DEMENTIA FRIENDLY GUIDE

NOTTINGHAM AND NOTTINGHAMSHIRE

If you're helping someone with dementia, whether it's Alzheimer's, vascular dementia, or another type, this guide is here to assist you.

It provides practical advice for dealing with daily challenges, managing changing relationships, and finding care services in Nottingham and Nottinghamshire for people with dementia.

Whether you're just starting to notice signs of dementia or seeking a diagnosis, this guide can help you understand and navigate the process.

Updated Dec 2023

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Introduction

In the UK, about 225,000 people develop dementia each year, which means one person gets it every three minutes. Dementia is a brain condition, and its effects can be different for each person. Everyone's experience with dementia is unique.

It's important not to wait too long to seek help. Getting a diagnosis is crucial to accessing and receiving the right services. Knowledge about dementia can help you deal with it, accept the situation, and plan for the future. You can use the internet and social media to find information and connect with others who can provide support but it's often more valuable to attend a local Dementia Café or support group.

If you have this guide, it's probably because someone you know has dementia or is showing signs of it. Whether you've been dealing with dementia for a while or it's new to you, this guide provides practical information for people living with dementia and those supporting them. Whether you're a family member, friend, or part of the community, this guide will provide information about dementia and how to cope with it day-to-day.

Throughout this guide, we'll refer to "you" as the person providing support to someone with dementia. This is not meant to exclude those living with dementia – the person with dementia should always be the focus.

For a quick link to the Nottingham and Nottinghamshire Dementia Directories CLICK HERE or visit www.nottshelpyourself.org.uk

Diagnosis

Getting a dementia diagnosis can be a big deal, whether it's expected or surprising. It affects the person getting the diagnosis and those close to them. Everyone's situation is unique, and there are choices to be made. Some people may choose not to obtain a diagnosis.

Getting diagnosed early can be important because it can provide information and support. But many things can influence when or if a person gets a dementia diagnosis.

Communication

Not everyone will read this guide at the same point in their dementia journey. Dementia symptoms get worse over time, which is tough to accept. In this guide, we're talking to you, a family member, or a close friend, but we're keeping the person with dementia in mind. Our aim is to reach everyone.

Talking about dementia can be hard, and people might not want to talk about it right away. This guide is here to help you and your family have those important conversations when you're ready, whether that's now or later.

Getting Help and Support

Accessing services and support can make a big difference for people with dementia and their families. While many people start this process with a dementia diagnosis, it doesn't have to be the case. This guide provides links to lists of local services and national services.

Planning Ahead

It's crucial to keep talking to the person with dementia, family members, and professionals as much as possible. This way, you're more likely to find answers to your questions and ways to deal with the ongoing changes that dementia brings. Regular appointments with professionals can also help address any questions that come up over time.

Services

Getting help and support can be really helpful for people with dementia and their families. In some areas, a dementia diagnosis is where you begin to get help. But it doesn't have to be that way. This guide has detailed lists of local services on page 41 and national services on page 43.

Planning

It's crucial to understand that a dementia diagnosis doesn't mean someone can't make choices about their future anymore. People can live well with dementia for a long time. They should be involved in decisions for as long as they can, so their daily life can match their preferences, and they can positively plan for the future.

Planning ahead, which may involve life stories, lasting powers of attorney, and advanced decisions, can give peace of mind to those worried about not being able to make important choices later on. It also ensures you won't have the added stress of making decisions for your loved one that might not align with their wishes.

Remember, a person with dementia is still an individual with their own life experiences, personality, and likes and dislikes. Recognising this is crucial for providing support and planning for their future. It also helps shape how they'd like to be cared for as their needs change, including their end-of-life and funeral preferences.

Care and Support

In the national strategies for dementia, there is a heartfelt commitment to ensuring that the people who provide adult social care really understand and believe in the unique needs of people living with dementia and their families. This approach is based on person-centred care, where we create individual plans, capture, and cherish life stories, and cultivate a deep understanding of the person with dementia. This not only enables caregivers to provide care but also to develop meaningful relationships, recognising that these connections are an essential part of life and of everyone’s individual identity.

There is a commitment to spreading awareness about dementia, not just in the professional sector but also among the wider public, in our communities, and in public services. The goal is to raise standards and promote a broader understanding of what constitutes excellent dementia care. The journey to raising public awareness begins with each one of us, as every small effort contributes to making a significant difference in the lives of those affected by dementia. Together, we can build a more compassionate and understanding world for them.

Living well with Dementia

This guide will support you, and the person living with dementia, all the way from diagnosis and daily living, to care and support, through to plans for end-of-life care. We 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.

Even if you are feeling isolated now, remember that there's a lot of help and advice available. In this guide, we've included real stories from people who care for someone with dementia, whether they're family members, dedicated dementia nurses, or trained caregivers. Keep in mind that the information you collect and your experiences while supporting someone with dementia can be valuable to other people. If you feel up to it in the future, consider passing on your knowledge and sharing your experiences with others.

People can live well with dementia for a long time. We hope is that this guide will provide you with the information you need to help the person in your life live well with dementia.

What is dementia?

If you suspect someone might have dementia or if you or a loved one has recently been diagnosed, you probably want to gather more information. Nowadays, it's common to turn to the internet (Nottshelpyourself) and search for 'dementia.' However, you might come across a vast amount of information covering various types of dementia. Sorting through all of it can be challenging, and you might feel overwhelmed by other people's experiences and symptoms.

If what you want is reliable information about dementia, it's essential to look for high-quality sources and sift through what you read. Organisations like Alzheimer's Society or Alzheimer's Research UK offer valuable publications that are written by experts but are presented in a way that's easy to understand. Starting with these sources is an excellent place to begin your search for information on dementia.

This guide aims to provide an overview of dementia, how to cope with its symptoms, and how to plan for the future. We'll start with some common examples and symptoms of dementia. However, it's important to remember that dementia affects each person differently, so people's experiences can vary.

Dementia is a term used for various conditions that lead to brain decline. Many people can continue to live well and have good memories, though some people may notice changes in memory over time. While ageing can increase the risk of certain types of dementia, dementia isn't a normal part of growing old. It can also affect younger people, not just older ones, although it's more common in those over 65.

Common types of Dementia

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

As with Alzheimer's disease, the symptoms of vascular dementia can develop in different ways in different people. However, commonly experienced symptoms can affect a person's concentration, and cause confusion or even seizures. Memory issues 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 symptoms of dementia. 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 similarly 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 other symptoms, including disturbed sleep, issues with attention span or spatial awareness.

Dementia with Lewy Bodies can occur together with 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. As a result of 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 to find the right words.

Rarer types of Dementia

There are other less common types of dementia besides the ones we've talked about. Alzheimer's Society provides explanations for all forms of dementia, even the rare ones, and they can also guide you to get help.

Diagnosis worries

If your loved one has received a formal diagnosis (we'll discuss this further in the next chapter), you may now have a specific name for their type of dementia. This might be the point when you think about looking for more information online. But remember, a diagnosis doesn't mean that the person will have all the "textbook" symptoms, or that their dementia will progress in a typical way.

Getting a diagnosis can be a crucial step in accessing services and support, but it's ultimately the person's choice whether or not to seek one. They might not even be aware of any symptoms nor understand why you believe there could be signs of dementia. That's why it's important to talk to them and focus on their thoughts, wishes, and concerns.

Whether the person with dementia has a formal diagnosis already or is considering one in the future, there are numerous national and local organisations ready to provide support and assistance. You're not alone on this journey, and help is available.

Is it dementia?

At some point in our lives, most of us have forgotten an appointment, misplaced our keys, or struggled to put a name to a face. It's a common part of being human. However, if these instances start happening more often, or it becomes increasingly challenging to remember certain things, it might be a sign of an underlying condition, especially if other changes are occurring at the same time.

According to Alzheimer's Society, people with dementia experience the symptoms differently, but some common signs may include:

- Memory lapses, like having trouble recalling recent events.
- Difficulty in absorbing new information.
- Losing track of conversations or TV programs.
- Struggling to remember names, people, or objects.
- Changes in the ability to reason or make decisions.
- Shifts in personality or behaviour, which can involve becoming frustrated, upset, or angry due to memory issues.
- Feeling disoriented in time or place, including changes in spatial awareness.

If you're worried that someone might be showing signs of dementia, it's helpful to keep a record of the changes you notice. Remember, dementia symptoms can vary greatly from person to person. It's not always just forgetfulness; it could be alterations in their personality, spatial awareness, confusion, or difficulty finding the right words.

Keeping track of these concerns can help you identify any patterns and whether they align with specific dementia symptoms. Having this information can be valuable if you decide to research online or start a conversation with the person displaying these symptoms or consult a healthcare professional. You're not alone, and your care and attention make a significant difference.

People have different views on getting a dementia diagnosis. Some want answers, while others worry it might label them. It's important to know that people can choose whether to seek a diagnosis now, later, or not at all.

Whatever you and the person with potential dementia think, a formal diagnosis can open doors to professionals, services, and support, and it can also lead to treatment if that's what the person wants. The choice is theirs.

Understanding the signs and symptoms

If someone shows signs of dementia, the first step is to consult their GP. If you're the one noticing these changes in someone, approach the matter gently and try to understand their point of view. They might not be aware of the changes or may not be ready to take action, so avoid pressuring them to see a doctor.

In such situations, you can approach the topic in various ways. Taking notes and showing them the written symptoms can be effective. A frank but sensitive conversation about your concerns can also help. Treat it like any sensitive subject, and your familiarity with the person's symptoms will help.

Don't hesitate to discuss your thoughts with a close family friend or relative who knows the person well; they may have noticed symptoms too.

Dementia isn't talked about as much as it should be, and many people delay these conversations. However, if the person showing symptoms is willing, it's crucial to seek help from a medical professional as early as possible. Early diagnosis is key for accessing treatment, support, services, and planning for the future. However, diagnosing it in the early stages isn't always easy.

When you visit the doctor, respect your loved one’s privacy. If they prefer you not to accompany them to the appointment, respect their choice. You can write down the symptoms you've noticed for them to take with them, or you may be able to contact the doctor in advance by phone, letter, or email.

Memory assessment

Sometimes, there are medical conditions that can cause symptoms similar to dementia. A doctor can help rule out these other possibilities. The GP might carry out/arrange blood and urine tests to check for underlying causes.

Diagnosing dementia isn't as simple as a single test. The doctor will probably ask the person with dementia symptoms about themselves, and they may also speak to you if you're present at the appointment. Any symptoms you've written down can be really helpful in building a clearer picture.

The doctor will also review your loved one's medical history and any existing health conditions or medications. This helps them identify if other issues should be managed or treated first. They might also offer a simple test for the person to complete during the visit.

In some cases, the GP may be able to diagnose dementia at this stage, especially if the symptoms are already quite advanced. However, they might be referred for further tests or wait for the results of medical tests.

The GP might refer to community mental health teams, memory clinics, or memory services, depending on the area where the person lives. These specialised services can carry out more in-depth memory tests for a dementia diagnosis or provide information and guidance. The NHS website has a good summary of the types of dementia tests that may be offered to confirm a diagnosis; visit https://www.nhs.uk.

Remember, it's essential to involve and inform the person with dementia at every stage of the process, and the GP should share details of assessments and any diagnosis.

If you ever feel that doctors are hesitant to diagnose dementia due to a lack of support from healthcare and social services, don't hesitate to have an open conversation with your GP. You can also seek a second opinion if you believe it's necessary.

Support services for people living with dementia and their families can vary across England, including healthcare, social care, primary care, and community services. Sometimes, these services work well together, but in other areas, they might not be as coordinated. This can be frustrating as you may find yourself repeating answers to the same questions and having to contact different services and departments.

Because of the differences in formal services across the country, many local voluntary services offer various forms of support.

Diagnosis

When a diagnosis of dementia is made, the treatments available will be discussed with you and the person with dementia. These treatments can vary, depending on the type of dementia and how far the symptoms have progressed.

If the dementia is caused by an underlying medical condition, treating that condition may help alleviate some symptoms. In certain cases, there might be medications available, although this isn't always the case and depends on several factors.

It's essential to understand that dementia is a progressive illness, and, although there are treatments to manage symptoms, there is no cure. Depending on the stage and type of dementia, medication may be offered to help slow down the progress of symptoms, but it's not suitable for everyone and may not be effective in all cases.

The NHS website provides information on different dementia treatments. It's advisable to discuss with a medical professional what options may be suitable for your loved one, although it's important to be aware that not all cases have a suitable treatment.

At the time of diagnosis, both you and the person with dementia should receive information and advice about local services and support groups. You'll also be informed about any benefits available and be provided with techniques to help manage the symptoms. This comprehensive approach aims to support both the person with dementia and their caregivers through the dementia journey.

Following diagnosis

Receiving a dementia diagnosis can be surprising for some people who've been experiencing symptoms and a relief for others. Everyone must take time to process this news.

Just as with any diagnosis, different people, including you, the person with dementia and their family and friends, may react differently. This is normal, and it's okay to need time to come to terms with it. Sometimes, people might feel isolated after a dementia diagnosis, but there are support services in your local area that can provide help and guidance when you need it.

It also helps to establish a strong support network, including family, friends, and people in your community like neighbours or members of religious or cultural groups. Talking to your local faith leaders, such as a vicar, rabbi, or imam, can also offer practical and spiritual support.

If you're not offered follow-up appointments with medical professionals, reach out to local organisations to find out what's available in your area. Consider attending 'Dementia Friends' sessions if you want to learn more about dementia and how to support someone with the condition. Some areas are becoming 'Dementia Friendly,' where individual people, shops, and organisations receive dementia training to support people with dementia in their community.
Dementia awareness e-learning courses:
The Social Care Institute for Excellence (SCIE)
The Wicking Dementia Research and Education Centre

Some people with dementia may find it fulfilling to participate in research studies after a dementia diagnosis. You can explore opportunities on the Join Dementia Research website, which matches people interested in dementia research with suitable studies. Also, the Dementia Engagement Empowerment

Project (DEEP) is a UK network of dementia voices, consisting of various groups aiming to improve the quality of life for people with dementia.

Trent Dementia is a Nottinghamshire-based charity which aims to improve the quality of care, support and wellbeing of people who are living with dementia in the East Midlands and further away. They run projects and events and aim to work together with people with dementia and their supporters. View their 'What's On' page to find a directory of Nottinghamshire contacts, support, activities and social groups.

Dementia is a progressive condition, so it's crucial to think about the future and make plans with the person who has dementia while they can still communicate their wishes. We'll delve into this topic in more detail in the following chapters but remember that starting to plan for the future sooner is often easier than later.

Planning for the future

Making a Life Story Record

Creating a life story record for a person with dementia is a wonderful way to cherish their unique life history and help support them as their condition progresses.

Why Create a Life Story Record?

- A life story record holds memories, anecdotes, and information about the person with dementia, which can become invaluable as the disease advances.
- It's a way to connect, share stories, and build a sense of togetherness, involving not just you, the caregiver, but also family, friends, and others who know the person well.
- As dementia affects short-term memory more than long-term memory, having a life story to refer back to can be reassuring and informative for the person with dementia.
- It can be a source of comfort and practical help as well. You can share this information with medical professionals and care staff, helping them to understand the person's preferences, routines, and personality. This, in turn, can inform personalised care plans.

What Goes into a Life Story Record?

A life story record is a collection of memories and anecdotes about the person with dementia. It could include various aspects of their life. To start, talk with them about their early life and significant events. Keep conversations positive, and if there are particularly significant negative events, record those separately.

Here are some conversation prompts to consider:

- Place of birth.
- Childhood town.
- Family - parents, siblings, and other close relatives - names, occupations, and interests.
- Childhood friends.
- Pets.
- School life.
- Childhood hobbies and favourite holidays.
- Occupations.
- Meeting their partner.

- Marriage.
- Having children.
- Family holidays.
- Significant family memories.

Feel free to adapt and choose topics that resonate with the person's memories and experiences. As you talk, you can also look through old photos, special items, or possessions that may spark further conversations. These items can be added to the record, whether it's a book, folder, memory box, or digital presentation. Be creative in finding materials, even if photos or items have been lost over time. For instance, you can use a recent map showing their place of birth or modern photos of a school they attended.

Continue to explore their likes and dislikes, daily routines, and habits:

- Clothing preferences.
- Hairstyle.
- Morning routine.
- Favourite meals.
- Food dislikes.
- Media preferences (radio, TV, music).
- Tea or coffee preferences.
- Religious activities.
- Hobbies and interests, including gardening and pets.

These specifics will be invaluable as dementia progresses, helping you, the caregiver, to understand and support better the person's needs, likes, and personality.

Care and Support Planning

Planning for care and support is crucial when dealing with dementia.

Discussing Care and Support:

- The care and support chapter (page 19 onwards) outlines services available.
- Planning for formal care services is essential. Discuss with the person with dementia what they prefer for receiving support: at home, in a care home, or in a care home with nursing.
- These conversations can be challenging, especially about care homes, but planning ahead makes future decisions easier.

Assessment and Planning:

- Social care providers or the local authority will assess the person with dementia to determine their needs.
- A care and support plan will be created, which may include formal services or activities like day programmes.
- Consulting other professionals involved in the person's life helps build a comprehensive picture of their needs.

Finding Care and Support Information:

- If you want more information about care and support available, visit www.carechoices.co.uk.

- When needs have been assessed and services arranged , the person's life story and personal details become vital.
- As dementia progresses, understanding the person's likes and dislikes helps you, the caregiver, understand their needs and how they behave.

Other Planning Considerations:

- Planning for the future is essential, including financial, legal, and end-of-life plans.
- As dementia symptoms progress, the person may lose the ability to make decisions, so these plans must be in place.
- Other plans to consider include advance care planning and using tools like Alzheimer's Society's "This is me" document. You can find more information further on in the guide.

It's never too late to plan

In an ideal world, everyone would receive a dementia diagnosis early, allowing them to plan for the future and express all their wishes. However, in reality, formal diagnoses may come later or not at all, and dementia symptoms can progress to a point where communication becomes challenging.

But this doesn't mean we can't plan. Dementia affects people differently and at different times. There might be moments when the person can recall specific events or stories. In these moments, photographs can serve as prompts. Involving friends and family can also help, as they may have stories to share.

It can also be helpful to play their favourite music and singing a song they love can be comforting. Write a playlist of favourite songs, use online music players to help compile a reminiscing playlist. Holding cherished items and familiar scents like perfume or a favourite meal can also be soothing.

Putting plans in place ensures that everyone around the person with dementia knows their likes, dislikes, life history, and future wishes. Though this process can be emotional and can take time, it is essential. It will be easier to make important decisions in the future, knowing that you've done your best to prepare.

When a loved one has dementia

Receiving a dementia diagnosis affects not only the person with dementia but also their broader circle of family, friends, neighbours, and social connections. If the person diagnosed is still employed, this diagnosis also needs to be shared with their manager and colleagues.

How each of us experiences dementia when someone close is affected can vary widely. The diagnosed person might learn to adapt to their changed life and live with their symptoms, while other people might deny or withdraw from the world around them.

As dementia symptoms progress, the person with dementia may not fully grasp the impact of their condition on themselves or those around them. This can lead to changes in family dynamics and relationships, which may become strained or redefined over time.

It's important to remember that dementia-related changes usually occur gradually, allowing for small adjustments to routines and life as time passes. A diagnosis doesn't mean immediate, drastic changes, but it's essential to be prepared for possible changes in the future.

Family and friends often experience a range of emotions, including denial, fear, a sense of loss, and sometimes guilt if they can no longer provide the level of care they want. Support from specialists like Admiral Nurses can be immensely valuable during these times, www.dementiauk.org.

Admiral Nurses offer support to the entire family and can help prevent caregiver burnout. However, their services are not available everywhere, so it's essential to check if there's a local Admiral Nursing team, or contact Admiral Nursing Direct on the **helpline 0800 888 6678**, or email helpline@dementiauk.org

If you're a caregiver, remember to care for yourself as well. Seek assessments of your needs from the local authority and explore the benefits available, such as a carer's allowance.

To have a conversation about your needs as a carer, you can contact Nottinghamshire County Council by calling **0300 500 8080.** Alternatively, visit: www.nottinghamshire.gov.uk/care/adult-social-care/contact-us

You can contact the Nottingham / Nottinghamshire Carers Hub Service directly at **0808 802 177**
Email: carershubinfo@carersfederation.co.uk WhatsApp or Text: **07814678460** or
visit: www.tuvida.org/nottinghamshirehub

A comprehensive information booklet for Nottinghamshire carers can be found at:
www.nottinghamshire.gov.uk/media/121169/carerbooklet.pdf

For partners of people with dementia, especially if the diagnosis occurs at a younger age, there can be a sense of loss regarding plans for the future. However, with adjustments, many plans can still be pursued, and dementia-friendly options exist for holidays and activities.

Intimacy and sexual relationships may change as dementia progresses, but it's important to remember that these changes are not personal rejections. They are symptoms of dementia that require support and understanding. For further resources click on the following link: Dementia and your relationships www.alzheimers.org.uk

Drawing on the strength of your relationship and preserving memories can help strengthen bonds. Some couples report developing even deeper connections as they face the challenges of dementia together.

When a parent or grandparent has dementia, unique relationship challenges can arise. Younger children may struggle to understand the changes in their loved ones. Alzheimer's Research UK has created a child-friendly website called "Dementia Explained" to help young people understand the impact of dementia better. This website offers information and interactive resources to explain how dementia affects the brain and its impact on families, allowing young people to share their experiences and learn more about the condition. Visit https://www.alzheimersresearchuk.org/kids/dementia-explained/ for more information.

Take a look at the list of further information and support towards the end of the guide where National and Local services have been listed.

Supporting people from different cultures

If the person with dementia comes from a different culture from you, the caregiver, you may each have unique experiences. As their dementia symptoms progress, they might start using their native language again, find comfort in childhood activities or food, or place more importance on their culture.

In your area, there might be culturally specific services available. When seeking formal support, a good service provider should consider the person's cultural background. However, it's essential to be aware that some services may not fully address the specific needs of a person with dementia from a different culture. In such cases, explore other services available.

Whatever your relationship with the person with dementia, you'll probably notice gradual changes in your connection. Being aware of these changes and adapting over time can be helpful. Some changes may be easier to handle than others but remember that your responses to these changes are natural, and there is support available to help you.

You can live well with dementia

People with dementia can have varying symptoms that change from day to day. Understanding these symptoms and how to manage them on a daily basis is crucial. Some people with dementia may have more insight into their condition than others, so it's essential to be patient and considerate.

As dementia progresses, a person's understanding and awareness may decline. If you're a close relative or caregiver, you might need to explain things or help with tasks. Patience and calmness are important in these situations, and you can seek support from others if needed.

It's vital not to take over tasks from the person with dementia as it can disempower them. Gradual changes will occur in daily living, such as driving or using household appliances, which need careful consideration. Technological solutions like sensors can improve home safety.

To cope with the challenges of dementia, gathering information and seeking support is empowering. You can research online, use helplines, attend support groups, or consult dementia advisers or Admiral Nurses. Don't hesitate to seek information and support, even if you initially decline it.

Remember that you experience your relative's dementia uniquely, and your emotions are tied to your specific relationship. Sometimes, it may feel overwhelming, and you might feel overlooked by healthcare services. However, you have the right to ask for an assessment of your own needs and seek support to take care of yourself. Seeking help is not a sign of weakness but an acknowledgement of your humanity and the need to care for yourself and your loved one with dementia.



Figure 1@scriberian drawing containing quotes from people attending Trent Dementia's activities

Managing your feelings

Caring for a loved one can be a really fulfilling and rewarding experience, but it's also important to acknowledge that you may encounter various challenging emotions like guilt, anger, and loneliness along the way. These feelings are entirely normal and should be addressed to maintain your own wellbeing. Here are some strategies to help you navigate these emotions:

1. Keep a Diary of Your Feelings

Maintaining a diary where you jot down your emotions and the circumstances surrounding them can be incredibly helpful. By doing this, you might notice patterns or triggers for specific feelings. For instance, you may realise that certain caregiving tasks or situations tend to evoke feelings of frustration or guilt. Recognising these patterns allows you to proactively manage your responses and find ways to mitigate negative emotions.

2. Talk to People

Sharing your feelings with someone you trust can be a powerful way to relieve emotional burdens. Friends can often provide a valuable outside perspective, as they are not as emotionally immersed in the caregiving situation as family members might be. Discussing your emotions can help you process them and gain insights into potential solutions or coping strategies.

3. Ask for Help

Caregiving responsibilities can be overwhelming, and you should not bear the entire burden alone. If you feel that other family members should be contributing more to caregiving tasks, it's crucial to communicate your needs and concerns with them early on. Addressing these issues openly can prevent tensions from escalating and promote a more equitable distribution of caregiving responsibilities.

4. Let Things Go

Caregiving often involves a multitude of daily challenges and stressors. Some of these may seem significant in the heat of the moment but appear less serious when viewed with a clear mind. Learning to let go of minor issues and stressors can help you maintain your emotional wellbeing. Prioritise what really matters and recognise that not everything warrants a strong emotional reaction.

5. Self-Care

Taking care of yourself is paramount in the caregiving journey. Make time for activities that bring you joy and relaxation, even if it's just for a short while. Whether it's reading a book, taking a walk, practicing mindfulness, or pursuing a hobby, self-care helps recharge your emotional and physical energy.

6. Seek Professional Support

If you find that your emotions are becoming overwhelming or persistent, consider seeking professional support. A therapist, counsellor, or support group can provide valuable guidance and a safe space to explore and address your feelings.

Remember that caregiving is a challenging role, and it's entirely natural to experience a range of emotions. By actively managing and addressing these feelings, you can maintain your own wellbeing and continue to provide the best care possible for your loved one.

Seven daily living tips for carers

Caring for someone with dementia requires patience, understanding, and flexibility. Here are some practical tips to provide the best support:

1. Offer Simple Choices

Empower the person with dementia by giving them simple choices. For example, you can ask if they'd like tea or coffee, enabling them to maintain a sense of control over their daily life.

2. Maintain Routine

Consistency is key. Familiar routines provide comfort and stability for people with dementia. Life story records can help you understand their routine better, making it easier to follow.

3. Flexibility

While routines are important, be open to flexibility. Dementia symptoms can lead to changes in behaviour and preferences. Adapt to these changes as long so they don't pose any harm or discomfort.

4. Live in Their Moment

Dementia can affect a person's sense of time and memory. Avoid causing unnecessary distress through living in their present reality. If they ask about someone who has, in fact, passed away, respond gently, without correcting them.

5. Redirection

When faced with challenging situations or moods, redirection can be a valuable technique. Shift their attention to something positive or engaging, like looking at photos or talking about familiar topics.

6. Apologise If Necessary

If the person becomes upset, consider defusing the situation by taking responsibility and apologising, even if it wasn't your fault. This act of empathy can help calm them, but it may not work in every situation, and you should only do it if you're comfortable with it.

7. Take Breaks

Caring for someone with dementia can be emotionally taxing. It's essential to prioritise your wellbeing too. If you feel overwhelmed, take short breaks. Make sure the person with dementia is safe and comfortable, and don't hesitate to ask for help from friends, family, or support groups if needed. Remember, self-care is as crucial as caregiving.

By implementing these tips, you can create a supportive and compassionate environment for your loved one who is living with dementia while also ensuring that you maintain your own physical and emotional health in the caregiving process.

Hobbies and pastimes

Engaging in various activities is often seen as a vital way to slow down the progression of dementia. These activities can take many forms and should be tailored to the preferences of the person with dementia and their loved ones.

If you're looking for ideas, Care UK (www.careuk.com) offers a helpful guide to dementia-friendly family outings on its website. Additionally, the National Activity Providers Association offers valuable publications, including a book of activities, which you can buy from their online shop, (https://napa-activities.co.uk).

It's important to understand that a person with dementia may continue to enjoy lifelong hobbies or may lose interest in them. Never force them to engage in something they no longer find enjoyable. Instead, view these changes as an opportunity to introduce new activities they haven't tried before.

In such situations, creating or expanding their life story record can be a wonderful, shared endeavour for your family. This resource can bring everyone together and provide enjoyment for all. For more information, please refer to the planning chapter starting on page 11 of the guide.

Remember that dementia should never be seen as a barrier to enjoying activities or trying new things, even if modifications are necessary. Learning something new, whether it's a language, a musical instrument, or technology, can be revitalising for the person with dementia and offer you, as well as other family members or friends, an opportunity to engage together. If you need to, consider befriending services in your local area, which can provide support while you take a break.

"I am a British Army Veteran diagnosed with PTSD. Being a regular helper and supporting my partner to care for her mum brings me enormous satisfaction. The Stapleford Memory Cafe is a wonderful place for people living with memory issues, their families, and volunteers to come together, socialise and share experiences. Everyone gets the rewards of being part of a caring community and having fun. The cafe is a bright and happy place to be".

Kevin

Library Services

It is free to join your local library and you can use your library card across Nottingham or Nottinghamshire libraries. These are the top three dementia specific offers:

- Dementia specific books and resources – including Reading Well for dementia, a national booklist of titles recommended by health professionals and people with lived experience
- General library services – including an acknowledgement that library services should be inclusive for everyone, free Home Delivery Services available for people with dementia

"I enjoy mixing up with people and having a sing-song. I still went when the weather was bad because I enjoy the company. I enjoy it with Renee"

Brenda

and/or their carers who are unable to get to the library in person, free access to eBooks, eAudio, eMagazines and eNewspapers.

- Dementia Groups and Activities – including theatre and film screenings, music events, and loaning of reminiscence objects, memory bags and puzzles.

Here are links to the County and City Library services: Inspire - Culture, Learning, Libraries (inspireculture.org.uk) and Dementia | Nottingham City Libraries www.nottinghamcitylibraries.co.uk

Daily living tasks, such as cooking or laundry, can also be considered activities in their own right. Involving the person with dementia in these tasks can create meaningful shared experiences. Simple prompts, like labels with words and pictures around the person's home, can help them participate more independently.

Explore the availability of day services in your community, which are often held in community halls or local care homes, www.nottshelpyourself.org.uk. These services can provide a change of scenery for both the person with dementia and for you. You may be able to drop them off and take some time for yourself. Some may even offer a carers' group, where you can relax, have a chat, or share experiences with others in a similar caregiving role.

Lastly, don't overlook the option of respite care. This provides a short break for the person with dementia, either at home or in a care setting, while you take some time for yourself. Respite care can be invaluable in allowing caregivers to recharge and focus on their own wellbeing.



Figure 2 Memory Cafes and groups provide stimulation and support for everyone affected by dementia

Therapies and medication

There is a wide variety of therapeutic interventions that can be beneficial for individuals living with dementia. These therapies encompass a broad range of activities, including massage, yoga, aromatherapy, physical exercise, music therapy, meditation, blogging, and brain training exercises. These interventions aim to improve the overall wellbeing of people with dementia and their quality of life.

Music Therapy

Listening to music is a universal experience that can significantly impact our mood. Advances in content delivery have made it more convenient to enjoy music at our leisure. The connection between music and memory is potent, evoking emotional recollections tied to significant life moments. People often use music to remember events like their first kiss, wedding songs, or moments with loved ones.

In the context of dementia, music proves to be beneficial. It can reduce anxiety and depression, maintain speech and language, enhance quality of life, and positively impact caregivers. There are three primary ways individuals with dementia, their families, and caregivers can derive enjoyment and benefits from music:

Firstly, listening to music or joining a singing group provides a readily accessible source of enjoyment, especially when shared with family and loved ones. Like walking, it is a cost-effective activity that requires careful management. Tailoring music choices to individual preferences is crucial, considering factors like hearing loss.

Secondly, initiatives that create personalised playlists for individuals with dementia can foster positive interactions. Musical memory, particularly from ages 10 to 30, appears more enduring, offering potential benefits in memory retention. Memory Radio: BBC Sounds provides a Radio-style archive and music-based programmes for people with dementia, their families and carers, accompanied by activity sheets for use in care homes. Programmes focus on specific decades and offer a mix of music, news archive and BBC comedy and drama clips. www.bbc.co.uk/programmes/p07mvnd1

Lastly, examples of expert musicians, such as Aaron Copland, Ravel, and Glenn Campbell, showcase the enduring power of musical memory, they continued to perform long after dementia diagnosis.

Many inspiring people with dementia have successfully integrated therapeutic strategies into their lives. For example, Chris Roberts, who maintains a blog at www.mason4233.wordpress.com, takes an active part in public events and trains people to become Dementia Friends as part of his proactive approach to managing his condition.

Kate Swaffer, living with dementia in Australia, utilises various therapeutic interventions to manage her dementia symptoms effectively. Her blog www.kateswaffer.com provides insights into the different therapeutic approaches she uses and explores therapeutic interventions more broadly.

Local memory clinics often offer various therapeutic interventions following a dementia diagnosis. Cognitive behavioural therapy (CBT) and cognitive stimulation therapy (CST) are among the most common therapeutic options. There may also be therapy groups in your local area specifically designed to support people living with dementia. However, it's essential to exercise caution and be sceptical of any claims of miraculous results from therapies.

In Nottingham, actress Vicky McClure joined forces with some of the country's leading experts to create 'Our Dementia Choir'. The choir took part in ground-breaking scientific studies to measure their emotional and physical responses to singing over three months of regular sessions….proving that people living with dementia can still achieve something truly remarkable. Find out more and join in by going to www.ourdementiachoir.com



Depending on the specific type of dementia diagnosed, people may be offered different medications to help slow down the progression of their symptoms. It's important to note that there are no pharmacological treatments at present that can prevent or reverse dementia. It is also essential to be aware that any medication prescribed for a person with dementia may or may not be effective and could have side effects.

If the person with dementia has other medical conditions and is already taking medications, or if additional medications are prescribed in the future, it's crucial to assess how these medications may interact with each other. It's advisable to ask for a medication review from the GP or local pharmacist, or even seek a second opinion if needed. This step ensures that the person with dementia is not taking unnecessary medications and allows for the reporting of any medication-related side effects. Keeping a daily record of medications, together with notes about any adverse effects experienced after taking a specific medication, can help manage their overall wellbeing.

"My Father has been coming to Radford Care Group for the past 4 years. When the Centre was forced to close through covid the deterioration that I witnessed was horrendous as he wasn't able to go out for 3 months. Due to this lack of social interaction my father has now developed vascular dementia . Dad lost over 2 stone in weight and his mobility declined. Pre covid my dad went to Radford Care Group 3 times a week. He was welcomed back long before other centres opened up again and although it was only for 1 day due to restrictions the change in him has been absolutely phenomenal. Radford Care Group has been an absolute lifeline for my dad in relation to social interaction, I am absolutely convinced that the reason he is still here with me is because I never gave up on him and neither did Radford Care Group"

Daughter

Care in the correct way

Caring for a family member of the opposite sex often brings up concerns related to dignity and privacy, which many caregivers grapple with. At first, you might feel uncomfortable helping with more intimate aspects of care, such as bathing, toileting, or dressing. This discomfort is entirely normal and something many caregivers experience.

If the person with dementia is your partner, you might feel uncomfortable, not because you're not used to seeing them undressed, but because you're now helping them with the personal care they used to manage independently. In the same way, if the person is your parent, helping them with intimate aspects of life may be unfamiliar and uncomfortable.

Taking your time to acknowledge these feelings and seeking practical or emotional support from healthcare or social care professionals is crucial if you find yourself struggling with this type of caregiving. You might also worry about whether you're providing care and support in the "correct" way, afraid of unintentionally causing discomfort or distress to the person with dementia. In such situations, exploring the possibility of receiving training can be helpful. Training options for family caregivers may vary in different locations, but you can be proactive by reaching out to local care homes to enquire if they offer training opportunities for family members.

As dementia progresses, supporting the person with mobility or incontinence can be particularly challenging for caregivers. Recognising this and being prepared can help you manage these difficulties. It's important to remember that paid care workers receive specific training in "moving and handling" and in supporting individuals with incontinence, so don't feel inadequate if you're unsure how to approach these challenges. Many caregiving skills require training and practice, and you may need extra help, such as training, equipment, or support from professional home care workers.

If you and the person with dementia attend dementia day services, the trained staff there may offer advice and guidance on caregiving challenges and may direct you to relevant training resources.

Modifying the home environment is another important aspect of caregiving. Simple adaptations can help delay the decline in the person's abilities. Examples include using signs or lights to guide the way to the toilet, ensuring even flooring to prevent hesitation on entering certain rooms, and keeping to an exercise regime and addressing joint problems to improve mobility.

Telecare technologies have advanced significantly and offer a wide range of devices to support independent living at home for people with dementia. Home modifications, such as installing grab rails, and step-in showers, or providing step-free access, can enhance confidence in navigating the home and reduce the risk of falls. Visit Adapting your home | Nottinghamshire County Council for further guidance, www.nottinghamshire.gov.uk/care/adult-social-care/help-living-at-home

There are various approaches to helping people with dementia live well at home, and it's worth researching and trying out these strategies.

Caring from a distance has unique challenges, especially if your loved one with dementia lives in a different part of the country. However, you can still support them by using technology to communicate and to remind them about important activities, like taking medication or eating. Adapting their home environment for increased independence is also possible, even from a distance. Explore different technologies and resources to help with long-distance caregiving.

For further information and resources on long-distance caregiving, you can visit Caring from a distance - Dementia UK Web: www.dementiauk.org

Common conditions

Dementia is often accompanied by other health conditions, such as high blood pressure, digestive problems (for example irritable bowel syndrome, constipation, or diarrhoea), heart issues (including chronic obstructive pulmonary disease), musculoskeletal problems (for example osteoporosis and arthritis), respiratory difficulties (such as asthma), skin conditions (including eczema), learning disabilities, and various types of cancer.

It's worth noting that pain is often under-recognised and undertreated in people with dementia. As dementia progresses, the person may struggle to say they are in pain or to ask for treatment, which can be challenging and distressing for caregivers.

Sensory Loss

It's essential to be mindful of sensory loss in people living with dementia. They may require glasses or hearing aids, but adapting to wearing them can be difficult for some of them. Professional assessment and help may be necessary to address these sensory issues.

Oral Health

Monitoring the dental health of someone with dementia is vital, as maintaining good oral hygiene can become increasingly challenging. Consulting a dentist experienced in treating people with dementia can help prevent oral health-related problems.

Eating and Drinking

People with dementia are at risk of dehydration and malnutrition due to forgetfulness or changes in taste preferences. Caregivers should consider trying out different flavours and textures of food, introducing finger foods, and providing a variety of drinks and hydrating foods like fruits. If malnutrition is a concern, a GP can prescribe food supplements.

Problems Swallowing

As dementia progresses, problems with swallowing (dysphagia) may develop, increasing the risk of chest infections. Consult the GP if difficulties swallowing are suspected. A speech and language therapist can assess and recommend strategies, including thickening foods and drinks, to help with safe swallowing.

Mobility

Reduced mobility can lead to pressure ulcers, but numerous products are available to prevent skin damage. Consult the GP to assess mobility and explore products that can help maintain skin health.

Mental Health

In addition to physical health changes, people with dementia may experience mental health issues, including depression and delirium. These conditions require specialised help, including medication and therapeutic interventions. If you, the caregiver, are concerned about the mental health of the person with dementia, you should consult the GP.

Hospital

When a person with dementia needs to go to a hospital, consider using a document like Alzheimer's Society's "This is me," a simplified life story document, to help hospital staff understand their needs. You can also support the "John's Campaign", advocating for the right for carers to stay in hospital with people with dementia (https://johnscampaign.org.uk/).

Flu Vaccination

Adults over 65, including those with dementia, should receive annual flu vaccinations to reduce the risk of complications. Caregivers can also be vaccinated to protect themselves and other people.

Incontinence

Incontinence is common in people with dementia, but there are ways to manage and address it. A proper assessment and treatment of reversible causes should be pursued. Continence products can be essential during this process.

Supporting someone with dementia involves numerous considerations and may require developing routines and techniques over time. Caregivers should not feel obliged to manage everything on their own; support networks, including family, friends, local groups, and national organisations, are available to help both caregivers and people with dementia. Taking good care of yourself is just as important in this caregiving journey.

For more information and resources, visit www.alzheimers.org.uk and search for "continence and dementia."

Looking after you, the Caregiver

Carers play a crucial role in helping individuals who may struggle to manage everyday life independently. Being a carer doesn't always involve living with the person you care for, and the help you provide doesn't have to be only physical. Partners, family members, friends, or neighbours can be carers.

Identifying as a Carer

If you're unsure whether you qualify as a carer, consider whether you help with any of the following tasks:

- Providing personal care, like bathing and dressing.
- Helping with toileting or managing incontinence.
- Supporting with eating or administering medications.
- Helping with mobility at home or outdoors.
- Offering practical help around the house or simply providing companionship.
- Providing emotional support and communication.

If you carry out any of these tasks, you are likely a carer. If you're caring for someone with dementia, ask your GP to register you as a carer. Make sure both your GP and the person with dementia's GP know about your caregiving role.

Looking After Your Health

It's essential to prioritise your wellbeing because by maintaining your health, you can care for the person with dementia better. Ask your GP for an assessment of your health and caregiving needs. This assessment focuses on you and helps ensure that you receive the necessary support to sustain your caregiving role.

You can also ask your local council for a carers' assessment, which examines various aspects of your life and explores how you can be supported in your caregiving role. This assessment may be carried out together with the person with dementia's assessment, but they are not obliged to have one too. If you prefer a private assessment, that option is available as well.

If you and the person with dementia both have assessments, these are usually carried out at the same time to facilitate respite care and short breaks for you, enabling you to take a break from caregiving responsibilities.

Benefits

Carers and people living with dementia may qualify for various state benefits, including:

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

Regular benefit checks are essential for both you and the person with dementia, especially as dementia symptoms progress. Local support organisations, such as carer support groups, dementia groups, Age UK, or Citizens Advice, can help with benefit checks.

Caring While Employed

If you are employed, consider discussing your caregiving responsibilities with your employer. Depending on certain criteria, you may have the right to request flexible working arrangements, although this is not guaranteed. Carers UK provides valuable information on combining employment with caregiving responsibilities (https://www.carersuk.org/help-and-advice/work-and-career/). Whether or not to disclose your caregiving role to your employer is a personal decision. While not mandatory, disclosing it can provide access to legal rights and additional support. Check your company handbook for any policies related to supporting carers.

Practical Support

National organisations like Alzheimer's Society, Dementia UK, Age UK, Carers Trust, and Carers UK offer various forms of carer support, including online resources, leaflets, helplines, and face-to-face support groups. Independent carer services may also be available in your area, and local sources, an internet search, GP surgery leaflets, or enquiries via your local Citizens Advice can help you locate them.
Young Dementia UK offers specialised support for caregivers if the person you're caring for was diagnosed at a younger age.

Some services provide training for carers through workshops or information sessions. Local carer organisations can provide information on training available in your area. In challenging situations, consider seeking an advocate to provide support during meetings and interactions with professionals, either for yourself or for the person with dementia. Events like "Carers' Week" in June, "Carers' Rights Day" in November, "National Dementia Carers Day," "Dementia Action Week" in May, and "World Alzheimer's Month" in September may offer additional support and advice during awareness-raising periods.

Young Carers and Sandwich Carers

Young carers and teenagers involved in dementia caregiving can find specific resources and support. The NHS outlines young carers' rights, and organisations like Barnardo's provide help for young carers. If you're

a "Sandwich Carer," caring at the same time for young children and ageing parents, seek support to help balance these responsibilities. You don't have to undertake everything on your own; support networks are available.

Peer Support

Peer support and mentoring can be invaluable, enabling you to connect with other carers and family members facing similar challenges. Consider joining carers' groups, participating in online forums like Alzheimer's Society's Talking Point, or engaging on social media for practical and emotional support. Specific organisations, such as the "Together in Dementia Everyday" network, can help carers (https://www.tide.uk.net/).

What if I can't carry on caring?

If your caregiving responsibilities become overwhelming, take action promptly. Seek advice from other family members and consider alternative care options for the person with dementia. Discussing alternative care can be emotionally charged, but it's essential not to feel pressured into continuing if you can't carry on. Plan in advance for the reasons why you may no longer be able to care, enabling contingency plans to be organised. Also, consider emergency planning for unforeseen circumstances like going into hospital.

Seeking Support for Your Loved One and Yourself

Caring for someone with dementia can bring unique challenges, and it's important to assess their needs regularly, even if they've been assessed before. Over time, their needs may change or become more demanding. Asking for a new assessment from your local authority can provide valuable insights to guide your caregiving decisions.

Your local authority can offer not only assessments but also a wealth of information and advice tailored to your situation. They can direct you to specific services designed to support both you as a carer and the person with dementia.

Respite Care: A Breather for You

Amid your caregiving journey, it's crucial to remember that you also need time for yourself. Respite care can offer a solution, granting you precious moments to recharge while knowing that your loved one is receiving the care they require.

Whether you need respite care on a regular basis or just occasionally, this service is adaptable to your needs. Respite care can range from a few days to several weeks, enabling you to find moments of respite in your caregiving role.

Caring for someone with dementia can be deeply rewarding, strengthening the bond between you and your loved one. Nevertheless, it's vital not to overlook your own wellbeing and to seek the support you need to continue your caregiving journey with resilience and compassion. Remember, you're not alone, and support networks are here to help you every step of the way.

Support from professionals

When you are facing the journey of dementia, it's common to interact with various healthcare professionals and support services. This can sometimes feel overwhelming, so let's demystify who they are and what they do, making sure you're well-informed.

These professionals may work for the NHS, local authorities, private businesses, or voluntary organisations. Here's a glimpse of the key professionals you may encounter:

General Practitioners (GPs)

Your local GP is often your first point of contact. They can offer a dementia diagnosis, refer you to specialists, and consider your own health needs as a caregiver.

Carers Champion

A staff member within a GP practice who can support carers. They can be a key point of contact for carers and also be a 'voice' for carers, they are able to support with navigating what support is available for unpaid carers, they can signpost and refer on to services.

Social Prescribing Link Worker

Link workers are embedded in GP practice, they give people time, focusing on '*what matters to me?*' to coproduce a simple personalised care and support plan, and support people to take control of their health and wellbeing.

Consultants

Consultants are doctors with specialised training. Depending on the situation, you may meet various types of consultants:

- Neurologists: Experts in brain and nervous system disorders.
- Geriatricians: Specialists in aging-related physical illnesses and care.
- Psychiatrists: Specialists in diagnosing and treating mental health conditions.
- Old Age Psychiatrists: Psychiatrists with additional training in older adults' mental health.

Consultants collaborate with nurses, social workers, and occupational therapists to provide comprehensive care.

Clinical Psychologists

Clinical psychologists assess memory, learning, and other cognitive abilities. They often work in memory clinics, offering support as part of a team.

Nurses

Nurses play a vital role, in providing support in various settings, including people's homes. They offer assessments, treatments, and care, as well as guidance on improving quality of life and overall health.

Admiral Nurses

These specialized dementia nurses provide practical advice and emotional support tailored to both people with dementia and their caregivers. They serve as a bridge between different aspects of care, ensuring everyone's needs are met.

Occupational Therapists (OTs)
OTs specialise in adapting care to evolving cognitive functions and promoting wellbeing for people with dementia. GPs can refer individuals with dementia to local OT services.

Speech and Language Therapists
These therapists offer advice on effective communication and help with eating or drinking if difficulties swallowing arise.

Continence Advisers
For issues related to continence, some areas may have advisers who can provide help and information about relevant equipment. You can seek referrals through your GP or contact the advisers directly.

Dietitians
Dietitians offer guidance on food, nutrition, appetite, weight management, and supplements. Your GP or consultant can arrange referrals.

Chiropodists
Healthy feet are essential for maintaining mobility. You can access NHS chiropody through your GP or consider a private chiropodist.

Ears, Teeth, and Eye Professionals
Regular check-ups with professionals for these areas are crucial, as issues can affect wellbeing and increase confusion. Referrals can be made through your GP.

Social Workers
Social workers, sometimes known as care managers, assess social care needs, and eligibility for services, and help plan and coordinate services to meet those needs.

Care Workers
Formally trained care workers help with daily activities such as personal care, housework, meal preparation, medication reminders, and accompanying people to social activities or appointments.

Understanding these professionals and their roles can make navigating dementia care more manageable, ensuring you and your loved ones receive the support and help you need during this journey.

Growing support needs

Navigating the Path of Care and Support

As dementia progresses, the need for help and support may become a daily reality. These support levels vary, from simple home aids that help with tasks as they become challenging, to formal social care services provided by home care providers, or residential care facilities. It's important to explore these options, and you can even consider completing an advance care plan with your loved one to determine the most suitable path.

Help with Daily Living
Small adjustments and aids in the home can significantly enhance independence. They can be discreet and designed to assist with everyday tasks. Examples include medicine dispensers, labelled cupboards or

pictures, brightly coloured crockery, or utensils with large handles. There's a wide array of such items available.

Additionally, there is an increasing availability of electronic devices and assistive technology products designed to support people with dementia. These can include sensors that detect gas or water left on and devices that alert when someone leaves the house. If you're uncertain where to begin, consider consulting an occupational therapist. If you haven't contacted your local authority's adult social care department, you may need to do so to access an occupational therapist. Independent living schemes in your area may also have their own occupational therapists. You can enquire about their services or search online for private occupational therapists.

The Living Made Easy website www.livingmadeeasy.org.uk offers valuable guidance on daily living and equipment.

Growing Support Needs

As the person with dementia's needs evolve, and the caregiver requires respite, formal care and support services become crucial. Support can encompass a range of services, from home help to assistance with personal care. Some people with long-term complex health needs qualify for free social care arranged and funded solely by the NHS. This is known as NHS continuing healthcare and more information can be found at www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/

Home Help:

Home help provides support with various household tasks, including cooking, shopping, gardening, companionship, and transportation to social activities or appointments. Some home help services also tackle minor maintenance tasks. Importantly, home help does not include personal care. If the person with dementia doesn't have specific care needs but could benefit from companionship or assistance with household chores, home help may be a suitable choice.

Home Care (Domiciliary Care):

Home care, also known as domiciliary care, involves trained care staff helping with personal care tasks. This can encompass tasks like getting up in the morning, bathing, dressing, meal preparation, and medication reminders. Care staff can visit regularly to meet individual needs. Before establishing a routine, visits are arranged in collaboration with the person with dementia, family members, and caregivers. A clear care and support plan is then developed.

Extra Care (Housing with Care):

This option offers affordable housing combined with care and support for people aged 55 and above who may struggle to live independently but do not require residential care. It promotes wellbeing and independence. Various care schemes, including those specialising in dementia care, cater for different care needs. Residents rent their own flats and receive scheduled personal care visits, emergency care, and access to communal areas and activities.

Personal Assistant (PA):

A PA can be employed to help with specific care needs based on your preferences. You can set tasks and choose the days and times for support. Websites such as I'm looking for a personal assistant | Nottinghamshire County Council can help you connect with local PAs.
www.nottinghamshire.gov.uk/care/adult-social-care/careers/personal-assistants/

Live-in Care:
For people with round-the-clock needs who wish to remain at home, live-in care can be a suitable option. Live-in carers help with personal care, household tasks, and companionship, providing 24-hour support.

Care Homes:
Care homes and nursing homes offer 24-hour care and support for those who can no longer live independently. Care homes provide assistance with personal care, while nursing homes have registered nurses for specific nursing needs. Selecting the right care home is crucial, as each one is unique. It is essential that staff are trained to support individuals with dementia and can meet specific needs is essential.

The path you choose depends on individual circumstances, and it's essential to assess the person with dementia's needs thoroughly to find the most suitable support. Remember, you're not alone on this journey, and there are various options available to ensure the best possible care and support for your loved one.

Specialist dementia care

In the realm of dementia care, relationships are extremely important. Our connections with other people define our lives and bring significance to our existence. This inherent value is equally important when we consider the provision of care and support. When engaging with various services—whether healthcare, social care, or any form of support—it is essential that these see the person with dementia as a person, above all else. This is where the concept of life story planning plays a pivotal role. Anchoring care and support in strong relationships and effective communication is fundamental to constructing person-centred care. This principle should be at the forefront of your considerations when evaluating potential care and support services.

When starting to look for care for someone with dementia, distinguishing between the providers who claim to support people with dementia and those who have received specialised training to tailor care to the unique needs of people with this condition can be challenging. While almost every care provider can claim to offer support for people with dementia, several key criteria can help you identify those who truly go the extra mile.

If you are exploring options for home care (domiciliary care), engaging in an in-depth discussion with the manager about their approach to supporting people with dementia and the specific training their staff have received is crucial. Consistency in caregiving is often pivotal for people with dementia. Enquiring about contingency plans for when the regular care worker is unavailable and whether you will be informed when a substitute is scheduled to visit is essential. It's equally important to ascertain whether these substitute caregivers are familiar to the person with dementia. Also ask about the flexibility of care workers regarding length of visits, especially if short visits are involved.

High-quality care providers place a strong emphasis on building relationships and prioritise person-centred care. In the context of dementia, this approach means above all else seeing the person as an individual and not focusing only on the health condition. It involves treating them as the unique person they are, despite their dementia diagnosis. Care staff should engage in meaningful conversations with the person with dementia, try hard to understand their interests, likes and dislikes, and make efforts to accommodate their

daily routines. Learning about their life history, including their childhood, career, and family, can significantly improve the quality of care. Life story records can be invaluable tools for this.

An important criterion for assessing a care provider's commitment to dementia care is the qualification and training of their staff. For instance, organisations like the Alzheimer's Society offer a Foundation Certificate in Dementia Awareness, which tests care staff's knowledge of dementia and their ability to provide person-centred support. Care providers and their staff often receive training in various aspects of care and support, including dementia care. Look for care providers who can demonstrate their commitment to dementia care through specialised training and accreditation. Some providers even have dedicated staff members responsible for caring for people with dementia.

These criteria collectively indicate a care provider's deep understanding of how to support individuals with dementia effectively. However, selecting a care provider is a highly personal decision that encompasses much more than these guidelines. If you discover a provider that takes the time to truly understand the person with dementia, values them as an individual, and provides relationship-centred support, and if you feel comfortable and confident with their approach, trust your instincts. Trial periods can be an effective way to gauge the person with dementia's comfort with the service, and you can always look for other options if you need to.

In the context of care homes or care homes with nursing, there are no specific "dementia care homes." All care homes and care homes with nursing are regulated by the Care Quality Commission and can claim to support individuals with dementia. However, there are ways these establishments can demonstrate their commitment to dementia care, their training in supporting individuals with dementia, and their dementia-friendly environment.

The physical appearance and layout of a care home can be vital considerations. Some people may prefer a homely look, while others may prefer an atmosphere more like a hotel. The comfort of the person with dementia in their surroundings is the most important thing.

Innovative design features such as circular corridors or gardens for independent exploration, cabinets outside residents' rooms containing personal items, and rummage boxes filled with period items for reminiscing can enhance the living environment.

Activities offered in a care home play a significant role in promoting engagement and quality of life for residents. Meaningful daily activities empower individuals and enable them to make choices, from selecting their meals to participating in daily tasks like setting tables, folding laundry, or gardening. Group activities, from tea dances to exercise, should be available and tailored to what residents like. Organisations like the National Activity Providers Association (NAPA https://napa-activities.co.uk/) and projects like My Home Life (https://myhomelife.org.uk) promote quality of life and positive changes in care homes for older people. Enquire whether the care home uses resources from NAPA or My Home Life.

Involving family members and caregivers in the person with dementia's care is pivotal. A good care home should value your input and think of you as a partner in their care and support. If you feel that a care home is not involving you as much as you would like, do not hesitate to communicate your worries to the manager.

For more guidance on identifying a care home with specialist training in dementia care and to explore care options in your area, visit www.nottshelpyourself.org.uk, www.asklion.co.uk or www.carechoices.co.uk. These resources offer a wealth of information and the ability to search for care providers in your specific region.

Hospital Visits and Dementia: Ensuring Comfort and Support

Hospital visits, whether planned or unexpected, can be confusing/unsettling for people living with dementia. However, when a person with dementia requires hospital treatment, there are essential steps you can take to minimise stress and discomfort during the visit.

It's important to acknowledge that a hospital stay can trigger confusion and disorientation due to the unfamiliar environment. The person with dementia may not recognise their surroundings or understand why they are in the hospital. They might even insist that they don't need to be there, which can be emotionally challenging. In such moments, it is particularly crucial to make sure that the hospital staff are well-informed about their condition. Making sure that the staff know about your loved one's dementia diagnosis is vital since they might not have prior knowledge or specialised training in caring for people with dementia. Consequently, you may need to remain closely involved to ensure your loved one's needs and preferences are communicated effectively, creating a comfortable and secure environment.

If the hospital visit is planned, it's advisable to enquire whether the hospital has a designated dementia champion with whom you can discuss supporting the person with dementia. In cases where no dementia champion is available, arranging a meeting with the named nurse can be a valuable alternative. This nurse should be able to address your questions and work with you to ensure the person with dementia receives excellent care.

Read this article on The Nottingham University Hospital News webpage: Hospitals, healthcare, dementia and frailty
Nottingham University Hospitals Trust Dementia Strategy: "View here"

During any hospital visit, be sure to fully inform the medical staff about your loved one's dementia. If you've compiled a life story record, consider taking it with you. Or you can use Alzheimer's Society's "This is me" document (https://www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me) . If your documentation contains critical medical information such as advance decisions or specific health and care considerations, it's wise to take copies to include in their patient file. These documents can be useful tools for medical staff, providing background information about the person's life, which can lead to more effective communication.

Even during emergency hospital visits, you can provide the medical staff with valuable information. As the main caregiver, you are in a unique position to anticipate potential triggers or sources of distress for the person with dementia. Sharing this insight with the nursing staff can help them understand better the person's needs and preferences, especially if they become anxious. Offering help during mealtimes, when necessary, may also be greatly appreciated by hospital staff. Mealtimes can be hectic, and the staff may not always have the resources easily available to help people living with dementia. Also, making sure that the person stays hydrated is crucial, as some symptoms of dehydration can mimic dementia.

If possible, regular visits by you or a friend or relative can provide comfort for the person with dementia during their stay in hospital. This also enables you to monitor their wellbeing and offer extra support when

needed. Being in hospital can be challenging, and you may notice a decline in the person's condition. In such cases, advocating for flexible visiting times can be helpful, enabling you to provide ongoing support if the person is having difficulty settling.

John's Campaign advocates for the right of people with dementia to have their loved ones stay with them in the hospital for as long as necessary, akin to the rights granted to parents of sick children. They encourage caregivers to assert their need to be present with the person with dementia and explain their reasons clearly. It's crucial to emphasise that a caregiver plays a different role from that of a visitor. Many hospitals have policies allowing caregiver access outside regular visiting hours, and some even have Carer Passports, although these are not always prominently advertised. Identifying yourself as a caregiver, as well as your role as the person's child, partner, companion, or friend, can help ensure that your essential role in providing nurture and a connection to the outside world is recognised. Don't be easily discouraged; if you are willing and able to be there, insist on being present.

The campaign's website, www.johnscampaign.org.uk, provides a list of participating hospitals that support this cause.

Formal Care After Hospitalisation

When they leave the hospital, the person with dementia may need formal care services, or existing services may need modification or reinstatement to support their return to their regular environment. Sometimes, long stays in hospital are necessary if services need to be arranged before the person can leave safely. In such cases, you may need to explore alternative accommodation if returning home is not the best option for the person with dementia.

To ensure a smooth transition, it's advisable to consult with the hospital discharge team. They will assess your loved one's needs and work with various professionals, including social services staff, occupational therapists, and medical specialists. Working together in this way should result in the development of a care plan and the arrangement of the services needed. In cases where the person with dementia doesn't need formal care services, they may return home with a few weeks of support to help them regain independence. This phase of support is often referred to as reablement or intermediate care. Formal care and support can greatly improve the lives of people with dementia and their families. Understanding their specific needs and engaging the most appropriate services, can mean that people are able to receive tailored support to live well with dementia in the setting that best suits their circumstances.

End of Life planning

Compassionate End-of-Life Planning for People Living with Dementia.

Discussing end-of-life matters is undeniably challenging. The idea of a loved one's impending passing is often heart-wrenching, and broaching the subject can be emotionally taxing. However, open communication and positive planning can be instrumental in preparing for the progression of dementia symptoms, offering solace along the way. This can be achieved through discussions that involve sharing and understanding the wishes of the person with dementia.

Dementia is an inexorably progressive condition, and, sadly, there is no cure. It is classed as a terminal illness, a fact that some people may not realise or may find difficult to accept. Early diagnosis, followed by honest conversations and thoughtful planning, is paramount. Although these conversations may not be easy, they ultimately help the person with dementia feel assured that their preferences and worries about

death are acknowledged and will be honoured when the time comes. These discussions can alleviate anxiety and give family caregivers the confidence to make important decisions when the need arises, as they have openly addressed the wishes of the person with dementia.

Starting Conversations About End-of-Life Plans

People cope with end-of-life considerations in different ways, and there is no one-size-fits-all approach. When someone receives a dementia diagnosis, they might immediately want to organise their affairs, including making arrangements for their will and estate. On the other hand, some people may be hesitant to confront these matters at once. Everyone's response is unique. Nevertheless, it is essential not to postpone discussions about life and death.

Dementia can take away the ability to communicate, underscoring the importance of starting these conversations sooner rather than later. The discussions should include end-of-life considerations, although they may be difficult, and some people, including the person with dementia, family members, or friends, might not want to broach these topics. However, it is crucial to involve the person with dementia in these conversations while they can still express their wishes, always keeping in mind that plans may change over time.

It has been noted that one of the main fears about dying is the perceived loss of control. Enabling the person with dementia to express their preferences for care and support as their condition progresses towards the end of life, lets them regain a sense of control. People should be supported not only in living well with dementia but also in dying well. Adequate information is essential to facilitate this planning process.

The Alzheimer's Society has factsheets on end-of-life care for people with dementia. Selecting the right time and place to start these conversations is crucial. The person with dementia may raise the subject themselves, or you may feel the need to start discussions. It is advisable to avoid stressful situations and to be attuned to the person with dementia's willingness to talk about their future. There is no universally correct way to deal with the topic of dying and end-of-life matters, but several sensitive approaches can be considered:

- Find a suitable time to broach the subject.
- Start with a question, such as, "Do you think we should talk about...?" or "Have you thought about...?"
- Or start the conversation directly but reassure the person with dementia, saying, "I know this isn't easy to talk about..." or "We've never talked about this before, but..."
- Some people may prefer to begin by saying what they do not want, such as expressing a desire not to die in a hospital. This can open the door to a more comprehensive conversation.
- Encourage everyone involved to be completely honest about their feelings from the beginning, recognising that there may be moments of both laughter and tears. Do not shy away from either of these.
- If the person with dementia is uncomfortable discussing death with loved ones, suggest that they consider talking to someone else, such as a GP, nurse, or friend.
- Do not let the fear of saying the wrong thing stop you from starting these conversations.

Advance Care Planning

During the planning process, the person with dementia may want to create an advanced care plan. This document outlines their preferences for future care, including where they want to receive care, what treatments they may or may not want, where they want to die, and whether they want to be resuscitated.

Advance care planning involves discussions between the person with dementia, their family (if desired), and any caregivers and support providers. A document can be created and kept by the people helping the person with dementia, healthcare or social care professionals, family members, and appointed attorneys (for more information on powers of attorney, refer to page 37. Within this process, it is possible to establish specific legal arrangements, such as an advance decision.

An advance decision, also known as a "living will", enables people to refuse specific types of treatment in the future. This can be especially valuable if the person with dementia is no longer able to communicate their wishes. The document can carry legal weight, so it is crucial to ensure that it accurately reflects the person's wishes, is signed by them and by a witness, and is discussed with a healthcare professional. The person with dementia must have the mental capacity to make these decisions, underscoring the importance of addressing them sooner rather than later.

Approaching the End of Life

As dementia symptoms progress, people with dementia may develop other health conditions (see page 20 for more information on health conditions associated with dementia). It is essential to prepare for this possibility.

Also. it is crucial to acknowledge the concept of pre-bereavement, as well as bereavement. Many people experience anticipatory grief before a loved one's passing, and support can be invaluable in helping them cope. Feelings of bereavement and grief can be a part of the process throughout, and various support networks are available to help if needed.

Regardless of the setting where the person with dementia is receiving care—whether in their own home, a care home, hospice, or hospital—it is imperative that the caregivers have the necessary training to ensure the person's end of life is as comfortable as possible. A thorough understanding of the person's wishes can facilitate this and help prevent unnecessary hospital admissions. Most people would prefer not to die in a hospital, and, with proper planning, everyone involved in their care should work towards this goal.

Healthcare, care, and support providers should have their own policies for end-of-life care. Don't hesitate to ask healthcare professionals about their policies and training in this area. End of life should be approached with empathy, and while maintaining professionalism, care staff should also be sensitive and understanding of the situation and emotions involved.

You may be offered the support of an Admiral Nurse or a Marie Curie nurse as the person with dementia nears the end of their life. Admiral Nurses are specialised dementia nurses who provide practical and emotional support, not just at the end of life but throughout the journey. They can support the person living with dementia, you, and your wider family.

Marie Curie nurses make it possible for people to pass away comfortably at home, surrounded by loved ones and in the way they wish. You can arrange for a Marie Curie nurse through your GP or district nurse.

Palliative Care

Palliative care focuses on relieving pain and other symptoms experienced during serious illnesses. Its objective is to improve quality of life by increasing comfort, preserving dignity, and providing support for the person with dementia and their loved ones.

People with dementia often live for many years after their diagnosis, which is why it is recommended to establish palliative care plans well before the end-of-life stage is reached. Palliative care neither accelerates nor prolongs the person's death; instead, it maximises the quality of life, even in situations where time is limited. It regards dying as a natural process.

Palliative care can be delivered in various settings, including at home, in care homes, hospitals, and hospices. Hospices offer palliative care services either at home, in day-care centres, or hospice inpatient units. After receiving inpatient hospice care, most people return home as soon as their care and support needs are met. Nottinghamshire Hospice (nottshospice.org) is a registered charity founded in 1980 by a group of local people who believed that everyone has a right to expect care and a death which:

- respects and celebrates their life
- is dignified
- is in a place with the people they care for around them.

Dying with dignity

In the context of end-of-life care for people with dementia, it is of paramount importance to provide compassionate, respectful, and supportive treatment, regardless of the place chosen for their passing. Even when speaking becomes difficult, acknowledging their wishes is crucial. As previously mentioned, open discussions and proactive planning for the end of life can greatly contribute to understanding what their wishes are, ultimately improving their quality of life until the very end.

Coping with the loss of a loved one is undeniably challenging. However, knowing they are receiving comfort, care, and peace can give some comfort.

Ensuring a high quality of life for people with dementia is a main aim. What makes a good quality of life varies from person to person, but it usually means being free from pain and discomfort while at the same time addressing any social, medical, emotional, or spiritual needs. This may include being surrounded by familiar belongings, loved ones, pets, or soothing music. Some people may want a connection with the outside world, the sounds of nature, or the companionship of their faith leaders if they have religious beliefs. These preferences are highly individual, reinforcing the importance of comprehensive planning and understanding their unique likes, sources of happiness and comfort, as well as their specific end-of-life wishes.

It's essential to recognise that a person's needs and wishes can change as they approach the end of life. If this happens, and they no longer want the things discussed during the planning stages, or if their needs change so much that it is impossible to keep to their initial wishes, it is acceptable to adapt the care plan to fit in with this. Flexibility in care provision ensures that their changing needs and their comfort remain a top priority.

Dying with dignity is a fundamental right for everyone, including people living with dementia. By starting conversations early, creating advance care plans, and adhering to compassionate care principles, we can ensure that the end-of-life journey for people with dementia is marked by respect, comfort, and support.

Here are some links to useful resources:
Coping with the death of a person with dementia | Alzheimer's Society (alzheimers.org.uk)
Dementia and end-of-life planning - NHS (www.nhs.uk)

Organisations for End-of-Life Planning and Support

1. Dying Matters (www.hospiceuk.org)and NHS Websites (www.nhs.uk) : These websites serve as valuable starting points for individuals and families facing end-of-life decisions. They offer comprehensive information on various aspects of end-of-life planning, including legal matters, emotional support, and practical services.

2. Legal and Advance Decision Assistance: End-of-life planning often involves making important legal decisions, such as writing wills and advance decisions (often known as living wills). Many organisations can help individuals understand the legal aspects of end-of-life care, ensuring that the person's wishes are documented and legally binding.

3. Emotional Support and Grief Counselling: Coping with the emotional toll of caring for someone with dementia and facing the prospect of their death can be incredibly challenging. Different people experience grief and emotions differently. It's essential to recognise that grieving can begin long before a loved one's passing. Seeking counselling and support services, whether at the time of diagnosis, during caregiving, or after the person has passed away, can be profoundly beneficial.

Funeral planning

Funeral planning can be a challenging and emotional process, but it's an essential part of honouring a loved one's memory and providing closure for those left behind. Whether you're planning for a loved one or your own funeral, this short guide will help you navigate the steps.

1. Start with a Budget

Funerals can vary widely in cost, so it's crucial to establish a budget from the outset. Determine how much you are willing and able to spend on the funeral, including burial or cremation costs, memorial services, and related expenses.

2. Choose Burial or Cremation

Decide whether the deceased will be buried or cremated. This decision often depends on personal, cultural, or religious beliefs. Burial involves buying a plot, casket, and headstone, while cremation usually requires an urn for ashes. A direct cremation is a contemporary choice for people who do not want a funeral service bound in tradition. It offers a low-cost funeral that allows you to say a respectful farewell in a simple and fuss-free way. Direct Cremation is typically the least expensive option as it can avoid the need for additional costs incurred in a traditional funeral service such as embalming, viewing of the deceased, the funeral service and additional transportation for the family or close friends.

3. Select a Funeral Home

Research and select a reputable funeral home or director to help you with the arrangements. Consider factors such as location, services offered, and cost. Get quotes from several providers to ensure you are comfortable with your choice.

4. Plan the Funeral Service

Work with the funeral director to plan the funeral service or memorial. This includes choosing a date and time, selecting a venue, and deciding on the format of the service. You can choose a religious ceremony, a secular service, a celebration of life, or no service.

5. Inform Loved Ones
Inform family members, friends, and close acquaintances about the funeral arrangements. Send out invitations or announcements giving the date, time, and place of the service. You may consider using social media or an online memorial page to reach a wider audience.

6. Prepare a Eulogy or Tribute
Designate someone to deliver a eulogy or tribute during the service. This speech should celebrate the life, accomplishments, and character of the deceased. Encourage other people to share their memories as well.

7. Choose Funeral Music and Readings
Select appropriate music, hymns, or readings to be included in the service. These elements can help set the tone and give comfort to the people attending.

8. Arrange for Flowers and Decorations
If desired, arrange for floral arrangements and decorations that reflect the deceased's preferences or personality. Flowers can be placed at the venue or on the casket or urn.

9. Consider Transport
Determine the transport needs for the deceased and the people attending. This includes organising funeral processions, hiring vehicles, and ensuring everyone can reach the service location easily.

10. Arrange for Burial or Cremation
Coordinate with the chosen cemetery or crematorium to finalise arrangements. Ensure that all necessary permits and paperwork are in order. For burial, choose a suitable burial plot.

11. Prepare for Post-Funeral Gatherings
Many families choose to host gatherings after the funeral for further remembrance and support. Arrange for refreshments, a reception venue, or a private gathering at home.

12. Create a Memorial or Obituary
Compose an obituary providing details about the deceased's life, family, achievements, and funeral arrangements. Share it with local newspapers or online platforms.

13. Review Legal and Financial Matters
Take care of any legal and financial matters related to the deceased's estate, such as wills, estates, and insurance claims. Seek legal advice if necessary.

14. Consider Preplanning and Prepaying
If you are planning a funeral, consider planning arrangements in advance. This can alleviate stress on your loved ones and ensure that wishes are honoured. Pre-paying for a chosen funeral plan can help protect you from rising funeral costs.

15. Seek Emotional Support
Funeral planning can be emotionally taxing. Lean on friends and family for support and consider speaking with a grief counsellor or therapist if you need to.

Remember that funeral planning is a personal process, and there is no one-size-fits-all approach. Tailor the arrangements to reflect the wishes and values of the deceased and provide a meaningful and respectful farewell.

Here is a link to useful resources taken from Planning for your funeral (ageuk.org.uk):

Resources for Caregivers After Loss

1. Life After Caregiving: When your caregiving journey comes to an end, it's normal to feel uncertain about what comes next. Many caregivers put their personal lives on hold to provide care, and the transition back to a more typical routine can be challenging. There are many resources available to help you adjust to your new circumstances, both practically and emotionally.

2. Support for Grief: Grief is a highly individual experience, and it can manifest in different ways. It's important to remember that everyone copes with death and dying differently, and there's no one-size-fits-all approach to grieving. Some people may find comfort in support groups, where they can share their experiences and feelings with other people who have gone through similar situations.

3. Counselling and Therapy: Seeking professional counselling or therapy services can be extremely helpful during the grieving process. This support can be beneficial at any stage—whether it's before, during, or after the loss of a loved one. Trained counsellors can help individuals navigate their emotions, provide coping strategies, and offer a safe space to talk about their feelings.

4. Open Communication: It's essential to maintain open and honest communication with family members and friends during this challenging time. Encourage dialogue about your feelings and experiences and be receptive to the emotions of other people. Remember that everyone's grief journey is unique, and showing empathy and understanding can foster a sense of connection and support.

In conclusion, while facing the end of a person's life, especially when dealing with dementia, can be emotionally taxing, there are numerous resources and organisations available to help people and their families plan for this difficult time. Whether it's legal matters, emotional support, or practical services, seeking help can make the process easier to manage and provide comfort.

Legal and financial affairs

This guide emphasises the importance of planning in the context of dementia care, particularly in legal and financial matters.

Planning in Dementia Care

- Early Diagnosis: Ideally, dementia is diagnosed early, allowing for comprehensive planning involving family and professionals. Planning together while the person with dementia can take an active part in discussions is considered the best approach.

- Planning Mechanisms: Even if dementia symptoms have progressed, there are mechanisms to help in making decisions. These may involve managing finances, property, and wellbeing.

Understanding Mental Capacity

- Mental Capacity: Mental capacity refers to the ability to make decisions, understand information, retain it, weigh options, and communicate decisions. Dementia can impair these abilities, but capacity can fluctuate.

- Mental Capacity Act 2005: This Act protects people in England and Wales who may lack the capacity for specific decisions. It presumes capacity unless proven otherwise and assesses it on a decision-by-decision basis.

Managing Financial Affairs

- Power of Attorney: Before the person with dementia's capacity changes, consider setting up a power of attorney, enabling trusted people to look after their financial affairs. It can be a Lasting Power of Attorney, covering decisions about money and healthcare.

- Registration: Powers of attorney must be registered with the Office of the Public Guardian before they can be used. Make, register or end a lasting power of attorney: Overview - GOV.UK (www.gov.uk)

When Is It Too Late for a Power of Attorney?

- Capacity Requirement: To prepare a power of attorney, the person with dementia must have the capacity to do so. Even if their dementia has progressed, they may still have moments of capacity. Legal advice is crucial to ensure the document is completed correctly.

- Deputy: If capacity is lost entirely, you can apply to the Court of Protection to appoint a deputy. A deputy can look after the financial affairs of the person with dementia.

Making a Will

- Importance of a Will: A will outlines a person's wishes about their assets and possessions after their death. Without a will, the law dictates how assets are distributed.

- Testamentary Capacity: To make a new will or assess testamentary capacity, a GP's assessment may be needed. If capacity is lacking, an application for a 'statutory will' can be made to the Court of Protection.

- Seek Legal Advice: Writing a will is a legal process, and specialist legal advice is recommended.

Planning is essential in dementia care, covering legal and financial aspects, mental capacity, and the creation of wills and powers of attorney. Seeking professional advice is crucial to ensure the best interests of the person with dementia are upheld in these matters.

Finding further information, advice, and support

Local Web directories
Information and services all in one place. Search 'Dementia' to find local groups, support and care providers.
Tel: **0300 500 8080**
Web: www.nottshelpyourself.org.uk
Web: www.asklion.co.uk
Nottingham and Nottinghamshire Dementia Directories CLICK HERE

Dementia Wellbeing Service Nottingham and Nottinghamshire
Expert dementia advisors listen, answer questions, and offer support and guidance to anyone at any time prior to diagnosis and throughout the journey of those affected by dementia.
Tel: **0333 150 3456** (Monday to Friday 09:00-17:00)
Web: www.alzheimers.org.uk/support-services/
Email: DementiaSupportLine@alzheimers.org.uk

Age UK: Dementia support services in your area
Support through a free advice line and specialist advisers.
Tel: **0800 678 1602**. Lines are open 8am-7pm, 365 days a year.
Web: www.ageuk.org.uk/services/in-your-area/dementia-support/

Dementia UK: offer a range of information and support along with fundraising events and other volunteering opportunities.
Tel: Dementia Helpline **0800 888 6678**
Web: www.dementiauk.org

Radford Care Group
Daytime activities, day-care services in addition to dementia training and respite for carers.
Tel: **0115 978 6133**
Web: www.radfordcaregroup.org.uk

The Studio
For people with dementia and their carers, offering individualised dementia day care and activities.
Tel: **07543 534336**
Web: www.thebeestonstudio.uk

Connect – Community Based Help
A free, friendly, and solution focussed service, helping people to maintain their independence.
Tel: **01623 488 217**
Email: Connect@ageuknotts.org.uk
Web: www.ageuk.org.uk/notts/our-services

Our Dementia Choir

‘Our Dementia Choir’ began as part of a documentary created for BBC1 in 2018, it is based in Nottingham and is always open to new members.
Web: www.ourdementiachoir.com

NHS Website
Has lots of useful information and links
Web: Dementia, social services and the NHS - NHS (www.nhs.uk)

Alzheimer's Society:
Trained staff are ready to give you the support you need. Opening hours: Mon to Weds: 9am – 8pm, Thurs and Fri: 9am – 5pm, Sat and Sun: 10am – 4pm
Tel: **0333 150 3456**
Web: www.alzheimers.org.uk

Trent Dementia
A charity which aims to improve the quality of care, support and wellbeing of people who are living with dementia in the East Midlands. Free weekly craft activities online, regular craft workshops, day trips, monthly walking groups, monthly dementia drop-in, and annual events.
Tel: **0115 74 84220**
Web: www.trentdementia.org.uk
Email: contact@trentdementia.org.uk

Nottingham City Libraries
Web: www.nottinghamcitylibraries.co.uk

Inspire - Culture, Learning, Libraries (Nottinghamshire County)
Web: www.inspireculture.org.uk

Pegasus card scheme | Nottinghamshire Police
For people who find it hard to communicate with the police – your pre-registered information is stored safe on can be access quickly if you call us. You don't need to repeat all your details.
Web: www.nottinghamshire.police.uk/pegasus

Hidden Disabilities Sunflower
Simply by wearing the Sunflower lanyard or badge, you’re just letting everyone know that you might need extra help, understanding, or just more time.
Web: https://hdsunflower.com/

Dementia friends
An initiative to change people’s perceptions of dementia. It aims to transform the way the nation thinks, acts and talks about the condition.
Web: www.dementiafriends.org.uk

Nottinghamshire Carer’s information booklet
Do you look after someone? Online booklet offering information for carers.
Web: www.nottinghamshire.gov.uk/media/121169/carerbooklet.pdf

Useful organisations and websites

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.livingmadeeasy.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: https://bethbritton.com/or www.d4dementia.com

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 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 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 Helper

Free and impartial money advice, including benefits.
Tel: **0800 138 7777**
Web: www.moneyhelper.org.uk/en

Music for Dementia

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.musicfordementia.org.uk/about

National Activity Providers Association

Charity committed to improving quality of life, through person-centered activities, for older people. Tel: 0207 078 9375
Web: **www.napa-activities.com**

The National LGB&T Partnership

Reducing health inequalities and improving access to health and social care for LGB&T 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**

Wicking Dementia Research and Education Centre

The Wicking Dementia Research and Education Centre is at the forefront of translational research and support for issues confronting people with dementia and their carers. Access free online courses.
Web: **www.utas.edu.au/wicking**

For edits and updates to this guide: Please feel free to email **communityfriendly@nottscc.gov.uk**