# Guide to living
## with Parkinson's disease

Welcome to the second edition of the 'Guide to living with Parkinson's disease', produced by H Lundbeck A/S and Teva Pharmaceutical Industries in close collaboration with the European Parkinson's Disease Association (EPDA).

This guide has been designed to answer the most immediate questions of a person diagnosed with Parkinson's disease and their carer. It provides information on the disease itself, as well as the many aspects of treatment and practical disease management, including medications, surgery, diet, exercise/physiotherapy, and emotional support.

Another very important part of living with Parkinson's disease is keeping a full and active life while maintaining good communication with others. With this in mind, the guide contains hints, tips and tools to help in daily communication with carers, family, friends and children, as well as with doctors and other members of the healthcare team. These resources can be used every day alongside the other elements of the binder, such as the 'Guide to healthy eating', the daily diary, and the medication record.

In order to keep this booklet a handy size, it has not been possible to include advice on every aspect of life with Parkinson's disease. However, where a subject is not dealt with in detail, the reader is directed towards other sources (books, websites, etc.) where more comprehensive information can be found.

We hope that you will find this guide valuable in everyday life, and that the combination of tools provided here will help you to maintain a full and active life following a diagnosis of Parkinson's disease.

**Acknowledgement:** H Lundbeck A/S and Teva Pharmaceutical Industries would like to thank the EPDA for their support in producing this guide, and for the expert advice, information and review comments provided by their committee members and associates. In particular, they gratefully acknowledge the help of:

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PWP=person with Parkinson's disease

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# 1. What is Parkinson's disease?

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## About Parkinson's disease (PD)

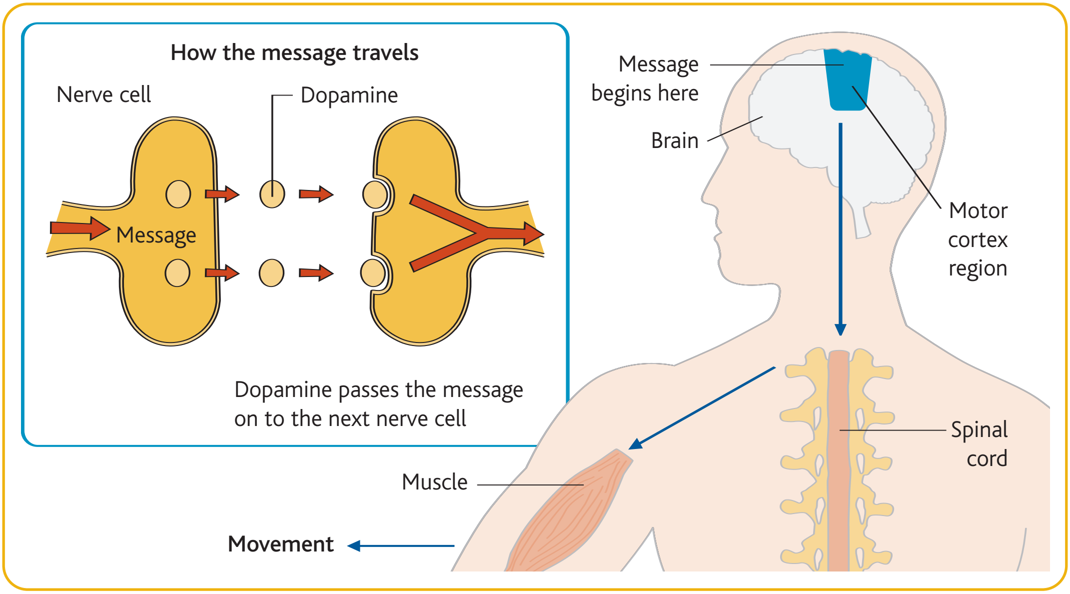
Parkinson's disease, which is commonly referred to as PD or just 'Parkinson's', was named after a London doctor called James Parkinson, who first described the symptoms of the disease in 1817.

PD is a condition of the nervous system (i.e., a neurological condition) that is characterised by problems with body movements, although other non-movement symptoms can also occur. Body movements are controlled by nerve cells in the brain that pass messages to one another. These messages are sent using chemicals (neurotransmitters), which pass between the nerve cells and, in healthy people, the messages are carried smoothly (see Figure 1).

One important neurotransmitter that is involved in controlling body movements is called dopamine. In people with PD, there is a lack of dopamine in the brain, and therefore the relay of messages is disturbed, and this creates problems with the control of movement.

The symptoms of PD often appear gradually, usually on one side of the body first, and slowly progress over time. The main physical symptoms of PD are slowness of movement, stiffness, and sometimes tremor and loss of balance, although the type and severity of symptoms vary from person to person. Different symptoms may appear as PD progresses.

**Figure 1: Dopamine produces movement**



PD is globally distributed, affecting all cultures and races, including an estimated 1.2 million people in Europe. More than 1 in 10 people with PD are diagnosed before the age of 50 years.

Although, at present, there is no cure for PD, the symptoms can generally be treated effectively by using a variety of medications. These medications help each person carry on with everyday life, and people with PD can continue to enjoy a good quality of life for many years. Treatments for PD are described later in this booklet (see Section 2, 'Managing Parkinson's disease', page 15).

## What is parkinsonism?

Parkinsonism refers to a collection of symptoms, including slow movement, tremor, stiffness and difficulty walking. This set of symptoms is present in several disorders, including PD, which are known as 'parkinsonian' conditions. Making a specific and definite diagnosis of PD is sometimes difficult, since various parkinsonian conditions produce similar symptoms, at least at the beginning of the illness.

Diseases that may be confused with PD include:

- **essential tremor** – produces a tremor of the limbs. There is usually only a tremor of the arms and head, typically present on both sides of the body, and becoming worse during activity. In contrast, the tremor in PD may affect only one side of the body, and is present at rest
- **drug-induced parkinsonism** – condition in which the symptoms of PD are mimicked by the use of a medication. The symptoms may disappear completely when the medication causing the problem is withdrawn
- **vascular parkinsonism** – condition in which individuals suffering from cerebrovascular disease (i.e., disease affecting blood vessels supplying the brain) have features that resemble PD but which do not respond well to treatment with the medication levodopa
- **rare parkinsonisms** – collection of uncommon disorders that appear similar to PD at the start, but often develop differently. These disorders include multiple system atrophy (MSA), progressive supranuclear palsy (PSP), and corticobasal degeneration (CBD).

## How is PD assessed?

PD is not always simple to diagnose, as every case of PD is unique and, as a neurological disorder, the symptoms are similar to many other disorders of the brain. However, an experienced neurologist should be able to make an accurate diagnosis. When making a diagnosis of PD, the doctor listens to the person's own experience of their condition, and carefully observes the symptoms during a physical examination.

The main symptoms of PD are slowness of movement, stiffness, and sometimes tremor and loss of balance, and it is the particular combination of these symptoms that may lead the doctor to make a diagnosis of PD. The first signs of PD may be noticed as difficulty with delicate movements such as those required for writing, sewing, shaving, etc. In addition, non-movement related symptoms (see 'Symptoms of PD', page 8) are being increasingly recognised for their potential in assisting with the early diagnosis of PD.

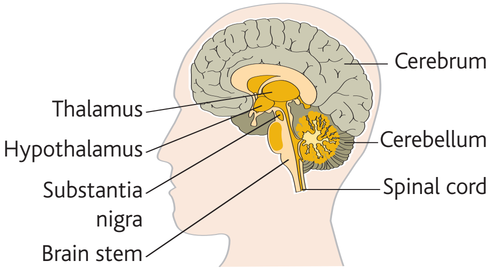
Although PD affects the brain, a brain scan is not usually able to positively identify PD and the changes that it produces in the brain. However, CT or MRI scans (which produce pictures of different sections of the brain) can be used to eliminate other disorders, which may be causing the symptoms. If the scan looks normal, then it is possible – but not definite – that the symptoms are caused by PD. Similarly, types of brain scan called PET and SPECT, which can visualise dopamine in the brain, may be used to support a diagnosis of PD and eliminate other causes – but again, these scans cannot prove that a person has PD. For this reason, diagnosis usually relies upon a physical examination, and description/observation of symptoms. In addition, there may be some extra tests such as X-rays and blood tests, which can help to show that the symptoms are not being caused by any other disorders.

If a person does have PD, then progress will be assessed at regular intervals based on the doctor's clinical impression, and sometimes by using one or more rating scales. These scales involve the doctor testing and observing the person's actions, and marking this down as a score. One of the most commonly used scales is the Unified Parkinson's Disease Rating Scale (UPDRS), which scores performance in all areas of movement and daily function. This sort of rating helps the doctor to monitor the progress of the person with PD, and to deliver the most appropriate type of treatment. Other scales that are used to help assess PD are the Hoehn & Yahr scale, which classes PD as being at one of five stages, and the Schwab & England scale, which rates the individual on their level of independence. A description of each of these scales can be found in the glossary at the end of this booklet (see page 77).

## What causes PD?

As described earlier, in PD there is a lack of a chemical in the brain called dopamine. This is because the brain has lost many of the nerve cells that normally make dopamine. Losing nerve cells is a completely normal process that occurs in even the healthiest person. However, when movement-related signs of PD appear, it indicates that a very large number of the lost cells are from a specific part of the brain called the substantia nigra (see Figure 2). This area is strongly involved with the control of body movement.

**Figure 2: Position of the substantia nigra within the brain**



In addition, it is thought that nerve loss also occurs in other parts of the brain, producing non-movement related effects, and adding to the large variety of symptoms that can be observed in PD.

Medical experts are not yet certain what destroys these nerve cells, or what causes some people to develop PD and not others. However, PD is not an infectious disease and it is not contagious.

Medical research is underway to find out about the role that genes play in PD, and whether they could be used as a form of diagnostic test. Current evidence indicates that the development of PD in people below the age of 40 or 50 may be inherited in some families, and further research is ongoing.

It is also possible that the nerve damage in PD may be caused by a factor from the environment. In the past, it was suggested that exposure to harmful chemicals such as pesticides, drinking polluted water, or even a physical factor such as a head injury may cause PD although, at present, there is no evidence to support these suggestions.

The current thought is that although PD itself is not inherited, there is some type of inherited factor ('in the genes' or 'genetic susceptibility') that makes some people more susceptible to the effects of harmful environmental factors such as those described above – and this may raise their risk of developing PD.

## Symptoms of PD

PD is referred to as a progressive disorder. This means that the symptoms of the disease gradually worsen over time (a period of years). In PD, symptoms usually appear slowly. The main symptoms are related to movement (known as 'motor' symptoms), although it is thought that the very earliest signs of PD may not be movement related (so-called 'pre-motor' symptoms) – for example, a reduced sense of smell, constipation, depression and sleep disturbances. Research is underway to find out how detection of these symptoms may help in the early diagnosis of PD.

Some of the most common symptoms of PD are described in more detail in this section. It is important to remember that not all of these symptoms are found in all people with PD, and that progression (i.e., the speed of development) can vary considerably from one person to another. Therefore, these variable factors can make PD difficult to recognise in some cases.

Many symptoms of PD are aggravated by stress and situations that cause anxiety, and may be improved by proper rest and sleep, as well as relaxation and stress management strategies. Medications are used to treat the symptoms of PD, although some symptoms, e.g., ankle swelling or postural hypotension (low blood pressure on standing), may be made worse by certain treatments, leading to a need for additional medications. Therefore, it is important that people with PD are carefully monitored for their reaction to medication, which can then be adjusted accordingly.

If PD symptoms are not troubling, some physicians may consider treatment unnecessary, but there is increasing evidence that early treatment can offer advantages – providing prompt relief of symptoms and potential long-term benefits (see section on 'Early treatment of PD', page 17). When treatment is required, symptoms can often be controlled simply with a small amount of medication. As PD progresses, treatments may involve more than one medication to control the symptoms. However, PD is not a terminal condition and, with the right support and advice, those diagnosed with the disease can continue to live full and active lives.

For more details on PD treatments, see the following section on 'Managing Parkinson's disease', page 15.

### Main symptoms

Although the symptoms of PD can vary from person to person, most people will experience three or more of the main (core or cardinal) symptoms, which are described below.

#### *Slowness of movement (bradykinesia)*

Bradykinesia literally means slow movement. The general effect of bradykinesia is that it takes more time and effort to complete daily tasks.

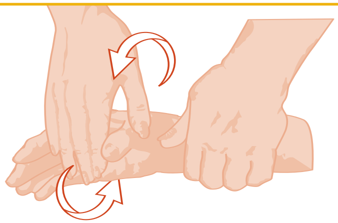
To begin with, bradykinesia affects small, precise movements such as those needed for fastening buttons and writing. Problems with rising from a chair or turning over in bed are also common. Later on in PD, starting to walk may become difficult, or a person may unexpectedly 'freeze' to the spot for a short time while walking. (Some tips on the use of cueing strategies to help overcome 'freezing' are given on page 38.)

#### *Stiffness (rigidity)*

Rigidity in PD is a stiffness of the muscles.

To test for rigidity, the examining doctor moves the relaxed body part slowly and gently, and tests for any resistance to movement (see Figure 3).

**Figure 3: Testing for rigidity in PD**

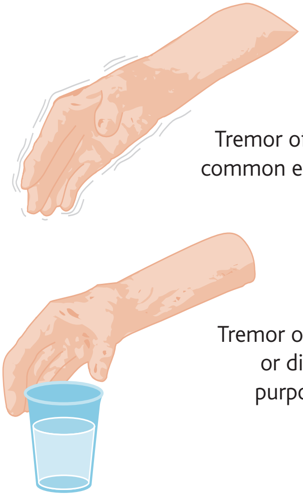


Examining doctor rotates patient's relaxed hand

#### *Tremor*

The type of tremor seen in PD is a shaking motion that mainly occurs at rest, and may become less during activity (although in some people, tremor can disappear during sleep, and appear with certain actions or postures) (see Figure 4).

**Figure 4: Tremor in PD**



Tremor of one hand is a common early sign of PD

Tremor often improves or disappears with purposeful function

Initially, tremor usually affects the arm, hand or fingers on one side of the body, and may begin as a slight twitch. The most common tremor movement in PD is a back and forth motion of the thumb and first finger known as 'pill rolling'.

A tremor isn't present in all cases of PD, but it can be a troubling symptom for some people. It is not usually disabling since the tremor is mainly present at rest.

### *Loss of balance (postural instability)*

The ability to maintain posture and balance may be affected in people with PD. This can lead to unsteadiness when walking, turning or standing, or when performing actions such as rising from a chair or bending over. Any of these unsteady movements may lead to a fall, which is a major cause of injury in people with PD.

There are many practical devices such as handrails, walking sticks, and walking frames that can help with stability and can prevent falls. A physiotherapist will be able to identify the right walking device for each person.

## Non-movement-related (non-motor) symptoms

As well as the four main symptoms described above, PD can produce other symptoms that are not related to movement, known as 'non-motor' symptoms. Non-motor symptoms such as a reduced sense of smell, and impaired speech and facial expression, may appear very early in the disease. Other non-motor symptoms appear more frequently in the later stages of the disease, e.g., problems with thought and response to everyday situations (i.e., behaviour). Treatment of both the motor and non-motor symptoms is vital for the successful management of PD.

Details of some of the most important non-motor symptoms are listed below. In addition, difficult/painful swallowing, problems with urination, sexual difficulties, and low blood pressure on standing, are other non-motor symptoms that may occur in PD.

### *Reduced sense of smell (hyposmia)*

A reduced sense of smell (also known as 'hyposmia') is now recognised as a very early feature that can be detected in some (not all) untreated, newly diagnosed people with PD. It is caused by damage to the nerve cells in the part of the brain that controls the sense of smell. Although this symptom is not physically disabling, it can impair the enjoyment of food (including reduced appreciation of the taste of food) as part of daily life. In the future, prompt recognition of this symptom may be important in producing an early diagnosis of PD.

### *Constipation*

Constipation is a common symptom in PD. It is caused by the muscles of the bowel moving more slowly than usual, together with the effects of less physical activity and/or a poor diet. This particular symptom is relatively easy to treat – either through the sensible use of diet and exercise, or by receiving medication from the doctor. It is also important to treat, as constipation can lead to other health problems and can reduce the effect of some medications, so dealing with it may actually improve function.

Drinking plenty of water (8–10 glasses per day), is essential to help manage constipation, and other tips on using diet to avoid/relieve constipation can be found in the 'Guide to healthy eating' that is included in this binder.

### *Sweating*

Sweating is one of the ways in which the body regulates temperature – the body cools down as water evaporates from sweat on the surface of the skin. Sweating is controlled by the nervous system, and PD (or PD medication) can sometimes interfere with this process, causing the body to produce either too much or too little sweat. If changes in sweating occur, then a doctor or PD nurse should be consulted about how to manage the situation – for example, advising on fluid intake, room temperature, or skin moisturising products.

### *Pain*

From time to time, people with PD may experience cramps, aches, and sensations of numbness, coldness or burning. This most frequently occurs in the legs, although lower back pain and headaches are also common.

There are many ways in which pain can be eased without using medication, and a physiotherapist will be able to provide specific recommendations for each person. Common strategies are gentle exercise, massage, and correct use of practical devices such as special cushions or mattresses. Some people also find that tonic water with quinine helps to relieve cramps – all options should be discussed with a member of the healthcare team.

### *Speech and facial expression*

Communication between people is an important part of everyday life – making connections outside the home, as well as within the family. This type of communication involves many aspects, including words, body language and the manner of speech. In people with PD, slow or reduced movement of the muscles can result in the face showing less expression than usual. These symptoms can sometimes make communication more difficult, and can be misinterpreted as annoyance, disinterest, or as a lack of understanding. Changes to the function of facial/throat muscles can also affect the voice in some people with PD, producing speech that may be quiet, hoarse, hurried or hesitant. Therefore, it is important that any changes are understood and managed promptly and effectively.

A doctor or PD nurse will be able to recommend a speech and language therapist to help with effective tips and exercises for minimising any speech problems. Advice on good posture, exercises to strengthen the vocal/facial muscles, and general guidance on communicating clearly can all help to manage the situation.

### *Sleep*

Some people with PD find that they have trouble sleeping, possibly because one of their symptoms (e.g., pain, stiffness or anxiety) makes it difficult to feel restful. Alternatively, sleep may be affected by a PD medication, or the changes in the brain that happen during PD itself.

As described later in this booklet (see section on 'Healthy sleep', page 36), it is very important for a person with PD to have enough sleep, as it can help to improve some symptoms, as well as benefiting health in general. The technical term for this is 'sleep benefit'.

### *Fatigue*

Fatigue is a physical and/or mental exhaustion that is very common in PD. It may be one of the first symptoms to appear.

Fatigue can be caused by one or more factors, including medications, the extra effort of managing PD symptoms, disturbed sleep, or depression. However, in most cases, fatigue is caused directly by the chemical changes in the brain that occur in PD.

It is important to identify the cause of fatigue. For example, if fatigue is associated with depression, then the depression should be treated; if it is caused by sleeping problems, then they should be assessed and treated. Fatigue that is caused directly by PD may be treated with PD medication.

Aside from treatment with medication, coping methods for fatigue include:

- allowing more time to complete daily activities
- learning to recognise times when fatigue is reduced
- ensuring that the daily diet is balanced, providing energy, and avoiding constipation (which can cause tiredness)
- using assistive devices, e.g., dressing aids, remote controls, which make daily activities less tiring
- taking regular gentle exercise to keep muscles active.

### *Behavioural and psychological symptoms*

Behavioural and psychological symptoms are non-motor symptoms that involve a person's response to the world around them, and the processes in the mind that control these responses. In some cases, disturbed sleep and fatigue (see descriptions above) may be caused by an underlying behavioural/ psychological symptom.

#### *Mood/depression*

A change in mood is a natural reaction to being diagnosed with PD, or developing a particular symptom. However, depression in PD can also be caused by the disease itself lowering the levels of chemicals in the brain that control mood. Signs of depression include: a negative view of oneself, one's surroundings and the future; loss of motivation, energy, and interests (including social and sexual); poor sleep and memory; and a decreased appetite.

Depression is a treatable condition and, because it can have such a big impact on everyday life, it is important that the doctor is told about any mood changes in order to provide prompt treatment (for further information on the treatment of depression, see section on 'Emotional support', page 40). In addition, relieving depression can improve a person's response to the therapy of other PD symptoms, and it can also offer relief to the caregiver, who may find it more difficult to offer support to a person who is depressed.

#### *Apathy*

Apathy is a lack of interest or motivation for daily life that may be seen in PD, and which is closely related to depression and other mood changes. As described above, apathy may be caused by the chemical changes occurring in PD itself, or may be a reaction to coping with the PD diagnosis and any associated lifestyle changes.

Apathy can have a significant impact on life for both the person with PD, and the people surrounding them, but is often not reported to the doctor as a symptom, as it is not seen as a 'medical problem'. However, as for all mood-related conditions, an approach of support, carefully selected therapies, and counselling can offer relief once the problem is recognised.

*Anxiety*

Anyone who experiences a new or stressful situation may become anxious. Anxiety disrupts sleep, and can also worsen PD symptoms such as tremor. Extreme anxiety can produce panic attacks, which include periods of dizziness, shortness of breath, and sweating. Anxiety may be experienced as a constant feeling, or it may be triggered by certain situations, e.g., going out in public. In addition to these triggers, anxiety may also be a sign of depression.

People with PD can be taught relaxation methods, and often find that therapies such as breathing techniques, muscle relaxation, massage, meditation, yoga, aromatherapy, Tai Chi, etc., can help to relieve anxiety. In some situations, medication can be prescribed.

*Thought and memory*

Because PD affects more than one part of the brain, some people find that they experience changes in thought and memory, in addition to the more common movement-related symptoms. In early PD, these may include difficulty with concentration, or subtle changes in memory and thinking – often barely noticeable to the person with PD. The ability to plan complex tasks or perform several tasks at once may also be affected. These impairments may gradually progress along with other symptoms of the disease, although it should be noted that medications can also have an effect on thought processes (e.g., producing confusion or hallucinations), and so any changes should be reported to a doctor as soon as possible in order to determine the cause.

## In summary

- Parkinson's disease (PD) is a condition that:
  - affects the nerve cells of the brain, and this causes…
  - an abnormally low level of a chemical called dopamine in the brain, and this leads to…
  - problems with controlling body movements.

- The main symptoms of PD are:
  - slow movements
  - stiffness
  - tremor
  - loss of balance and altered walking/standing position (gait/posture).

- PD also produces symptoms that are not related to movement, e.g., depression, constipation, and sleep problems. Some of these symptoms are thought to be amongst the first signs of PD and may be helpful in early diagnosis.
- Doctors are often able to diagnose PD by observing the symptoms, although it can be a difficult condition to identify because other diseases can cause similar symptoms.

# 2. Managing Parkinson's disease

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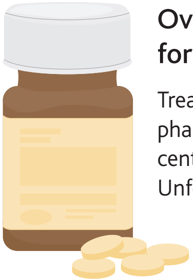
## The multidisciplinary team

PD has many aspects and, therefore, it is best managed in the context of a multidisciplinary team. The PD multidisciplinary team is led by the person with PD and their carer/family, and also includes one or more of the following professionals, depending on the specific needs of an individual:

- **doctor** (specialist and/or general practitioner, GP)
- **specialist PD nurse** – a doctor does not always have enough time available to discuss all the concerns of a person with PD and, consequently, the nursing team can provide a valuable bridge between the person with PD and their doctor. In addition, there is an increasing number of PD nurses who are specially trained to advise people on daily life with PD, and liaise with the doctor on their behalf in between one visit and the next
- **physiotherapist** – has expertise in the management of mobility problems from the point of diagnosis to the later stages of the disease. A physiotherapy programme consists of an exercise regime, movement strategies (such as cueing and cognitive movement strategies, which deal with the specific functional problems caused by PD – see section on exercise, page 38), and consideration of the person's specific needs. Physiotherapy can also help to improve the effects of medication by preventing complications due to reduced mobility, and provide techniques for managing periods when medication offers poor control of movement
- **occupational therapist** – enables people with PD to adapt and develop life skills to help with their new or altered capabilities – thereby promoting independence. The occupational therapist can also suggest practical aids to help at home or in the workplace
- **sex therapist** – provides advice and counselling on all areas of sexual health that are of concern to a person with PD and/or their partner
- **speech/language therapist** – encourages communication, suggesting tips to overcome any oral difficulties such as swallowing, and recommending exercises for the face, to keep muscles strong, and to help improve speech
- **dietician** – advises on healthy diet, and any other specific dietary needs
- **pharmacist** – gives advice on prescribed medications
- **social worker** – in some countries, the social care system can help with recommending carer support and other available community and financial services
- **psychologist/counsellor** – can help with cognitive behavioural therapy and talking through any aspect of PD that is having emotional effects including depression, anxiety and communication
- **psychiatrist** – assists with mental health problems such as depression and anxiety
- **national/local PD organisation** – source of information and advice on all aspects of PD, including self-help groups.



## Overview of medication for PD

Treatment with medications (i.e., pharmacological treatment) is central to the management of PD. Unfortunately, no treatment has yet been proven to cure the disease, but there are many efficient medications that are able to treat the symptoms of PD and reduce their effects on everyday living (see below).

In addition, some medications have been shown to protect brain cells in the laboratory, and researchers are investigating whether these medications can help to slow down the progression of the disease in people with PD. Findings from recent clinical studies in this area have been encouraging, including new evidence suggesting that it is possible for medications to delay disease progression – that is, alter the course of the disease.

**A single medication may be known by several brand names – often differing from country to country. In addition, not all medications are available in all countries. Therefore, before travelling abroad, it is very important for a person with PD to find information about the name(s) of their medication in the destination country – just in case medical treatment is needed. Information about these different names can be found on the EPDA website (www.parkinsonsdecisionaid.eu.com/medInfo)**

Details of other treatment options such as surgery and complementary therapies are described later in this booklet (see pages 34 and 36).

### Dopaminergic therapies

As explained earlier, the movement-related symptoms of PD are caused by the lack of a chemical called dopamine in the brain. Currently, PD is mostly treated with medications that replace, or increase, the amount of dopamine in the brain. Medications that are used to restore dopamine levels in this way are called dopaminergic medications.

There are several types of dopaminergic medication. They all aim to increase dopamine levels, but they work in different ways. This means that each medication is better at treating some symptoms than others, and will also produce different patterns of side effects. In addition, different forms of medication delivery (e.g., fast-dissolving or slow-release tablets) are continually being developed to improve treatment convenience/compliance, and to optimise treatment outcomes.

The different dopaminergic medications and the ways in which they work are described in more detail later in this section, but a summary of the available therapies is given in Table 1.

Table 1: Currently available dopaminergic therapies (brand names may differ between countries – examples are given)

| | |
|---|---|
| **Levodopa** | Levodopa is most commonly prescribed under the brand names Madopar® and Sinemet®.<br>These tablets contain levodopa together with another substance to help it reach the brain (e.g., Sinemet® contains levodopa with carbidopa, and Madopar® contains levodopa with benserazide). The tablets come in many colours and strengths to help with different dose schedules. They are also available as slow-release tablets, or as a gel via the 'Duodopa® pump', which may be helpful for some people. |
| **MAO-B inhibitors** | Currently, there are two MAO-B inhibitors on the market, rasagiline (Azilect®) and selegiline (Eldepryl®, and Zelapar® – a fast-dissolving tablet). |
| **Dopamine agonists** | There are many dopamine agonists on the market, and these include ropinirole (ReQuip®, and ReQuip® LP – a slow-release tablet), cabergoline (Cabaser®), bromocriptine (Parlodel®), pergolide (Celance®), pramipexole (Mirapexin®), and rotigotine (Neupro® – an adhesive skin patch). In addition, apomorphine (Apo-Go®) is given by injection to produce rapid control of symptoms in people with advanced PD. Apomorphine is not related to the medical use of morphine in any way. |
| **COMT inhibitors** | There are two COMT inhibitors currently available, entacapone (Comtess®) and tolcapone (Tasmar®).<br>COMT inhibitors are only effective when taken together with levodopa, and entacapone is available as Stalevo® – a combination tablet that also contains levodopa and carbidopa (available without entacapone as Sinemet®, see above). |

## Early treatment of PD

When the first symptoms of PD appear, medication may or may not be prescribed. This decision depends on many factors such as whether disease symptoms are having a negative effect on life at work or at home, and whether the person with PD has other medical conditions to be considered. The treatment decision should therefore be discussed in detail between the person with PD and their doctor/PD nurse. The aim of this discussion is to ensure that each person receives the treatment best suited to their individual needs.

In addition, there is a lot of debate regarding whether starting treatment early (i.e., soon after the disease has been diagnosed) has a long-term advantage over a delayed treatment start. Those who support early treatment argue that the use of a suitable medication will improve control of symptoms. Those who support delayed treatment initiation feel that, in the early stages of PD, any small treatment benefits on mild symptoms are outweighed by the risk of short-term and long-term side effects of medication. However, if medications are approved for modifying the course of PD and slowing its progression, then starting treatment as early as possible is likely to become a more relevant treatment strategy.

Whenever treatment is started, a single medication will usually be given, with the doctor and person with PD working together to establish the most effective dose. This medication is most commonly an MAO-B inhibitor, a dopamine agonist, or levodopa – although the use of levodopa may be delayed for use later on in the disease. As PD progresses, doses may need to be altered and medications switched or added to provide the best control for the particular symptoms experienced. However, throughout the disease, the person with PD will always have the final say on when and how treatment is given.

## Why are different medications given at different times?

When treatment is given, there are several reasons why different medications may be given at different times.

- PD is a neurological disorder with a wide range of symptoms, so each person will be given different medications to treat their particular symptoms.
- PD is a progressive disease and symptoms change over time. A combination of medications may be needed – especially in the later stages of PD – as some medications treat certain symptoms better than others.
- Some of the medications used in PD may cause unpleasant side effects and, if this happens, the doctor may change the medication or prescribe extra medication to treat the side effects.
- Most people with PD will receive levodopa at some point during their treatment. This is an effective medication that provides the brain with extra dopamine. However, when the disease progresses, there may be periods of the day when the effects of the medication appear to 'wear off'. At this point, other medications can be added to reduce the wearing off phenomenon, and the dose of levodopa reduced accordingly.
- Because the effects of levodopa can begin to wear off, or cause other side effects, after several years of use, doctors have tended to delay the use of levodopa for as long as possible. Consequently, a person may begin treatment on another medication (such as an MAO-B inhibitor or dopamine agonist) to control the symptoms of early disease, and to delay the use of levodopa until it is really needed. However, it has recently been suggested that it is the disease becoming more severe over time, rather than long-term levodopa use, that causes the effects of levodopa to wear off. Therefore, early treatment with levodopa may be considered for some people with PD – particularly the elderly, due to levodopa's effectiveness against movement-related (motor) symptoms. Starting treatment with a dopamine agonist is preferred in younger people, as they are prone to developing long-term complications (motor fluctuations – see below).

## Describing motor fluctuations

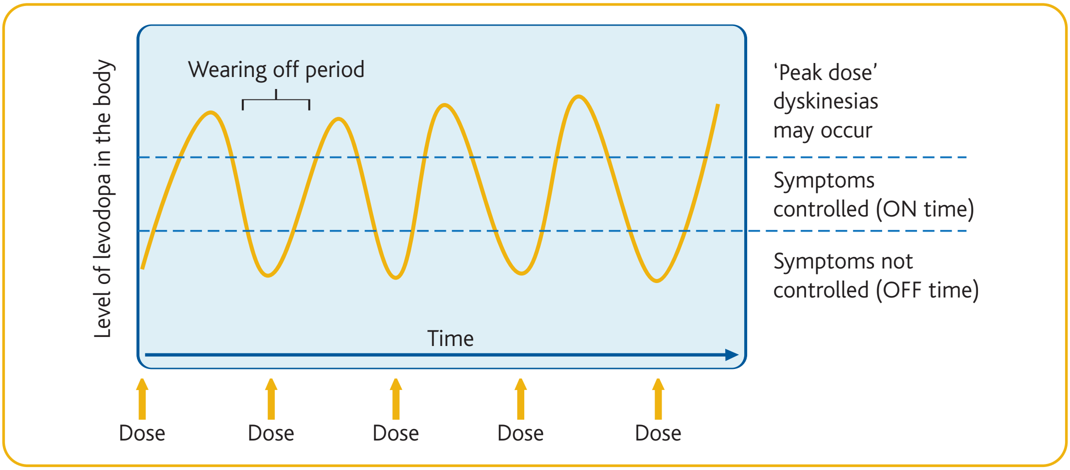
In PD, there are times when symptom control is good and the medication seems to be working well – this is called 'ON time'. At other times, symptom control may be poor with symptoms not appearing to respond to medication – this is called 'OFF time'. 'Motor' is the scientific word that is used to refer to anything to do with movement, and the term 'motor fluctuations' or ('ON–OFF fluctuations') refers to a state where a person with PD changes between ON time and OFF time. This situation is common in people who have been receiving levodopa treatment for many years. Another change in symptom control can be seen during the peak of levodopa absorption from the digestive system, when a person may experience restless movements known as dyskinesias ('peak-dose' dyskinesias) – almost as if there was 'too much' movement. On the other hand, when levodopa levels are at their lowest (i.e., before the dose has been absorbed), abnormal and painful posture may occur, which is known as dystonia (usually 'OFF dystonia').

The questions and answers below discuss some of the issues associated with motor fluctuations.

### What is wearing off?

'Wearing off' is a common phrase used in PD. It describes the period of time between the end of the effect of one dose of medication, and the beginning of the next one. That is, the beneficial effects of the previous dose appear to be 'wearing off' (see Figure 5).

**Figure 5: Wearing off between levodopa doses**



### Why does wearing off occur?

There is no definite explanation for what causes wearing off. Levodopa works by supplying dopamine to the nerve cells of people with PD. However, as PD progresses, it is possible that the levodopa medication is less able to compensate for the increasing loss of dopamine-producing nerve cells. Another possibility is based on the theory that, in early PD, the extra dopamine supplied by each levodopa dose is stored and then released when needed. In more advanced PD, the dopamine can no longer be stored and so it is released all at once, beginning by working well (ON time), progressing to working too well (ON with dyskinesias), returning to working well again (ON time), and then wearing off (OFF time). These variations are examples of motor fluctuations.

### What are the symptoms of wearing off?

The symptoms of wearing off vary from person to person, and may not occur after every dose of levodopa. Wearing off tends to produce a mild and gradual increase in symptoms, with some people noticing an increase in tremor or slowness. In contrast, other types of motor fluctuations associated with more advanced PD, such as those known as ON–OFF fluctuations, have more rapid and sometimes unpredictable switches between periods of good function and periods of poor function. People may experience a return of symptoms including tremor, stiffness, anxiety, depression, and pain.

### Treating wearing off

As might be expected, wearing off is relieved by taking the next dose of levodopa – although there is often a delay of up to 1 hour before the medication takes effect. A doctor may be able to reduce the effects of wearing off by recommending:

- smaller, but more frequent, levodopa doses
- a different form of levodopa that releases the medication more gradually (i.e., a slow/controlled/extended-release tablet)
- chewing the levodopa tablets or taking them with carbonated drinks to increase the speed of their effect
- not taking levodopa with meals (food slows its action)
- treating constipation (levodopa is absorbed just beyond the stomach and, if a person is constipated, the dose may stay in the stomach for several hours, unable to work).

An alternative option is to add another medication (MAO-B inhibitor, dopamine agonist, or COMT inhibitor) to minimise the wearing off symptoms. The addition of this second medication is known as adjunct or combination therapy.

It is clear that treatment of motor fluctuations is a complicated process, and therefore doctors tailor the treatments for each individual. For this reason, it is sometimes helpful if the person with PD keeps a daily diary of their symptoms and the effects of medication, noting any variations during the day. This gives the doctor extra information when recommending a therapy, and saves the person from having to remember these details from visit to visit.

**Wearing off diary**

The wearing off diary supplied with this binder contains enough pages for you to record your daily symptoms for a period of 6 months.

If, after this time, you would like to continue making the diary, there is a laminated 'diary master card' at the back, which can be photocopied to generate more pages.

When visiting the doctor, write out any questions that you want to ask, as it is a well known fact that you will only remember the most important questions when on your way home after the consultation! For more tips on communicating with your doctor, see the 'communication card', which is also at the back of the diary.

## In summary

- A person with PD should receive treatment from a multidisciplinary team, the members of which can advise on all types of therapy, community/home services and medication.
- There are many effective medications that can control the symptoms of PD, although in the early stages of PD people may experience excellent control of symptoms with only minimal doses of medication, and little intervention from doctors.
- Currently, no curative treatment is available for PD, although new evidence suggests that it is possible for some medications to slow disease progression.
- 'ON time' is a period when symptoms are responding well to medication.
- 'OFF time' is a period when symptoms are responding poorly to medication.
- Levodopa is a well-established treatment for PD. Over time, there is often a fluctuation in the response to levodopa therapy, and symptoms may begin to reappear as the effect of a levodopa dose wears off.
- MAO-B inhibitors and dopamine agonists may be prescribed to:

– treat the early symptoms of PD
– treat symptoms that are poorly controlled by levodopa therapy
– reduce the impact of motor fluctuations and dyskinesias caused by levodopa therapy (COMT inhibitors may also be considered).

## Medication options

As described earlier (Table 1), there are many different medications available to treat the symptoms of PD. To help understand the use of these therapies, Tables 2–5 and Figures 6–9 summarise how each type of medication works, and present the relative benefits of each of these classes of therapy.

**Guide to Parkinson's disease medications** ✓

**A summary card, listing the key information about the different PD medications is provided at the back of the diary supplied with this binder. It can be used as a quick reference guide.**

### Levodopa

**Table 2: Levodopa therapy**

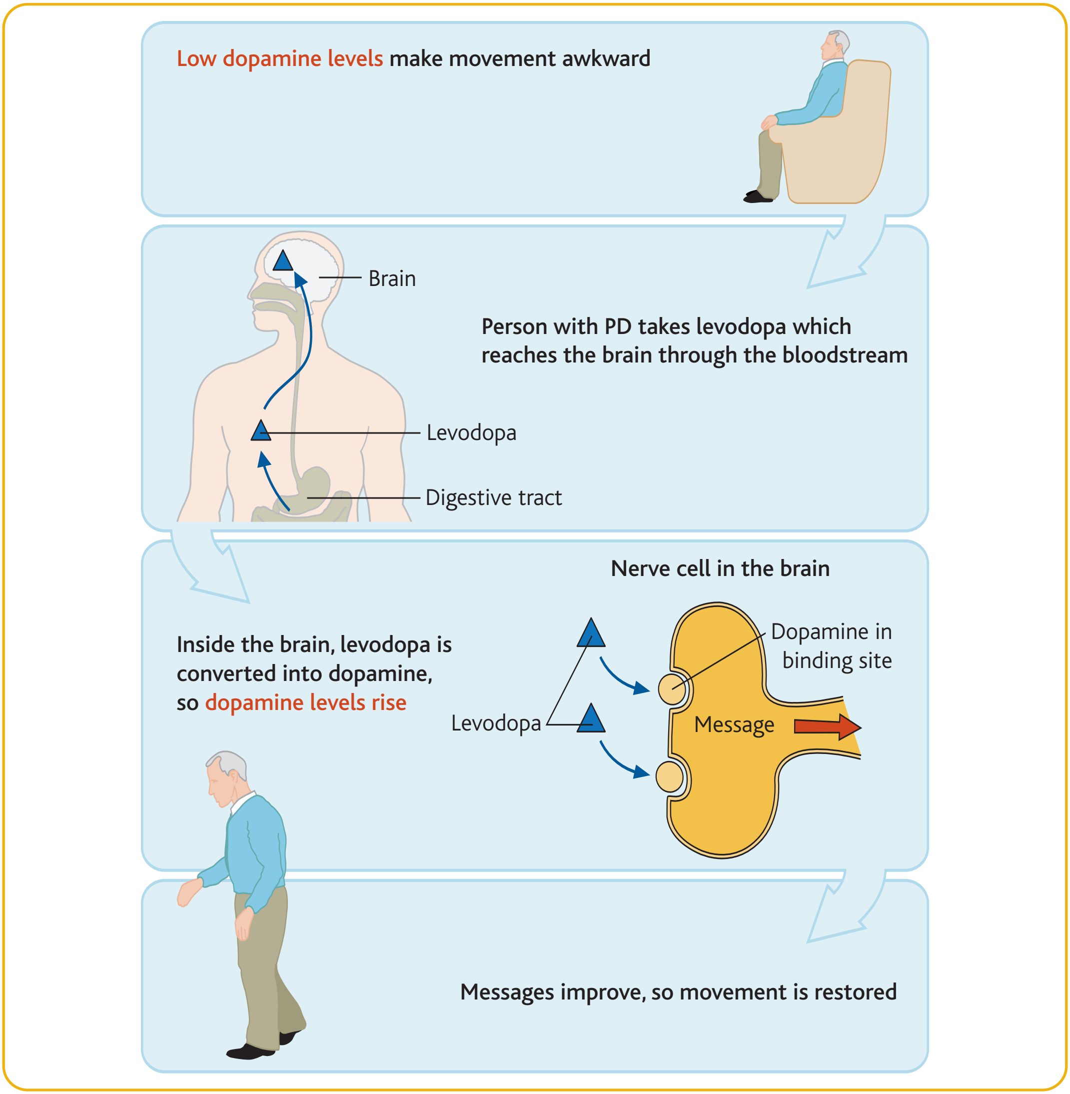
| | |
|---|---|
| **How does it work?** | Levodopa can be changed into dopamine in the body and in the brain. Therefore, it directly supplies the brain with more dopamine (see Figure 6).<br>Levodopa is always prescribed with other medications such as dopa-decarboxylase inhibitors (DDIs) and COMT inhibitors, which prevent it from being broken down before it reaches the brain. Combination with these other medications reduces the dose of levodopa needed, and prevents some unpleasant side effects. |
| **What are the benefits?** | Levodopa is a well-established treatment for PD, and is thought of as the 'gold standard' treatment. Most people with PD will be prescribed levodopa at some point during their therapy.<br>Levodopa is very effective at preventing slow movements and stiffness, especially in the early stages of PD. It is also used to reduce tremor. |
| **What are the side effects?** | Levodopa may cause side effects including nausea, vomiting, low blood pressure upon standing, sleepiness, hallucinations and abnormal dreams.<br>Those people who have had PD for a number of years will begin to experience changes in the effectiveness of levodopa – freezing, and 'wearing off' and ON–OFF fluctuations. In addition, dyskinesias (restless movements) may begin to appear.<br>Some of the side effects of levodopa (e.g., vomiting) may disappear over time, while others may be improved by a reduction in dose or use of a slow-release form of levodopa. Medication can be prescribed to help relieve nausea, and this should be discussed with a doctor or PD nurse. |

#### *The Duodopa® pump*

In addition to oral tablets (Sinemet®), the combination of levodopa and carbidopa can also be administered in a form known as Duodopa®. Duodopa® contains the two medications in a gel that is delivered directly into the digestive tract (duodenum), via a tube from a portable pump operated by the person with PD or a carer.

The tube is inserted in a minor surgical operation. This delivery system is designed to provide a more even supply of the medication, which is not influenced by emptying of the stomach, thereby potentially reducing the occurrence of wearing off, and ON–OFF fluctuations.

Figure 6: How levodopa works



Low dopamine levels make movement awkward

Person with PD takes levodopa which reaches the brain through the bloodstream

Inside the brain, levodopa is converted into dopamine, so dopamine levels rise

Messages improve, so movement is restored

## MAO-B inhibitors

**Table 3: MAO-B inhibitors**

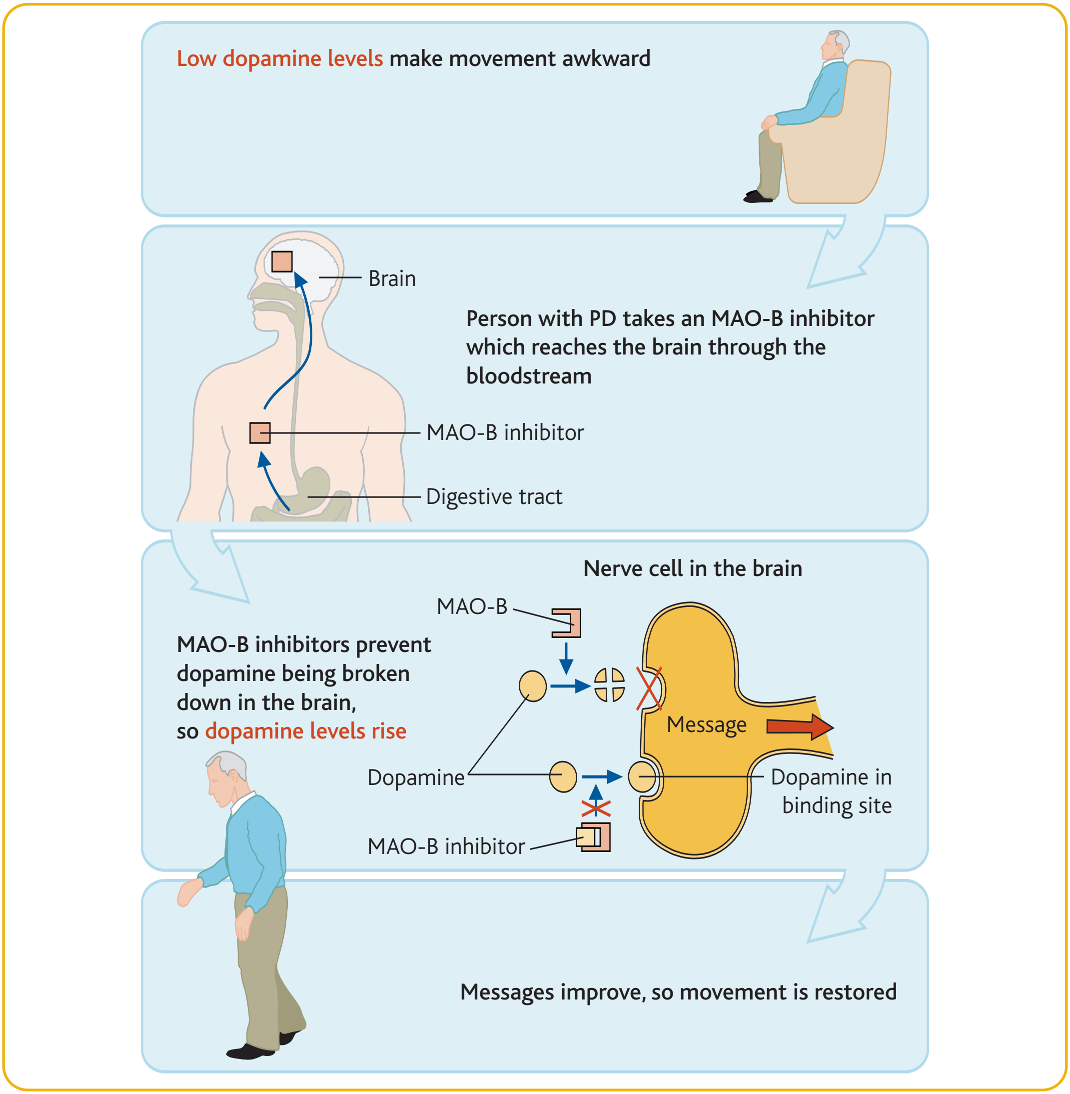
| | |
|---|---|
| **How do they work?** | In the brain, a substance (enzyme) called MAO-B (short for **m**ono**a**mine **o**xidase **B**) breaks down dopamine, thus preventing its action – a normal control mechanism. MAO-B inhibitors stop MAO-B from working, and this raises the levels of dopamine in the brain (see Figure 7).<br>Therefore, in PD, MAO-B inhibitors (e.g., rasagiline, selegiline) can be given to prevent dopamine being broken down – thereby prolonging the action of dopamine in the brain (including the dopamine provided by treatment with levodopa). |
| **What are the benefits?** | MAO-B inhibitors are useful in the very early stages of PD, and may be used as a first treatment – delaying the need for levodopa. When levodopa is required, MAO-B inhibitor treatment can be continued or newly added to the regimen, allowing a lower dose of levodopa to be used, and therefore helping to delay the start of the motor fluctuations that appear with long-term levodopa treatment.<br>There has been some discussion as to whether the MAO-B inhibitors protect brain cells and can slow down the progression of PD. This has been investigated in clinical trials with rasagiline, which indicate that it may be able to slow the progression of disease (although no medication is yet approved by the authorities for this use). |
| **What are the side effects?** | Rasagiline is generally well tolerated, with the most common side effects including headache (when taken alone, i.e., as monotherapy), dyskinesia, vomiting, constipation, accidental injury, and low blood pressure on standing (when taken together with levodopa).<br>Selegiline is also generally well tolerated, with dry mouth and sleeping disorders being some of the most common side effects. However, as it helps to increase the action of levodopa, selegiline also increases some of levodopa's side effects such as dyskinesia, nausea, confusion, hallucinations, low blood pressure on standing, and vertigo. The increase in levodopa-related side effects may be alleviated by adjusting the levodopa dosage. Side effects of selegiline relating to the central nervous system (hallucination, confusion and changes in blood pressure) may be due to its breakdown product (amphetamine metabolite). |

### *MAO-B inhibitor formulations*

A practical advantage of the MAO-B inhibitor, rasagiline, is that it is taken as a once-daily dose, at any time of day, with or without food, and requires no titration (the gradual increase in dose that is sometimes used to find the most effective level of treatment), thus providing a convenient administration schedule.

A new tablet form of selegiline has been developed to quickly dissolve in the mouth – helping to avoid some of selegiline's side effects, and also providing a useful method of administration for people with PD who have difficulty swallowing tablets.

Figure 7: How MAO-B inhibitors work



Low dopamine levels make movement awkward

Person with PD takes an MAO-B inhibitor which reaches the brain through the bloodstream

MAO-B inhibitors prevent dopamine being broken down in the brain, so dopamine levels rise

Messages improve, so movement is restored

## Dopamine agonists

**Table 4: Dopamine agonists**

| | |
|---|---|
| **How do they work?** | Dopamine agonists (e.g., ropinirole, cabergoline, bromocriptine, pergolide, pramipexole, rotigotine) imitate the action of dopamine in the brain. The brain cells respond as if more dopamine were present (see Figure 8).<br>There are several types of dopamine agonist, and they each work in a slightly different way. |
| **What are the benefits?** | Dopamine agonists are useful in the early stages of PD, and may be used as a first treatment. Eventually, levodopa is usually required, and dopamine agonists can be given with levodopa, allowing a lower dose of levodopa to be used.<br>Long-term treatment with dopamine agonists tends to cause fewer dyskinesias and ON–OFF fluctuations than levodopa, and tends to be preferred in younger people with PD. However, there is no strong evidence that starting treatment with a dopamine agonist is preferable to starting treatment with levodopa. |
| **What are the side effects?** | Dopamine agonists can sometimes cause nausea, vomiting, low blood pressure on standing, confusion and hallucinations, constipation, abnormal dreams, and fatigue. However, some of these can be reduced by gradual introduction of the medication, or by reduction of the dose. The rotigotine patch can also cause skin reactions at the patch application site, e.g., rash or itchiness.<br>Because of the way they work, different dopamine agonists tend to be associated with different side effects. |

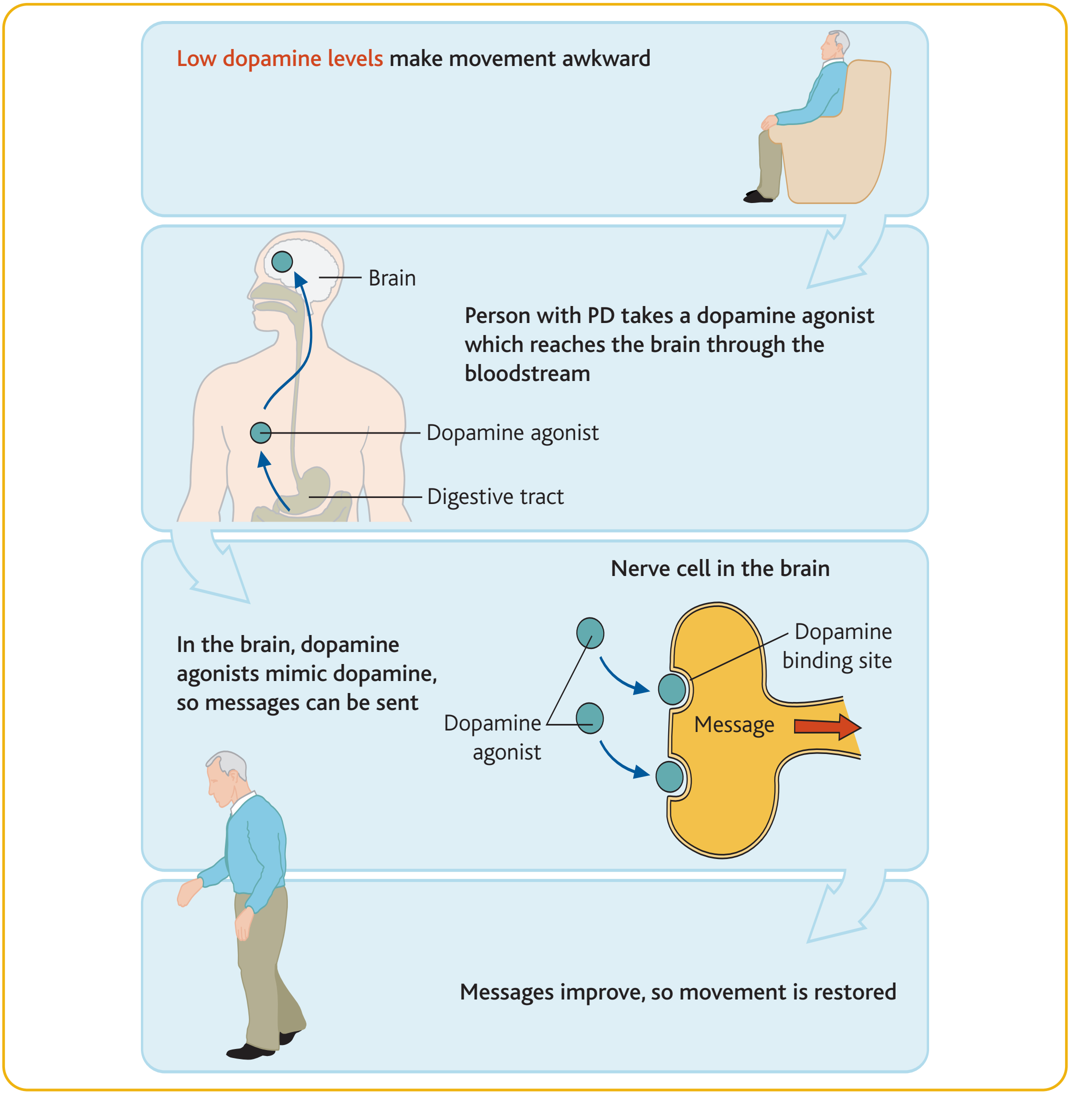
### *The rotigotine patch*

Rotigotine has been developed as an adhesive skin patch that is replaced every 24 hours, with the medication being absorbed into the body through the skin. The patches are available in several doses (more than one patch may be necessary to achieve the appropriate dose), and may be a practical alternative to oral tablets for some people with PD – although the patches must be stored in a refrigerator prior to use.

### *Ropinirole XL/CR*

A slow-release form of ropinirole has been developed, which allows a more convenient once-daily dosing schedule.

Figure 8: How oral dopamine agonists work

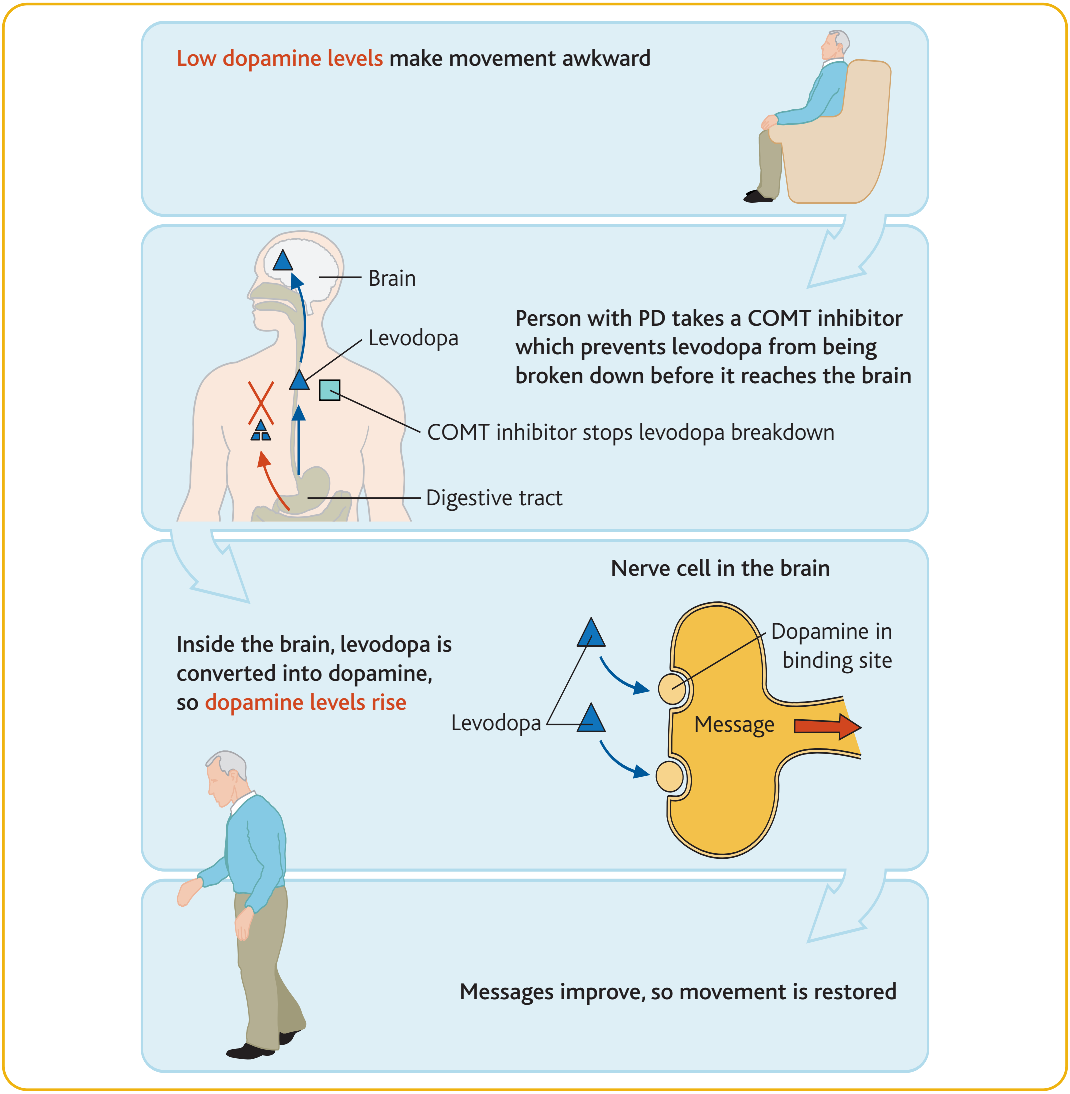


## COMT inhibitors

Table 5: COMT inhibitors

| | |
|---|---|
| **How do they work?** | COMT (short for **c**atechol-***O***-**m**ethyl**t**ransferase) inhibitors, e.g., entacapone, tolcapone, are always given with levodopa, and never alone. This is because they prevent levodopa from being broken down before it gets to the brain (see Figure 9). |
| **What are the benefits?** | When people begin to experience end of dose wearing off with levodopa treatment, a COMT inhibitor can be added to decrease OFF time, and reduce fluctuations – improving the response to levodopa. In such cases, the levodopa dose may need to be reduced. |
| **What are the side effects?** | COMT inhibitors generally produce few side effects, and those that do occur are usually caused by the increasing dopamine levels produced by the medications. Entacapone may cause dyskinesia, nausea, hallucinations, urine discolouration, diarrhoea, and stomach pain. However, these effects are often reduced by lowering the levodopa dose. Diarrhoea lasting longer than 2 weeks should be reported to a doctor.<br>Tolcapone has been associated with adverse effects on the liver (hepatotoxicity), and therefore liver monitoring is required while taking this medication. |

Figure 9: How COMT inhibitors work



### Other medications

Although they are less commonly used than the medications just described, other medications that might be employed in the treatment of PD include anticholinergics and amantadine.

#### *Anticholinergics*

Anticholinergics were commonly used as a PD treatment before the discovery of levodopa. They work by inhibiting the action of a neurotransmitter called acetylcholine, thereby restoring the balance between dopamine and acetylcholine in the brain. Since the discovery of levodopa, anticholinergics have been used less, but may still be prescribed for younger people with early, mild symptoms, especially tremor. In older people, anticholinergics can cause problems with memory and confusion and, in high doses or in combination with levodopa, may produce unacceptable levels of side effects. Examples of anticholinergics include orphenadrine, trihexyphenidyl, procyclidine, and benztropine, although these medications are not available in all countries.

#### *Amantadine*

Amantadine is a medication that was initially used to treat influenza, but was later found to have an effect in PD via its influence on several neurotransmitters including dopamine, acetylcholine and glutamate. It is sometimes taken (alone or in combination with levodopa) to treat mild PD, and is especially useful in treating levodopa-induced dyskinesias (restless movements).

### Guide to Parkinson's disease medications

**A summary card, listing the key information about the different PD medications is provided at the back of the diary supplied with this binder. It can be used as a quick reference guide.**

## Managing PD medications

Maintaining the right balance of medications is often difficult in PD. People with PD need a treatment schedule that is tailored for their particular symptoms and that takes into account their personal preferences.

When beginning treatment with any medication, the dose level may be slowly increased until the most effective dose is found. This process is called titration. The chosen dose needs to be strong enough to control symptoms, but not so strong that it causes troublesome side effects.

As PD progresses, different combinations of medication will be needed from time to time.

### Medication management over the long term

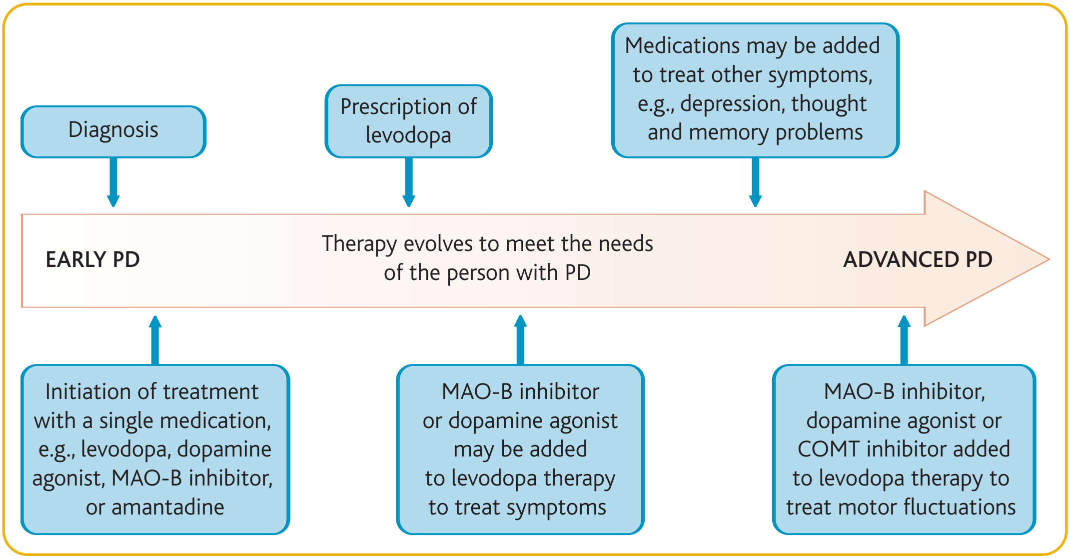
PD is a long-term neurological condition involving mild symptoms that progress, over a period of years, to more severe symptoms. Therefore, treatment plans must take into consideration the fact that people are likely to be treated for PD for more than 15 years.

In the early stages of PD, a single dopaminergic medication (most commonly levodopa, an MAO-B inhibitor, or a dopamine agonist) is usually a sufficient treatment.

As PD progresses, most people will need a combination of various medications, including levodopa. Early medications, e.g., MAO-B inhibitors, do not need to be discontinued when levodopa treatment is started. In later disease, once the effects of levodopa start to wear off, become unpredictable, or produce dyskinesias (restless movements), MAO-B inhibitors, dopamine agonists, or COMT inhibitors can be added to the treatment schedule to control these complications (see Figure 10). If the person with PD experiences problems with thought and memory, depression, or hallucinations/psychosis, then cholinesterase inhibitors, antidepressants, or antipsychotic medications may be prescribed, respectively.

In addition to therapy with medications, there are other ways in which people with PD can manage the condition, and improve their overall well-being in the long term. These options are described in more detail in the 'Complementary/alternative treatments' section (page 36). Consequently, it is often difficult to determine the precise effects of any long-term treatment for PD, as the person may also be receiving other types of therapy.

**Figure 10: Long-term management of PD**



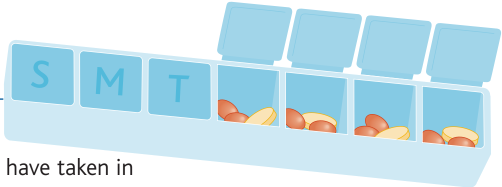
### Tips for managing medications

Every PD medication has specific dosing instructions – the medication may need to be taken several times a day, at particular times, or before or after meals. These instructions are to ensure that the medication is working at its best. Therefore, it is very important to keep to the treatment schedule, without missing doses, as PD is a condition in which a small change in medication or timing can make a big difference to symptoms. In total, each person may need to take a combination of medications for PD, together with any medications that they are already taking for other conditions. The 'tip boxes' below and on the following page list some practical ideas that may help to make managing medications easier.

### Medication record

**Included in the diary provided with this binder is a section for you to record all of your medication details. This can be useful as a personal reminder, as a help to your doctor, or as an aid to medical staff during a hospital stay – whether planned or emergency.**

**Remember to include details of all your medications in the medication record – not just those you are taking for PD. There is plenty of space for you to change the information if your medication is altered.**



## Tips

### Jogging the memory

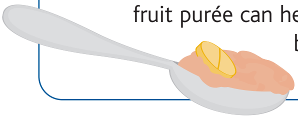
- Make a written record of all the medications you take (and have taken in the past), and the times at which you take them. A medication record – ready to be filled in with these details – is provided in the diary supplied with this binder.
- In advance, prepare weekly tables with the names, doses and timing of medications – especially when the dose of medication is being changed (increased or decreased). This list can then be ticked as each dose is taken (the medication record card in this binder can also be used for this purpose).
- Use a pill box with separate compartments to set out each day's doses.
- If you are on a simple dosing schedule, e.g., one daily dose of a single medication, then set your watch or mobile phone alarm as a reminder to take your medication – if appropriate, ask your carer to do the same.
- If your treatment schedule is more complicated, set a timer as a reminder to take each dose of medication – some pharmacists sell timers especially for pill taking, including a wrist watch with an alarm that can be set to ring or vibrate up to ten times a day and which displays the medication required on its screen.
- If you have problems with vision, ask the pharmacist to prepare your medications with large-print labels.
- If you wish, ask a family member or close friend to accompany you to medical appointments. It can be useful for another person to listen to the doctor's explanations and advice as, between both of you, more may be remembered afterwards! Ask for written information if you feel this is necessary.

### Out and about

- If you are leaving the house for a period of time, take extra medication with you – just in case the trip lasts longer than expected, and you need to take more doses.
- Keep your medication record (or a copy of it) with you at all times so that you can refer to it, or a medical person can follow it if required.
- If you need to go into hospital, it is especially important to take a list of your medications. A small change in medication or timing can make a big difference to symptoms, and the hospital staff will need to be aware of your specific needs. If appropriate, and timing is a concern, ask if you are allowed to administer PD medications yourself (self-medicate).
- For tips on travelling on holiday/abroad with medication, see the 'Travel and leisure' section (page 47).

### Taking the medication

- Ask your pharmacist to supply your medication in non-childproof bottles, as opening secured containers can become difficult for a person with PD. Remember to keep such bottles out of the reach of children. If popping tablets out of blister packs is a problem, then say so.
- If taking your medication causes a feeling of sickness, this may be improved by taking it together with some low-protein food, e.g., a piece of bread or some vegetables. However, check this with your doctor first, as some medications should not be taken together with food.
- Keep the first morning dose of medication by the bedside, so that it is easy to reach if mobility is a problem early in the day. A small pack of crackers could also be kept there in case nausea is a problem.
- If you find it difficult to swallow pills, then taking a mouthful of water, or putting the pill into a spoon of fruit purée can help it slip down. (NB. It is generally advisable to take levodopa pills with water only, but ask your doctor about this.) Alternatively, it may be worth asking your doctor or PD nurse if your pills can be crushed, or if any liquid forms are available.



### Being pro-active

- It is always helpful to learn as much as you can about the medications you are taking – ask your medical team or support group for all the information you need.
- If you experience any worrying effects such as hallucinations or confusion, then report these to your doctor immediately. They may be a side effect of your medication.

## Surgery

Surgery can be used to treat PD, but it is not suitable for everybody. Currently, no operations provide a cure for PD, although they can offer benefits for some people by improving certain symptoms and sometimes reducing the need for medications. However, even following successful surgery, a person with PD is still required to take continuous medication.

Any person with PD who is being considered for surgery will undergo a very detailed assessment of their condition, often over 1–2 days. These assessments are carried out to make sure that the person has symptoms that would respond well to surgery, without any unusually high risk of complications. They also provide a valuable opportunity for the healthcare team to discuss all aspects of surgery and ensure that the person with PD and their family have realistic expectations of what the proposed operation can achieve.

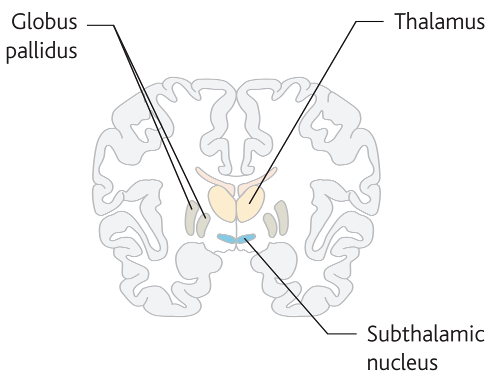
People with PD who are likely to benefit from surgery are those who respond well to their PD medication but in whom this response has become unpredictable and/or short-lived, has led to troublesome dyskinesias (restless movements), or has been poorly tolerated (i.e., causing unacceptable side effects). Surgery has not been shown to improve symptoms that do not respond to dopamine medication – apart from tremor, which can be resistant to medication but generally responds well to surgery.

The three areas of the brain currently targeted during PD surgery (see Figure 11) are:

- **thalamus** – can improve tremor
- **globus pallidus** – can improve levodopa-induced dyskinesia, rigidity and sometimes tremor
- **subthalamic nucleus** – can improve tremor, slowness and stiffness, and may allow PD medication to be reduced.

New targets that may be helpful for treating people with PD are also being researched, including an area of the brain called the pedunculopontine nucleus (PPN), which may be targeted to help relieve symptoms related to walking pattern (gait).

**Figure 11: Cross-section of areas of the brain targeted during surgery for PD**



### Types of surgery

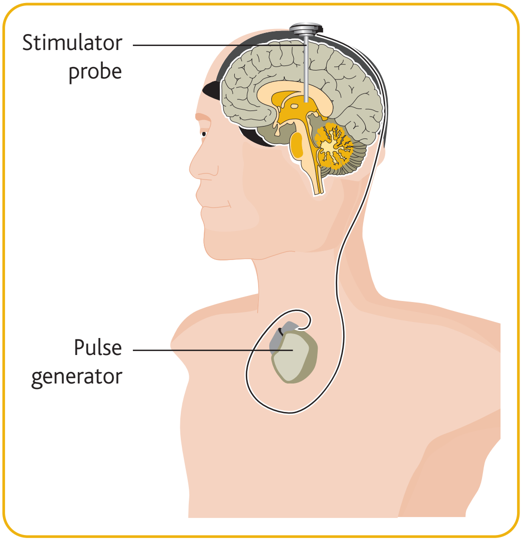
Surgery in PD may be necessary for practical reasons, e.g., if a person is prescribed Duodopa® gel (see page 22), a minor surgical procedure is required to insert the tube for delivery of the medication into the digestive tract (duodenum). Surgery can also be used to directly address symptoms by targeting specific areas of the brain. There are two main forms of brain surgery currently used for PD:

- **deep brain stimulation (DBS)** – the most commonly used procedure at present. It involves implanting wires into the specific areas of the brain that are overactive in PD and connecting these wires to a device that delivers electrical pulses. This device, called a pulse generator, is implanted under the skin on the chest wall or abdomen (see Figure 12). The electrical signals are sent to the corresponding overactive areas of the brain to reduce their activity. This technique does not destroy any brain tissue and is reversible, but is usually intended as a long-term measure (may be permanent). DBS can be referred to as thalamic, pallidal, or subthalamic, depending upon which brain area is targeted (see Figure 11).
- **lesioning** – involves destroying part of the specific brain region that is causing PD symptoms. The operation is named after the part of the brain that is targeted i.e., thalamotomy, pallidotomy, or subthalamotomy. Because it is destructive, lesional surgery is rarely performed for PD nowadays and, indeed, in most centres, subthalamotomy is not offered at all. Thalamotomy can only be carried out on one side of the brain and is therefore not usually very helpful for people with PD, whose symptoms almost always affect both sides of the body. Pallidotomy may be considered for a few people with very severe dyskinesias who cannot have subthalamic nucleus DBS, but it is also, generally, only performed on one side of the brain.

### Case story

**Mrs P was becoming unable to continue to live at home on her own because she was experiencing severe gait freezing and tremor when in the OFF state and was therefore taking quite large doses of PD medication, including a dopamine agonist. As a result of this medication, she had also become increasingly confused and her family did not feel that it was safe for her to live at home on her own. Following subthalamic DBS, she was able to substantially reduce her PD medications because her gait freezing and tremor were controlled by the deep brain stimulator. Her confusion subsequently also resolved and she continued to live at home for several more years.**

Figure 12: Deep brain stimulation (DBS)



Other therapies are being developed to try to restore the normal function of the brain rather than just treating the symptoms of PD. These are still in the early experimental phase and include:

- **stem cell transplantation** – involves implanting dopamine-producing cells (from human embryos) into the brain to replace those that have been lost in PD
- **transplantation of genetically-engineered cells** – similar aim as stem cell transplantation, but using cells that have been synthetically altered to produce dopamine
- **infusion of growth factors** – factors are infused into specific areas of the brain to stimulate growth of dopamine-producing cells in these areas.

In the future, these and other experimental restorative procedures, may offer improved treatment for people with PD.

### Complications

As with any neurosurgery, brain surgery for PD can be associated with complications. There are risks associated with the operation itself, including a small risk of bleeding into the brain, or of causing other problems – with speech or balance, for example. It is generally considered that the likelihood of these complications is less with DBS than with lesioning. However, there are some risks associated with DBS and its stimulator system, for example, infection or hardware failure. Side effects of DBS can also occur. Specifically, subthalamic DBS is associated with memory difficulties and other thought-related problems, and pallidal DBS is associated with emotional disorders (e.g., depression, anxiety). These complications are mostly reversible over time, and may be avoided by careful programming of the stimulator, although some people can experience permanent complications.

Because of the risks, surgery is only considered for people whose symptoms are not controlled adequately by medication and, aside from their PD, are in a generally good state of health.

## Complementary/alternative treatments

In addition to surgery and treatment with medications, there are other therapies that can be used to improve the well-being of a person with PD. A complementary treatment is one that is used alongside a more traditional therapy such as medication, and many people with PD find these therapies very helpful – physically and/or emotionally. Delivery of the complementary therapy is usually performed by a member of the multidisciplinary team, e.g., physiotherapist. In contrast, an alternative therapy is one that is given in place of a traditional medication e.g., herbal medicine, enzyme Q10.

Before starting or discontinuing any therapies, it is important to discuss all safety aspects with a doctor.

### Healthy sleep

Sleep may not sound like a therapy, but it is an essential part of maintaining a healthy body and mind. PD can be an exhausting disorder and, therefore, getting enough sleep is very important. In addition, some PD symptoms are improved by sleep, and many people find that their body movements are better in the morning after a good night's rest. Conversely, symptoms may become (temporarily) worse after a late night.

Unfortunately, PD and the medications used to treat the condition can sometimes cause problems such as insomnia and vivid dreams, as well as pain and stiffness, which prevent restful sleep. Therefore, it can be helpful to establish a routine to promote sleep. This could include going to bed and getting up at regular times, avoiding oversleeping or daytime napping (or limiting it to a fixed period of time), and making the bedroom a dark, uncluttered, and restful place. It may also help to avoid caffeine drinks (e.g., coffee, cola) before bedtime, and not to read, eat or watch TV in bed.

Relaxation methods such as breathing techniques, yoga, massage, acupuncture or aromatherapy can reduce stress and prepare the body for sleep. However, if all these techniques fail, then it might be possible for the doctor to prescribe some sleeping medication, or to alter the doses of any medications that could be causing sleep problems. As always, no changes in medication should be made without first consulting a doctor.

### Diet

Diet is a very important aspect of living with PD. Maintaining a healthy and balanced diet is essential for the body to cope with PD symptoms. In addition, the type of food and the time that it is eaten could change how some PD medications work. For example, protein may slow the action of levodopa. In addition, drinking plenty of water (8–10 glasses per day) is very important, and it is a good idea to keep any alcohol consumption in moderation. Further details about diet and PD are presented in a separate 'Guide to healthy eating'.

### Guide to healthy eating

The 'Guide to healthy eating' that is supplied with this binder contains helpful information on diet and how it can help in daily life with PD. It also provides some useful hints and tips on how to get the maximum benefit from your diet.

In addition, the guide contains some meal ideas, which can help you to eat well with the minimum of effort – so it's not just words and advice, but real food!

### Exercise

PD has many movement-related symptoms and exercise can help to ease some of these movement difficulties. Exercise is also necessary to maintain fitness and, no matter how fit a person is, it is important to ask for advice on exercise regimes from the moment of diagnosis.

Exercise can have a very positive effect on people with PD, switching the focus onto healthy body functioning. It also provides a sense of achievement and fun, alongside improving:

- muscle strength, joint flexibility, balance, walking, and energy levels,

and by helping to prevent:

- constipation, sleep difficulties, and bone wasting (osteoporosis – exercise reduces the risk).

Exercise should not be strenuous or uncomfortable, but rather gentle, enjoyable and beneficial to the person with PD. For example, something as simple as a daily walk is a useful form of exercise, as it gets the heart, lungs and muscles pumping, improves flexibility and relieves stiffness. Tai Chi and certain types of yoga can be done by many people with PD, providing relaxation techniques and a gentle exercise routine, leading to a feeling of well-being. In some people, dancing can also be very beneficial as music, especially music that emphasises rhythm, e.g., tango or marching, not only improves general mobility but may also improve balance and help overcome freezing episodes. Taking exercise as part of a group can be a social activity, or a short routine of stretches and strengthening exercises can be done at home.

A doctor or physiotherapist should be able to suggest a safe exercise routine to use, as well as specific exercises for the most affected parts of the body.

There are many exercises that can be recommended according to the needs of each individual, and a selection of these is shown in Figure 13. In addition, a ‘Parkinson’s flexibility exercise programme’ sheet, providing illustrated instructions for 14 useful exercises, is available to print from the Parkinson’s Association of Ireland website (www.parkinsons.ie/chartpr.htm).

### Cueing and cognitive movement strategies

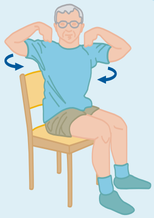
People with PD sometimes find that their medication is not as effective as expected and this can cause problems such as ‘freezing’. Freezing is when a person with PD feels frozen/fixed to the spot when trying to start to walk or when walking through a narrow space, e.g., a doorway. The use of visual cues, such as a line on the floor or doorframe, or auditory cues such as following the sound of a metronome or listening to marching music, are useful strategies to help with getting moving again.

People with PD may also have difficulty performing long sequences of movements, such as transferring from sitting to standing. The good news is that breaking the long sequence of movements into small sections using cognitive movement strategies (i.e., performing one section after the other and concentrating on each step), can be a successful approach. For example, to rise from a sitting position, move to the left, to the right, to the left, to the right, ‘1... 2... 3...’, and stand up.

A physiotherapist will be able to identify the most suitable cueing and cognitive movement strategies for each specific situation.

**Figure 13: Key exercises**

### Trunk twists – to promote mobility in neck, shoulders and trunk muscles



1. Place hands on shoulders.
2. Twist head, neck and trunk from side to side, slowly and as far as possible, feeling a gentle stretch in the trunk muscles.
3. Repeat 10 times.

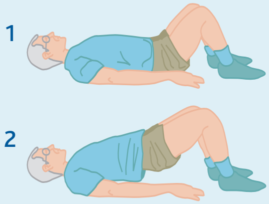
### Hamstring stretch – to promote knee flexibility and good standing posture

1. Place one leg up on a small stool with the other foot flat on the floor.
2. Place hands on knee and lean forward, feeling a stretch in the back of the knee. Hold for a count of 10.
3. Repeat 5 times with each leg.

### Head turns – to promote neck flexibility

1. Turn head slowly from side to side, looking over each shoulder, feeling a gentle stretch in the neck muscles. Hold each turn for 10 seconds.
2. Repeat 10 times.

### Bridging – to strengthen hip muscles



1. Lie down on a bed or floor with feet flat and knees bent.
2. Raise hips as high as possible off the surface.
3. Repeat 10 times.

### Standing

When standing, keep the shoulders back, and body straight (without leaning forwards). Avoid standing with hips or knees bent.

### Walking

Walking is an excellent activity for conditioning and endurance.

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**Emotional support**

Emotional support is a key part of managing PD, and can bring many benefits to people with PD, their carers and families.

It is common for people with PD to experience depression at some point during their illness. The depression may occur as a reaction to being diagnosed with PD and, in such cases, the depression can be treated by reducing stress levels, effectively treating movement symptoms, and taking part in exercise. These straightforward measures aim to improve quality of life for the person with PD and thereby improve mood.

Cognitive behavioural therapy is another complementary method that can be used to treat the psychological symptoms of depression. This type of therapy examines a person's thoughts and behaviour and helps to change a counterproductive negative outlook into a more positive and realistic attitude.

However, it is possible that some cases of depression are caused by PD itself lowering the levels of chemicals in the brain that control mood. If this is the case, then the depression can be treated with antidepressants, although this should always be discussed fully with a doctor as some antidepressants can be harmful for people with PD, possibly reacting badly with PD medications already taken.

Whether or not a person experiences depression, it is important that their emotional needs are looked after, as well as their physical requirements. Happily, there are many organisations that offer all kinds of emotional support ranging from a simple chat over the phone, to group meetings and practical help. Even if there are family and friends to offer care and support, there may be times when either the person with PD or their carer/family needs someone else to turn to – this is the purpose of these groups. There are many national and local PD organisations, and contact details for some national organisations can be found on the EPDA website (www.epda.eu.com/aboutUs/membership/membershipOrganisations.asp). Details of the local groups can be obtained from a member of the multidisciplinary team, via the national PD groups, the EPDA, or even from the telephone directory.

Aside from depression, people experiencing life with PD may feel that they need emotional help in other ways including stress management, and/or psychological support. Again, assistance is readily available from support groups and counsellors (in some countries it is obligatory for a doctor to refer a person with PD to a counsellor), or from the medical team in the form of therapies such as cognitive behavioural therapy. Members of the multidisciplinary team will be able to provide advice on what help is available/appropriate for each individual.

### Other therapies and management methods

There are many other non-pharmacological/non-surgical therapies available to improve the physical well-being and quality of daily life of a person with PD. These include expert techniques such as physiotherapy (to improve muscle strength and movement), speech therapy, occupational therapy (practical advice on the home, workplace, or general living environment), sex therapy (see section on 'Intimacy', page 45), breathing techniques, acupuncture, Alexander technique, spinal manipulation, massage, yoga and aromatherapy.

Appropriate practical tips for living with PD can also have a big impact on daily life (tips related to taking medication have been discussed previously, see page 32). For example, simple changes to the home such as making sure that walkways are clear and well lit, securing (or removing) loose rugs or slippery flooring, adding handrails, and tidying away trailing electrical cables, can make it easier to move around the house. Arranging storage places and commonly used items so that they are easily accessible can also help with everyday living. As listed above, occupational therapists are available to offer specialist guidance on all these topics, and physiotherapists will also be able to advise on the selection of appropriate walking aids.

People with PD often report that these therapies have a positive impact on their quality of life. Anyone who is interested in finding out more should speak to a member of their multidisciplinary team, who will either be able to provide the therapy themselves, or recommend the best source of information.

### Meeting the challenge

PD can be managed and treated in many ways, with medications, surgery, exercise, diet, complementary therapies, emotional support and strong relationships all playing important roles. However, the quality of life of a person with PD is not just related to treating PD and its symptoms. Finding out more about PD, relating to the new situation in life, and learning to accept new goals and challenges, is just as important as practical management. In addition, a focus on what can be achieved, rather than what can't, is a helpful and positive attitude. The following quote is taken from a book entitled 'Health is between your ears. Living with a chronic disease' by Svend Andersen, a psychologist and past EPDA Board member, who has PD.

> **'I believe that the most important decision you can make when life deals you a hard blow is: "No matter what happens, I will manage, and get something good out of it." Such a decision implies that you are prepared to be knocked out by life, but you have the will to bounce back up again.**
>
> **Will you become a victim of the illness and let it decide your life, or will you use the situation to learn something new and to find new meaning on a new basis, where illness gets the space it needs, and no more?'**

An example of this determined spirit is contained in the book, 'Shake well before use', by Tom Isaacs, an EPDA board member. Tom was diagnosed with young-onset PD, and the book describes his experiences on a 4,500 mile walk round Britain's coastline (see 'Helpful reading', page 72).

## In summary

- PD is often treated using a balance of different medications to replace or increase the levels of dopamine in the brain.
- Many of these medications are now available in different forms such as slow-release tablets, fast-dissolving tablets, once-daily tablets, or skin patches, which can provide more convenient means of medication delivery for some people with PD.
- Levodopa is currently the most commonly used medication for PD therapy. When it reaches the brain, it is changed to dopamine. As PD progresses, use of levodopa can be associated with problems such as motor fluctuations and dyskinesia.
- MAO-B inhibitors and dopamine agonists are other classes of medication that are frequently used to treat PD by promoting the action of dopamine. They can be used alone in the early stages of PD, or in combination with levodopa in later stages of PD.
- COMT inhibitors can be used in combination with levodopa to prolong its action.
- Surgery may be an option for some people with PD, following a detailed assessment.
- Complementary therapies such as physiotherapy, speech therapy, occupational therapy and relaxation techniques often bring benefits to people with PD. Healthy sleep, diet, exercise, and emotional support are all important parts of PD management.

# 3. Society and relationships

# 3. Society and relationships

PD is much more than a neurological disorder needing medical treatment. There are many social aspects that need to be considered and, in the long term, community services may play a very important part. It is worth finding out what help is available in the local community – asking a doctor or PD nurse can be a useful starting point. A person with PD should not be afraid to ask for help – in the long term it can promote independence, and keep life as normal as possible for as long as possible.

## Intimacy

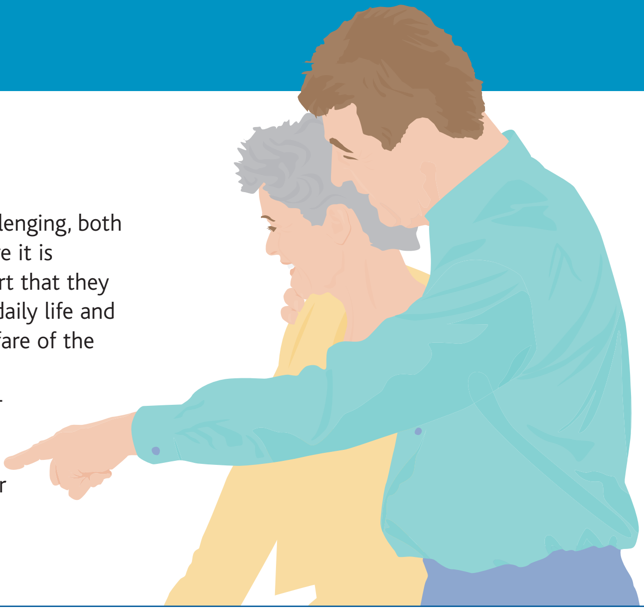
Showing and receiving affection is an important part of life for every person, and maintaining a close and intimate relationship is a valuable support. The intimacy between partners can take many forms, and may include hugs, cuddles, loving words and gestures, or physical love making. However, changes can occur in any kind of relationship, and a diagnosis of PD often brings forward questions and concerns regarding relationships and intimacy.

In some cases, PD may alter the way in which a person feels about themselves, and may therefore make them feel less inclined towards physical closeness, including sexual activity. Whatever these concerns, the key factor is that they should be discussed. Partners should try to talk openly with each other about worries or feelings, as this can reduce tension, may resolve some concerns, and can also help to maintain closeness between a couple. In addition, people with PD should not be shy to ask for advice about relationship/sexual problems from medical professionals, PD organisations or counselling services. Many PD organisations also run helplines that offer confidential advice on all matters relating to people with PD and their partners.

One frequent concern, that is not always raised, is 'How does PD affect sexual activity?' – an issue that is relevant to people within stable relationships as well as sexually active individuals without a regular partner. As PD has many different forms and effects, there is no universal answer to this question – some people find that PD has little influence on their physical relationship, while others find that they need to seek help and advice. In general, PD may affect sexual function in two ways:

- **physical effects** (e.g., effects on orgasm, erection or sexual drive) caused by altered flexibility/movement or increased tiredness. In addition, PD medications may cause side effects in some people, which can impact on sexual function and/or sexual drive. A doctor or physiotherapist will be able to advise on ways to manage these changes and, in some countries, medications may be prescribed that help resolve erection difficulties. Therefore, it is important to mention any noticeable sexual changes to a doctor.
- **psychological effects** such as depression, stress or anxiety which can, in some cases, alter the sexual response, or reduce the desire for sex/close contact. It can be a vicious circle, as sometimes the stress/anxiety may be about sex itself. Again, these concerns should be discussed fully between partners, and also with a doctor or other member of the multidisciplinary team.

If a person with PD and/or their partner wish to take advantage of professional support, then a doctor or PD nurse will be able to recommend a counsellor, physical/psychological therapist or sex therapist. At times, it can be difficult to talk about such personal issues, but loving, strong relationships are a vital part of living a fulfilling life with PD, and any difficulties should be addressed as a priority.



## Caring for carers

Caring for a person with PD can be challenging, both physically and emotionally, and therefore it is important that carers receive the support that they need. The help of a carer is vital to the daily life and health of a person with PD, but the welfare of the carer should not be forgotten (www.rewritetomorrow.eu.com/en/QoL-issues/Carers).

Some examples of ways in which a carer can derive support are listed below.

## Tips

A carer may find it helpful to:

- find out about PD, and make sure that the person with PD receives the most effective treatment for their symptoms. This offers relief to the carer because the person with PD is better able to cope with daily activities, and is also less likely to succumb to distressing emotional disorders such as depression or anxiety
- communicate well with the person with PD – allowing them to have their own 'voice'. The ability to share experiences and laugh together can be a great stress reliever
- maintain interests outside the home – whether it is talking to a friend on the telephone, pursuing hobbies, attending a regular club/meeting, or visiting a PD carer support group
- take good care of their own health, and visit the doctor to discuss medical treatment, practical/emotional support, or personal concerns such as sexual issues. Exercise, a balanced diet and sleep are also vital for good health
- seek help as soon as it is needed
- contact community services, who may be able to help with daily chores, and can also offer daycare or holiday relief schemes, which can give both the person with PD and the carer a break
- find time for themselves, and make a point of relieving any stress. In addition to the ideas described above, relaxation techniques such as massage, yoga or aromatherapy can be beneficial for both a carer and a person with PD.

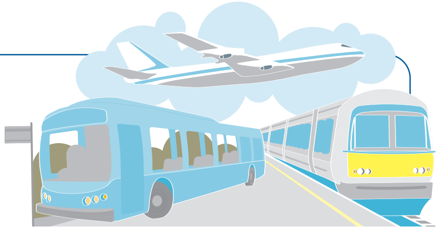
## Travel and leisure

This section contains hints and tips to help a person with PD enjoy the full benefit of leisure time, holidays and travel. More detailed information about sport, leisure and travel can be found on the EPDA website (www.epda.eu.com/links.shtm).

### Holidays and travel

Holidays are a good way to relieve stress and take a break from everyday life. For a person with PD, it can help to make arrangements well in advance – especially if planning to travel abroad. Some travel tips are given below, and these are also included on the 'hints and tips card' supplied in the diary part of this binder.

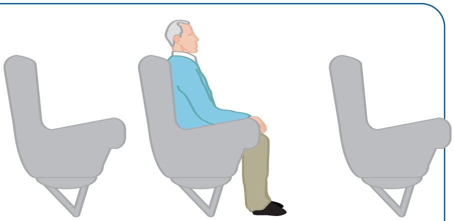
## Tips



### General travel tips

- Plan routes and stopovers – allowing time for extra tiredness and regular stops to stretch aching muscles or go to the toilet.
- Find out as much as you can about the facilities available at your destination before you set off, e.g., will stairs be a problem?
- Ask your doctor to provide a letter describing your condition and the medications that you take – in case treatment is needed at your destination. Taking along the prescribing information from each pack of medication, together with a note of the dosage can also be helpful to a treating doctor. In some instances, it is worthwhile to have this letter translated into the language spoken in the country to which you are travelling.
- When you pack your medication, be sure to pack more than you need in more than one bag – just in case your stay is longer than expected or you get separated from some part of your luggage. It is also a good idea to take along your prescription, and to ask your carer/partner to carry a duplicate pack of medication.
- Before you depart, ask your doctor to find out the name and address of a GP and/or hospital at your destination – in case of emergencies.
- Keep your medication in its original labelled container, so that it can be easily identified.
- People with mild PD are usually allowed to continue driving – although you should notify the licensing authority and your insurance company (not doing so could render your insurance null and void in the event of an accident). If the service is available in your country, ask your doctor/nurse to help arrange a disabled car sticker so that you can park closer to amenities, and reduce the amount of walking needed. Note that these stickers can go out of date, so remember to check and renew!
- PD organisations are experienced in offering advice for people with PD who want to travel. Links to contact details of organisations in individual countries are given at the end of this booklet (page 74).

**Booking transport and accommodation**



- Book your transport well in advance, and let the travel company know about any special requirements, e.g., extra leg room, assistance getting onto the train/plane/coach.
- Don't be afraid or embarrassed to ask for all the help you need. For example, there can be a lot of walking at either end of a journey, and if use of a wheelchair would make things easier, then you should request one. Most companies are happy to provide this, along with an escort to guide you. However, such service isn't always available, or must be booked in advance, so ask ahead. In addition, some airlines limit the number of people with mobility problems or disabilities it will carry on one plane.
- Ask the travel company about the assistance they can provide, and compare several different companies. Ask if there will be extra charges for these services.
- Note that travel insurance may be more expensive, or more difficult to obtain for a person with PD. Read the policy carefully as sometimes cover includes accidents and illness, but not PD.
- Find out about car parking, and how close this is to the transport terminal.
- Booking early is also useful when arranging accommodation, so that you can ask for a ground floor room, or one that is close to a lift. You can also ask about facilities such as ramps, hand rails, or rooms that have been specially designed for less mobile people.

### *Holidays for carers*

Carers also need to plan short breaks and holidays into their caring routine. Many PD and carer organisations offer advice on providing temporary or respite care while the main carer takes a break – this can be a regular arrangement (e.g., weekly), or can be planned to fit in with a longer holiday. Some countries provide State allowances for this purpose.

**Travelling abroad**

- It may be useful to learn the phrase "I have Parkinson's disease. Please allow me time," in the language of the country that you are visiting, or have it written down on a piece of card. The EPDA has developed a pocket-sized 'PD doc' that includes this phrase (in a choice of 25 languages), and which is available online to customise with individual details – see www.epda.eu.com/projects/PDdoc for more information. This, along with other phrases describing any particular difficulties you have, e.g., slowness or quiet speech, can help explain to others why you have special requirements.
- Keep your medication with you in your hand luggage at all times.
- Check with your doctor or insurer about your health insurance and what it covers at your destination.
- Contact the embassy of the country you are visiting to ask about their regulations for bringing prescription medications into the country – this can prevent any problems at customs, and is another reason for asking your doctor to prepare a signed letter describing your medication needs. Some countries also require prescription medications to be in their original labelled containers.
- Medications are sometimes known by different brand names in different countries, therefore it can be helpful to find out the name used in your destination country before you travel. Information about these different names can be found on the EPDA website (www.parkinsonsdecisionaid.eu.com/medInfo).
- If you need a syringe to deliver your medication, you will also need to check on regulations in individual countries. If you are travelling by air, explain your situation to the airline – especially if you will need to use a syringe during the flight.
- If you need vaccinations to travel to your destination country, ask your doctor if these are safe to have in combination with your PD medication.
- If you are travelling to a different time zone, think about how you are going to plan your medication schedule.
- It may be helpful to make contact with a PD organisation in the country to which you are travelling before you go. Details of many local and national organisations are held by the EPDA, who can be contacted by telephone/fax: +44 (0) 1732 457683; by e-mail: info@epda.eu.com; or by visiting the website (www.epda.eu.com).

### Leisure activities

People with PD can live full and active lives, and an important part of this is leisure time. PD can make some activities difficult, but often the only restriction is the interest of the individual. A person with PD should make an effort to keep up their social contact, continuing to interact with others and taking pride in their appearance. Someone who is open and honest about PD has no reason to feel anxious when out in public or when in the company of friends.

In addition to improving the overall quality of life, leisure activities can also:

- provide an interest away from the daily presence of PD
- take the focus away from 'self' and on to others
- reduce stress and anxiety
- revive personality and promote independence
- exercise the body, e.g., gardening, walking; and brain, e.g., crosswords, reading
- encourage a new or existing interest that makes the most of the often increased sensitivity of people with PD, e.g., painting, photography, textiles, nature appreciation, or music (making and listening)
- provide an opportunity to enjoy an activity together with a carer.

PD organisations have many local branches, which arrange meetings and activities for their members. People with PD and their carers may welcome the opportunity to contact one of these organisations and meet other people with PD on a social basis (remembering that the topic of conversation is not always based around PD!). PD groups can also give advice on leisure activities that are specially organised for people with disabilities such as PD – these can range from adventure holidays and sailing to more gentle pursuits like visiting stately homes, painting, and appreciating music. Other ideas/advice can be found on the EPDA website (www.epda.eu.com/links.shtm). In addition, an occupational therapist may be able to help regarding leisure activities – either by advising on how to maintain existing activities or offering support when exploring new choices.

The significant impact of activities such as those mentioned above is, literally, illustrated by the artwork below, which was produced by members of the 'Painting with Parkinson's' art group from Canberra, Australia. The paintings were displayed as part of the 'Catalyst' exhibition at the Penny School Gallery, Kingston-upon-Thames, UK, with interactive workshops also held at this event.

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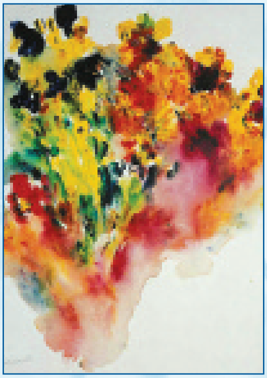
b



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d

- a 'Two ducks' by Charles
- b Artist applying watercolours
- c 'Flower' by Christine
- d Musician Barbara Thompson at a Catalyst workshop
- e Watercolour of flowers

## Continuing with work

If a person with PD is in employment, or wishes to return to employment, then it is quite natural to think about how a diagnosis of PD will affect a future career. More information about this very important aspect of life with PD can be found by researching the Internet or by contacting local government offices for advice on health-related work issues.

### In summary

- Personal relationships, work, leisure pursuits, and holidays and travel are all important parts of life for a person with PD and their carer.
- A lot of information, advice and support is available in all these areas, and should be sought as soon as it is required.

# 4. Communication

# 4. Communication

A positive outlook is a vital part of living with and treating PD. However, this attitude not only relies on the individual with PD, but also on their interaction with those around them. It can often help to be open with family and friends about PD and the effects that it may have, because this will help greatly in reducing any possible misunderstandings, and relieving any tension in social situations. Most people with PD are pleasantly surprised at how positively others react. This section contains important information and advice about communicating with health professionals, carers, and children, following a diagnosis of PD.

## Communicating with health professionals about the management of PD

To manage PD successfully, and to gain the most from everyday living, it is very important to communicate well with the treating doctor and other members of the multidisciplinary team. In this way, the team can work together with the person with PD to find the best management strategies.

### Key questions

Whatever questions or points that you wish to discuss with your doctor, it is very important to write them down beforehand, and take this list with you to your appointment. Some examples of the type of question that you might wish to ask your doctor are listed below.

- Why am I taking this medication? Why has this medication been changed/added to my regimen?
- How long will I stay on this medication?
- What side effects can occur with this medication?
- Does my medication have long-term complications?
- I am unhappy about part of my treatment. Can something be done about it?
- I find a certain symptom very troublesome. Can this be treated?
- What should I do if I experience side effects with my treatment?
- Now, or in the future, I will need help at home. Whom should I contact?
- What can I do in order to improve my living surroundings, as a person with PD?
- I feel overwhelmed and could do with some emotional support. Can you recommend a local organisation and/or counsellor to help?
- *If you have been recently diagnosed as having PD:* Although I don't currently have serious mobility problems, can I be referred to a physiotherapist for advice on exercises/activities to improve the way that I move now and to help prevent problems in the future?
- *If you experience stiffness in muscles and joints, and/or have difficulty with movements such as getting up from a chair, turning in bed or keeping your balance:* Can I be referred to a physiotherapist to seek advice regarding my mobility problems?

## Essential points

When you meet with your doctor or PD nurse, there are certain things that are especially important to talk about. A list of these points is given below.

- Describe any symptoms that you have experienced, including whether they have worsened or improved since the last visit, e.g., poor control of movement, stiffness, shaking/tremor, difficulty walking, sickness, dizziness, etc.
- Explain when your symptoms occur, for example, shortly before your next dose, early in the morning, after a certain event/trigger, or in relation to food.
- Discuss all concerns or worries about PD or the medication you are taking – i.e., your opinion regarding PD and its treatments.
- Let the doctor know if you would like a change in your medication.
- Tell the doctor about any other medications you are taking, including any bought over-the-counter. This is very important, as some medications may not be suitable to take while receiving PD therapies.
- Keep the doctor up-to-date on any significant changes in your life – for example, stressful events such as bereavement, or changes that may affect your medical routine. These events could influence your symptoms.
- Discuss how people around you are coping with PD and its treatment.
- Make sure you understand exactly how and when your medication should be taken, before you leave the surgery/clinic. If necessary, write these instructions down, or ask to have them written down for you.

## General discussion points

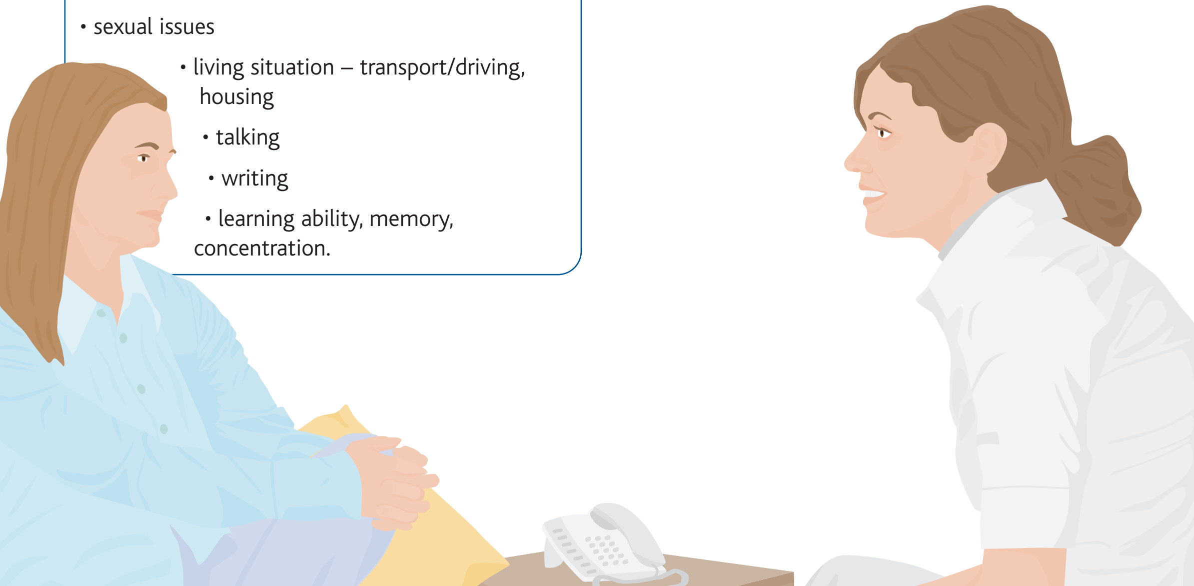
When speaking to your doctor, here are some other topics related to everyday life that you may wish to discuss:

- posture (standing, walking)
- sleeping, turning in bed
- use of hands (trembling, rigidity)
- depression and anxiety
- tiredness
- typical daily activities
- diet – eating, drinking, swallowing
- exercise
- going to the toilet – delayed or difficult bowel movements, difficulty passing water
- skin condition/problems
- pain
- sexual issues
- living situation – transport/driving, housing
- talking
- writing
- learning ability, memory, concentration.

### Communication card

**It can sometimes be difficult to know which questions to ask your doctor. The 'Key questions' and 'Essential points' from the sections above have been reproduced on a communication card that is provided in the diary supplied with this binder.**

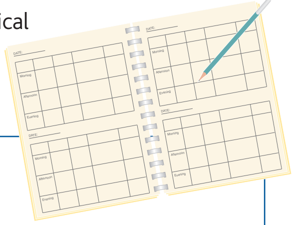
**This communication card can be taken to your doctor's appointment, during which you may want to ask some of these questions, or use them as a basis for questions of your own.**



Communicating well with the doctor has two main benefits. First of all, it allows the person with PD to gain more understanding about their condition and the treatments that are prescribed. Secondly, because PD is a very variable disease, it gives the doctor a better idea about the symptoms that are experienced in each individual case. As a result, the most appropriate treatment can be prescribed. Having a good relationship with the doctor also means that the person with PD will feel able to discuss any concerns that may arise as the condition progresses.

If the doctor does not appear to be as responsive as the person with PD would wish, then they should insist upon being referred to another doctor, PD specialist or neurologist. If necessary, a supportive friend or family member may be able to help with conveying this message during an appointment.

In the box below are some tips for good communication that have been recommended by doctors and other medical professionals.



## Tips

- Prepare for your doctor's appointment – make a list of any points that you wish to discuss, and take this with you. Make the questions as specific as possible.
- It might be helpful to make a regular diary (daily, weekly or monthly) to record how you have been coping with your symptoms. Read this before your appointment, and note down anything you want to mention.
- If there is a lot you need to discuss with the doctor, then make this clear when you book your appointment. You might be given a longer appointment, or be asked if you wish to talk with another professional such as a specialist nurse.
- You may find it helpful to take someone with you when you visit the doctor – for moral support, or for help with communicating. However, on some occasions, it may be more appropriate to speak to the doctor on a one-to-one basis.
- If you have prepared a list of medications (a medication record card), then take this to your appointment. It can save time and long explanations.
- Make sure that you are honest about your symptoms. Making symptoms seem better or worse than they are will give the doctor a false idea of how the treatment is working.
- Don't feel obliged to use medical words with the doctor when describing symptoms – use language that you are comfortable with to give simple, accurate descriptions.
- If you don't understand what the doctor says, then say so. Ask if it can be explained again or in another way. It is very important that you understand.
- Write down, or ask the doctor to write down, anything important if you feel it will help you remember.
- If there is any issue that you feel unable to discuss with your doctor, then you can contact another member of the multidisciplinary team, your local PD association, or support group.

## Communicating with your carer

The relationship between a person with PD and their carer is very important to the successful management of everyday life with PD. Good, truthful communication is vital, and some communication tips for a person with PD and their carer are described below, and on the 'communication card' provided with this binder.

## Tips

**For a person with PD and their carer**

- Stay calm – remember that, at times, PD can be frustrating for both the person with PD and the carer. If you feel annoyed, try closing your eyes or counting to 10 before you react to the situation.
- Be open and honest about PD – discuss any aspects of PD or daily life that are bothering you, and try to find a solution together.
- Be clear about when you do and don't need help.
- Use practical aids – if communication is a practical problem, ask the multidisciplinary team about speech therapy or practical devices such as voice amplifiers.
- Discuss your feelings – not only with each other, but also with a friend or support group. If needed, your multidisciplinary team can advise on counselling and emotional support.
- Be patient and understanding – PD sometimes makes it difficult to speak clearly or to understand quick or complicated speech, so keep all speech calm and simple (while avoiding being patronising), and ask for patience from your carer when movement is slow or frozen. At those times when you feel like a patient – BE PATIENT.
- Show your appreciation – remember to thank and compliment each other, and never forget to show affection. PD sometimes limits facial expressions, but this does not mean that there is a lack of feeling.
- Don't always focus on PD – take time to enjoy activities together, and talk about matters apart from PD.
- Attend medical appointments together from time to time. This can help with understanding PD, and the doctor may also find it valuable to hear the view of the carer. However, a carer should avoid speaking on behalf of the person with PD.

## Communicating with children

Explaining a diagnosis of PD to a child can be a daunting prospect. However, in the following article and accompanying tips, Svend Andersen describes how talking to children about PD can benefit the whole family.

### Children's reactions

When a family member is diagnosed with PD, family relationships and how they relate to one another change. Generally one can say that how parents relate to the fact that PD has become a part of their family can influence the way a child, teenager or grown-up reacts. If a child or teenager can see that the parents are managing this change successfully in their life, they can relax.

Children's reactions when a family member becomes ill vary depending on their age. Younger children adapt more readily. They ask if the illness can cause death and are satisfied when they are told no and can carry on with their childhood games. Their main concern is that their parents will be there; they are open and curious and will ask quite naturally 'why do you tremble?'

Teenagers react differently; they can express anger to both parents and towards the disease. Behind this anger is sorrow and a deep felt wish for the parent to be well again and as a result they can try to help too much, especially girls. They can become self-conscious and react with embarrassment, especially with their friends, until they see that their friends accept the change in their parents.

The reaction of grown-up sons and daughters who have left home are again different. They can experience anger and develop a 'pull yourself together' attitude, not realising that before their visit home, the ill parent will have rested so as to enjoy their visit with their children, resulting in an unrealistic view of the impact that PD is having. Such a reaction can prove to have a positive effect as shown by the following case story.

#### Case story

'Mrs S, who has PD, was asked by her elder daughter to look after her young child, as she was unable to find a place in a kindergarten. Mrs S protested that she could not do this, but her daughter insisted and Mrs S later commented that her daughter's confidence in her, despite the fact that she had PD, helped her to find courage and develop a lust for life that she had lost since being diagnosed with PD. With a smile, she concluded that her daughter was now pregnant for the third time, but Mrs S had said that she did not need to have more children just to help her mother!'

Many of the children's worries and anxieties about their ill parent can be relieved if the parents provide good information about PD and communicate openly with their children about their worries and concerns.

## Tips

- Don’t try to hide the truth from your child, because you can’t. The child will feel instinctively that something is wrong and their fantasies of what could be wrong can be far more frightening than the truth.
- Give brief, clear information about PD.
- Ask for help when you need it so that the child does not have to guess, get it wrong and feel guilty that they did not help in time.
- Listen with an open mind to any thoughts and concerns that the child may have and try to alleviate their fears.
- Explain about changes within the home and how this will affect everyone, but that by talking and working together, you will be able to manage.
- Encourage older/grown-up children to learn more about PD, based on sources you recommend, such as those found in Section 6 of this guide, and on the ‘Rewrite Tomorrow’ website (www.rewritetomorrow.eu.com/en/PDresources/children.htm).
- Show the child that it is alright to have worries and concerns and that you can manage these.
- Be realistic and hopeful about the management of PD.
- Last but not least, show by example that life is good and that every day is alright, despite living with PD.

## In summary

- It is important to communicate well with your doctor – good communication can produce more effective treatment for your PD.
- It is also important that your doctor communicates well with you – don't be afraid to ask for better explanations or more information.
- Prepare for doctor's appointments, and write down questions that you may want to ask.
- Try to describe your symptoms as accurately as possible during your appointment.
- Let your doctor know about any concerns or worries that you have about PD, or the medication that you are receiving.
- If you would like a change in your medication, discuss this with your doctor.
- If you find it difficult to talk to your doctor about any issues, then make sure that you find someone to talk to – support groups and PD associations are there to help.
- Aside from communication with the medical team, maintaining good communication with a carer (who may be a relative or partner) is another vital aspect of daily life with PD. Communication should be kept open and honest, while recognising the importance of showing appreciation.
- If relevant, prepare to explain PD to children – the truth should not be hidden, and talking about PD can help them to understand and alleviate any fears.

# 5. The future of Parkinson’s disease treatment

# 5. The future of Parkinson's disease treatment

## What is the future of PD?

PD is generally considered to be a neurological disorder that affects the older population, but more than 1 in 10 people with PD are diagnosed before the age of 50 years. Nowadays, with people living longer, PD is set to become more common with the overall rise in the number of elderly people worldwide.

PD is already an important area for medical research. However, with growing numbers of people with PD, there will be an even greater drive to develop new treatments. In addition, care and support facilities will become more experienced in coping with the challenges of PD.

## What are the future treatments for PD?

In recent years, great progress has been made in developing new treatments for PD. This means that people can now be offered more effective control of their symptoms than ever before.

Clinical research is investigating therapies with the potential to stop the progression of PD or even cure it completely. These are two main aims of PD research that may hold promise for the coming years. However, new treatments that could produce better symptom control and fewer side effects would also help to improve quality of life.

Medical research for PD is focussing on the following areas:

- understanding what causes PD
- diagnosing PD early
- protecting the brain against PD
- preventing progression of PD
- restoring dopamine-producing nerve cells in the brain
- improving treatment of symptoms
- limiting the side effects associated with PD medications
- investigating more convenient and effective ways to deliver medications to the body
- studying new surgical methods to treat or cure PD.

## Slowing disease progression

As listed previously, one of the key research targets for PD is finding a way to stop the disorder developing and progressing – i.e., finding a treatment to modify the disease course. However, this effect is difficult to measure in a clinical study, and it also requires many years of follow-up to confirm any outcomes.

Despite these problems, several PD medications have been investigated in trials specifically designed to assess the rate of disease progression, and recently published findings for the MAO-B inhibitor, rasagiline (Azilect®), suggest that it could slow the progression of PD. The dopamine agonist, pramipexole (Mirapexin®), is also being investigated for this purpose, although study results are not yet available. Currently, no medication is approved/licensed for modifying PD progression, although this possibility remains an exciting prospect for the future.

## In summary

- PD research is a rapidly expanding area.
- Scientists are researching what causes PD, and how its progression can be slowed or stopped.
- Modification of disease progression is an important target for future PD therapies.

# 6. Sources of further information

# 6. Sources of further information

There are many ways to find out more about PD. Learning about PD can not only answer specific questions, but can make someone better prepared for dealing with the illness, and can help with more effective communication with the medical team.

This section begins with a list of useful websites, but there are also helpful books and, most importantly, PD organisations that can be contacted in all sorts of ways – by phone, post, fax or e-mail. Every one of them is there to give information, help and support.

## Useful websites

**Parkinson's Decision Aid**
www.parkinsonsdecisionaid.eu.com
www.parkinsonsdecisionaid.eu.com/medInfo

**European Parkinson's Disease Association**
www.epda.eu.com

**Parkinson's Awareness**
www.parkinsonsawareness.eu.com

**Rewrite Tomorrow**
www.rewritetomorrow.eu.com

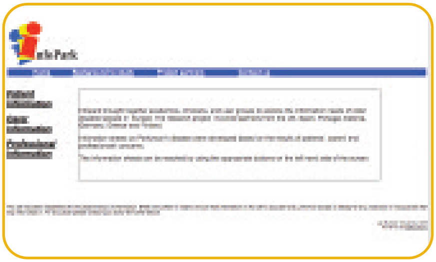
**Coping Strategies**
www.epda.eu.com/projects/copingStrategies/dvd

**We Move**
www.wemove.org

**National Parkinson Foundation**
www.parkinson.org

**World Parkinson Disease Association (WPDA)**
www.wpda.org

To look for further web-based information on PD, try putting the words/phrases 'Parkinson's disease', 'support group', 'patient information', or 'local association', into your Internet search engine, along with the name of your area/country if you require local advice, or the topic of interest (e.g., travel, accommodation, treatment, holiday, symptoms).



**InfoPark**
(information available in 7 European languages)
infopark.cardiff.ac.uk/Infopark/index.htm (or access via www.rewritetomorrow.eu.com/en/default.htm#)

## Helpful reading and DVDs

There are many books available on PD. The following short list contains a few suggestions of English language books that are specially written for people with PD and their carers. Details of other helpful publications can be found online at www.rewritetomorrow.eu.com/en/PDresources and www.wpda.org

For a list of books on PD in other languages, contact your national PD association (www.epda.eu.com /aboutUs/membership/membershipOrganisations.asp).

### *For people with PD and their families*

**100 questions & answers about Parkinson disease**
Authors: Abraham Lieberman with Marcia McCall
Publisher: Jones and Bartlett Publishers Inc. 2008
ISBN: 0763762504
*A set of answers to common questions about PD and its treatment. It is written from a US perspective, meaning that some questions are specific to the US system.*

**Answers to frequently asked questions in Parkinson's disease: a resource book for patients and families**
Author: David A Cram
Publisher: Acorn Publishing. 2003
ISBN: 0971098883
*A book for individuals and families coping with PD, written by a doctor who has had PD for 12 years. The book deals with a variety of topics from less common symptoms to improving the quality of everyday life.*

**Living with Parkinson's disease**
Author: Bridget McCall
Publisher: Sheldon Press. 2006
ISBN: 0859699579
*This book takes a modern, detailed look at PD and its management, including medications, surgical techniques, and therapies such as physiotherapy, speech and language therapy, and occupational therapy, and also provides practical suggestions for self-care to improve quality of life.*

**Next to me: luck, leadership and living with Parkinson's**
Author: David Jones
Publisher: Nicholas Brealey Publishing Ltd. 2005
ISBN: 1857883578
*The autobiography of David Jones who was diagnosed with PD at 39, and continued to build his career as a successful businessman.*

**Parkinson's disease: 300 tips for making life easier**
Author: Shelley Peterman Schwarz
Publisher: Demos Medical Publishing Inc, USA; second edition, 2006
ISBN: 1932603530
*A practical guide to coping with everyday living for people with PD, giving hints and tips on planning daily tasks and using labour-saving devices.*

**Parkinson's disease: a complete guide for patients and families**
Authors: William J Weiner, Lisa M Shulman, and Anthony E Lang
Publisher: Johns Hopkins University Press; second edition, 2007
ISBN: 0801885469
*A comprehensive resource designed to help people with PD and their families cope with the medical, emotional, and practical challenges of PD, and to help them communicate effectively with their physicians.*

**Parkinson's disease: a guide to treatments, therapies and controlled symptoms**
Author: David A Grimes
Publisher: Constable & Robinson Ltd. 2004
ISBN: 1841199141
*A simple, comprehensive guide to PD that also contains many practical tips for managing life with PD.*

**Parkinson's: a patient's view**
Author: Sidney Dorros
Publisher: Class Publishing. 1997
ISBN: 1872362702
*A deeply moving autobiography of one man's experiences of coming to terms with life with PD, and achieving 'accommodation without surrender'.*

**Parkinson's: the 'at your fingertips' guide**
Authors: Bridget McCall and Adrian Williams
Publisher: Class Publishing; third edition, 2004
ISBN: 1859591108
*Written as a series of answers to common questions.*

**Parkinson's disease – the way forward! An integrated approach including drugs, surgery, nutrition, bowel and muscle function, self esteem, sexuality, stress control and carers**
Authors: Leslie Findley, Geoffrey Leader, Lucille Leader, Aroldo Rossi, and Lia Rossi Prosperi
Publisher: Denor Press. 2003
ISBN: 0952605686
*This user-friendly book provides advice on optimising function and well-being through the educated use of medication, nutrition, and physical, sexual and emotional strategies, so that people with PD can make a tangible difference to their lives.*

**Ponderings on Parkinson's: an inside view of Parkinson's disease**
Author: Sarah Nock
Publisher: Ferry House Books. 2007
ISBN: 0955701104
*An uplifting and often amusing book written by someone who had PD for more than 20 years, recounting what it is really like to live with the condition.*

**Shake well before use**
Author: Tom Isaacs
Publisher: Cure Parkinson's Press. 2007
ISBN: 0955773008
*This is the story of a challenging 4,500 mile walk around the coast of Britain, as experienced by the author, Tom Isaacs, who was diagnosed with young-onset PD.*

### *For carers*

**The comfort of home for Parkinson's disease: a guide for caregivers**
Authors: Maria M Meyer, Paula Derr, and Susan C Imke
Publisher: Care Trust Publications. 2007
ISBN: 0966476778
*A practical hands-on guide that provides information to help carers through all stages of PD.*

**The complete carer's guide**
Author: Bridget McCall
Publisher: Sheldon Press. 2007
ISBN: 0859699951
*A good general practical guide to caring, including what it involves, the issues affecting carers, and sources of help.*

*For children*

**I'll hold your hand so you won't fall – a child's guide to Parkinson's disease**
Author: Rasheda Ali
Publisher: Merit Publishing International. 2005
ISBN: 1873413130
*Written by the daughter of Muhammad Ali (the champion boxer who was diagnosed with PD over 20 years ago) to help children understand the condition that may be affecting their parent or grandparent, creating a foundation for dialogue, and offering answers that children can easily understand.*

Details of other publications on PD that are specifically written for children and teenagers can be found at www.rewritetomorrow.eu.com/en/PDresources/children.htm

*For healthcare professionals*

**Fast facts: Parkinson's disease**
Authors: Christopher G Clough, K Ray Chaudhuri, and Kapil D Sethi
Publisher: Health Press; second edition, 2007
ISBN: 1905832036
*A concise guide to provide doctors, nurses and therapists with up-to-date information in order to provide optimum care and improve the lives of those with PD and related disorders.*

**Parkinson's disease: questions and answers**
Author/editor: Dr Robert A Hauser
Publisher: Merit Publishing International; fifth edition, 2006
ISBN: 187341319X
*Written by medical specialists in the field of PD, the book is aimed at doctors and well-informed people with PD. It also includes a CD-ROM showing individual case studies.*

**Therapeutics of Parkinson's disease and other movement disorders**
Authors: Mark Hallet and Werner Poewe
Publisher: Wiley-Blackwell
ISBN: 0470066482
*Includes a comprehensive update on therapies for PD and other movement disorders, and describes the basic mechanisms of neurodegeneration, pharmacological interventions and surgical management. It also features summary tables and algorithms as a quick reference guide for practical treatment decisions.*

**Your questions answered: Parkinson's disease**
Authors: Dr Thomas Foltynie, Dr Simon Lewis, Dr Roger A Barker
Publisher: Churchill Livingstone. 2003
ISBN: 0443064172
*A clear guide to the medical aspects of PD, aimed at doctors and people with PD who have some knowledge of science and/or medicine.*

## DVDs

**Being there**
Publisher: The Parkinson's Disease Society (UK). 2007
Contact: available free of charge at www.parkinsons.org.uk
*A DVD for people newly diagnosed with PD.*

**Living with Parkinson's**
Publisher: Norges Parkinsonforbund
Contact: info@epda.eu.com
*A series of five films providing a realistic picture of the challenging opportunities faced by people with PD and their families.*

## Key organisations

The purpose of Parkinson's disease (PD) organisations is to offer information and help to people with PD and those who care for them. Many PD organisations have websites, fact sheets, and phone lines for asking advice or for listening to worries and problems, and they also arrange regular meetings in local areas.

For full names and addresses of European PD organisations, please visit:
**www.epda.eu.com/aboutUs/membership/membershipOrganisations.asp**

For full names and addresses of international PD organisations, please visit:
**www.epda.eu.com/internationalPDOrgs**

### European Parkinson's Disease Association (EPDA)

The EPDA is non-political, non-religious, and non-profit making, concerned with the health and welfare of people with PD and their families.

Collaboration with European patient and neurological organisations, the European Commission, the World Health Organisation, the World Federation of Neurology, and the pharmaceutical industry has resulted in the development of quality of life research projects, information and education materials, and multidisciplinary conferences.

Contact details:
4 Golding Road
Sevenoaks
Kent TN13 3NJ
United Kingdom
Tel/fax: +44 (0) 1732 457683
E-mail: info@epda.eu.com
Websites: www.epda.eu.com,
www.rewritetomorrow.eu.com,
www.parkinsonsawareness.eu.com,
www.parkinsonsdecisionaid.eu.com,
www.epda.eu.com/projects/copingStrategies/dvd

### Professional organisations

The following organisations are the European forums for some of the professionals involved in the treatment of a person with PD.

**Association of Physiotherapists in Parkinson's Disease Europe (APPDE)**
The APPDE can be contacted via the EPDA (see previous column), or directly at:
Résidence Lara
16, rue Boltgen
L-4037 Esch-sur-Alzette
Luxembourg
E-mail: info@appde.eu
Website: www.appde.eu

**European Federation of the Association of Dietitians**
E-mail: secretariat@efad.org
Website: www.efad.org

**Standing Liaison Committee of Speech and Language Therapists and Logopedists (CPLOL) in the European Union**
145, Bd Magenta
F-75010 Paris
France
E-mail: info@cplol.eu
Website: www.cplol.org

# 7. The glossary

# 7. The glossary

These few pages contain definitions of some of the words and terms that you may come across in the area of PD.

**Adjunct therapy** – treatment/medication that is added to a person's existing treatment.

**Akinesia** – complete, or almost complete, loss of movement.

**Bradykinesia** – slow movement.

**Central nervous system (CNS)** – network of nerve cells that is present in the brain and spinal cord. Information is passed from the CNS to the rest of the body via the peripheral nervous system (PNS).

**Combination therapy** – situation where two or more medications are used together to treat one illness.

**Complementary therapy** – treatment/medication that is added to the person's existing treatment.

**COMT** – abbreviation for **c**atechol-***O***-**m**ethyl**t**ransferase, an enzyme that breaks down levodopa in the body and the brain.

**COMT inhibitors** – group of medications used as a treatment for PD. COMT inhibitors are given alongside levodopa to prevent it being broken down by COMT before it reaches the brain.

**Corticobasal degeneration (CBD)** – rare, progressive form of parkinsonism. It causes stiffness, difficulties with recognition, jerky movements and memory problems.

**CT scan** – computerised tomography (CT) is a type of X-ray where the scanner rotates around the body to produce an image of the body or brain in cross-section.

**Deep brain stimulation (DBS)** – surgical method used in some people with PD. Devices are implanted in the body and brain to send electrical currents to specific overactive parts of the brain, prevent their action, and reduce symptoms of abnormal movement.

**Disease modification** – term used to refer to the action of a treatment that changes the natural course of an illness (as opposed to simply relieving symptoms). In PD, this may mean slowing or halting the progress of the disease.

**Dopa-decarboxylase inhibitors (DDIs)** – medications that are given with levodopa (often in the same tablet) to improve its action, reduce the dose needed, and limit side effects. The DDI used in Sinemet® is called carbidopa, and the DDI in Madopar® is called benserazide.

**Dopamine** – one of many chemicals (neurotransmitters) that send messages between nerve cells. Dopamine sends signals between some of the nerve cells that control movement.

**Dopamine agonists** – rapidly expanding group of medications that can be given as a first treatment for PD to delay the need for levodopa, and they may also be given with levodopa to treat the motor fluctuations of long-term treatment. They work by imitating the action of dopamine in the brain.

**Dopaminergic medications** – general name for medications that work by increasing the level/activity of dopamine.

**Drug-induced parkinsonism** – disorder where PD-like symptoms are caused by a medication. When the medication causing the problem is removed, the symptoms disappear in the majority of cases.

**Dysarthria** – difficulty with articulating words.

**Dyskinesias** – group of disorders that produce uncontrolled, abnormal, restless movements or postures.

**Dystonia** – form of dyskinesia (abnormal movement) that produces muscle spasms in the face, neck and limbs. This can lead to awkward, fixed body positions.

**Essential tremor (ET)** – shaking of the limbs that is sometimes made worse by movement. ET is often confused with the tremor that is seen in PD, but whereas the parkinsonian tremor is usually one-sided at the start, ET typically affects both sides of the body.

**Freezing** – symptom of advanced PD where the person becomes 'glued' to the spot for a few seconds or minutes before being able to walk.

**Gait** – pattern of walking.

**Hallucination** – symptom that can be produced by disease or medications, which makes a person believe they are seeing, hearing or feeling things that are not really there – usually without awareness that the sensations are not real.

**Hoehn & Yahr scale** – system used to rate PD as one of five stages – stage 0 means no symptoms, and stage 5 means the most severe disease stage.

**Hypomimia** – reduced facial expression, caused by poor action of the face muscles in PD.

**Hypophonia** – abnormally quiet/whispering speech.

**Hyposmia** – reduced sense of smell.

**Insomnia** – inability to sleep.

**Lesioning** – surgical method used to destroy specific overactive parts of the brain that cause symptoms in PD.

**Levodopa** – most commonly used medication for the treatment of PD – the 'gold standard'. After administration, levodopa is converted into dopamine, and is able to raise the levels of dopamine in the brain. It produces effective control of PD symptoms, although its long-term use is associated with complications such as fluctuations and dyskinesias.

**MAO-B** – abbreviation for **m**ono**a**mine **o**xidase **B**, an enzyme that breaks down dopamine in the brain.

**MAO-B inhibitors** – class of medications that are used to treat the symptoms of early PD, as well as to treat motor fluctuations in more advanced disease. They work by stopping dopamine being broken down by MAO-B in the brain.

**Micrographia** – very small handwriting.

**Motor** – term used to refer to movement.

**Motor fluctuations** – switches between good and bad movement control with levodopa treatment. People may begin to experience motor fluctuations with levodopa treatment when they have had PD for a number of years.

**MRI scan** – magnetic resonance imaging (MRI) is a scan that uses radio waves to generate an image of body tissues. It is especially useful for examining the nervous system, muscles and bones.

**Multiple system atrophy (MSA)** – form of parkinsonism that is difficult to distinguish from PD, although poor balance and low blood pressure on standing are the main problems in MSA. It does not typically respond to standard PD treatments.

**Nausea** – feeling sick/queasy.

**Nerve cell transplantation** – surgical technique that is being investigated for use in PD. It involves implanting new dopamine-producing nerve cells in the brain to replace those lost in PD.

**Neurological** – describing any condition or symptom that affects the nervous system.

**Neurology** – area of medicine that is concerned with the nervous system.

**Neurone** – another name for a nerve cell.

**Neuroprotection** – protection of nerve cells. This is a strategy for PD treatment in the future, with research into medications that can prevent nerve cell loss and damage in the brain.

**Neurotransmitter** – chemical that is present in the nervous system to carry messages between different nerve cells. Examples of neurotransmitters include dopamine, acetylcholine, noradrenaline and serotonin (the 'feel good' chemical). Dopamine is not the only neurotransmitter that is involved in PD.

**OFF time** – period when PD symptoms respond poorly to treatment, making movement difficult.

**ON time** – period when PD symptoms respond well to treatment, allowing good movement control. Sometimes it is associated with dyskinesias ('peak-dose' dyskinesias).

**ON–OFF fluctuations** – changes between good and bad periods of movement control. These correspond to how well the medication is working, and generally appear after many years of treatment with levodopa.

**Orthostatic/postural hypotension** – low blood pressure in response to a person standing up quickly from a sitting or lying position. It is caused by the blood rushing down to the lower body as the person becomes upright, meaning that there is less supply to the brain and, in turn, this can cause effects such as dizziness. It can be prevented/minimised by taking more time to stand up.

**Osteoporosis** – wasting disease of the bones.

**Pallidal stimulation** – surgical technique where wires with electrodes on their tips are passed into the globus pallidus, and connected to a pacemaker-like device that, once switched on and set, delivers low voltage pulses of electricity to the globus pallidus. This is the equivalent of lesioning, but is not necessarily permanent, i.e., may be removed.

**Pallidotomy** – surgical technique where the globus pallidus region of the brain is destroyed or modified. It is used to reduce overactivity in this area of the brain, and improve symptoms of PD including levodopa-induced dyskinesia.

**Parkinson's disease (PD)** – long-term, progressive movement disorder which involves a loss of dopamine-producing nerve cells in the brain.

**Parkinsonism** – refers to a set of slow movement-related symptoms (tremor, rigidity, etc.) that are common to several conditions (parkinsonian conditions), including PD.

**PET scan** – positron emission tomography (PET) is a scan that can detect chemicals in the brain. It is sometimes used to produce images (scans) showing the arrangement of dopamine-producing nerve cells.

**Postural instability** – difficulty with keeping steady body positions such as standing, sitting upright or walking.

**Progressive disorder** – condition that becomes worse over time.

**Progressive supranuclear palsy (PSP)** – form of parkinsonism that produces early symptoms such as problems with balance and walking, eye movements, speech and swallowing. It does not respond to medications as well as PD.

**Psychosis** – type of disorder of the mind that involves a loss of contact with reality, e.g., hallucinations, paranoia.

**Rigidity** – stiffness.

**Schwab & England scale** – system that is used to rate a person with PD according to their level of independence. 100% relates to total independence, and this falls to a minimum of 0%, which relates to a state of complete dependence.

**SPECT scan** – single photon emission computed tomography (SPECT) is a scan that can produce images of the brain. In PD, it is sometimes used to detect dopamine-producing nerve cells in the brain.

**Substantia nigra** – area of the brain where dopamine is produced.

**Subthalamic stimulation** – surgical technique where wires with electrodes on their tips are passed into the subthalamic nucleus, and connected to a pacemaker-like device that, once switched on and set, delivers low-voltage pulses of electricity to the subthalamic nucleus. This is the equivalent of lesioning, but is not necessarily permanent, i.e., may be removed.

**Subthalamotomy** – surgical technique in which a small part of the subthalamic nucleus region of the brain is destroyed. It is used to reduce overactivity in this area of the brain, and improve symptoms of PD.

**Thalamic stimulation** – surgical technique in which wires with electrodes on their tips are passed into the thalamus, and connected to a pacemaker-like device that, once switched on and set, delivers low-voltage pulses of electricity to the thalamus. This is the equivalent of lesioning, but is not necessarily permanent, i.e., may be removed.

**Thalamotomy** – surgical technique in which a small part of the thalamus region of the brain is destroyed. It reduces overactivity in this area of the brain, and improves symptoms of PD, especially tremor.

**Titration** – way in which doses of medication are gradually altered to find a dose that is effective, but does not produce unacceptable side effects.

**Tremor** – rhythmic shaking of part of the body. It is one of the main symptoms of PD, although it does not occur in all cases.

**UPDRS scale** – scoring system that is used to follow the progression of PD by monitoring a person's physical and mental abilities, performances in activities of daily living, and the response to treatment.

**Vascular parkinsonism** – neurological disorder in which the symptoms of parkinsonism are a result of small strokes, rather than a gradual loss of nerve cells.

**Wearing off** – term used to describe the gradual return of symptoms that occurs at the end of a dose of levodopa.

**Young-onset PD** – PD that occurs in people aged below 40 or 50 years (10–15% of people with PD are diagnosed before the age of 50). This is more unusual than the form of PD that is found in older people, and displays some different symptoms. Research has shown that young-onset PD may have some family inheritance patterns, especially if the disease is diagnosed before the age of 40.

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