

THINKING ABOUT ADVANCED PARKINSON'S

PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

This booklet looks at the advanced stage of Parkinson's. 'Advanced stage' means a time when Parkinson's symptoms are more complex and may be having more of an effect on your day-to-day life. It may be a time when you need help from someone else, perhaps a carer, to complete day-to-day activities, like washing and dressing.

Each person with Parkinson's is different and their symptoms will progress at a different rate, so this stage of the condition will not be reached at a particular age, or length of time since diagnosis.

Living with advanced Parkinson's or caring for someone in the later stages of the condition won't be easy for either the person with the condition or those around them. But we hope this booklet will give you ideas and practical tips to help you and your carer live as well as possible, as the condition progresses.

Contents

Introduction.....	5
When should I read this booklet?.....	5
What else is available?	6
About Parkinson's.....	7
What is advanced Parkinson's?	7
How does Parkinson's progress?	8
Who can help?	8
Parkinson's symptoms	9
Other symptoms.....	11
I care for someone with Parkinson's. How will this affect me?.....	17
Mental health symptoms.....	17
Parkinson's and dementia.....	23
Coping with other conditions	26
Managing the condition	29
Medical treatments	29
Drug treatments.....	30
Side effects of medication.....	35
What about surgery for Parkinson's?	40
Which professionals can help me?	42
Preparing for appointments.....	46
Self-help	47
Diet and exercise	50
The people around me	53
Relationships.....	53
Support for carers, family and friends.....	57

Employment and money

Employment, financial support and Parkinson's.....60

Care62

Healthcare arrangements62

Social care arrangements.....64

Taking a break70

The place where I live74

Other housing options74

Palliative care.....77

Making decisions about end of life.....79

Making your wishes known80

More information and support82

Counselling82

Parkinson's nurses.....82

Information and support from Parkinson's UK.....83

Healthcare organisations.....84

Mental health support85

Organisations for carers86

Support organisations.....87

Glossary91

Non-motor symptoms questionnaire.....94

My contacts list.....98

Index.....99

INTRODUCTION

This booklet is for people with Parkinson's and those who care for them. Although not everyone with Parkinson's will have a carer, in this booklet we use this word to describe a partner, family member or friend who may be involved in the care of a person with Parkinson's.

While we've highlighted particular areas that may be of interest to carers, and there is a separate section for carers, you may find it useful to read the whole booklet. People with Parkinson's may also find it useful to read the carers' sections, too.

As Parkinson's progresses, the condition can affect the carer's life as much as it does the person with Parkinson's. There may be a sudden shift in the dynamic of your relationship at this stage, where you realise your role has changed from being a partner, family member or friend to being a carer as well.

When should I read this booklet?

You can read this booklet whenever you feel ready. Although you, or someone you care for, may not be experiencing advanced symptoms, you may wish to read this booklet so you can plan ahead.

It may be you're not sure whether you want to think that far ahead, and instead enjoy life and deal with the future when it happens. But if you're at an earlier stage of Parkinson's, you may find it useful to discuss some of the issues in this booklet with any family members or friends. It will allow you to be prepared as things come up, and be able to deal with any difficult decisions that need to be made.

It also gives you the chance to plan for your future while you are well. You'll have the chance to think about what you may like to happen if you become unwell and to write it down or discuss it with your family or carer, so your wishes can be considered.

Thinking in advance about things such as finances and employment, and whether you'd like to stay in your own home with help, or go into residential care, can allow you to be ready for important decisions, as and when you need to make them.

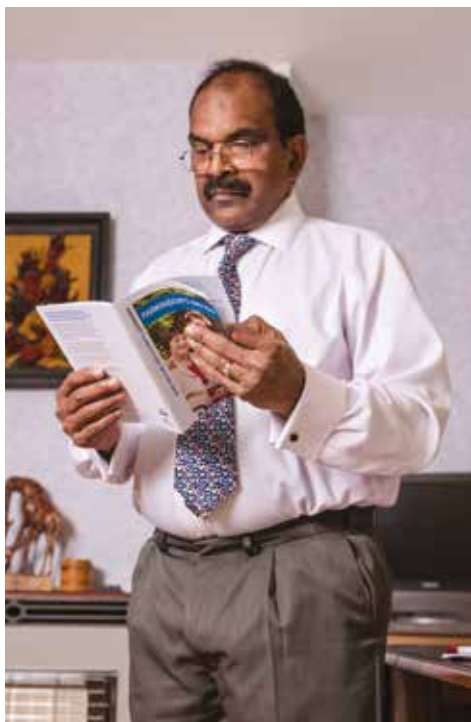
Some people with Parkinson's may be affected by dementia in the advanced stages of the condition. Planning ahead now will allow your family and friends to make decisions about your care that they know you will be happy with.

You can read more about dementia on page 23.

What else is available?

This booklet is part of a set of resources that provide information for each stage of the condition. These include:

- Parkinson's and you – for people recently diagnosed with Parkinson's
- Living with Parkinson's – information about all aspects of day-to-day life with Parkinson's
- Preparing for end of life – information to help you plan for the future



Information in other languages

We have information available in a range of different languages and can translate items on request. Please call our helpline on **0808 800 0303** if you would like any information in another language.

Large print

All of our information is available in large print versions. Please let us know what you need when you place an order.

ABOUT PARKINSON'S

Parkinson's is a progressive neurological condition. This means that it causes problems in the brain and gets worse over time.

People with Parkinson's don't have enough of the chemical dopamine because some nerve cells in the brain that make it have died.

Without dopamine people can find their movements become slower so it takes longer to do things.

Healthcare professionals often refer to different 'stages' of the condition. Parkinson's can be broadly divided into:

- Early or 'diagnosis' stage: the time when someone is first experiencing symptoms, being diagnosed and then coming to terms with this.
- Living with or 'maintenance' stage: when symptoms are controlled, perhaps by medication.

- Advanced stage: this is often called 'complex phase'.
- Palliative stage.

People will be at different stages for differing amounts of time.

What is advanced Parkinson's?

Although there is no specific definition of what advanced or complex Parkinson's is, it usually refers to when Parkinson's symptoms begin to significantly affect your everyday life. It is nothing to do with your age or how long you have had the condition.

It may no longer be possible to carry on as before, and you may need to use more effort for tasks you could previously do easily. This is when changes need to be made – possibly to do with work, domestic arrangements or personal relationships.

It may also be a time when Parkinson's drugs are less effective at managing your symptoms, or

their side effects are outweighing their benefits. You may also have a more complex drugs regimen.

People at the advanced stage may also have less independence and need help with daily living because the condition is less controlled as the treatment becomes less effective.

You can read more about the side effects of Parkinson's medication on page 35.

How does Parkinson's progress?

It's difficult to predict how the condition will progress, because the speed that it progresses and the way it progresses is different from person to person.

Not everyone with Parkinson's will have the same 'set' of symptoms. The symptoms someone might have, how they affect them and how quickly the condition develops, will differ from one person to the next.

The symptoms you experience may also have changed over the course of the condition, but there is no set order for which symptoms are experienced at any given time.

Parkinson's can affect you differently from day to day and even hour to hour. Some days will

be better than others – you may have days when you can do more, and some when you can do less. This presents challenges for care, but with the right help, many of the symptoms can be managed.

Who can help?

It's important to speak to your GP and ask them to refer you to your Parkinson's nurse (if you have one) or specialist about any of these issues. They can review your medication and adjust it so you get the best from your treatment with the least side effects.

Your specialist or Parkinson's nurse will aim to find the best combination of treatments that will help you to manage your symptoms as well as possible. This includes problems that affect your movement and those that don't, such as communication or emotional problems. They will also be able to refer you to healthcare professionals who can help with other therapies.

For example, a physiotherapist can help with your reduced movement, while an occupational therapist can visit you at home to recommend adjustments to your home that would make life easier. In many cases these will be done free of charge.

See page 42 for more information about health and social care professionals who can help.

Parkinson's symptoms

Current treatments focus on managing the main movement (motor) symptoms of the condition – tremor, rigidity and slowness of movement. Over time, these symptoms can affect day-to-day activities, such as walking, talking, swallowing and eating.

See page 29 for more information about medical treatments.

As well as difficulties with movement, some people with Parkinson's might experience other symptoms, such as tiredness, pain and constipation, all of which can be treated.

You may find your movement (motor) symptoms are outweighed by some of these other symptoms.

See page 11 for more information about other symptoms.

In the advanced stage of Parkinson's, you may find that your movement (motor) symptoms are no longer controlled by your medication or that the medication used to treat them causes its own problems.

“We know that Parkinson's symptoms can be made worse with stress, so be kind to yourself. While life can be stressful, try to avoid situations you know will upset you.”

Lynn Gill,
Parkinson's nurse

Responses to medication can fluctuate and the side effects of the medication, in some cases, can be more troubling than the symptoms of Parkinson's. You may also find that you experience changes in how your mind works.

This may be a side effect of some Parkinson's medication, or may be due to the progression of the condition, and can include difficulties with memory, hallucinations, confusion, anxiety and depression. All of these can affect your decisions, attention and ability to concentrate on any one thing.

See page 17 for more information about mental health symptoms and page 35 for more information about medication side effects.



Other symptoms

Symptoms that are not related to movement, called 'non-motor' symptoms, can affect people at all stages of the condition, but you are more likely to experience one or more of these in the advanced stages of Parkinson's. They can have a significant effect on quality of life.

Some of these are related to mental health, and will be covered from page 17.

Communication problems

People with Parkinson's may find that they are affected by a variety of communication problems, including problems with their speech, writing, facial expressions and body language.

Although this can affect people at all stages of the condition, it may be more noticeable as Parkinson's progresses. Problems with speech and body language may affect relationships with a partner, family, friends and people you meet.

A speech and language therapist can give advice and exercises to help with all types of communication. It is also important to make sure any hearing aids are working and that glasses are the right prescription, especially if you care for someone with very advanced Parkinson's or

dementia who may not be able to raise this as a problem.

Pain and Parkinson's

Some people will experience pain as a main symptom of the condition, and some find this becomes more likely in the advanced stages of the condition.

There can be many causes of pain in Parkinson's and it can be an increasing feature as the condition progresses. Most often this will be pain in muscles and bones, felt as an ache around joints or in the arms or legs. It will stay in one area and won't shoot down limbs. Painkillers may help, but you may also wish to speak to a physiotherapist for advice on how to manage your pain.

Pain management is very important for quality of life in the advanced stages of Parkinson's. Once you've been prescribed painkillers, it's important to take them regularly to keep yourself pain-free. You should also speak to your GP, specialist or Parkinson's nurse about reviewing your prescription from time to time.

Muscle cramps and dystonia

Pain can also come from muscle cramps. You can try easing these with movement if possible, or stretching and massaging the affected muscle.

Involuntary muscle spasms or contractions, known as dystonia, can make an affected body part go into spasm, which can be very painful. Speak to your specialist or Parkinson's nurse about treatment options for this.

Find out more: see our [information sheets *Pain in Parkinson's and Muscle cramps and dystonia.*](#)

[Dental, saliva and swallowing problems](#)

It's important to keep your mouth and teeth healthy. You may experience problems such as excess saliva (see below) and dribbling, or a dry mouth, which may be caused by the constant loss of saliva. Movement problems, particularly as your condition progresses, may make it more difficult to clean your teeth or dentures or to get to the dentist.

When you see your dentist, let them know you have Parkinson's. Also, let them know if you have had deep brain stimulation – you may need to be given antibiotics before major dental procedures to help reduce the chance of getting an infection.

Find out more: see our [information sheet *Dental and oral health in Parkinson's.*](#)

“ I didn't realise that pain could be so severe in Parkinson's. It's not easy to deal with. My husband had a second hip replacement on the same hip that never healed, and I thought that was the cause of the pain. He had good pain management, but after a long time, that seemed not to work too well. ”

Eva, whose husband had Parkinson's

[Saliva and swallowing problems](#)

As Parkinson's progresses, you may find you have problems with swallowing. This may make it more difficult for you to get the nutrition you need. It can also cause problems with excess saliva.

As the condition progresses, there is a risk of silent aspiration. This is when food or liquids aren't swallowed properly and enter the lungs by mistake. This may make you more likely to have chest infections. If left untreated, this can lead to pneumonia. Pneumonia is a common

cause of death in the later stages of Parkinson's.

If you have problems with swallowing, you should ask your GP, specialist or Parkinson's nurse to refer you to a speech and language therapist.

Falls

Loss of balance and falling can be common in Parkinson's and the problem may increase over time. You may become more likely to fall in the later stages of Parkinson's.

Some people fall because they experience freezing, where a part of their body freezes when they are moving or trying to start a movement.

As Parkinson's progresses, your posture can change – you may become more stooped and your muscles may become more rigid. This can increase your risk of falling, because it's more difficult for your body to move, and for you to protect yourself if you lose your balance.

Anxiety or fear of falling can make it more likely to happen again, so it's important to get help. Your GP, specialist or Parkinson's nurse can offer advice, or refer you to a physiotherapist or occupational therapist.

There are techniques you can use to avoid falls or to make coping with falls easier, as well as simple changes you can make to your home to minimise the risk of falling. You may also find a walking aid useful. Your physiotherapist can advise on this.

Find out more: see our [information sheet *Falls and Parkinson's*](#).

Fatigue

You might find you feel exhausted, lack energy and experience an overwhelming sense of tiredness – this is fatigue. It can affect people at all stages of the condition.

But if the fatigue continues, it may be a good idea to ask your GP if you could have a blood test to make sure you're not anaemic – as this can also be a cause of lack of energy.

Fatigue can often trigger a cycle in which you become less and less active. This can start a vicious circle – the less active you are, the weaker your muscles may become and so the more tired you'll feel. Because of this, it is important to keep active, both physically and mentally.

Find out more: see our [information sheet *Fatigue and Parkinson's*](#).

Skin and sweating problems

Parkinson's can cause the glands in your skin to make too much of a substance called sebum, which can make your skin and scalp greasy and scaly. Sweating, especially at night, can be caused by the condition or some Parkinson's medications.

Find out more: see our information sheet *Skin, scalp and sweating problems in Parkinson's*.

Sleep and night-time problems

You may experience problems sleeping that will leave you feeling tired during the day. There are many different reasons for these problems, including changes in how you react to your medication, muscle spasms (dystonia) and restless legs syndrome – an irresistible desire to move your legs.

Find out more: see our booklet *Sleep and night-time problems in Parkinson's*.

Restless legs syndrome

This can cause pins and needles, painful sensations or burning in the legs. It may feel like an irresistible urge to move your legs while relaxing, such as while sitting watching TV, or getting to sleep. Night-time pain related to restless legs may be treated with Parkinson's medication. In rare situations, other

medications may be recommended. Speak to your GP, specialist or Parkinson's nurse to find out more.

Find out more: see our information sheets *Sleep and night-time problems in Parkinson's* and *Restless legs syndrome and Parkinson's*.

Bladder and bowel problems

Not everyone with Parkinson's will have bladder and bowel problems, but some people may have difficulties during the course of their condition. This may become more of an issue as the condition advances, because activity and movement keep the bowel functioning well, so it may be affected by reduced mobility. Also, movement symptoms may make it more difficult to access the toilet.

If you are experiencing a bladder problem, remember that it might not necessarily be caused by Parkinson's. For example, it may be caused by an infection, which can be treated. So speak to your GP, specialist or Parkinson's nurse.

Bladder incontinence

You may experience an overactive bladder, where messages to the brain telling the bladder to wait aren't getting through properly. You'll feel the need to urinate



immediately, before you've had the chance to find a toilet.

If you have an overactive bladder, you may feel the need to urinate during the night. This is called nocturia and can cause incontinence if you are unable to get to the toilet in time. This may wake you up, or your bladder may empty while you are asleep. This is a common problem, and sometimes people will delay seeking help as they are embarrassed. But your GP, specialist or Parkinson's nurse may be able to refer you to a specialist continence nurse who can suggest solutions to ease these problems.

You may also experience other bladder problems that are common among the general population, not just people with Parkinson's. These include stress incontinence, a leakage of urine when under physical (not emotional) stress or exertion, such as coughing, laughing or exercising. This is more common in women, who have a shorter and weaker bladder outlet than men.

For some men, enlargement of the prostate (a small gland that surrounds the first part of the tube that carries urine from the bladder) can cause a feeling of needing to urinate more often. There are several options for treating an enlarged prostate gland – including surgery and medication.

It's important to seek help and to avoid any extra stress that these problems can cause. You can speak to your GP, specialist or Parkinson's nurse, or you may be referred to a specialist continence nurse.

Treatments for bladder problems may include:

- Medication – depending on the problem you're having, your GP, specialist or Parkinson's nurse may be able to suggest something suitable.

- Bladder training – this is to help control an overactive bladder. You keep a record of how often you urinate, then attempt to delay when you feel the urge – to practise holding on.
- Pelvic floor muscle exercises – exercising these muscles can help with stress incontinence by strengthening internal muscles around your bladder outlet.
- Surgery – if stress incontinence is a real problem, and pelvic floor muscle exercise or drug treatments haven't helped.
- Catheterisation – if you have trouble emptying your bladder, you may be able to use a catheter. This involves inserting a small plastic tube into the bladder to drain out urine.
- If someone has problems chewing or swallowing food, it makes it harder to have a diet with plenty of fibre, which helps keep stools soft and easy to pass. It can also be a problem if someone doesn't drink enough water.

Constipation can also be made worse by some medications.

In some cases, it can affect how well your Parkinson's medication works. This is because your bowel is full of hard stools, so it is harder for your medication to be absorbed.

Diarrhoea can also affect people with Parkinson's for the same reasons as those without the condition, but it may be more difficult to deal with. Some people with Parkinson's may find it difficult to squeeze the muscles in their bottom, causing a leak before they reach the toilet.

Bowel problems

Constipation can affect many people with Parkinson's. This is because:

- Parkinson's symptoms, such as slow movement and rigidity, can affect muscles in the bowel wall.
- For people unable to move around or exercise, the bowels aren't stimulated enough to work properly.

You should speak to your GP about any change to your bowel habit, particularly if you see blood in your stools. It's important to remember that although you have Parkinson's, which is a long-term condition, it may not be the cause of any new health problems that come up. So you need to see your GP and discuss them as a separate issue.

Find out more: see our booklet *Looking after your bladder and bowels when you have Parkinson's*.

The Bladder and Bowel Foundation's *Just can't wait* toilet card is printed with the words 'The holder of this card has a medical condition and needs to use a toilet quickly. Please help.' This may be useful if you need to use a toilet in a hurry but don't want to explain yourself. Use the contact details in the 'More information and support' section to order a card.

I care for someone with Parkinson's. How will this affect me?

If the person you care for has mobility problems, you may need to help them to go to the toilet. You may also have to help someone go to the toilet at times when their medication is not working so well.

You may be worried about how this type of intimacy will affect your relationship. We suggest you don't do anything you feel uncomfortable with or that you're not physically capable of doing. Speak to your Parkinson's nurse or a continence nurse for advice, and ensure anything you do is

taken into account in a carer's assessment (see page 58).

For some people, bladder and bowel problems can affect their intimate relationships. See page 55 for more information.

Mental health symptoms

Depression, psychosis, apathy and anxiety can affect people with Parkinson's.

Some people will have psychosis and hallucinations that are mistaken for dementia. This may lead to someone being placed in a nursing or a care home, so it's important that any issues are raised with a healthcare professional so they can be managed correctly and appropriately.

More information about dementia can be found on page 23.

Depression

Some people with Parkinson's may be affected by depression during the course of their condition. We don't know for sure why people with Parkinson's get depression, although there is some research to suggest that the lack of the chemical dopamine, which causes the symptoms of Parkinson's, can be a trigger for depression.

It's an illness that is usually diagnosed when someone has feelings of extreme sadness for a long period of time, although some people experience a sense of emotional 'emptiness', rather than sadness. It can affect someone's ability to concentrate, and can affect sleep, appetite and energy levels.

Depression can be common in advanced Parkinson's. Many people will get depressed because of the effect living with Parkinson's has on their lives, or as their symptoms become more noticeable.

Depression is a treatable condition – first, it's important to make sure your Parkinson's symptoms are as well controlled as possible. Speak to your specialist or Parkinson's nurse about any adjustments to your medication.

Some people may respond to self-help, such as complementary therapies. You should also try to make sure you get enough sleep and take regular exercise. You may also find counselling useful.

Although not all types of antidepressants are suitable for people who take Parkinson's medication, in some cases, people may take this type of medication. Speak to your healthcare professionals if you are worried about taking this type of medication.

You may need to take antidepressants for six to eight weeks before you feel any better, and once you are better, it's important to continue to take them regularly. It's also important not to stop taking your medication without talking to your specialist or Parkinson's nurse.



Some carers will also experience depression, as their quality of life will also be affected by someone close to them having Parkinson's. It's important to seek help in these circumstances. Looking after someone with Parkinson's can be tiring and difficult at times. So it's important that the carer's health and wellbeing is looked after as much as the person with Parkinson's.

Find out more: see our [information sheet *Depression and Parkinson's*](#).

Hallucinations and delusions

A hallucination is where a person sees, hears or feels things that aren't there, whereas delusions are unusual thoughts or beliefs that aren't based on reality.

Hallucinations and delusions can be a common problem in advanced Parkinson's. They may be a side effect of Parkinson's medication (see page 35), but not everyone who takes Parkinson's drugs will experience them. It depends on the type of medication, the dose and the person taking them. In some cases they can be brought on by the addition or withdrawal of Parkinson's drugs. There are other causes too, such as infections or dementia.

Some people will be aware that they are hallucinating, but others won't be. Either way, they may be frightening for some people. How they affect a person will depend on how bad their experiences are, how other people around them respond, and whether they have other mental health issues.

If you're experiencing hallucinations and delusions, or they are getting worse, the first step is to get medical advice. Your GP, specialist or Parkinson's nurse may be able to rule out other causes. They may be able to suggest changes to your Parkinson's medication that could help to ease the problem.

If you care for someone who is experiencing hallucinations and delusions, you can also seek advice from their GP, specialist or Parkinson's nurse. The person affected may not realise they are experiencing hallucinations or may be reluctant to seek help, but as a carer, you can speak to the GP, specialist or Parkinson's nurse about any concerns you have.

Hallucinations and delusions can be difficult to manage. As a first step, the dose of some types of Parkinson's medication may be reduced or the medication withdrawn and replaced with other types of Parkinson's drugs.

This must be done gradually and under the guidance of a specialist or Parkinson's nurse to avoid further problems. If the hallucinations still do not go away, then your specialist might introduce medication that can stop hallucinations and control delusions.

For some people, this may not provide a solution, and your Parkinson's nurse may seek advice from a local mental health specialist in order to get the best care for you. The mental health specialist will offer strategies for coping with hallucinations and delusions and prescribe other medication.

Coping with hallucinations and delusions can be stressful and tiring for people with Parkinson's and the people who care for them. So it is important to seek help and support.

Find out more: see our [information sheet *Hallucinations and delusions in Parkinson's*](#).

Anxiety

People with Parkinson's can often experience feelings of anxiety or panic attacks. Anxiety may be based on worry about living with the condition, or mood changes may also be caused by your medication level. If you're 'on' you might feel better, but if you're 'off', your

negative thoughts may increase (see page 35 for information about 'on' and 'off' periods). This may even lead some people to experience panic attacks (see below).

Anxiety can be a difficult problem to live with. If it significantly affects quality of life, it is important to seek help from your specialist or Parkinson's nurse. They may suggest adjustments to your Parkinson's drugs, or may refer you to a mental health specialist. They may also recommend trying talking or relaxation therapies, or drug treatment.

Find out more: see our [information sheet *Anxiety and Parkinson's*](#).

Panic attacks

Panicking is the body's natural reaction to fear or danger, but some people have panic attacks for no clear reason.

A panic attack is an overwhelming feeling of fear or terror that comes out of the blue. Someone having a panic attack might feel sweaty, have a racing heart and feel short of breath. People with Parkinson's may be more likely to suffer from panic attacks and these may be affected by certain medications. They can also happen at times

when your medication is 'wearing off' or working less well. You might have a panic attack because you're worried about Parkinson's and how you'll cope as the condition progresses.

Panic attacks won't harm you, but they can be frightening. Unless they're controlled, they can stop you doing things because you're worried about having an attack. Talk about this problem with your GP, specialist or Parkinson's nurse. They might also suggest medication or some types of therapy. Exercises to help you relax might help, such as counting slowly in your head or listening to soothing music.

Apathy

You may experience apathy. This is where you feel like you don't want to do very much and don't feel sad about it. You may feel detached or indifferent. In the advanced stages of Parkinson's, if you experience reduced mobility and problems with communication, this may make social contact more difficult. This can make you more likely to experience feelings of apathy.

Who can I talk to?

If you're finding it hard to cope with Parkinson's, talking to someone else about your feelings can help you to

realise what's really worrying you. Then you can focus on ways to deal with any difficulties you might face. It's really important to get help before the situation gets worse. Finding ways to deal with your thoughts and feelings can help you manage all the practical issues that Parkinson's throws at you every day.

Who you talk to depends on your personal situation, what you're finding hard to deal with and who you feel most comfortable with.

You may choose to talk to someone who knows you well, such as a partner, relative or friend. But some people like to speak to someone who is not close to them. This could be a health or social care professional. It might be a Parkinson's nurse or your local Parkinson's UK information and support worker.

You could also speak to a professional counsellor. They will help you look at your life and the feelings you have in a safe environment. They won't give you medical advice, but they'll give you space and time to consider your feelings and actions to give you an idea of what you find hard and why. This can help you to sort out your feelings, accept your situation or make changes to your life.

Many GP surgeries have counsellors attached to their practice or they can give you information about other local counsellors. There are also other counselling organisations that can give you information and details of private counsellors. These include Relate and the British Association for Counselling and Psychotherapy. See the 'More information and support' section for contact details of these organisations.

You may also meet someone at your local Parkinson's UK group that you can speak to about living with the condition. This may be a person with Parkinson's or carer, who is going through a similar experience and so

can understand your point of view. See page 83 for more details.

If you don't want to meet people face to face, or if you live in an area with no local Parkinson's UK groups nearby, you can call our helpline on **0808 800 0303** for information and support. There are also online forums where you can talk to other people, including ours at **parkinsons.org.uk/forum**

The mental health charity Mind has a guide, *Making Sense of Counselling*. This covers what counselling is, how it can help, what it involves, the types available and how to find a counsellor. There is a small charge for this booklet. See page 85 for contact details.



Parkinson's and dementia

The risk of dementia is higher in people with Parkinson's than those without and the development of dementia is not uncommon. But many people live with Parkinson's for years before developing significant cognitive problems and some may never experience dementia at all.

What is dementia?

Dementia symptoms are caused by a significant loss of brain function. Dementia affects thinking and memory and can have a big impact on different aspects of life.

There are two forms of dementia most commonly associated with Parkinson's:

Parkinson's dementia

Some people will develop the physical symptoms of dementia after living with Parkinson's for some time. When someone has Parkinson's motor symptoms for at least a year before experiencing dementia, this is known as Parkinson's dementia.

Dementia with Lewy bodies

Dementia with Lewy bodies is diagnosed when someone has the symptoms of dementia either before or at the same time as developing Parkinson's-like problems with

“As a carer, it can be difficult to understand that someone with Parkinson's dementia may sometimes be lucid, but at other times won't be. For someone to have both physical and mental needs is hard. For example, if someone doesn't move when you ask them to, you do not know whether it is because of their movement symptoms or because they don't understand you.”

Marian, whose husband has Parkinson's

movement. In some cases, no motor symptoms may develop at all.

What are the signs of dementia?

Dementia can cause problems with attention, memory and language, and changes in appetite and energy levels. Changes in behaviour, such as aggression, may appear before dementia is even considered as the cause.

How does dementia affect daily life?

It can affect the ability to carry out everyday tasks, such as dressing, cooking and cleaning. Changes in sleeping patterns may mean someone sleeps more during the day. They can also become less engaged with what's going on around them or less interested in things they used to enjoy.

Who can help?

A GP, specialist or Parkinson's nurse may not be able to give all the support someone with dementia or other mental health problems need. If necessary, ask for a referral to a local mental health team.

It's important to seek help. If you're a carer, looking after someone all day can make you feel extremely tired. This, together with broken sleep can become overwhelming and lead to a crisis.

At the advanced stage of Parkinson's, it is likely that someone with the condition will need a range of services in order to ensure their physical, psychological, social and spiritual needs are met effectively. For more information see 'Making decisions about the end of life' on page 79.

Treatment

It is important to get a diagnosis confirmed by a specialist to rule out other problems, such as depression or side effects of medication. Then, if someone is experiencing dementia, their Parkinson's medication may need to be adjusted. It may also be necessary to stop any other drugs that act on the central nervous system. There are also some dementia medications that will be suitable for people with Parkinson's.

Agitated behaviour is a common symptom of dementia. It is important to look broadly for the causes of agitation or distress in people with dementia but one such cause is pain, which must be treated effectively.

Treatment for this should be tailored to the person with dementia and may include complementary therapies such as aromatherapy, multi-sensory stimulation, therapeutic use of music and/or dancing, animal-assisted therapy (therapy with a professional who brings along a pet) or massage in the first instance.

Drug treatments may also be an option, but this is usually only the case if the person with dementia is severely distressed or there is an immediate risk of them harming

themselves or others. Speak to your specialist or Parkinson's nurse to find out more.

Dementia can't be cured, but it can be managed.

- Someone with dementia may be referred to a psychiatrist or a memory clinic. A community psychiatric nurse may visit at home. Care should be shared between the psychiatric team and Parkinson's specialists. Other health and social care professionals such as physiotherapists can also support the person with dementia and their carers. Referral can be through a GP, specialist or Parkinson's nurse, or in some areas people can refer themselves at the local hospital or community health clinic.
- The side effects of Parkinson's drugs can make dementia symptoms worse. A specialist or Parkinson's nurse can adjust medication. Treating dementia often requires a balance between managing Parkinson's symptoms and managing issues caused by dementia.
- Dementia medication is suitable for some people, depending on the stage of dementia and the person's health. It can't cure

dementia or slow down the condition's progress, but it can treat symptoms such as hallucinations and confusion. There isn't a cure or specific treatment for dementia with Lewy bodies, but there are medications some people may find effective. Any medication needs to be carefully monitored.

Find out more: see our [information sheet *Parkinson's dementia or Dementia with Lewy bodies*](#).

Making decisions

If you've been diagnosed with early stage dementia, you may want to make some decisions about your finances or Will, and what sort of health and social care you'd like in the future. You might also want to make a legal agreement for someone you trust to handle your affairs.

Considering the issues at the right time, before a time when you may no longer be able to do this for yourself, is important.

See page 79 for more information about making decisions about end of life care or see our booklet *Preparing for end of life*.

Caring for someone with dementia

If someone becomes less able because of their dementia, it might be necessary for others to start helping with tasks such as shopping or cooking. This can have a big impact on the partner or family of someone with Parkinson's. But there are things that can help:

- Contact your local authority to apply for a carer's assessment. From this you can find out what support you are entitled to (see page 58 for more information).
- Consider services such as day care, flexible respite breaks and home care, to give you a chance to have time to yourself, to go shopping, have your hair done, meet friends for a coffee or maybe catch up on some sleep.
- Our local groups can offer invaluable support. There will be other carers there who are looking after other people with dementia and coping with similar problems to yours.

Caring for someone with dementia can be difficult and emotionally exhausting. It is important to know that help is available. Seek advice from your GP, specialist or Parkinson's nurse.

You can also call our free helpline on **0808 800 0303** for information and support, or for details of your local information and support worker.

Contact details for other organisations that can help can be found in the 'More information and support section' on page 82.

It is important to take a break from caring, if only a few hours, to recharge your batteries. Breaks from caring are usually called respite breaks. For information on respite care, contact the organisations on page 86, or contact your local information and support worker who can direct you to options available in your area.

Coping with other conditions

Checking symptoms

Whether you have been diagnosed with a health issue other than Parkinson's or not, it can be easy to assume that any new symptom you have is the result of your condition getting worse.

But it is important to remember that some problems, such as bladder and bowel problems or some infections, can be common in the general population. So there may be other causes.

If you experience any new symptoms it is important to speak to your GP, specialist or Parkinson's nurse, to make sure you get the most appropriate treatment.

Tell your healthcare professionals

For some people, their Parkinson's symptoms may be similar to other conditions they have. This can

sometimes make these symptoms harder to recognise and to treat, such as pain or bladder and bowel problems.

Make sure all the healthcare professionals involved in your care are aware of all of your health issues. Also make sure they know about any treatments that have



been suggested or prescribed by any other healthcare professionals you may have seen.

Recovery time

Sometimes, if you have health issues other than Parkinson's, the symptoms of one can have a knock-on effect on the other, and another condition may cause your Parkinson's symptoms such as stiffness, slowness or tremor to get worse.

People with Parkinson's have also told us that having an infection can affect their Parkinson's symptoms. With this in mind, it is usually advisable to wait until you feel better before making any decisions about making any changes to your Parkinson's medication. Speak to your GP, specialist or Parkinson's nurse if you have any concerns.

Multiple medications

If you're living with more than one condition, you may have to take a lot of different medications.

If you are prescribed any new medications, make sure you discuss your full medication regimen with your GP, Parkinson's specialist, Parkinson's nurse (if you have one) and your pharmacist.

It is important to read the information leaflet that comes

with any new medication you are prescribed.

Going into hospital

Having more than one medical condition may mean more visits to hospital. If you need to go into hospital, make sure you take your Parkinson's medications with you and the phone number of your Parkinson's nurse – even if your visit is not Parkinson's related.

Explain to staff about your medications and the way you take them. If you feel you are well enough and able to cope, ask if you can keep and self administer your medications while you are in hospital. Make sure you can take your medication on time.

As part of our Get It On Time campaign, we have a range of materials to help you get the message across that people with Parkinson's need their medication on time, every time.

For a copy of our information resources catalogue visit parkinsons.org.uk/getitontime or call **0845 121 2354**.

MANAGING THE CONDITION

Medical treatments

There is no cure for Parkinson's yet, but there are treatments that can help you to control the symptoms and enjoy a better quality of life. These include drugs, surgery, physiotherapy, speech and language therapy, and occupational therapy.

Medication is the main treatment used for the movement (motor) symptoms of Parkinson's.

Managing non-movement symptoms

People with Parkinson's will often receive the same or similar treatment for non-movement related symptoms, such as sleeping problems, as people without Parkinson's would – as long as the medication used is compatible with their Parkinson's medication and other factors of the condition.

In some cases, non-motor symptoms will mean Parkinson's medication will need to be adjusted by your specialist or Parkinson's nurse.

In some cases, they may discuss with you the possibility of reducing or withdrawing some of your medication. This may reduce side effects, but may mean your movement (motor) symptoms are less controlled than before. This needs to be done gradually to avoid any further problems. You can read more about this on page 30.

Will the type of medication I take change as my condition progresses?

You may have been taking medication to control your Parkinson's symptoms for some time. Changes and additions may be made to your medication as your condition progresses, to help you keep control of your symptoms.

For example, you may find that you have to take a more complicated combination of medication to treat your symptoms.

Many people find their Parkinson's medication works very well when

they start taking it, but this can change over time and side effects of some Parkinson's drugs can develop. You can read more about these on page 35.

Some people's side effects will have a big impact on their lives and these have to be kept under control along with the symptoms. Speak to your GP, specialist or Parkinson's nurse, as changing or adding to your medication regimen might help.

Your Parkinson's medication may also interact with the medication you are taking for other conditions, such as depression or dementia. Your specialist or Parkinson's nurse will advise you on this.

There may come a time when medication taken as tablets, capsules or patches is no longer working so well to control your symptoms. This is when other solutions may be considered, such as surgery or stronger types of medication. You should also explore different types of therapy, such as physiotherapy and occupational therapy.

Other treatment options include:

- injection or infusion of a dopamine agonist under the skin

- levodopa/carbidopa gel inserted into your stomach by a tube
- deep brain stimulation surgery

Your specialist or Parkinson's nurse may start talking about these options when you have complex symptoms or your drugs regimen has become complicated.

Medication withdrawal

For many people with advanced Parkinson's, drugs may start being reduced if side effects outweigh the benefits of taking medication. This must always be done gradually and under the guidance of a specialist or Parkinson's nurse.

It can sometimes be difficult to accept that reducing your medication is the best option when, prior to this, medication will have been added to your regimen to help manage your condition. But if some of the drugs are reduced, then you may find you get the benefits of the remaining ones, rather than the side effects. You'll also have a simpler drugs regimen that's easier to follow.

Drug treatments

This is a brief overview of the different types of Parkinson's drugs. Information about surgery can be found on page 40.

More detailed information about Parkinson's drugs can be found in our booklet *Drug treatments for Parkinson's*.

Levodopa

Other names: co-beneldopa (Madopar, Madopar CR), co-careldopa (Caramet CR, Duodopa, Sinemet, Sinemet Plus, Sinemet CR, Half Sinemet CR, Lecado), co-careldopa plus entacapone (Stalevo)

Levodopa can be used at all stages of Parkinson's, but it has side effects that build up over time (side effects are more likely if your dose is increased). After a while, you may have a less predictable response to levodopa. When this happens, sometimes your specialist or Parkinson's nurse will change the dose, the form of the drug or how you take it. Taking other Parkinson's drugs with levodopa may help it to be more effective in treating the symptoms of Parkinson's.

As well as tablets, other forms of levodopa include:

Controlled release or prolonged release capsules or tablets

These options let levodopa enter your body slowly rather than all at once. They can reduce the number of times you experience side effects

and may be taken before bed to reduce stiffness during the night.

Dispersible tablets

This form can be mixed with a small amount of water to make a drink. It takes effect more quickly as it doesn't need to be broken down by your stomach to release the active ingredient and it can be used if you have trouble swallowing tablets or capsules.

Its effects last for a short period but it can be useful when you freeze or when you wake up feeling stiff in the morning. However, if you take it too often you may get side effects, such as involuntary movements (see page 36).

Intestinal gel (duodopa)

This option is only suitable for a very small number of people, whose symptoms can't be controlled with the more common forms of treatment. The drug is pumped continuously through a tube that is surgically inserted in the intestine.

If you are prescribed this option you are less likely to experience involuntary movements. You might also have fewer 'off' periods. It may help to control your symptoms at night and may be used in people who are fed via a tube because they cannot swallow. It may be an



alternative option for people who are not suitable for surgery for Parkinson's (see page 40).

Dopamine agonists

Other names: bromocriptine (Parlodel), cabergoline (Cabaser), pergolide, pramipexole (Mirapexin, Mirapexin prolonged release), rotigotine (Neupro), ropinirole (Adartrel, Ralnea XL, Requip, Requip XL, Spiroco XL), apomorphine (APO-go PEN, APO-go PFS)

These drugs may be given on their own or prescribed alongside levodopa or other drugs to help them to work better. They can be prescribed at any stage of the condition. As well as

standard tablets or capsules, there are prolonged release options that can be taken less frequently but work longer in the body.

Other forms of dopamine agonists include:

Skin patches (rotigotine)

This may be good if you have trouble swallowing tablets, as well as for those who have problems with drooling and gastritis (inflammation of the lining of the stomach). It might also reduce stomach upsets.

Injection or infusion (apomorphine)

Apomorphine is given by injection

or infusion pump. It is the strongest known dopamine agonist. It is usually saved for more advanced Parkinson's that does not respond as well to oral drug treatments. If you continue to have sudden and unpredictable changes in your symptoms that aren't controlled by other Parkinson's medications, these may be helped by apomorphine.

Despite its name, there is no morphine in the drug and it can be a useful drug for treating Parkinson's. But this treatment won't suit everyone and you will be given a trial at the hospital to see if it could help you.

You may need to have injections of apomorphine between doses of your usual tablets. There is a ready-to-use injection pen that works within 10 minutes and is often used as a 'rescue' measure. This is very useful if you have a sudden 'off' period.

If you need apomorphine more often, you can use a portable, battery-driven pump, which gives the drug through a very small needle, similar to a drawing pin, under the skin. Nodules (solid, raised area under the skin) can form around the needle sites, however, and physiotherapists can give advice on massaging the area.

They can also use ultrasound therapy to reduce nodule size.

Ideally, apomorphine will be started in hospital, under the guidance of a Parkinson's specialist. Once you are settled on this treatment, and you and your carers have been trained in how to use it, apomorphine can be continued at home.

Apomorphine can cause severe short-term nausea and sickness, so an anti-sickness drug called domperidone (Motilium) will also be given for at least two weeks when it is started.

Monoamine oxidase type B (MAO-B) inhibitors

Other names: rasagiline (Azilect), selegiline (Eldepryl, Zelapar)

These drugs are sometimes used alone in early Parkinson's, or with levodopa and sometimes other drugs, in late Parkinson's. There is a form that dissolves on the tongue, which may be useful if you have problems swallowing.

Catechol-O-methyltransferase (COMT) inhibitors

Other names: entacapone (Comtess), tolcapone (Tasmar), co-careldopa plus entacapone (Stalevo)

In late Parkinson's, COMT inhibitors are used alongside levodopa to help it work more smoothly. They can be tried if your dose of levodopa is not working for long enough.

Glutamate antagonist

Other names: amantadine (Symmetrel)

This is mostly used with other Parkinson's medication and has an effect on tremor and stiff muscles.

Anticholinergics

Other names: orphenadrine (Disipal, Biorphen), procyclidine (Arpicolin, Kemadrin), trihexyphenidyl (Broflex)

These drugs are not used very often for Parkinson's but sometimes they are used for reducing tremor and stiff muscles.

Medication timing

Whichever Parkinson's drugs you take, it's very important to take them on time, every time, as far as possible. Your specialist or Parkinson's nurse will work with you to get this right. This will let you manage your symptoms as well as possible.

Find out more: see our booklet *Drug treatments for Parkinson's*.

If you're taking a number of medications, you may find it useful to keep a record of what you take and when. This can help you to keep track of a complicated drugs regimen, or to alert others in an emergency. There are a few items you may find will help with this, such as the following:

'Bottle in the fridge'

The 'bottle in the fridge' scheme is an emergency information service that is provided free of charge by some local charities and hospitals – ask your local information and support worker or GP if the scheme exists in your area.

The bottle may contain details of your medical conditions and a list of the drugs you take. It is stored in the fridge as most households have one, and it is usually easy to find. Ambulance crews are trained to look in your fridge for these bottles. They are particularly useful if you need to be taken to hospital urgently, as it lets staff know what medication you are taking.

Parkinson's UK Medication card

You can also order our medication card to carry in your purse or wallet. You can write details of the drugs you are taking, your GP's number and your emergency contact details on this.

Drugs leaflets

It may be useful to keep a copy of the leaflet that comes with each drug that you take in a safe place, known to your family, friends and carer (if you have one).

Parkinson's UK Alert card

You can order our alert card, which has some brief messages that will explain you have Parkinson's if you have trouble speaking. This is useful for when you're out and about.

MedicAlert

You can also wear an item of jewellery, such as a MedicAlert bracelet or pendant, that holds contact details and medical information. Medical staff will use these if you're taken to hospital in an emergency. (See page 89 for how to contact MedicAlert.)

Side effects of Parkinson's medication

All prescribed drugs can have potential side effects, including those used to treat Parkinson's. You may find that your Parkinson's medication works well when you start taking it, but this may change over time and side effects develop.

If you've been taking Parkinson's medication for some time, you are more likely to experience some of the following side effects.

Wearing off

When Parkinson's medication is working well, Parkinson's symptoms will be well controlled. This is called being 'on'.

When symptoms are not well controlled and don't respond to medication, this is called being 'off'. As Parkinson's progresses, some people find that a dose doesn't last as long as it used to. This is called 'wearing off'.

Sometimes the effects of wearing off can happen quickly and there will be a sudden change between being 'on', when you are able to do all the things you want to and your symptoms are in good control, to going 'off', where you may not be able to do things you would like to do, such as walking. This may become more frequent as your condition progresses and you may find your 'on' time is limited.

You may experience fluctuations as part of your movement symptoms and in symptoms that aren't related to movement. You can read more about these other symptoms on page 11.

In particular, the non-movement symptoms you may experience from 'wearing off' include anxiety, drenching sweats, slowness of

thinking, fatigue, and a feeling of restlessness and a need to keep moving.

Involuntary movements

You may also develop uncontrollable, often jerky movements (called dyskinesia) that you do not intend to make. This can affect your arms, legs, head or your whole body and can be troublesome and embarrassing.

At first these will happen at 'peak dose' when the level of levodopa in your bloodstream is at its highest, but then may appear at any time as a side effect of long-term use of the drug.

They can also happen if you don't take your medication regularly, or if you take more than you've been prescribed.

Because motor fluctuations and involuntary movements are related to levodopa treatment, they can be difficult to treat. Reducing your dose may lessen their effect, but may also mean you experience other symptoms again, such as reduced movement or more stiffness. As your condition progresses, they may become more of a feature of your day-to-day life.

Often, these movements can happen when you're in a stressful

situation, for example when you visit the hospital to see your specialist, but they usually ease off when you settle down again.

Hallucinations and delusions

These can be a side effect of Parkinson's medication and/or related to Parkinson's itself. See page 19 for more information.

Impulsive and compulsive behaviour

Impulsive and compulsive behaviour is a potential side effect of some types of Parkinson's drugs.

A relatively small number of people are affected by this, but it can have a big effect on their lives and the lives of those around them. Most of these take dopamine agonist medication, but it can affect people taking some other Parkinson's drugs, too.

Impulsive behaviour is when a person can't resist the temptation to carry out certain activities, such as gambling, becoming a 'shopaholic' or binge eating.

Hypersexuality is where someone is focused on sexual feelings and thoughts. Sexual impulses become more intense and may be felt at inappropriate times, and towards people who are not their partner. Someone may use the internet

more and visit websites they might not have used before, such as pornographic sites. Someone may behave in a way that is socially unacceptable. They may find family members or friends attractive, or visit prostitutes.

Compulsive behaviour is when a person has an overwhelming urge to act in a certain way, often repetitively, to reduce the worry or tension that they get from their urge. This behaviour includes punting, which is repetitive collecting and sorting of objects.

If you're experiencing this kind of behaviour, speak to your GP,



specialist or Parkinson's nurse as soon as possible. Your family should also know about this potential side effect so they can spot any unusual signs. It's important to be honest about anything that's happening. Some of this behaviour may be embarrassing and you may feel uncomfortable talking to a healthcare professional.

Remember this behaviour doesn't reflect badly on you. Your healthcare professional will have spoken to others with similar problems before and everything you tell them will be treated confidentially.

Recognising the problem and getting help sooner will make it easier to deal with rather than waiting until further down the line when the issue has become more difficult to deal with.

Beware that sometimes, people who experience these side effects may not realise they have a problem. So if carers notice any unusual behaviour, they should talk to the person with Parkinson's about it and seek help from a healthcare professional.

Find out more: see our [information sheet *Impulsive and compulsive behaviour in Parkinson's*](#).

Dopamine dysregulation syndrome

This is when people have the compulsion to take more medication than is needed to control their Parkinson's symptoms. This is a type of impulsive and compulsive behaviour. If someone is taking too much levodopa, this can lead to further side effects, such as severe involuntary movements (dyskinesia). If this is suspected, you should get help from the person's specialist or Parkinson's nurse.

If you suspect a severe drug reaction, report it to the Medicines and Healthcare products Regulatory Agency (MHRA) using their yellow card reporting scheme – call **020 3080 6000** or visit **mhra.gov.uk**

Dopamine agonist withdrawal syndrome

Dopamine agonist withdrawal syndrome can happen when someone very suddenly stops taking dopamine agonists, perhaps because they are experiencing impulsive and compulsive behaviour. It can lead to symptoms including depression, anxiety or pain. Any withdrawal from Parkinson's drugs needs to be done gradually, under the supervision of a health professional, to avoid the risk of this syndrome.

I'm a carer of someone with advanced Parkinson's and responsible for their medication. How can I make sure I get it right? Parkinson's medication can be one of the biggest concerns of day-to-day life with Parkinson's. Someone with Parkinson's may have a complicated medication regimen, taking a number of different tablets each day at specific times. So, being responsible for medication may feel quite daunting, especially as the condition progresses.

Ask for support from your GP, specialist, Parkinson's nurse or pharmacist to get a good understanding of the type and timing of medication – a chart or diary may be useful to help you record this. Having this information written down will help you to discuss this with the relevant healthcare professional. Talking it through will help to ease any worries you may have. Remember to be kind to yourself, as you are doing your best and may not get it right every time.

Having this information means you can plan the regimen around your daily activity, allowing you to maintain a good standard of living and to continue doing the things you enjoy. It can also help when you have to plan for special occasions, such as holidays.

You may also find using a pill timer useful. Pill timers are boxes that you can store Parkinson's drugs in. There are many different types and sizes. Some have sections for different times of day, while others are big enough to hold your tablets for a whole week, with sections for each day. Some weekly pill timers are also split into times of day. Some pill timers have labels on each section that show days or times. Others have a timer or a digital clock face with an alarm to remind you to take your medication.

The Disabled Living Foundation, an organisation that provides information on a range of equipment for disabled and older people, can also advise you on options available. Contact them at:

Disabled Living Foundation

Helpline: **0300 999 0004**

(10am to 4pm Mondays to Fridays)

helpline@dlf.org.uk

www.dlf.org.uk

You may also find the Parkinson's UK medication card and medication record useful. See page 34 for more details.

Looking out for side effects

If you care for someone with Parkinson's, medication side

effects can be difficult and tiring to cope with. It may be that the person having side effects such as hallucinations, delusions or impulsive and compulsive behaviour does not realise they are experiencing them. It is important to seek help from your specialist or Parkinson's nurse as soon as you notice an issue, as there may be changes they can make to medication.

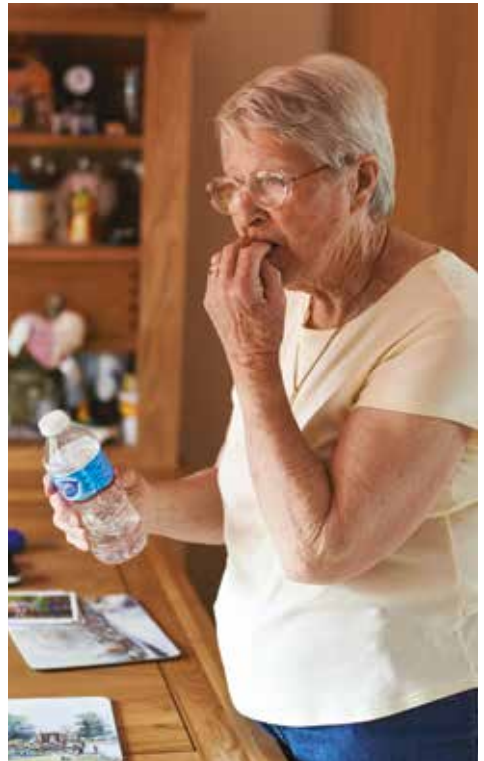
For impulsive and compulsive behaviour, signs to look out for include:

- Have they recently put on weight? There may be a number of reasons for this, but you might want to look for the signs of binge eating.
- Are they being more protective than usual about their finances?
- Have they started collecting or organising certain objects?
- Have you noticed any repetitive behaviour?
- Have you noticed an increase in their sex drive or a change in their sexual behaviour towards you or others?
- Are they going shopping more often than usual?

- Are they spending more time than usual on their computer (perhaps on shopping, gambling or pornographic websites)?
- Are they taking more of their Parkinson's medication than they should, and either denying or refusing to discuss it?
- Do they have aggressive outbursts over small things, or for no apparent reason?
- Is there a family history of gambling or alcoholism, or any of the behaviour above? Try to be honest and seek help. There is nothing to be ashamed of, either for you or the person with Parkinson's. Most of the difficult behaviour is a side effect of medication and is not the person's fault.

Always seek help from your GP, specialist or Parkinson's nurse if someone has these symptoms. See page 82 for other sources of support.

If you are helping someone to manage the side effects of Parkinson's medication, it is also important that you take any opportunity you can to have breaks from caring. See page 70 for more information on this.



What about surgery for Parkinson's?

Surgery doesn't cure or slow down the progress of Parkinson's, but it can help some people to control their symptoms.

Because of the risks involved in surgery on the brain, surgery for Parkinson's is mainly used to treat people whose symptoms can't be controlled by drugs.

It may also be used if you are experiencing strong involuntary movements. It may not be an option

My story

by Chris, whose husband has Parkinson's

“

My husband was diagnosed with Parkinson's in 1999 at the age of 60. At first, we continued much the same and he was able to work until he was 63. But as his condition gradually deteriorated, his medication increased to a mixture of 23 tablets per day, taken at five different times.

Together with increased movement problems, he became more and more confused and suffered from hallucinations and paranoia. I retired at the end of 2010 to become his full-time carer. I was hopeful I'd be able to cope, but he fell a lot, which resulted in a punctured lung and he was admitted to hospital for three weeks. Worse than his physical condition was how agitated he was.

He had almost completely entered his other world and sometimes didn't recognise his home or me as his wife. It was impossible to leave him. We were in a downward spiral and I'd reached rock bottom and was on the point of total defeat.

Around this time, my husband was referred to a new specialist who was concerned about the medication he was taking. He told us he hadn't prescribed this type of drug for six years and that it was probably responsible for my husband's confusion. Added to this, to counteract the side effect of confusion, my husband was taking a drug the specialist thought was probably the cause of his falls.

Under the specialist's instruction, we've gradually reduced the old medication and eliminated one of them. The result is beyond my wildest dreams. Bryan still has classic Parkinson's symptoms but his falls are less frequent. The major difference is that his mind seems to have cleared almost completely of the terrible hallucinations that haunted him. We can start living again – I have my husband back.

The message is: do not assume, as I did, that hallucinations and paranoia are necessarily symptoms of the condition. Question the medication and ask for a second opinion. There may be hope for some improvement. ”

if you have uncontrolled high blood pressure, heart and lung disease, severe depression, confusion, dementia or psychosis.

Deep brain stimulation

Deep brain stimulation is the main type of surgery for Parkinson's. It involves inserting very fine wires, with electrodes at their tips, into the brain. Surgery is performed in a different way at each surgical centre – in some places it is done under local anaesthetic, so the person is awake. In other places it is carried out under general anaesthetic with the person asleep.

When the wires are inserted into 'stimulation areas', an electric current is passed through the wires – and this will have an effect on the person's symptoms. The wire is then connected to a unit that is implanted under the skin of the chest, like a pacemaker. This is done under general anaesthetic.

Talk to your specialist or Parkinson's nurse about whether surgery is an option for you.

How long will the effects of surgery last and will I still have to take medication?

Surgery for Parkinson's should significantly increase quality of life and your ability to do day-to-day

tasks, but it does not stop the progression of Parkinson's.

Symptoms will continue to develop after any operation. Although your medication regimen will change after surgery and some drugs may be reduced or removed altogether, you may still have to take some Parkinson's medication, and this may need to increase as your symptoms worsen.

Lesioning

Another type of surgery for Parkinson's is called lesioning. This involves damaging certain cells within specific parts of the brain (by making a lesion). These lesions are known to have a good effect on some Parkinson's symptoms such as tremor or dyskinesia. Lesioning is, however, rarely used because it can cause irreversible side effects.

Find out more: See our booklet *Surgery for Parkinson's*.

Which professionals can help me?

In the advanced stages of Parkinson's, it is likely that the person with the condition will need a range of services in order to ensure their physical, psychological, social and spiritual needs are met effectively. This will enable them to live in the place they choose.

There is a range of health and social care professionals who can provide specialist advice and care at all stages of Parkinson's. As the condition advances and your symptoms become more complex, the number of people involved in your care may increase to involve a range of different professionals. You and your carer, if you have one, are key members of this team.

Your GP may have limited knowledge of Parkinson's, but can refer you to a range of healthcare professionals. The healthcare service available and the types of professionals you can see will vary between different areas, but ideally, it will include those shown below.

Your **specialist** or **Parkinson's nurse** (if you have one) should be your first point of call about



enquiries related to Parkinson's or Parkinson's medication.

Your Parkinson's nurse and specialist will be looking after people at different stages of the condition – with a wide variety of problems ranging from problems with movement to hypersexuality and delusions. So there is no need to be embarrassed about discussing your problems whatever they are. They will have heard similar problems before and will want to help.

They can also refer you to any of the professionals below, depending on what is available in your area. In some cases you may be able to self refer.

A **dietitian** can give advice on getting the nutrients you need, especially if you have problems with chewing or swallowing. Weight loss can affect many people in the advanced stages of Parkinson's, so a dietitian can advise on a suitable diet for you for maintaining your weight. They can also advise on diet to manage symptoms such as constipation, which can have an effect on how well your medication works.

Occupational therapists help reduce the impact of any health problems on your day-to-day life and can help you to maintain

participation in family life, work and leisure activities. They can give advice on activities of daily life, such as washing, bathing, dressing, eating, reading and leisure. They can also advise you on equipment or adaptations around your home.

Find out more: see our [information sheet *Occupational therapy and Parkinson's*](#).

Physiotherapists advise on movement, balance and posture problems at home and elsewhere (an occupational therapist can also help you with equipment for this). Exercise is important for all people with Parkinson's, but as the condition progresses, it may become more difficult to be as mobile as you would like.

A physiotherapist can advise you on suitable exercises. Even for people with very limited movement, they can suggest exercise or other therapies.

Find out more: see our [information sheet *Physiotherapy and Parkinson's*](#).

Speech and language therapists give advice on anything to do with communication and also on swallowing problems. Speech and swallowing problems affect many

people with advanced Parkinson's and a speech and language therapist can give you ways to deal with these issues.

Find out more: see our [information sheet *Speech and language therapy and Parkinson's*](#).

Your **pharmacist** can help you understand more about your medication and can give you advice on how to manage when you have to take a number of medicines each day. It may be that you have other health conditions as well as Parkinson's.

They can advise you how to take medication for these alongside your Parkinson's drugs and whether any drugs you buy over the counter or from a health food shop are compatible with your Parkinson's medication.

You may be referred to a **Macmillan nurse** or a **hospice**. These aren't just for the end of life, or for people with conditions such as cancer, so don't be alarmed if this happens. They can help at earlier stages with managing pain and symptom control.

A **continence adviser** is a specialist nurse who assesses and manages incontinence.

A **chiroprapist** or **podiatrist** diagnoses and treats problems with feet and can help you to choose the right footwear. They may be helpful if you experience problems with freezing, balance and falls. You may be able to be referred to this service in your area.

If the service is available in your area, you may see a **sex therapist** who will explore issues to do with Parkinson's and intimate relationships. Problems with sex can affect many people with Parkinson's and this may become more of an issue as the condition progresses. For example, if your physical symptoms have an effect on intimacy, they can suggest techniques to overcome this or different positions to try.

You may be in contact with a **social worker** from your local authority, regarding any care or housing arrangements. They can advise on any local or national resources available to you, including financial support you may be eligible for.

Your **local NHS or Health Service mental health team** can be a useful point of contact if you have certain symptoms, such as hallucinations, delusions, paranoia or anxiety. They can also help with any emotional issues, such as problems coping with more complex symptoms.

As your condition progresses, it may be that you have **home carers** or **carers** in a residential home, who will help you with day-to-day tasks. Find out more about care arrangements on page 62.

If you have a carer – a friend or family member that is unpaid for the care they provide – they will be a crucial part of your health and social care team. The skills and experience they have from looking after you day to day can be helpful to health and social care professionals wanting to understand more about your specific experience of Parkinson's. We have two resources that may be helpful for carers:

- *The carer's guide*
- *Keeping a diary: for carers*

Preparing for your appointments

At this stage, you may be used to living with a number of issues that affect you day to day, such as communication or sleep problems.

When you go to an appointment, make a list of problems to discuss, but list them in order of what is causing you the most difficulty.

This will help a healthcare professional to look at and treat

the most significant issues and will make the most of any appointments you have.

Use the non-motor symptoms questionnaire on page 94 to tick anything you're experiencing problems with. You can then take this with you to your next appointment with your specialist or Parkinson's nurse. You can use the results of this questionnaire to build up a list of priorities.

Before your appointment, think about how you will talk about the issues affecting you. Plan for your clinic appointments and what you want to get out of them. You may find it helpful to write down any questions you may have and take this with you on the day.

At the end of the appointment ask the specialist to write down any recommended actions or advice, or with the help of your carer, friend or family member, write notes yourself during, or as soon as possible after, the appointment.

Find out more: see our [information sheet *Talking to your GP, specialist or Parkinson's nurse about Parkinson's.*](#)

Self-help

How do I ensure I have a good quality of life when living with advanced Parkinson's?

Life with advanced Parkinson's will be tough at times, but there are things that can help you have a better quality of life, both for you and the people who care for you. Taking time out is an important part of this – whether it's time to do or experience things that are nothing to do with Parkinson's (listening to music, taking in a beautiful view or fresh air) or time for you and your carer to be apart, allowing you both to do your own thing for a while.

Preparing yourself with as much information as possible about the condition and the issues you may face will help you to prepare for anything that may crop up. Knowing more about the choices and options available to you – whether it is about treatments, living arrangements or so on – will help you to have more control of your life and the way you want to live wherever possible.

Looking at your diet, exercising where you can and seeking advice from all of the professionals in the multidisciplinary team will help you to live as good a life as possible.

You may also want to try complementary therapies (see page 49), which may help to boost your wellbeing.

Self-management training: A path through Parkinson's

This is a self-management programme developed by Parkinson's UK and people living with the condition. It aims to give you information, an opportunity to think, and help to decide what your priorities are.

We run self-management groups for people fairly recently diagnosed; those who have been living with Parkinson's for longer; and for mixed groups. All groups are also for carers and partners.

Come along and you'll have the opportunity to learn from others with a similar experience of Parkinson's. The groups will discuss:

- what self-management is
- looking ahead and plans for the future
- relationships, feelings and emotions
- what's important
- top tips

- taking care of yourself
- support from Parkinson's UK

Self-management groups are run by trained volunteers, who have first-hand experience of Parkinson's, and run for two, three or six weeks.

For more information on dates and locations in your area or to book a place please visit **parkinsons.org.uk/selfmanagement**, email **selfmanagement@parkinsons.org.uk**, or call our helpline.

Top tips for self-management

You have a key role in making sure your Parkinson's is well managed.

As much as you can, try to:

- keep as active as you can. If you are not able to move very easily, a physiotherapist can give you advice on suitable exercises or movements
- maintain as normal a routine as you can – physically, emotionally and socially – even if you cannot go far from home. An occupational therapist can help you to find suitable activities or ways to maintain your social life
- tell your specialist or Parkinson's nurse about the symptoms that

bother you most, even if you're not sure they're Parkinson's-related

- don't be afraid to ask for advice
- continue to do as much for yourself as you can, even if it takes longer
- remember that everyone has a different experience of the condition
- seek the support that is available from Parkinson's UK – see page 83. This includes our peer support service, where you can be matched with a volunteer going through a similar experience of Parkinson's to you. Over a series of sessions they will talk through any issues you have. You can also speak to people on our online forum at **parkinsons.org.uk/forum**
- visit your local Parkinson's UK group for support from others going through a similar experience. They may have tips for managing different aspects of life with Parkinson's
- make the most of the multidisciplinary team, including therapies as well as drug treatments

Practical day-to-day solutions

As your physical symptoms and medication side effects begin to have more of an effect on your everyday life, you may find you need more help to get around. Not everyone will want to or need to use mobility aids, but some people may benefit from speaking to a physiotherapist or occupational therapist about what options are available to them. Your GP, specialist or Parkinson's nurse may be able to refer you.

You can also get practical tips for coping with a range of Parkinson's symptoms from our information resources. For example, practical suggestions for communication can be found in our information sheet *Communication and Parkinson's*.

Our booklet *Tips and hints for people with Parkinson's* includes a range of practical tips from people with Parkinson's for coping with day-to-day aspects of life with the condition.

We have a range of publications available to order for free. See the inside back cover for details of how to order.

What are complementary therapies and how can they help?

Complementary therapies are non-conventional health treatments,

which may be used alongside conventional medicine. Examples include acupuncture, the Alexander technique, aromatherapy, creative therapies (involving art, music, dance or drama), conductive education, herbal medicine, Pilates, reflexology, t'ai chi and yoga.

There is not very much scientific evidence available about the benefits of complementary therapies, but many people report that they help them with things like controlling their posture, fitness, relaxation, social interaction and personal development. Relaxation therapies have been found to be very helpful, as stress can make Parkinson's symptoms worse.

If you are thinking of trying a complementary therapy, talk about it with your GP, specialist or Parkinson's nurse to make sure the therapy is right for you. This is very important if you want to use herbal medicines, as some cannot be used with, or have bad effects on, Parkinson's medication.

You should also make sure that the therapist you use is properly trained and is linked to a professional organisation that ensures they work to certain standards.

Find out more: see our booklet *Complementary therapies and Parkinson's*.

Diet and exercise

Diet

While there is no specific diet recommended for people with Parkinson's, it is important to eat a wide range of foods that help you to get the nutrients you need.

As Parkinson's progresses, people may experience changes in their weight and some people will find they lose weight. This may be due to swallowing problems or because of movement symptoms that mean your muscles are

constantly working. Ask your GP, specialist or Parkinson's nurse to refer you to a dietitian, who can discuss your diet and ways to help you get the nutrients you need to maintain a healthy weight.

Protein and levodopa

Taking levodopa with food can sometimes help to reduce feelings of sickness. However, for some people, protein (which is found mainly in meat, fish, eggs, cheese and beans) seems to interfere with how well levodopa medication works, by stopping how well the drug is absorbed by the body. If this affects you, you may benefit from taking your medication 30 minutes before you eat.



Your specialist or Parkinson's nurse can advise you on timing your doses and this should be discussed with them when you are first prescribed the drug. They can also help you get advice from a dietitian.

Nutrition for swallowing problems

Swallowing problems may prevent you from getting the nutrition you need. Ideally you should be referred to a dietitian who can help you plan your diet.

They may advise:

- avoiding tough or chewy meats or moistening them with gravy or sauce, or trying fish because the flesh is usually very soft – be careful of bones though
- trying alternative types of food, for example thicker, creamier soups rather than thin watery ones or those with bits in
- adding 'extras' to food, such as cream, butter, sugar or honey, which can give food more energy and make it taste better
- liquidising or pureeing food or using a milk-based sauce or gravy for extra energy
- using thickening agents such as milk powder, instant potato

powder, custard powder or yoghurt, which can add texture to pureed food

- changes to your eating position
- taking smaller mouthfuls
- making sure that if you wear dentures, they fit properly
- trying mashed potato, pasta or noodles as a change from bread
- trying soft, moist biscuits rather than dry crackers or toast
- having a drink with your meal to make chewing and swallowing your meal easier. Sipping iced water may help you to swallow

Find out more: see our booklet *Diet and Parkinson's*.

Equipment to help you eat and drink

Some people may find it helpful to use special equipment, such as cups with wide bases and double handles or beakers, adapted cutlery and plates with a lip. You can speak with an occupational therapist about what may be most suitable for you.

Alternative feeding options

For some people in the advanced stages of Parkinson's, swallowing problems become so severe that alternative feeding options may be necessary. These may include tubes that are surgically inserted which deliver a nutritionally complete 'feed' directly into the stomach. In some cases, Parkinson's medication can also be given using this method.

Your specialist or Parkinson's nurse will be able to discuss this with you. During this discussion, ask any questions you may have and this will help you to make an informed choice whether you would like to have the tube inserted.

If you have dementia, the specialist will take into account the thoughts and feelings of your relatives or carer, but the decision on whether to insert a tube will usually be a medical one.

Find out more: see our [information sheets *Eating, swallowing and saliva control and Speech and language therapy and Parkinson's*](#).

How can I stay mobile in the advanced stages?

For all people affected by Parkinson's, it is important to keep mobile. Exercise can benefit mental as well as physical health.

A physiotherapist will be able to advise you on exercises that are appropriate to your level of mobility. They may recommend exercises that can help to ease stiffness or to ease pain.

Exercise in advanced Parkinson's attempts to maintain a person's function, especially for physical activity such as getting in and out beds, chairs and cars, and walking safely, reducing the amount of assistance (and strain) from another person. Even if you are unable to move from a chair or a bed, there may be exercises a physiotherapist can recommend.

It is important to keep moving to reduce the risk of inactivity, which causes numerous health problems, from heart and lung disease to pressure sores. Keeping active may also help you to reduce fear of falling if you feel unsteady on your feet.

As with all exercise, there is no right and wrong. Try to accept the limitations of the condition, and adapt by taking longer breaks and slowing the pace. You can still find the fun in keeping active.

Find out more: see our [information sheet *Physiotherapy and Parkinson's*](#).

THE PEOPLE AROUND ME

Relationships

How will others react to how Parkinson's affects me as it progresses?

As your symptoms become more noticeable and have more of an effect on your day-to-day life, you may be worried about how others will react.

Everyone will react differently – there will be a range of emotions involved in this, depending on the relationship you have and their knowledge about Parkinson's.

Our range of information resources will help you to give people information about Parkinson's (see inside back cover for details of how to order). You may also get carers and close family members involved in your meetings with your Parkinson's nurse and Parkinson's UK information and support worker.

How will children react – won't it be too frightening for my youngest grandchildren to see me as my Parkinson's progresses?

What you choose to tell young children about Parkinson's is up to you of course, but we hear many positive stories from grandparents who have been open and honest with their grandchildren about having Parkinson's and talked with them, in language they understand, about what they are going through. We produce a range of story books that may help you explain Parkinson's to young children.

Find out more: see our information sheet called *Talking to children about Parkinson's*, our books for children aged three to seven, *My gran/grandad/mum/dad has Parkinson's*, and our booklet for teenagers, *Parkinson's in your life: a guide for teenagers*.



How will I be affected as a long-distance carer?

With many families living miles apart from their relatives, it is common for people to live away from a relative who has Parkinson's. We hear from many people who have a parent, grandparent, other relative or friend with Parkinson's who lives some distance away, but they still want to feel involved in their lives and sometimes in their care.

It is important to maintain contact, however possible, with the person with Parkinson's (not just with their carer).

It may be difficult for someone who has been away for a while to adjust to the changes they see when they

return to spend time with the person with Parkinson's. Staying in contact and getting regular updates may, however, help you prepare for the changes.

Might my relationship with my partner change?

Not everyone who has Parkinson's experiences problems with relationships, but you may find your relationship changes in ways you hadn't expected.

You and your partner may have experienced a range of emotions while coming to terms with life with the condition.

If you have Parkinson's, your self-image may have been affected by

symptoms, such as involuntary body movements, poor posture or excess saliva. If you have low self-esteem, you may become withdrawn, which may affect your relationship.

In some cases, symptoms themselves may cause problems. For example, communication problems such as reduced facial expressions or quietened speech can make it more difficult to express yourself to your partner. They may also be mistaken for low mood or depression. If you do experience depression or anxiety, this may also affect your relationship.

Talking openly as a couple can bring you closer. But some people may find they're dealing with these emotions on their own. They may feel isolated and resentful. If this sounds familiar, you may want to try relationship counselling. A counsellor from Relate can help you both talk about the problems you're facing together (see page 90 for contact details).

Find out more: see our [information sheets](#) *Communication and Parkinson's*, *Speech and language therapy and Parkinson's*, *Depression and Parkinson's* and *Intimate relationships and Parkinson's*.

I care for someone with Parkinson's. How will this affect me?

If caring for a partner:

- You may have to get used to different roles within the relationship than you previously had.
- If your sleep is disrupted it may mean you have to sleep separately, but it is very important that you get enough rest.
- Parkinson's can sometimes affect sexual relationships.

Intimate relationships

Your sexuality is a core part of who you are and if you're in a relationship, intimacy may form a crucial part of this. This is a challenge faced by many people with advanced Parkinson's and their partners, who may also be their carer.

Sex is an important part of life for many people. Sexual problems can be overcome altogether or an alternative form of intimacy can be found. Touch is an essential part of being human and you can experience this, whatever your physical condition. Finding the right solution for your individual circumstances may involve a number of healthcare professionals.

Difficulties with sex happen when something disrupts your sexual responses. This can affect many people, not just those with Parkinson's. But the physical ability to have sex is affected by the nervous system, so it is common for people with neurological conditions, such as Parkinson's, to experience problems with sexual function.

For people with Parkinson's, the physical symptoms of the condition, such as stiff, rigid muscles and slowness of movement, can mean you have to make changes to the way you have sex.

Because symptoms can vary and be affected by so many factors, treatment of sexual problems for people with Parkinson's has to consider all factors that may contribute to the problem and involve a combination of therapies.

As well as problems with sexual arousal, your GP or specialist will look to treat any depression or mood problems you may experience. They will also look at treating, or finding ways to deal with issues including fatigue and bladder and bowel problems, which may affect your ability or confidence in intimate relationships. They may also look at other medications that could be affecting your sexual responses.

“ I found my wife's 'helpful' reminders annoying, so we set up a system where we decided which issues my wife could remind me of, without fear of me accusing her of nagging. We decided on things like, 'Have you taken your drugs today?' Other topics we didn't agree on, she makes fewer comments about. ”

Peter, diagnosed in 1994

Find out more: see our booklet *Intimate relationships and Parkinson's*.

The charity Age UK produces a range of factsheets on relationships for older people. These include information for people who are lesbian, gay, bisexual or transgender. See page 87 for contact details.

People with Parkinson's who are also carers

If you have Parkinson's and you are also a carer, it may be difficult to look

after your own health needs when you feel those of the person you care for are greater than your own.

But, like any carer, it is important that you take time to learn more about your own condition, take time out for yourself when you can, and make sure you attend appointments and do whatever you need to help manage your own condition in the best way possible.

Our helpline advisers speak to many people in this situation so can give information, details of your local information and support worker and can direct you to other organisations that can support you. Call **0800 800 0303**.

Support for carers, family and friends

Caring for someone with advanced Parkinson's

Caring for someone with advanced Parkinson's can be demanding physically, psychologically and socially. The fluctuating nature of the condition can also put extra stresses and demands on a carer. As someone's Parkinson's advances, they may become increasingly dependent and rely on you more and more for support.

Symptoms that aren't related to movement (non-motor symptoms), especially cognitive function and depression, are more likely to become more of an issue. If someone is unable to get out and about as they once did, they may experience social and emotional isolation and stress. This may lead to depression, frustration and anger.

These emotions may also affect a carer. It is not uncommon for carers of people with any long-term condition to feel frustrated about their situation. It is crucial to know what support is available, whether from your local social services or social work department, or from Parkinson's UK.

It can also be difficult to see others with Parkinson's going through a range of symptoms. Because Parkinson's is experienced differently by everyone with the condition, comparing the progression of the condition in the person you care for with others may not be helpful.

Support for carers

Making your own informed choices, finding help, and accepting services and entitlements will help you care for yourself and the person you support.

The services most likely to affect you are those that will give you a break from caring (see more in the 'Taking a break' section on page 70). Other services include:

- support – such as counselling, local carers' groups or projects
- advice and information – for example on benefits
- equipment and aids – to help make caring tasks easier

How can I get this support?

Your local authority, usually through its social services or social work department, or your local health and social care trust, arranges and provides support services for local people.

The services are not just for older people or those with disabilities, they are also for carers.

The person you care for is entitled to an assessment to find out what services they need. If you regularly provide a substantial amount of care, you can also have your needs recognised in a 'carer's assessment'. It doesn't cost anything to be assessed.

When help is offered as a result of an assessment, your ability to pay

“ Go out and mix as much as possible, and get as many breaks from caring as you can. A short break out in the real world helps to put it all in perspective and will help you cope better for a while. ”

Marian, whose husband had Parkinson's

for that help may also be assessed. Depending on the results of this assessment, you may have to pay for some or all of the services offered. Charges depend on your circumstances and local criteria.

You don't have to have a financial assessment if you don't want to, but this will mean you have to pay for services yourself.

Carer's assessments

Carers have a right to an assessment. Ask for one if you think you need support. You can have your needs assessed even if the person you're caring for doesn't want to be assessed. You shouldn't feel forced to take on responsibility that you don't think you can cope with.

There may be pressure from family and friends for someone to take on a caring role, but be realistic and kind to yourself. If you feel unable to become a carer or give the amount of care someone with Parkinson's needs, feel free to say so and other options of care can be explored.

After your assessment, if your local authority agrees you have needs as a carer, they will arrange services to help you. The range of services available varies across the UK.

Having an assessment doesn't mean you have to take a service if you don't want to. But try to accept help wherever possible. Carers who receive help and support cope much better and for longer than those who refuse help and become overwhelmed.

To find out more, you'll find the contact details for your local authority in your local phone book, or speak to your Parkinson's UK information and support worker or GP. You can also call our helpline on **0808 800 0303**.

[Register as a carer with your GP surgery](#)

Some GP surgeries have a carers' register or database. If you're on this, you will be given special consideration because of the

pressures and responsibilities of your role.

Many GP surgeries use this register to:

- give you access to appointments quickly if you need them and help to get the services you need at the right time, without you having to tell everyone, every time, about your caring responsibilities
- point you towards other useful services
- give you up-to-date information about events for carers
- offer appointments for more appropriate times
- ensure outpatient appointments and admission letters state that you are a carer
- offer free flu vaccinations

If your GP surgery doesn't have a carers' register, explain to them how operating one will help them to consider your and other carers' needs.

Find out more: [read our booklet *The carer's guide*](#).

MONEY MATTERS

Employment, financial support and Parkinson's

More information about working with Parkinson's can be found in our booklets *Living with Parkinson's* and *Employment and Parkinson's*.

While many people continue to work for years after diagnosis, in the advanced stages of Parkinson's, your symptoms may mean you are no longer able to work.

There are welfare benefits available to people who are unable to work because of ill health.

It can sometimes be tricky to work out what you are entitled to, and many people miss out on money they could have received. If you would like more information and support, call our helpline on **0808 800 0303** to speak to our advisory officer for benefits and employment. You can also ask for details of the information and support worker in your area.

We also have a range of information sheets on the different welfare benefits that are available. See the inside back cover for details of how to order these.

If you're a carer

As a carer, you may also have concerns about employment. Some people find they have to stop working, but others find they can make arrangements to work more flexibly.

If you care for someone with Parkinson's you are protected from being discriminated against or harassed at work because of your association with a disabled person. This means that it is unlawful to treat you less favourably than another employee who is not associated with a disabled person or for anyone to use offensive language about your association with someone with Parkinson's.

You do not have the right to reasonable adjustments because of your association with a disabled person. You may, however, have

the right to ask your employer under the Flexible Working Regulations to work flexibly (eg change your hours or work from home to fit your caring arrangements). Your employer must give serious consideration to your request but it can be refused if there are good business reasons for doing so.

For more on who can ask for flexible working visit www.gov.uk/flexible-working

[Welfare benefits for carers](#)

As a carer, you may be entitled to receive Carer's Allowance.

Find out more: see our [information sheet *Carer's Allowance*](#).



CARE

Healthcare arrangements

Going into hospital

In the advanced stages of Parkinson's, you may be more likely to be admitted to hospital, not necessarily due to the symptoms of Parkinson's.

To be prepared for any situation, make sure you have a list of the medications you take. This can be kept in a bottle in the fridge or you could use our medication card (see page 34 for details of both ways of recording your medications). If you're preparing for a stay, remember to take this list so the drugs can be easily identified.

You may also wish to make a list of your needs to take with you. This may include likes, dislikes, and preferences, so staff can build up a picture of who you are and what care you need. You should include anything that is important to you. What makes you anxious? Do you carry out personal care in

a certain order? Do you have any religious or cultural needs? You can also record your day-to-day symptoms and problems.

The Alzheimer's Society has produced a simple and practical tool you could use as a guide for the type of information you'd like to share. This booklet may be helpful for hospital staff to see, to give them an idea of what you're like day to day. You can find out more on their website, www.alzheimers.org.uk/thisism

If you have a Parkinson's nurse, they can give you more help on what to do if you go into hospital. If you have the chance to plan ahead for your hospital stay, you should be able to talk about your needs to staff before you go. Your Parkinson's nurse may be able to do this for you.

Parkinson's UK is continuing to campaign to make sure people with Parkinson's get their medication on time, every time, when they're in hospital.

As part of our Get It On Time campaign, we encourage care home and ward staff to:

- tell all team members when they have a patient with Parkinson's
- use pill timers or alarm clocks to remind themselves when people with Parkinson's have to take medication outside of normal drug rounds
- encourage patients to self-administer medication, when the hospital has a policy in place for this
- make sure everyone knows how important the timing of Parkinson's medication is
- set up training sessions on Parkinson's and medication
- order our Get It On Time resources

Our Get It On Time materials include resources to help you prepare for a hospital visit. For example, the Parkinson's UK washbag helps you to inform ward staff that you need to take your medication on time. It includes a medication record book, a card to put by your bed and reminder slips to tell staff you have Parkinson's. See the inside back

page for information on how to order our resources.

If you are admitted in an emergency, you or your loved ones should give ward staff details of your specialist Parkinson's team.

Find out more: see our booklet *Going into hospital*.

You can also give our booklet *Caring for your patient with Parkinson's* to ward staff to give them more information about your condition.

Caring for someone following their hospital stay

If you will be providing regular and substantial care for someone being discharged from hospital, you have the right to ask for an assessment.

An assessment of you and the person you care for will usually be carried out before they are discharged from hospital. If you are already caring and have had a carer's assessment in the last 12 months, your needs must be reassessed before the person leaves hospital to see whether you need further support.

If the hospital believes the person you support will need community care services when they leave hospital, they must contact the

relevant body to carry out an assessment. But they have to speak to both of you first.

Continuing healthcare

Most people who need help to pay for their care receive help from their local council or in Northern Ireland through social services. However, if you have complex health care needs, which lead you to have a 'primary health need', the NHS is responsible for arranging and paying for your care. This is because your needs are beyond the responsibility of your local council or social services.

In England and Wales this is called NHS continuing healthcare or continuing care. In Scotland and Northern Ireland it is referred to as continuing healthcare.

Adults over the age of 18 who have needs because of disability, accident or illness can receive continuing care. Where you can receive care, for example, at home or in a care home or hospital, varies in the different countries of the UK. Contact your local Parkinson's UK information and support worker for help finding out what is available in your area.

How you qualify for NHS Continuing Healthcare varies

according to where you live in the UK and the criteria to decide who receives care is complicated, making it difficult to understand and apply. The charity Independent Age has published a useful guide to help people understand it. It's called *Guide 27 Continuing Healthcare: should the NHS be paying for your care?* and is available from Independent Age's website www.independentage.org You could also call their advice line on **0845 262 1863**.

Social care arrangements

Getting assessed for social care

A care manager or social worker will carry out a needs or care assessment. This will usually take place in your home and will take into account your personal needs and your social and cultural background.

In Northern Ireland, health and social care are integrated and any healthcare professional can make the assessment, for example an occupational therapist. See www.nidirect.gov.uk/health-and-social-care-assessments for more information.

Care needs

A care manager or social worker should explore with you the support and services you may

need, and what's available in your area. Based on this information they will develop a care plan with you and give you a copy of it.

This might be provided by your local social services or social work department, or department of health and social services, or by private agencies and voluntary organisations.

Different local authorities have different ways of deciding who gets access to which services.

If you are not happy with your assessment, or its outcome:

- tell social services, and ask for another assessment if necessary
- ask your Parkinson's UK information and support worker for help or call our helpline on **0808 800 0303**
- if still not resolved informally, ask for details of the local authority's complaints procedure and make a formal complaint
- go along to your local politician's surgery and ask them to raise the matter at a higher level



Carers' needs

Your carer can ask for their needs to be included in your assessment. This means their needs are taken into account when your services are planned, if they are receiving services or need more help. They can also have an assessment in their own right.

This can happen even if the person they care for doesn't want to be assessed. It gives the carer the chance to talk about what help they need for their wellbeing.

The types of services available will change according to where you live, but might include help in your home with caring tasks, or housework, day care, equipment or changes to your home, or chances for leisure and meeting people.

Who pays for care?

The assessment is free of charge. Who pays for any services that social services recommend depends on your finances and whether you qualify to receive the services where you live.

This is usually decided after a care manager or social worker has assessed your finances. This might happen during the needs or carer's assessment. If you don't give this information, social services may assume you can pay for everything.

Your local authority may offer you financial support if you need it, as long as you meet their requirements. They should also be able to tell you about other financial help that's available.

In Scotland and Northern Ireland, personal care is available without charge for everyone in the country aged 65 and over who have been assessed by the local authority as needing it. (Check with your local authority for what they consider personal care to be, as this can vary.) Free nursing care is available for people of any age.

In Wales, the Social Care Charges (Wales) Measure 2010 means that people who live in the country and receive homecare and other non-residential social services will pay a maximum charge of £50 a week for these services. They may pay less than this or nothing, depending on local authority charging policies and individual circumstances.

Personal budgets and direct payments

A personal budget is an agreed amount of money from your council that you can use to arrange and pay for your care and support, after your needs have been assessed.

You can receive it as a direct (cash) payment, through a managed account or by a mixture of the two.

If you receive a direct payment yourself and manage your budget yourself, you may only spend the money on services or equipment for the needs shown in your assessment (which will be noted in your care plan, see page 64), but you can choose the ones that best suit you and your lifestyle.

The agreed amount must be enough to meet your eligible needs and your council will check that the money is being spent appropriately, as set out in your care plan.

If you don't want to manage your budget yourself, the council can do it for you based on your needs and wishes. Alternatively, you can set up a user-controlled trust, which means your money is managed for you by someone else, for example a friend, family member, solicitor or service provider.

In Scotland, the Social Care (Self-Directed Support) Act 2013 requires councils to offer people eligible for social care support the option of a direct payment, an individual budget managed by the council, a service commissioned by the council or a mixture of any of the three.

You can ask your council for advice and support to help you choose which way of managing your budget is best for you.

An individual budget is very similar to a personal budget, but includes funding from other services such as healthcare, housing-related support and disabled facilities grants.

Both individual and personal budgets can be paid to you in different ways. The aim of this scheme is to give people greater choice and control over their lives, and will help them to make their own decisions about how their care and support is delivered and paid for. Payments could go towards respite care or caring support. The amount of the direct payment will depend on the financial position of the person who is assessed. Part of the assessment will determine how much they will need to contribute towards their personal budget.

The authority responsible for care where you live should offer direct payments to people who meet the necessary criteria, but direct payments don't have to be used if someone would prefer the local authority to arrange services for them.

A break from daily routines and responsibilities is important, especially if you care full-time because you are retired or don't work and are with the person you care for 24 hours a day.

Find out more:

- Contact your local council social services, social work department or health and social care trust, your information and support worker, or our helpline on **0808 800 0303** for more information.
- In England and Wales, visit **www.gov.uk** to find out more about direct payments.
- You can find out more about Direct Payments on the NHS Choices website **www.nhs.uk**. Alternatively call the Carers Direct helpline on **0300 123 1053**.
- In Northern Ireland, find out more at **www.nidirect.gov.uk**. There are guides to direct payments available to download on the website. You can also order these by calling **028 9052 2910**.
- Find out more about self-directed support in Scotland at **www.selfdirectedsupportscotland.org.uk**

My story

by Richard, whose dad had Parkinson's

“ My father, John, died at the age of 74 after living with Parkinson's for almost 10 years. During the last two and a half years of his life, he lived in a local nursing home, as his condition was too severe for him to either live at home or in the local cottage hospital.

Before he moved into a nursing home, dad spent time in and out of hospitals, due to the many medical complications related to his Parkinson's.

He didn't have a continuing care assessment before moving in and we didn't know he was entitled to receive one.

Soon after dad moved in, my mother had a visit from social services to carry out a financial assessment. This was very distressing for everyone, as my mother was told that she might have to think about selling her home to pay for dad's nursing home fees. I lost complete faith in both the NHS and social services, as it was clear that the proper procedures were not being followed. We received a lot of conflicting advice.

I logged a complaint with the social services and NHS, and, after a lot of letter writing, I was able to refer the matter to a review panel. It took a long time to resolve before it was agreed that John's nursing home costs should be covered by the NHS because his primary care need was medical.

It is very sad to see that almost 10 years on from when our family had to fight for our father's rights, people with Parkinson's still suffer from having to prove they have a medical care need. To anyone facing this battle, do not give up and document everything. It is your right. ”

Taking a break

Taking a break is important, both for a person with Parkinson's and anyone who may be caring for them. A break from caring, usually called respite, gives both people a chance to recharge their batteries and to spend time away from their usual environment or to socialise with other people. They can increase the patience and confidence of both people and help them to return to each other refreshed.

Your local authority has a responsibility for arranging services that help carers and the people they care for to take a break.

A carer's assessment by your local social services, social work department or health and social care trust (see page 58) will demonstrate the carer's need for a break. Support to take time out varies from area to area.

Services may be provided by social services, social work or voluntary organisations. Care can also be funded in different ways: by yourself, your local authority, or charities.

Find out more: see our booklet *The carers guide*.

Everyone needs time to relax – neither person should feel guilty about respite or day care. Carers who have breaks and a chance to recharge their batteries are able to carry on being a carer far longer than those who never take a break and become physically and emotionally exhausted.

If you have Parkinson's, try to be understanding of why a carer may want to take a break. It's not to do with you – they need to take care of their own needs in this time. Your carer may experience tiredness or feel down occasionally, so look out for the signs of this and ensure they are taking the time away that they need to. Making sure your carer takes a break gives you both a chance to take time off from your roles as carer and 'cared for'.

Respite can vary from a few hours' break to a longer holiday, and can be given in a variety of ways, including the following.

Care for the person with Parkinson's in their home

It can be arranged for someone, for example a social services care worker or someone from a charity, to visit the person with Parkinson's at home regularly. This gives the carer time to do their own thing – at home or elsewhere. It can be a

short period, just two to three hours a day, or overnight, and can be occasional or frequent.

Find out more about the charity the Carers Trust, who offer this kind of support, in the 'More information and support' section on page 82.

Day care for the person with Parkinson's outside of the home

A person with Parkinson's can spend some time at a day centre, providing their carer with time to do whatever they need to do. Many day centres offer therapy or sports sessions, classes, and other recreational activities.

Care away from home for the person with Parkinson's

The person with Parkinson's could have short, perhaps regular, stays in a care or nursing home.

Trips and holidays together with the person with Parkinson's

This may be to a centre or hotel where there are care services supplied. This gives both parties a rest and change of scene.

If you're a carer, try to remember that respite care is recognised as a 'break' for you, rather than time for you to catch up on caring-related tasks.

It's your time to recharge your batteries and enjoy doing something for yourself.

Do we have to pay for respite care?

Depending on the outcome of your carer's assessment, respite care may be funded by your local authority, a charity or yourself.

What organisations run respite care breaks?

Aside from some local authorities, the following organisations offer respite care:

Vitalise is a charity providing short breaks (respite care) and other services for disabled people, visually impaired people, and carers. The scheme is open to everyone in the UK, but they only have centres in England. See the 'More information and support' section for contact details.

A small number of the Carers' Centres that work in partnership with the Carers Trust provide respite care. If they do not provide this service in your area they can give you information and support about what is available locally (see the 'More information and support' section for contact details).

Crossroads Caring for Carers Northern Ireland and Crossroads Caring Scotland offer support for carers and short-term respite care. See the More information and support section for contact details.

For information about taking a break from caring see Carers UK's leaflet, *Taking a Break*, or visit their website www.carersuk.org

Preparing for your break

- If you are going away for a break, confirm that the venue will definitely meet all your needs (access, mobility, diet, religious requirements, arrangements for children, pets, etc).

- Prepare, so you can make the most of your time away.
- Check that the people providing services for the person with Parkinson's know what to do – routinely and in the case of an emergency.



My story

by Neil, whose wife has Parkinson's

“ My wife was diagnosed with Parkinson's in 1995 when we were both 53. In 1999, when my wife's symptoms became more noticeable, I resigned from my job so that we could go on some long-haul holidays while we were both still active. We went to a range of different places in Asia and Australasia. Sadly, our trip to the Grand Canyon was cancelled due to her ill health.

Now, our holidays are restricted to flights of fewer than six hours, otherwise the travelling becomes unbearable. I have been amazed in the intervening years at the improvements in the care and courtesies extended by most airlines and airports to wheelchair-bound passengers and carers. Although EU countries have excellent toilet facilities for disabled persons, this is not always the case elsewhere, so I'm regular male face in the ladies'. The embarrassment for me has disappeared totally. Also, being small enough, we can both enter and exit airline toilets together, much to the amazement of airline crew and other passengers.

My wife's condition continues to progress, but we have benefited from advice from our specialist and Parkinson's nurse, and the therapies they have recommended. We did a three-month trial with an apomorphine pump to improve her movement and reduce the number of falls but there wasn't a significant enough improvement to outweigh the inconvenience of carrying the pump around.

We've been married for more than 40 years. When I was employed, my wife was a full-time housewife and mother of our three daughters. Now it's my turn to reverse the roles and become proficient with cooking, washing, ironing and cleaning – in return for the excellent home life I've enjoyed.

I'm still 'allowed out' twice a week to enjoy a game of golf, which sadly I can't now play with my wife. Having a community alarm system and mobile phones mean we both have peace of mind when I'm away. ”

The place where I live

Where you live can have a big effect on your quality of life. In the advanced stage of Parkinson's, it is likely that you will need extra support to carry out day-to-day tasks, and this may affect your choice of home.

Care at home

You may be able to function very well at home with adaptations to make it easier to use and easier to get around. If you live with someone else, they may be your carer and provide this help.

Even if they do, if you need help with day-to-day tasks such as getting up and going to bed or bathing, your social services or social work department, or health and social care trust in Northern Ireland, has a responsibility to assess your needs and arrange services that can help you stay in your home (see page 64 for more information on being assessed for social care).

How can I make sure my home is safe?

An occupational therapist can advise you on safety in and around your home. This can help prevent falls or other injuries and help you manage day-to-day activities safely. They may suggest options such as rearranging furniture to make

moving around your house safer, installing grab rails or equipment that can make some activities easier and safer.

A physiotherapist can also help you with ways to prevent and manage falls.

In an emergency

Whoever is caring for you, if you worry about having an accident or falling ill while you're alone at home, you may want to sign up to a community alarm scheme. This may involve wearing a pendant with a button you press in an emergency.

Other housing options

Increasing needs

As your condition progresses you may need more support to help you – ask your local authority to review your needs and see if there are any additional services they can provide. Even with this help at home, you may feel you can no longer manage, and may have to consider alternative options.

Speak to your local authority's housing department to find out more about any options that are available.

Sheltered or retirement housing

This is specially designed for older people. It may appeal if you want

to live independently but in a smaller and easier to manage home. 'Extra care' sheltered housing offers more support – in some cases including personal care. Residents have the independence of living in their own flat but may have meals prepared for them.

You can move into this type of housing with your partner.

Care homes

A care home will offer more personal care than sheltered housing. As Parkinson's symptoms progress and someone's needs increase, a move to a care home may be something you need to think about. Care homes are staffed 24 hours and day and meals are provided. Some care homes provide nursing care too, which will offer extra support for medical needs. Some will also give activities.

If you move into a care home you will usually live on your own rather than with your partner.

How you pay for a care home will depend on your personal situation, which will be assessed.

What should I think about when choosing a care home?

There are some care homes that have experience of dealing with

specific conditions, including dementia. Some may already have residents with Parkinson's, but some carers may not have experience of looking after someone with the condition.

Age UK produces a checklist to help you choose a suitable care home. Things you may want to consider include:

- Will there be a contract between you and the home or the home and the local authority, and will your place be secure? What would happen if the home closed?
- What do your fees cover, and are there any extras?
- Is there a trial period so you can leave if the home doesn't provide what you're looking for?
- Can you keep your own GP and manage your own medication if you want to and are able to?
- Will you be able to choose when you go to bed and wake up?
- Does the care home provide regular activities for people of all capabilities. Is there a garden to use?

- How do staff seem when you visit. Do they spend time with residents?
- How would any dietary needs be catered for?
- Will you have to move if you need a higher level of care?

You can also get further advice from the charity, the Residents and Relatives Association. They advise on all aspects of living in a care home. You can visit their website **www.relres.org** or call their helpline on **020 7359 8136** or email **info@relres.org**

The Alzheimer's Society also produce a useful factsheet about choosing a care home called *Selecting a care home*. You can download it from their website **www.alzheimers.org.uk** or call their helpline on **0845 300 0336**, open 9am–5pm Monday to Friday and 10am–4pm Saturday and Sunday.

Our local education and training officers can deliver training sessions for care home staff, and we also produce resources to give them more information about Parkinson's. These include our booklet, *Caring for your resident with Parkinson's*, and our DVD, *Medicine management for residents with Parkinson's*.

If you're living apart from your loved one

Many carers have contacted us to say they feel guilty that their partner has had to move into a care home – feeling that it is their fault for not being able to care for them properly. From the numbers of people who've said this, it's a natural reaction. But Parkinson's is a complex condition and someone in the advanced stages may have considerable care needs, which may be too much for a carer to manage, particularly if they are older or have their own health concerns.

Age UK produces some useful factsheets on housing options and things you may want to think about, such as whether you will be able to live with your partner. See page 87 for contact details. We have a helpline adviser with a specific experience of social care. Call **0808 800 0303** to discuss your specific situation.

You can also speak to others at your local Parkinson's UK group. You may find people who have experiences of housing in your local area. To find your local group, visit **parkinsons.org.uk/localgroups**

Registered Nursing Care Contribution

If you move to a nursing care home (on a permanent basis or for temporary respite care) there are funds available to help with the cost. Your GP can refer you for an assessment for the Registered Nursing Care Contribution, which is carried out by a registered nurse, who will confirm whether you need nursing care. If you do, payment of the contribution will start.

The money is paid direct from the NHS to the care home you live in. The amount you may receive varies between England, Wales, Scotland and Northern Ireland, but currently, in England it is £108.70 per week. This will not cover the whole cost of your care – your local social services department may contribute towards the rest, based on a means test of your finances.

To find out more, call our helpline on **0808 800 0303**. Age UK also produce a factsheet called *NHS Continuing care healthcare and NHS-funded nursing care* available from **www.ageuk.org.uk** or by calling **0800 169 6565**.

Palliative care

As Parkinson's advances, many people will need some element of care and support alongside

“As much as I liked living in my garden flat, living alone did become a problem as I started to go ‘off’ more often. After I tripped over a chair I began employing an overnight carer, but this became expensive. I made the decision to move into a residential home and I’m glad I did. I enjoy living here and it is good to know that someone is here to help me if I need them.”

Duncan, diagnosed in 1997

their treatment. Palliative care is about helping you keep your quality of life through managing symptoms, relieving pain and suffering and managing any other distressing aspects of the condition.

Palliative care should mean that people affected by Parkinson's and their carers have the best quality of life possible. There is no set time for how long the palliative phase lasts. It can potentially be a long time, and Parkinson's can still change and develop further within this time.

What does palliative care involve?

Palliative care is a holistic approach that supports the personal, social, psychological and spiritual needs of you and your family. It gives you some control and choice over areas, such as treatment options and where you will be cared for, as well as advice and support to all the people involved in your care.

Palliative care must address physical problems, including pain, breathlessness, losing your appetite, immobility and constipation. If you are immobile, professionals should check to make sure you are not developing pressure sores, but should help to manage them when you do.

As well as physical needs, there are other issues that need to be considered:

- Relationships – between the person with Parkinson's and their partner or carer, children, extended family and friends.
- Social issues – loss of employment, any role change within a family unit, such as a change from being primary earner, fear for any dependants.

- Spiritual or existential issues – whether religious or not, someone may be thinking more about big issues, such as the meaning of life, or asking 'why?'
- Psychological problems – fear, depression, anxiety, uncertainty and guilt.

Who provides palliative care?

Palliative care can be delivered whether you're at home, living in a care home or in hospital. It may be provided by a Parkinson's nurse who liaises with a multidisciplinary team for both day-to-day and specialist care.

Specialist palliative care teams can be accessed through a referral from the Parkinson's team, local hospice or GP. They can guide the management of complex symptoms.

Physiotherapists, occupational therapists, speech and language therapists and dietitians can all have important roles to play in the advanced stages of Parkinson's.

Being referred to specialist palliative care does not mean your usual Parkinson's team stops caring for you. Most specialist palliative care professionals will work alongside your Parkinson's nurse or specialist. They will work together

to achieve the best quality of life for you.

How to arrange palliative care

A GP, Parkinson's nurse or your specialist will usually be involved in arranging palliative care.

How can I involve my family?

Involving your family in the early stages of your decision-making will help you all feel more comfortable about the future.

Your family may have spent time providing you with care and support – and so should be considered a key part of the multidisciplinary team involved in your palliative care.

If you are a carer

This period may be particularly difficult if you are a carer and it is important to be aware of what support is available to you. Respite care when you need it is essential to give you time away from your caring responsibilities.

Making decisions about end of life

Could I die from Parkinson's?

For the majority of people, Parkinson's does not significantly affect life expectancy. However, some of the more advanced symptoms can lead to increased

disability and poor health, which can make someone more vulnerable to infection, such as pneumonia and other health problems.

When should I start thinking about end-of-life issues?

It may be difficult to start thinking about end of life and how you will be cared for in the later stages. Nevertheless, it is important that you consider your options as early as you can, while you are well enough to make your wishes known.

This will help make sure your needs are met in the future and give you and your family peace of mind.

Why should I think about end-of-life issues?

Planning your future care is about being aware of the decisions you may have to face. Having the opportunity to plan your treatment and care for the later stages of your condition can give you peace of mind.

There has been increasing media and professional interest in the idea of having a 'good death'.

This can mean:

- physical comfort and freedom from pain

- being at peace with yourself and loved ones
- a feeling of being ready to say goodbye
- knowing that your wishes are known and respected
- being treated with dignity and care

Guidelines for healthcare professionals state that, where reasonable, you have a right to decide where you wish to live and to die, and you should receive support to help you with this.

Planning your future care now means that difficult decisions can be made with more consideration and everyone is clear about your wishes and can take them into account wherever possible, when the time comes.

Thinking about end-of-life issues can be difficult. But considering the future now and discussing your wishes and preferences with the people in your life may help you feel more confident and assured about what lies ahead.

Talking to someone you know and trust about future decisions can also be helpful. This might be a

person with an understanding of Parkinson's, such as your GP, specialist, Parkinson's nurse, or one of our helpline advisors or information and support workers.

Will my Parkinson's medication be reduced?

Parkinson's medication may be reduced (or withdrawn) if you no longer experience any benefits from it. Reduction (or withdrawal) may also be necessary if side effects such as hallucinations become intolerable. Medication should only be changed, with your or a carer's consent, gradually and under the guidance of your specialist or Parkinson's nurse.

Making your wishes known

Advance care planning

It's a good idea to decide in advance what you would like to happen towards the end of your life, or when you become unable to make decisions for yourself.

This is particularly important if communication becomes a problem in the future. Your views may change over time, so it is useful to have regular discussions and update the relevant documents if necessary.

Medical treatments require consent. But in case you're unable

in the future to make decisions about your healthcare, it is possible to make an Advance Decision to Refuse Treatment (also known as an Advance Directive or Advance Decision to Refuse Treatment and Living Will). You can specify which treatments you would accept or refuse under certain circumstances.

An advanced statement allows you to retain a degree of control to the end of your life. One Parkinson's nurse has told us that she discusses the options of this in plenty of time with the people with Parkinson's she sees, before it would be needed. It allows you to think about and write down your preferences for end of life care.

You may want to think about issues such as where you want to be cared for in the later stages of life, whether you would want to know about the effects of treatment you may be offered, what you want your final days to be like and who you'd like around you.

For more information on advance care planning you can contact Compassion in Dying on **0800 999 2434** or visit **www.compassionindying.org.uk**

You can also contact Age UK on **0800 169 6565** or visit **www.ageuk.org.uk**

Looking after your affairs

You may want to be thinking about your wishes and writing them down, for when you are unable to make decisions yourself.

On the more practical side of things, leave instructions for your family so they know where to find keys or important documents such as financial details, insurance policies, mortgage documents and your passport.

You can read more about practical arrangements for end of life, including making a Will, in our booklet *Preparing for end of life*. The booklet also includes information on getting a Power of Attorney. This is a legal document that gives someone else authority to take actions and make decisions on your behalf.

MORE INFORMATION AND SUPPORT

Counselling

Counsellors are trained to help people deal with any given situation. They can help a person understand their own feelings and talk about them. Talking to someone outside your circle of family and friends can give you the opportunity to have frank and confidential conversations, that may make it easier to cope with things.

Where is counselling available?

Your GP can refer you to a counsellor but availability can depend on local authority funding, and waiting lists can be long.

There are other sources of counselling, such as private therapists, but this will involve a fee. Telephone counselling is also an option. This is ideal for anyone who is not mobile.

More information on all types of counselling is available from the British Association for Counselling and Psychotherapy on **0870 443 5252** or visit **www.bacp.co.uk**

Your Parkinson's nurse or information and support worker will know what is available in your local area.

For details of the information and support worker in your area, please call the Parkinson's UK helpline on **0808 800 0303** or visit **parkinsons.org.uk**

Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also make contact with other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospital settings.

Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication,

so someone with Parkinson's doesn't always need to see their specialist for changes to or queries about their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services.

You can find out more at **parkinsons.org.uk/nurses**

Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**.

We run a peer support service if you'd like to talk on the phone with someone affected by Parkinson's who has faced similar issues to you. The service is free and confidential – ring the helpline to talk to someone about being matched with a volunteer.

Our helpline can also put you in touch with one of our local information and support workers, who give one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.



We also have a self-management programme for people with Parkinson's, partners and carers. It is an opportunity to reflect on life with the condition, learn about self-management and think about the future. To find out if there is a group near you visit **parkinsons.org.uk/selfmanagement**

Our website **parkinsons.org.uk** has a lot of information about Parkinson's and everyday life with the condition. You can also find details of your local support team and your nearest local group meeting at **parkinsons.org.uk/localtoyou**

You can also visit **parkinsons.org.uk/forum** to speak with other people in a similar situation on our online discussion forum.

Healthcare organisations

Asian Health Agency

Provides a range of services including counselling, advocacy and respite care for Asian elders, disabled people and carers in England.

020 8811 1501

www.taha.org.uk

The Bladder and Bowel Foundation

Helpline **0845 345 0165**

info@bladderandbowel

foundation.org

www.bladderandbowel

foundation.org

British Association/College of Occupational Therapists

020 7357 6480

www.cot.org.uk

Chartered Society of Physiotherapy

020 7306 6666

www.csp.org.uk

Local health services

Find your nearest primary care trust (in England), Health Board (in Scotland or Wales) or Health and Social Care Trust (Northern Ireland) in your local phone book or on the following websites:

England

www.nhs.uk

Northern Ireland

www.hscni.net

Scotland

www.show.scot.nhs.uk

Wales

www.wales.nhs.uk

NHS Direct (England)

111

Textphone **18001 111**

www.nhsdirect.nhs.uk

NHS Direct (Wales)

0845 4647

www.nhsdirect.wales.nhs.uk

NHS24 (Scotland)

08454 242424

www.nhs24.com

Northern Ireland out-of-hours medical service

Local details can be found at

www.nidirect.gov.uk

Patient and Client Council

(Northern Ireland)

0800 917 0222

Info.pcc@hscni.net

www.patientclientcouncil

hscni.net

Patient's Association

0845 608 4455

helpline@patients-association.com

www.patients-association.org.uk

Mental health support

Action on Depression (Scotland)

0808 802 2020

www.actionondepression.org

Alzheimer's Society

0300 222 1122

enquiries@alzheimers.org.uk

www.alzheimers.org.uk

Alzheimer Scotland

0808 808 3000

alzheimer@alzscot.org

www.alzscot.org

Anxiety UK

08444 775 774

info@anxietyuk.org.uk

www.anxietyuk.org.uk

British Association for Counselling
and Psychotherapy

01455 883300

Minicom 01455 550307

Text 01455 560606

bacp@bacp.co.uk

www.bacp.co.uk

Depression Alliance

Charity supporting anyone with
depression in England and Wales,
and their families.

0845 123 2320

information@depressionalliance.org

org

www.depressionalliance.org

Mind

A mental health charity.

0300 123 3393

contact@mind.org.uk

www.mind.org.uk

Mind Cymru

02920 395 123

contactwales@mind.org.uk

Northern Ireland Association
for Mental Health

028 9032 8474

www.niamh.co.uk

No Panic

A charity that helps people to
overcome anxiety disorders.

0808 138 8889

www.nopanic.org.uk

Royal College of Psychiatrists

020 7235 2351

www.rcpsych.ac.uk

Scottish Association for
Mental Health

0800 917 3466

info@samh.org.uk

www.samh.org.uk

Organisations for carers

Carers Trust

A national charity that exists to make it easier for carers to cope by providing information, support and practical help.

It has Carers' Centres across the UK and lots of web-based information, including a section for young carers.

0844 800 4361

info@carers.org

www.carers.org

www.youngcarers.net

Wales office

02920 221 788

The Princess Royal Trust

for Carers in Scotland

(Part of Carers Trust)

0141 221 5066

Carers UK

CarersLine **0808 808 7777**

(Wednesdays and Thursdays only,
10am–12pm, 2pm–4pm)

advice@carersuk.org

www.carersuk.org

Cynhalwyr Cymru

02920 811 370

www.carersuk.org/wales

Carers Northern Ireland

02890 439 843

**www.carersuk.org/
northernireland**

Carers Scotland

0141 445 3070

www.carersuk.org/scotland

Care Information Scotland

08456 001 001

www.careinfoscotland.co.uk

Crossroads Caring for Carers Northern Ireland

Information and support for carers
in Northern Ireland.

028 9181 4455

mail@crossroadscare.co.uk

www.crossroadscare.co.uk

Crossroads Caring Scotland

A charity providing home-based
respite through short breaks or
longer periods of support for
carers, and personal care for people
living alone across Scotland.

0141 226 3793

www.crossroads-scotland.co.uk

Revitalise

Provides breaks for disabled adults,
children and carers, including
the visually impaired.

0303 303 0145

info@revitalise.org.uk

www.revitalise.org.uk

Support organisations

AbilityNet

A charity helping disabled adults and children to use computers and the internet by adapting and adjusting their technology. It has links to centres across the country.

0800 269545

enquiries@abilitynet.org.uk

www.abilitynet.org.uk

Age UK England

0800 169 6565

contact@ageuk.org.uk

www.ageuk.org.uk

Age Cymru

0800 223 444

enquiries@agecymru.org.uk

www.ageuk.org.uk/cymru

Age NI

0808 808 7575

info@ageni.org

www.ageuk.org.uk/northern-ireland

Age Scotland

0845 125 9732

www.ageuk.org.uk/scotland

Canine Partners

A charity that trains assistance dogs for disabled people.

0845 658 0480

www.caninepartners.co.uk

Care and Repair

A charity set up to improve the housing and living conditions of older people and disabled people.

Cymru

02920 674 830

www.careandrepair.org.uk

England

0115 950 6500

www.careandrepair-england.org.uk

Care and Repair Forum Scotland

0141 221 9879

www.careandrepairsotland.co.uk

Cause mental health (Northern Ireland)

0845 603 0291

www.cause.org.uk

The Cinnamon Trust

This organisation helps people aged over 60 years or terminally ill people to stay with their pets for as long as possible.

01736 757 900

admin@cinnamon.org.uk

www.cinnamon.org.uk

Citizens Advice

England **0844 411 1444**
Wales **0844 477 2020**
Text Relay **0844 411 1445**
info@nacab.org.uk
www.nacab.org.uk

Northern Ireland

028 9023 6522
info@citizensadvice.co.uk
www.citizensadvice.co.uk

Scotland

0808 800 9060
www.cas.org.uk
Website for online advice:
www.adviceguide.org.uk

Community Health Council (CHC) – Wales

0845 644 7814
enquiries@waleschc.org.uk
www.patienthelp.wales.nhs.uk

Disability Action (Northern Ireland)

This organisation works to ensure that people with disabilities attain their full rights as citizens, by supporting inclusion, influencing government policy and changing attitudes in partnership with disabled people.

028 9029 7880
Textphone **028 9029 7882**
www.disabilityaction.org

Disabled Living Foundation

Helpline **0300 999 0004**
(Monday–Friday 10am–4pm)
helpline@dlf.org.uk
www.dlf.org.uk

Disability Rights UK

Provides people with disabilities with information on their rights and benefits, including its Disability Rights Handbook. There is a charge for this publication, but this is reduced for people claiming benefit.

020 7250 3222
enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org

The Expert Patients Programme

0800 988 5550
get.info@epccic.co.uk
www.expertpatients.co.uk

Gov.uk

Website of the UK government, with information on public services and sections specifically for carers.
www.gov.uk

Health Rights Information Scotland (HRIS – Scotland)

0141 226 5261
nhs.inform@nhs24.scot.nhs.uk
www.hris.org.uk

Help the Hospices

The UK charity for hospice care.

020 7520 8200

info@helpthehospices.org.uk

www.helpthehospices.org.uk

In Control Support Centre

01564 821 650

admin@in-control.org.uk

www.in-control.org.uk

Independent Age

A national charity providing information, advice and support services for older people. It also produces publications, such as the *Care Home Handbook*.

0845 262 1863

advice@independentage.org

www.independentage.org

Lifeline

The Northern Ireland crisis response helpline for people experiencing distress or despair.

0808 808 8000

Textphone **18001 0808**

808 8000

www.lifelinehelpline.info

MedicalAlert

This charity produces alert bracelets and other identification items, for people with medical conditions.

0800 581420

info@medicalert.org.uk

www.medicalert.org.uk

Motability

The Motability Scheme helps disabled people exchange their mobility allowance for a car, scooter or powered wheelchair.

0845 456 4566

www.motability.co.uk

The Multiple System Atrophy Trust

020 7940 4666

office@msatrust.org.uk

www.msatrust.org.uk

The Outsiders

A club for people who are isolated because of their disability. Also offers advice for people have concerns about sexual or personal relationships.

07074 990 808

info@outsiders.org.uk

www.outsiders.org.uk

Sex and Disability Helpline

07770 884 985

sexdis@outsiders.org.uk

www.outsiders.org.uk

The Pet Fostering Service, Scotland

0844 811 9909

www.pfss.org.uk

Pets as Therapy

01844 345 445

www.petsastherapy.org



chat service where you can talk to a relationship or family counsellor for up to 30 minutes for free.

0300 100 1234

www.relate.org.uk

Relationships Scotland

0845 119 2020

www.relationships-scotland.org.uk

Talisman Ltd (SOS Talisman)

Produces jewellery that contains information about the wearer, in case of accident or illness.

020 8554 5579

sostalisman@btinternet.com
www.sostalisman.co.uk

PSP Association

0300 0110 122

helpline@pspassociation.org.uk
www.pspassociation.org.uk

Relate

Provides relationship counselling and support services, delivered at 400 locations, by phone and online. The organisation also offers a live web

The Relatives and

Residents Association

Provides information and advice on care homes (fees, standards, complaints, etc), as well as a 'listening ear' for those with emotional concerns.

020 7359 8136

info@relres.org

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 Services team on **020 7932 1303** or visit our website at **parkinsons.org.uk/support**. Thank you.

GLOSSARY

Akinesia

Slowness of movement.

Anticholinergics

A type of drug, less commonly prescribed, that may be useful in the early stages of the condition. They block the action of acetylcholine, a chemical messenger that helps to send messages from your nerves to your muscles.

Bradykinesia

Slowing of voluntary movements – one of the three main symptoms of Parkinson's.

Cognitive processes

Mental processes involving thinking and memory.

Compulsive behaviour

Behaviour resulting from an uncontrollable need to perform a particular action.

COMT inhibitors

Drugs reduce Parkinson's symptoms by blocking an enzyme that breaks down levodopa, prolonging its effect.

Cues

A way to help someone complete a task by offering prompts.

Deep brain stimulation

A form of surgery that is used to treat some of the symptoms of Parkinson's.

Delusions

When a person has thoughts and beliefs that aren't based on reality.

Dopamine

A neurotransmitter or chemical messenger. This chemical helps to control the messages the brain sends to the muscles to help people perform sequences of movement. Dopamine also contributes to some thinking and memory processes.

Dopamine Agonist Withdrawal Syndrome (DAWS)

A syndrome that occurs when a person's dopamine agonist treatment is abruptly stopped or reduced.

Dopamine dysregulation syndrome

When a person takes more medication than they need to control their Parkinson's. A form of impulsive and compulsive behaviour.

Dysphagia

Swallowing difficulties.

Dyskinesia

Involuntary movements, often a side effect of taking Parkinson's medication for a long period of time.

Dystonia

A sustained, involuntary muscle contraction that can affect different parts of the body.

Freezing

A symptom of Parkinson's where someone stops suddenly while walking or when starting a movement, during speech, while eating or carrying out repetitive movements. Some people also find their thought processes freeze.

Get It On Time

A Parkinson's UK campaign to make sure that people with Parkinson's get their medication on time, every time.

Glutamate antagonist (amantadine)

A drug mostly used with other Parkinson's medication which has an effect on tremor and stiff muscles.

Hallucinations

When a person sees, hears or feels things that aren't there.

Hypotension

Low blood pressure.

Illusions

When a person sees things in a different way from how they look in real life.

Impulsive behaviour

When a person can't resist the temptation to carry out certain activities.

Involuntary movements (dyskinesia)

Uncontrollable, often jerky movements which can affect the whole body.

Lewy bodies

When someone has the symptoms of dementia either before or at the same time as developing Parkinson's-like problems with movement.

Levodopa

The most effective drug treatment for Parkinson's.

It replaces dopamine, the chemical that is lost in Parkinson's.

Multidisciplinary team

A group of healthcare professionals with different areas of expertise who can unite and treat complex medical conditions. Essential for people with Parkinson's.

Motor symptoms

Symptoms related to movement.

Neurological

Involving the nervous system (including the brain, spinal cord, the peripheral nerves, and muscles)

Non-motor symptoms

Symptoms associated with Parkinson's that aren't associated with movement difficulties.

'On/off'

A potential side effect of levodopa and some other Parkinson's medication. When your medication is working well, your Parkinson's symptoms will be well-controlled. This is called 'on' time. When symptoms are not well-controlled and don't respond to medication, this is called being 'off'.

Parkinsonism

An umbrella term that describes conditions which share some of the symptoms of Parkinson's (slowness of movement, stiffness and tremor).

Patient-centred care

A focus on the needs of a person with a long-term condition as an individual who is expert in their own needs.

Silent aspiration

When food enters the windpipe and goes into the lungs without a person coughing or choking. Caused by difficulties swallowing.

'Wearing off'

This is where a Parkinson's drug becomes less effective before it is time for a person's next dose. This may cause you to go 'off'.

NON-MOTOR SYMPTOMS QUESTIONNAIRE

Name:

Date:.....

Age:

Centre ID: Male Female

Have you experienced any of the following in the last month?

All the information you supply through this form will be treated with confidence and will only be used for the purpose for which it has been collected. Information supplied will be used for monitoring purposes. Your personal data will be processed and held in accordance with the Data Protection Act 1998. Developed and validated by the International PD Non Motor Group.

Non-movement problems in Parkinson's

The movement symptoms of Parkinson's are well known. However, other problems can sometimes occur as part of the condition or its treatment. It is important that the doctor knows about these, particularly if they are troublesome for you.

A range of problems is listed below. Please tick the box 'Yes' if you have experienced it during the past month. The doctor or nurse may ask you some questions to help decide. If you have not experienced the problem in the past month tick the 'No' box. You should answer 'No' even if you have had the problem in the past but not in the past month.

		Yes	No
1	Dribbling of saliva during the daytime.	<input type="checkbox"/>	<input type="checkbox"/>
2	Loss or change in your ability to taste or smell.	<input type="checkbox"/>	<input type="checkbox"/>
3	Difficulty swallowing food or drink or problems with choking.	<input type="checkbox"/>	<input type="checkbox"/>
4	Vomiting or feelings of sickness (nausea).	<input type="checkbox"/>	<input type="checkbox"/>
5	Constipation (less than three bowel movements a week).	<input type="checkbox"/>	<input type="checkbox"/>
6	Bowel (faecal) incontinence.	<input type="checkbox"/>	<input type="checkbox"/>
7	Feeling that your bowel emptying is incomplete after having been to the toilet.	<input type="checkbox"/>	<input type="checkbox"/>
8	A sense of urgency to pass urine makes you rush to the toilet.	<input type="checkbox"/>	<input type="checkbox"/>
9	Getting up regularly at night to pass urine.	<input type="checkbox"/>	<input type="checkbox"/>
10	Unexplained pains (not due to known conditions such as arthritis).	<input type="checkbox"/>	<input type="checkbox"/>
11	Unexplained change in weight (not due to change in diet).	<input type="checkbox"/>	<input type="checkbox"/>
12	Problems remembering things that have happened recently or forgetting to do things.	<input type="checkbox"/>	<input type="checkbox"/>
13	Loss of interest in what is happening around you or in doing things.	<input type="checkbox"/>	<input type="checkbox"/>

		Yes	No
14	Seeing or hearing things that you know or are told are not there.	<input type="checkbox"/>	<input type="checkbox"/>
15	Difficulty concentrating or staying focused.	<input type="checkbox"/>	<input type="checkbox"/>
16	Feeling sad, 'low' or 'blue'.	<input type="checkbox"/>	<input type="checkbox"/>
17	Feeling anxious, frightened or panicky.	<input type="checkbox"/>	<input type="checkbox"/>
18	Feeling less interested in sex or more interested in sex.	<input type="checkbox"/>	<input type="checkbox"/>
19	Finding it difficult to have sex when you try.	<input type="checkbox"/>	<input type="checkbox"/>
20	Feeling light-headed, dizzy or weak standing from sitting or lying.	<input type="checkbox"/>	<input type="checkbox"/>
21	Falling.	<input type="checkbox"/>	<input type="checkbox"/>
22	Finding it difficult to stay awake during activities such as working, driving or eating.	<input type="checkbox"/>	<input type="checkbox"/>
23	Difficulty getting to sleep at night or staying asleep at night.	<input type="checkbox"/>	<input type="checkbox"/>
24	Intense, vivid or frightening dreams.	<input type="checkbox"/>	<input type="checkbox"/>
25	Talking or moving about in your sleep, as if you are 'acting out' a dream.	<input type="checkbox"/>	<input type="checkbox"/>
26	Unpleasant sensations in your legs at night or while sitting, and a feeling that you need to move.	<input type="checkbox"/>	<input type="checkbox"/>

		Yes	No
27	Swelling of the legs.	<input type="checkbox"/>	<input type="checkbox"/>
28	Excessive sweating.	<input type="checkbox"/>	<input type="checkbox"/>
29	Double vision.	<input type="checkbox"/>	<input type="checkbox"/>
30	Believing things are happening to you that other people say are not.	<input type="checkbox"/>	<input type="checkbox"/>

Chaudhuri KR, Martinez-Martin P, Schapira AHV, Stocchi F, Sethi K, Odin P et al (2006) 'An international multicentre pilot study of the first comprehensive self-completed non motor symptoms questionnaire for Parkinson's disease: The NMSQuest study' *Mov Disord*; 21(7):916-923.

This questionnaire should be completed and given to your GP or specialist at your next appointment. Please do not return it to Parkinson's UK. Thank you.

All the information you supply through this form will be treated with confidence and will only be used for the purpose for which it has been collected. Information supplied will be used for monitoring purposes. Your personal data will be processed and held in accordance with the Data Protection Act 1998. Developed and validated by the International PD Non Motor Group.

My contacts

GP

Specialist

Parkinson's nurse

Information and
support worker

Physiotherapist

Occupational
therapist

Speech and
language therapist

Parkinson's UK local
group contacts

Other

In an emergency
please contact

INDEX

- Akinesia:** 91
- Apomorphine:** 32, 33
- Anticholinergics:** 34, 91
- Anxiety:** 20, 35, 38, 45, 55, 78
- Apathy:** 17, 21
- Benefits:** 60
- Bladder problems:** 14, 17
- Blood pressure:** 42, 92
- Body language:** 11
- 'Bottle in the fridge':** 34, 62
- Bradykinesia:** 91
- Care home:** 63, 64, 75–7, 78
- Communication problems:** 11
- Complementary therapy:** 24, 49
- Compulsive behaviour:** 36–9, 91
- COMT inhibitors:** 33, 91
- Constipation:** 9, 16, 44, 78
- Counselling:** 82
- Death:** 13, 79
- Deep brain stimulation:** 12, 30, 42, 91
- Dementia:** 23–6, 75
- Dental problems:** 12
- Depression:** 17–19
- Diagnosis:** 7, 24
- Diet:** 16, 44, 51
- Dopamine:** 7, 17, 91
- Dopamine agonist:** 32–3, 36
- Dopamine agonist withdrawal syndrome:** 38, 91
- Dopamine dysregulation syndrome:** 38, 92
- Duodopa:** 31
- Dysphagia:** 92
- Dyskinesia:** 36, 38, 92
- Dystonia:** 11, 14, 92
- Employment:** 60
- Equipment/Aids:** 39, 44, 51, 58, 66
- Exercise:** 16, 44, 52
- Facial expressions:** 11, 55
- Falls:** 13, 74
- Fatigue:** 13, 56
- Freezing:** 13, 45, 92
- Get It On Time:** 28, 63, 92
- Glutamate antagonists:** 34, 92
- Hallucinations and delusions:** 19, 36, 80, 92
- Hypersexuality:** 36, 44
- Impulsive behaviour:** 36, 38–9, 92
- Intimate relationships:** 17, 45, 55
- Involuntary movements:** 12, 36, 92
- Lesioning:** 42
- Levodopa:** 30–2, 36, 38, 50, 92
- MAO-B inhibitors:** 33
- Medication:** 29
- Memory problems:** 9, 23
- Money matters:** 60
- Muscle cramps:** 11
- Muscle spasms:** 12, 14
- Nausea:** 33

Non-motor symptoms: 11, 29, 57, 93
Nursing care: 66, 71, 75, 77
Occupational therapy: 8, 13, 44, 74, 78
Pain: 9, 11, 14, 77–9
Palliative care: 77–9
Panic attacks: 20–21
Parkinson’s UK Alert card: 35
Parkinson’s UK Medication card: 34, 39,
Personal budgets: 66–67
Physiotherapy: 8, 11, 13, 29, 44, 52, 74, 78
Registered Nursing Care Contribution: 77
Relationships: 53
Respite care: 26, 67, 70–2, 79
Restless legs: 14
Rigid muscles: 56
Saliva: 12, 55
Self-help: 47
Sex: 39, 55–56
Sheltered/retirement housing: 74 –5
Skin problems: 14
Sleep problems: 14–5, 18, 24, 55
Social care: 64–8
Speech problems: 11, 55
Speech and language therapy: 44, 78
Stiff muscles: 34
Surgery: 40–42
Swallowing problems: 9, 12, 16, 44, 50–1
Sweating problems: 14
Tremor: 9, 28, 34, 42

Welfare Benefits: 60–1
Wearing off: 21, 35, 93

Thinking about advanced Parkinson's (2014)

If you have comments or suggestions about this booklet, we'd love to hear from you. This will help us ensure that we are providing as good a service as possible. We'd be very grateful if you could complete this form and return it to:

**Information content team, Parkinson's UK,
215 Vauxhall Bridge Road, London SW1V 1EJ.**

Or you can email us at publications@parkinsons.org.uk. Thanks!

Please tick...

- I have Parkinson's. When were you diagnosed?
- I'm family/a friend/a carer of someone with Parkinson's
- I'm a professional working with people with Parkinson's

Where did you get this booklet from?

Please tick...

- GP, specialist or Parkinson's nurse
- Parkinson's UK local group or event
- Our website
- Information and support worker
- Ordered from us directly
- Other

How useful have you found this booklet?

(1 is not useful, 4 is very useful) 1 2 3 4

Has this resource given you information that might help you manage your condition better?

- NA It hasn't helped It has helped a little It has helped a lot

Have you found the publication easy to read/use? Yes No



Continued over the page

What aspects did you find most helpful?

Were you looking for any information that wasn't covered?

Do you have any other comments?

If you would like to become a member of Parkinson's UK, or are interested in joining our information review group (people affected by Parkinson's who give us feedback on new and updated resources), please complete the details below and we'll be in touch.

- Membership
- Information review group

Name

Address

Telephone

Email

What is your ethnic background?

Please tick...

- Asian or Asian British
- Black or Black British
- Chinese
- Mixed
- White British
- White other
- Other (please specify)



Thank you to everyone who contributed to or reviewed this booklet:

Professor Richard Walker, Consultant Physician, North Tyneside General Hospital

Lynn Gill, Parkinson's Disease Nurse Specialist, Northern Devon Healthcare

Annette Hand, Nurse Consultant in Parkinson's, Northumbria Healthcare NHS Foundation Trust

Anne Martin, Parkinson's Disease Nurse Specialist

Fiona Lindop MCSP, Specialist physiotherapist in Parkinson's disease and related conditions, Derby

Bhanu Ramaswamy MCSP, Independent Physiotherapy Consultant, Sheffield

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

All of the photographs in this booklet feature people affected by Parkinson's, health and social care professionals involved in caring for people with Parkinson's and Parkinson's UK staff. Thank you to everyone involved for letting us use their photograph.

We make every effort to make sure that our services provide up-to-date, unbiased and accurate information. We hope that this will add to any professional advice you receive and will help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at publications@parkinsons.org.uk.

How to order our resources

0845 121 2354

resources@parkinsons.org.uk

Download them from our website at parkinsons.org.uk/publications

We're the Parkinson's charity that drives better care, treatments and quality of life.

**Together we can bring forward the day
when no one fears Parkinson's.**

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

Free confidential helpline **0808 800 0303**
(Monday to Friday 9am–7pm, Saturday 10am–2pm).
Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with
smart phones, tablets, PCs and other devices).
For more information see **www.ngts.org.uk**

hello@parkinsons.org.uk
parkinsons.org.uk

Order code: B003

Last updated August 2014. We review our information
within three years. Please check our website for the most
up to date versions of all our information.

© Parkinson's UK, June 2017. Parkinson's UK is the operating name of the
Parkinson's Disease Society of the United Kingdom. A charity registered in
England and Wales (258197) and in Scotland (SC037554).

