

LIVING WITH PROGRESSING PARKINSON'S DISEASE

Understanding and managing change - information
and support to help you and those around you



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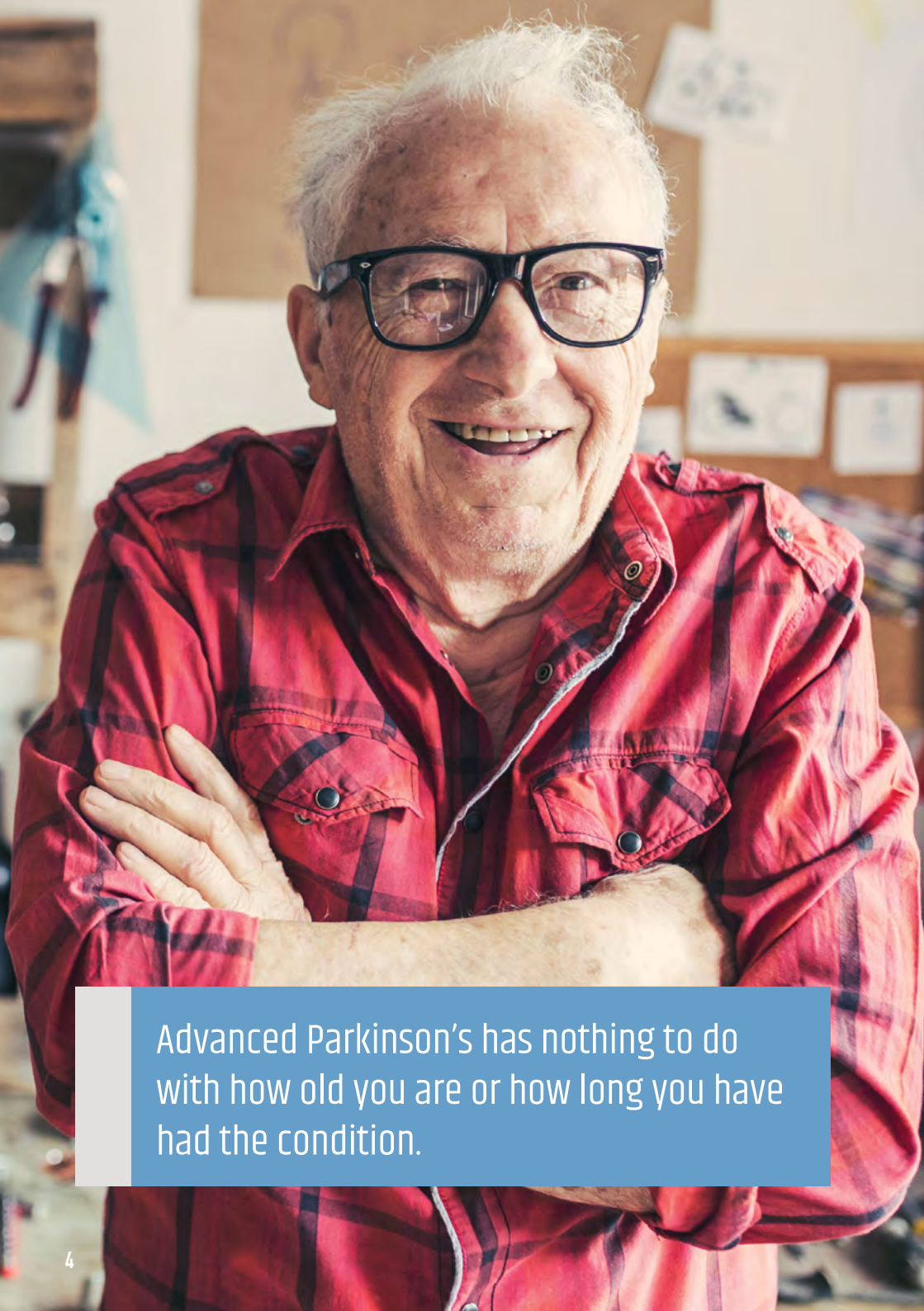
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TEAR-OFF INFORMATION CARD

At the back of this booklet you will find a removable information card that may help you understand what you are going through as your Parkinson's progresses, with a checklist of symptoms to help identify your needs. Take this card to your doctor to discuss your options for living life well.

#1

YOUR PARKINSON'S: WHERE YOU ARE NOW



Advanced Parkinson's has nothing to do with how old you are or how long you have had the condition.

Parkinson's disease (Parkinson's) occurs when the nerve cells in the brain that produce a chemical called dopamine are destroyed. Dopamine plays an important role in controlling the movement of the body.

When the body doesn't have enough healthy nerve cells to produce sufficient dopamine, it can cause the typical symptoms of Parkinson's, such as tremor, stiffness of muscles and slowness of movement.

Over time, Parkinson's progresses. Your symptoms may become more prominent and everyday activities might become more difficult as fewer and fewer nerve cells are produced or able to store dopamine.

This booklet aims to help you identify the signs of advanced Parkinson's and how these could affect you. It also outlines the most common therapy options used to address some of the mobility symptoms of advanced Parkinson's – therapeutic options that might make a difference to your quality of life.



As Parkinson's progresses

The course of Parkinson's varies from person to person, so not everyone experiences the same symptoms. Some people have quite mild symptoms for many years, while for others the condition advances more quickly, leaving them with limited mobility.

Recently you may have noticed that a slight tremor in your hand or arm has become worse, or that symptoms that used to affect only one side of your body now affect both sides. Problems with walking, talking or doing various everyday activities may also develop. For instance, your handwriting may be getting smaller or there may be signs of tremor in what you've written.

At this point, you may have also developed the troublesome involuntary movements known as dyskinesia, and be relying increasingly on the support of the people who care for you. These are typical signs that Parkinson's is progressing.

A photograph of an older man with a joyful expression, wearing a white button-down shirt and a straw hat with a brown band. He is sitting outdoors, with green foliage in the background. A portion of a vintage-style car is visible to his left.

What is advanced Parkinson's?

Advanced Parkinson's has nothing to do with how old you are or how long you have had the condition.

Reaching this point also doesn't mean you haven't been managing the condition well, or that your previous treatments haven't worked. These changes are simply the result of the condition advancing.

The symptoms of your Parkinson's may be considered to have 'progressed' or 'advanced' when your current treatment is no longer able to consistently control your symptoms, and the condition is starting to significantly impact your everyday life.

Controlling your symptoms

Up until now, you have probably been taking your medication in tablet or capsule form. This is one of the main medicines used to treat Parkinson's.

Although your medication can usually treat symptoms effectively, the improvement is not permanent and your doctor may have had to make repeated adjustments to your medications – increasing the dosage and/or the number of times you take them, or prescribing a combination of two or more medications.

Despite these adjustments, as it becomes increasingly difficult to achieve good symptom control, your doctor may recommend other therapies that are new to you.

Some symptoms may not be representative of your condition. If you have any concerns about these or other symptoms you may have, talk to your doctor or another member of your healthcare team.

Signs of advanced Parkinson's

As your Parkinson's progresses, you may notice more pronounced movement issues (motor symptoms) or fluctuations, as well as other troubling health issues (non-motor symptoms) that affect your quality of life.

The movement issues

After years of taking medication for Parkinson's, the smooth and even control of symptoms that the treatment once gave you may no longer be dependable. You might experience fluctuating symptoms known as motor fluctuations – dyskinesia, 'on/off' mobility and wearing off.

1 Dyskinesia

These involuntary movements of the limbs and/or head are a side effect of the long-term use of oral medication. They occur in more than half of people with Parkinson's who have been taking medication for between five and 10 years. This percentage increases over time.¹

What causes them? This depends on several things: your age at the onset of Parkinson's, and its severity; how much oral medication you took and for how long; and possibly other unknown factors.

Dyskinesia is more common in people who were young when symptoms started.

2 'On/off' mobility

Some people who have had Parkinson's for a long time experience these periods of poor mobility that come and go unexpectedly – like a light switch being turned on and off, as some people describe it. These periods of unpredictability may last for up to several hours.

What causes these? They are a late side effect of oral medication, probably caused in combination with the Parkinson's – not the medication alone.

3 Wearing-off

In the early stages of Parkinson's, 'off' periods can occur before the next dose of medication is due. This is known as 'early wearing off'. However, as Parkinson's progresses, 'on/off' fluctuations become less closely related to the timing of the medication dose – and more unpredictable.

The other health issues

Known as non-motor symptoms, this is a wide-ranging group of behavioural, neuropsychiatric and physical symptoms that can significantly impact your quality of life.

How common are they?

These frequent and disabling symptoms are very different from mobility problems, but are still often an integral part of Parkinson's. Recent surveys have shown that almost 90 per cent of people with the condition have at least one non-motor symptom, with almost a quarter experiencing four or more.² And you may experience even more depending on how long you've had the disease and how severe it is.

What are some of the symptoms?

These can involve your senses (loss of smell), cognition (ability to think quickly), mood (anxiety, depression and irritability), sleep quality (insomnia) and bowel function.

As your symptoms become more complex, you might need your partner or carer to help you with everyday tasks.

You can read about some of these other health issues in detail on pages 17-24.



TELL YOUR DOCTOR

Many factors other than Parkinson's – including medication side effects and other medical conditions – can cause symptoms similar to the non-motor symptoms of this disease.

It's very important to tell your doctor if you experience these, because they can have such a big impact on your life – often greater than your mobility problems. They are also a major cause of hospitalisation and need for professional care.

#2

MOBILITY: YOUR TREATMENT OPTIONS



People respond in different ways to different treatments.

It isn't possible to say with certainty if or when your doctor might advise moving from one treatment phase to another. Your doctor may suggest other treatment options to help improve your quality of life, when your current medication is no longer meeting your needs. Any treatment options will be aimed at managing your symptoms so that you can continue with your everyday activities as normally as possible.



Treatment options for Parkinson's

In recommending a treatment, your doctor will take a number of factors into account, including your age and whether or not you have any other medical conditions. Your doctor will take your circumstances into consideration, too, like the level of support you have from those around you and your ability to manage a treatment. Here we examine oral medication as well as other treatment options that may be considered once oral medication is no longer managing your Parkinson's symptoms. Bearing in mind that people respond in different ways to different treatments, the information here is intended only as a guide. You should discuss your options with your family as well as your doctor or Parkinson's nurse specialist.

Oral medication (tablets or capsules)

Oral medication can be taken to improve the main symptoms of Parkinson's disease, such as shaking (tremors) and movement problems. The three types of oral medication commonly used are levodopa preparations, dopamine agonists, and monoamine oxidase-B (MAO-B) inhibitors. Other medicines that are also sometimes used include catechol-o-methyltransferase (COMT) inhibitors, anticholinergics and glutamate antagonists. Over time, you may experience problems with your medication wearing off and changes and additions may be made to your medication regimen to manage your symptoms. For example, you may find that you have to take a more complicated combination of tablets to treat your symptoms. When your symptoms become difficult to control with oral medication alone, a number of other treatment options may be considered.

Non-oral therapies

Pump therapy – intestinal gel infusion

A type of levodopa which comes as a gel can be continuously pumped into your gut (small intestine) through a tube which is surgically inserted through your abdominal wall. An external pump is then attached to the end of the tube, which you carry around with you. Patients are required to stay in hospital in order for the tube to be implanted and for observation while the external pump is fitted and adjusted.

Pump therapy – under the skin

A dopamine agonist can be injected under the skin (subcutaneously) by a continuous infusion. This requires a needle and infusion line to be fitted to an external pump, which you carry around with you. Patients receiving continuous infusions are required to stay in hospital so the needle and infusion line can be set up, and for observation while the external pump is fitted and adjusted.

Neurosurgery (brain surgery)

This is a form of brain surgery called deep brain stimulation. This procedure involves having very fine wires inserted into the brain to conduct electrical impulses to the affected nerve cells – a bit like the way a pacemaker stimulates the heart. The wires are connected to a unit (called an internal pulse generator or IPG) that is implanted under

the skin of the chest. A hand-held device lets you switch the stimulation on and off to adjust it to your needs. Other forms of neurosurgery include thalamotomy and pallidotomy. Both of these procedures involve a surgeon making an incision (cut) on a part of the brain to alleviate specific symptoms.

In making a treatment decision, your doctor will discuss with you how your condition is affecting your quality of life, and whether you have other health concerns. Your doctor will also explain the risks and benefits of treatment, including any side effects that may occur. Seeing your doctor and Parkinson's nurse specialist regularly will help ensure you are getting the best possible treatment.





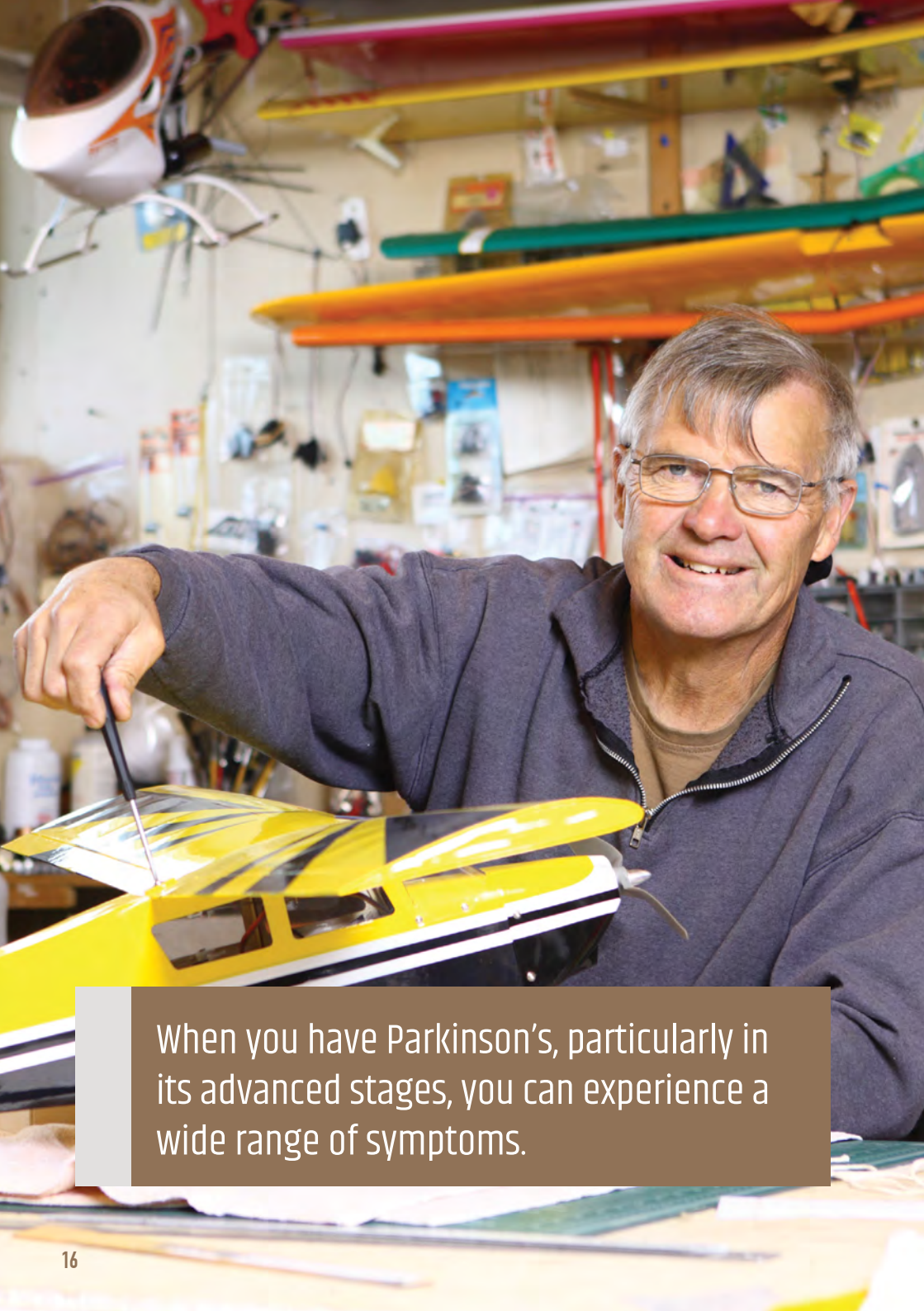
10 questions to ask your doctor

You and your partner or carer should discuss your personal circumstances with your doctor. Ask anything you want to know about the different therapies before you make a decision. The following questions might be a good place to start.

- 1 Which of the Parkinson's treatments am I suitable for and why?
- 2 What is the likelihood of me experiencing a significant improvement in my symptoms with each of the options available to me?
- 3 Which (if any) of my symptoms will not be helped by these treatments?
- 4 When is the best time to start treatment to see the greatest benefits?
- 5 What can I do to maximise the chances of doing well with these treatments?
- 6 Will any of these treatments interfere with the other medications I take?
- 7 What other therapies are available to me (physiotherapy, occupational therapy)?
- 8 What would be the next step if the treatment doesn't work as well as hoped?
- 9 What are the benefits of one treatment over another?
- 10 Can you explain the side effects of each treatment option?

#3

OTHER SYMPTOMS: WHAT TO WATCH FOR



When you have Parkinson's, particularly in its advanced stages, you can experience a wide range of symptoms.

The other health (non-motor) symptoms of advanced Parkinson's can be more difficult to manage than the motor fluctuations.

A study involving 50 people with Parkinson's who experience mobility fluctuations showed that all 50 of them had at least one type of non-motor fluctuation.³ The most common were anxiety, drenching sweats, slowness of thinking, fatigue and a feeling of inner restlessness and needing to be in constant motion.

TELL YOUR DOCTOR

When you have Parkinson's, particularly in its advanced stages, you can experience a wide range of symptoms – and no two people will have the same pattern of symptoms over the same time frame.

This emphasises the importance of effective communication between you and your doctor or other healthcare professionals. Tell them about any health problems you're having so you can get the right treatment for your needs.

An A-Z of symptoms

This is by no means a complete list, but it will give you a general guide to some of the more common non-motor symptoms.

ANXIETY

Anxiety is thought to affect up to 40 per cent of people with Parkinson's to some degree.⁴

It can range from worry and stress to bodily symptoms associated with fear and panic (the 'fight or flight' response), including sweating, pounding of the heart, shortness of breath and tightness in the chest.

If anxiety goes on for a long time, it can cause other symptoms and might even lead to depression.

Contributing factors may include:

- Feeling self-conscious about symptoms
- The unpredictable 'on/off' state of the motor symptoms, especially when they're 'off' and movement is difficult
- Possible changes in certain brain chemicals

APATHY

Apathy is a lack of motivation or interest, with a neutral mood and a sense of indifference. A person with apathy often lacks concern about themselves and is indifferent to events that would usually cause emotion, such as receiving bad news.

Apathy affects more than 10 per cent of people with Parkinson's.⁵ It is particularly common in those with depression and/or dementia. The partner, family and friends of the person with apathy often feel the greatest impact.

CONSTIPATION

Constipation is particularly common in people with Parkinson's, possibly affecting up to 67 per cent of them.⁶ Constipation and other bowel problems result from:

- **Mobility symptoms** Slow movement, limited movement and muscle rigidity affect the bowel muscles, causing a reduction or slowness of bowel movements.
- **Low-fibre diet** Because chewing and swallowing food is often a problem, some people find it difficult to eat fibre-rich fruit, vegetables and whole grains – the foods that help form soft, bulky stools and aid bowel function.
- **Reduced activity** It can be difficult to remain active as Parkinson's progresses. This leads to reduced stimulation of the bowel, and the intestines become sluggish.



- **Fluid intake** Some people may unintentionally reduce their fluid intake. This can make stools hard and more difficult to pass, and can lead to impacted stools.
- **Anxiety** about bowel movements can make it difficult to relax the body and muscles sufficiently to pass a stool.
- **‘Off’ periods** may also affect the necessary relaxation of the pelvic floor to pass stools.
- **Medications** Diarrhoea may occur as a side effect of certain Parkinson’s medications.

If you experience any of the above, please talk to your doctor.

DEMENTIA

The word ‘dementia’ describes a group of symptoms, caused by the impact of disease on the brain, that interferes with normal day-to-day functioning. One study has shown that more than three-quarters of people with Parkinson’s develop dementia after eight years with Parkinson’s.⁷

While each person will experience dementia in their own way, symptoms typically include problems with planning, short-term memory, speech and perception. Dementia in Parkinson’s is often also associated with difficulties in problem-solving and planning activities.

Contributing factors may include:

The drugs used to treat Parkinson’s do not cause dementia. However, they may make it worse or bring to light the symptoms of dementia, such as hallucinations, confusion or aggressive behaviour.



DEPRESSION

As many as 40-50 per cent of people with Parkinson's experience significant feelings of depression at some stage.⁵ However, it is often under-diagnosed and under-treated because some symptoms, such as tiredness, are also symptoms of Parkinson's.

What are the signs of depression?

Someone who is depressed will typically have low mood and/or lack of interest in, or pleasure from, usual activities and interests almost continuously for several weeks.

Other symptoms of depression include: difficulty concentrating; poor energy; appetite disturbance (usually weight loss, but sometimes also increased appetite and weight gain); tiredness; difficulty sleeping, early waking; inability to carry out everyday activities.

In Parkinson's, depression is slightly different. Feelings of guilt appear to be less common, whereas extreme pessimism and negative thinking appear to be more common. Anxiety is also commonly associated with depression in Parkinson's.

Possible causes

The causes of depression will vary from individual to individual. Changes in brain chemicals may play a role, making it more likely for some people with Parkinson's to become depressed.

People who have become depressed during difficult times in the past are more likely to become depressed because of the challenges of Parkinson's.



The negative effect of symptoms on quality of life might be a factor, too, and that could be why younger people with Parkinson's seem to be more at risk.

In fact, depression is the main measure of quality of life in Parkinson's.

Partners and carers

Depression is also very common in partners or carers. Often the main cause of their distress – and deterioration in their quality of life – is that the person they care for has depression.



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FATIGUE

Fatigue is a lack of energy and motivation and should not be confused with drowsiness or feeling a need to sleep.

Around half of people with Parkinson's experience fatigue.⁵ And about one-third of those with Parkinson's consider fatigue to be their most severe disease-related problem; worse than their motor symptoms.⁵



Activity and fatigue

People with Parkinson's need much more energy than others, which is likely to lead to greater fatigue.

How does fatigue affect quality of life?

- Mental and physical fatigue can affect psychological and emotional wellbeing
- Fatigued people may become less active and unable to pursue hobbies and interests
- Because social activity requires energy, people with fatigue will have a greater tendency to become withdrawn
- Less inclination to be active brings with it reduced stamina, reduced fitness and further muscle weakness

For all these reasons, it is important for people with fatigue to try to keep as active as possible.

What causes it?

The precise mechanisms that cause fatigue are still not understood. These are some of the factors that may be involved:

- **Anti-Parkinsonian medication** Some medications may affect sleep and so add to fatigue.
- **In people with tremor**, rigidity and dyskinesia, the muscles have to work harder to perform simple movements or tasks. This might cause some degree of fatigue.
- **Slowness of movement** may also increase fatigue because activities and tasks take longer.
- **Lack of activity** Reducing or stopping active leisure pursuits and sports inevitably leads to degrees of unfitness – and fatigue.
- **Poor quality sleep** This often occurs for a variety of reasons and tends to lead to excessive daytime sleepiness and napping, adding to the fatigue.

SLEEP PROBLEMS

Sleep problems are thought to affect 60–98 per cent of people with Parkinson's⁵, and there are many different reasons for this.

Sleep disruption

- The 'wearing off' effect of some medications that results in worsening symptoms, such as stiffness, pain and tremor, and the inability to turn over in bed.
- A painful early morning cramp in the hands and feet.
- The urge to urinate, often complicated by an immobilising 'off' period.

Wakefulness can be caused by some medications, particularly if taken in the evening.

Sleep and behaviour disorders, such as nightmares and sleepwalking, can occur on waking or when light sleep changes to deep sleep.

Violent dreams caused by rapid eye movement sleep behaviour disorder (RBD). People may act out these dreams, causing them to fall out of bed, cry or shout or even hurt their bed partner.

Other causes Caffeine (as contained in coffee, tea, cola drinks) taken in large amounts at bedtime; diuretics (water tablets) taken at night-time; and some medications.

EXCESSIVE DAYTIME SLEEPINESS

Excessive daytime sleepiness (EDS) causes people with Parkinson's to fall asleep or doze frequently during normal waking hours. It can be caused by poor sleep, sleep disorders and certain drugs.



#4

YOU AND YOUR WELLBEING



The support of the people around you is particularly important now... Try to involve them in this decision-making.

Parkinson's can turn your life upside down, especially as symptoms start to progress. It can take time to get used to, accept and cope with the changes that will continue to throw up new challenges. Talking to your family and your doctors can help you face these challenges together.

Keeping healthy

There are some simple things you can do to help manage your Parkinson's, such as staying active and focusing on your general health. Your doctor or nurse will be able to offer information to make this easier, and can put you and the people who help you in touch with other healthcare professionals who offer specialised advice.

If you are having problems chewing or swallowing, your doctor may refer you to a speech pathologist. Your doctor may also refer you to a dietitian, who will be able to offer advice to help ensure you get all the vitamins and minerals you need to maintain your strength and avoid unhealthy weight loss.

Simple tips such as taking smaller mouthfuls, avoiding foods that are difficult to eat and using specially adapted cutlery may make a real difference to your diet and your enjoyment of food.

A dietitian or continence nurse may be able to help with tips on how to manage symptoms such as constipation, which can affect some people with Parkinson's disease.

Staying active

You should also try to stay active. Keeping both mentally and physically active can help to fight fatigue and maintain muscle strength and maximise movement. A regular exercise routine can help you maintain your abilities, strengthen your muscles, increase mobility in your joints and build up your general fitness and health. Making exercise part of your regular routine provides a sense of achievement and can reduce feelings of stress, anxiety and depression. Again, your doctor will be able to refer you to a physiotherapist who can help you with exercise ideas and support.

Practical lifestyle tips

If your symptoms are changing, it's a good idea to plan for changes in your lifestyle. Some people find that rethinking their environment can help them to manage this phase of the condition and improve their quality of life.

Remove clutter Having fewer obstacles in the house can simplify movement.

Avoid buttons Wearing clothes without buttons helps make dressing easier.

You and those closest to you know what's best for you – you are the experts when it comes to managing changes and coping with your Parkinson's.

Occupational therapists can also assist with suggestions on equipment and safety measures around the house.

Making changes together

The support of the people around you is particularly important now. Tell them how your symptoms may be progressing and let them know what changes you feel you need to make as a result.

Try to involve them in this decision-making and ask for their input, because whatever changes you make may also impact on how they feel and how they are able to support you.

Your social life

As your Parkinson's changes, so will your relationships. Keeping your friendships going, as well as looking to your spouse or family for support, can help you manage more easily.

Having your friends and family around as your condition changes can provide an emotional boost and also ensure that you have physical support when you need it. Try to be honest with friends, and realistic about how the effects of your Parkinson's might affect your relationships.

Spend time with friends and family and try to ensure these times are relaxing rather than stressful. Maintaining a social life is also important for any friends and family who are helping you.

Talking and sharing

As your condition changes, you may find that you can avoid unpleasant or embarrassing situations by being open about your symptoms and explaining how you're affected.

This can help others understand what you are experiencing.

If you find it difficult to share what you're going through with friends and family, try talking to a member of your healthcare team about how you're feeling, and ask for help to make this process easier.

Or ask a family member or close friend to share information about your condition with others. You could do this together, or ask them to tell others on your behalf.

While your experience of Parkinson's is unique, it may help to talk to other people with the condition and learn from their experiences. Ask your healthcare team about a local support group, or contact one through your local Parkinson's association. This may also help your friends and family as it brings them into contact with others who help people with Parkinson's.



Caring for your emotional wellbeing

Changes to your symptoms may have an effect on the way you feel. Being aware of these feelings, and noticing how your changing symptoms are affecting you, can help you to manage this situation.

Here are a couple of ways to cope if your Parkinson's is getting you down or you're struggling to deal with some of the thoughts or feelings that result from it.

Share your thoughts and feelings

Talking honestly about your emotions can often help you consider them afresh and work on ways that can help.

Uncertainty about the future direction of your Parkinson's can lead to feelings of anxiety or stress. Making plans with your friends and family about managing your condition in the future may help ease some of this uncertainty.

Planning can also help to identify situations that make you feel happier or more content and encourage you to spend more time doing these things. Fresh air, music, time in the garden, time spent chatting to an old friend – anything that helps lift your spirits and give you 'time out' from thinking about your Parkinson's can have an impact on the way you feel.

This 'time out' can also be good for the people who care for you. Seeing you happier and more relaxed is likely to also put them at ease and make them feel happier as well.



Ask for help

Make sure you take advantage of emotional support when you need it most. Managing a lifelong condition can be emotionally draining and lead to anxiety and depression.

If you ever have trouble coping with your mood, or have extended periods when you're feeling down, try to confide in a loved one or talk with a member of your healthcare team.

Top tips for talking to others

Being able to talk to people and get your thoughts and feelings off your chest can play a big role in managing your Parkinson's. The simple act of talking with people about experiences and shared memories can help you to maintain bonds and also provide good emotional support for you.

- 1 Try to think through what you want to say in advance – even ask someone to help you to write it down to help you remember.
- 2 Take into account whether the person you're talking to has any experience or knowledge of Parkinson's. If you're explaining your treatment, you might need to be more patient with them than with those closer to you.
- 3 If you're trying to explain your treatment or how your symptoms are advancing, give examples of how Parkinson's affects you so the other person can better understand.
- 4 Bear in mind, too, that your partner and your children may be experiencing a range of emotions that they need to come to terms with. They might need reassurance and support from you in return.
- 5 No matter how you get your message across, the number one thing is to express your thoughts and feelings when you need to, and not keep them bottled up inside.

What's next?

If at any time in the future you or those around you have questions about your treatment or about Parkinson's in general, try to talk to your healthcare team.

Having questions answered as they come up means you can put any concerns at rest and focus on the management of your condition.

Look to friends and family for support. You can also use local Parkinson's support groups and organisations – either in person or online – to find information and to share common experiences.

WHERE TO FIND OUT MORE

1 Parkinson's Australia

www.parkinsons.org.au or Freecall 1800 644 189

For advice, FAQs and information sheets

2 Parkinson's Australia in your State

Parkinson's NSW www.parkinsonsnsw.org.au

Parkinson's W.A. (inc. NT) www.parkinsonswa.org.au

Parkinson's S.A. www.parkinsonssa.org.au

Parkinson's Queensland www.parkinsons-qld.org.au

Parkinson's Victoria www.parkinsonsvic.org.au

Parkinson's ACT www.parkinsonsact.org.au

Or Freecall 1800 644 189 and you'll be directed to your local office.

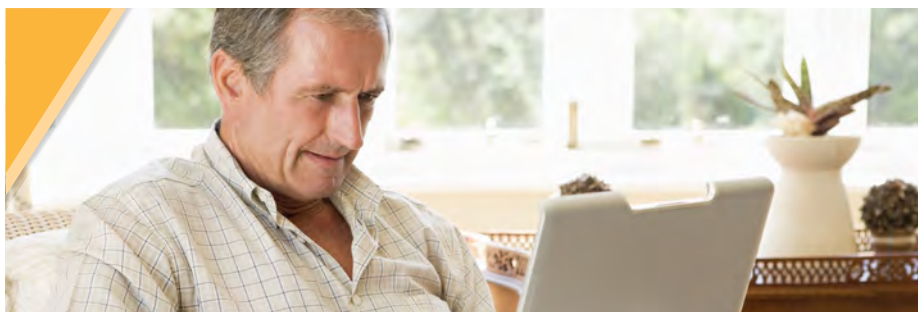
3 European Parkinson's Disease Association (EPDA)

www.epda.eu.com

Patient-friendly information on a comprehensive range of topics, from treatments and therapies to tips for carers.

4 Parkinson's Disease Non-Motor Group

Go to www.pdnmg.com/tools/nms-quest.pdf for a free download of their non-motor questionnaire, a comprehensive list of symptoms. Tick those that affect you and give it to your doctor.



#5

GLOSSARY OF TERMS



Keeping both mentally and physically active can help to fight fatigue and also maintain muscle strength.

This alphabetical list of medical terms could come in handy. We've included things you might hear from time to time during your treatment and, though it's not a complete reference, it might be useful when you need a quick explanation.

Autonomic nervous system

Part of the peripheral nervous system that controls functioning largely below the level of consciousness, e.g. heart rate, digestion, salivation, perspiration, diameter of the pupils, urination and sexual arousal

Bradykinesia

Abnormal slowness of movement; sluggishness of physical and mental responses

Central nervous system (CNS)

Contains the majority of the nervous system and consists of the brain, the spinal cord and the retina

Cognition

The process of thought

Deep brain stimulation (DBS)

A surgical treatment involving the implantation of a medical device which stimulates specific parts of the brain with electrical impulses

Dopamine

A neurotransmitter that is produced in several areas of the brain, including the substantia nigra

Dopamine agonist

A type of medication that activates dopamine receptors in the absence of dopamine

Dysphagia

Difficulty in swallowing

Dystonia

A condition characterised by involuntary, sustained muscle contractions

Fluoroscopy

An imaging technique commonly used by physicians to obtain real-time moving images of the internal structures of a patient through the use of a fluoroscope

Lewy body

An abnormal mass of protein that develops inside nerve cells in Parkinson's and some other disorders

Monotherapy

Treatment of a condition by means of a single drug or therapy

Motility

The ability to move food through the digestive tract



Neuropsychiatric disorder

A disease of the nervous system

Neurotransmitter

A chemical that transmits a signal from one nerve cell to the next

Olfaction

The sense of smell

Orthostatic hypotension

A sudden drop in blood pressure on standing up which causes dizziness. Sometimes known as postural hypotension

Parasomnias

A type of sleep disorder that involves abnormal and unnatural movements, behaviours, emotions, perceptions and dreams. They can occur while falling asleep, while sleeping or when waking up

Peroral

Administered or performed through the mouth, as surgery or administration of a medication

Postural instability

Unsteady balance

Psychosis

Any form of severe mental disorder in which the individual's contact with reality becomes highly distorted. People experiencing

psychosis often exhibit personality changes, inappropriate behaviour and a deterioration in normal social functioning

Rapid Eye Movement (REM) sleep

A normal stage of sleep characterised by the rapid movement of the eyes. It is physiologically different from the other phases of sleep and is the phase when vividly-recalled dreams mostly occur

REM sleep behaviour disorder

A sleep disorder that involves abnormal behaviour during the REM phase of sleep that is characterised by the absence of normal muscle paralysis. It is associated with movement ranging from simple limb twitches to more complex and sometimes violent activity in which people appear to be unconsciously acting out their dreams

Subcutaneous

Underneath or below all the layers of the skin

Substantia nigra

A brain structure located in the midbrain that plays an important role in reward, addiction and movement. Parkinson's is caused by the death of dopaminergic neurons in the substantia nigra

Unified Parkinson's Disease Rating Scale (UPDRS)

A scale used to follow the progression of Parkinson's disease. The recently updated version of the scale is in four sections:

Non-motor aspects of experiences of daily living

Motor aspects of experiences of daily living

Motor examination

Motor complications

UPDRS-motor

The part of the UPDRS that evaluates motor symptoms and complications





References: **1.** Schrag A, Quinn N. Brain 2000;123:2297–2305. **2.** Shulman LM et al. Mov Disord 2001;16:507-510. **3.** Witjas T et al. Neurology 2002;59:408-413. **4.** Richard IH et al. J Neuropsychiatry Clin Neurosci 1996;8:383-392. **5.** Borek LL et al. CNS Spectr 2006;11:541-554. **6.** Sakakibara R et al. Parkinsons Dis 2011;2011:924605. doi: 10.4061/2011/924605. Epub 2011 Sep 12. **7.** Aarsland D et al. Arch Neurol 2003;60:387-392.

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Understanding your treatment journey

Parkinson's disease progresses differently from person to person. Some experience mild symptoms for many years, while others find their symptoms become more bothersome more quickly.

Either way, there are options available to help people like you **live life well**.



Diagnosis



Treatment



Improved symptom control



Symptoms return or become worse

Are your symptoms changing?



Difficulties in managing symptoms

Is your current treatment still working?



Discussing your options

Do you need to talk to your doctor about your current treatment?

Improved symptom control

It's important to check on your symptoms and treatments throughout your journey. Use the tool overleaf to help you understand what to look out for...

Keeping symptoms and treatments in check

Use the following checklist to help you identify changing symptoms.

Are your symptoms changing? (please tick ✓)

- ☐ More than 1-2 hours a day of 'off time' when symptoms appear to be worsening
- ☐ Uncontrolled troublesome dyskinesia
- ☐ Loss of balance and falls
- ☐ Problems swallowing
- ☐ Problems sleeping
- ☐ Problems with bladder/sexual dysfunction
- ☐ Feeling nauseous, being constipated or dribbling saliva

With your current treatment, do you (please tick ✓)

- ☐ Require levodopa (a medication for Parkinson's) four or more times a day?

Do you need to talk to your doctor about your current treatment?

- If you have ticked any of the boxes above, make an appointment to see your GP/Specialist.
- Take this checklist with you to help you talk through the changes you are experiencing and together with your healthcare team you can discuss and plan your next treatment steps.



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