



DEMENTIA GUIDE

Part 2 Growing needs

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.

Part 1: “Living Well with Dementia” can be found [HERE](#)



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Introduction

Welcome to part 2 of the Dementia Guide which covers information and advice regarding the growing needs associated with dementia.

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 Part 1 of the guide “Living Well with Dementia” and the Nottingham and Nottinghamshire Dementia Directories [CLICK HERE](#) or visit www.nottshelpyourself.org.uk

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. Further guidance can be found at www.nottinghamshire.gov.uk/care/adult-social-care/adult-social-care-hub/what-if-i-need-more-support or [Care and Support Needs \(nottinghamcity.gov.uk\)](http://www.nottinghamcity.gov.uk)

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](https://napa-activities.co.uk/) (NAPA <https://napa-activities.co.uk/>) and

projects like [My Home Life](https://myhomelife.org.uk) (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.

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](https://www.alzheimers.org.uk/get-support/publications-factsheets/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 41). 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 \(nottshospice.org\)](http://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 \(alzheimers.org.uk\)](https://www.alzheimers.org.uk)

[Dementia and end-of-life planning - NHS \(www.nhs.uk\)](https://www.nhs.uk)

Organisations for End-of-Life Planning and Support

1. [Dying Matters](http://www.hospiceuk.org) (www.hospiceuk.org) and [NHS Websites \(www.nhs.uk\)](https://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 \(ageuk.org.uk\)](https://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 \(www.gov.uk\)](https://www.gov.uk/government/guidance/make-register-or-end-a-lasting-power-of-attorney) A member of a Nottinghamshire Patient Participation Group compiled a useful information sheet which can be found here: <https://practice365.co.uk/uploads/sites/1461/2023/11/Lasting-Power-of-Attorney.pdf>

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](#)

[Nottinghamshire Carer's information booklet](#)

Do you look after someone? Online booklet offering information for carers.

Web: www.nottinghamshire.gov.uk/media/npld134m/carersbooklet.pdf

[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

[Carers Hub Service](#)

A free and confidential service that supports unpaid Carers living in Nottingham City or Nottinghamshire.

Tel: **0808 802 1777**

Web: <https://www.carersfederation.co.uk/>

[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: <https://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

Forget Me Notts (Trent Bridge Community Trust)

Free Sport and social sessions for people living with Dementia and their Carers. All on Tuesdays 10.30 - 12.00pm. Low-impact sporting activities, varied social activities, carer support and signposting and a cuppa.

Web: [The Trent Bridge Community Trust: Forget Me Notts](http://www.trentbridge.co.uk/trust/forget-me-notts) (www.trentbridge.co.uk/trust/forget-me-notts)

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.facebook.com/D4Dementia/

Care Choices

Assistance with finding care and support.

Searchable website.

Web: www.carechoices.co.uk

Care Confidence

An online tool to help you make decisions about paying for social care.

Web: www.careconfidence.org.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

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

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 LGBT&T Partnership

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

Tel: **0207 064 6506**

Web: [The National LGBT Partnership – Publications](http://www.consortium.lgbt/nationallgbtpartnership/publications/)

(www.consortium.lgbt/nationallgbtpartnership/publications/)

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 on tour'.

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@nottsc.gov.uk