

# Dementia

## Information Handbook

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# Introduction



Getting a diagnosis of dementia can come as a shock and can take time for you and your family to process. Even if you were expecting it, you may still have lots of questions and need to know where to get help and support.

This booklet has been developed as a guide to help you to find information on practical steps you may need to take, how to find out more about dementia and details of local services and support.

**Although some of the information may not be relevant to you now, it is worth checking the Practical Steps section on the following four pages, for things you may need to do sooner rather than later.**

# Practical Steps

## Lasting Power of Attorney

**Lasting Power of Attorney (LPA)** is a legal document that lets you appoint someone you trust as an 'attorney' to make decisions on your behalf. These documents should be completed and registered whilst you have capacity (are still mentally capable).

**There are two types of LPA:**

**Property and Financial Affairs LPA** - this relates to decisions about financial matters.

**Health & Welfare LPA** – relating to decisions affecting health or personal welfare.

You must register your LPA with the Office of the Public Guardian if your document is to have a legal standing.

**For more information contact The Office of the Public Guardian  
0300 456 0300 or visit their website**

[www.gov.uk/government/organisations/office-of-the-public-guardian](http://www.gov.uk/government/organisations/office-of-the-public-guardian)

**Alzheimer's Society provide a LPA digital assistance service** offering telephone support to help people create and register LPAs. The service is for people with dementia and carers who do not have access to the internet or find completing forms online difficult. **Contact 0333 150 3456**

**Please note:** An Ordinary Power of Attorney (OPA) sometimes known as General Power of Attorney (GPA) gives someone temporary powers to deal with your financial affairs but it can't be used for people who have lost capacity to make their own decisions. **It is therefore not suitable for future planning for people with dementia.**

## Future Care Planning

There are different ways to plan ahead for your care and treatment, such as:

**Advance Decision** (sometimes known as a living will) is a decision you can make now to refuse a specific type of treatment at some time in the future. The treatments you're deciding to refuse must all be named in the advance decision. If you are refusing life-sustaining treatment your advance decision must be written down, signed by you when you have capacity and signed by a witness. You should make healthcare professionals, those close to you and your GP aware of your advance decision.

**Advance Statement** gives you an opportunity to think and talk about, and write down your preferences and priorities for your future care, including how you want to receive your care towards the end of your life. If it is important to you, then record it, no matter how insignificant it may appear. An advance statement is not legally binding, but if decisions are made about you in the future, your wishes should be considered.

**ReSPECT** stands for Recommended Summary Plan for Emergency Care and Treatment. In a crisis, health professionals may have to make rapid decisions about your treatment, and you may not be well enough to participate in making choices. The ReSPECT process empowers you to guide the health professionals on what treatments you would or would not want to be considered for. It can also record the things that are most important to you and that should be prioritised, as well as treatments that would not work for you. For further information visit: [www.respectprocess.org.uk](http://www.respectprocess.org.uk) or ask your healthcare professional for a leaflet.

For further information about planning for the future including how to make an advance decision or advance statement, request a copy of the Planning Ahead booklet from the Alzheimer's Society on **0333 150 3456** or visit [www.alzheimers.org.uk/get-support/publications-and-factsheets/living-with-dementia-planning-ahead](http://www.alzheimers.org.uk/get-support/publications-and-factsheets/living-with-dementia-planning-ahead)

## Working

If you are still working when you get a diagnosis of dementia you may want to continue to do so for as long as you can. Although you may feel reluctant to do so it is a good idea to talk to your employer. People living with dementia are protected from discrimination under The Equality Act 2010 in England, Scotland and Wales. The act requires employers to make 'reasonable adjustments' in the workplace to help you do your job. This could mean introducing flexible working hours, for example, or moving your working area somewhere quieter. Giving up work can have both financial and emotional implications so it is important to seek advice and support before making any decisions. The Alzheimer's Society has a useful publication in its Living with Dementia series here at [www.alzheimers.org.uk/get-support/publications-and-factsheets/living-dementia-employment](http://www.alzheimers.org.uk/get-support/publications-and-factsheets/living-dementia-employment) or call **0333 150 3456** to request a copy. A government funded website can also help with information and advice Work | Help with work-related issues | MoneyHelper here at [www.moneyhelper.org.uk/en/work](http://www.moneyhelper.org.uk/en/work), and your local Citizens Advice Bureau.



## Financial help – Welfare Benefits

Getting a diagnosis of dementia does not automatically entitle you to disability benefits as these are based on the help that you need to manage everyday tasks and to stay safe. Listed below are the main disability benefits that can be claimed. If you think you may be eligible then contact your Dementia Adviser or Managing Memory Together for further advice.

**Personal Independence Payment (PIP)** is for people aged **under 65** who need help with personal care and have problems getting around may be able to claim. To claim call the PIP claim line **0800 917 2222** Text phone: **0800 917 7777**. PIP has replaced Disability Living Allowance (DLA)

**Attendance Allowance (AA)** is for people **aged 65 and over** whose illness or disability means that they need help to manage everyday activities including personal care (can claim). To request a form call **0800 731 0122**. The forms can also be downloaded from [www.gov.uk](http://www.gov.uk)

***Claims for PIP and AA are not affected by the amount of savings or income you have. Awards are based on the help the person with dementia needs to live independently.***

**Council Tax Discount:** People with a diagnosis of dementia may be entitled to full Council Tax Discount if they live alone or a 25% reduction if another adult lives with them. To qualify the person with dementia must be in receipt of certain disability benefits and a doctor must agree that they are 'severely mentally impaired'. To claim request a form from your local council. The discount category that dementia comes under is severe mental impairment.

**Carers Allowance** is paid to carers who are looking after someone for 35 hours a week or more who are in receipt of a qualifying disability benefit. There is strict eligibility criteria and in some circumstances if other benefits are in payment carers allowance may not be payable.

**You may be eligible for other benefits.** Rules for claiming welfare benefits are complicated. Further information is available at [www.gov.uk](http://www.gov.uk) and Citizens Advice Bureau [www.citizensadvice.org.uk/benefits](http://www.citizensadvice.org.uk/benefits) You can also contact Managing Memory Together **0800 694 8800** for advice and signposting.

## Dementia and Driving

A diagnosis of dementia does not automatically exclude you from driving; however, there is a legal obligation to inform the Driver and Vehicle Licensing Agency (DVLA) of the diagnosis. You should also inform your car insurance company.

The DVLA will ask you to complete a questionnaire and with your permission will contact medical professionals involved in your care. They may also ask you to complete a driving assessment at a DVLA driving assessment centre.

You can arrange an independent assessment of your driving performance and safety whilst you still hold a licence to drive. There is a charge for this service. People can self-refer or be referred by a healthcare professional. See [www.drivingmobility.org.uk/our-services/driving-assessments](http://www.drivingmobility.org.uk/our-services/driving-assessments) for details. For information on costs please contact your nearest Mobility Centre [www.drivingmobility.org.uk/find-a-centre](http://www.drivingmobility.org.uk/find-a-centre) if you wish to speak with someone call **0800 559 3636**, however this number is not always manned so you may need to leave a message and they will return your call.

If you do not want to carry on driving you should return your driving licence to the **DVLA, Swansea SA99 1TU**. Call **0300 790 6806**.

**Call Managing Memory Together 0800 694 8800 for a copy of our leaflet 'Memory problems, dementia and driving'.**

If you are no longer driving, but need help with transport, it may be worth contacting **Community Connexions** for details of transport options in Gloucestershire. Call **0345 680 5029** or email [info@communityconnexions.org.uk](mailto:info@communityconnexions.org.uk) or visit [www.communityconnexions.org.uk](http://www.communityconnexions.org.uk)

**Blue Badges** are usually issued for people, who are registered blind, severely sight impaired or who have severe mobility issues problems. This has now been extended to include people with hidden disabilities such as dementia. If you have a non-visible (hidden) condition, you will be asked how journeys between your vehicle and destination are affected by your condition (The badge can be used in any car that the badge holder is travelling in).

To request an application form call the Blue Badge Team **01242 532302** or Email [bluebadge@gloucestershire.gov.uk](mailto:bluebadge@gloucestershire.gov.uk) or visit [www.gloucestershire.gov.uk/health-and-social-care/disabilities/apply-for-a-blue-badge](http://www.gloucestershire.gov.uk/health-and-social-care/disabilities/apply-for-a-blue-badge). The Alzheimer's Society have some useful guidance that is worth reading before making your application [www.alzheimers.org.uk/blog/how-apply-blue-badge-person-dementia](http://www.alzheimers.org.uk/blog/how-apply-blue-badge-person-dementia)

## Checklist

- ☐ **Lasting Power of Attorney applied for/in place**
  - ☐ Property and Financial Affairs LPA
  - ☐ Health & Welfare LPA
- ☐ **Advanced Statement**
- ☐ **Advanced Decision**
- ☐ **ReSPECT**
- ☐ **Work:** Informed employer about diagnosis (if applicable)
- ☐ **Welfare Benefits applied for** (if applicable)
- ☐ **Driving:** Informed the DVLA
- ☐ **Blue Badge applied for** (if applicable)





# Living well with Dementia

A diagnosis of dementia does not mean that life is over. Living one day at a time, staying healthy, doing the things you enjoy and finding ways to maintain independence can all help you to live as well as possible with dementia.

## Staying Healthy

**Try to maintain a healthy diet and exercise as often as you feel able**

- Rest when you are tired
- Take medications as prescribed
- Stay connected to family and friends
- Ask for help when you need it

Contact Dementia UK to request their Staying healthy leaflet on **0800 8686678** or download from their website [www.dementiauk.org/get-support/diagnosis-and-next-steps/staying-healthy](http://www.dementiauk.org/get-support/diagnosis-and-next-steps/staying-healthy)

## Hobbies

If you have hobbies such as cooking, gardening, fishing or sports, continue making them a part of your routine.

## Living in the moment

Remember to take pleasure in living in the moment, appreciating the small joys of life, such as seeing flowers coming into bloom, watching birds at a feeder and listening to your favourite music. Capture these moments and enjoy them.

## Reminiscing

Consider starting a life history book. Use a simple scrapbook or photo album to record details of your past and present life that will be helpful for anyone who may be supporting you. Your friends and family can help you, which is also a great opportunity to share your history, memories and thoughts with those close to you.

**Local Support and Activity Groups provide an opportunity for people with dementia and their carers to meet and socialise with others. This may be a local walking group, a memory café or club, or maybe an art or singing group.**

For details of local services visit [www.yourcirlce.org.uk](http://www.yourcirlce.org.uk) Call Managing Memory Together **0800 694 880** or contact your Dementia Adviser on **01452 525222**

Everyone deals with the challenges of dementia in their own way. See Age UK's document Living Well with Dementia that provides some ideas that have helped others living with dementia. [www.ageuk.org.uk/information-advice/health-wellbeing/conditions-illnesses/dementia/living-well-with-dementia](http://www.ageuk.org.uk/information-advice/health-wellbeing/conditions-illnesses/dementia/living-well-with-dementia) Call Age UK to request a copy **01452 422660**

**Living with Dementia Toolkit** is an online set of resources based on research and expert experiences of people with dementia and their carers. [www.livingwithdementiatoolkit.org.uk](http://www.livingwithdementiatoolkit.org.uk)





# Learning More About Dementia

**The dementia guide:** Living well after your diagnosis | Alzheimer's Society  
[www.alzheimers.org.uk/publications-about-dementia/the-dementia-guide](http://www.alzheimers.org.uk/publications-about-dementia/the-dementia-guide)

Order online or request a copy from Managing Memory Together or your Dementia Adviser.

## Dementia information emails

Sign up to the NHS website Dementia Information Service, which can help guide you through the often-difficult time after a dementia diagnosis.

You'll receive a weekly email for 6 weeks, each one covering a different need-to-know topic. Find out more about the [www.nhs.uk/conditions/dementia/dementia-information-service](http://www.nhs.uk/conditions/dementia/dementia-information-service)

## Managing Memory Together Information sessions

There are online and face-to-face sessions for people at early stage dementia and carers of people with dementia. They can help you to find out more about dementia and enable you to meet others who also have the condition. For more information see page 27.

## Reading Well Books on Prescription

Recommends books about dementia that you might find helpful. These are available in all Gloucestershire Libraries.

## Telling Children and Young People

If you have children or grandchildren, it is a good idea to tell them about your dementia. Visit [www.youngdementiauk.org/telling-children](http://www.youngdementiauk.org/telling-children), or request information from Managing Memory Together.

## Gloucestershire Dementia Videos in English, Polish, Cantonese and Gujarati

Four short films made in Gloucestershire provide information about the signs and symptoms of dementia and addresses the stigma and misunderstanding about dementia. Each film also directs people to local help and support services. To view visit [www.ghc.nhs.uk/conditions/memory](http://www.ghc.nhs.uk/conditions/memory)

People from ethnic communities can also contact Managing Memory Together to access details of culturally appropriate information, groups and services in the county. Call **0800 694 8800** or email [managingmemory@ghc.nhs.uk](mailto:managingmemory@ghc.nhs.uk)

Dementia publications in other languages can be found on the Alzheimer's Society website [www.alzheimers.org.uk/get-support/publications-and-factsheets/publications-other-languages](http://www.alzheimers.org.uk/get-support/publications-and-factsheets/publications-other-languages)

# Staying Safe

## At Home

Request a **FREE Home Safety Check** from **Gloucestershire Fire and Rescue Service** to ensure that your household is as safe as possible from the dangers of fire and to get smoke alarms installed or checked. They can also provide specialist equipment e.g. hearing impaired alarms and linked alarms for people with memory issues. Call **0800 180 4140** Email: [home.safety@glosfire.gov.uk](mailto:home.safety@glosfire.gov.uk) or visit [www.glosfire.gov.uk](http://www.glosfire.gov.uk)

Pendant alarm is a button worn around the neck or wrist that can be pressed to call for assistance. A Community Alarm provider may be able to cover this need. To check suitability and for details of the provider in your locality call Managing Memory Together **0800 694 8800** or search for '**Alarm Service**' at [www.yourcircle@gloucestershire.gov.uk](http://www.yourcircle@gloucestershire.gov.uk)

## Medication

Ask your doctor's surgery or pharmacy about repeat prescription and collection services. Pharmacies can advise you about dosette boxes. These can help people to remember to take tablets at the right time.

Electronic medication reminders can also help – call Managing Memory Together for advice or visit [www.gloucestershire.gov.uk/telecare](http://www.gloucestershire.gov.uk/telecare)

**Lions Message in a Bottle** is a simple and effective way to keep your basic personal and medical details where they can be found in an emergency - in the fridge. You can get a free bottle from Managing Memory Together **0800 694 8800**, or your local health centre, doctor's surgery or pharmacy.

**Keysafes** are useful to have fitted in case you lock yourself out or lose your key and/or need to allow access to care workers. They are available to purchase from most DIY stores and locksmiths.



## When out and About

**The Herbert Protocol** is a form which is kept at home, or in a safe place, with important information about a vulnerable person. Should the person go missing, information is on hand about their routines, medical requirements and favourite places. This can easily be handed over to the police without the worry of collating it together during a stressful time. Visit [www.gloucestershire.police.uk](http://www.gloucestershire.police.uk) or call **101** or **01452 726 920**

**Helpcards** are credit card size and printed with either 'I have memory problems', or 'I have Alzheimer's disease' or 'I have dementia'. You add your personal details and contacts. Carrying a card can help if you get confused and need help when you are out on your own. For more details and how to get a Helpcard, call the Alzheimer's Society **01452 525222** or visit [www.alzheimers.org.uk/get-support/publications-and-factsheets/helpcards](http://www.alzheimers.org.uk/get-support/publications-and-factsheets/helpcards)

**Telecare – Help Me Home** is a wrist bracelet engraved with a unique ID number. The bracelet also has the telephone number for the monitoring centre that holds contact details of family members or friends who can respond. They can then be contacted if the wearer becomes lost or needs help when out an about. Call Adult Helpdesk **01452 426868**.

## Scams

"Age UK Gloucestershire is aware Scams are becoming increasingly common and many people are easily caught out. This is an area of concern for many older people and those living with dementia. If you are concerned about a potential scam or want advice on how to avoid becoming a victim of a scammer you can call the Age UK Gloucestershire Help Team **01452 422660** or [Helpteam@ageukgloucestershire.org.uk](mailto:Helpteam@ageukgloucestershire.org.uk). The Help Team will be happy to talk through any concerns and offer guidance on who to report things to; they can also send you a free Age UK booklet "Avoiding Scams" and a leaflet and sticker for your door to help you remember what to do to avoid becoming a victim of a doorstep scam."

**"Age UK Gloucestershire is aware Scams are becoming increasingly common and many people are easily caught out"**

**Avoid becoming a victim!**



# Dementia Support in Gloucestershire

## Managing Memory Together

Managing Memory Together is a service provided by Gloucestershire Health and Care NHS Foundation Trust. As well as a Memory Assessment Service they also have an Information and Education Service and a Community Dementia Practitioner Service.

**A Community Dementia Practitioner (CDP)** is a professional who is experienced in working with people with dementia and their families. If difficulties arise in managing the condition a CDP can arrange to meet with you to assess the situation and to develop a plan with you to address issues and any immediate care needs. A CDP also provides support to GP practices in the diagnosis, management and treatment of dementia. Part of the CDP role is to provide annual reviews of dementia medications. You can be referred to the service by your GP or you can access the service by contacting Managing Memory Together.

**The Information and Education Service** is for people worried about memory, people with dementia and family members/carers of people with dementia. The service also offers information sessions for people with dementia and carers. For all Managing Memory Together services call **0800 694 8800** or email [managingmemory@ghc.nhs.uk](mailto:managingmemory@ghc.nhs.uk)

## Young Onset Dementia

Dementia is considered 'young onset' when it affects people under 65 years of age. It is also referred to as 'early onset' or 'working age' dementia. As well as the other services listed in this document that people can access, people with Young Onset Dementia may also be able to access support from the **Specialist Young Onset Dementia Nurse** who works within the Managing Memory Together service. Call **0800 694 8800**.

**Gloucestershire Carers Hub** and Managing Memory Together host a monthly online support group for people who are caring for a family member or friend with Young Onset Dementia. Contact Managing Memory Together for details.



**Alzheimer's Society 01452 525222** has a Young Onset Dementia Activity (YODA) group that meets monthly.

**Young Dementia UK** is a national information and support charity focusing specifically on young-onset dementia. Created with and for younger people, families, friends and supporters. Call **01993 776295** or email [mail@youngdementiauk.org](mailto:mail@youngdementiauk.org) or visit [www.youngdementiauk.org](http://www.youngdementiauk.org)

## Dementia Adviser Service – Alzheimer's Society

This service provides support for people with dementia and their carers to help them maintain independence, improve their sense of well-being, and put people more in control of their life. They can also help you to access appropriate services. This service can be provided through one to one support, home visits or as appropriate. For more information call Alzheimer's Society **01452 525222** or visit [gloucestershire@alzheimers.org.uk](mailto:gloucestershire@alzheimers.org.uk)

## Acute Hospital Inpatient Support – Admiral Nurse

If any support is required during a hospital admission to Gloucestershire Royal Hospital or Cheltenham General please call Asma Pandor on **07492 999224** or email [Asma.Pandor@nhs.net](mailto:Asma.Pandor@nhs.net)



# Health Research

Dementia research is important. It can help people living with the condition now, as well as helping to prevent people from developing dementia in the future. If you want to register your interest in finding out about local and national research please call **Gloucestershire Health and Care NHS Foundation Trust Research Department** 01242 634490 or email [research@ghc.nhs.uk](mailto:research@ghc.nhs.uk)



# Getting Extra Help

The following information may be helpful to you if you need practical help or support with personal care, nutrition, mobility or safety.

It is advisable to discuss your situation and to get advice either from your Dementia Adviser, Managing Memory Together or from one of the agencies listed towards the end of the information sheet, prior to arranging services yourself.

It may also help to contact **The Care Advice Line (TCAL)** which is a free information and advice service for adults with current or future care and support needs, and their carers and families. It can help you to make informed decisions about how you pay for care and support and the impact this will have on your finances.

Call **01452 222200** or email [enquiries@thecareadvice.org](mailto:enquiries@thecareadvice.org)

## Help at Home from a Paid Carer

You can organise and purchase services yourself

**Your Circle** [www.yourcircle.org.uk](http://www.yourcircle.org.uk) website enables you to search for home care (domiciliary care) agencies in your area. The Gloucestershire Care and Support Guide gives guidance on choosing and paying for care and support as well as lists of agencies. Call Managing Memory Together **0800 694 8800** or Gloucestershire County Council Adult Helpdesk **01452 426868** to request a copy.

To request a care needs assessment call the Adult Helpdesk **01452 426868** or email your enquiry to [socialcare.enq@gloucestershire.gov.uk](mailto:socialcare.enq@gloucestershire.gov.uk). An assessment is an opportunity to have a conversation with a trained assessor about the things that matter most to you and find out what will improve your wellbeing now and in the future. The way that the council works out if you are eligible for means-tested support is by completing a care needs assessment and a financial assessment.

As a general rule if you have savings **over £23,250** (not including the property you live in) you will be expected to pay for care yourself. If you have less than this you may get some financial help to fund the care you are assessed as needing.







**Help with Meals** options include, ready meals delivered from your local supermarket, hot, chilled and frozen meals to order from a range of Gloucestershire providers, or hot meals at lunch clubs. In some circumstances, the council may arrange subsidised community meals for you. For more information call Managing Memory Together **0800 694 8800** or visit [www.yourcircle.org.uk](http://www.yourcircle.org.uk) and search for Community Meals and select the information tab.

**Telecare** equipment uses sensors in the home to monitor potential accidents and emergencies. (e.g. falling, flood, fire etc.) There are activity monitors which can allow a carer to check if the cared for person visits the bathroom or kitchen or if they wander from home. For more information visit [www.gloucestershire.gov.uk/telecare](http://www.gloucestershire.gov.uk/telecare) where you can complete an online assessment tool. You can also call the Adult Helpdesk on **01452 426868**.

If you would like to request an **occupational therapy assessment** call **01452 426868**. Where people meet the criteria for help, home mobility aids and equipment can be provided free of charge.

## NHS Continuing Healthcare (CHC)

Some people with long-term complex health needs qualify for free social care arranged and funded solely by the NHS. NHS continuing healthcare can be provided in a variety of settings outside hospital, such as in your own home or in a care home. Your eligibility for NHS continuing healthcare depends on the person's assessed needs, and not on any particular diagnosis or condition. The process involved in NHS continuing healthcare assessments can be complex. An organisation called Beacon gives free independent advice on NHS continuing healthcare.

Visit [www.beaconchc.co.uk](http://www.beaconchc.co.uk) or call the free helpline **0345 548 0300**. You can also talk to your healthcare professional or the team in Gloucestershire if you think you may be eligible. Continuing Healthcare, NHS Gloucestershire, CCG call **0300 421 0302** or email [GLCCG.CHC-SPA-Team@nhs.net](mailto:GLCCG.CHC-SPA-Team@nhs.net)

# Support for Carers of People with Dementia

The term carer in this document refers to people who provide unpaid support to someone with dementia who could not cope without their help.

## Gloucestershire Carers Hub (managed by Peopleplus)

Provides information advice and guidance for carers, including advice on benefits, access to carer support groups, carer training and activity sessions, carers assessment and support planning, carers counselling service and a peer mentoring service. Carers can sign up to receive e-newsletters and are invited to training events and trips.

They also manage the following services:

### Carers Emergency Scheme

This scheme is free and offers you peace of mind, about what would happen to the person you look after, if you were taken ill or caught in some kind of emergency.

The scheme operates at two levels:

**Level 1:** The carer is asked to nominate two contacts who would be willing to respond in an emergency. These details are passed to a 24hr helpline.

**Level 2:** Carers looking after someone with high care needs have the additional option of having a support worker supplied in an emergency by a CQC Registered Care Agency to take over their caring role for up to 48 hours (72 over a bank holiday). The care is provided free of charge.

### Carers Assessments

Any carer who appears to have a need for support must be offered an assessment. A carer's assessment will explore what help and support you might need to continue looking after the person you care for. It is not an assessment of how well you carry out the caring role. An assessment will usually start with an initial telephone conversation with Gloucestershire Carers Hub.

## Skills and Development Training

Gloucestershire Carers Hub offers a variety of training courses to match your needs as a carer. Topics include five ways to wellbeing, managing stress, staying safe, dealing with continence issues and condition specific sessions. They also offer craft workshops and pamper sessions. The provision is designed to support you in your caring role. They also offer online sessions.

## Carer Break Services

A number of services provide home based short breaks or outdoor activities for the cared for person. This can help relieve stress for carers and give them some time to themselves. Sometimes these breaks can be free if a carer's assessment has identified the need for one under the Care Act (2014). It is a good idea to ask for help at an early stage as agencies and services often have waiting lists. To request a Carers Assessment please call Gloucestershire Carers Hub **0300 111 9000**.

Private home care agencies will provide carer break / befriending / respite and help with personal care, overnight care and 24 hour care in the home. Please see the Gloucestershire Care and Support Guide available from the Adult Helpdesk. Call **01452 426868** for more details. You can also search for agencies that operate in Gloucestershire online at [www.yourcircle.org.uk](http://www.yourcircle.org.uk).

As well as support at home, attendance at a day care facility can benefit the person with dementia, enabling the carer to have a break.

## GP Carers Register

Ask to be placed on the Carers Register at your GP surgery. The services offered by GP surgeries to carers vary from surgery to surgery. Find out how your surgery can support you. At a minimum you should be offered an annual flu jab.

**Please contact Gloucestershire Carers Hub for more details and access to the services listed above**

Call **0300 111 9000** or email [carers@peopleplus.co.uk](mailto:carers@peopleplus.co.uk) or visit [www.gloucestershirecarershub.co.uk](http://www.gloucestershirecarershub.co.uk).

# Keeping a Check on Physical Health and Wellbeing

Keeping as physically well as possible is important for all of us. When we are physically unwell this will affect the way in which we behave and our ability to concentrate and do things. People with dementia can sometimes be less aware that they are physically unwell and may be less able to describe how they are feeling. So if there is an unexpected change in behaviour it is important to rule out physical causes.

**People with dementia are often at greater risk of developing conditions such as delirium.**

Delirium is a state of mental confusion that can happen if you become unwell. Pain, infections, poor nutrition, constipation, poor hydration, medication and changes in the environment can all cause delirium. It often starts suddenly, but usually improves when the condition causing it gets better. Delirium can develop in as little as one to two days. Symptoms of delirium can range from agitation and restlessness to hallucinations or delusions or suddenly becoming withdrawn or more sleepy. It is important to ensure that sudden changes in the condition of the person you care for are checked out with their GP. Keeping an eye on fluid and food intake can help prevent dehydration and problems with constipation. Regular medical reviews and recognising signs of pain in the person you care for will help prevent discomfort which can often affect behaviour.

## **Pain**

## **Infections**

## **Nutrition**

## **Constipation**

## **Hydration**

## **Medication**

## **Environment**

Being alert to signs/symptoms of pain or infection

Good balance of fluid intake

Having regular medication reviews

Keeping as active as possible



# Getting Help When Things Change

## Assess the situation

### Has there been a rapid change in the person?

Rapid changes usually indicate that the person has an infection or is in pain so you should make an appointment with the GP as soon as possible.

If you feel you need advice in the meantime you can call Managing Memory Together during office hours 9am-5pm Monday to Friday or out of hours call **NHS 111**.

**If you or the person you care for is at risk you should seek medical help immediately by calling 999**

### Have you noticed a gradual deterioration in the person's ability to manage everyday tasks?

### Are they becoming much more confused?

### Is the person hallucinating either for the first time or more frequently?

**Could this be delirium** (Delirium is a worsening or a change in the person's mental state that happens very quickly – see above section keeping a check on physical health and wellbeing).

**Dementia is progressive** which means that the person's condition will get worse. However, it is still important to seek help and advice if you are concerned.

In the first instance you should contact the GP. The GP may refer to a Community Dementia Practitioner at Managing Memory Together who can support you to manage these changes.

You can also call Managing Memory Together on **0800 694 8800** for advice.

### When you call for help explain:

- ▷ Why you are worried?
- ▷ What has changed?
- ▷ What help you think you or the person you care for needs.

**Sometimes (unless it is an emergency) it helps to write things down before you call.**

**It is still important to  
seek help and advice if  
you are concerned**



# Useful Contacts

Listed below are contact details for local and national organisations that provide information, advice and support services for people with dementia and carers of people with dementia.

If you are not sure who it would be best to contact to please call on **0800 694 8800** Monday - Friday, 9am-5pm or email [managingmemory@ghc.nhs.uk](mailto:managingmemory@ghc.nhs.uk).

**Please note: If you need emergency support you should contact your GP or emergency services.**

## Adult Helpdesk

(Gloucestershire Adult & Community Care Directorate) provides information, advice and access to social care services.

**Community Development Support Team** helps people from ethnic minorities to access appropriate services and maximise their own, or their families' independence.

Call **01452 426868** or email [socialcare.enq@gloucestershire.gov.uk](mailto:socialcare.enq@gloucestershire.gov.uk) or visit [www.gloucestershire.gov.uk/health-and-social-care](http://www.gloucestershire.gov.uk/health-and-social-care)



## Age UK Gloucestershire

Age UK Gloucestershire is a local, independent charity here for all older people in Gloucestershire. It offers information and advice to help people navigate later life, services to ensure people can remain independent at home for as long as they want to (e.g. the Out of Hospital Service), as well as helping people to connect socially and access activities in their local community e.g. walking sports.

Call **01452 422660**. Email [enquiries@ageukgloucestershire.org.uk](mailto:enquiries@ageukgloucestershire.org.uk) or visit [www.ageuk.org.uk/gloucestershire](http://www.ageuk.org.uk/gloucestershire)



## Alzheimer's Research UK

Alzheimer's Research UK is the world's leading dementia research charity dedicated to causes, diagnosis, prevention, treatment and cure.

Any questions about dementia research and how to get involved call **0300 111 5111**. Email: [infoline@alzheimersresearchuk.org](mailto:infoline@alzheimersresearchuk.org) or visit [www.alzheimersresearchuk.org](http://www.alzheimersresearchuk.org)





## Alzheimer's Society (Gloucestershire)

Provides services including the Dementia Adviser Service, singing for the brain, memory cafés and a specialist group for younger people with dementia. Call **01452 525222** or email [gloucestershire@alzheimers.org.uk](mailto:gloucestershire@alzheimers.org.uk) or visit [www.alzheimers.org.uk](http://www.alzheimers.org.uk)



## Alzheimer's Society (National)

Free factsheets about memory problems and dementia are available in a range of languages. Information, advice and guidance is available by contacting the Alzheimer's Society Dementia Connect Support Line. The service can also provide interpreters for people whose first language is not English.

- Dementia Connect Support Line on **0333 150 3456**.
- Dementia Connect Online directory [www.alzheimers.org.uk/find-support-near-you](http://www.alzheimers.org.uk/find-support-near-you)
- Telephone support is available seven days a week.



Talking Point: an on-line forum for people with dementia and their carers is available at [www.alzheimers.org.uk/get-support/dementia-talking-point-our-online-community](http://www.alzheimers.org.uk/get-support/dementia-talking-point-our-online-community)



Lasting power of attorney digital assistance service provides telephone support to help people create and register LPAs. **0333 150 3456** The service does not offer legal advice.

## Attendance Allowance Helpline

To request claim forms call **0800 731 0122** or, forms can be downloaded from [www.gov.uk/government/publications/attendance-allowance-claim-form](http://www.gov.uk/government/publications/attendance-allowance-claim-form)



## Gloucestershire Carers Hub (managed by PeoplePlus)

Provide information advice and guidance for carers, including advice on benefits, access to carer support groups, carer training and activity sessions, carers assessment and support planning, carers counselling service, carers breaks and carers emergency scheme. Carers can sign up to receive e-newsletters and are invited to training events and trips for carers.

Call **0300 111 9000** Mon - Fri. Email [carers@peopleplus.co.uk](mailto:carers@peopleplus.co.uk) or visit [www.gloucestershirecarershub.co.uk](http://www.gloucestershirecarershub.co.uk)



## Community Wellbeing Service

Community Wellbeing Service can offer one to one support for individuals and can also signpost or refer people to activities and groups available in their area.

## Cheltenham & Tewkesbury - CCP

Call **0300 365 6463**. Email [glccg.ccpcommunitywellbeing@nhs.net](mailto:glccg.ccpcommunitywellbeing@nhs.net) or visit [www.ccp.org.uk/communitywellbeing](http://www.ccp.org.uk/communitywellbeing)



## Cotswolds District - Gloucestershire Rural Community Council

Call **01452 528491**. Email [Info@grcc.org.uk](mailto:Info@grcc.org.uk) or visit [www.grcc.org.uk](http://www.grcc.org.uk)



## Dementia UK

Dementia UK Admiral Nursing Dementia Helpline can offer you specialist practical and emotional support on their dementia helpline or their online service. Their website also has a wide range of information on dementia.

Call **0800 888 6678** Mon-Fri 9am - 9pm, Sat & Sun 9:00am – 5:00pm or visit [www.dementiauk.org](http://www.dementiauk.org)



## Forest of Dean - Forest of Dean District Council

Call **01594 812447** or **01594 812399**. Email [community.wellbeing@fdean.gov.uk](mailto:community.wellbeing@fdean.gov.uk) or visit [www.fdean.gov.uk/communities-health-and-leisure/community-health-and-wellbeing/community-wellbeing-service](http://www.fdean.gov.uk/communities-health-and-leisure/community-health-and-wellbeing/community-wellbeing-service)



## Gloucester Home Group

Call **0300 131 0024**. Email [hgl.communitywellbeing.gloucester@nhs.net](mailto:hgl.communitywellbeing.gloucester@nhs.net) or download [www.homegroup.org.uk/media/2qconils/gloucester-support-hub.pdf](http://www.homegroup.org.uk/media/2qconils/gloucester-support-hub.pdf)



## Stroud District - Independence Trust (Herefordshire Housing)

Call **0345 863 8323**. Email [Referrals-CCStroud@independencetrust.co.uk](mailto:Referrals-CCStroud@independencetrust.co.uk) or visit [www.independencetrust.co.uk](http://www.independencetrust.co.uk)



## Community Connexions

(Community Transport Throughout Gloucestershire) Accessible transport solutions for groups and individuals to any destination. Using minibuses and volunteer cars driven by experienced, DBS checked, highly trained drivers. They provide door-to-door community transport, community bus routes, excursions, vehicle loan and more.

Call **0345 680 5029**. Email [info@communityconnexions.org.uk](mailto:info@communityconnexions.org.uk) or visit [www.communityconnexions.org.uk](http://www.communityconnexions.org.uk)



## Dementia Carers Count

Expert support to family members and friends who are looking after someone with dementia. Everything we do is developed together with family carers and is delivered by health and care professionals. For more information call **020 3096 7895** or email [support@dementiacarers.org.uk](mailto:support@dementiacarers.org.uk)

Please visit our Virtual Carers Centre website [www.dementiacarers.org.uk](http://www.dementiacarers.org.uk)



## Gloucestershire Carers Hub (managed by PeoplePlus)

Provide information advice and guidance for carers, including advice on benefits, access to carer support groups, carer training and activity sessions, carers assessment and support planning, carers counselling service, carers breaks and carers emergency scheme. Carers can sign up to receive e-newsletters and are invited to training events and trips for carers.

Call **0300 111 9000** Mon - Fri. Email [carers@peopleplus.co.uk](mailto:carers@peopleplus.co.uk) or visit [www.gloucestershirecarershub.co.uk](http://www.gloucestershirecarershub.co.uk)



## Gloucestershire Fire and Rescue Service Safe and well Checks

Contact the fire service to request a **FREE** Home Safety Check to ensure that your household is as safe as possible from the dangers of fire and to get smoke alarms installed or checked. They can also provide specialist equipment e.g. hearing impaired alarms and linked alarms for people with memory issues.

Call **0800 180 4140**. Email [home.safety@glosfire.gov.uk](mailto:home.safety@glosfire.gov.uk) or visit [www.gloucestershire.gov.uk/glosfire/your-safety/safe-and-well](http://www.gloucestershire.gov.uk/glosfire/your-safety/safe-and-well)



## Gloucestershire Health and Care NHS Foundation Trust

Contact the Patient and Carer Experience Team for Comments, concerns, complaints about the trust. The team also incorporated a Patient Advice and Liaison Service (PALS)

Call **0800 0151 548** or visit [www.ghc.nhs.uk/get-in-touch/give-us-views](http://www.ghc.nhs.uk/get-in-touch/give-us-views)



## Healthwatch

Gloucestershire supports people to have a voice and influence the delivery and design of local health and social care services.

Call **0800 652 5193**. Email [info@healthwatchgloucestershire.co.uk](mailto:info@healthwatchgloucestershire.co.uk) or visit [www.healthwatchgloucestershire.co.uk](http://www.healthwatchgloucestershire.co.uk)



## Let's Talk

May be able to help if you are feeling stressed, anxious or depressed. The service is part of the Gloucestershire Health & Social Care NHS Foundation Trust Mental Health Intermediate Care Team, which offers nursing and therapy in primary care to people older than 18 in Gloucestershire, with depression and/or anxiety. They offer talking therapy treatments through courses, one to one telephone support and face to face individual support. To discuss the best treatment and support for your situation, call **0800 073 2200** or email [2gnft.talk2gether@nhs.net](mailto:2gnft.talk2gether@nhs.net) You can also visit [www.letstalkglos.nhs.uk](http://www.letstalkglos.nhs.uk)



## Mindsong

Mindsong is a Gloucestershire charity supporting people with dementia and their carers through music and music therapy. Our Music Therapy at Home service is for people with more advanced dementia, living and being cared for at home. Music therapy can support wellbeing, isolation, engagement and communication. Carers benefit too. If you would like to find out more, please call **01684 219966** or email [admin@mindsong.org.uk](mailto:admin@mindsong.org.uk)

## POhWER advocacy

POhWER provide advocacy services for people who live in Gloucestershire. POhWER is there for anyone who needs information, advice support and advocacy. They will empower people to have a voice, make choices, enforce their rights. They provide a range of advocacy roles.

Call **0300 003 1162** or Minicom **0300 456 2364**. Text: send the word '**powher**' with your name and number to **81025**. Email [glosadvocacy@pwer.net](mailto:glosadvocacy@pwer.net) or visit [www.pohwer.net](http://www.pohwer.net)



## Young Dementia UK

Young Dementia UK (now part of Dementia UK) is a national information and support charity focusing specifically on young-onset dementia. Created with and for younger people, families, friends and supporters.

Call **01993 776295**. Email [mail@youngdementiauk.org](mailto:mail@youngdementiauk.org) or visit [www.youngdementiauk.org](http://www.youngdementiauk.org)



## Your Circle

Your Circle is a website managed by Gloucestershire County Council that provides information about services in the county to help people stay independent, safe and well. This includes information on home care, care homes, health and social care organisations as well as local groups and activities.

Email [yourcircle@gloucestershire.gov.uk](mailto:yourcircle@gloucestershire.gov.uk) or visit [www.yourcircle.org.uk](http://www.yourcircle.org.uk)



# Managing Memory Together Information Sessions

## Connect with others and learn more about dementia

The sessions run in small groups where people can meet others to find out about dementia, share experiences, ask questions, and connect with others. The sessions are 1.5 hours online at present and delivered by health and social care professionals.

**We currently offer the following programmes online. Register to be kept updated and find out when face to face sessions are arranged.**

### Living Well Programme

These sessions are for people who understand their diagnosis and feel comfortable meeting others in a group situation where dementia will be discussed. People with dementia are welcome to invite someone to join the sessions with them. There are four sessions in the programme:

1. **Introductions** provides an opportunity to meet other participants, find out what to expect from the programme and allows time to feel comfortable using Zoom.
2. **Memory and Dementia** explores how dementia affects you, causes, treatments and support.
3. **What's important to you** gives participants an opportunity to think about some of the challenges that having a diagnosis of dementia brings. To explore the benefits of keeping busy and to discuss ideas and information for living well with dementia.
4. **Next Steps** explores topics relevant to the group, provides information on Peer Support Groups, Technology and Me and Getting Involved.

### Learning about Dementia Together

These sessions are for people who are caring a family member or friend who has dementia. There are three sessions in the programme:

1. **About Dementia** looks at dementia symptoms, causes, treatments and provides information on services to support people with dementia and carers.
2. **Dealing with Changes** explores the impact of dementia on the person and discuss strategies and ideas for coping with changes.
3. **Positive Communication** explores how communication is affected for the person with dementia and provides guidance and advice to support communication with the person with dementia.

The sessions will be delivered using the **Zoom** online platform. We will send you full joining instructions.

Contact us at Managing Memory Together for session dates and to book places. Call **0800 694 880** or email [managingmemory@ghc.nhs.uk](mailto:managingmemory@ghc.nhs.uk)

Your views are important to us. If you need advice or have feedback on a community hospital in Gloucestershire, or on our community health and adult social care services, you can contact one of the advisers from our service experience team. All enquiries are completely confidential. You can contact us between 9.00am and 5.00pm, Monday to Friday.

**This leaflet can also be supplied in braille, audio format, PDF, large print, easy read and other languages on request.**



**0300 421 8313** (answerphone available outside office hours)



[experience@ghc.nhs.uk](mailto:experience@ghc.nhs.uk)



**Patient and Carer Experience Team**

Gloucestershire Health and Care NHS Foundation Trust  
Edward Jenner Court  
1010 Pioneer Avenue  
Gloucester Business Park  
Brockworth  
Gloucester  
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[www.ghc.nhs.uk](http://www.ghc.nhs.uk)