



Your guide to living fully after a Parkinson's diagnosis

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Purpose of this guide

This quick-reference guide covers some of the key things you need to know after being diagnosed with Parkinson's, with a focus on the early stages. In Parkinson's, this is the time after diagnosis when symptoms are usually mild to moderate and manageable, and you can still do most of the things you enjoy. Regardless of your age at diagnosis, this guide offers practical tips and advice to help you cope with your diagnosis, manage your symptoms and navigate the challenges of daily life so you can continue to live a full life with Parkinson's.

How to use this guide

There are five sections in this guide which you can go through at your own pace. Take your time; you can return to a section as many times as you need to.

Each section also includes links and resources to connect you with others or further information if you would like to learn more. If you are worried or unsure about something, you can always speak to your doctor for advice.

This guide provides information to help you learn about Parkinson's. It should not be used to diagnose or treat any medical condition, or replace advice from your doctor. If you have any questions or worries about your health, your treatment, or the information in this guide, please talk to your doctor. Always ask your doctor before starting or changing any treatments.

How can I cope with my early-stage Parkinson's diagnosis?

A Parkinson's diagnosis can feel overwhelming, bringing a mix of emotions. It is important to have support in place to help you navigate the changes that you may experience. This section provides tips and practical suggestions for adapting to life after diagnosis.



I decided to fight back and find out everything about Parkinson's.

– Parkinson's Foundation Forum Member⁷



Navigating the emotions of an early-stage Parkinson's diagnosis

You may be feeling:¹⁻³

- **Confusion and anxiety** – unsure what this means for your future
- **Sadness** – you don't understand why this has happened to you
- **Relief** – the symptoms you've been experiencing finally make sense

Remember that each person will react to their diagnosis differently, and that is completely normal.

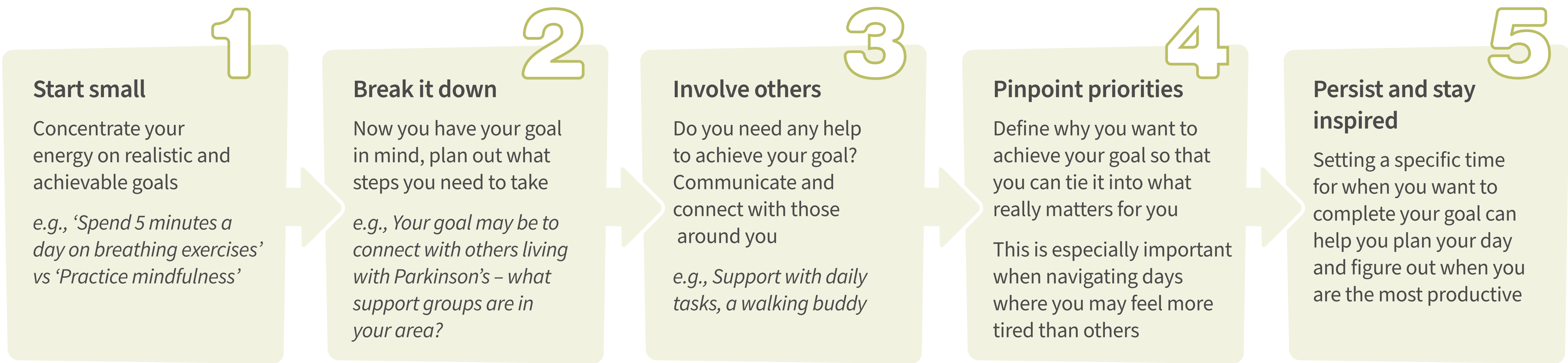
Taking charge of your emotional well-being

Below are some ideas to help you navigate the emotional challenges of a Parkinson's diagnosis:

- Learning about Parkinson's can help you to feel more in control⁴
- Talking to your family, friends or doctor can help to ease your anxiety and process your concerns⁵
- Joining a support group can help you feel less isolated⁶
- Writing down your thoughts and feelings can release bottled-up emotions and may be a useful way to identify anxiety triggers⁵
- Relaxation techniques (e.g., breathing exercises) can help calm your mind and body⁶
- Meditation or symbolic practices such as prayer can be a source of comfort and strength⁵

Adapting to change, one step at a time

Parkinson’s can affect your daily routine, as you may not have the same levels of energy as you used to. Some days may feel more frustrating and challenging than others but there are steps you can take to help you prepare for these changes.^{8,9}



Adapting to change will take time, but it gets easier

“ I have just had to learn to go with it, and to give myself way more time to do things than I think I actually needed.
– Parkinson’s UK, Person with Parkinson’s (4 years after diagnosis)¹⁰ ”



TOP TIPS

Here are some things you can ask for support with:¹¹

- Connecting with others with Parkinson's or their families/care partners to share experiences and with local Parkinson's organisations for resources and support
- Exploring what benefits or financial aid may be available to you
- Managing important notifications, including letting your insurance company know about your driver's license
- Coordinating your healthcare appointments and medications

While this guide focuses on the early stage of Parkinson's, your age at diagnosis can affect your experience. Younger people with Parkinson's may face different challenges related to their career or raising a family compared with older people. Connecting with support groups for people like you can make a big difference.¹²



The best thing I did was join the Parkinson's UK forum. Within a very short time I had responses coming in from people who knew exactly what my husband and I were going through. It helps to know you are not on your own and others are feeling exactly the same way you are.

Parkinson's UK Forum Member¹³



Talking to your employer about Parkinson's

Deciding when to tell your employer about your diagnosis is a personal choice. For some jobs, you might need to have that conversation sooner rather than later. Many people delay it because they're worried about being judged or treated differently. Although it can be a difficult decision, talking to your employer can help you get the support you need to continue working with Parkinson's.¹⁴



TOP TIPS

Top tips for talking to your employer^{14,15}

- Plan what you want to share about your Parkinson's and how it might affect your work
- Highlight your strengths and suggest any changes that might help you keep working well
- Connect with Parkinson's organisations and support groups for advice about work, including your rights

A Parkinson’s diagnosis can feel overwhelming, but there are many ways to manage these emotional challenges. Remember, it is okay not to know everything right now, and there are plenty of resources and support available to help you navigate this journey.

Find out more about coping with an early-stage Parkinson’s diagnosis

Click on the links below to find out more about topics covered in this section.

Find local support groups

[Newly diagnosed with Parkinson’s | Parkinson’s UK](#)

[Support for family and friends | Parkinson’s UK](#)

[Local groups | Parkinson’s UK](#)

[Find your chapter | Parkinson’s Foundation](#)

A guide for people newly diagnosed with Parkinson’s

[Newly Diagnosed Guide | Parkinson’s Foundation](#)

Caring & Coping: A Care Partner’s Guide to Parkinson’s Disease

[Caring & coping: A care partner’s guide to Parkinson’s disease | Parkinson’s Foundation](#)

Living Your Best Life: A guide to Parkinson’s Disease

[Living your best life: A guide to Parkinson’s disease | Parkinson’s Foundation](#)

A video playlist for coping strategies

[Coping strategies – tips & tricks | YouTube](#)

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What should I know about early-stage Parkinson's and managing it?

You've been diagnosed with Parkinson's, but what does it actually mean? This section provides an overview of Parkinson's in the early stages, including typical symptoms and available treatment options to help you understand what living with Parkinson's may look like.

Tracking early-stage symptoms

Some symptoms, known as 'motor' symptoms, may affect your movement. Non-motor symptoms are other symptoms that do not affect movement (see table on the next page for examples). It's helpful to keep track of these so you can let your healthcare team know how they can support you.¹



I was around 30 when I first went to the GP. I remember smelling something awful, like electrical burning – an ionised, smouldering aroma. It had happened a couple of times, until one day I lost my sense of smell completely. My GP put it down to scuba diving when I was younger... Almost 20 years later, after developing a tremor in my finger, I was given a diagnosis of Parkinson's. It was only then that I found out the two were linked.²

– Parkinson UK Forum Member



Keep a record of the following:

NON-MOTOR SYMPTOMS		MOTOR SYMPTOMS	
Problems with sleep	Is your sleep pattern disrupted?	Tremor and uncontrollable movement	How often are these symptoms?
	If so, which problem are you experiencing? <i>E.g., insomnia, waking up throughout the night (‘nocturia’), periodic leg movements, excessive daytime sleepiness, pauses in breathing during sleep (‘apnoea’)</i>		How long do they last?
	Potential disruptors: • Is there something specific on your mind? • Any new activity? • A new environment?		How severe are they?
Losing sense of smell	Are you experiencing strange smells?	Slowness of movement	Note down what you were doing at the time of the occurrence to identify any potential triggers
	If so, how frequently?		
	Is your sense of taste affected?		
Bladder and bowel problems	Do you have an urgent need to urinate without warning?	Stiffness, inflexibility and cramps	
	Do you wake up more than twice to urinate throughout the night? If so, does this affect your sleep?		
	Is there a change in your bowel movements – diarrhoea or constipation?		

Is it ageing or Parkinson’s?

Though some Parkinson’s symptoms might overlap with ageing, there are key differences.

Here are some examples of what to look out for in Parkinson’s:^{3,4}



I believe that exercise and weight training remain the most essential self-help one can practice, in addition to diet.

– Parkinson’s Foundation Forum Member⁶



Walking difficulties

- A stooped posture
- Reduced arm swing
- Shuffling with your feet flat rather than walking with a heel-toe stride
- Sudden moments of ‘freezing’ where you feel unable to move your feet, even if you want to

Bladder problems causing urinary incontinence

- Frequent and sudden moments where you may feel the urge to urinate
- Typically experienced during the night

Problems with sleep

- Acting out dreams in your sleep
- Insomnia
- Periodic leg movements
- Affected breathing

Managing your Parkinson’s symptoms

There are different ways to manage your symptoms and help to limit their impact on your life.

Physical activity: Building exercise into your routine can have a positive impact both physically and mentally. This could include taking long walks, playing tennis, joining Parkinson’s-specific boxing or dance classes, or even simple actions like walking up the stairs.⁵ Talk to your healthcare team about which activities are best for you.

Lifestyle changes: Making small changes to your diet, such as replacing caffeinated drinks and reducing your intake of refined sugars and salty foods, can help manage tremors and sleep problems.⁶

Medication: Your healthcare team will explore the different medications available to recommend one which is suitable for you.⁷

Complementary therapies: It’s important to get the right level of emotional support, which may include seeking professional help through a counsellor. Massages, acupuncture and cognitive behavioural therapy may help relieve symptoms such as anxiety.⁸

Understanding Parkinson’s progression

Parkinson’s and its symptoms progress over time, but everyone experiences Parkinson’s differently. Your symptoms might change from day to day, and how quickly the condition progresses varies from person to person. However, with proper management and support, you can maintain a good quality of life for many years.

There are different ways of managing your symptoms, and keeping track of them is important. This information will help you and your doctor explore options together to find what works best for you.

Find out more about managing early-stage Parkinson’s symptoms

Click on the links below to find out more about topics covered in this section.

Early-stage symptoms

[Parkinson’s symptoms | Parkinson’s UK](#)

[10 early symptoms of Parkinson’s | Parkinson’s UK](#)

Treatment options for managing your symptoms

[Treatments and therapies for Parkinson’s | Parkinson’s UK](#)

[Treatment | Parkinson’s Foundation](#)

[Treatment | Parkinson’s Europe](#)

[Prescription medications | Parkinson’s Foundation](#)

[Over the counter & complementary therapies | Parkinson’s Foundation](#)

Exercises for managing your symptoms

[Physical activity and exercise | Parkinson’s UK](#)

[Physical activity and exercise | Parkinson’s Europe](#)

How Parkinson’s progresses

[How does Parkinson’s progress? | Parkinson’s UK](#)

[Stages of Parkinson’s | Parkinson’s Foundation](#)

Practical tips and lifestyle adjustments

[Practical pointers | Parkinson’s Foundation](#)

A guide to ‘living your best life’

[Living your best life: A guide to Parkinson’s disease | Parkinson’s Foundation](#)

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8. Parkinson’s UK. Getting to know a cognitive behavioural therapist. <https://www.parkinsons.org.uk/information-and-support/your-magazine/experts/getting-knowa-cognitive-behavioural-therapist>. Accessed December 2024.

How can I live well with early-stage Parkinson's?

Living with early-stage Parkinson's brings changes, but there are ways to manage them.¹ This section covers common symptoms that may affect how you think and feel, their impact on your daily life and relationships, and how you can improve your well-being.

Common symptoms may affect the way you think and feel

Parkinson's can cause symptoms that impact how you think and feel, often before movement symptoms appear. Some people experience one or two of these symptoms, while others notice more. Fortunately, many find that therapy, lifestyle changes or adjusting medication can help.^{1,2}

Depression²

- Feeling very sad or empty for a long time
- Linked to Parkinson's or the timing of medication

Anxiety²

- Feeling very worried or scared, often about living with a long-term condition
- Can cause physical symptoms like a racing heart or trouble breathing

Fatigue¹

- More than just feeling tired – it's a deep exhaustion that doesn't go away with rest
- Can limit daily activities and can vary from day to day

Memory and concentration changes¹

- Trouble remembering things, concentrating or making decisions
- Difficulty following instructions and conversations or finding the right words
- Can become more noticeable to you or your loved ones over time

Apathy¹

- Feeling less motivated or interested, making hobbies and socialising harder

Changes may impact your daily life and relationships

Communication³

- Changes in speech, like a softer voice or difficulty finding words
- Handwriting might also become smaller or harder to read

Facial expressions and body language⁴

- Difficulty showing reactions like smiling or frowning
- May lead others to misread how you feel

Intimacy and sexual health⁴

- For some, movement symptoms and fatigue make intimacy challenging
- Bladder and bowel control issues can affect self-esteem and reduce sex drive
- For others, increased sexual thoughts and desires lead to a higher sex drive



TOP TIPS

Top tips for communication:

- Have one-on-one or small group conversations to make communication easier⁵
- Regularly practice your communication skills. This could include working with a speech and language therapist or physiotherapist, joining a choir or taking part in other activities that involve communication⁴

Top tips for intimacy:⁴

- Plan intimacy for when your medication works best and you have the most energy
- Set the mood with playful activities, like massages or trying new lingerie
- Try different positions to find what feels most comfortable
- Talk to your doctor. Medication changes might help with issues like side effects

Making a personalised self-care plan can improve your well-being

Creating a personalised self-care plan can help you manage your symptoms and improve your well-being.⁶ Use the template to set goals and work them into your routine.

Self-care plan

Creating a personalised self-care plan can help you manage your symptoms and improve your well-being. Use the template below to set goals and work them into your routine.

HOW TO USE

- 1. Choose an achievable activity or goal for each area (e.g., mental health). Something you enjoy, like going to a family event or a physical activity, can boost your mood
- 2. Break down each goal into smaller steps
- 3. Track your progress and reward yourself to stay motivated

SUPPORTERS

List who will support your plan and how they can help (e.g., family, friends, doctor)

EXAMPLE	MENTAL HEALTH Choose an activity like meditation, practising gratitude or writing down your thoughts and feelings		
	Activity	Meditate for 10 minutes every morning	
	What you will gain	I will feel calmer and ready to start the day	
	Steps involved	1. Before bed, set aside 10 minutes in the morning 2. Wake up and load meditation app 3. Set a timer for 10 minutes 4. Meditate	Progress ✓ ✓

MENTAL HEALTH Choose an activity like meditation, practising gratitude or writing down your thoughts and feelings		
Activity		
What you will gain		
Steps involved		Progress

EMOTIONAL HEALTH Do a hobby, spend time with loved ones or attend a support group		
Activity		
What you will gain		
Steps involved		Progress

Continues on next page | 1/2

Please use the self-care plan at the end of this document >

While Parkinson’s presents challenges, there are steps you can take to help you live well. By learning about symptoms, building supportive relationships and keeping healthy habits, you can improve your well-being and enjoy a fulfilling life.

Find out more about living well with early-stage Parkinson’s

Click on the links below to find out more about topics covered in this section.

Symptoms that may affect the way you think and feel

[10 early symptoms of Parkinson’s | Parkinson’s UK](#)
[Symptoms of Parkinson’s | Parkinson’s Europe](#)

Changes impacting your daily life and relationships

[Communication, relationships and Parkinson’s | Parkinson’s Europe](#)

How your care partner and family can support you

[Caring & coping: A care partner’s guide to Parkinson’s disease | Parkinson’s Foundation](#)

Top tips for living well

[5 steps to living well | Parkinson’s Foundation](#)

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How could joining a clinical trial help me and others with early-stage Parkinson's?

Clinical trials offer a chance to try new therapies and help with vital research in early-stage Parkinson's.¹ This section looks at the role of clinical trials in developing new treatments and the benefits and risks of participating.

What are clinical trials?¹

Clinical trials are research studies designed to learn more about a condition and test the safety of new medicines and how well they work.

In a Parkinson's clinical trial, researchers might:

- Look for measurable signs of Parkinson's to diagnose it or track its progression
- Test if a new treatment is safe and works well
- Study the role of genes and proteins to develop better treatments
- Explore how things like diet and lifestyle affect the condition
- Look at ways to help slow the progression of Parkinson's, such as physical activity

How are researchers and the Parkinson's community working together to improve Parkinson's care?^{2,3}

People living with Parkinson's and their care partners have an important role in helping researchers decide what to study and how to study it. By taking part in clinical trials, you can help to improve understanding of Parkinson's and support the development of new and better treatments.



There's nothing to lose and so much to gain. Do it! You may benefit from the introduction of a groundbreaking drug. Personally, I know that having Parkinson's is hard. It's really tough. So if there is something I can do to help others, and potentially even myself, I'm going to be a part of it. We need this research to improve the condition for us all.

– Trial participant⁴



What are the benefits and possible downsides of taking part in clinical trials?^{1,5}

Benefits

- Early access to potentially helpful treatments
- Learn more about your condition and get guidance from experts
- Feel more in control and empowered by being part of something important
- Help researchers understand more about Parkinson's and how different people respond to treatments
- Support the global search for better treatments and a cure for future generations

Possible downsides

- Treatment may not work
- Some trials use placebos, or dummy treatments, meaning not all participants will receive the medicine
- Treatments might have side effects, though they're taken under close supervision and a health professional will explain possible risks before you start

What does joining a clinical trial involve?⁵

As part of a clinical trial, you might:

- Answer questions or fill out surveys at home or in person
- Take new medicines that might help to improve Parkinson's symptoms
- Have your movement, thinking and memory tested to understand changes in Parkinson's
- Provide samples like blood or saliva to help researchers understand how genes and proteins are involved in Parkinson's



I was lucky to meet Lynn, a nurse educator. She gave me lots of reading material to learn what Parkinson's is, and what I could do for myself.

– Parkinson's Foundation Forum Member⁶



Joining a clinical trial is a great way to help yourself and others with Parkinson’s. By using the resources shared below, you can learn more about clinical trials and find one that’s right for you. Taking part helps pave the way for new treatments that could change the future of Parkinson’s care.⁷

Find out more about clinical trials for Parkinson’s

Click on the links below to find out more about topics covered in this section.

Understanding clinical trials, what they might involve and why it’s important to take part

[Take part in research | Parkinson’s UK](#)

[Where and how to take part in Parkinson’s research | Parkinson’s Europe](#)

[Clinical trials | Parkinson’s Foundation](#)

Why people from all backgrounds with Parkinson’s should take part in research

[INVISIBLE | Equality Health](#)

How to find a clinical trial

[Recruiting trials | PDTrialTracker](#)

Share your experience of Parkinson’s

[Survey data | Parkinson’s Foundation](#)

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Could disease-modifying therapies change the course of early-stage Parkinson's in the future?

As you navigate early-stage Parkinson's, you might wonder what the future holds. Scientists and clinical developers are investigating disease-modifying therapies that aim to slow the progression of Parkinson's, rather than just manage symptoms.¹⁻³ This section explores their potential benefits and development challenges.

Today's treatments manage symptoms, but don't target the root cause⁴⁻⁶

How Parkinson's progresses

- Our brain cells use different chemical messengers to communicate, including dopamine
- Parkinson's causes the loss of brain cells over time, especially cells that produce dopamine
- As a result, Parkinson's and its symptoms progress over time

Today's treatments and what's still missing

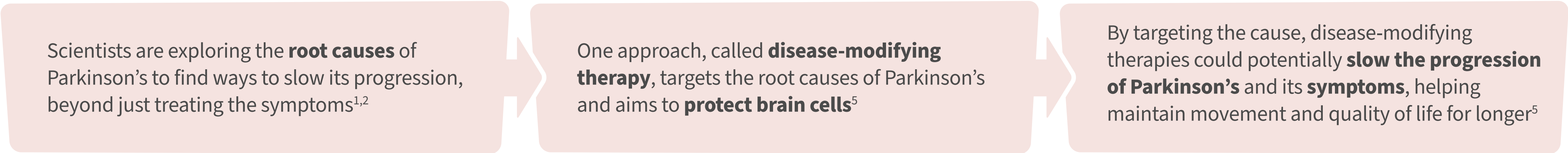
- Right now, there are treatments that help to manage some symptoms caused by Parkinson's, but they don't target the root cause, so the condition continues to progress
- Over time, more medicine is needed to help manage the symptoms as the condition gradually gets worse

We need new solutions

- We need new treatments that can protect brain cells and slow down the worsening of Parkinson's

Disease-modifying therapies could potentially slow down Parkinson’s

What are disease-modifying therapies?



Disease-modifying therapies are an active area of research

There are many disease-modifying therapies currently being tested in clinical trials, and different approaches are being explored:⁷⁻⁹

No disease-modifying therapies are currently approved to treat Parkinson’s.

- 1. Exercise:** Regular physical activity may not only improve symptoms but also slow disease progression
- 2. Repurposing existing medicines:** Some medicines already approved for other conditions might help in Parkinson’s
- 3. Proteins and genetics:** Researchers are studying proteins and genes involved in Parkinson’s to find ways to protect brain cells from damage
- 4. Stem cells:** This involves replacing damaged cells with healthy ones

How will we know if disease-modifying treatments are working in clinical trials?

- Disease-modifying therapies may not have obvious or immediate effects like other treatments¹⁰
- Symptoms in Parkinson’s can change daily and progress differently for everyone, making it hard to track changes¹¹
- Small, subtle changes in early-stage Parkinson’s can be hard to see, so it may be difficult to measure how well disease-modifying therapies work¹¹

How biomarkers could improve Parkinson’s care

Researchers are developing ‘biomarkers’ – tools to detect subtle changes in the body related to Parkinson’s. These biomarkers could help measure the effects of disease-modifying therapies even before you notice any changes in your symptoms.⁹⁻¹¹

Research into disease-modifying therapies for Parkinson’s is quickly evolving, with many clinical trials underway. There have been major steps in disease-modifying therapy research for other brain diseases, like multiple sclerosis, where therapies have slowed disease progression.^{2,9,12} This gives us hope for similar progress in Parkinson’s. By protecting brain cells, disease-modifying therapies have the potential to help people with Parkinson’s maintain their movement and other abilities for longer.^{3,4}

Find out more about disease-modifying therapies

Click on the links below to find out more about topics covered in this section.

Disease-modifying therapies, their potential benefits and development challenges

[Disease-modifying research pipeline holds possibility for Parkinson’s | Parkinson’s Foundation](#)

No disease-modifying therapies are currently approved to treat Parkinson’s.

Staying informed and involved in ongoing research

[Advancing research | Parkinson’s Foundation](#)

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Living with Parkinson's has its challenges, but there are ways to manage your condition and maintain your quality of life for longer. We hope this booklet has given you helpful information and practical tools to support you on your journey. Remember, your family, care partner, healthcare team, and support groups are there for you every step of the way.

Self-care plan

Creating a personalised self-care plan can help you manage your symptoms and improve your well-being. Use the template below to set goals and work them into your routine.

HOW TO USE

- 1. Choose an achievable activity or goal for each area (e.g., mental health). Something you enjoy, like going to a family event or a physical activity, can boost your mood
- 2. Break down each goal into smaller steps
- 3. Track your progress and reward yourself to stay motivated

SUPPORTERS

List who will support your plan and how they can help (e.g., family, friends, doctor)

EXAMPLE

MENTAL HEALTH Choose an activity like meditation, practising gratitude or writing down your thoughts and feelings

Activity	Meditate for 10 minutes every morning	
What you will gain	I will feel calmer and ready to start the day	
Steps involved	1. Before bed, set aside 10 minutes in the morning 2. Wake up and load meditation app 3. Set a timer for 10 minutes 4. Meditate	Progress ✓ ✓

MENTAL HEALTH Choose an activity like meditation, practising gratitude or writing down your thoughts and feelings

Activity		
What you will gain		
Steps involved		Progress

EMOTIONAL HEALTH Do a hobby, spend time with loved ones or attend a support group

Activity		
What you will gain		
Steps involved		Progress

DAILY LIFE OR RELATIONSHIPS Set a goal such as going for a walk with a friend or having dinner with family

Activity		
What you will gain		
Steps involved		Progress

PHYSICAL ACTIVITY Plan regular exercise into your routine. Start with short sessions and build up to longer ones

Activity		
What you will gain		
Steps involved		Progress

NUTRITION AND SLEEP Plan healthy, balanced meals in advance or get an early night

Activity		
What you will gain		
Steps involved		Progress