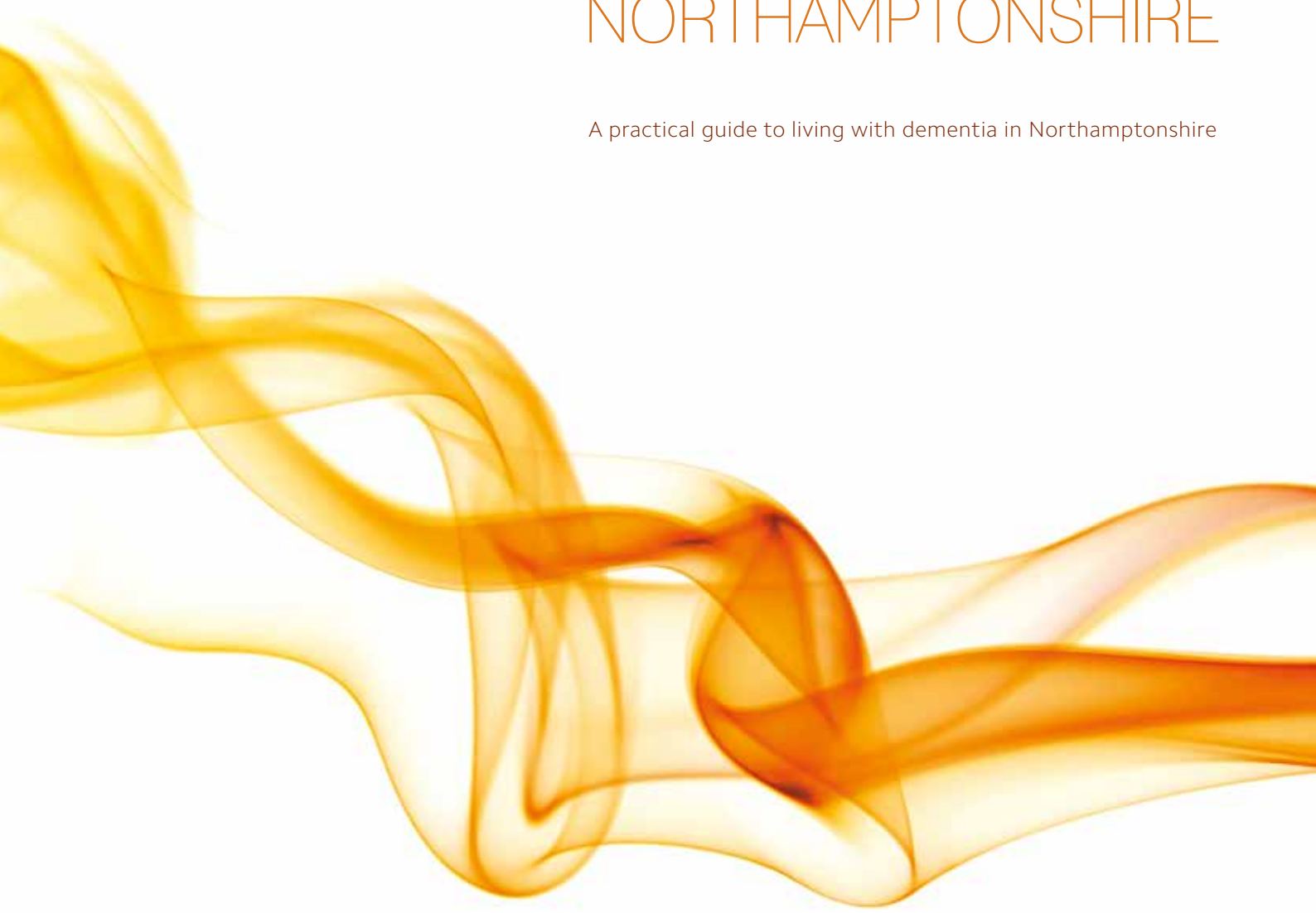


DEMENTIA FRIENDLY²⁰¹⁹ NORTHAMPTONSHIRE

A practical guide to living with dementia in Northamptonshire





*We make it our
business to care*

Can we help provide care for you?

We provide **reliable, experienced** and **highly skilled** care and support workers

- All our care staff have DBS clearance
- Assistance with personal care; bathing, showering and shaving
- We can ensure prompt assistance for medication
- Light domestic tasks can be undertaken
- Support with cooking, shopping and laundry
- We offer competitive rates and tailored care packages

For more details ring Karen on:

01604 635 090 or 07969 689 935

1 Notre Dame Mews, Northampton, NN1 2BG karen@nortonnurses.co.uk

www.nortonnurses.co.uk



**Our aim is to ensure the care you receive is
professional and responsible**



We are
registered
by the
CareQuality
Commission

**Northamptonshire's fastest growing
Care and Support Agency**



Contents

Foreword	4
Introduction	6
What is dementia?	9
Is it dementia? Symptoms and diagnosis	12
Planning for the future	17
When a family member has dementia	22
Living well with dementia	27
Top tips from an Admiral Nurse	38
Looking after you	39
People you may meet	43
What dementia taught me	46
Care and support needs	47
Wider initiatives addressing dementia	56
Planning for end of life	58
Legal and financial affairs	63
Northamptonshire Dementia Action Alliance – members and services	67
Dementia support in Northamptonshire	77
Useful organisations and websites	83



Alternative formats



This Guide is available electronically at www.carechoices.co.uk/dementia. There is also a Browsealoud option for those requiring the information in spoken word.

Foreword

From Chair of the Northamptonshire Dementia Action Alliance.



In January 2017, I was really pleased to be invited by the membership of the Northamptonshire Dementia Action Alliance (NDAA) to be its Chair. I felt that this would be a great opportunity to build on the excellent work completed by my predecessor, Veronica Male from Tollers Solicitors, who had significantly increased both its membership and project work during her tenure.

As a member, I had been the University of Northampton's representative on the NDAA since 2012. In my role at the University, I am the Professor of Applied Mental Health, Director of the Northamptonshire Dementia Research and Innovation Centre, Chair of the Dementia Friendly Community of Practice and lead for Public and Patient Involvement. I am also the Deputy Chair of Research at National Young Dementia Network and a member of the pan European Group, InterDEM. I am an experienced mental health nurse and have established four community-based social groups for people with dementia: the UnityDEM Centre; the Forget-Me-Nots Social Young Onset Dementia Group; Qualified by Experience (QBE) for former carers in Northamptonshire; and the Lutterworth Share & Care Group for people with dementia and their carers in South Leicestershire. I have worked extensively with local organisations to evaluate the provision of health and social care services, including community-based interventions for people living with dementia.

As Chair of the Northamptonshire Dementia Action Alliance and the University of Northampton Dementia Friendly Community of Practice, I have worked with the Chair of the Northampton

Dementia Action Alliance and the members to combine Alliance meetings and work under the name of the Northamptonshire Dementia Action Forum (NDAF). This combined group will continue to work on reviewing the current Northamptonshire Dementia Strategy; contributing to the development of a county-wide dementia care pathway; supporting Northamptonshire to become a Dementia Friendly county; establishing a Northamptonshire Public Patient Forum for people who are living with dementia and their carers; leading on the development of this Dementia Friendly Northamptonshire Guide; and delivering the annual Memory Day.

Our hope in developing this Guide is that those who read it will find practical information about dementia and the sources of support that are available in the county.

The flowchart opposite has been developed to highlight possible sources of support with the various stage of dementia, and this is supported with more detailed descriptions of existing and developing services, beginning on page 77. The Guide also contains more general information about dementia, signs and symptoms, legal issues, how to live well with dementia, and sources of information and support post-diagnosis. You will find details of specific services and organisations that are available for information, support and care in Northamptonshire and nationally starting on page 77.

It has been a huge privilege to work with the NDAA membership to produce this Guide. Our hope is that you find it helpful.

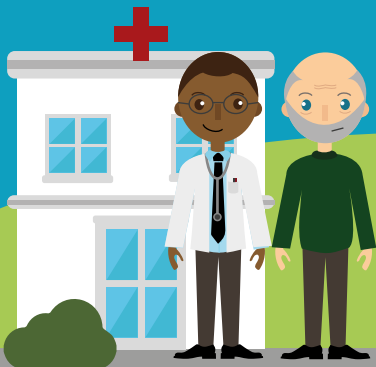
Best wishes,

Professor Jacqueline Parkes

Chair of the Northamptonshire Dementia Action Alliance and Director of the Northamptonshire Dementia Research & Innovation Centre, University of Northampton

The Dementia Pathway

There are various services available to help you and your family, from support during and after diagnosis to planning for the future.



Diagnosis support

If you are having difficulties with your memory or want help with getting a diagnosis, you can speak to your GP and ask for a referral to the memory assessment service.



Information and education

There are lots of ways to access information about dementia, from factsheets to attending awareness sessions and courses.



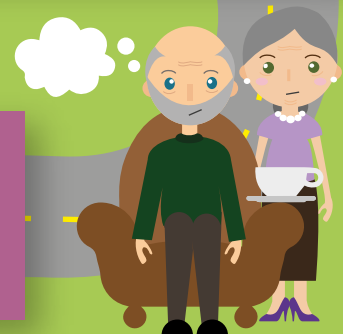
Carer and family support

Family carers are entitled to support in the form of carers' assessments, one-to-one support, carer cafés and groups and more.



Future planning

It can be helpful to seek advice and support when planning for the future. Information and services are available to assist you with this.



Respite and time out

Respite comes in many forms – you could use a sitting service, attend a day centre, look into carers' breaks, or a care home that offers short breaks.

Health and wellbeing

If you're concerned about your health and wellbeing, always contact your GP. There are also several services available which can support you.



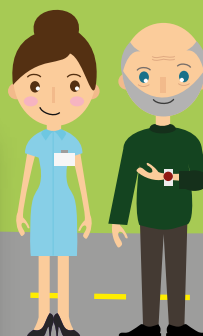
Crisis and prevention

Having a plan in place before a crisis can be really helpful. There are also services available to support you and your family through challenging times.



Assistive technology

Assistive technology can be a great support for some people with dementia. New options are being developed all the time.





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 77. There is also a list of useful national organisations starting on page 83.

PLANNING

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

positive plan for their future.

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

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

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

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

CARE AND SUPPORT

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

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

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

LIVING WELL WITH DEMENTIA

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

Other **useful publications and sources** start on page 83. We have also included further links to websites, videos and blogs, where people share their experiences to help you and the person you support.

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, though 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.

Useful sources begin on page 83.

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 77 will give you more information on what's available locally. **National organisations** and other sources start on page 83.



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'.

6 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. 7

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 that 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 Choices 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.

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

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 77 could help you to find services nearby.

DIAGNOSIS

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

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

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

The NHS Choices 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 77. Information on **benefits** is on page 40 and the chapter on **living with dementia** starts on page 27.

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

AFTER DIAGNOSIS

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

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

There should be support available to help at this time and into the future. Take a look at the **local services** starting on page 77.

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 77 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.





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 47 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 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 63. Making plans for **end of life** including funeral wishes are covered in more detail on page 58.



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.

If someone's capacity to make decisions over their **legal, financial and healthcare affairs** changes significantly, the chapter on page 63 covers the available options in more detail.

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



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.

‘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** and there are **top tips from an Admiral Nurse** on page 38.

The chapter starting on page 39 looks at carers, their rights, needs and support. However, it is worth mentioning now that if you are a carer, you need to look after yourself to enable you to look after the person with dementia. Consider contacting the local authority for an assessment of your needs; you have a right to have your needs assessed and you may be eligible for support. Also explore any benefits like carer's allowance. Local support organisations may be able to help you apply for benefits.

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

PARTNERS

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

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

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

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

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

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



understandable that you could feel rejected.

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

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

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

WHEN A PARENT OR GRANDPARENT HAS DEMENTIA

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

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

The website, www.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 microelements of dementia. I also think the information should be more readily available, because having to find out most of the information on my own during the early stages just added to the stress.

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

yourself and seek respite care and help.

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

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

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

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

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

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

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



Living well with dementia

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

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

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

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

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

to do unaided.

Patience and calmness are important qualities in these situations, and you may want to call upon coping strategies like silent counting in your head or deep breathing techniques, to keep your cool if you need to. Also, consider if there is anyone you can call upon if you need to, whether that's to come over for a chat or to offer practical support. There is no shame in calling for assistance.

It is vital, whenever you support a person with dementia, to ensure that you don't find yourself taking over from them. It can often seem easier, and quicker, to simply do things for a person. However, by doing this, you may be contributing to them becoming more disempowered; losing skills and, ultimately, relying on you more than they might otherwise need to.

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

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



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

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

The chapter on **care and support**, starting on page 47, explains this in more detail.

THE SYMPTOMS OF DEMENTIA AND THE CHANGES THEY BRING

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

you can realistically take in.

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

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

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

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

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

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

caring role and any impact it has on you. Even if they don't approach you, you have the right to ask them for an assessment of your own needs, see page 38. 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 about dementia, join a support group.’

Let things go

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

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

DAILY LIVING TECHNIQUES

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

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



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

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

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

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

KEEPING BUSY – HOBBIES AND PASTIMES

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

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

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

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

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

For more information on this, see the **planning chapter** starting on page 17.

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 77.

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, Kate discusses the various interventions she uses and looks at therapeutic interventions generally. Visit www.kateswaffer.com

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 pastime or hobby.

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

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

PERSONAL CARE TASKS

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

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

CARING FROM A DISTANCE

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



COMMON CONDITIONS

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

Sensory loss

It is also important to be mindful of sensory loss in a person who is living with dementia. The person with dementia may need glasses or hearing aids, which they will need to be assessed for. They may

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

Oral health

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

The Publisher of this Guide, Care Choices, also produces Care Services Directories for Bedfordshire, Buckinghamshire, Cambridgeshire, Lincolnshire, Northamptonshire, Oxfordshire and Warwickshire



www.carechoices.co.uk

For free copies, call

Bedfordshire – Bedford Borough Council on **01234 267422**
Central Bedfordshire Council on **0300 300 8303** or
Care Choices on **01223 207770**

Buckinghamshire – Care Choices on **01223 207770**

Cambridgeshire – email carechoices@cambridgeshire.gov.uk

Lincolnshire – Customer Service Centre on **01522 782155**

Northamptonshire – Customer Service Centre on **0300 126 1000**

Oxfordshire – Social and Health Care team on **0345 050 7666**

Warwickshire – Warwickshire County Council on **01926 410410**

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 to make sure that the person with dementia has access to 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 different 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 early 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 pressure-relieving products on the market, and if they are becoming increasingly 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 is 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 mental health conditions need specialist help, and medication or other therapeutic interventions may be offered. 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, growing in momentum, to give carers the right to remain with the person they are caring for when they are in hospital. It is called *John's Campaign – For the right to stay with people with dementia in hospital*, visit www.johnscampaign.org.uk

For more information on **hospital stays**, see page 54.

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. For more information about the work of Admiral Nurses, see page 44.



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, you should make your GP aware of this. If your GP is different from the GP of the person with dementia, it is worth making both doctors aware of your role. It is important that you look after your health and consider your needs, this will enable you to look after the person with dementia.

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

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

You may also want to request a carers’ assessment from your local council. This is different from any GP assessment and should look at other aspects of your life including 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.

For information on **local services**, see page 77. Alternatively, the **Money Advice Service** offers free and impartial financial advice, visit **www.moneyadviceservice.org.uk**

CARING WHILST WORKING

If you are in employment, you may want to talk to your employer about your caring responsibilities. As a carer, you may have the right to request flexible working depending on certain criteria, however, it is not guaranteed that you will receive it. Carers UK has a 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 77, 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 Awareness 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 Choices 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.

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 48.

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.

“It is important not to feel pressured into something you feel like you can't carry on with.”



People you may meet

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

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

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

GPs

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

CONSULTANTS

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

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

are arranged. The consultant may be a:

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

treating a range of mental health conditions.

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

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

CLINICAL PSYCHOLOGISTS

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

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

NURSES, DISTRICT NURSES OR COMMUNITY MENTAL HEALTH NURSES

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

treatment, care and support.

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

ADMIRAL NURSES

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

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

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

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

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

OCCUPATIONAL THERAPISTS (OTs)

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

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

SPEECH AND LANGUAGE THERAPISTS

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

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

CONTINENCE ADVISERS

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

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

DIETITIANS

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

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

CHIROPODISTS

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

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

EARS, TEETH AND EYE PROFESSIONALS

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

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

SOCIAL WORKERS

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

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

CARE WORKERS

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

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

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.’

Many people are surprised by what is available and the difference it can make to them and the person with dementia.

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.

For online information on what you may find useful, the **Living Made Easy** website offers help and advice on daily living as well as details on equipment. For more information, visit **www.livingmadeeasy.org.uk/** The website works in conjunction with **AskSARA**, which can also help you find useful advice and products that make daily living easier, visit **www.asksara.org.uk**

GROWING SUPPORT NEEDS

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

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

Depending on 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 around the home, 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, if needed; 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 7am until 10pm. 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 care and support 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 on the staff to undertake any specific nursing needs. The media gives a poor impression of care homes, however, the right care home can make a huge difference to someone's quality of life.

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

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.



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

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

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

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

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

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

SUPPORTING SOMEONE WITH DEMENTIA IN A CARE HOME

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

knowing the person and their life story.

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

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

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

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

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

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

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

Home 1

Home 2

Home 3

Fees per week

£	
£	
£	

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

Design

Are there clear signs throughout the home? ☐ ☐ ☐

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

Are the home and grounds secure? ☐ ☐ ☐

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

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

Choices

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

Are residents encouraged to be independent? ☐ ☐ ☐

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

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

Activities

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

Are there activities on each day? ☐ ☐ ☐

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

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

Are there rummage boxes around? ☐ ☐ ☐

Health

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

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

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

Do GPs visit the home regularly? ☐ ☐ ☐

Staff

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

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

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

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

Approach to care

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

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

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

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

HOSPITAL ADMISSIONS

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

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

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

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

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

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

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

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

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

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

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

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

yourself as a carer, as well as the person's child, spouse, companion or best friend. There is often a policy that will cover carers. Be clear that you are there to provide that totally essential nurture and connection back to the outside world. If you're able and willing to be there, don't let yourself be turned away.

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

FORMAL CARE OUT OF HOSPITAL

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

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

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



Wider initiatives addressing dementia

The Government is aware of the rising number of people with dementia and has a number of initiatives to make England ‘the best country in the world for dementia care and support and for people with dementia, their carers and families to live.’

‘ 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. ’

PRIME MINISTER’S CHALLENGE

The *Prime Minister’s challenge on dementia 2020* was set up by David Cameron as part of the Government’s dementia strategy, with the aim to ‘improve health and care services, create more Dementia Friendly Communities and make dementia research a priority.’ As part of this, £150 million in funding has been pledged to the UK’s first Dementia Research Institute to drive research and innovation in fighting dementia.

DEMMENTIA FRIENDLY COMMUNITIES

Also, as part of the Challenge, by 2020 the Government wants over half of people living with dementia to be living in Dementia Friendly Communities. Dementia Friendly Communities are places where people with dementia feel supported to continue in the day-to-day activities they enjoy and to lead more fulfilling lives.

Dementia Friendly Communities work to provide

the best possible support to people with dementia and their carers. They involve everyone from the local council to shops and services. Alzheimer's

Society has more information on Dementia Friendly Communities, as well as a list of which communities are dementia-friendly.

POST-DIAGNOSTIC CARE AND SUPPORT

A joint declaration had been made by government, health, social care and voluntary organisations to deliver better services to people with dementia.

This shared approach focuses on improving the care and support people with dementia, their families and carers receive following a diagnosis.

DEMENTIA PLEDGE

A number of leading care and support providers have signed up to provide great dementia care. The *Dementia Pledge* covers four main principles:

1. Know the person who is living with dementia.
2. Quality care, quality life.
3. Everybody has a leadership role.
4. Value-focused care.

It aims to: ensure that people who deliver adult

social care services fully understand and meet the needs of the person with dementia and their families; ensure commissioners are committed to commissioning for quality, and only commission services from providers who demonstrate that their workforce understands the needs of people with dementia and are committed to providing excellent dementia care; and to increase public awareness of excellent dementia care and make them intolerant of anything less.

DEMENTIA CARE AND SUPPORT COMPACT

The *Dementia Care and Support Compact* has been developed by Dementia Action Alliance. Any care provider in the UK can sign up to the Compact. Providers who sign up challenge the perceptions surrounding social care services for people with dementia. Signatories' services provide the right care, in the right place, at the right time. They focus on quality of life for people with dementia, as well as quality of care through knowing the person, their life history and their personal culture to deliver personalised care and support.

Signatories set a benchmark for high-quality, relationship-based care and support for people with dementia and inspire and encourage the sector to take responsibility for delivering this, building on existing good practice. They will engage and involve the wider community to

improve support for people with dementia, including GPs and healthcare professionals. They will play a part in supporting the wider community, sharing the knowledge and skills of staff, and inviting people into their care settings. If you are thinking of employing a service, or if the person with dementia needs to move into a care home, it is worth asking whether the service is part of the Dementia Pledge, has signed up to the Compact or whether they apply these principles when they support someone with dementia.

The Government is undertaking many initiatives to improve the lives of people living with dementia and their families and friends. Explore what is happening in your region, you may live in a dementia friendly community, or your health or social care professionals may be dedicated to helping improve lives of people with dementia.



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 64). 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, 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 63.

APPROACHING THE END OF LIFE

As the symptoms of dementia progress, the person with dementia may develop other conditions – see page 36 for more information on health conditions associated with dementia. It's important to be prepared for this.

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

Look at the **local services** starting on page 77 and the **useful national contacts** on page 83.

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 that 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 44.

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

PALLIATIVE CARE

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

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

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

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

DYING WITH DIGNITY

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

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



them comfort plus their specific end of life wishes.

However, consider that people’s needs and wishes may change towards the end of their life. If this happens, the person with dementia may not want the things they had discussed when planning their end of life care. Consider their needs regularly and if it is clear that something they have requested distresses them, or if their needs change to the point that you cannot follow their wishes, it is 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 in *My Funeral Wishes*, a form produced by Dying Matters and the National Association of Funeral Directors. Visit **www.dyingmatters.org/page/my-funeral-wishes**

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 Choices websites are useful starting points.

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

Life after caring can also seem daunting. If your future has been put on hold whilst you care for someone with dementia, you may feel uncertain

about where you go from here. There are lots of resources available to support you as you adjust to your new situation and it can help to talk openly.

Many people grieve while the person is still alive but bear in mind that the grieving process can come out in many ways. Also, consider that different people deal with death and dying differently, and just because someone isn't grieving in the same way as you, doesn't mean they're not grieving. Counselling and support can be very useful when dealing with the prospect of someone dying. This doesn't have to be towards the end of their life, it can be at diagnosis, after they have passed away or at any stage in-between.



Legal and financial affairs

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

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

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

WHAT IS MENTAL CAPACITY?

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

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

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

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

relevant decision.

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

WHAT HAPPENS IF SOMEONE LACKS CAPACITY?

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

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

Pre-2007, someone may have had an Enduring

Power of Attorney – this will still be valid if prepared before October 2007. However, if prepared after that time, the document is known as a Lasting Power of Attorney. There are two types, one dealing with welfare decisions and the other dealing with finances. It is not necessary to have both documents, but it is worth considering whether to empower an attorney to act in best interests with regard to decisions about finances and healthcare.

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

In a Lasting Power of Attorney, the person with dementia can set out their plans for managing their affairs. If there is more than one attorney appointed, they can decide whether the attorneys can act together, or independently of each other. They can also place restrictions on what attorneys can and can’t deal with, should they wish. If they set no restrictions, then the attorney has the power to access all of the

person's financial affairs, including being able to buy and sell any property on their behalf, as long as they are acting in the person's best interests.

If granted attorneyship in relation to health matters, then similarly this person will be able to access the person with dementia's health records and be involved in decision-making with professionals involved in managing their care. By appointing an attorney, the person with dementia is essentially placing their life in the hands of one or more people, enabling them to help make

decisions for them. This is why attorneys should be someone the person with dementia trusts and believes will act in their best interests at all times.



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

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

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

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

WHAT IS A DEPUTY?

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

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

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



Search for care in your area

www.carechoices.co.uk 

With so many providers to choose from, where do you start?

 CareChoices

- 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

Northamptonshire Dementia Action Alliance – members and services

The organisations and initiatives in this section are all run by members of the Northamptonshire Dementia Action Alliance (NDAA). Members are committed to ensuring good quality of life for people with dementia and those like you who care for them.



Northamptonshire Dementia Action Alliance (NDAA)

The NDAA was the first local alliance to be set up in the East Midlands. The local alliance held its first meeting in February 2013 which was followed by an official launch that May during dementia awareness week. The current Chair is Professor Jacqueline Parkes. Aims for 2019 are to increase local involvement; develop a Northamptonshire-wide forum for people living with dementia and their carers; and make Northamptonshire a more Dementia Friendly place to live and work in. Members include:

- Age UK Northamptonshire
- Alzheimer's Society Northamptonshire
- Home Instead Senior Care East Northants
- Kettering General Hospital
- Northampton Borough Council
- Northamptonshire Carers
- Northamptonshire Fire and Rescue Service
- Northamptonshire Healthcare NHS Foundation Trust
- Northamptonshire Police
- Olympus Care Services
- Skills for Care
- St Andrews Healthcare

- The University of Northampton
- Tollers Solicitors

The Northamptonshire Dementia Research & Innovation Centre (NDRIC)



The University of Northampton is proud to announce the launch of its Centre of Excellence.

Around a fifth of people aged 85 or older are living with some form of dementia. It currently affects about 850,000 people, which is projected to rise to one million in the UK by 2025 and two million by 2050. In Northamptonshire, the number of people with dementia is predicted to rise from nearly 7,000 in 2008 (of which 65% are female) to almost 12,000 in 2025. Given the predicted increase in the prevalence of dementia in the next 30 years, early identification and recognition of symptoms should be promoted, to enable people living with dementia to develop social support networks and personal coping strategies to facilitate the ability to live well with dementia in affected communities.

NDRIC works in partnership with people living with dementia, carers like you, health and social care providers, voluntary organisations and students. NDRIC aims to design, develop, implement and evaluate new approaches to person-centred, community-based care and support. These approaches include the development of the UnityDEM Centre and a Northampton centre for post-diagnostic dementia support.

Through its local, national, and international networks, NDRIC brings a host of research sources to bear on these developments. These initiatives provide excellent opportunities to

incorporate current best practice into their design, development, and delivery.

In conjunction with the Dementia Friendly Community of Practice (CoP) membership held by NDRIC, the team looks at the social and care related experiences, hopes and expectations of people living with dementia and their carers like you.

This knowledge can then be used to improve the quality of life and social and health care outcomes for people living with dementia and those like you who provide care.

With this in mind, five key priority research areas have been identified. These include:

1. Designing, developing, implementing and evaluating community-based services which are specifically designed to promote social interaction.
2. Investigating the challenges faced by health and social care professionals in detecting the early signs and symptoms associated with dementia.
3. Exploring the impact of initial diagnosis on quality of life and subsequent life choices from your perspective and from people living with dementia.
4. Identifying the sources of community healthcare and social support networks for you and for people living with dementia.
5. Promoting the integration of policy into practice, for example in relation to Dementia Friendly initiatives.

NDRIC is committed to ensuring that both you and people living with dementia are actively engaged in all aspects of training, education and research undertaken by the Centre. These views are at the heart of all NDRIC offers, in the hope that service delivery across Northamptonshire and beyond can be shaped by real-life experiences of dementia.

For more information about **NDRIC**, please email jacqueline.parkes@northampton.ac.uk and for further information about the **CoP**, please visit www.copnorthants.co.uk

NORTHAMPTON DEMENTIA ACTION ALLIANCE

Northampton has a strong commitment from public, private and voluntary sectors to support, promote and work towards a greater awareness of dementia.

The county has a strong Northamptonshire Dementia Action Alliance (NDAA) and has recently created a local Northampton Dementia Action Alliance (DAA) which will feed into the Northamptonshire group.

Aims for Northampton DAA

The current aim is to raise awareness about dementia and improve the lives of carers like you and those of people living with dementia around Northampton.

The ultimate aim is for Northampton to become a Dementia Friendly Community, demonstrating a commitment to people living with dementia.

The Northampton DAA is in its very early stages and is looking for any public, private or voluntary services who have an interest in Northampton to join the DAA and form part of the Alliance. The DAA is also aiming to engage with carers like you and people living with dementia in the near future.

The DAA is currently being led by Louise Musson, Call Care Manager for Northampton Borough Council. Louise has worked with people living with dementia for 13 years in the Call Care

Service. Recently, Louise had the pleasure of meeting a customer, Mrs. H, who had a Lifeline, door sensor and key safe fitted by Call Care. Louise was delighted to have met Mrs. H and uses the visit to demonstrate how, with some support, people can still live well with dementia at home.

Mrs. H had lived in her property for over 20 years and her dog was her best friend and companion.

Mrs. H did not want to leave her home, but her family had concerns because Mrs. H would go for a walk and not find her way home.

Mrs. H had a door sensor fitted that linked to her alarm, so every time her door opened, the Call Care team were able to speak to her and encourage her to stay in. If there were any problems, the team were able to contact her family.

Because of her dog, the door sensor was activated several times a day and the team became very fond of Mrs. H; on each activation, the team would speak to her and ask how her day was going. When finishing the call, the team often heard Mrs. H speaking to her dog and saying what nice people the team were.



If you are interested in knowing more about the Northampton DAA and being part of this project, please contact its administrator **Julie Grainger** on jgrainger@northampton.gov.uk



THE UNITYDEM CENTRE

The UnityDEM Centre is an 18-month pilot project which is providing post-diagnostic support to carers like you and newly diagnosed people with dementia in Northamptonshire. A team of professionals and volunteers provide psycho-social support and informative activities from 10.00am until 4.00pm on Mondays, Wednesdays and some Fridays. The Centre is unique in that the focus is on helping you and the person with dementia to feel:

- less isolated and more supported;

- able to adapt and cope with the diagnosis;
- valued for any existing knowledge, skills and abilities; and
- more self-confident and mentally well.

The UnityDEM Centre Project will initially run as an 18-month pilot, during which it will be evaluated. For further information about this project, please email

Jacqueline.parkes@northampton.ac.uk

MEMORY ASSESSMENT SERVICE (MAS)

Northamptonshire MAS is for people over the age of 65 who have been referred by their GP or other hospital specialist due to memory concerns.

The MAS covers the whole of Northamptonshire and has been developed to provide:

- a comprehensive and holistic memory assessment;
- diagnosis; and
- information and support following diagnosis.

The MAS team consists of psychiatrists, speciality doctors in old age psychiatry, community psychiatric nurses, occupational therapists, community support workers and clinical and assistant psychologists.

How do referrals to MAS work?

The person will be referred to MAS by their GP and will be contacted by MAS, providing an invitation to an appointment. The GP will complete some blood tests and other physical assessments before the person is seen by MAS. This information helps MAS in the assessment process.

It is usually best for MAS to conduct its initial assessment in the clinic, but a home visit may be preferred in some cases.

What happens at the initial assessment?

Assessments will be conducted by a member of the MAS team and the appointment will usually take one and a half hours. MAS encourages the person being assessed to bring a relative, friend or carer like you who knows them well.

The MAS staff member will talk to you, a relative or a friend and the person being assessed and carry out an initial assessment.

The person being assessed will be asked to describe any difficulties they are having and how

these affect them day-to-day (the person being assessed may find it helpful to write their thoughts down beforehand); about illnesses they have had in the past and any illnesses they have now, including what medications they are taking; plus other questions about their life.

The person being assessed will be asked to complete a questionnaire covering their thinking skills, memory and possibly their mood. You will also be asked to complete a questionnaire on how your abilities may have changed over time.

MAS may need to arrange further tests such as a brain scan or neuropsychological tests; these will be explained to the person being assessed if they are necessary.

What happens after the assessment?

The person will be given a follow-up appointment to discuss their assessment results. The MAS worker will discuss any diagnosis and explain what treatment is recommended.

If the doctor feels the person would benefit from drug treatments, medication will be prescribed and arranged to be reviewed with the person. Even if there is no specific drug treatment available, changes could be made to other medication.

MAS can signpost the person to, or provide further information on, different sorts of groups and therapy which the person may find beneficial.

The person may be referred to the ongoing memory monitoring service for annual reviews provided by MAS.

Northamptonshire Healthcare, NHS Foundation Trust, St Mary's Hospital,
Kettering NN15 7PW
Tel: **01604 682682**
Web: **www.nhft.nhs.uk**

FIRE SAFETY SUPPORT FOR THOSE LIVING WITH DEMENTIA

Northamptonshire Fire and Rescue Service offers free home fire safety checks to help people with dementia stay safe.

Minimising the risk of a fire in the home is important for everyone, but for those living with dementia it can present particular challenges.

As part of its prevention work, Northamptonshire Fire and Rescue Service (NFRS) offers free home fire safety checks and is encouraging referrals to help protect people living with dementia.

Lisa Bryan, of the NFRS home fire safety team says, 'For those living with dementia, or if you care for someone who does, our team is there to help and support safe, independent living for as long as possible.'

'Each home fire safety check offers friendly, personalised advice to address individual circumstances, including those relating to a dementia diagnosis. The team can also fit free smoke alarms for vulnerable people.'

'Requesting a check is very simple so if you would like help in reducing the risk of fire for yourself, a friend, relative or patient, please get in touch.'

Making a referral

Requests for home fire safety checks can be made by the householder themselves, a healthcare professional or a relative or carer like you. Requests can be submitted via a simple online form or over the telephone.

Once a request is made, the home fire safety team will arrange to carry out the check.

Lisa adds, 'If a householder is very vulnerable or doesn't have capacity then the team will try to do a joint visit with a third party such as a housing officer, social worker or the person's next of kin.'

Practical fire safety measures which may help people with dementia include devices which stop the gas supply if a cooker is left on, or a gas tap which can be turned off to prevent unsupervised cooking.

REQUEST A FREE HOME FIRE SAFETY CHECK

Individual requests:

If you, or somebody you care for has internet access, visit **www.northantsfire.gov.uk** and click on 'Home safety' to fill out a request form. Visits can also be requested by calling **01604 797000**.

Professional agency referrals:

Online referrals can be made by visiting **www.northantsfire.gov.uk/** Click on 'Visit our safety section' and complete the agency referral form.

Home fire safety tips:

- always stay with any cooking;
- take extra care when cooking with oil or fat;

- consider using a microwave instead of an oven;
- ensure the cooker is safe with regular servicing by a qualified engineer;
- try to have, or buy, fire-resistant furniture;
- never smoke in bed or leave lit candles unattended;
- fit at least one smoke alarm on every floor at home and test them weekly; and
- if a fire does break out, don't try to put it out. Leave the building immediately, call **999** and stay out until the fire service says it is safe to return.

THE HERBERT PROTOCOL

If you care for someone living with dementia and worry about them going missing, the Herbert Protocol is here to help. Run by Northamptonshire Police, the scheme encourages relatives and carers to fill out a detailed form about the person with dementia, which is stored in the person's home.

If the person with dementia goes missing the

form can be handed straight to the police, saving time by putting vital information into the hands of officers searching for the person, to help find the person as quickly as possible.

Find out more and download the **Herbert Protocol** form at www.northants.police.uk/HerbertProtocol

ASSISTIVE TECHNOLOGY FOR DEMENTIA

Assistive technology can bring benefits that help people with dementia to live well. It can:

- promote independence and help improve self-confidence;
- improve quality of life;
- help manage potential risk scenarios in and around the home;
- support people to live at home for longer; and
- provide peace of mind to carers like you.

What is available?

There are many innovative products which have been, and will continue to be, developed specifically for someone with dementia. Northamptonshire Adult Social Services offers a free assessment to everyone in Northampton who appears to be eligible; this is highly recommended to ensure the equipment is personalised specifically to you and the user.

Out and about with dementia

People with dementia may have a need to walk about. Often, this is not a problem for the person – walking can have both physical and psychological benefits. However, there may be times when walking does present risks, such as the if the person is unable to find the way home, is leaving the house at unusual times of the day or night or is not suitably dressed for the weather.



One Touch is a personal alarm that can be used to raise an alert outside of the user's home. When the SOS button is pressed, the device automatically calls up to three emergency responders at the same time. Once the call is answered, the user and the responder can have a conversation. The authorised users can request the location of the device and create geofencing zones. Geofencing zones offer peace of mind as alerts are automatically triggered if the user leaves a 'safe' area or enters an 'unsafe' area.

At home with dementia

‘Lifeline’ or ‘telecare’ usually refer to a system or devices that remotely monitor people living in their own home, enabling access support or response services when necessary. The technology is connected via a telephone line. Telecare systems can include community alarms, sensors and movement detectors.

Lifeline or telecare systems are often used to support independence and personal safety. The systems may help to reduce the risks associated

with living alone and can be useful for people living with dementia. Lifeline can assist the person to help them to do things (for example, remind them to take their medication). It can also alert others if, for example, the person fell or left the gas on. Sensors around the home can be linked to contact you or a call centre. The system monitors things like activity and temperature and can trigger an alarm if a problem occurs.

The alarm can also be triggered by a person pressing a panic button or community alarm.

ALZHEIMER’S SOCIETY SERVICES IN NORTHAMPTONSHIRE

Alzheimer’s Society local services provide information and support for you and for people diagnosed with dementia. For all these services, call the local office at Islip on **01832 736670** or email **northamptonshire@alzheimers.org.uk** unless otherwise stated.

You can also call the National Helpline on **0300 222 1122** or log onto the online forum at **www.alzheimers.org.uk/talkingpoint** to chat with people who may be in a similar situation to you.

Side by Side

This service provides befrienders for people with dementia. It can help people feel less socially isolated by supporting them to continue or re-engage in hobbies and interests or to take up new leisure pursuits.

Please contact the Side by Side co-ordinator, Russell Simpson on **01832 736670** if you are interested in volunteering for, or someone you care for is interested in using, this service.

Singing for the Brain®

These weekly sessions bring people together in a friendly and fun environment to enjoy singing familiar songs and sometimes learn new ones. The sessions are usually attended by the person with dementia along with a family member or

carer like you. For details of times and locations, please contact the local office on **01832 736670**.



Dementia Support – One-to-One Service

Personalised information and guidance to help people navigate the maze of information and services after a dementia diagnosis. Trained staff can work with you and people living with dementia to help understand the diagnosis. Staff can also make you aware of things you may like to consider, such as finances, support at home, how to access activities, and respite. You can also complete carers’ assessments on behalf of Northamptonshire County Council.

Memory Matters

Keeping an active social life is key to helping someone with dementia feel happy and motivated.

Activities include something for everyone and are respectful, creative, innovative, multi-sensory and fun. Activities are supported by skilled staff encouraging someone with dementia to do something creative and realise their potential, improving self-esteem and reducing loneliness.

Caring for someone with dementia can be extremely difficult, so having emotional support

and practical advice from someone who understands what you're going through might be beneficial.

Memory Matters offers a reassuring, confidential and safe place to talk to others about how dementia affects your life.

Come along and make new friends, share experiences and be honest, without fear or embarrassment. Get tips from group members on how to support someone with dementia, as well as how to keep looking after yourself and have your questions answered by our highly skilled, compassionate and experienced staff who run the sessions

Information Workers: creating Dementia Friendly communities

Dementia Awareness sessions and Dementia Friends sessions are facilitated by Information Workers across Northamptonshire.

Sessions include what it is like to live with dementia and how people can contribute to making communities in Northamptonshire more Dementia Friendly.

The one-hour, age-appropriate sessions are suitable for:

- children, young people and students, for example schools, Scouts and Girl Guides;
- recreation and leisure staff, for example people who work in cinemas, arts centres or swimming pools;
- businesses and shops;
- transport staff, for example taxi and bus companies; and
- community and faith groups.

Contact the local office on **01832 736670** for the latest about Information Workers in Northamptonshire.

AGE UK – FORGET-ME-NOTS DAY CARE

Age UK Northamptonshire is the leading local charity helping older people across the county. It runs a wide range of services, including day care at its Wellbeing Centres.

It runs dedicated, small Forget-Me-Not groups at the Venton Centre in Northampton for people who need a quieter, more supported environment because of dementia. In addition to providing stimulating, enjoyable sessions for clients living with dementia, these sessions provide some much-needed respite for family and carers like you.

This service is open to everyone, whether living at home with a partner, by themselves or in sheltered housing. Possible places for people living in residential care can also be discussed. The aim of the sessions is to give people the opportunity to take part in activities that are

tailored to individual needs and to enjoy being in company.

Some people come every weekday; others come just once a week. Clients all have different needs but fully-trained staff take the same good care of each client, ensuring the best possible experience of any time spent at the Centre.

A range of activities is always on offer and may include:

- looking at photographs, videos or other media together to stimulate recollection and conversation;
- playing skittles or other games with soft equipment;
- singing or listening to music; and



- other individually tailored, person centred, activities.

Clients in the Forget-Me-Not groups often join in with events taking place in the larger rooms at the Centres, such as carol singing, or when an entertainer is visiting, but staff are careful to ensure people are not overwhelmed.

The cost of Day Care at Age UK Wellbeing Centres is generally between £39 and £49 per day, depending on an assessment of the person's needs, if the person requires additional support or transport to and from the Centre, and whether the person pays by invoice.

Day Care clients with dementia can also enjoy

a day out at one of the other six centres run throughout Northamptonshire – see the website for the locations of these centres.

Come for a 'Taster Visit'

Why not visit to see whether the Wellbeing Centre suits the person you care for or another member of your family? Meet the friendly staff and have a chat with the other clients at the centre.

Please call the **Access Team** on **0845 677 2220** to find out more (Monday to Friday, 8.30am to 12.30pm) or look on the website for more details at **www.ageuk.org.uk/northamptonshire**

NORTHAMPTONSHIRE CARERS – DEMENTIA CARE ADVICE SERVICE



Northamptonshire Carers provides the Dementia Care Advice Service for the whole of Northamptonshire. The service is designed to support both those who are living with dementia and their unpaid family carers like you. Operating around a Hub model, it offers a comprehensive range of support and opportunities to enable you to maintain and sustain your own health, wellbeing and resilience in your caring role. The service supports both you and the cared-for person and takes a whole-family approach when considering the best range of support to meet individual needs.

The Hub model, with a Carers Support Line at its core, enables staff to signpost people to a wide range of support services. Anyone can make a referral to the services, including you, the person living with dementia or professionals.

Northamptonshire Carers offers a variety of support options for you and those living with dementia. These include:

- emotional support and listening;
- telephone and face-to-face assessments;
- home visits;
- support planning;
- contingency planning;
- benefits checks;
- carers cafés and support groups;
- carers choir and ukulele group;
- take-a-break opportunities (e.g. trips out);
- gym access;
- reiki and relaxation; and
- education and training.

The service can also help families with looking at future planning, accessing benefits and financial support, navigating legal and social care systems, assisting with care home visits and exploring

respite options. It is easy to access support by simply calling, emailing or making an enquiry via the website.

If you contact the team, you may be asked some questions about your situation and have some personal details noted down. The team can give you information, answer any questions you have, and may post out information for you to look at. The team will also usually offer you a home visit with one of the Dementia Care Advisers

at a time that is convenient for you so that the team can talk to you in more detail about your situation, how help can be provided and other organisations and services that may be able to help you.

Carers support line: **01933 677907**
General enquiry line: **01933 677837**
Email: **carers@northamptonshire-carers.org**
Web: **www.northamptonshire-carers.org**

FORGET-ME-NOTS SOCIAL GROUP

A social group run by and for people with dementia, their partners, carers and family like you. The group meets on the last Tuesday of every month, usually from 5.00pm to 7.00pm.

Join the group for a meal, a chat and a chance to have a fun evening out. All new members are welcome, including those living with dementia or if you are a carer or a family member.

Visit the website to view the programme of activities for 2019, **www.copnorthants.co.uk/**

forget-me-nots-social-group

The group is sponsored by Women in Business Northampton and Stress at Work Northampton.

For further information, please contact
Alison Ward.
Tel: **01604 893559**
Email: **alison.ward@northampton.ac.uk**
Facebook: **www.facebook.com/groups/ForgetMeNotsNorthampton**

TOLLERS SOLICITORS

Tollers Solicitors has its own specialised team that supports people and their families through the complexities of care funding and planning for later life.

Tollers Solicitors guides and supports clients to put in place wills, Lasting Powers of Attorney and to ensure appropriate estate planning. The team also specialises in supporting clients to manage personal financial affairs.

The team focuses on enabling clients to maintain financial independence for as long as possible, offering support with appointing and registering a Lasting Power of Attorney at The Office of

the Public Guardian and helping to make sure that clients' wishes are reflected and respected.

Where clients have not appointed an attorney and, due to the advancement of a condition, are unable to appoint a power of attorney, the team can help you, families and friends to make an application to the Court of Protection for a Deputyship.

The Court of Protection may also appoint a Panel or Professional Deputy for matters that come before the Court where the person cannot appoint an attorney, or if the attorney or



previous Deputy has abused a position of trust. If Tollers Solicitors are appointed as a Panel or Professional Deputy, all clients can be visited in a care environment, can review the care plan annually and can have any concerns raised about the quality of care provided.

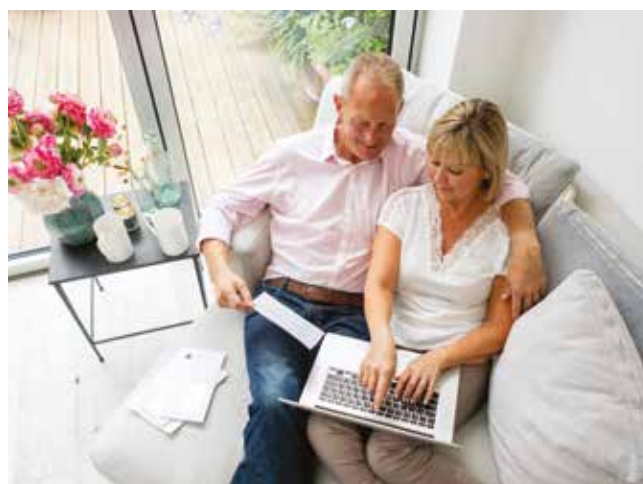
Families can also raise concerns over a relative's welfare or a possible situation of financial mismanagement. The team can offer advice on the legal steps that can be taken, or at least signpost to the relevant authorities.

Tollers Solicitors has a specialist in its team who can support in bringing a claim for compensation if a client has suffered neglect or abuse in a care home which has caused an injury.

Tollers Solicitors ensure all clients get the full entitlement of available financial support, for

example, the team can check if individuals are claiming all available benefits pending eligibility and can challenge Continuing Healthcare funding decisions.

Specialist legal advisers are members of Solicitors for the Elderly and Dementia Friends.



Dementia support in Northamptonshire

Please contact any groups or cafés before visiting. Opening times 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.

Age UK Northamptonshire

31 Billing Road, Northampton NN1 5DQ

Tel: **01604 611200**

Email: access@ageuknorthants.org.uk

Web: www.ageuk.org.uk/northamptonshire

Age UK Wellbeing Centres – day care

Offers a safe, stimulating environment where the person you care for can take part in activities and meet and make new friends. Unless otherwise

stated, call the Access Team on **0300 303 3929** or **01604 611207** to find out more; Monday to Friday, 9.00am to 12.00pm.

Candleford Court

Candleford Close, Brackley NN13 6JW

Every Wednesday, 10.00am to 3.00pm.

Chappell House

Northampton Lane North, Moulton NN3 7QS

Monday and Thursday, 10.00am to 3.00pm.

Four Seasons

School Lane, Kettering NN16 0DH

Monday to Friday, 10.00am to 3.00pm.

Tel: **01536 484259**

Jubilee House

Meadway, Bugbrooke, Northampton NN7 3RN
Every Tuesday, 10.00am to 3.00pm.

Leeson Court

Leeson Road, Towcester NN12 6HS
Monday to Thursday, 10.00am to 3.00pm.

Spring Gardens

Oxford Close, Daventry NN11 4XY
Monday and Friday, 10.00am to 3.00pm.
Tel: **01604 611200**

William and Patricia Venton Centre

A separate group, the Forget-Me-Nots, is also run here every weekday specially for people with dementia.

York Road, Northampton NN1 5QG
Monday to Friday, 10.00am to 3.00pm.
Tel: **01604 604500**

Alzheimer's Society

Northamptonshire Local Office
Acorn House, Acorn Industrial Estate,
Islip NN14 3FD
Tel: **01832 736670**
Email: **northamptonshire@alzheimers.org.uk**

National Dementia Helpline

If you have concerns about Alzheimer's disease or about any other form of dementia, Alzheimer's Society National Dementia Helpline can provide information, advice, support, and signposting to other appropriate organisations. Callers speak to a trained Helpline Adviser. Calls to the Helpline are confidential.

Tel: **0300 222 1122**

Talking Point

An online support community for you, the person you care for and their family and friends to discuss all aspects of the condition. The forum is open 24/7 and is a safe place to ask questions, share your experiences and receive advice and support.

Web: **www.alzheimers.org.uk/talkingpoint**

Alzheimer's Society also provides the services listed below. For more details on any of these services or groups, call Alzheimer's Society Northamptonshire on **01832 736670**.

Day care and support

Provides care and support in a safe and comfortable group setting. Activities are based on your individual needs and interests and those of the person with dementia.
Northampton Church of Christ, Shadowfax Drive, Overstone Lodge, Northampton NN3 8DB

Singing for the Brain®

Based around the principles of music therapy, the stimulating group sessions include vocal warm-ups and singing a variety of familiar and new songs.

Corby

West Glebe Pavilion, West Glebe Park,
Cottingham Road, Corby NN17 1SZ
Every Monday, 2.00pm to 3.30pm.

Greens Norton

Greens Norton Community Centre, Towcester Road, Greens Norton NN12 8BL
Every Monday, 10.00am to 11.30am.

Kettering

Main Room, Corn Market Hall, London Road, Kettering NN15 7QX
Every Thursday, 10.00am to 11.30am.

Northampton

Northampton Church of Christ, Shadowfax Drive, Overstone Lodge, Northampton NN3 8DB
Every Friday, 10.00am to 11.30am; and 2.00pm to 3.30pm.

Memory Matters

Keeping an active social life is key to helping someone with dementia feel happy and motivated.

Activities include something for everyone and are respectful, creative, innovative, multi-sensory and fun. Activities are supported by skilled staff encouraging someone with dementia to do something creative and realise their potential, improving self-esteem and reducing loneliness.

Caring for someone with dementia can be extremely difficult, so having emotional support and practical advice from someone who understands what you're going through might be beneficial. Memory Matters offers a reassuring, confidential and safe place to talk to others about how dementia affects your life.

Come along and make new friends, share experiences and be honest, without fear or embarrassment. Get tips from group members on how to support someone with dementia, as well as how to keep looking after yourself and have your questions answered by our highly skilled, compassionate and experienced staff who run the sessions.

Corby

West Glebe Pavilion, West Glebe Park,
Cottingham Road,
Corby NN17 1SZ
Second Wednesday of the month, 10.00am to 12.00pm.

Daventry

Daventry Methodist Church, Golding Close,
Daventry NN11 4FB
Second Tuesday of the month, 1.00pm to 3.00pm.

Kettering

Ise Lodge Community Centre,
St Vincent's Avenue,
Kettering NN15 5DR
Fourth Tuesday of the month, 10.30am to 12.30pm.

Northampton

Simon de Senlis Court, Robert Street,
Northampton NN1 3AE
First Thursday of the month, 1.30pm to 3.30pm.

Towcester

Sawpits Centre, Richmond Road,
Towcester NN12 6EX
Third Tuesday of the month, 1.30pm to 3.30pm.

Wellingborough

Salvation Army, Salem Lane/Queen Street,
Wellingborough NN8 4JT
Second Thursday of the month, 10.00am to 12.00pm.

Side by Side Northamptonshire

Helps people with dementia to continue to live independently and remain active members of their local community. Volunteers will provide support to enable people with dementia to go out and about in their community and keep doing the things they enjoy or to try out new activities. The service is unique to each individual as it is based upon what the person with dementia would like to do.
Acorn House,
Acorn Industrial Estate,
Islip NN14 3FD

SUPPORT FOR CARERS

Age UK Carers' Sitting Service

Tel: **01604 611207** or **0300 303 3929**
Email: **access@ageuknorthants.org.uk**

Northamptonshire Carers

123 Midland Road, Wellingborough NN8 1LU

Tel: **01933 677837**

Carers' Support Line: **01933 677907**

Email: **carers@northamptonshire-carers.org**

Web: **www.northamptonshire-carers.org**

Northamptonshire Carers also provides the

following services and carers cafés. For more information, call **01933 677837** unless otherwise stated.

Needs and aspirations

Facilitated by Nene Valley Community Action (NVCA), this project gives you and other carers a wide range of activities for both training and leisure. This gives you the chance to have some time out from your caring role and to meet other people in similar situations.

Write to: Nene Valley Community Action,
7 West Street, Rushden NN10 0RT
Monday to Thursday, 8.30am to 4.30pm.

Tel: **01933 313526**

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

Web: **www.northamptonshire-carers.org/needs-and-aspirations**

Carers' Sitting Service

An opportunity for you to provide short-term care for someone who is over 18. The cared-for person must have low-level support needs; you can provide befriending, but cannot provide personal care or cook meals, clean or do shopping. Support can be provided on a regular or semi-regular basis, for three hours at a time.

Emergency Carers Service

Provides emergency breaks to support you and other carers at short notice, to deal with emergency situations or to prevent a crisis from occurring. The service also provides support for one-off appointments and events. You are eligible for a maximum of three breaks per year, up to 72 hours each time. There is no cost to you.

Tel: **07789 111318**

Email: **healthprojects@carerstrustem.org**

Carers Ukulele Group

Meets every Monday during term time only, 9.30am to 10.30am at the Wellingborough office. New members are always welcome. Contact Sarah Drage.

Tel: **01933 677837**

Email: **sarahd@northamptonshire-carers.org**

Carers Choir

Meets every Monday during term time only, 10.45am to 12.15pm at the Wellingborough office. New members are always welcome.

Contact Sarah Drage. • Tel: **01933 677837**

Email: **sarahd@northamptonshire-carers.org**

Carers' Cafés

Corby Carers Café

Coronation Pavilion, Elizabeth Street,
Corby NN17 1PN
Fourth Tuesday of the month, 1.00pm to 3.00pm.

Daventry Carers Café

The Abbey Centre, Market Square,
Daventry NN11 4BH
First Thursday of the month, 10.30am to 12.30pm.

Kettering Carers Café

Windsor Gardens, Lower Street,
Kettering NN16 8DV
Second Tuesday of the month, 11.15am to 1.15pm.

Kettering Evening Carers Support Group

Windsor Gardens, Lower Street,
Kettering NN16 8DV
Second Thursday of the month, 7.00pm to 9.00pm.



Northampton Carers Café

Elim Church, Gladstone Road,
Northampton NN5 7EG
First Tuesday of the month, 11.00am to 1.00pm.

Oundle Carers Café

Oundle Rural Mind, Dovedale, 1 Herne Park,
East Road, Oundle PE8 4BX
Fourth Thursday of the month, 1.00pm to 3.00pm.

Wellingborough Carers Café

123 Midland Road, Wellingborough NN8 1LU
Third Tuesday of the month, 1.00pm to 3.00pm.

Dementia Care Advice Service

Designed to support both those who have dementia and you as a carer. The service offers emotional and practical support and liaises with other organisations who can also provide services such as benefits help or care packages.

OTHER LOCAL DEMENTIA SUPPORT

Dancemind

Enables those affected by dementia to share experiences, enjoyment and creativity through the medium of dance, movement and music.
Tel: **07739 315084** • Email: **info@tinaheeley.com**
Web: **www.dancemind.co.uk/Contact.aspx**

Dementia Harborough

Supports those who are newly-diagnosed with dementia and their families and provides a place to have fun and support each other. Contact Peter Hirst for more information on Dementia Harborough and the groups below, both of which are held at Jubilee Hall, Congregational Church, Bowden Lane, Market Harborough LE16 7JD.
Write to: 8 Granary Close, Kibworth Beauchamp, Leicestershire LE8 0HZ
Tel: **07961 538671**
Email: **info@dementiaharborough.org** or **groups@dementiaharborough.org**
Web: **www.dementiaharborough.org**

Singing for Memories

An enjoyable afternoon of singing and playing musical instruments, from 2.00pm to 3.30pm on the first Tuesday of every month.

Dementia Café Market Harborough

Has a varied programme of speakers and activities and is an opportunity to meet, share experiences, get information, and give mutual

support and companionship. The café runs from 2.00pm to 4.00pm on the third Thursday of every month.

Lunch clubs

Meet and make new friends, whilst enjoying good food for a reasonable charge. A list of clubs can be found at **www.ageuk.org.uk/northamptonshire/activities-and-events/lunch-clubs**

Northamptonshire Fire and Rescue Service

Tel: **01604 797000** (Monday to Friday, 8.30am to 4.30pm).
Email: **enquiries@northantsfire.gov.uk**
Web: **www.northantsfire.gov.uk**
Twitter: **@northantsfire**

Silverstar

Offers discounted long-distance travel to people aged 55 and over. Any company profits help to support the introduction of Admiral Nurses in Northamptonshire.

Tel: **01604 583332** or **07790 666581**
Web: **www.silverstarnorthampton.co.uk**

Total Voice Northampton

Offers many different types of advocacy.
Tel: **01604 592702**
Email: **tvn@voiceability.org**
Web: **www.voiceability.org/services/northamptonshire**

OTHER DEMENTIA CAFÉS AND GROUPS

ACES Day Care Centre

ACES has a home-from-home atmosphere where older people can socialise and be cared for in a safe and supportive environment.

ACES Day Care Centre, 2 Park Avenue North,
Northampton NN3 2HS

Tel: **01604 715044**

Christian Dementia Support Group

A culturally-sensitive group providing holistic support for people with a diagnosis of dementia and those like you who care for them. A number of the group's activities are faith-based, and the group aims to raise awareness of dementia within Black and minority ethnic communities.

Tel: **01536 763590** or **07913 747417**

Email: **cdsgr01@gmail.com**

Web: **www.cdsg.uk**

Dementia Café at The Well

Newly-diagnosed people with dementia, their families and you, can meet other carers in the same situation, share experiences and enjoy activities. All while enjoying coffee, cake and conversation. Every second Monday of the month at 2.00pm. Run in conjunction with Dementia Harbough. Drop in at The Well or use the contact details below.

45 High Street, Kibworth Beauchamp,
Leicester LE8 0HS

Tel: **0116 279 0148**

Email: **manager@thewellkibworth.org**

Web: **www.thewellkibworth.org/dementiacafe.aspx**

Forget Me Nots Social Group

Provided by the University of Northampton, this is a social group run by and for people with dementia, their partners, families and other caregivers like you. Members meet for a meal, a chat and a chance to have a fun evening out.

Web: **www.copnorthants.co.uk/forget-me-nots-social-group**

Glamis Hall VIP Club

Provides a safe, welcoming environment for people over 50, from 9.30am to 3.00pm, Monday to Friday. You can stay all day, enjoy games, activities and entertainment or just spend some time with others. A Lunch Club also operates between 11.30am and 1.30pm, Monday to Friday and is open to all. The three-course lunch is served at 12.00pm at a cost of £6; booking is required before 10.30am on the day, or in advance.

Glamis Hall, Goldsmith Road,
Wellingborough NN8 3RU

Tel: **01933 677326**

Web: **www.glamishall.org.uk**

Saturdays for Seniors

Volunteers at St Giles Church run an all-day event four times a year for older people. There is a £10 charge to contribute towards the cost of refreshments, a cooked lunch, activities, entertainment and transport to and from the Church Centre. An application form must be completed due to a limited number of allocated guests. Visit the website below for more information about how to apply for the next event.

Tel: **01604 706146**

Web: **www.stgilesnorthampton.org.uk/church-life/third-age/way-cafe**

If you provide or attend a dementia support group in Northamptonshire that is not listed here, please email details to **enquiries@carechoices.co.uk**





Useful organisations and websites

These useful organisations and websites were used in the compilation of this book. For full links to references, visit **www.carechoices.co.uk/dementia**

Age UK

The country's largest charity dedicated to helping everyone make the most of later life.

Tel: **0800 055 6112**

Web: **www.ageuk.org.uk**

Alzheimer's Disease International

The international federation of Alzheimer's associations around the world.

Tel: **0207 981 0880**

Web: **www.alz.co.uk**

Alzheimer's Society

The UK's leading dementia support and research charity. Also runs an online discussion forum for anyone affected by dementia and has video content on YouTube.

Tel: **0300 222 1122**

Web: **www.alzheimers.org.uk**

Web: **www.alzheimers.org.uk/talkingpoint**

Web: **www.youtube.com/AlzheimersSociety**

Alzheimer's Research UK

The UK's leading research charity aiming to defeat dementia.

Tel: **0300 111 5555**

Web: **www.alzheimersresearchuk.org**

AskSARA/Living Made Easy

Guided advice about daily living and equipment.

Tel: **0300 999 0004**

Web: **www.asksara.org.uk**

Web: **www.livingmadeeasy.org.uk**

Barnardo's

Barnardo's transforms the lives of the most vulnerable children through services, campaigning and research.

Web: **www.barnardos.org.uk**

Belong

A charitable organisation that provides high quality but affordable residential care for older people.

Tel: **01270 610666**

Web: **www.belong.org.uk**

Beth Britton

Freelance campaigner, consultant, writer and blogger specialising in issues affecting older people, health and social care and specifically dementia. Blogs at D4Dementia.

Web: **www.bethbritton.com** or
www.d4dementia.blogspot.co.uk

Care Choices

Assistance with finding care and support. Searchable website.

Web: **www.carechoices.co.uk**

Carers Trust

A major charity for, with and about your caring role, with a dedicated site for professionals.

Tel: **0300 772 9600**

Web: **www.carers.org** or
<https://professionals.carers.org>

Carers UK

The UK's only national membership charity supporting carers like you. A support network and a movement for change.

Tel: **0808 808 7777**

Web: **www.carersuk.org**

Carers Week

Annual awareness campaign to celebrate and recognise the vital contribution made by the UK's 6.5 million carers.

Web: **www.carersweek.org**

Care Quality Commission

Independent regulator of care services in England.

Tel: **03000 616161**

Web: **www.cqc.org.uk**

Care UK

The UK's largest independent provider of health and social care.

Tel: **0333 321 0939** • Web: **www.careuk.com**

Chris Roberts

Chris Roberts blogs about his life with dementia.

Web: **www.mason4233.wordpress.com**

Citizens Advice

Free independent and confidential advice on a range of topics.

Tel: **0344 411 1444**

Web: **www.citizensadvice.org.uk**

DSDC The Dementia Centre

International centre of knowledge and expertise dedicated to improving the lives of people with dementia.

Tel: **01786 467740**

Web: **www.dementia.stir.ac.uk**

Dementia Action Alliance

Organisations across England committed to transforming the lives of people with dementia and their carers, like you.

Web: **www.dementiaaction.org.uk**

Dementia Adventure

A registered community interest company offering dementia holidays, training, research, dementia-friendly venues, consultancy and more.

Tel: **01245 237548**

Web: **www.dementiaadventure.co.uk**

Dementia Challengers

Information if you are caring for a relative with dementia.

Facebook: **[@dementia.challengers](https://www.facebook.com/dementia.challengers)**

Dementia Friends

Alzheimer's Society's Dementia Friends programme, the biggest ever initiative to change people's perceptions of dementia.

Web: **www.dementiafriends.org.uk**

Dementia Roadmap

A web-based platform providing information about dementia alongside local information to assist primary care staff.

Web: **www.dementiaroadmap.info**

Dementia UK

Dementia UK offers specialist one-to-one support and expert advice for people living with dementia. Also offers an Admiral Nurse service.

Tel: **0800 888 6678**

Web: **www.dementiauk.org**

Department of Health and Social Care

The Government department responsible for public health issues. Information on what the Government's doing about dementia and video content on YouTube. Also features blogs for anyone working in, or receiving support from, the care and support sector.

Web: **www.youtube.com/departmentofhealth**

Web: **<https://socialcare.blog.gov.uk>**

Dying Matters

A coalition which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.

Web: **www.dyingmatters.org**

GOV.UK

Government services and information.

Web: **www.gov.uk**

Helpguide.org

An American guide to mental, emotional and social health.

Web: **www.helpguide.org**

Hospice UK

Charity for all those involved in palliative, end of life and hospice care.

Tel: **0207 520 8200** • Web: **www.hospiceuk.org**

Join Dementia Research

A nationwide service that allows people to

register their interest in volunteering for dementia research studies.

Web: **www.joindementiaresearch.nihr.ac.uk**

Kate Swaffer

Kate lives with dementia and blogs about the critical issues impacting a person living with a diagnosis of dementia and their families and close friends.

Web: **www.kateswaffer.com**

Learning for the Fourth Age

Seeks to address the gap in provision of educational and learning services to people who receive social care support.

Tel: **07545 842315**

Web: **www.l4a.org.uk**

Life Story Network – tide

Tide – 'together in dementia everyday' is an involvement network that recognises family carers of people with dementia are experts by experience, experts that can play a significant role in supporting other carers, influencing policy and shaping improved, responsive, local commissioned services.

Tel: **0151 237 2669**

Web: **www.tide.uk.net**

Marie Curie

Charity supporting people living with any terminal illness, and their families.

Tel: **0800 090 2309**

Web: **www.mariecurie.org.uk**

Mental Health Foundation

Charity improving the lives of those with mental health conditions.

Web: **www.mentalhealth.org.uk**

Money Advice Service

Free and impartial money advice, including benefits.

Tel: **0800 138 7777**

Web: **www.moneyadviceservice.org.uk**

Music for Dementia 2020

A campaign designed to improve the accessibility of music as a tool to support emotional health and wellbeing for people living with dementia in the UK.

Tel: **07989 355388**

Email: **info@m4d2020.com**

Web: **www.musicfordementia2020.com**

National Activity Providers Association

Charity committed to improving quality of life, through person-centred activities, for older people.

Tel: **0207 078 9375**

Web: **www.napa-activities.com**

The National LGBT Partnership

Reducing health inequalities and improving access to health and social care for LGBT people.

Tel: **0207 064 6506**

Web: **www.nationallgbtpartnership.org**

NHS Choices

Information from the NHS about all aspects of health and living well.

Web: **www.nhs.uk**

The Orders of St John Care Trust

Care provider operating across Lincolnshire, Oxfordshire, Gloucestershire and Wiltshire.

Tel: **0800 988 8133**

Web: **www.osjct.co.uk**

Revitalise

A national charity providing respite care in a holiday setting for disabled people and carers, like you.

Tel: **0303 303 0145**

Web: **www.revitalise.org.uk**

RICE

The Research Institute for the Care of Older People.

Web: **www.rice.org.uk/memory+clinic**

Royal Voluntary Service

A volunteer organisation that enriches the lives of older people and their families.

Tel: **0845 608 0122**

Web: **www.royalvoluntaryservice.org.uk**

Social Care Institute for Excellence

Information, guidance, resources and accredited training if you are supporting someone with dementia.

Web: **www.scie.org.uk/dementia**

Sensory Trust

Creates accessible and engaging outdoor experiences, including projects for people living with dementia.

Web: **www.sensorytrust.org.uk**

The Silver Line

Free 24-hour helpline providing information, friendship and advice for older people.

Helpline: **0800 470 8090**

Web: **www.thesilverline.org.uk**

Tommy On Tour

One man's mission to raise awareness of dementia. Has video content on YouTube – search 'Tommy ontour'.

Web: **www.tommy-on-tour-2011.blogspot.co.uk**

Tourism for All

A national charity dedicated to standards of world class tourism, which are welcoming to all.

Tel: **0845 124 9971**

Web: **www.tourismforall.org.uk**

Truthful Kindness

Tru is a person with dementia symptoms who blogs about her life.

Web: **www.truthfulkindness.com**

Young Dementia UK

A charity that helps people whose lives are affected by young onset dementia.

Web: **www.youngdementiauk.org**

More than just a care home...

**NURSING & RESIDENTIAL
RESPITE & DEMENTIA CARE**

Let us welcome you to our Village Care Home. A warm, comfortable and friendly place where we support elderly residents with nursing, residential and dementia care.

We have state-of-the-art facilities, private en suite bedrooms and beautifully appointed lounges and dining rooms.

Enjoy the wider Village complex with your family including:

- Restaurant, café and bar
- Hair salon and therapy room
- Games lawn and landscaped gardens
- Family events and activities
- Book ahead respite breaks available

9.8

Review score on
carehome.co.uk
(January 2019)



Dementia Friends sessions are held regularly at the village.

Contact us for more details



Tel: 01604 432602 | Email: northampton@richmond-villages.com

www.richmond-villages.com/northampton

Richmond Northampton, Bridge Meadow Way, Grange Park, Northampton NN4 5EB

Find us on

carehome.co.uk



CALL CARE



HELP AT THE TOUCH OF A BUTTON

Call Care – Your local provider of Lifeline Alarms.

Our Northampton based team of installers and Call Operators have been supporting independence in Northamptonshire for 30 years.

Independence and peace of mind for people living with Dementia and their Carers, to support them living in their own home.



Customer's feedback: -

"Thank you to the staff for the wonderful service you provide. It is much appreciated and glad to know you are on hand when I need you."

For more information from an experienced Officer please contact our Northampton based Control Room on:- **01604 230227**
or **Callcare@northampton.gov.uk**



**NORTHAMPTON
BOROUGH COUNCIL**

SAVOUR EVERY MOMENT

With our delicious frozen meals and desserts by award-winning chefs and delivered free by your local team, you've more time to enjoy the things you love.

For your free brochure call your local office on

01536 420505 or visit
wiltshirefarmfoods.com

WILTSHIRE

EST. **FARM** 1991

FOODS

OVER 300 DELICIOUS DISHES

FREE FRIENDLY DELIVERY

TRUSTED LOCAL SERVICE

Homes of Reassurance

Barchester homes are more than care homes.

They're respectful homes. Specialist homes.

They're homes of supportive dementia care.

Places to re-connect with loved ones in surroundings that are as reassuring as they are comfortable.

**You're welcome to visit our homes
anytime for friendly advice and a tour.**

Collingtree Park

Collingtree Park,
NN4 0XN

01604 321 305

Juniper House

Brackley,
NN13 6JZ

01280 428 134


BARCHESTER
Celebrating life

www.barchester.com

Expert care from highly trained staff • Safe surroundings • Tailored activities • Nutritious menus



The Premium Dementia Care Provider in Northamptonshire

Avery Healthcare is a leading and award winning national care provider that has a range of care homes throughout the county for residential and dementia care. The Memory Care suite at all Avery homes perfectly reflects their progressive and sector-leading model of care for people living with the many forms of dementia. Highly trained staff work together with resident and family to enable each individual to continue to live their life well in a calm environment based upon the most up-to-date dementia care research.

For the best in Northamptonshire, look no further.



Spencer House

Northampton
T. 01604 976067



Cliftonville

Northampton
T. 01604 976066



Dukes Court

Wellingborough
T. 01933 589140



Ashurst Mews

Moulton
T. 01604 976065



Glenmoor House

Corby
T. 01536 629518



Seagrave House

Corby
T. 01536 629520



See all of our homes on Facebook or Search 'Avery Northamptonshire'



Care With
A Difference



Helping Hands
Care and Nursing at Home
Est. 1989

Do you need a helping hand?

If you are looking for an alternative to residential care or extra support for those everyday tasks that are becoming difficult for you or a loved one – then we're here to help in Northamptonshire from **30 minutes** per week to **full-time live-in care**.

Our care teams have been providing **award-winning quality** home care since 1989 and can help with: personal care, housekeeping, help getting around or even to provide a break to an existing family member or care-giver.

Looking for care?
0808 274 2935

For more information
www.helpinghands.co.uk







- Mobility Scooters
- Adjustable Beds
- Wheelchairs, Bathing & Toileting Aids
- Daily Living Aids – Dementia Friendly



Call: 01604 407702 or visit our store at
25 Weston Favell Shopping Centre
Northampton NN3 8JZ
www.morethanmobilitynorthampton.co.uk

ADAPTAWear

clothing for care

- ✓ Discreetly adapted clothing to help independent living & assisted dressing
- ✓ Making getting dressed easier and less painful
- ✓ Ladies' & men's daywear, underwear and nightwear
- ✓ Zips, Magnets and Velcro replacing buttons

Call 0800 051 1931 for a **FREE** brochure or visit www.adaptawear.com



Brockfield House



Inspected and rated
Good
Care Quality Commission

Brockfield House is situated in the village of Stanwick, with stunning views of the countryside and is close to amenities and local transport.

We specialise in caring for people living with the effects of **long-term mental health problems** and those living with **dementia**. Our trained nurses and care staff are **respectful and sensitive** to the individual needs and choices of residents, providing **excellent care** in a **comfortable and safe environment**.

For more information, please contact us:
01933 625555
admin@brockfieldhouse.co.uk
Villa Lane, Stanwick, Wellingborough NN9 6QQ



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





Dementia Services
Northampton



St Andrew's
HEALTHCARE

Supporting a dementia friendly Northamptonshire

As a specialist hospital supporting people with complex and progressive neurological conditions, including dementia, we understand the full range of therapeutic, social and environmental services required to help people to live well with their disease.

We utilise innovative technology and tailored nursing approaches that reflect the cognitive, physical and emotional needs of our patients, including Dementia Care Mapping (DCM), Virtual Reality and a full range of occupational therapy to enhance the quality of life for those in our care.

Our staff are committed to specialist training, which is why the CQC recently recognised our 'Outstanding practices', which highlights our relentless pursuit of excellence in neurobehavioural care. We work closely with local charitable, academic and health services and are proud to support a dementia-friendly Northamptonshire.

For more information on our dementia services visit:



www.stah.org/dementia



Transforming lives together



Glenside

CARE HOME

Day Care | Respite Care | Short & Long Term Care



- Person Centred Dementia & Mental Health Care for age 40 and over
- Staff all Fully Trained
- Private Rooms some with En-suite
- Open Visiting – Call at your leisure
- Activity Programmes & Outings to meet individual needs
- Specialist Diets catered for and 'Heartbeat Award' for Home Cooked Foods
- Easily accessible from Northampton and surrounding areas

Telephone: 01604 753104 for a brochure • Website: www.glensidecarehome.com

Address: 179 – 181 Weedon Road, Northampton NN5 5DA



HOLLYHOUSE RESIDENTIAL HOME

Holly House provides care for the elderly and for persons with dementia.

Situated in the picturesque village of Milton Malsor, 10 mins from Hunsbury Tesco, Holly House provides 22 spacious single rooms with en-suites. Personalised care is designed to enhance each individual residents' quality of life with a homely atmosphere. Respecting dignity, independence and privacy with 24/7 care and support.



36 Green Street, Milton Malsor,
Northampton NN7 3AT

For more information, please contact us
on **01604 859 188**

or email info@hollyhouserresidential.com
www.hollyhouserresidential.com



**Do you care for
someone with
dementia and
worry they
may go
missing?**



**The Herbert Protocol
is here to help find
them if they do**

For more information visit
www.northants.police.uk/herbertprotocol



**THE
HERBERT
PROTOCOL**
Safe & Found





www.carechoices.co.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

The Publisher of this Guide, Care Choices, also produces Care Services Directories for Bedfordshire, Buckinghamshire, Cambridgeshire, Lincolnshire, Northamptonshire, Oxfordshire and Warwickshire



www.carechoices.co.uk

For free copies, call

Bedfordshire – Bedford Borough Council on **01234 267422**
Central Bedfordshire Council on **0300 300 8303** or
Care Choices on **01223 207770**

Buckinghamshire – Care Choices on **01223 207770**

Cambridgeshire – email **carechoices@cambridgeshire.gov.uk**

Lincolnshire – Customer Service Centre on **01522 782155**

Northamptonshire – Customer Service Centre on **0300 126 1000**

Oxfordshire – Social and Health Care team on **0345 050 7666**

Warwickshire – Warwickshire County Council on **01926 410410**

With thanks

The compilation of this guide would not have been possible without assistance, contributions and support from Beth Britton; Sharon Blackburn CBE RGN RMN, National Care Forum; Professor Jacqueline Parkes, Northamptonshire Dementia Action Alliance; University of Northampton; Mary Burton, OT Lecturer, University of Northampton; Claire Henry, The National Council for Palliative Care 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 Northamptonshire 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 Northamptonshire. ©2019 Care Choices Limited. Care Choices Limited reserves all rights in the titles Care Choices and HOMES Directories and their design.

Care Choices™ is a trademark of Care Choices Limited.

Ref. No: 4001/DFNorthamptonshire2/0219. 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**.

Publisher: Robert Chamberlain. **Director of Sales:** David Werthmann.

Editor: Angharad Burnham. **Content Editor:** Emma Cooper. **Junior Editor:** Henry Thornton.

Regional Team Manager: Russell Marsh. **Sales Manager:** Paul O'Callaghan. **Regional Sales Supervisor:** Vanessa Ryder.

Senior Sales Executives: Mark Dalton, Mustafa Kanuni. **Sales Executives:** Claire Cornish, Jake Harvey.

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

Assistant Studio Manager: Holly Cornell. **Creative Artworkers:** Kieran Bitten, Ruth Clarry. **Distribution:** Gemma Hunter.



Live well, your way
with care at home

Your home is where you feel the most comfortable and the happiest.

With Home Instead Senior Care, caring for an ageing loved one doesn't have to be a struggle. It's why we offer everything from individualised help around the house to advanced Alzheimer's Care - to keep your loved ones safe and sound at the place they know best, "Home".



Our care

- ✓ Home help
- ✓ Companionship
- ✓ Personal care
- ✓ Dementia care

Contact us for more **information**

Northampton: **01604 211190**
www.homeinstead.co.uk/northampton

East Northants: **01933 678775**
www.homeinstead.co.uk/eastnorthants