Alzheimer's Society

Leading the fight against dementia

Dementia with Lewy bodies: Understanding your diagnosis

About this booklet

If you have recently been diagnosed with dementia with Lewy bodies, this booklet is for you. It will help you, and your family and friends, to understand more about the condition and how it can affect you. It covers feelings you might have and suggests ways of staying positive.

In section 2 you can read about dementia with Lewy bodies. This booklet also includes different aspects of living with dementia, including treatments, support and services that are available.

You are not alone – around 850,000 people in the UK have dementia. It is possible to live well with dementia with Lewy bodies. Support is available for you and your family.

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Coping with your diagnosis

When you find out you have dementia with Lewy bodies, you may feel a range of emotions. Give yourself time to think things through.

Remember that there is no 'right' or 'wrong' way to feel. However you feel, it is right for you, at this moment. And don't worry if it all seems to be overwhelming at first. There are good and bad times, and with support many people come to terms with their diagnosis.

It may help to talk things over with friends and family, or with a health or social care professional who understands dementia.

Things you should try to think about after a diagnosis include:

- emotions and relationships
- treatments and ways to stay active and healthy
- financial matters and planning ahead
- your job – if you're still working
- driving
- practical and emotional support – from the NHS, social services, private companies or voluntary organisations.

You won't need to think about all these things straightaway, so take things at your own pace.

Managing your feelings

You may have a number of different feelings after a diagnosis. This is normal and there are ways to cope with them.

- Many people feel a sense of sadness or loss after their diagnosis. You may feel that you will no longer be able to do the things that you enjoy or that you had planned. It is true that having dementia may mean you need to make changes. But with the right information and support, you can carry on with regular aspects of your life for some time

- Shock, disbelief and denial are all common reactions to a diagnosis of dementia with Lewy bodies. Sometimes this can be a good thing. It can give you the time you need to deal with your diagnosis.

- Fear is another very common reaction. You may be afraid of the future, of losing control or of becoming a burden to your family. Talking about this with others can help. It is important not to feel that you are on your own.

- Some people worry that they did something wrong to get dementia with Lewy bodies, or did not do enough to prevent it. In many cases it is not known why dementia develops. Don't dwell on this. Instead, try to keep going with a positive outlook.

- A few people feel relief after a diagnosis. This may sound strange, but it can be better to have an explanation for the changes you have been experiencing, rather than worry about what else it could be. Once you have a diagnosis, you can deal with it and do something about it.

After a diagnosis, you may want to talk things over with other people. You might only want to do this with your partner, or with close family and friends. You may not want to talk about it at all.

Talking to others with a similar experience can help as well. You could try:

- finding a support group – where you can talk to others with a similar experience (see 'Services and support' on page 28)
- joining an online discussion forum (for example, Alzheimer's Society's Talking Point)
- talking with a dementia support worker or dementia adviser
- seeing a qualified counsellor or psychotherapist.

Changes to relationships

Dementia changes your relationships with people. You and the people close to you will have to adapt to new challenges. It's important to be aware of this, talk about it as openly as you can, and look for solutions together.

Those close to you will need to offer you more support in daily life. In time they may become your 'carer'.

Telling young children

If you have young children or grandchildren, it is a good idea to tell them about your dementia. Do this in a way that feels right for their age and ability to understand things. You might be surprised at how adaptable they are.

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What causes dementia?

Dementia is not a natural part of ageing. It is the name for a group of symptoms that occur when the brain is affected by a disease.

These symptoms may include memory loss and difficulties with thinking, planning, problem-solving, perception or language. They are severe enough to interfere with daily life. Some people may also experience changes in mood or behaviour.

There are many causes of dementia. The most common are Alzheimer's disease and vascular dementia. Some people have a combination of these, known as mixed dementia. Dementia with Lewy bodies is a less common type, though evidence suggests it is currently under-diagnosed.

What is dementia with Lewy bodies?

This type of dementia is named after tiny clumps of protein that develop inside brain cells called Lewy bodies. They disrupt the way the brain functions and can cause brain cells to die.
The following section describes how dementia with Lewy bodies affects people.

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How does dementia with Lewy bodies affect people?

Dementia with Lewy bodies affects everyone differently. However, some common symptoms are described in this section. You might recognise some of your own experiences here.

Early symptoms

The earliest symptoms of dementia with Lewy bodies can be mild, but they gradually get worse. You will usually have some of the symptoms of Alzheimer's disease (for example, memory loss) and some of the symptoms of Parkinson's disease (for example, slow movements), which is also caused by Lewy bodies.

Early symptoms can include:

- problems with attention and alertness that usually vary a lot over the day, and sometimes even from minute to minute
- difficulties with judging distances, such as when using stairs,
- seeing and perceiving objects, for example when picking things up
- visual hallucinations (seeing things that are not there) and delusions (thinking things that are not true)
- problems with movement – these are similar to symptoms of Parkinson's disease (for example, slow, rigid movements, problems with balance)
- falls, faints and 'funny turns'
- sleep disorders, including falling asleep during the day but having very disturbed nights
- problems with planning and organising
- depression.

Later stages

Dementia with Lewy bodies is progressive – this means that your symptoms will become worse over several years and you will need increasing amounts of help.

Everyone is different but, as the condition progresses, symptoms can include:

- becoming more confused about the time and places
- memory problems becoming worse – forgetting events, names and faces
- having more severe problems with communication and speech
- changes in behaviour – for example, asking the same questions over again or getting agitated
- walking more slowly and less steadily, losing weight and having difficulties with swallowing or eating.

In the later stages of dementia with Lewy bodies, someone will generally need full-time care and support. This may be distressing to think about, but it can help to be prepared.

‘It’s important to remember that no two cases of dementia are the same, and just because someone who has been diagnosed is experiencing a certain set of symptoms doesn’t necessarily mean you will go on to develop those same symptoms.’

Carer of person with dementia

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Treatments

Although there is no cure for dementia with Lewy bodies, it is possible to live well with the condition, with the right support. You and people close to you will need to try and be flexible as your symptoms may vary day to day.

Managing dementia with Lewy bodies

You will need help from different professionals at different times.

Health professionals should agree a treatment plan with you. Usually this will start with the symptoms that are causing you the most trouble.

Often the same medications used in Alzheimer's disease (for example, rivastigmine or donepezil) are used in dementia with Lewy bodies to help with mental abilities and hallucinations. Non-drug approaches are also very important.

Ask your GP or memory service for details of what non-drug treatments and activities are available in your local area. Also see the section on Alzheimer's Society services on page 32.

'The most important advice I can give you is to keep contact with whatever family and friends you have already and try to make new ones through whatever associations there are locally. Other people who have already been through the experience invariably have something useful to offer.'

Wife of person with dementia

Problems with mental abilities and mood

You will benefit from staying active, doing things you enjoy and keeping in touch with people. Some other ideas for non-drug treatments and activities are given below.

- **Talking therapies**, such as counselling, might help you to come to terms with your diagnosis. Another talking treatment, **cognitive behavioural therapy**, may help with depression or anxiety. Your doctor may suggest you have cognitive behavioural therapy and take medication at the same time.

- **Cognitive stimulation therapy** is done in small groups and involves a number of sessions that are usually weekly. (These may involve activities such as games, songs and talking about current affairs). People find this helps memory and communication.

- **Life story work** is an activity for you and a friend, family member or professional providing care or support. You make a record of experiences, people and places in your life. This may be an enjoyable way of helping with memory problems. It can also help any professional carers who support you to understand you better.

- **Reminiscence** involves talking about a theme from your past such as schooldays, holidays or simply daily life. Reminiscence often includes prompts such as photos and objects from that time. It could help your mood as well as your memory.

- **Cognitive rehabilitation** is a type of therapy that allows you to set your own practical goals (for example, handling money confidently or learning to use a mobile phone). You then work with a therapist (for example, a psychologist or occupational therapist) to achieve these.

Hallucinations and delusions

- Hallucinations and delusions will feel real at the time, and they can be very distressing. People around you may offer reassurance or gently try to distract you. They should not deny that what you are experiencing is real to you.

- If you wear glasses or a hearing aid, get them checked regularly. If faulty, they can cause problems with how you see or hear things. This can make you more confused or even trigger a hallucination.

- Your doctor might suggest you take medicine if the hallucinations or delusions are very distressing. This will usually be one of the drugs given to people with Alzheimer's disease (for example, rivastigmine).

- Very occasionally, someone with dementia with Lewy bodies will be given a strong medicine for very upsetting hallucinations or delusions, called an antipsychotic. This can cause severe side effects and should only ever be done with extreme caution by a specialist doctor.

'She sleeps better if she's had a walk, has participated in activities and has had a relatively anxiety free day.'

Carer of person with dementia

Sleep disorders

Some people have problems with sleep, such as very vivid dreams, violent movements or calling out during sleep. If you find you're not sleeping properly, you can try the following:

- Get more physical exercise and don't take naps during the day.
- Avoid alcohol, caffeine and nicotine late at night.
- Keep your bedroom quiet and at a comfortable temperature.

If things don't improve, your GP might suggest medicines to help you sleep.

Movement problems

If you're having difficulty with walking and balance, your doctor may refer you to other professionals who can help you to stay independent. These include:

- a neurologist with expertise in movement disorder – they may prescribe the drug levodopa, which is given to people with Parkinson's disease
- a physiotherapist – they can help you with exercises to keep you moving safely
- an occupational therapist – they will help you to cope with daily living and can advise on aids and adaptations in your home (for example, handrails in the bathroom).

‘The most frightening time for the person with the disease and for the people who love them seems to be the start of the disease, when everything is new and no one knows how they’ll cope. Later on, we find out from experience that ordinary life does go on, there are still joys to be had as well as new challenges to be managed.’

Relative of person with dementia

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Living well

Living with dementia is challenging. You may feel angry or frustrated at times. Your plans for the future might change, but dementia doesn't change who you are. There are some practical things that can help you live as well as possible.

Keeping active

Keeping as active as possible – physically, mentally and socially – will help you to stay as healthy and independent as possible.

As long as you feel safe, you can still do the things that you've always done. Try to keep up with your hobbies. You may need to change the way you do things, or have some support.

Coping with memory loss

There are lots of things you might try to help with memory loss:

- Use a large diary to write down things you want to remember.
- Place useful telephone numbers by the phone.
- Put a note on the door to remind yourself to lock up at night.
- Ask your pharmacist about putting your pills in a dosette box.
- Consider whether any gadgets or pieces of technology might work for you.

Staying healthy

Having dementia with Lewy bodies disease doesn't mean you should feel ill. See the doctor if you're feeling unwell, or if someone that you trust suggests you should. If you have other medical conditions (such as high blood pressure, diabetes or heart problems), it is particularly important to have regular check-ups for these.

You might find the following tips useful:

- Try to eat balanced meals and drink plenty of fluids.
- Take regular physical exercise.
- If you smoke, consider stopping.
- Take your medications and tell your doctor about any side effects.
- If you find yourself regularly feeling low, anxious or irritable, see your GP.
- If you are in pain, it is important to tell your doctor or carer.
- Keep up to date with your vaccinations.
- Have regular check-ups for eyesight, hearing, your teeth and foot care.

‘To begin with we told nobody. I think we needed time to get used to the diagnosis ourselves. I then told close family as they were the ones who were most likely to see the changes. Gradually I told close friends. Many years down the line I now tell everyone. Everyone is different and it will depend on how your partner feels.’

Wife of person with dementia

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Planning ahead

As dementia with Lewy bodies progresses, it will become harder for you to make decisions about your health, care and finances. If you're able to, try to think about your future, talk to others and plan ahead as soon as you can.

Advance care planning

You can make decisions now so that your future care and finances are handled in a way that reflects your wishes – this is called 'advance care planning'. It can help you to worry less, knowing that you have some control over future events.

Advance care planning can be done in a number of ways:

- lasting power of attorney
- an advance statement – where you write down how you would like to be cared for
- an advance decision to refuse treatment – where you create a legal document to refuse certain medical treatments (for example, resuscitation) in the future
- a 'do not resuscitate' order – a decision not to have your heart or breathing restarted if they stop.

Discussions about care at the end of life can be difficult for you and your family. You shouldn't feel under any pressure to have them. But if you're thinking about advance care planning, it is important to do it while you can.

Lasting power of attorney

Many people with dementia choose to give someone they trust 'power of attorney'. This person – the 'attorney' – will make certain decisions for you if you lose the ability to do this.

The legal document used to give someone this power is called a 'lasting power of attorney' (LPA). There are two types:

- LPA for health and welfare – for things like medical treatment or where you will live.
- LPA for property and affairs – for things like accessing bank accounts, paying bills or selling your house.

If you live in Northern Ireland you will need to make an 'Enduring power of attorney' (EPA). Talk to a solicitor or the Citizens Advice Bureau. New laws about mental capacity are due to be brought into Northern Ireland by 2017.

Financial matters

It's important to have a safe place to keep all your essential documents – for example, bank and pension details and your will. Tell someone that you trust where this place is.

Talk to your bank about what they can do to help you manage your money.

Benefits

You and your carer may be entitled to a range of benefits. Accessing them can seem complicated but help is available. Ask a social worker, a local welfare rights service, a Citizens Advice Bureau or Age UK about a full benefits check.

Wills

Everyone should make a will. Talk to a solicitor about this. Alzheimer's Society can put you in touch with an approved solicitor through our Will to Remember scheme.
See **alzheimers.org.uk/willtoremember** for details.

Driving

When you're diagnosed with dementia it doesn't necessarily mean you have to stop driving straightaway. But by law you must tell the Driver and Vehicle Licensing Agency (DVLA) in Great Britain or Driver and Vehicle Agency (DVA) in Northern Ireland promptly that you have dementia. You must also tell your car insurance company.

Working

If you're working, you might want to carry on, or you may feel that reducing your hours or stopping work is for the best option for you. You might consider volunteering. This would be a way of still taking part in meaningful activity but on a more flexible basis.

If you're experiencing difficulties at work, talk to your employer or get advice. Try your human resources department, trade union, Citizens Advice Bureau or your local Jobcentre Plus office.

Once your employer knows you have dementia, they must try to make 'reasonable adjustments' so you can keep working, if you're able to. The government can provide financial support to help you stay in work through their Access to Work grants. If you decide to stop working or retire early, seek advice from an independent financial adviser about your pension rights.

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Services and support

Asking for help can feel difficult, particularly if you've always been independent.

You might not feel you need it straightaway, but it can be useful to know that a wide range of information and support is available for you and your carer and family.

- The NHS – your GP, psychiatrist, neurologist, community nurse, dietitian, occupational therapist or psychologist can help you with a number of health problems.

- Social services – a social worker from the local council can work with you to see what care and support is needed. Ask your GP or look up 'social services' in the phone book or online and ask for a needs assessment (also called a 'community care assessment' in Wales and Northern Ireland).

- Charities and not-for-profit organisations – these can be a good source of local support, advice and information. National organisations include Alzheimer's Society, Dementia UK and Age UK.

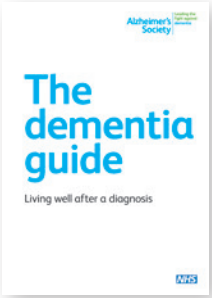
- Private companies – these can provide care and support services at home, which you may have to pay for. Professional care workers could help you with cooking, dressing, medication or going to work. Ask your local social services or contact the UK Homecare Association to see what is available in your area.

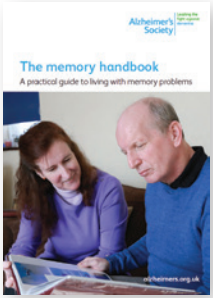
Further reading

This booklet gives an introduction to dealing with dementia with Lewy bodies. Alzheimer's Society produces a wide range of additional resources that might provide further helpful information. This includes more than 70 factsheets on specific topics as well as leaflets and books.

You can see the full list available by ordering a publications catalogue (code PL1) on 0300 303 5933. Alternatively visit alzheimers.org.uk/publications

The following titles may be especially relevant.





The dementia guide (872)
The memory handbook (1540)
Managing your money (1501)
Keeping safe at home (1502)
Who are all these health professionals? (1503)
Driving (1504)
Keeping involved and active (1506)
Living alone (1508)
Employment (1509)
Planning ahead (1510)

‘As you get your financial circumstances sorted, with help, you will feel better. No it won’t take the symptoms away but it will relieve some of your stress. If you can try and put things in place that may help you remember some of the important things that you need/want to do.’

Person with dementia

Alzheimer's Society services

Alzheimer's Society provides a range of services and resources to support people affected by dementia.

National information and support services

These are available wherever you live in England, Wales and Northern Ireland.

National Dementia Helpline – 0300 222 1122

The Helpline is for anyone who is affected by dementia or worried about their memory. Trained advisers provide information, support, guidance and signposting to other appropriate organisations. The Helpline is open 9am–8pm Monday–Wednesday, 9am–5pm Thursday and Friday, and 10am–4pm Saturday and Sunday. You can also contact the Helpline by email at **helpline@alzheimers.org.uk**

Talking Point online discussion forum

Talking Point is an online support and discussion forum for anyone affected by dementia. It's a place to ask for advice, share information, join in discussions and feel supported. Talking Point is available 24 hours a day, every day of the year. Visit **alzheimers.org.uk/talkingpoint**

Printed and online information

You can read and order publications online at **alzheimers.org.uk/publications**

You can also order printed copies by phoning **0300 303 5933**.

Local services

Alzheimer's Society provides a range of local services in England, Wales and Northern Ireland.

Contact your local Alzheimer's Society office or the National Dementia Helpline for more information about Society services in your area, or visit **alzheimers.org.uk/dementiaconnect**

Other useful organisations

Age UK
Tavis House
1–6 Tavistock Square
London WC1H 9NA

T 0800 169 2081 (advice line 8am–7pm)
0800 169 8787 (general enquiries)
E contact@ageuk.org.uk
W www.ageuk.org.uk

Age Cymru (in Wales)
T 029 2043 1555
E enquiries@agecymru.org.uk
W www.ageuk.org.uk/cymru

Age NI (in Northern Ireland)
T 0808 808 7575 (advice and information)
E info@ageni.org
W www.ageuk.org.uk/northern-ireland

Provides information and advice for older people.

Citizens Advice Bureau (CAB)
Various locations

W www.citizensadvice.org.uk

Citizens Advice Bureau offers free, confidential, impartial and independent advice to help people resolve problems with debt, benefits, employment, housing and discrimination. To find your nearest CAB, use the website above or look in the phone book.

Diabetes UK
Macleod House
10 Parkway
London NW1 7AA

T 0345 123 2399 (Careline, 9am–7pm Monday–Friday)
E careline@diabetes.org.uk
W www.diabetes.org.uk

The UK's leading diabetes charity. They care for, connect with and campaign on behalf of all people affected by and at risk of diabetes in local communities across the UK.

GOV.UK
W www.gov.uk

Online government services and information, covering benefits, driving, housing, money and tax, working and pensions.

Lewy Body Society
Hudson House
8 Albany Street
Edinburgh EH1 3QB

T 0131 473 2385
E info@lewybody.org
W www.lewybody.org

NHS Choices
www.nhs.uk

The UK's biggest health website provides a comprehensive health information service that aims to put people in control of their healthcare.

Parkinson's UK
215 Vauxhall Bridge Road
London SW1V 1EJ

T 0808 800 0303 (helpline 9am–7pm Monday to Friday, 10am–2pm Saturday)
E hello@parkinsons.org.uk
W www.parkinsons.org.uk

This publication has been reviewed by people affected by dementia and health and social care professionals. A full list of sources is available on request.

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Alzheimer's Society

Leading the fight against dementia

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 3,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

If you have any concerns about Alzheimer's disease or any other form of dementia, visit **alzheimers.org.uk** or call the **Alzheimer's Society National Dementia Helpline** on **0300 222 1122.** (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)

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58 St Katharine's Way
London E1W 1LB

020 7423 3500
info@alzheimers.org.uk
alzheimers.org.uk

Health & care information you can trust
The Information Standard Certified Member

Code 37