am); and
The Coffee House, Betsy Lane, Christchurch
BH23 8AQ (third Monday each month, 11.30am).
Tel: **07775 908330**
Email: **df.ringwoodandbransgore@gmail.com**

Bransgore Memory Lane Café

Shackleton Square BH23 8AJ
Second and fourth Monday each month,
2.00pm to 4.00pm.
Tel: **01425 674513**

Butterfly Café

Victoria Rooms, Bridge Street,
Fordingbridge SP6 1AH
Second Tuesday each month, 10.30am to 12.00pm.
Tel: **01425 473777**

Coates Centre Dementia Support Group

Oak Room, Oakhaven Hospice, Lower Pennington
Lane, Lymington SO41 8ZZ
Thursdays, 10.30am to 12.00pm.
Email: **cynthia.doughty@btinternet.com**

Dementia Care Hub Art Group

Totton and Eling Community Centre,
Totton SO40 3AP
Thursdays, 10.15am to 11.45am.
Tel: **07769 009599**
Email: **info@materialcitizenship.com**

Dementia Care Hub Social Group

Totton and Eling Community Centre,
Totton SO40 3AP
First, second and third Monday each month,
10.30am to 12.30pm.
Tel: **07769 009599**
Email: **info@materialcitizenship.com**

Dementia Care Hub Wellbeing Group

Respite service for carers.
Totton and Eling Community Centre,
Totton SO40 3AP
Wednesdays, 12.00pm to 4.00pm.
Tel: **07769 009599**
Email: **info@materialcitizenship.com**

Dementia-friendly Art Session

Victoria Rooms, Bridge Street,
Fordingbridge SP6 1AH
First and third Tuesday each month.
Tel: **01425 473777**

Forget-me-not Singing Club

Brockenhurst Methodist Church Hall, Avenue
Road, Brockenhurst SO42 7RT
Fridays, 2.00pm to 3.30pm.
Tel: **07590 827887**
Email: **amy@thesongwritingproject.co.uk**

Horrill Carers' Café

Horrill Centre, Challenger Place, Challenger Way,
Dibden Purlieu SO43 5SZ
First Wednesday each month,
11.00am to 12.30pm.
Tel: **023 8084 1115**

Hythe Huddle

Cornerstone Hythe United Reformed Church,
New Road SO45 6BR
First Wednesday each month, 2.00pm to 4.00pm.
Tel: **023 8020 7623**
Email: **office.fm.hurc@gmail.com**

Lymington Support Group

United Reformed Church, High Street SO41 9AG
Tuesdays, 9.30am to 12.30pm.
Tel: **07942 704515** or **07855 985375**

Memory Works Activity Group

New Milton Community Centre, Osborne Road,
New Milton BH25 6EA
Third Friday each month, 10.30am to 12.00pm.
Tel: **07590 503210**
Email: **hello@memoryworks.org.uk**

Memory Works Cognitive Stimulation Therapy Group

Milford on Sea Village Community Centre, 9 Sea Road, Milford on Sea, Lymington SO41 0PH; New Milton Community Centre, Osborne Road, New Milton BH25 6EA (Tuesdays, 1.30pm to 2.30pm); Oakhaven Hospice, Lower Pennington Lane, Lymington SO41 8ZZ (Tuesdays, 10.30am to 11.30am); and Totton Three Score Club, Library Road, Totton SO40 3RS (Wednesdays, 10.30am to 11.30am).
Tel: **07590 503210**
Email: **hello@memoryworks.org.uk**

Music for a Healthy Mind

Milford on Sea Community Centre, Sea Road, Milford on Sea SO41 0PH
Second and fourth Thursday each month, 2.00pm.
Tel: **01590 644861**
Email: **enquiries@moscommunitycentre.org.uk**

Music Unlocking Memories

Trinity Centre, Christchurch Road, Ringwood BH24 1DY
First Thursday each month, 11.00am to 12.30pm.
Tel: **01425 402065**

Outdoor Table Tennis

Bransgore Recreation Ground BH23 8AY
First and third Monday each month, 2.00pm to 3.00pm.
Tel: **07775 908330**
Email: **df.ringwoodandbransgore@gmail.com**

Ringwood Coffee Drop-in

Ringwood Meeting House and History Centre, 22 Meeting House Lane BH24 1EY
Second and fourth Wednesday each month.
Tel: **07775 908330**
Email: **df.ringwoodandbransgore@gmail.com**

Support and Social Group

St Mary Magdalene Church Hall, Church Lane, New Milton BH25 6QL
Wednesdays, 2.30pm to 4.30pm.
Tel: **0344 324 6589**
Email: **support@mydementiasupport.org**

Table Tennis

Greyfriars Activities Hall, Christchurch Road, Ringwood BH24 1DW
Mondays, 1.30pm to 3.30pm.
Tel: **01425 472613**

Totton Café

Trinity Church, Hazel Farm SO40 8WU
Third Thursday each month, 1.30pm to 3.30pm.
Tel: **023 8029 2046**

Test Valley

Andover Mind – Carers' Group

The Oak Room, White Hart Hotel, Bridge Street SP10 1BH
Fourth Tuesday each month, 1.30pm to 2.30pm.
Tel: **01264 332297** (option three).
Email: **enquiries@andovermind.org.uk**

Andover Mind – Dementia Drop-in

Carers Together, Love Lane, Romsey SO51 8DE
First Thursday each month, 1.30pm to 3.30pm.
Tel: **01264 332297** (option three).
Email: **enquiries@andovermind.org.uk**

Andover Mind – Memory Choir

South Street SP10 2BN
Tuesdays, 11.00am to 12.00pm.
Tel: **01264 332297** (option three).
Email: **enquiries@andovermind.org.uk**

Andover Mind – Young Onset Dementia and Carer Support Group

Wisdom House, The Abbey, Romsey SO51 8EL
Third Wednesday each month, 4.00pm to 6.00pm.
Tel: **01264 332297** (option three).
Email: **enquiries@andovermind.org.uk**

Arts and Crafts Session

Green Room at the Plaza Theatre, Winchester Road, Romsey SO51 8JA
First Friday each month, 10.30am to 12.30pm.
Tel: **01794 501605**
Email: **pamela@shadow26.plus.com**

Coffee, Craft and Chat

9 Love Lane, Romsey SO51 8DE
Fourth Friday each month, 10.30am to 12.30pm.
Tel: **01794 519495**
Email: **admin@carerstogogether.org.uk**

Dementia Sing-along

Organised by Braishfield Ukulele Musical Society (BUMs).
All Saints Church Room, Braishfield, Romsey SO51 0QH
Third Monday each month, 2.30pm to 4.00pm (September to June).
Email: **dementiasingalong@gmail.com**

Forget-me-nots Group

Crosfield Hall, Broadwater Road, Romsey SO51 8GL
Third Tuesday each month, 10.30am to 12.30pm.
Email: **admin@romdag.co.uk**

Romsey Memory Choir

Abbotswood Court Care Home, Minchin Road, Romsey, SO51 0BL
First Monday each month, 2.40pm to 3.30pm.
Tel: **07872 955050**
Email: **hello@king.co.uk**

Romsey Carers Café

Hampshire Carers Centre, 9 Love Lane, Romsey SO51 8DE
Third Friday each month, 11.00am to 1.00pm.
Email: **admin@carerstogogether.org.uk**

Romsey Rendezvous Community Café

Carers Together, 9 Love Lane SO51 8DE
First Friday each month, 10.00am to 1.30pm.
Email: **admin@carerstogogether.org.uk**

Sporting Memories Club

Andover Leisure Centre, West Street, Andover SP10 1QP
Fridays, 1.00pm to 3.00pm.
Email: **angie@sportingmemoriesnetwork.com**

Themed Reminiscence Sessions

Green Room at the Plaza Theatre, Winchester Road, Romsey SO51 8JA
Third Friday each month, 10.30am to 12.30pm.
Tel: **01794 501605**
Email: **pamela@shadow26.plus.com**

Winchester

Andover Mind – Carers' Coffee Morning

The Dower House, Springvale Road SO23 7LD
Third Wednesday each month, 10.30am to 12.00pm.
Tel: **01264 332297** (option three).
Email: **enquiries@andovermind.org.uk**

Andover Mind – Meon Valley Carers' Group

Paterson Centre, Church Road, Swanmore SO32 2PA
Fourth Tuesday each month, 2.00pm to 4.00pm.
Tel: **01264 332297** (option three).
Email: **enquiries@andovermind.org.uk**

Badger Farm Activity Group

Badger Farm Community Centre, 2 Badger Farm Road SO22 4QB
Third Friday each month, 10.30am to 12.00pm.
Tel: **01962 736681**

Brendoncare's Community Clubs

Available in Weeke and Otterbourne.
Tel: **01962 857099**

Everyman Dementia-friendly Cinema

Everyman Theatre, Southgate Street SO23 9EG
First Wednesday each month, 10.15am.
Tel: **01962 736681**

Kim's Café

All Saints Church Hall, Hambledon Road, Denmead PO7 6NN
Second Wednesday each month, 11.00am to 12.20pm.
Tel: **07787 112380**
Email: **nikki.shepherd2@nhs.net**

Kitbags Live On

Activity group for veterans living with dementia. Community Centre, Connaught Road, Worthy Down SO21 2QY
Second Tuesday each month, 1.30pm to 3.30pm.
Tel: **023 8202 5787**
Email: **sphilpott@britishlegion.org.uk**

Memories Box Café

Shawford Springs, Otterbourne Road SO21 2RT
Second Thursday each month, 2.00pm to 4.00pm.
Tel: **01962 571850**

Memory Wellbeing Centre

Winchester Sport and Leisure Park, Bar End Road SO23 9NR
First and third Monday each month, 1.00pm to 3.00pm.
Tel: **01962 858282**
Email: **dementiasupport@stjohnswinchester.co.uk**

Musical Memories Social Afternoon

Shawford Springs, Otterbourne Road SO21 2RT
Third Tuesday each month, 2.00pm to 3.30pm.
Tel: **0344 324 6589**
Email: **support@mydementiasupport.org**

Singing for the Brain

The Community Hub, Brendon Care, Otterbourne Hill SO21 2FL
Last Thursday each month, 10.30am to 11.30am.
Tel: **01962 736681**
Email: **hants@homeinstead.co.uk**

Wickham Friendship and Memory Café

Wickham Room, Community Centre, Mill Lane PO17 5AL
Second Wednesday each month, 2.00pm to 4.00pm.
Tel: **01329 596706**
Email: **john.james@homeinstead.co.uk**

Winchester Wellbeing Lunch Club

St Barnabas Church, Fromond Road, Weeke SO22 6DS (Mondays, 11.00am to 1.00pm); and Winchester Baptist Church, Swan Lane SO23 7AA (contact for opening hours).
Tel: **07907 503421**
Email: **winchesterwellbeing@gmail.com**

ACCESSIBLE CYCLING

Alice Holt Inclusive Cycling

Alice Holt Forest, Bucks Horn Oak, Farnham GU10 4LS
Thursdays, 9.30am to 12.30pm.
Tel: **07701 003026**
Email: **help@aliceholtinclusivecycling.com**

Cycles4All

Pavilion on the Park, 1 Kingfisher Road, Eastleigh SO50 9LH
Tel: **023 8061 2710**
Email: **cycles@paviliononthepark.org**
Web: **www.cyclinguk.org/group/cycles4all**

PEDALL

Provides guided rides in the New Forest for people of all ages with physical or intellectual disabilities, social or mental wellbeing needs, a visible or

unseen condition or living with a health diagnosis.

Tel: **01590 646640**

Email: **info@pedall.org.uk**

Web: **www.pedall.org.uk**

GETTING OUTSIDE

New Milton Dementia Action Group Community Allotment

Becton Mead off Becton Lane BH25 7DL
Tuesdays, 10.00am to 12.00pm.
Tel: **01425 619120**

Social Gardening

Ringwood Long Lane Allotments BH24 3BX
Tuesdays, 10.00am to 12.00pm.
Tel: **07775 908330 / 07593 299405**
Email: **df.ringwoodandbransgore@gmail.com**

PALS Walking Group

Contact for more details.
Tel: **07710 389343**



YOUNG-ONSET DEMENTIA

Saturday Club Activity Group

For people living with Young Onset Dementia (aged 65 and under).
Second Saturday each month.
Tel: **07870 866114**
Email: **cliff.cropley@hotmail.co.uk**

Andover Mind – Young Onset Dementia and Carer Support Group

Wisdom House, The Abbey, Romsey SO51 8EL
Third Wednesday each month, 4.00pm to 6.00pm.
Tel: **01264 332297** (option three).
Email: **enquiries@andovermind.org.uk**

Andover Mind – Young Onset Dementia and Carer Support Group

Dashwood Manor Care Home Café, Bradley Way, Basingstoke RG23 7GF
Third Friday each month, 10.30am to 12.00pm.
Tel: **01264 332297** (option three).
Email: **enquiries@andovermind.org.uk**

If you provide or attend a dementia support group in Hampshire that is not listed here, email **jane.ward@dementiafriendlyhampshire.org.uk**

If you are based in Portsmouth or Southampton and you wish to update your current listing, email **enquiries@carechoices.co.uk**



Live well, *your* way

Your home is where you feel the most comfortable and the happiest. It is the place you know the best. If you want to stay living comfortably at home, Home Instead® can help make that possible.



Home Instead Southampton

Tel: 01489 345884

homeinstead.co.uk/southampton

Home Instead Basingstoke

Tel: 01256 840 660

homeinstead.co.uk/basingstoke

Home Instead Central Hampshire

Tel: 01962 736681

homeinstead.co.uk/centralhampshire

Home Instead East Hampshire & Midhurst

Tel: 01420 543214

homeinstead.co.uk/easthampshireandmidhurst

Home Instead Andover & East Wiltshire

Tel: 01672 555565

homestead.co.uk/andover-east-wilts

Home Instead Farnborough, Fleet & Farnham

Tel: 01252 758716

homeinstead.co.uk/farnborough

Home Instead Havant & Emsworth

Tel: 02393 190091

homeinstead.co.uk/havant

Home Instead Fareham & Gosport

Tel: 01329 282 469

homeinstead.co.uk/farehamandgosport

Home Instead Portsmouth

Tel: 023 9431 8319

www.homeinstead.co.uk/portsmouth



Dementia-friendly homes in Hampshire.

If you're considering dementia care for an elderly loved one, a warm, welcoming place close to family and friends means a lot. That's why our choice of care homes in Hampshire could be something for you to think about.

Call us for advice on care today
023 8098 1654

Lines are open 8am to 6.30pm Monday to Friday, 9am to 12.30pm Saturday. Closed Sundays and bank holidays. Calls are charged at no more than local rate and count towards any inclusive minutes from mobiles. We may record or monitor our calls.



We follow strict UK infection control standards. Roll out available vaccines. Carry out regular tests and make sure our team always have PPE. **That's our Safety Promise you can rely on.**

☒ All types of funding welcome ☒ No health insurance needed



Knights' Grove
Southampton SO52 9EW

- ✓ Nursing dementia
- ✓ Palliative
- ✓ Residential dementia
- ✓ Short stay



Oak Lodge
Southampton SO19 7NG

- ✓ Nursing dementia
- ✓ Short stay



Wilton Manor
Southampton SO15 2HA

- ✓ Nursing dementia
- ✓ Palliative
- ✓ Residential dementia
- ✓ Short stay



Bespoke home care

Supporting people to live **independently**

We provide a range of services from regular and reliable visiting care to 24-hour live-in care. Whether it's a short daily visit or round-the-clock support, our dedicated care plans are centred around you or your loved one.

- ✓ Rated 4.7 on ★ Trustpilot
- ✓ Regulated by the CQC and CIW
- ✓ Free care assessments
- ✓ Providing care for over 30 years

Contact your local branch today!

Basingstoke 01256 588 455	Fareham 01329 640 193	Cosham 02394 278 079
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New Milton 01425 529 105	Southampton 02382 558 905
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for more details visit: helpinghands.co.uk

• • • *Because, life is better at home* • • •



There's nothing like the comfort of your own home.



We can provide:

- Elderly support
- Dementia care
- Companionship
- Emergency care
- 24-hour care
- Live-in care
- Respite care
- Mental health support
- Brain & spinal injury care

Navigating the challenges of dementia, whilst staying independent at home can be daunting. Moving into a care facility may feel inevitable, but it doesn't have to be.

We will work closely with you to handpick your loved one's carers, so you can genuinely connect with your team. We will make sure you're able to continue doing all the things you love such as staying active, socialising or cooking.

Care at home has many benefits for those living with dementia, such as staying within safe and familiar surroundings can improve cognitive function.

Whether you require weekly, daily or Live-in care, we can build a unique plan to suit your every need.

08000 622 622
nursepluscareathome.com

Nurseplus
Care at home



St Elmo Care Home is a 23 bedded home nestled in the Ringwood area with close access to the New Forest, Ringwood and the town's facilities.

The care home provides Residential care, and specialises in providing care for people living with dementia, with a reputation for the excellent quality of care it provides.

For more information, please contact **Lesley Hatton** on **01425 472922** or visit www.stelmocare.co.uk

St Elmo Care Home, Gorley Road, Ringwood, Hampshire BH24 1TH





Search for care in your area

www.carechoices.co.uk 

With so many providers to choose from, where do you start?

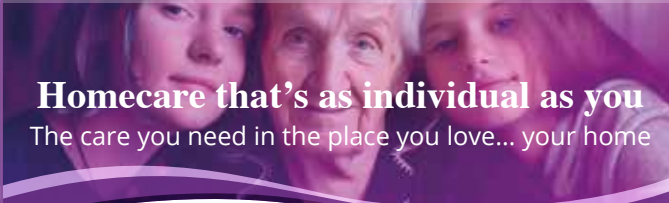
- Find care providers quickly and easily
- Search by location and care need
- Information on care quality
- Links to inspection reports
- Additional information, photos and web links
- Brochure requests

 CareChoices

Crown Home care
Caring hands

HAMPSHIRE HOMECARE PROVIDER OF THE YEAR
Winners 2023-2024

INSPECTED AND RATED
Q CareQuality Commission **GOOD**




Homecare that's as individual as you

The care you need in the place you love... your home

We are passionate about you and your well-being


There comes a time in life when you may need the **support of care** which you can choose to have in your own home, for you or a loved one. This is one of the most important decisions that you may have to make. We want to offer you the care to **maintain your life style** no matter the level support you need.


- Daily Care
- Live In Care
- Respite Care
- Companionship Service
- Palliative Care
- Dementia Care
- Bespoke Care Packages




For more information, contact us:

Tel: 01252 844923
Email: info@crown-homecare.com
Web: www.crown-homecare.com

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CARE PROVIDERS

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- ◉ What have you found useful?
- ◉ What could we do better?

Share your feedback

Take our five minute survey

 CareChoices

www.carechoices.co.uk/reader-survey



The lifestyle site for parents and carers of children with additional needs and those who support them.

www.myfamilyourneeds.co.uk

✉ hello@myfamilyourneeds.co.uk •  [@WeAreMFON](https://twitter.com/WeAreMFON)

- Birth to adulthood
- Real life blogs
- Directory
- Ask the experts
- Monthly columnist

Ask questions

Get involved

Join the family



Welcoming new residents at our specialist dementia care homes

We're proud to offer high-quality, affordable dementia care in our Hampshire homes. We support a variety of dementia needs, and make it our mission to make our homes as unique as the residents living in them. Our dedicated teams are highly trained in all levels of dementia care and provide bespoke care and support tailored to each residents needs.

Both homes are situated in the heart of Hampshire with Gorseway Park minutes from Hayling Island beach and Cordelia House just a 15 minute drive from historical Portsmouth Harbour. Both homes have stunning landscaped gardens which residents have the option to utilise for gardening activities and our summer BBQ's, as well as a range of bright communal spaces for those relaxing days in.

Gorseway Park, Hayling Island

Gorseway Park Retirement Village is an idyllic home-from-home on beautiful Hayling Island. We are just a stone's throw from the stunning beach.



Cordelia House, Fareham

Cordelia House care home in Fareham is delighted to be welcoming new residents. We are located in a stunning market town just outside of Portsmouth.



IN OUR
2022 CARE HOME
SATISFACTION SURVEY:

100%

of residents said
they feel safe with
the care team

98%

of residents said they
feel satisfied overall
with the service

Call today to book a visit!

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Est. 1986
Agincare
Caring in your community



THE WHITE HOUSE

Caring for younger and older people living with Dementia



Inspected and rated

Outstanding ★



THE WHITE HOUSE is a stunning country home set in 18 acres of beautiful formal gardens, woodland and paddocks. It offers a safe, homely and caring environment whilst providing a high standard of person centred care for up to 46 residents of any age, who have a diagnosis of Dementia or associated mental health problems.

The White House is a successfully run family business created by Julie Harrison in 1983. Julie's daughter, Emma is the Registered Manager and her son, Neil manages both the maintenance and the grounds. Together they share the day to day management of the home.

The home consists of the Main House and 3 purpose built connected units which allow free-flowing access to all areas, for all residents. The Main House is set over 3 floors with a lift and two stairwells providing easy access for all.

For more information on how we can help and the services we provide, please contact us using the details below.



01489 210080

www.thewhitehousecurdridge.co.uk

The White House, Vicarage Lane, Curdridge, Nr Southampton SO32 2DP



9.7

Average Group
Review score 2023
carehome.co.uk

*carehome.co.uk scores are based on independent reviews with a maximum score of 10. Rating correct as at 19/10/2023



Read Anita's story



Trust us to help Marcella stay in touch

We know who is close to Marcella's heart

Mayflower Court

SOUTHAMPTON | HAMPSHIRE

Orchard Gardens

BISHOPSTOKE | HAMPSHIRE

Mayflower Court
luxury care home

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Southampton,
Hampshire, SO17 1DP
02380 980 562

www.MayflowerCourt.org.uk

Orchard Gardens
luxury care home

1 Garnier Drive,
Bishopstoke, Eastleigh,
Hampshire, SO50 6HE
02380 980 557

www.OrchardGardens.org.uk



Live Safe & Well

Avery Healthcare offers a safe and supportive environment where residents can flourish, make new friends, remain part of their local communities and live a life of possibility.

- Residential, nursing, dementia, and respite care
 - Nutritionally balanced seasonal menus
 - Spacious, beautifully decorated bedrooms
- Stimulating schedule of daily activities and entertainment
 - Highly trained staff teams

Lavender Lodge
Farnborough

☎ 01252 490584

Pemberley House
Basingstoke

☎ 01256 670006

averyhealthcare.co.uk





Your care matters

with Barchester

**Everyone deserves uncompromising care.
That's the passionate belief of the
experts in our care homes.**

That's why you'll find our people are well-trained in a variety of skills.
They're dedicated people who want to celebrate life and improve well-being.
And it's why support is given with kindness, respect and dignity.

**These are the things that mean the most.
And because they matter to you, they matter to us.**



barchester.com/Hamps

Call to arrange a visit or to find out how we can help:

Ashcombe House • 01256 214 386
65 Worting Road, RG21 8YU

Denmead Grange • 02392 009 120
Forest Road, PO7 6XP

Orchard House • 01983 623 183
189 Fairlee Road, PO30 2EP

Snowdrop Place • 01489 222 076
Pavilion Road, SO30 2ZS

Challoner House • 02380 019 437
175 Winchester Road, SO53 2DU

Florence Court • 01329 655 910
243 Segensworth Road, PO15 5FF

Rothsay Grange • 01264 252 061
Weyhill Road, SP11 0PN

St Thomas • 01256 441 458
St Thomas Close, RG21 5NW

Wimborne • 02392 800 186
Selsmore Road, PO11 9JZ

Vecta House • 01983 623 188
24 Atkinson Drive, PO30 2LJ

Cherry Blossom Manor • 01256 441 447
German Road, RG26 5GF

Marnel Lodge • 01256 441 453
Carter Drive, RG24 9US

Shawford Springs • 01962 383 150
Otterbourne Road, SO21 2RT

The Fernes • 01329 655 819
Samuel Mortimer Close, PO15 5NZ

Residential care • Nursing care • Dementia care • Respite care and short breaks
Hair & beauty salon • En-suite bedrooms • Landscaped gardens • Café • Spa bathroom

Quality care you can trust, delivered in the comfort of your own home



We provide high quality, personalised care services, enabling you to continue living independently in the comfortable and familiar surroundings of your own home.

Our valued and professional CareGivers are a trusted, friendly face, dedicated to supporting you to live life to the full.

Did you know, we also offer full time live-in care?

With our live-in care service, one of our fully-trained and approved CareGivers will live with you in your own home, giving you the flexibility of help and support whenever you need it, day or night.

How can we support you?

- Companionship
- Transportation & errands
- Meal preparation
- Light housekeeping
- Hospital to home services
- Personal care
- Medication reminders
- Post-operative support
- Holiday & respite cover
- Specialist dementia care
- 24/7 live-in care

For more information on Right at Home's services, please contact:

02380 009595

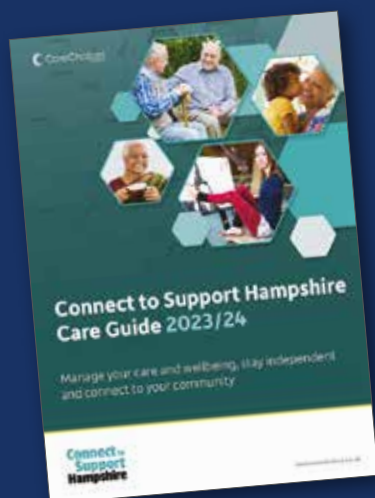
shannon.haines@rightathome.co.uk
www.rightathome.co.uk/midhants

Inspected and rated

Outstanding ☆



The publisher of this Guide, Care Choices, also produces the Connect to Support Hampshire Care Guide, in collaboration with Hampshire County Council. A new, 2023/24 edition is available, giving readers crucial information on how to access, and pay for, care services throughout Hampshire.



www.carechoices.co.uk

If you're growing concerned about your care options, or just want some more information on what your choices may be, the **Connect to Support Hampshire Care Guide** can help. With information to help you understand your options, where to go for advice and how the paying for care system works, it can support you to make informed decisions.

There are comprehensive listings of all registered care services throughout Hampshire, plus checklists to help you ask the right questions when visiting services.

For a free copy of the **Connect to Support Hampshire Care Guide 2023/24**, call **023 9268 0810** in Portsmouth or **023 8083 3003** in Southampton. Residents in the Hampshire County Council area can pick up an additional copy of the Guide from their local library.

With thanks

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An established care provider for over 20 years,

Working in partnership with local authorities providing a full range of services.
Enabling our clients in the Hampshire, Portsmouth, West Sussex
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Personal Care



Dementia Care



Shopping Services



Companionship



Domestic Support



Palliative Care



To discuss your care needs
or to join our team.
Please call **02392 362222**
or email **caring@bscare.co.uk**



Inspected and rated

Good



Inspected and rated

Good



Dedicated dementia care is just a phone call away

Looking for dementia care services in Hampshire?

Our professional care teams are here to help you and your loved ones. Brendoncare is a Hampshire based charity offering three homes with dedicated dementia care: Alton (East Hampshire), Otterbourne Hill (South of Winchester) and St Giles View (in the heart of Winchester).

We're welcoming new admissions now. Book your tour today.



Otterbourne Hill

Providing nursing and dementia care for up to 64 residents plus 20 apartments in a family-like environment with an inclusive community feeling.

Nursing care • Dementia care
Extra care • Respite care
End of life care



Alton

75 Bedrooms across five self contained households, with a home-like atmosphere of small family units and mature gardens.

Nursing care • Dementia care
Extra care • Respite care
End of life care



St Giles View

60 Bedrooms for nursing and dementia care, with en-suite facilities giving residents as much independence as possible.

Nursing care • Dementia care
Respite care
End of life care

"I felt a huge weight was lifted from my shoulders. My mother feels safe again and now enjoys the company she had been missing. The focus is 100% on the residents' well-being, care and safety" | ★★★★★ 5 Star carehome.co.uk review

Call **01962 673590** or visit
brendoncare.org.uk

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