

Parkinson's Disease Practice Guidance

Using this guidance

This guidance has been written by tri.x to support practitioners to understand the needs of people with Parkinson's Disease, and think about some of the ways that they may need to adapt their practice to maximise their involvement in care and support processes.

It should be used as supplementary guidance to available procedures, and all statutory requirements of the Care Act 2014 apply.

What is Parkinson's Disease?

Parkinson's Disease is a condition in which brain cells that produce the chemical Dopamine become progressively damaged over many years.

Dopamine is a neurotransmitter. It transmits messages from the brain to parts of the body to make things happen (e.g. movement). As Dopamine levels reduce the body behaves differently and it becomes increasingly harder to control.

The symptoms of Parkinson's Disease

The three main symptoms of Parkinson's Disease are;

- a) Involuntary shaking of particular parts of the body (also known as tremors);
- b) Slow movement; and
- c) Stiff and inflexible muscles.

How a person experiences the three main symptoms of the condition will be unique to them but could include;

Involuntary shaking

Involuntary shaking can occur internally as well as externally, and can lead to muscle spasms and cramps impacting on;

- a) Sleep;
- b) Balance;
- c) Fine motor skills; and
- d) The ability to regulate body temperature.

Slowed movement

Slowed movement refers to slowed physical movement, but also to slowed thought processes, and can include;

- a) Slowed gross movement of limbs, eyes etc;
- b) Slowed reaction times;
- c) Difficulty concentrating on more than one thing at a time;
- d) Delays in processing changes in the environment;
- e) Delays and difficulty finding the right words; and
- f) Delays in making decisions and processing information;

Stiff or inflexible muscles

Any muscle in the body can be affected and, as well as causing pain at times stiffness or inflexibility can impact on a person's ability to;

- a) Carry out tasks independently (for example dressing, preparing food or eating);
- b) Sit down, stand up, walk around and use stairs;
- c) Drive and get around in the community;
- d) Speak loudly and clearly;
- e) Chew, swallow and digest food;
- f) Breathe normally.

Other impacts

Other impacts include;

- a) Fatigue (from the increased thought processes involved in trying to control the body);
- b) Depression and anxiety; and
- c) Loss of sense of smell.

Treatment

Although there is currently no cure for Parkinson's Disease, treatments are available to help reduce the three main symptoms and maintain quality of life for as long as possible. These treatments involve taking a medication that the brain responds to in the same way as it would to Dopamine.

The impact of medication is normally significant in terms of symptom relief. The effect is only temporary though, and medication needs to be taken regularly throughout each day. As medication is wearing off in between doses symptoms can begin to return, meaning a person with Parkinson's Disease can have good and bad parts of each day.

As the condition progresses, the symptoms of Parkinson's Disease can get worse and treatment can reduce in its effectiveness. As a result it can become increasingly difficult to carry out everyday activities without assistance.

Parkinson's Disease doesn't directly cause people to die, but the condition can place great strain on the body, and can make some people more vulnerable to serious and life-threatening infections.

Supporting the Medication Regime

The impact of an effective medication regime on a person's symptoms and independence cannot be underestimated.

Taking medication on time can literally mean the difference between a person being able to carry out tasks independently or being totally reliant on others.



When establishing needs practitioners must understand;

- a) When the person takes their medication;
- b) Any support the person may need to take their medication;
- c) How long it takes for their medication to alleviate their symptoms;
- d) The impact of the medication on their ability to carry out tasks; and
- e) How long the medication remains effective.

This will enable them to arrange any care and support services in a way that will optimise the person's ability to carry out tasks for themselves.

If a person requires support to take their medication their Care and Support Plan should be explicit about the timing of their medication, and any care provider **must** be able to demonstrate an ability to deliver support at the required time.

If a person requires support with daily tasks, this support should only be provided when they have taken their medication and the initial side effects (which can include involuntary movements and loss of muscle control) have worn off. This normally takes around 30 minutes.

Positive case example

Ross needs to take his medication at 7am. He does not need any support to do this. It normally takes around 30 minutes for the medication to alleviate symptoms so that Ross can get up and move around. At this point Ross is normally able to manage most of his personal care routine independently if he takes his time, but needs support to get dressed and clean his teeth. Ross has support at 7.30am each day, in recognition that this is the optimum time for him. The person providing the support establishes from Ross what he needs help with that day and does not get involved in those tasks that he is able to carry out independently.

Negative case example

Jenny needs support to take her medication throughout the day. As the time for her next dose approaches she tends to experience increased muscle stiffness. If her medication is delayed for whatever reason she can become temporarily immobile, which has a direct impact on her ability to carry out tasks and functions, such as using the toilet or preparing food. Jenny needs to take her medication every 3 hours for maximum effect. However, she regularly only receives support every 4 hours. This means that her symptoms are often unmanaged for around 6 hours of each waking day, during which her dignity is reduced and her dependence on others is increased.



Preventing, Delaying and Reducing Needs

With the right support the need for formal care and support services can be reduced or delayed, and the person's independence promoted and maintained for as long as possible.

The table below shows some of the ways that Local Authority services could support a person with Parkinson's Disease to prevent, reduce or delay the need for care and support.

Service	Support and Impact
Reablement	A short term reablement service can help a person to test out new ways of carrying out specific tasks, maintaining their independence for longer. If a person is not able to carry out a task without support, a reablement service can explore and evidence the optimum time to provide support around their medication regime in order to promote independence.
Assistive Technology	<p>Gadgets can help a person to take their medication on time. This not only helps manage their symptoms but ensures that the medication has taken effect when any person providing support with tasks arrives, so that their ability to carry out the task for themselves is optimised.</p> <p>Gadgets can also remind a person to carry out a different task, that otherwise they may forget to do altogether, or forget to do at an optimum time.</p>
Occupational Therapy	<p>Occupational Therapists can assess the environment, and identify potential hazards or difficulties for the person. This could be loose carpets, steps or access issues. Minor works or adaptations can be arranged to reduce any risk and enable the person to use their home safely.</p> <p>The person's needs around mobility can also be assessed, as can their ability to carry out key tasks such as bathing. Equipment can then be provided to reduce any risk and promote independence.</p>

Social work

Personal budgets can be used effectively to prevent, reduce or delay the need for more formal methods of care and support by purchasing gym memberships, swimming sessions or a piece of exercise equipment for the home. Exercise is known to alleviate muscle spasms and stiffness, reduce associated pain and maintain the person's ability to carry out tasks independently for longer.

Specialist Information and Advice

The person with Parkinson's Disease, their families and carers will likely have a lot of questions about the condition.

Steps should be taken to ensure that they have access to the information and advice that they need, or that would be of benefit to them.

Parkinson's UK has a dedicated national helpline. The number is 0808 800 0303.

Independent Age also has a dedicated line, and can provide information and advice specifically about maintaining independence. The number is 0800 319 6789.

Parkinson's Nurse

A person with Parkinson's Disease should be provided with support from a specialist Parkinson's Nurse, who can help them to understand the condition and manage their symptoms over time.

As part of any intervention practitioners should establish whether the person is receiving this support and, if not take steps to enable them to access it. The referral to a Parkinson's nurse can only normally be made by a health professional, so this may involve contacting the person's GP or Consultant on their behalf (subject to normal consent rules).

Maximising Involvement in Care and Support Processes

There is no reason why a person with Parkinson's Disease cannot be fully involved in *all* care and support process.

The table on the following page demonstrates some of the ways that practitioners can maximise and support this.

Do	Why?
Try to maintain a calm environment and reassure the person about the process taking place.	A tremor (shake) can worsen when the person is anxious or distressed.
Ask the person how they are feeling and do not make any assumptions or judgements based on their facial expression.	A person may find it difficult to change the expression on their face to match their mood.
Allow the person to finish what they are doing before talking with them. This could be drinking a cup of tea, or thinking about a previous question.	<p>A person may find it difficult to concentrate on something if they are already involved in another task.</p> <p>If time is not allowed they may forget the task they were previously thinking about, and this could lead to e.g. choking.</p>
Meet in a place where distraction is limited.	Environmental distractions affect concentration.
Arrange to speak to a person at an optimum time for them, normally between 30 minutes and 2 hours after medication has been taken.	If medication has not taken effect the person may find it difficult to concentrate, and have slowed reaction time to processing information and communicating their views.
Meet with a person in the optimum environment for them, normally their own home.	Different environments can increase symptoms because the person may not feel at ease. They can also lead to freezing (a sudden inability to move).
Sit where you can hear the person and consider whether they want to write the information down instead of speaking (although take into account their fine motor skills and ability to write at that time).	If the person has difficulty with the muscles in their throat they may find it hard to speak clearly or loudly.

<p>Be mindful that the person may become tired, and offer to rearrange a meeting or pause for a break.</p>	<p>Much of the muscle control that happens naturally in most people requires significant thought, which can result in fatigue.</p>
<p>Allow time for the person to consider things and respond.</p> <p>Do not make a judgement about their capacity based on a slowed reaction time.</p>	<p>A person can experience delays in processing information, and finding the right words.</p>

Supporting Carers

The impact of caring for a person with Parkinson’s Disease should not be underestimated and every carer is likely to need support at some point over the course of their caring role.

The risk to the wellbeing of carers is increased when;

- a) They have limited informal networks of support;
- b) The person with Parkinson’s has difficulties sleeping that impact on the carer; or
- c) The person’s symptoms are not well managed.

All carers should be offered a carers assessment in line with the statutory requirements of the Care Act.