

# THINKING AND MEMORY CHANGES IN PARKINSON'S

Find out more  
about thinking and  
memory changes in  
Parkinson's and how  
to manage these  
symptoms

In partnership with



University College  
London Hospitals  
NHS Foundation Trust

**PARKINSON'S<sup>UK</sup>**  
**CHANGE ATTITUDES.**  
**FIND A CURE.**  
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## Thinking and memory changes can be a normal part of getting older, but they may affect you more if you have Parkinson's.

This booklet aims to answer the most common questions you might have about thinking and memory changes, and looks at what you can do to manage these symptoms. It's for people living with Parkinson's, their family, friends and carers.

You do not need to read all of the information in this booklet at once. You can skip to the sections that are most relevant to you, or read parts only when you feel ready to.

The information in this booklet was put together by experts at University College London, people living with Parkinson's and thinking and memory changes, and Parkinson's UK. Find out more about this collaboration on page 43.

You can also read this information online at **[parkinsons.org.uk/thinkingandmemory](https://parkinsons.org.uk/thinkingandmemory)**

# CONTENTS

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What are thinking and memory changes?	4
Will thinking and memory changes happen to me?	15
What happens when I speak to a specialist?	19
Moving forwards: How can I live well with thinking and memory changes?	24
Can medication help?	33
Practical things to know about	36
Can I get involved in research?	41
How we developed this information	43
More information and support	46

# WHAT ARE THINKING AND MEMORY CHANGES?

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## In this section:

- What are the signs and symptoms of thinking and memory changes?
- What happens if thinking and memory changes get worse?
- Parkinson's dementia
- What is the difference between Parkinson's dementia and dementia with Lewy bodies?
- How is Parkinson's dementia different from other dementias, such as Alzheimer's?

Thinking and memory changes include things like becoming more forgetful, or taking a bit longer to remember things. For example, you might not remember why you've entered a room, or forget people's names. These changes can be a normal part of getting older because as we age, our brains become slower at processing information.

But if you have Parkinson's, these symptoms can be more noticeable. As well as forgetfulness, you may experience confusion, problems concentrating or difficulty making decisions.

These don't usually cause problems day-to-day. But if they get worse, they can start to affect everyday life. There are some steps you can take to improve these symptoms, so it is worth understanding them better.

## What are the signs and symptoms of thinking and memory changes?

If you have mild memory or thinking problems with Parkinson's, you may have:

- problems planning or doing a few things at the same time (multitasking). Or moving quickly from one task to another
- problems with attention and concentration. You might find it difficult to do everyday activities such as reading a newspaper article from start to finish
- difficulty using a computer or reading maps
- slowness of thoughts. You might find it harder to make decisions or respond to questions

Generally, these symptoms may not affect your daily life too much, but they might make you feel less organised than you used to be. Or you may get confused, particularly if you're feeling stressed.

It's important to remember that Parkinson's affects everyone differently. Not everyone will experience these symptoms or have the same combination of symptoms.

If you're experiencing these symptoms, your Parkinson's specialist may diagnose you with **Parkinson's with mild cognitive impairment**.

If you are worried about or are experiencing these symptoms, speak to your specialist doctor or Parkinson's nurse, as there may be positive steps you can take to improve them.

[See the section 'What happens when I speak to a specialist' to find out more.](#)



Isabelle was diagnosed with Parkinson's in 2004. Isabelle's partner, Graham, has noticed the positive effects of having her friends over.

# ISABELLE AND GRAHAM'S STORY

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“ I used to have physical symptoms, such as my hand shaking when trying to carry something. But recently, I’ve started noticing changes in my thinking too.

I used to struggle to remember people’s names, so instead I associated them with other things, like flowers. Now, my husband also has to prompt me. I’ve noticed that I have to think more about most things, but that writing a lot of these things down is helpful.”

Isabelle

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“ She is the happiest when her friends are around – she becomes quite bubbly and it takes her mind off of what she is going through. They talk on the phone together or come over for tea, and she opens her heart to them. I walk in the room and she has a big grin on her face.”

Graham

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## What happens if thinking and memory changes get worse?

For some people, their symptoms may get worse over time. But this doesn't happen to everyone.

If you have thinking and memory problems that get worse and start to affect everyday life, including things like cooking, cleaning and dressing, then **it's important to speak to your specialist**. They will be able to talk to you about useful things that you can do which could improve your symptoms. [See the section 'What happens when I speak to a specialist'.](#)

## Parkinson's dementia

If your thinking and memory problems are serious enough to affect your ability to carry out everyday tasks, your Parkinson's specialist may diagnose you with **Parkinson's dementia**.

Not everyone who experiences thinking and memory changes goes on to develop Parkinson's dementia.

Parkinson's dementia is very similar to another type of dementia, called **dementia with Lewy bodies**, and they share the same symptoms. These are the two main types of dementia that can affect people with Parkinson's.



## **People with Parkinson's dementia and dementia with Lewy bodies may experience:**

- difficulty with visual and practical tasks. For example, reading clocks or putting on trousers correctly
- slowness in thinking, difficulty finding words, or trouble concentrating, which can affect how you talk or communicate with others
- changes in thinking during the day – sometimes being alert but other times being confused
- changes in sleeping patterns. For example, taking more naps during the day despite getting a normal amount of sleep, or nodding off during meal times
- visual hallucinations (seeing something that is not there), and mistaking objects for other things. For example, a pile of clothes might look like a dog
- being less engaged, or finding you do not have as much interest in the activities you used to enjoy (apathy)
- anxiety, depression or feeling agitated

You may find that symptoms fluctuate from hour to hour, and day to day.

## What is the difference between Parkinson's dementia and dementia with Lewy bodies?

There are many different types of dementia. Parkinson's dementia and dementia with Lewy bodies are the two types of dementia that are most likely to affect people living with Parkinson's.

The main difference is the timing of when you start experiencing symptoms. If you've had movement symptoms (such as tremor or stiffness) for at least one year before symptoms of dementia, specialists will often give a diagnosis of Parkinson's dementia.

If you get dementia symptoms before or at the same time as movement symptoms, specialists will usually give a diagnosis of dementia with Lewy bodies.

These two conditions are sometimes grouped under an umbrella term: **Lewy body dementia**, which can be useful as the two conditions have similar symptoms. The term Lewy body dementia may also be used where it is not clear exactly when the thinking and memory problems started.

The causes and ways of managing symptoms in Parkinson's dementia and dementia with Lewy bodies are the same.

## How is Parkinson's dementia different from other dementias, such as Alzheimer's?

Parkinson's dementia is different from Alzheimer's disease, although some of the symptoms overlap. People with Alzheimer's experience memory problems, which means they may repeat questions and conversations. This is less common in Parkinson's dementia. People with Alzheimer's may also have trouble recognising their family and loved ones, which does not usually happen in Parkinson's dementia.



Pauline was diagnosed with Parkinson's around two years ago and more recently, with Lewy body dementia. Her partner, Antoine, describes her experience.





## PAULINE AND ANTOINE'S STORY

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“ At first, Pauline’s main symptoms were thinking and memory changes, confusion and changes in her behaviour. She seemed different, not herself and I was finding it very difficult to understand what was happening. Soon after this, her doctors said that she had Lewy body dementia. She now experiences visual hallucinations, where she describes seeing family members in the house when they are not there.

Her symptoms have progressed relatively quickly and I have now taken over most of the work around the house. I do most things because she often forgets to turn the stove off if she tries to cook, for example. I worry that I cannot leave her alone. It can be challenging to juggle caring for Pauline, whilst also carrying on working. However, having carers who come in for a few hours every couple of days can be very helpful.

It is not easy, but I try my best to go on this journey with her and keep her happy. I have found that being very patient and calm can go a long way.

Having our children come to visit makes a big difference. Our eldest son often comes over at the weekend. He will put the cooking channel on TV and talk about it with her, or they will go on YouTube and watch videos together. He engages a lot with her and is very patient and she enjoys his company. Our daughter also recently had a baby, who she brings around and this really cheers her up.”

Antoine

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# WILL THINKING AND MEMORY CHANGES HAPPEN TO ME?

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## In this section:

- What causes memory and thinking changes?
- Why do some people get these symptoms, and others don't?

Thinking and memory changes are common in Parkinson's. Around half of all people with Parkinson's will experience some form of thinking and memory changes within 10 years of their diagnosis.

But this doesn't mean you will go on to develop more serious problems. Everyone's Parkinson's is different.

If you're worried, you should speak to your Parkinson's specialist. There are different ways to improve symptoms or even slow the progression of these changes. So it's helpful to recognise them early.

[See the section 'Practical things to know about' to learn about the support available for you and your family members.](#)

## What causes memory and thinking changes?

Parkinson's leads to physical changes in the brain. As Parkinson's progresses, more brain areas are affected. One of the reasons for this is that there are lower levels of a brain chemical called acetylcholine, as well as dopamine. Another cause is that proteins can build-up in the brain and affect different brain areas. There is still a lot of research happening to understand the brain changes that cause thinking and memory symptoms in Parkinson's.

## Why do some people get these symptoms, and others don't?

It is not clear why some people are affected by these changes and others aren't.

Research shows that different things might increase the risk of developing thinking and memory changes if you have Parkinson's.

**These are called risk factors, and can include:**

- **Age.** People who are older when they are diagnosed with Parkinson's are more likely to develop these changes.
- **Genetics.** Researchers have found that some genes are linked with a higher risk of developing thinking and memory problems. One example is a gene called GBA.
- **Sleep changes.** Some types of sleep changes are linked with higher risk of developing thinking and memory symptoms. These include moving or shouting out during sleep.



- **Depression.** Whilst depression is common in Parkinson's, research has shown that it is also linked with a higher risk of developing thinking and memory problems.
- **Heart disease and stroke.** These conditions can have an effect on the structure of the brain, which can affect thinking and memory. For this reason, lowering the risk of heart disease and stroke is also important in Parkinson's.

These risk factors are highly variable between people. This means that if you have one or more of these risk factors, it doesn't mean that you will definitely develop thinking and memory problems. A significant proportion of people living with Parkinson's will never develop serious thinking and memory symptoms.

**Other things can also affect your focus and concentration. It's important to know about these, as there are things you can do to manage them.**

**For example:**

- **Anxiety and depression.** These symptoms can have a big impact on your ability to think, remember and process information properly. They can also affect your attention span and concentration. It's important to talk to your specialist if you're experiencing these symptoms so that you can get treatment.
- **Poor quality sleep.** If you're feeling tired or run down, or you're not sleeping well, this can affect your thinking, concentration and memory. Talk to your specialist if you are having trouble with your sleep, as they may be able to recommend things that may help.

- **Hearing or visual loss.** This will make it harder to respond to people and surroundings. Improving these through hearing aids, or treating visual loss, can improve thinking and memory symptoms.
- **Being unwell for other reasons.** Other issues like being constipated or having an infection can affect your thinking and memory and ability to concentrate. If you experience a sudden change in your thinking or memory, speak to your GP or Parkinson's nurse to see if they can rule these things out.

See the section 'Can I get involved in research?' to find out about research into thinking and memory changes.



# WHAT HAPPENS WHEN I SPEAK TO A SPECIALIST?

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## In this section:

- Questions to ask your specialist
- What to take to your appointment

If you've noticed changes in your thinking and memory, or are worried about developing symptoms, you should talk to your Parkinson's specialist at your next appointment. It's important to act early as there may be treatments that you can benefit from and things that you can do to improve your symptoms.

In your appointment, your specialist will ask questions to understand more about the changes you are experiencing. You may find it helpful to keep a diary or record your symptoms to help you to explain what has been happening.

You may be asked to do some assessments, such as drawing or copying simple pictures, writing a sentence, or performing a short thinking and memory test.

Your specialist may also carry out a physical examination, or arrange blood or urine tests. Sometimes, symptoms like confusion can be caused by other conditions. So they will need to rule out any other potential causes. They may also arrange a brain scan.

If possible, it is very helpful to bring someone who knows you well to your appointment. This can be your partner, family member or friend. This will be helpful for your specialist, as they can also give information about the changes they've noticed.

If your specialist diagnoses you with Parkinson's mild cognitive impairment or Parkinson's dementia, they may suggest a change to your current medication, or suggest starting a new medication for your thinking and memory. They may also suggest extra support for you or your family if that is needed, and you may be referred to a memory clinic for more support.

## Questions to ask your specialist

It might be helpful to take some questions with you to your appointment.

### For example:

- What changes can I expect?
- What can I do to slow the progression of thinking and memory changes?
- What help can I get?
- What help is available for my partner or family?
- What things do I need to think about to plan ahead?

## What to take to your appointment

- Notes of the changes you've noticed
  - A list of your current medications
  - Your questions
  - Someone who knows you well, if possible
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**“It’s important to talk about the issues you are experiencing, especially when it comes to your memory or ways that you think. Letting us know what you are going through, or worried about, means we can respond in a timely way and help get the right support for you and your partner or family members.”**

**Emma Edwards, Parkinson’s Nurse Specialist**

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It can be frustrating and scary to experience thinking and memory changes. There is lots of support available for you and family members if you are worried about these changes. [See the section 'Practical things to know about' to learn about the support available for you and your family members.](#)



Lilla's sister, Jasmine, was diagnosed with Parkinson's in 2020.

## LILLA AND JASMINE'S STORY

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“For me to help Jasmine, I thought – I am going on a journey with her through this. That’s how I started going to appointments with her and building trust. She had to feel comfortable making certain decisions and I was there to support her. Often after an appointment, we will go to a coffee shop to discuss the appointment and any medication changes needed. The connection we built through this time was very important. Being in this journey together has strengthened our relationship.”

Lilla (pictured left)

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# MOVING FORWARDS: HOW CAN I LIVE WELL WITH THINKING AND MEMORY CHANGES?

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In this section:

- Being active
- Eating well
- Reducing alcohol and smoking
- Managing other symptoms
- Challenging your brain
- Staying social
- Practical tips

Even if you've already started experiencing thinking and memory changes, there are things you can do to help manage symptoms.

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**“Some people believe that nothing can be done about thinking and memory changes in Parkinson's. But that isn't the case. There are several important steps that people can take for themselves to improve and even slow thinking and memory changes.”**

**Dr Rimona Weil, Consultant Neurologist**

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## Being active

Being physically active is important for people with Parkinson's. It's especially important for managing thinking and memory symptoms.

Regular, moderate to vigorous physical activity may help improve your cognitive ability and help your brain to work more efficiently. It can also reduce the risk of anxiety and depression.

Physical benefits of being active include better muscle and bone strength, better balance and a reduced risk of falls. It can also reduce the risk of developing other health problems such as heart disease and stroke. These can affect thinking and memory, so reducing the risk of these is important.



## What should I aim for?

Physical activity can include everyday things you may already be doing like walking, gardening, and climbing the stairs. You should try to find activities that you enjoy to raise your heart rate and also some activities that focus on flexibility, balance, strength, and multitasking.

Ideally you should aim for 2.5 hours of physical activity a week. This is around half an hour, five days a week. Scheduling activity each day at a specific time can create a habit, and make it easier to maintain. It can also be helpful and enjoyable to exercise with other people. The most important thing is choosing something that you find enjoyable and achievable.

**Find out more:** It can be tricky to know how to get started, or what you should be doing. Our guide *Being active with Parkinson's* has lots of suggestions and tips on where to start, and includes advice from experts and other members of the Parkinson's community. You can order it for free by calling **0330 124 3250**, or go to **[parkinsons.org.uk/exercise](https://parkinsons.org.uk/exercise)** to download it online.

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**“Having a dog means I keep active and stay positive. I often suddenly realise I have walked twice as far as I thought I would.”**

**Nick, person with Parkinson's**

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## Eating well

While there is no specific diet that is recommended for Parkinson's, having a healthy and balanced diet will improve your overall wellbeing and may even help your thinking and memory.

**Find out more:** see our information on diet and Parkinson's.

## Reducing alcohol and smoking

It's important to continue to have a fulfilling and enjoyable life. However, your specialist may speak to you about moderating how much alcohol you drink, and cutting down or stopping smoking.

You can ask your GP whether any changes to your lifestyle might help you. For example, making sure your blood pressure is well controlled could help prevent thinking and memory problems getting worse in the future.

## Managing other symptoms

If you have hearing or visual loss, improving these can have a positive effect on your thinking and memory. This is because anything that makes it harder to follow what is going on around you, will affect how well you can respond to things.

Make an appointment to get a hearing test if you have noticed problems with your hearing. Or if you have visual symptoms, get advice from your optician or eye doctor.

Not sleeping well will affect how clearly you can think during the day.

How often you need to get up at night to use the toilet can affect your sleep. If this is a problem, try to avoid tea, coffee, alcohol, or fruit juice in the evening, as these can make you need the toilet more.

If this does not help, you can speak to your specialist about medications that can help with managing how often you need to use the toilet.

## Challenging your brain

If you enjoy doing puzzles, games and crosswords, these can keep your brain stimulated. Other examples of activities to challenge your brain are reading, learning and socialising (see below).

## Staying social

Social activities and maintaining social connections can keep your brain engaged and could help your thinking and memory symptoms.

This might be something like going to social clubs, continuing to do hobbies and things you enjoy, and staying in touch with friends and family. Some people also find religion, faith and spirituality, as well as staying connected to their community can be helpful. Social activities are really important to manage and even improve symptoms.



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“Joining support groups can be very inspiring because it helps you understand that you are not alone in going through this. This is all about learning and finding tools to help you manage your life. This isn’t something that will just go away, it is part of life, but also something that should not hold you back from enjoying your life.”

Bina, person with Parkinson’s

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There is lots of in-person and online support to help you live well with Parkinson’s. Search online at **[parkinsons.org.uk/support](https://parkinsons.org.uk/support)** to find your nearest local group, emotional and practical support, health and wellbeing services or social activities.

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“Studies show that there are things that we can all do to look after the health of our brains, and prevent or slow thinking and memory problems.

Keep active – physically, mentally and socially. Keep well hydrated and eat a balanced, nutritious diet. Get a good night’s sleep.

And if you are concerned about changes that you’ve noticed in your thinking and memory, then act early and tell your specialist. There may be treatments that you can benefit from and things that you can do yourself that might help.”

Prof Camille Carroll, Neurologist

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## Practical tips

If you find that thinking and memory problems are starting to affect your daily life, there are tips and techniques that might help.

### Visual prompts

- Having calendars, clocks, noticeboards and notices around your home may help jog your memory.

### Routine and being organised

- Having a clear daily routine can be helpful. Being as organised as possible can help you stay focused and reduce stress.
- You might find it helps to keep a list of things to do. You can see what you have achieved as you tick off each task.
- Remember that sometimes it helps if you slow down and tackle one thing at a time, rather than trying to do multiple things at once.
- Prioritise the things you have to do and the things you want to do, and choose which things you can leave for later.
- Giving your undivided attention to whatever you're doing can help you avoid mistakes. This can reduce stress and help you feel in control.

## Thinking and memory aids

- A basket or box to keep things like your keys, wallet and glasses in one place.
- Drug dispensers and pill timers can be a useful reminder to take your medication, as it's important to take it at the times advised by your specialist or Parkinson's nurse.
- Keep a diary of your symptoms. This can help you explain any problems when you see your healthcare professionals.

## Therapies and support services

There are many types of therapies and other support services that may be able to improve or help manage some of your symptoms.

These include:

- physiotherapy
- speech therapy
- occupational therapy
- support from specialist mental health services, such as neuropsychology

Your specialist and Parkinson's nurse can talk to you about what type of treatment is best for you.

[We have lots of information on the above therapies. See the 'More information and support section' for details on how to order our other information.](#)



# CAN MEDICATION HELP?

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## In this section:

- Rivastigmine (also called Exelon and Prometax)
- Donepezil (also called Aricept and Adlarity)
- Galantamine (also called Reminyl and Razadyne)
- Memantine (also called Evixa, Nemdatine and Valios)

If you're diagnosed with Parkinson's dementia, your specialist may review your medication. This is because some of the side effects of Parkinson's medication can make the symptoms of Parkinson's dementia worse.

But reducing the dose, or stopping these drugs, may mean that the movement symptoms of your Parkinson's are not as well controlled as before. For this reason, treating the dementia symptoms needs to be balanced with managing physical symptoms.

Your specialist will also talk to you about what medication might help.

Do not stop or change your medication by yourself. Always speak to your specialist or Parkinson's nurse if you are having issues.

Medications that are **often** used to help in Parkinson's dementia include:



### **Rivastigmine (also called Exelon and Prometax)**

Rivastigmine belongs to a group of drugs called Cholinesterase Inhibitors. They stop the breakdown of acetylcholine in the brain. Acetylcholine allows nerve cells to communicate with each other. Rivastigmine increases the levels of acetylcholine in the brain, and boosts thinking and memory.

Rivastigmine comes in two forms – a capsule, usually taken twice a day, and a patch that is put on once a day. For both of these, the dose is usually increased gradually over time by your specialist.

Rivastigmine can sometimes cause side effects. The most common side effects are stomach problems such as feeling sick, or diarrhoea. Occasionally, it can also cause trembling, slight worsening of Parkinson's symptoms, or nightmares. It can slow the heart rate, so your pulse will be checked before starting, and some people may have an ECG (heart tracing).

### **Donepezil (also called Aricept and Adlarity)**

Donepezil is also a Cholinesterase Inhibitor, like Rivastigmine, and works in a very similar way to boost thinking and memory. It is taken as a tablet, usually once a day.

Donepezil has the same side effects as Rivastigmine, with some people feeling sick, or experiencing diarrhoea. It can make movement symptoms of Parkinson's worse. Similar to Rivastigmine, it can also slow the heart rate, so a pulse check or ECG may be needed before starting.

Other medications that are **sometimes** used include:

### **Galantamine (also called Reminyl and Razadyne)**

Galantamine also acts by increasing the amount of acetylcholine in the brain. It is taken as a capsule and causes similar side effects to Rivastigmine and Donepezil.

### **Memantine (also called Evixa, Nemdatine and Valios)**

Memantine acts on a group of receptors in the brain called "NMDA receptors". These help communicate nerve signals in the brain that help with learning and memory.

Memantine is usually taken as a tablet, once a day, and the dose is gradually increased over a few weeks.

The most common side effect of memantine is sleepiness. It can also cause headaches and constipation.

# PRACTICAL THINGS TO KNOW ABOUT

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## In this section:

- How do I plan for the future?
- Practical support for loved ones
- Should I tell other people?

## How do I plan for the future?

If you have thinking and memory problems, or support someone who does, it's important to try to plan for the future.

If your thinking and memory problems get worse, then having plans set in place will make things like managing legal documents, money and your health easier.



Planning ahead can also reduce stress. These are some things to consider, when you feel ready to.

### **Power of Attorney**

Consider setting up a power of attorney. This means that you nominate one or more people that you trust to make decisions on your behalf about legal and health matters. This gives you more control and helps you to decide in advance what happens if you have an accident or an illness and cannot make your own decisions.

Visit [parkinsons.org.uk/lpa](https://parkinsons.org.uk/lpa) to find out more

### **Driving**

If you've been diagnosed with Parkinson's dementia and still drive, you have to tell the Driver and Vehicle Licensing Agency (DVLA), or Driver & Vehicle Agency (DVA) in Northern Ireland, about your diagnosis. You must also tell your car insurer.

**Find out more:** see our information on driving and Parkinson's

### **Insurance**

If you've been diagnosed with Parkinson's dementia, you may also need to tell your travel or life insurance company about your diagnosis.

## Benefits and financial support

Feeling in control of your finances is incredibly important for your mental and physical health. From benefits and grants to loans and other support, there is support out there.

Our advisers can help you find what's available to you. Call our helpline to see what you might be entitled to on **0808 800 0303**.

## Advanced care planning

Advanced care planning is a way to support people to ensure they have the care they want at any stage. This includes at the end of life.

By thinking about the future and talking about what you want, you can be more in control about what lies ahead.

You can also make your wishes known about your care using a framework called ReSPECT, which stands for Recommended Summary Plan for Emergency Care and Treatment. The ReSPECT process creates a personalised recommendation for your clinical care in emergency situations where you are not able to make decisions or express your wishes.

You can learn more about this on their website at **[www.resus.org.uk/respect](http://www.resus.org.uk/respect)**

Our helpline can offer practical advice on care planning. Contact our helpline for free on **0808 800 0303** to speak to an adviser.

## Practical support for loved ones

You might be a family member, a partner, or a friend, providing care and support to someone with Parkinson's who has thinking and memory problems.

- If you regularly provide support or care for someone with Parkinson's dementia, you have a right to a 'carer's assessment'. This is done through your local authority. After your assessment, if your local authority agrees you have needs, they will arrange services to help you. To find out more, contact your local authority or speak to your GP.
- You may also be able to get financial support. This includes benefits like Carer's Allowance and help with council tax bills.
- There are many local support groups and services for carers of people with Parkinson's. [See the 'More information and support section' to find out more.](#)

## Should I tell other people?

It can be daunting explaining Parkinson's to other people. This may be especially true if you're experiencing thinking and memory changes. You may find it difficult or upsetting, or not know what to say.

Other people might include friends, wider family members or your manager at work.

**There are some benefits about talking to others about these symptoms. It can:**

- make you feel more able to cope with any worries you have

- help extend your support network
- strengthen and build new relationships
- help you to feel more in control and empowered
- help to raise awareness and educate others

### **These are some tips on how to approach conversations:**

- Be prepared. You may want to make a list of things you would like to say during the conversation or try to anticipate questions that other people are likely to ask. You could also have information leaflets or booklets ready (like this one) to provide others with more information during conversations.
- A comfortable and relaxed environment is best, where you won't be distracted. Some people may also find it easier to talk when you are out walking or doing something where you are beside each other.
- During the conversation, try not to rush. Remember that you can take time to think about your responses and take a break if you need to.
- It's important to think about reactions during the conversation. People that you talk to may react in unexpected ways and some may not know how to react. Others may find the conversations upsetting. It's important to acknowledge this and take a break if needed.

**Find out more:** see our information on speech and communication problems in Parkinson's.



# CAN I GET INVOLVED IN RESEARCH?

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Researchers are making a lot of progress in why thinking and memory changes happen in Parkinson's.

**Researchers are currently focusing on:**

- the proteins that build-up and how they affect the brain
- understanding why these changes happen and the causes
- what can slow down the progression of symptoms, including better medications and treatments

Researchers rely on people who are experiencing symptoms like thinking and memory changes to understand why they happen and make progress. You are the expert. The more people that take part in research, the more we will learn about the condition.

Getting involved in research can take many forms, including volunteering for studies and clinical trials, giving blood for genetic research, or sharing your views on the healthcare you receive through questionnaires. It's possible to get involved in some types of research from the comfort of your own home.

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**“We have been involved in research, which we both find a very worthwhile thing to do. We can both say we have given something back.”**

**Chris and Sian, person with DLB and his partner**

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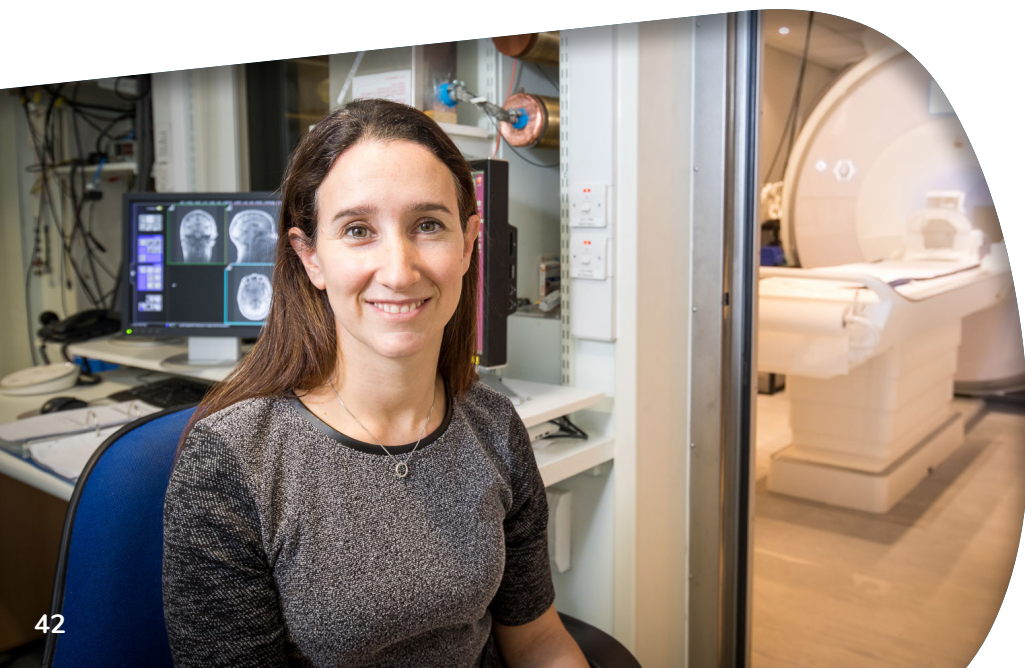
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“Current research is looking at why people with Parkinson’s often have such different symptoms. It’s possible that different people with Parkinson’s have different proportions of these proteins building up. We hope that if we can understand this better, then in future, when new treatments are developed, we will be able to target the right treatment to each individual person with Parkinson’s.”

Dr Rimona Weil, Neurologist and Neuroscientist, UCL

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If you would like to know more about current research projects, and get involved in ongoing studies local to you, please visit the Take Part Hub on the Parkinson’s UK website at [parkinsons.org.uk/research](https://parkinsons.org.uk/research)



# HOW WE DEVELOPED THIS INFORMATION

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This booklet was co-developed as part of a multidisciplinary project, led by **Dr Rimona Weil**. The project, Patterns of Perception in Parkinson's (PoP-PD), was co-developed with people living with Parkinson's and Parkinson's UK. Dr Weil is a Neurologist at the National Hospital for Neurology and Neurosurgery, and Neuroscientist at UCL.

**The project involved a collaborative core team including:**

- Public engagement experts (based at UCL)
  - » Joanne Thomas
  - » Cassie Hugill
  - » Sian Rose
- Researchers (based at UCL)
  - » Ivelina Dobрева
  - » Dr Moïse Roche
  - » Charlotte Dore
- Artists (based at Central Saint Martins)
  - » Anne Marr
  - » Ruairiadh O'Connell



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- Emma Edwards, Parkinson's Specialist Nurse, Plymouth
- Dr Jennifer Foley, Psychologist, London
- Prof Tom Foltynie, Neurologist, London
- Dr Victoria Haunton, Geriatrician, Plymouth
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- Prof Monty Silverdale, Neurologist, Salford
- Dr Aida Suarez-Gonzalez, Psychologist, London
- Dr Ajenthan Surendranathan, Neurologist, London
- Dr Caroline Williams-Gray, Neurologist, Cambridge
- Prof Alison Yarnall, Geriatrician, Newcastle

**Find out more:** read about the collaboration at [engagement.fil.ion.ucl.ac.uk/projects/pop-pd](https://engagement.fil.ion.ucl.ac.uk/projects/pop-pd)

**Photo on pages 22, 29, 45 by Gareth Johnson.**



# MORE INFORMATION AND SUPPORT

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## Alzheimer Scotland

Provides support to people living with dementia in Scotland.

**0808 808 3000**

**helpline@alzscot.org**

**www.alzscot.org**

## The Alzheimer's Society

Information, advice and support for people with dementia and their families.

**0300 222 1122**

**enquiries@alzheimers.org.uk**

**www.alzheimers.org.uk**

## Dementia UK (Admiral Nurses)

Provides support for families facing dementia through their dementia specialist nurses.

**0800 888 6678**

**enquiries@dementiauk.org**

**www.dementiauk.org**

## The Lewy Body Society

Information and resources on Lewy body dementia.

**01942 914000**

**info@lewybody.org**

**www.lewybody.org**

## Parkinson's nurses

Parkinson's nurses have specialist experience and knowledge of Parkinson's.

They can provide support, help people to manage their medication and make referrals to other professionals.

Talk to your GP or specialist for more details on speaking to a Parkinson's nurse.

## Parkinson's UK information and support

You can read our most up-to-date information at **[parkinsons.org.uk](https://parkinsons.org.uk)**

You can order printed information by calling **0330 124 3250** or visiting **[parkinsons.org.uk/orderingresources](https://parkinsons.org.uk/orderingresources)**

Our specialist adviser team can provide information about any aspect of living with Parkinson's.

Call our team on **0808 800 0303** or email **[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)**

If you'd like to meet other people living with Parkinson's in your local area, you can find friendship and support through our network of volunteers and local groups. Go to **[parkinsons.org.uk/localgroups](https://parkinsons.org.uk/localgroups)** or call our helpline to find out more.

Our forum is also a very active space to share and chat with others who really understand, at a time that suits you. Visit **[parkinsons.org.uk/forum](https://parkinsons.org.uk/forum)**

## Feedback

If you have any comments or feedback about our information, please call **0800 138 6593**, email **[feedback@parkinsons.org.uk](mailto:feedback@parkinsons.org.uk)**, or write to us at **Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ.**

If you'd like to find out more about how we put our information together, please contact us at **[healthcontent@parkinsons.org.uk](mailto:healthcontent@parkinsons.org.uk)** or visit our website.

## Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's. If you would like to get involved, please contact our Supporter Care team on **0800 138 6593** or visit our website at **[parkinsons.org.uk/donate](https://parkinsons.org.uk/donate)**

**Thank you.**



We are Parkinson's UK.  
Powered by people.  
Funded by you.  
Improving life for everyone  
affected by Parkinson's.  
Together we'll find a cure.

**PARKINSON'S<sup>UK</sup>**

Free confidential helpline **0808 800 0303**  
Monday to Friday 9am–6pm, Saturday 10am–2pm  
(interpreting available)  
NGT relay **18001 0808 800 0303**  
(for textphone users only)  
**hello@parkinsons.org.uk**  
**parkinsons.org.uk**

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



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