

DEMENTIA FRIENDLY

2022

LEICESTER, LEICESTERSHIRE
& RUTLAND

A practical guide to living with dementia in Leicester,
Leicestershire & Rutland





Public Health
England

NHS

Do you have?

- heart disease
- kidney disease
- liver disease
- diabetes
- COPD (e.g. bronchitis or emphysema)

Flu can be serious and lead to hospitalisation.

Speak to your GP surgery or pharmacy today about getting a flu jab. It's free because you need it.

**HELP US
HELP YOU**

STAY WELL THIS WINTER

nhs.uk/flu vaccine

This is not a full list of conditions. If you have a long-term health condition, talk to your GP surgery or local pharmacist to see if you are eligible for a flu jab.

**Cheril Sowell,
Registered Nurse**



Contents

Welcome from Leicester, Leicestershire and Rutland Dementia Friendly Communities	4
Introduction	5
What is dementia?	8
Is it dementia? Symptoms and diagnosis	11
Planning for the future	16
When a family member has dementia	21
Living well with dementia	26
Top tips from an Admiral Nurse	36
Looking after you	37
People you may meet	41
What dementia taught me	44
Care and support needs	45
Planning for end of life	54
Legal and financial affairs	59
Dementia Friendly Communities	62
Dementia support in Leicester, Leicestershire and Rutland	64
Community support groups for people living with dementia in Leicester, Leicestershire and Rutland	65



Alternative formats



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.

Welcome from Leicester, Leicestershire and Rutland Dementia Friendly Communities

We are pleased to introduce the 3rd edition of the Dementia Guide.

As Chair of the Leicester, Leicestershire and Rutland Dementia Friendly Communities, we work with a wide range of organisations from across these three areas, all with the same aim: to improve the lives of people living with dementia and their carers. We aim to increase the awareness about living well with dementia, promote best practice and learn from each other – as well as influence change in communities and within the health and social care system.

We were also involved in the development and implementation of the local 'Living Well with Dementia Strategy 2019-2022.' We are currently working with partners to refresh our priorities for the new three-year strategy.

Leicester, Leicestershire and Rutland (LLR) has an estimated 13,000 people living with dementia. Whether they are living in the inner city or remote rural areas, LLR has a diverse population which we are proud of.

The challenge for people living with dementia, their families and carers, is to be able to access information that is suitable and relevant for their individual needs at the right time. We see

this Guide as one way for people to gain this information. Throughout the Guide, there are also contact details and suggestions about where other information and support can be found.

We welcome the 3rd edition of this Guide and we hope those who read it will find practical information about dementia and a range of support available locally.

We hope that you find it useful.

Best wishes,

Samantha Clarke
Chair of Leicester, Leicestershire and Rutland Dementia Friendly Communities



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



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, 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, a member of the community, 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 services and

support. However, it doesn't have to be, and this Guide has comprehensive lists of local services starting on page 65. Local services may be able to put you in touch with other support in your area.

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.

The **local organisations** starting on page 65 will give you more information on what's available in your area to support you and the person living with dementia.

Finally, we know that you're not alone in supporting someone with dementia. That is why 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, although it's important to consider that no one person experiences dementia in the same way – 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.

Local organisations begin on page 65.

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 65 will give you more information on what's available in your area to support you and the person living with dementia.



Is it dementia? Symptoms and diagnosis

Many people live well for a long time and have 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 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 65 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.

“ The person with dementia should be fully involved, and informed, at every stage. ”

Dementia is a progressive illness and, although there are treatments, there is no cure. If someone has been diagnosed with dementia, they may

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

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 65. Information on **benefits** is on page 38 and the chapter on **living with dementia** starts on page 26.

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

local services starting on page 65.

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 65 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.

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.

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.

Looking for care and support in Leicester, Leicestershire & Rutland?

Care Choices' essential guide to choosing and paying for care and support for adults

The Leicester, Leicestershire & Rutland Directory will be available in print and online, where it can be listened to via Recite Me.

In association with



Leicester
City Council



Leicestershire
County Council



Rutland
County Council



NEW



For further information contact **Care Choices** on **01223 207770**



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. 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.

6 **Social services are an invaluable resource and aren't going to take the person with dementia away.** 9

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** are 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).

‘ 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. ’

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 is 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.dementiaexplained.org** 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 micro elements 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 with dementia understands about their symptoms and how they are progressing is completely individual. Some people have more insight than others, and it's important to reflect on the variations that can occur, and if their symptoms are particularly challenging, feel they are 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. 9

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 ok 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 on 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 niggles and stresses during your day. When you step back from the situation and look at it with a clear head, you may find 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 16.

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 65.

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, 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 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 to 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.

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. They may need glasses or hearing aids, which they will need

to be assessed for. They may develop 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 may also be eligible to receive the 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. This may depend on the cause of the incontinence but products such as pads should not be used as treatment until all other options have been tried.

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. Look after yourself as much as you look after the person you support.

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, as 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 your ability to carry on caring. 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 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.

The **local organisations** starting on page 65 will give you more information on what’s available in your area to support you and the person living with dementia.

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 65, 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.



‘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. 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.

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. Local emergency planning services for carers can help with this.

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.

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.

For information about local Admiral Nurse services in Leicester, Leicestershire and Rutland, see 'Admiral Nurse services' on page 64.

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

The Dementia UK National Dementia Helpline is **0800 888 6678**.

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.

What dementia taught me

‘As a nurse, it was easy to assume that I’d know exactly what to do should one of my loved ones be diagnosed with dementia. However, while I had a lot of knowledge of the practical realities of dementia, the emotional reality is something you can never predict.’

‘My mother, Josie, was diagnosed with vascular dementia aged 69. My husband and I noticed that she started to repeat herself during our conversations, and suggested she go for an assessment. As it happens, my mum had had the same idea; she had already made an appointment.

‘Even though we’d had our suspicions, the diagnosis was still hard to hear. In a way it didn’t really bother my mum, because she quickly forgot about it and carried on. But I couldn’t do that. Finding out that a loved one is ill is never easy, but that’s only the beginning. You don’t think about all of the things that come with it.

‘It was hard, but I eventually learned to accept help when I needed it. For a long time I felt I was the only person who could look after my mum, but it became overwhelming, especially as her condition worsened. I’d advise anybody in this position to get in touch with your local services, and remember that support is there for you, as well as your loved one.

‘About three years after her diagnosis, living independently, or even semi-independently, was no longer an option. It was devastating for my mum to leave the family home, which made it a traumatic experience for us all, but I knew moving into some kind of sheltered accommodation was the best option. My research led me to Belong Warrington.

‘My mum moved into an apartment at Belong and made the most of the fantastic home care service, Belong at Home. She also went along to the Experience Days, which are activity days for people with dementia to help them get involved and interact with others in a similar situation to their own.

‘I honestly couldn’t recommend them enough. Even with a big network of friends and family, dementia can be incredibly isolating, but my mum was able to make new friends who understood her situation and get back some of her independence. It was also an opportunity for me to take some time for myself, which was something I often neglected.

‘Looking back, I can see that it has been a learning curve, even after working as a nurse for many years. If I’d known how brilliant the staff at Belong would be, especially during mum’s transition into a full-time care household, where she currently lives, both of our lives would have been much less stressful.

‘While it can be hard for somebody living with dementia to move into a new home, remember that you’re doing it for their wellbeing.

‘I’d also recommend looking around your local area to find activities that they can get involved in and accept the help that’s out there – for your loved one and yourself.’

With thanks to Gill Byrne and Belong Warrington.



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, devices that notify if someone leaves the house and voice commands to remind your loved one of specific actions. You can even record the messages yourself to offer a familiar voice.

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.

Lightbulb offers aids and adaptations, energy advice, home safety, home improvements and support with moving home from hospital. Lightbulb is piloting a new Assistive Technology offer to help people with dementia live more independently at home. See page 65 for more information and contact details.

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 the situation, 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 (perhaps because of your financial situation, for example) 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.

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 give 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.

Housing with care

If the person with dementia's needs are such that they are unable to live independently at home but don't necessarily require the support that a care home might offer, they could consider moving into a housing with care scheme. Housing with care offers a mid-ground for people with care and support needs, with a combination of services and independent living. This can promote a person's wellbeing, giving them back independence they may have feared lost. It can also enable partners to stay together when the

other option is for the person with dementia to enter a care home.

Housing with care is a catch-all term that can cover a lot of different schemes, offering all levels of support. Some schemes will be more suited to people with lower care and support needs while others can cater for people with more complex needs requiring high levels of support. Typically, people can buy or rent a property on the site and have care and support services provided by a contracted company. There is likely to be a community alarm system and access to services such as meals on wheels and home care.

The amount of support the person with dementia can receive in a housing with care scheme can

change, depending on their level of needs.

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.

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.

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 – these 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 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 – 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, who 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.

- University Hospitals of Leicester (UHL) is part of John's Campaign, using the strap line 'Stay with Me'. This is part of its family, carers and friends charter.
- Patients admitted to Leicester's hospitals

with a known dementia diagnosis may have a forget-me-not flower placed in their bed space. This is to let staff know that extra time and support is needed.

- UHL has 1,600 older people and dementia champions, who have received additional training to support patients and families.
- Meaningful Activities Facilitators support people living with dementia through varied activity provision.
- Admiral Nurses support both the person with dementia and their family/carer.

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 60.

APPROACHING THE END OF LIFE

As the symptoms of dementia progress, the person with dementia may develop other conditions – see page 27 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 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 support networks.

The **local organisations** starting on page 65 will give you more information on what's available in your area to support you and the person living with dementia.

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 64 and there are tips from an Admiral Nurse on page 36.

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 the 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 OK 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. Things to consider are included on ‘How to arrange a funeral’, a webpage created by Hospice UK. Visit www.hospiceuk.org/information-and-support/i-need-support-bereavement/how-arrange-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?
- Are they a registered organ donor?
- 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 campaign website, from Hospice UK.

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 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 Friendly Communities



A dementia friendly community is a city, town or village where people with dementia are understood, respected and supported.

In Leicester, Leicestershire and Rutland, we are working towards this. These local dementia friendly communities have developed in response to local interest and can link closely to local community groups, organisations and businesses.

They provide an opportunity to network with

a range of professionals and local people to share ideas and information and seek advice and support from other members.



OUR AIM

We want a place where people will be aware of and understand dementia, so that people with dementia and their carers can continue to live in the way they want to and in the community they choose.

There are local dementia friendly communities and forums in the following areas – please get in touch with the contacts below if you are interested in joining the community, or becoming a dementia friend or dementia champion.

Area – Blaby District

Who to contact – Samantha Clarke
 Email: Samantha.Clarke@blaby.gov.uk
 Tel: **0116 272 7544**

Area – Charnwood

Who to contact – Louise Millington
 Email: louise.millington@charnwood.gov.uk
 Tel: **01509 634764**

Area – Harborough

Who to contact – Peter Hirst
 Email: membership@dementiaharborough.org
 Tel: **07954 649566**

Area – Hinckley and Bosworth

Who to contact – Lindsay Orton
 Email: lindsay.orton@hinckley-bosworth.gov.uk
 Tel: **01455 255805**

Area – Leicester City

Who to contact – Diana Dorozkinaite
 Email: Diana.Dorozkinaite@leicester.gov.uk
 Tel: **0116 454 4773**

Area – Leicester, Leicestershire and Rutland

Who to contact – Samantha Clarke
 Email: Samantha.Clarke@blaby.gov.uk
 Tel: **0116 272 7754**

Area – Oadby and Wigston

Who to contact – Lesley Pickles
 Email: outreachtmc@outlook.com



LLR DEMENTIA PROGRAMME BOARD

This group meets every three months and manages the local strategic health, social care and community priorities for dementia across the area and oversees the local Living Well with

Dementia Strategy that it developed. To enquire about membership and the terms of reference, contact Beverley White by emailing Beverley.White@leicester.gov.uk



Search for care in your area

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

Dementia support in Leicester, Leicestershire and Rutland

Local statutory services work closely with Dementia Friendly Communities and provide specific services and advice for people affected by dementia.

Admiral Nurse services

These services provide specialist dementia support. When things get challenging or difficult for people living with dementia and their families, Admiral Nurses offer one-to-one support, expert guidance and practical solutions tailored to individual needs and challenges. Contact the service using the details below for referral criteria.
Email: admiralnurse@rutland.gov.uk (Rutland).
Email: stuart.kennedy@charnwoodgpnetwork.nhs.uk (Charnwood and Watermead).
Email: Andrew.Gallagher-Casals@GP-C82098.nhs.uk (Blaby, Countesthorpe and Lutterworth).
Email: admiralnursing@uhl-tr.nhs.uk (University Hospitals of Leicester NHS Trust, based at the Leicester Royal Infirmary).
Web: www.dementiauk.org

Adult social care departments

Your local council can provide a range of support and information about living with dementia. Eligibility criteria will apply, but information and signposting to other services is also available.

Leicester City Council

Tel: **0116 454 1004**
Web: www.leicester.gov.uk

Leicestershire County Council

Tel: **0116 305 0004**
Web: www.leicestershire.gov.uk

Rutland County Council

Tel: **01572 722577**
Web: www.rutland.gov.uk

Dementia Support Services, The

The first point of contact for people who are affected by dementia are often the local Dementia

Support Services. The services are provided by Age UK Leicester Shire and Rutland and are funded by the NHS and local authorities. Dedicated Dementia Support Workers provide information, advice and guidance for people concerned about their memory, those with a diagnosis, family members and informal carers. The services can be accessed at any point, including pre- and post-diagnosis and as a person's needs progress.

Age UK Leicester Shire and Rutland

Tel: **0116 223 7363** (Leicester City and Leicestershire) and **01572 823942** (Rutland).
Email: dementia.support@ageukleics.org.uk (Leicester City and Leicestershire) and yvonne.rawlings@ageukleics.org.uk (Rutland).
Web: www.ageuk.org.uk/leics/our-services/living-with-dementia

East Midlands Ambulance Trust

This service was the first in the country to adapt its ambulances to be dementia friendly. Web: www.emas.nhs.uk (search 'dementia').

Leicestershire Fire and Rescue Service

Protecting communities across Leicester, Leicestershire and Rutland. The service carries out home fire safety checks for people living with dementia. • Tel: **0116 210 5555**
Text: **07860 063686** (for deaf, deafened, and hard of hearing people only).
Web: <https://lfrs.egressforms.com/Form/HomeFireSafetyCheck>

Leicestershire Police

Leicestershire Police support the Prime Minister's challenge of creating Dementia Friendly Communities and will work with local agencies in Leicester, Leicestershire and Rutland to support initiatives and work which supports this aim.

One initiative that local police are promoting is the Herbert Protocol. This form helps people

to be found more quickly if they go missing. You can download the form by visiting www.leics.police.uk/notices/af/herbert-protocol and it is also available in local police stations.

Lightbulb

The Lightbulb service helps support the residents of Leicestershire to remain safe and well in their own homes. Lightbulb brings together a range of support such as aids and adaptations, energy advice, home safety, home improvements and support with the transition from hospital to home. Lightbulb is currently piloting a new Assistive Technology offer to help people with dementia live more independently in their own homes. Please get in touch to share what technology you would like to see in this offer.

Tel: **0116 272 7655**

Email: lightbulb@blaby.gov.uk

Web: www.lightbulbservice.org

Local NHS services

Memory issues are often the first thing that people notice with dementia. If you're worried that your memory is getting worse or is beginning to affect everyday life, the best thing to do is talk to your GP.

Memory Assessment Service, The

The Memory Service provides diagnostic assessment and treatment for people with dementia by Leicestershire Partnership NHS Trust. The service is accessed via a referral from your GP. This service is provided across Leicester City, Leicestershire County and Rutland. The service is provided by psychiatrists and mental health nurses. Leicestershire Partnership NHS Trust also provides a range of services for people affected by dementia and further information can be found on its website or by speaking with your GP. Visit www.leicspart.nhs.uk

University Hospitals of Leicester NHS Trust

The University Hospitals of Leicester (UHL) Dementia Strategy Group has trust-wide, multi-professional representation, with members from Alzheimer's Society and includes patient and public involvement. The group is responsible for improving the quality of care for people with dementia and their carers who are admitted to UHL hospitals, ensuring recommendations from key national and local policies are implemented. Please tell staff if you have dementia and look out for the forget-me-not logo around the hospital. The Dementia Support Service and Admiral Nurses operate within Leicester hospitals too.

Community support groups for people living with dementia in Leicester, Leicestershire and Rutland

Please contact any dementia support groups or cafés before visiting. Opening times and costs may vary. Every effort has been made to ensure contact details are up to date. Local services may be able to put you in touch with other support in your area.

Academy for Dementia Research and Education

This service supports people in the early

stages of dementia and their families and friends who are living in the communities of South Leicestershire and Northampton to live independently for as long as possible. The service runs from 9.00am to 4.00pm, Monday to Friday, at Lutterworth College. • Tel: **01455 550416**
Email: jane@academyfordementia.org
Web: www.academyfordementia.org

Age UK Leicester Shire and Rutland

Operates an extensive range of services for local communities for anyone living with dementia or concerned about their memory and their families. Services include Maintenance Cognitive Stimulation Therapy, day care services, help at home and community activities such as dementia walks, cafés and carer support groups.

Lansdowne House, 113 Princess Road East, Leicester LE1 7LA • Tel: **0116 299 2233**

Email: enquiries@ageukleics.org.uk

Web: www.ageuk.org.uk/leics

Community Resource Centres

Local facilities providing useful walk-in services for older people coupled with the opportunity to take part in activities and events.

Web: www.ageuk.org.uk/leics (search 'community resource centres').

Clarence House

46 Humberstone Gate, Leicester LE1 3PJ

Tel: **0116 299 2233**

Email: reception@ageukleics.org.uk

Earl Shilton Senior Citizens Centre

Kings Walk, Earl Shilton LE9 7NL

Tel: **01455 847666** or **01455 844520**

Email: earlshilton@ageukleics.org.uk

Gloucester House

3 Norman Way, Melton Mowbray LE13 1JE

Tel: **01664 410253** or **01664 410108**

Email: rhonda.fazackerley@ageukleics.org.uk

Day care

Support and companionship within your local community, alongside the chance to participate in a range of activities and trips. Groups are available in Birstall, Braunstone, Coalville, Earl Shilton, Fleckney, Leicester City, Loughborough, Market Harborough, Melton Mowbray, Moira, Mountsorrel, Oakham, Rearsby and Uppingham. Tel: **0116 222 0572** or **0116 222 0558**

Email: enquiries@ageukleics.org.uk

Web: www.ageuk.org.uk/leics (search 'day care groups').

Maintenance Cognitive Stimulation Therapy (MCST)

A group treatment designed to support people who are living with mild to moderate dementia. MCST is recommended by the National Institute for Health and Clinical Excellence (NICE) and is currently being offered through relaxed weekly sessions facilitated by experienced Age UK staff in Earl Shilton, Oakham and Melton Mowbray, with plans to launch the service in Leicester City too.

Tel: **0116 299 2273**

Web: www.ageuk.org.uk/leics (search 'MCST').

Memory cafés

Safe, comfortable and supportive environments for people with dementia and their carers to socialise, enjoy refreshments or undertake activities.

Tel: **0116 223 7363**

Email: dementia.support@ageukleics.org.uk

Bluebells Memory Café

Glenfield Sports Pavilion, Gynsill Lane, Glenfield LE7 7AG

Charnwood Memory Café

John Storer House, Wards End, Loughborough LE11 4HA

Coalville Memory Café

Marlene Reid Centre, 85 Belvoir Road, Coalville LE67 3PH

Forget Me Not Memory Café

Countesthorpe Village Hall, Station Road, Countesthorpe LE8 5TB

Market Harborough Dementia Café

Market Harborough Methodist Church, Northampton Road, Market Harborough LE16 9HE

Poppies Memory Café

Syston Community Centre, School Street,
Syston LE7 1HN

Rutland Memory Café

Tel: **01572 823942**

Email: **yvonne.rawlings@ageukleics.org.uk**

Men and Women in Sheds

If you are 50+ and interested in learning or sharing skills in a sociable workshop environment, then Men and Women in Sheds is for you.

Available in Loughborough and Rutland.

Tel: **0116 299 2235**

Email: **owen.jones@ageukleics.org.uk**

Blaby District Council – A Place to Grow

Community garden project in Enderby, for people living with dementia, mental health and learning disabilities in Blaby District.

Tel: **0116 272 7703** • Email: **leisure@blaby.gov.uk**

Web: **www.blaby.gov.uk** (search 'a place to grow').

Buddhi बुद्धि घिषी

Offers those living with dementia, their families and carers therapies using mindfulness activities including art and crafts, non-conventional exercises and relaxation to support emotional, mental and physical wellbeing. Mainly in South Leicestershire.

Tel: **07730 693084**

Email: **BuddhiByM@outlook.com**

Web: **www.facebook.com/BuddhiByManjit**

Comfort Discharge and Reablement Services

Provides support to people with dementia mainly in the Hinckley and Bosworth area.

Email: **info@cdrservices.co.uk**

Web: **www.cdrservices.co.uk**

Community transport services

Each local authority website (see page 64) provides signposting information to community transport groups. Search 'community transport in your area' or call the numbers below.

Web: **www.choosehowyoumove.co.uk**
(search 'community transport').

Leicester City Council

Tel: **0116 454 1000**

Leicestershire County Council

Tel: **0116 232 3232**

Rutland County Council

Tel: **01572 722577**

Curve Theatre

Dementia Friendly Performances are tailored to support audience members living with dementia, their families and carers.

Tel: **0116 242 3595**

Web: **www.curveonline.co.uk/dementia-friendly-performances**

Dementia Café at The Well (Harborough)

A place for people with dementia, together with their carer, to talk, share and take part in varied activities, information and support. Open from 2.00pm to 4.00pm on the second Monday of each month.

The Well, 45 High Street,
Kibworth Beauchamp LE8 OHS

Tel: **07594 649566**

Web: **www.thewellkibworth.org/activities**

Dementia Café Fleckney (Harborough)

Open to people living with dementia and their carers.

Fleckney Library, School Street LE8 8AS

Tel: **0116 240 3218**

Email: **stevearobson@hotmail.co.uk**

Web: **www.fleckneycommunicare.co.uk**

Dementia Exercise Class (Charnwood)

An opportunity for those living with dementia to remain active. Classes are both mixed ability and gender in the Charnwood area.

Tel: **07730 801967** (Tina Coles).

Email:

gp-referral-chnwood@fusion-lifestyle.com

Dementia Harborough – Dementia Café

A place for people with dementia, together with their carer, to talk, share and take part in varied activities. Open from 2.00pm to 4.00pm on the third Tuesday of each month.

Jubilee Hall, Congregational Church,
Bowden Lane, Market Harborough LE16 7JD
Web: www.dementiaharborough.org

Dementia Harborough – Singing for Memories

A place for people living with dementia together with their carer, this group is designed to evoke memories through a range of familiar songs chosen by those in attendance. Open from 2.00pm to 4.00pm on the first Tuesday of each month.

Jubilee Hall, Congregational Church,
Bowden Lane,
Market Harborough LE16 7JD
Tel: **07594 649566**
Web: www.dementiaharborough.org

Dementia support – weekly drop-in

For people with dementia, their families and carers. Held at Blaby library every Tuesday, from 11.00am to 12.00pm. Come along for a chat, some support and advice. • Tel: **0116 305 3516**

Dove Cottage – dementia support group (North East Leicestershire and Rutland)

Friendly and informative sessions for carers to get information about dementia and gain peer support to help with their caring role. Held on the second Friday of every month, from 10.30am to 12.00pm. A home sitting service is also offered. Tel: **01949 860303**

Email: chris@dovecottage.org
Web: www.dovecottage.org/dementia-support

East West

The East West Community Centre provides social welfare, recreational and leisure facilities and activities for older people, including those with dementia. Open seven days a week, between 9.30am and 2.30pm.

10 Wilberforce Road, Leicester LE3 0GT
Tel: **0116 255 0575**
Email: eastwestproject@gmail.com

First Contact Plus Leicestershire

A partnership of services working together to ensure local people receive the right information and support. • Tel: **0116 305 4286**
Email: firstcontact@leics.gov.uk
Web: www.firstcontactplus.org.uk

Forget Me Not Group (Charnwood)

A social support group of people who are caring for a loved one with dementia as well as those living with dementia themselves. It runs fortnightly sessions at Loughborough Baptist Church and once a month, the group supports just those with dementia to enable carers to have respite time. Tel: **01509 215642**
Email: office@lbcweb.org.uk

Forget Me Not Groups (Hinckley and Bosworth)

A social support group for people living with dementia and their carers, including refreshments and activities. There is a cost of £3 per person and their carer. Tel: **07943 026977**
Email: john.coglan@leics.gov.uk

Desford

Every first and third Thursday at 10.30am at St Michael's Church.

Newbold

Every second and fourth Thursday at 10.30am at the library.

FTM Dance (Wigston and Leicester)

A performing arts respite service for children and adults with additional needs, including those with dementia. Various days and locations in Wigston and Leicester. Tel: **0116 380 5608**
Email: management@ftmdance.co.uk
Web: www.ftmdance.co.uk

GBT Day Centre

Offers a luncheon club and day care activities such as knitting, computer classes, cooking activities, board games, day trips, shopping trips, exercise classes, cultural activities and transport services. Supports people in Leicester and Leicestershire.

106 East Park Road, Leicester LE5 4QB

Tel: **0116 274 1683**

Email: **info@gtbdaycentre.com**

Web: **www.gtbdaycentre.com**

Guru Nanak Day Care Centre

Provides support, care and assistance to Punjabi speaking older people. Supports people in Leicester and Leicestershire.

Manor House, Haddenham Road,
Leicester LE3 2BG

Tel: **0116 222 1021**

Email: **gngcentre@hotmail.com**

Web: **www.gndaycentre.co.uk**

Holmfield Dementia Day Care Centre (North West Leicestershire)

A purpose-built facility dedicated to supporting people living with dementia and their families.

1 Croft Road, Beaumont Leys LE4 1HA

Tel: **0116 236 8115**

Email: **holmfield@midlandscare.co.uk**

Web: **www.midlandscare.co.uk** (select 'Holmfield Dementia Day Care Centre').

Home Independence Occupational Therapy

Specialist home-based falls prevention focus advising on equipment, daily living aids, adaptations and assistive technology. Cognitive assessments and therapeutic activities are also available. Covering Leicester and Leicestershire.

Tel: **07341 265564** (Sophia Dickinson).

Email: **info@homeindependenceot.co.uk**

Web: **www.homeindependenceot.co.uk**

J&S Day Services Ltd (South Wigston)

Specialist day service for people living with dementia or physical and sensory needs in an

environment designed to be calming and sociable.

1 Tigers Close, South Wigston LE18 4WS

Tel: **0116 278 5444**

Email: **hello@jandsdayservices.com**

Web: **www.jandsdayservices.com**

Lavender Mill Care Services (Rutland)

Provides high-quality day care services for adults living with dementia and older adults who may be isolated and are looking to meet new people. Activities aim to help memory recollection and improve mental and physical wellbeing. Runs on Fridays at Ashwell Village Hall in Rutland.

Tel: **07977 709588**

Email: **sally_radford@hotmail.co.uk**

Leicester Musical Memory Box (Leicester City and Leicestershire)

Based around the principles of music therapy, these sessions include a variety of vocal warm-ups and singing familiar and new songs in a safe and friendly environment.

Wolsey Building, Abbey Park Street,
Leicester LE4 5AF

Tel: **07736 841558**

Email: **lmmbox2018@gmail.com**

Web: **www.leicestermusicalmemorybox.co.uk**

Leicestershire Information and Support Directory

An online directory of local care and health services. The directory is managed by Leicestershire County Council, but it does not recommend or endorse any of the organisations listed.

Web: **www.leicestershire.gov.uk/lisd**



Leicestershire libraries

Leicestershire libraries offer books suitable for those living with dementia. Many libraries also offer events and activities to support your health and wellbeing, including support groups, Make Friends with a Book groups and craft and chat sessions. Many library staff are Dementia Friends. Local Area Co-ordinators also run drop-ins for people living with dementia, depending on local need.

Web: www.leicestershire.gov.uk
(search 'libraries').

Leicestershire Shared Reading

Delivering reading activities to reduce social isolation among members, including those suffering from depression and dementia.

Tel: **07415 125409**

Web: www.facebook.com/LEsharedreading

Local Area Co-ordinators (LACs)

Providing a variety of services including signposting people to local activities or community groups, linking people together and working with them to help them achieve their goals. To find out if you have a LAC in your area, refer to the contact details below.

Tel: **0116 305 9646**

Email: anna.christie@leics.gov.uk

Web: www.leicestershire.gov.uk (search 'local area co-ordinators').

Lutterworth Share and Care Group

A social support group for people with dementia and their families, providing person-centred activities which focus on helping both the individual and their family adapt to living with dementia. Covering South Leicestershire, Lutterworth and the surrounding villages. Sessions throughout the week at various venues.

Tel: **07801 735242**

Email: sophie@academyfordementia.org

Web: www.academyfordementia.org/site/share-and-care-timetable

Mind for You

Local service but with national coverage providing holidays as well as digital social events and activity packs for people living with dementia and their carers.

5 The Willows, Burton on the Wolds,
Loughborough LE12 5AP • Tel: **01509 351008**
Web: www.mindforyou.co.uk

MyChoice

A directory for care and support products and services for people living in Leicester City.

Web: <https://mychoice.leicester.gov.uk>

Rotary Club of Oadby Memory Café

Meet up in an informal atmosphere and engage socially with other people living with dementia and their carers. Refreshments are provided alongside a range of dementia friendly activities, including arts and craft, games, puzzles, singing and reminiscing.

The Barnabas Centre, St Pauls, Hamble Road,
Oadby LE2 4LZ

Tel: **0116 241 4455** (Mandy)

Mobile: **07966 311946** (Peter)

Email: mandypenfold@hotmail.com

Web: www.rotary-ribi.org/clubs/homepage.php?ClubID=431

Royal Voluntary Service – Remember Me Café

A supportive group, providing information and advice, with fun and engaging activities for all. Gorse Covert Community Centre Maxwell Drive Loughborough LE11 4RZ • Tel: **07815 515227**

Email: leicestershiredementiasupport@royalvoluntaryservice.org.uk

Rutland Information Service

Provides a range of information and contact details for local services in Rutland.

Web: ris.rutland.gov.uk

Santosh Community Centre

A day care service for people aged 55+ who are socially isolated and/or physically or mentally

ill. It specialises in providing food and activities that are tailored to people from South Asian communities and supports people in Leicester and Leicestershire.

2A Wingfield Street, Leicester LE4 5DS

Tel: **0116 266 9577**

Web: **www.santoshdaycare.co.uk**

Sapcote Memory Hub (Blaby District)

Group sessions providing cognitive stimulation therapy, activities and social interaction for people with mild to moderate dementia or memory problems. The service can cover all local areas and is open most weekdays, but please enquire.

Rugby House, Hinckley Road, Sapcote LE9 4FS

Tel: **07983 803896** (Katie Grigg).

Email: **sapcotememoryhub@outlook.com**

Web: **www.facebook.com** (search 'sapcote memory hub').

Sharing Precious Memories

Offers advice and support after diagnosis for people living with dementia and their carers; support is available at home as well as the provision of personalised activities. • Tel: **07947 344433**

Email: **sandi52@hotmail.co.uk**

Web: **www.facebook.com** (search 'sharing precious memories').

Singing Café, The

A fully inclusive activity for anyone (including carers) challenged with their mental health, including dementia. Weekly cafés running from Melton, Wigston, Shepshed, Loughborough, Coalville and Ashby, in the main town libraries.

Tel: **07875 378628** (Catherine Henderson).

Email: **thesingingcafe@outlook.com**

Web: **www.thesingingcafe.co.uk**

Singing Café, The (Hinckley)

A fortnightly get together for people living with dementia and their carers. Singing, dancing, quizzes and plenty of tea and cake.

Pathways Centre, Hinckley Baptist Church, Baptist Walk, Hinckley LE10 1PR

Tel: **01455 890026**

Email: **pathways@hinckleybaptist.com**

Web: **www.hinckleybaptist.com**

Singing for the Brain (Blaby District)

Based around the principles of music therapy, these sessions include a variety of vocal warm-ups and singing familiar and new songs in a safe and friendly environment.

Blaby and District Social Centre, Leicester Road, Blaby LE8 4GQ • Tel: **07736 841558** (Kyle).

Email: **singinglady98@gmail.com**

Sounds Familiar and Simply Sounds

Free archive of sound recordings and activities, ideal for reminiscence. Visit the website to download sounds, photos and conversation starters. Created as part of a project with the British Library, University of Leicester and Culture Leicestershire.

Tel: **0116 305 7890**

Email: **esther.shaw@leics.gov.uk**

Web: **www.cultureleicestershire.co.uk/unlocking-sounds**

Starleng Arts

Improving mental wellbeing for individuals using person centred art therapy.

Tel: **07377 686822** (Lyni Sargent, Trainee Art Therapist).

Web: **www.linktr.ee/Starleng**

Take-a-Break (Hinckley)

Lunch and social club with a variety of activities for people living with early to mid-stage dementia.

Pathways Centre, Hinckley Baptist Church, Baptist Walk, Hinckley LE10 1PR

Tel: **01455 890026**

Email: **pathways@hinckleybaptist.com**

Web: **www.hinckleybaptist.com**

Technology and equipment

A source of information and advice about aids and technology, supported by Leicestershire and Rutland councils.

Web: **www.safeandwell.co.uk/leicestershire**

Thrummy Drummers Dementia Social and Support Group (Charnwood)

A friendly and welcoming group whose sessions include socialising, music-related entertainment and refreshments.

Elizabeth Park Sports and Community Centre,
Thurmaston, Leicester LE4 8FN

Tel: **07484 147524** (June Norris).

Trent Dementia

This organisation provides dementia care training, regional conferences and project work such as walking groups, online groups and Life with Dementia events, organised by people living with dementia. • Tel: **0115 748 4220**

Email: **deep@trentdementia.org.uk**

Web: **www.trentdementia.org.uk**

Young Onset Dementia Support Group (Hinckley and Bosworth)

Provided by the Shuttlewood Clarke Foundation, this is a free social group for people living with dementia under the age of 70 to support each other, share knowledge and laugh together. Optional activities include curling, skittles, quoits, darts, bocchia and crafts.

Shuttlewood Clarke Foundation,
Activity Centre, Ulverscroft Manor,
Priory Lane, Ulverscroft, Markfield LE67 9PH

Tel: **07860 639693** (Kathleen).

Email: **kathleen@shuttlewood-clarke.org**

Web: **www.shuttlewood-clarke.org**

SUPPORT FOR CARERS

Age UK – Leicester City Carers Support Service

Provides support and information to all carers over the age of 18 in the City of Leicester.

Services are hosted at the Carers Hub, based at Clarence House, or at other locations throughout the city.

Clarence House, 46 Humberstone Gate,
Leicester LE1 3PJ

Tel: **0116 222 0538**

Email: **carers@ageukleics.org.uk**

Web: **www.ageuk.org.uk/leics** (search ‘carers support service’).

Mobile: **07738 820910**

Email: **yvonne.rawlings@ageukleics.org.uk**

Carers Centre, The

A Leicestershire-based charity supporting family carers across the diverse population of Leicester, Leicestershire and Rutland who look after people with different needs, providing information, advice, training and signposting to local support services.

Tel: **0116 251 0999**

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

Web: **www.claspthecarerscentre.org.uk**

Age UK – Loughborough Carers’ Support Group

A drop-in support group for carers of people with dementia and memory loss. The group also arranges activities and guest speakers.

Trinity Methodist Church Centre,

Royland Road LE11 2EH • Tel: **0116 231 1114**

Age UK – Rutland Carers’ Support Group

Offers carers of older people living with dementia the chance to meet and mutually support each other. There is also a collection of speakers and activities suitable for carers of those with long-term care needs.

Tel: **01572 823942**

Leicestershire Carer Support Service

The Carer Support Service is run by VASL. It provides a dedicated phone line, manned by Carers’ Wellbeing Officers, who offer information advice and support in all aspects of your caring role. VASL also provides carers’ groups across the county and a telephone befriending service.

First Floor, Torch House, Torch Way, Northampton Road, Market Harborough LE16 9HL

Tel: **01858 468543**

Email: **maureen@supportforcarers.org**

Web: **www.vasl.org.uk** or

www.supportforcarers.org



Agincare

Live-in Care



Fully managed high quality
affordable live-in care
from £995 per week



0808 291 2996 | agincare.com



Helping Hands
Caring since 1989

“ Home Care to support
you in Leicestershire ”

We provide personalised home care packages with care visits available from 30 minutes all the way up to full-time live-in care. Supporting you to live independently in the home you know and love, including:

- Personal Care
- Getting out and about
- House keeping
- Short term-care and more.



Call us today on: 01162 145 445



The Best in Care

Avery Healthcare offers a safe and supportive environment where residents can flourish, make new friends, maintain contact with their local communities and live a life of possibility.

- Residential, respite and dementia care
- Nutritionally balanced seasonal menus
- Spacious, beautifully decorated bedrooms
 - Safe visits for family and friends
- Stimulating schedule of daily activities and entertainment
 - Highly trained staff teams

Hinckley House

Hinckley
0116 4042025

South Lodge

Leicester
0116 4042026

averyhealthcare.co.uk



The publisher of this Guide, Care Choices, also produces Care and Support Services Directories for Derbyshire, Lincolnshire, Northamptonshire, Stoke-on-Trent and Warwickshire.



www.carechoices.co.uk

For free copies, call

Derbyshire – Call Derbyshire on **01629 533190**

Lincolnshire – Care Choices on **01223 207770**

North Northamptonshire Customer Service Centre on **0300 126 3000** or West Northamptonshire Customer Service Centre on **0300 126 7000**

Nottinghamshire – Care Choices on **01223 207770**

Stoke-on-Trent – Social Care Contact Centre on **0800 561 0015**

Warwickshire – Care Choices on **01223 207770**

With thanks

The compilation of this book would not have been possible without assistance, contributions and support from Beth Britton; Sharon Blackburn CBE RGN RMN, National Care Forum; Sharon Aiken and Samantha Clarke, Dementia Friendly Communities; Claire Henry, Hospice UK and Dying Matters; The Orders of St John Care Trust; Home Instead; Belong; Care UK and those who supplied their personal stories of supporting someone with dementia.



Care Choices Limited has taken every care to ensure that the information contained in Dementia Friendly Leicester, Leicestershire & Rutland is accurate at the time of print. The company cannot accept responsibility for any errors or omissions in the publication, including if an organisation varies from the information included in an advertisement or the editorial. Care Choices Limited does not endorse or support any particular organisation included in Dementia Friendly Leicester, Leicestershire & Rutland ©2022 Care Choices Limited. Care Choices Limited reserves all rights in the titles Care Choices and HOMES Directories and their design.

Ref. No: 4001/DFLeicestershire03/0222. Reproduction of any part of this publication in any form without the written permission of Care Choices Ltd is prohibited. This publication is available free of charge from Care Choices.

Published by: Care Choices Ltd, Valley Court, Lower Road, Croydon, Nr Royston, Hertfordshire SG8 0HF. Tel: **01223 207770**.

Director of Policy and Communications: Jo Dovey. **Director of Sales:** David Werthmann.

Editors: Olivia Hubbard, Henry Thornton. **Content Editor:** Aislinn Thompson.

Sales Manager: Paul O'Callaghan.

Regional Sales Supervisor: Vanessa Ryder.

Senior Sales Executives: Claire Cornish, Kerri Chapman, Sue Speaight.

Sales Executives: Tony Boyce, Hannah O'Neill.

Director of Creative Operations: Lisa Werthmann. **Studio Manager:** Jamie Harvey.

Lead Designer: Ruth Keating. **Graphic Designers:** Jack Elsworth, Ella Sherwin.

Distribution: Gemma Seaber-Shinn.

Westroyd House Care Home is a *happy* place to live

“Each time I have visited my son, I have been warmly welcomed by all the members of staff- who have always been attentive, pleasant and helpful. This is so important and reassuring, especially as these occasions can sometimes be emotional - it means a great deal.”

***** Review on carehome.co.uk

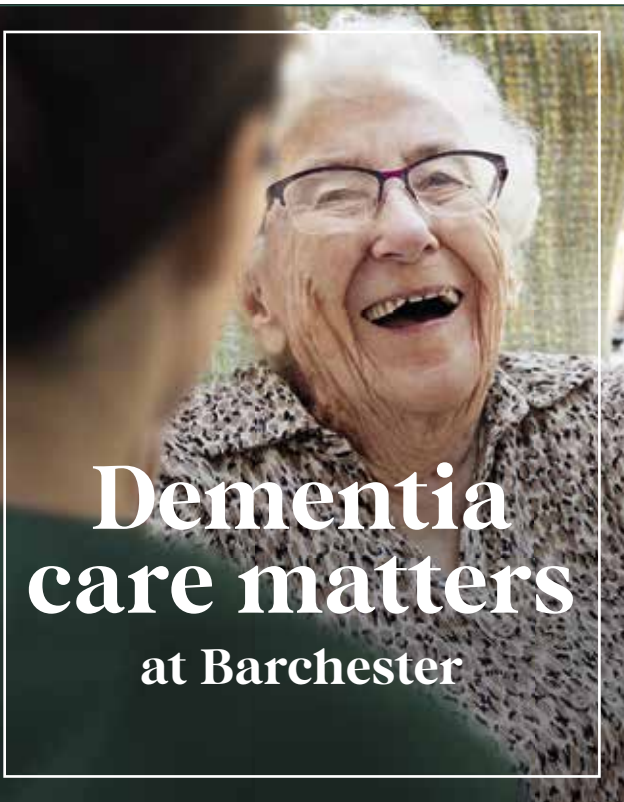
Our Care Team offers Residential Care for those who need help with daily tasks, as well as Residential Dementia care where we support people to maintain their independence and individuality, encouraging social activity and building relationships within the home.

Call today on: 01509 860579

Westroyd House Care Home
Tickow Lane, Shepshed,
Leicestershire, LE12 9LY
www.fshc.co.uk/westroydhouse



Four Seasons Health Care



Life with dementia should be a life well-lived. That's the total belief of our dementia care team.

We strongly believe people living with dementia should enjoy a fulfilled and happy life, with specialist support to continue doing the everyday things they love. As a sector-leading provider of dementia care we pride ourselves on delivering the highest quality of care with dignity and respect for each individual.


**These are the things that mean the most.
And because they matter to you, they matter to us.**



Chater House Care Home • 01780 778184
High Street, Ketton, Stamford, PE9 3TJ

Tixover House Care Home • 01780 778199
Tixover Grange, Tixover, Rutland, PE9 3QN

For information about Barchester and our care homes visit: www.barchester.com

A photograph of a female nurse, Heidi Nielsen, is the background of the advertisement. She is wearing a dark blue NHS uniform with white piping around the collar and cuffs. Her name tag, which also features the NHS logo, reads 'Heidi Nielsen' and 'Nurse'. She has her hair pulled back and is looking towards the camera with a slight smile. The background is a blurred hospital corridor.

Think you need medical help right now? Call 111

You can help us help you get
the right medical attention urgently.

Our fully trained advisors
are available 24 hours
a day and can put you
straight through to
healthcare professionals.

**HELP US
HELP YOU**

KNOW WHAT TO DO

Heidi Nielsen,
Nurse

CALL
111