

# **Dementia: a guide to local support and services**

Peterborough and surrounding areas



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## What is dementia?

As we get older, it's normal for memory to be affected by age, stress, tiredness, or certain illnesses and medications. This can be annoying if it happens occasionally, but if it's affecting your daily life, or is worrying you or someone you know, you should seek help from your GP, including a review of your medications, any supplements you take, your lifestyle, and your physical and mental health. It's important for your GP to find out if any of these are affecting your memory and treat them, or if it could be dementia.

Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of the brain and its abilities. This includes problems with:

- Memory loss
- Thinking speed
- Language and/or communication
- Understanding and judgement
- Changes in mood, personality and behaviour
- Movement
- Carrying out everyday tasks

We know that a diagnosis can affect the person getting the diagnosis and everyone around them, but it is important to get a diagnosis of dementia to ensure you all get the support you need moving forward. An early diagnosis can help people get the right treatment, support, and help for those close to them to prepare and plan for the future. Every situation is unique and how you feel may change over time as well. With treatment and support, many people can lead active, fulfilled lives.

You can find lot more information on

<https://www.nhs.uk/conditions/dementia/> and on

<https://www.alzheimers.org.uk/>

It's important to remember you're not alone, there is help for people affected by dementia and those that know them after receiving a diagnosis of dementia. Read on for more information and to find out where to get help.

## Caring for someone with dementia

Who is a “carer”? A carer is anyone who looks after a family member, partner or friend who needs help because of a physical or mental health problem and may not be able to cope without their support. The care they give is unpaid. It can be difficult for carers to see their caring role as separate from the relationship they have with the person for whom they care.

Caring for someone with dementia can be stressful and overwhelming. But there is a wide range of advice and support available locally, including:

- A range of carer support and resources via the Dementia Support Service
- Various support services through Peterborough City Council, such as:
  - An assessment of your needs as a carer
  - Information on Carers Allowance, which is a non-means tested benefit
  - Register for the Emergency Support for Carers Plan
  - Benefit eligibility information
- Other voluntary services or charities who are on hand to help

There may also be benefits the person with dementia is eligible for such as Attendance allowance and council tax reduction or even exemption if they live alone.

There’s no “one size fits all” when it comes to caring for someone with dementia and everyone needs different levels of support at different times, so it’s important to get advice and utilise the support available to you to help navigate this journey after someone gets a diagnosis.

For information and assistance about these services and more, contact the Dementia Team at the Dementia Resource Centre on **01733 865 710**

## The Dementia Support Service

The Peterborough Dementia Support Service has been commissioned by Peterborough City Council and is delivered by Alzheimer's Society.

Support is for both the person with dementia and their families/carers. The Dementia Team are a 'one-stop shop', offering information and practical guidance to help people understand dementia, cope with day-to-day challenges, and prepare for the future. They offer support face-to-face, over the phone or in writing.

The service is available Monday – Friday by phoning **01733 865 710**, or you can visit them at the Dementia Resource Centre, 5 York Road, Peterborough PE1 3BP. You can just pop in, no appointment is necessary, though you can arrange one if you prefer.

## Contacting the council for support

If you or the person you care for needs support, you can contact the council and ask for an assessment of their needs. You can do this by phoning **01733 747474**, option 4

The Customer Service Team will take your information and pass it to a social care professional for a decision. The council can also conduct a financial assessment to see whether you would be eligible for council-funded support. Often the first step that the council will take is to offer you a period of 'Reablement'.

You can also contact the council if you'd like a referral for an occupational health assessment, they can help with mobility aids and adaptations in your own home.

You may also be able to eligible for support from the council to provide periods of respite, such as "sitting services" or you can access this privately via care companies.

## Reablement

Reablement aims to give people with dementia the opportunity, motivation and confidence to re-learn or regain some of the skills they may have lost. It may also enable you to learn new skills that can help develop and maintain your independence. The reablement service provides intensive support for a maximum of six weeks and can help with a range of tasks, including:

- Personal care tasks such as washing and dressing
- Domestic skills such as food and drink preparation
- Encouraging you to be confident when moving around

Access to reablement services is through a discussion with a social care professional. If you still have ongoing care and support needs following the period of reablement, you may be eligible for care and support. If you need more info, please contact the council on **01733 747474**, option 4

## Emergency support for carers

As a carer you may worry about what would happen to the person you care for if you are involved in an emergency. The Peterborough Carers Wellbeing Service from Making Space is designed to help you think about who could support you in such circumstances.

We encourage you to speak to family, friends and neighbours to help you put the plan together, however if you would like support from one of the Carer Support Workers at Making Space this can be arranged. Making Space are commissioned by the council to provide this service for carers.

Once completed the plan can either be kept in a safe place at home or it can be returned to Making Space to store, and they can then provide support if you need to activate your plan. This support may include ringing emergency contacts on your behalf or helping to arrange small amounts of temporary professional care.

You can find more information and the plan on the Making Space website: <https://www.makingspace.co.uk/support-for-carers/peterborough-carers-wellbeing-service> or calling on **01480 211006**

## Planning ahead and making decisions

Living with dementia involves making a wide range of decisions. As someone's dementia progresses, their cognitive (mental) abilities will decline, which will affect their ability to make their own decisions. When this happens, carers, family members, and health and social care professionals need to become involved in the decision-making process.

There are steps that people with dementia can take to ensure that they have more control over decision-making in the future. Family members and others who may need to become involved should be made aware of things that have been put in place.

### Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

In a crisis, health professional may have to make rapid decisions about your treatment, and you may not be well enough to participate in making choices. The ReSPECT process helps you work with health professionals on a personalised plan so that you have your wishes on a range of situations in a form you can bring with you to hospital.

Find out more at [www.respectprocess.or.uk](http://www.respectprocess.or.uk) or contact your healthcare team.

### Lasting Power of Attorney (LPA)

You can choose someone (or more than one person) you trust to have the ability to make decisions on your behalf. You outline your wishes in a legal document.

There are two types of LPA, one relating to managing property and finances, and one relating to health and care decisions. Read more about it at:

<https://www.gov.uk/power-of-attorney>

### Advance Decision

You can also choose in advance the type of medical treatment you want to refuse in the future. This legal document ensures that your wishes are carried out at a later stage when you lack capacity to decide.

## Mental Capacity

The Mental Capacity Act 2005 is a law in England and Wales that explains how to decide whether someone can make decisions for themselves, and how to make decisions if they are not able to do so. It is assumed that every person has capacity unless it is proven otherwise. A Mental Capacity Assessment will be undertaken by a social care professional.

## Driving

If you have received a diagnosis of dementia and want to continue to drive, by law you must inform the Driver and Vehicle Licensing Agency (DVLA). You must also inform your car insurance company, or your policy may become invalid. You have an option to have a driving assessment; ask the Dementia Team for information **01733 865710**

## Herbert Protocol

The Herbert Protocol is a national scheme to help make sure that people living with dementia who are at risk of becoming lost can be found and brought home safely. Police forces and emergency services across England and Wales use the Herbert Protocol as a kind and proactive way to help when someone with dementia is reported missing. You can also get a wristband which is a safeguarding tool used by police forces across the UK to help reunite vulnerable people living with dementia with their families if they become lost.

Find out more by going to: <https://herbertprotocol.com/>

## Hidden Disability Sunflower

The Hidden Disabilities Sunflower is a simple tool for you to voluntarily share that you have a disability or condition that may not be immediately apparent and that you may need a helping hand, understanding, or more time in shops, at work, on transport, or in public spaces.

Find out more at: <https://hdsunflower.com/>

## More information

There's lots to think of when planning for the future, please reach out to your local dementia support team on **01733 865710** for support with this.

## Technology Enabled Care (TEC)

Technology enabled care is equipment and technology to help you stay independent. An example is having a 'lifeline' which is a call button worn as a pendant or on your wrist. There are lots of pieces of equipment that can help people with dementia stay safer at home. These include:

- Fall and motion detectors
- Automated prompts and reminders
- Automatic lights
- Automated shut-off devices for gas and cookers
- Clocks and calendars
- Medication aids
- Communication aids

And more. There are a good number of examples at the Dementia Resource Centre, where you can pop in to have a look. Or you can arrange a visit to Peterborough City Council's 'Smart Flat' to see how some of these operate by calling **01733 747474, option 4**

More information can also be found on the Alzheimer's Society website at <https://www.alzheimers.org.uk/get-support/living-with-dementia/using-technology-everyday-life>

## Activities and things to do during the day

There are lots of activities for people with dementia and their carers available in Peterborough. Below are some of the activities provided at the Dementia Resource Centre:

- Singing for the Brain®
- Peer support groups for people with dementia and for carers
- Young Onset Dementia Activity Group
- Arts and Crafts
- Carer Information and Support
- Help with digital devices
- Exercise groups
- Social gatherings and events

Find out their latest timetable by phoning **01733 865710**, emailing [Peterborough@Alzheimers.org.uk](mailto:Peterborough@Alzheimers.org.uk) or pop in to have a chat.

There are also Dementia Cafés held around the city by various groups regularly. Dementia Cafés provide information about living with dementia and local services in an informal and comfortable environment. They are places to relax, socialise, and meet other people with dementia and their carers.

There are also other dementia friendly groups in and around Peterborough, contact the Dementia Resource Centre to find out more and see the activity calendars.

# Hospital Services

When someone goes into hospital it can be worrying but when someone is living with dementia this worry can seem overwhelming. The below information will help you navigate this process:

## John's Campaign

John's Campaign is a UK-based initiative advocating for the right of family carers to support patients with dementia in hospitals and care homes. It promotes open visiting policies, allowing carers to be with loved ones outside of normal hours to provide support, reduce anxiety, and aid in decision-making. It encourages hospitals and care homes to sign up and welcome family members as partners in care, not just visitors.

Find out more: <https://johnscampaign.org.uk/>

## Carers passport

A Carer Passport is a record that identifies a carer in some way and sets out an offer of support, services or other benefits in response. A Carer Passport helps carers to be identified, recognised and supported as part of the day-to-day life of an organisation or community.

Carer Passports can:

- increase identification and support for carers
- raise awareness of caring
- provide a concrete, easily understandable offer of support or services
- make carers feel valued
- provide help/assistance to managers or key professionals
- provide a short-cut so carers don't have to repeatedly explain themselves
- help organisations benefit from carer involvement.

To find out more about these scheme or access support while in hospital, you can ask to speak to the dementia specialist nurses or the care advisers during yours or your loved ones stay, ask the ward staff for more information.

## Making a move to supported accommodation

Whilst every effort is made to support people to remain independent in their own homes through, in some case you or the person you care for are no longer able to cope at home. In these instances, you may want to consider moving to more appropriate accommodation. There are a number of options for you:

- Extra Care Housing/assisted living
- Residential and Nursing care homes

### Extra Care Housing

Extra Care Housing or 'Assisted Living' may be appropriate for people with dementia as it provides independence, while having care staff onsite 24 hours a day to respond to emergencies. Extra Care also allows for the changing needs of individuals to be quickly identified and supported. There are several Extra Care Housing schemes locally, and details can be found in the Peterborough guide to independent living. For some schemes you will need to be referred by Adult Social Care.

### Residential and Nursing Care

If you feel that you or the person you care for are no longer able to manage at home and would also not be sufficiently supported in extra care, you may want to consider residential or nursing care. Details of care homes in the area can be also found in the Peterborough guide to independent living.

Whichever option you choose, we recommend that you make some time to read the care provider's inspection reports on the Care Quality Commission's website [www.cqc.org.uk](http://www.cqc.org.uk) or you can speak to the Dementia Team.

### Peterborough Care and Support Directory

There is a comprehensive list of care options on the Peterborough council's information network by visiting <https://fis.peterborough.gov.uk/>

You can request a copy of the Peterborough guide to independent living by calling **01733 747474** and selecting option 4 or you can search online to download or order a copy to be sent in the post via [www.carechoices.co.uk](http://www.carechoices.co.uk)

## Who pays for social care?

Many people with dementia will need care and support as their condition progresses. The types of care put in place will be different for everyone, according to their individual needs.

To work out what a person's needs are, it can be helpful to get a care needs assessment from the local authority. This will show whether the person has 'eligible care needs'. If they do, the local authority will then talk to the person and their carer (if appropriate) to produce a care and support plan.

Once a support plan has been made, the local authority will decide who will pay for the care and support provided. The rules about paying for care in England are set by the Care Act 2014. The decision will usually depend on:

- the financial assessment of the person's capital and income
- the type of care and support that the person needs – this could be homecare, replacement care or permanent residential care
- where they live (market rates can vary)
- what care and support is available

Some people will pay for all of their care costs, this is called being a 'self-funder'. Most people will pay part of their care costs, with their contribution decided by the financial assessment. Sometimes, the person's care will be fully-funded by the local authority or the NHS.

The local authority may charge you for care and support services, and for arranging them, but some types of care and support must be free of charge such as aids and minor adaptations to the home, intermediate care or reablement following a stay in hospital.

A person with dementia can ask for a financial assessment even if they think they may pay for their own care, it may still be helpful to them.

This is a complex subject, so if you would like more information on who pays for care, please contact your dementia support team on **01733 865710** or by calling the council on **01733 747474** and choosing option 4 for adult social care.

## Research Opportunities

Dementia research aims to improve our understanding of dementia diagnosis, treatment, and care. It helps researchers answer the most important questions about the disease. Many people find that taking part in a clinical research study is an interesting and rewarding experience. Some of the reasons people have shared with us include:

- To help make a difference in the future
- Accessing new devices or therapies that might improve symptoms
- Access to information, tests and support that may not otherwise be available
- To learn more about their condition and its treatment
- Having a sense of purpose and control

Find out more and read stories from people who have taken part in research on <https://www.alzheimers.org.uk/what-we-do/our-research/take-part-dementia-research>

Locally, we have a fantastic and dedicated research team who are keen on talking to anyone who is interested in being part of research.

Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) is a top research active NHS trust with bases to visit at Fulbourn Hospital and the Cavell Centre in Peterborough. The specialist CPFT Research team works with global, national and local partners to conduct high quality, groundbreaking research into mental and physical health, and support innovation to improve care services. Our research translates the latest scientific discoveries and evidence into NHS care at CPFT. Every year we run studies with thousands of participants to learn more about conditions and find new therapies and treatments that work for different people, and we also offer opportunities for people to shape research with your views and experiences.

Find out more by contacting CPFT Research: 01223 219753 or emailing: [RandD@cpft.nhs.uk](mailto:RandD@cpft.nhs.uk)

Learn more at: <https://www.cpft.nhs.uk/research/>

Take part in research with CPFT: <https://bepartofresearch.nihr.ac.uk/>

# Checklist

Use this checklist to help you keep track of arrangements and make any further notes in one place:

- Attendance Allowance / PiP
- Carers Allowance
- Council tax reduction/exemption
- Pension Credit (if applicable)
- Blue Badge
- If you work, inform your employer of dementia diagnosis
- Book a hearing and eye test if these are due
- Lasting Power of Attorney
- Wills done
- Emergency support plan
- Spoken to your local dementia team
- Informed DVLA and vehicle insurer of dementia diagnosis
- Arrange for carers assessment and needs assessment from adult social care

## Notes

## It's okay to ask for help

Dementia can be overwhelming; whether you're worried about someone's memory, a recent diagnosis, or caring for someone, you don't need to face it alone. We know it can be difficult to ask for help, but so many people say that they wish they'd asked for it sooner.

So if you need advice, or even just a listening ear, please don't hesitate to give the dementia support team a call on **01733 865710** or email us at [Peterborough@Alzheimers.org.uk](mailto:Peterborough@Alzheimers.org.uk)

Should we be unavailable, you can reach the national dementia support line on **0333 150 3456**

### National Dementia Support Line opening hours:

Monday to Wednesday 9am – 8pm

Thursday and Friday 9am – 5pm

Saturday and Sunday 10am – 4pm

This information booklet has been brought to you by your local Peterborough dementia support team. All information is correct at time of printing but may be subject to change.



It will take a society to beat dementia