

What support can I get to help me cope with planning for the future?

From the point of diagnosis onwards, you should be able to get help for issues that affect your quality of life, for example maintaining dignity, preventing complications and minimising distress. Your GP or PDNS can help if you want to discuss what support and choices are available to you and your carer during the advanced stages of Parkinson's.

What can I do if these standards are not being met in my area?

If you want to make a complaint about your NHS services you can contact your local Patient Advice and Liaison Service (PALS) for information and support if you live in England. You can find the details of your local PALS at www.pals.nhs.uk or call the National PALS Office on **01625 509 155**. If you live in Wales your local Community Health Council (CHC) can help. Visit www.patienthelp.wales.nhs.uk or call the Wales Board on **0845 644 781**.



Here are some of NICE's key recommendations:

- Quick referral to neurologist or geriatrician for diagnosis before treatment
- Regular check-ups with a neurologist, geriatrician or Parkinson's nurse specialist
- Access to a Parkinson's disease nurse specialist (or same level of care)
- Access to appropriate treatment including:
 - medication
 - surgery where eligible
 - physiotherapy, occupational therapy and speech and language therapy
- Treatment for other health problems associated with Parkinson's
- Access to care in the advanced stages of Parkinson's

Where can I go for more information?

You can order a free copy of the 'Understanding NICE guidance: Parkinson's disease' leaflet by calling the NHS Response Line (**0870 1555 455** quoting N1053).



Or you can find out more from the Parkinson's Disease Society's (PDS) website www.parkinsons.org.uk

Large print versions of this leaflet is available on request.

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what you need to know about the NICE guideline for Parkinson's disease

Putting you in the picture



Information for people with Parkinson's and their carers



What is the NICE Guideline for Parkinson's?

The National Institute for Health and Clinical Excellence (NICE) advises the NHS in England and Wales on the most effective treatment and care for all patient groups.

In June 2006 NICE published a guideline explaining exactly what the NHS should provide for the diagnosis and treatment of Parkinson's - whether at home, in hospital or in residential care. Because Parkinson's affects each person differently treatment must be tailored to the individual's needs.

Parkinson's is often regarded as a movement disorder, with tremor, stiffness and slowness of movement as early symptoms. Many people find that over time they develop other symptoms too such as depression, disturbed sleep, problems with bladder and bowel function, and some will have problems with dementia.

Your local NHS should be working towards providing the care and treatment set out in the NICE Guideline.



What does NICE say about diagnosis and check-ups?

NICE says *diagnosis* should be made by either a neurologist or, for older people, a geriatrician with expertise in Parkinson's. If your GP suspects you have Parkinson's, they should refer you without delay to one of these consultants before starting you on any medication. It is recommended that you should see a neurologist or geriatrician within six weeks.

The Guideline recommends that you have *check-ups* with a neurologist, geriatrician or PDNS every 6-12 months to ensure your diagnosis is correct and to monitor your current treatment.

Information and choices Your healthcare professionals should help you to make decisions about your treatment and care, provide information and talk you through your options in an honest and realistic way. Information for your family and carers including their entitlements and support should also be made available.

You should also be given the name of a person that you can contact if you have any questions or concerns, such as a *Parkinson's Disease Nurse Specialist* (PDNS). A PDNS is a nurse with specialist knowledge of Parkinson's. They can provide regular checks to see how your medication is working, information about Parkinson's and the symptoms you may be experiencing and help with referrals to other health professionals.

You can ask your doctor if there is a PDNS in your area, or alternatively call the Parkinson's Disease Society (PDS) Helpline to locate your local nurse.

If there is no nurse specialist in your area you should have access to another health professional who can be your regular point of contact, providing the same level of care as outlined above.

Does NICE say anything about medicines and treatments?

NICE makes many recommendations on medical treatments (including drugs and surgery) that should be available to help you manage your condition.

Your doctor should discuss with you what treatment is suitable for you.

Can I get help for the other Parkinson's symptoms like depression and sleep problems?

As the condition progresses, some people might develop a range of health problems related to Parkinson's other than those affecting movement. NICE recommends that you should be offered treatment if you experience any such problems associated with Parkinson's as they can have just as much impact on your daily life as tremor, stiffness and slowness of movement. It is important to discuss these with your GP, consultant or PDNS.

Can any other health professionals, such as physiotherapists, help me manage my condition?

NICE says you should have access to physiotherapy, occupational therapy and speech and language therapy as these can assist with many issues including mobility, speech and swallowing difficulties and managing day-to-day activities. You can ask your doctor or PDNS to refer you.