



**Mersey Care**  
NHS Foundation Trust

Community and Mental Health Services

# Halton

Frequently asked questions from patients and carers after a diagnosis of dementia

[merseycare.nhs.uk](https://merseycare.nhs.uk)



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## **1. What is dementia?**

Dementia is not a disease itself. It is a description of the range of symptoms caused by progressive damage to the brain which increase over time. These symptoms include memory loss, confusion, mood changes and communication difficulties. There are different medical conditions which cause dementia. The most common are:

### **1.1 Alzheimer's disease**

Is the most common form of dementia. It is more common as we get older but is not a part of normal ageing.

Alzheimer's disease causes changes that go beyond normal ageing such as a build-up of proteins in the brain. As Alzheimer's progresses, it causes increased damage in the brain which in turn increases the severity of the symptoms (leading to dementia).

### **1.2 Vascular dementia**

Is the second most common form of dementia. It occurs when blood flow to brain cells is reduced, resulting in the symptoms of dementia.

If the memory and thinking problems caused by the reduced blood flow is not severe enough to be considered dementia, it is called vascular cognitive impairment.

### **1.3 Dementia with Lewy bodies (DLB)**

Is the third most common form of dementia. It is caused by clumps of protein building up inside nerve cells in the brain which damage the way they function and communicate. The nerve cells that are affected are in areas of the brain that control thinking, memory and movement. People with DLB can also show some changes in the brain that are typical of Alzheimer's. This sometimes makes it hard to tell the difference between the two diseases.

## **2. Will I get better?**

Unfortunately, dementia is a deteriorating condition which will not get better. However, if we diagnose early it is possible to prescribe medication to slow down the progression and manage many of the symptoms that you may experience.

As a LLAMS team we believe that it is possible to live well with your dementia diagnosis and we will work closely with you and your family to achieve this. We will help you to focus on the tasks that you can still do, and we will support you throughout your dementia journey.

## **3. How will medication help?**

The medication is to try to slow down the progression of symptoms. These include worsening mental abilities (such as disorientation) and problems carrying out daily activities such as getting dressed.

Information about the medication that you have been prescribed will be given to you when you collect your medication.

## **4. How will my condition progress?**

How quickly each person's dementia progresses and the path it takes is unique to them.

Health professionals use a range of clinical scales to measure mental ability and overall functioning. These are used, alongside a holistic view of the person's capabilities and needs, to monitor any change.

## **5. Is dementia hereditary?**

Alzheimer's is common, and many people have a relative who has the disease. This doesn't mean they will inherit it. Some research has suggested that if someone has a parent or grandparent with Alzheimer's who developed the disease over the age of 65, then their own risk of developing Alzheimer's may be slightly higher than someone with no family history.

Research has identified several genes that are associated with a higher risk of late onset Alzheimer's in some people. Having these genes does not definitely mean someone will develop the disease, only that their risk is higher than those with a different genetic make-up.

In some instances, early onset Alzheimer's can run in families and may be caused by faulty genes. In these cases, many members of the same side of the family are affected, often in their 30s, 40s or 50s. These types of Alzheimer's are very rare. For more information visit the web site: [www.alzheimersresearchuk.org/about-dementia/helpful-information/genes-and-dementia/](http://www.alzheimersresearchuk.org/about-dementia/helpful-information/genes-and-dementia/)

## **6. Who do I contact for advice or if I have a question?**

The Memory Assessment and Treatment Team provide an assessment, diagnosis and treatment service for people with memory problems. They can prescribe medications and, when needed, arrange access to local services, such as home care or activity visits. Your GP will be kept fully informed about everything the team does and once your condition is stable you will be monitored by your GP.

If you have any questions, or your condition changes, do not hesitate to contact your GP. If needed your GP can either seek advice from the Memory Assessment and Treatment Team or arrange for you to see them.

The Alzheimer's Society has a wide range of high quality information and can offer free independent advice.

They can be contacted at:

Alzheimer's Society,  
Victoria House, Croft Street,  
Widnes, WA8 0NQ

Tel: 0151 420 8010

Email: [Halton&StHelens@alzheimers.org.uk](mailto:Halton&StHelens@alzheimers.org.uk)

Website: [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

## **7. What services and support are available to me?**

There are a wide range of services and support groups which people in Halton can access. Some of these are specifically aimed at people with dementia while others are open to all Halton residents and valued by many people with dementia.

For more information on what's available please see the Halton Community Services Directory, set up and maintained by Halton Healthwatch.

Tel: 0300 777 6543

Website: [www.healthwatchhalton.co.uk/a-z-directory/](http://www.healthwatchhalton.co.uk/a-z-directory/)

## **8. How do I obtain care and support?**

Both the Memory Assessment and Treatment Team and your GP are happy to discuss your care needs and support options at any time. Do not hesitate to call them if you have any questions or if your needs change.

Halton Borough Council has details of a wide range of support and social organisations.

## **9. Are there any therapy groups I can attend?**

The Halton LLAMS team facilitate Cognitive Stimulation Therapy (CST) courses. This is an evidence based programme for people with memory problems. The course runs over a six week period in a weekly two hour session. CST involves activities and exercises that stimulate thinking, concentration, communication and memory in the person with dementia.

The Next Steps Carers course is an educational course developed to give carers of people living with any type of dementia the skills and knowledge to enable them to take better care of the person that they care for. This course is run at the same time and venue as the CST group.

Please ask the LLAMS team for more information.

### **10. Will mental or brain stimulation exercises (brain training) help to slow down my deterioration?**

Many people engage in “brain training” activities such as: crosswords, puzzles or learning new hobbies. There are also many computer based “brain training” games which also challenge memory, problem solving and reasoning. The idea is the more you use your brain the more resilient it will become. In common phrasing, “use it or lose it”.

This is a new area of research and according to the Alzheimer Society, “most studies have been too small and too short to test any effect of “brain training” on the development of cognitive decline or dementia.”

Some studies have found that “brain training” improves some aspects of memory and thinking and may help older people manage their daily tasks better. But none have shown it prevents dementia.

### **11. Are there any services or support groups to help carers?**

Halton Carers Centre supports carers in Halton. They offer advice and a wide range of services.

**They can be contacted at:**

Halton Carers Centre  
62/64 Church Street, Runcorn,  
Halton, WA7 1LD

Tel: 01928 580 182

Website: [www.haltoncarers.co.uk/](http://www.haltoncarers.co.uk/)



## **Admiral nurses**

Our admiral nurses work with families and carers of people with dementia to help them cope with the pressures of caring for someone with dementia.

Speak to your GP about accessing this service or contact the team directly on 0151 244 4369 to request a referral form.

The Alzheimer's Society

Tel: 0151 420 8010

Email: [Halton&StHelens@alzheimers.org.uk](mailto:Halton&StHelens@alzheimers.org.uk)

Carers are entitled to a carers assessment carried out by Halton Borough Council. This identifies their needs and signposts them to the support they can access. It does not judge or assess their ability as a carer.

## **12. What benefits or help can I get?**

The benefit system is complex and it is always advisable to get high quality accredited advice. Halton Citizens Advice Bureau offers free, confidential advice on a range of benefits:

### **Runcorn Office**

Ground Floor, Grosvenor House,  
Runcorn, WA7 2HF

### **Widnes Office**

Unit 3, Victoria Buildings,  
Lugsdale Road, Cheshire, WA8 6DJ

Website: [www.haltoncab.org.uk/](http://www.haltoncab.org.uk/)

Email: [advice@citizensadvicehalton.org.uk](mailto:advice@citizensadvicehalton.org.uk)

Tel: 0344 477 2121

Attendance Allowance (AA) and Personal Independent Payment (PIP) are benefits paid to many people with dementia who need regular help with personal care. They are non means tested and are paid regardless of any other income or savings.

Some people with dementia may be eligible for discounts or exemptions on their council tax. Contact Halton Borough Council for more information or to apply for a discount or exemption.

### **12.1 Blue badge**

Many people with dementia are entitled to a blue badge so they, or their carer, can park close to where they need to be.

However, the blue badge criteria focuses on mobility needs, so some people with dementia may find it difficult to meet the conditions. For many people their dementia affects balance, co-ordination and spatial awareness which need to be stressed when applying for a blue badge. Applications can be made by contacting Halton Borough Council or online at: [www.apply-blue-badge.service.gov.uk/applicant](http://www.apply-blue-badge.service.gov.uk/applicant)

### **13. Do I have to contact social services?**

No, as part of your initial assessment the nurse will consider if your needs require a referral to social services and if you and your carer agree it is necessary, the nurse will complete the referral. The nurse will also offer your carer an assessment.

The social services referral and carer's assessment will be revisited during your post diagnostic visit by the nurse.

#### 14. Can I continue to live at home or do I need to enter a care home?

Dementia makes many things more difficult, especially as it progresses. However, many people with dementia, especially in the early and middle stages, continue to live safely in their own home.

There is a wide range of equipment and 'assistive technology' that may help.

#### For more information contact:

Halton Independent Living Centre  
Collier Street, Runcorn, WA7 1HB.

Tel: 01928 582920

or

The Alzheimer's Society

Tel: 0151 420 8010

Email: [Halton&StHelens@alzheimers.org.uk](mailto:Halton&StHelens@alzheimers.org.uk)

Simple tips which may help include:

- 1 Good lighting, use a night light or leave the bathroom light on
- 2 Remove all trip hazards (such as loose rugs) and clutter
- 3 Leave a set of house keys with a neighbour you trust (or install a "key safe" outside your house)
- 4 Keep a list of emergency telephone numbers by the phone (or save them on your phone if this is easier).

## **15. Can I obtain any financial assistance?**

NHS services are free at the point of care, but those provided by a local authority, including residential home charges, are means tested.

However, there are some services which a local authority cannot charge for. These include aids and minor adaptations to the home costing less than £1,000.

For full details of Halton Borough Council's charging policy

Tel: 0303 333 4300

Website: [www3.halton.gov.uk/Pages/adultsocialcare/Social-Care-Charges.aspx](http://www3.halton.gov.uk/Pages/adultsocialcare/Social-Care-Charges.aspx)

## **16. What is Lasting Power of Attorney?**

Lasting power of attorney (LPA) allows one person to give another, known as the Attorney (often a family member or carer) the authority to make decisions on their behalf.

An LPA can only be taken out by people aged over 18 who have the mental capacity to do so. If a person no longer has mental capacity, they cannot make an LPA.

Having an LPA makes things easier and less expensive should family or friends need to make any decisions on your behalf in the future. Some people use the LPA as a way to begin talking about their wishes for the future with family or friends.

There are two types of LPA, Property and Affairs for financial decisions and another for Health and Welfare decisions. You can choose to make both or just one. You can appoint the same person to be your attorney for both or you can have different attorneys.

The National Dementia Helpline provides support to complete LPA forms, but cannot offer advice. Tel: 0300 222 11 22.

Some people choose to pay for independent legal advice from a solicitor but this is not always necessary, especially in straightforward cases.

## **17 Can I still drive with dementia?**

The legal position focuses on the individual's ability to drive safely rather than any specific diagnosis such as dementia.

### **17.1 Do I have to inform the DVLA?**

If you are diagnosed with dementia and want to continue driving, you must immediately inform the DVLA of your diagnosis on form CG1 available online:

[www.gov.uk/government/publications/cg1-online-confidential-medical-information](http://www.gov.uk/government/publications/cg1-online-confidential-medical-information)

Failure to do so can result in a £1000 fine.

Once informed, the DVLA will ask you to complete a questionnaire and will ask your permission to obtain a medical report from your GP and/or consultant. To see the questionnaire go to:

[www.gov.uk/alzheimers-disease-and-driving](http://www.gov.uk/alzheimers-disease-and-driving)

The DVLA will make a decision based on what your doctor says. They may decide to:

- 1 Renew your licence. This is usually for one year
- 2 Revoke (cancel) your licence immediately
- 3 Obtain more information. This may be more medical reports, or they may ask you to take an assessment, including an "on road driving assessment".

You can ask for a copy of the report detailing the DVLA decision with reasons.

### **17.2 Do I have to inform my car insurance company of my diagnosis?**

Yes. As soon as you've been diagnosed with dementia, you should inform your car insurance provider. If you don't, your policy may be invalid.

## 18. Advice from other carers

- "Do your own research"
- "Join service user/carer groups"
- "Speak to as many people as possible, don't be scared to ask questions"
- "Don't worry about contacting social services, GP or memory service at any stage"
- Request that social services carry out a survey of your home to identify and supply free of charge any items of equipment which may both assist you and keep you safe
- "Stimulation for the service user can really help, such as dementia cafes, day care centres or the Salvation Army"
- "Develop your own strategies to help protect yourself and the person you are caring for"
- "Take care of yourself!"

We would like to thank Elaine and Chris, both carers of people living with dementia, for their invaluable help in creating this booklet

## **Our patients matter**

**Mersey Care NHS Foundation Trust** listens and responds to patients and their carers to help improve the services we deliver.

If you have any comments, compliments or concerns you can speak with a member of staff or contact our **Patient Advice and Liaison Service (PALS) and Complaints Team**.

Telephone: **0151 471 2377**

Freephone: **0800 328 2941**

Email: [palsandcomplaints@merseycare.nhs.uk](mailto:palsandcomplaints@merseycare.nhs.uk)

To request this leaflet in an alternative format or language, please speak to a member of staff.

**Mersey Care NHS Foundation Trust**

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