

Young-onset Parkinson's Best practice statement

“ I feel there is less support for younger people with Parkinson's. And if I had a penny for everyone (including doctors) who said that I was too young to have Parkinson's, well, I'd be better off financially.”

“ The consultant actually giving me information [would have been helpful], not just saying 'You have Parkinson's, take these tablets, see you in six months'.”

Younger people with Parkinson's survey, July 2016

Parkinson's is usually thought of as a late-life condition. However, 1 in 20 people with Parkinson's develop symptoms before the age of 50.¹ This is known as young-onset Parkinson's.

In 2016, Parkinson's UK surveyed more than 300 younger people with Parkinson's about their specific needs. Responses showed that lack of awareness that younger people can develop the condition contributed to a delay in diagnosis, and being provided with appropriate information and support.²

Diagnosis may come at a time when people are leading active lives. They may be developing their career, have financial commitments, be caring for older relatives or raising a family. They also face living with the condition for many decades.

All these aspects should be considered when supporting a younger person with Parkinson's, as well as the importance of an early introduction to multidisciplinary services.

This statement summarises the available evidence and expert recommendations for healthcare professionals. The goal is for everyone with Parkinson's to achieve the best possible quality of life, no matter when they're diagnosed.

Who is this statement for?

This statement is aimed at all those involved in the diagnosis, management and care of patients with young-onset Parkinson's.

It should be used in conjunction with [NICE](#) and [SIGN](#) guidance, and in discussion with the younger person with Parkinson's themselves.

¹ Wickremaratchi et al (2009) 'Prevalence and age of onset of Parkinson's disease in Cardiff: A community based cross sectional study and meta-analysis' *Journal of Neurology, Neurosurgery, and Psychiatry* <https://jnnp.bmj.com/content/80/7/805>

² Parkinson's UK (2016) Younger people with Parkinson's survey

Topics covered by this statement

Challenges of diagnosis

Other possible diagnoses

- Wilson's disease
- Drug-induced parkinsonism
- Essential/dystonic tremor
- Dopa-responsive dystonia
- Multiple system atrophy

Managing the condition

- Genetic support
- Medical management
- Neuroprotection
- Deep brain stimulation
- Self-management
- Exercise

Mental health

- Connecting to other younger people

Relationships, friends and family

- Talking about Parkinson's
- Relationships and sex

Pregnancy

Work, finances, driving and legal

Research

Frequently asked questions

Challenges of diagnosis

Younger people with Parkinson's can face particular delays in diagnosis. Parkinson's needs to be proactively considered – in both primary and secondary settings – in younger patients presenting with symptoms.³

Some distinctive features of young-onset Parkinson's should be factored into diagnosis. Evidence shows that:

- tremor is less common in people with onset under 45, compared to those with onset over 64 years⁴
- dystonia affects many younger people with Parkinson's, with people whose condition began before age 48 being more likely to experience this symptom³

When making a diagnosis, DaTSCAN, biochemical, MRI and genetic testing should be considered to evaluate the possibility of alternative diagnoses. It's particularly important to exclude Wilson's disease, a treatable copper deposition disorder.

► UK Parkinson's Excellence Network Clinical Summary: Use of DaTSCAN:
parkinsons.org.uk/professionals/clinical-summary-use-datscan

Other possible diagnoses

Wilson's disease

Presentation and diagnosis: Patients with Wilson's disease usually have a low serum caeruloplasmin and abnormal MRI brain imaging, with high signal on T2 imaging in the putamen and globus pallidus in the early stages. Slit-lamp corneal examination and 24-hour copper excretion are important adjunctive tests.⁵

Parkinsonism-dystonia due to Wilson's does not respond to levodopa, and patients often develop prominent facial and bulbar features, and tremor.

Treatment: The earlier the diagnosis, the better the prognosis. A number of drugs are available to treat Wilson's disease, including D-penicillamine, trientine, zinc, tetrathiomolybdate, and dimercaprol. Once the diagnosis has been made, treatment needs to be life-long. Untreated, Wilson's disease is fatal.⁶

Drug-induced parkinsonism

Presentation and diagnosis: A small number (around 7%) of people diagnosed with parkinsonism developed symptoms following treatment with dopamine-blocking medication – usually neuroleptic or anti-emetic drugs. The symptoms of drug-induced parkinsonism tend to be static.

³ Rana AQ et al (2012) 'Challenges in diagnosis of young onset Parkinson's disease' *Journal of Neuroscience* ncbi.nlm.nih.gov/pubmed/22989613

⁴ Wickremaratchi et al (2011) 'The motor phenotype of Parkinson's disease in relation to age at onset' *Movement Disorders* doi.org/10.1002/Mds.23469

⁵ Czlonkowska A et al (2018) 'Wilson disease' *Nature Reviews Disease Primers* dx.doi.org/10.1038/s41572-018-0018-3

⁶ European Association for Study of Liver (2012) 'EASL Clinical Practice Guidelines: Wilson's disease' doi.org/10.1016/j.jhep.2011.11.007

Treatment: All people with suspected Parkinson's should be given a comprehensive medication review. Dopamine blocking drugs should be stopped or changed to alternative medication if possible. This may require liaison with other doctors, particularly psychiatrists in patients with drug-induced parkinsonism related to psychiatric treatment.

Essential/dystonic tremor

Presentation and diagnosis: Patients with essential/dystonic tremor usually have an action tremor (worse on writing, using a knife and fork or pouring) without parkinsonism. Sometimes there can be a rest tremor component which can be difficult to distinguish from Parkinson's. Careful history and examination usually helps in defining the correct diagnosis. DATscan may be helpful

Treatment: Patients with essential/dystonic tremor may respond to beta-blockers or primidone. Patients who are severely affected and do not respond to medication may respond to deep brain stimulation.

Dopa-responsive dystonia

Presentation and diagnosis: In children, teenagers and young adults, dopa-responsive dystonia (DRD) is a rare but important differential diagnosis of parkinsonism-dystonia. Patients with this DRD usually have a normal DaTSCAN. DRD should be actively considered as a possible diagnosis in patients presenting with early-onset Parkinson's.⁷

Treatment: Patients with DRD usually respond very well to relatively low doses of levodopa (3-400 mg/day).

Multiple system atrophy

Presentation and diagnosis: In patients in their thirties to fifties, multiple system atrophy (MSA) can be mistaken for Parkinson's. MSA can be identical to Parkinson's in its initial presentation, but is distinguished by a poor response to levodopa, prominent urinary symptoms with incomplete bladder emptying and incontinence, and prominent postural hypotension, sometimes with postural syncope.⁸

Treatment: Patients with MSA should be evaluated by a movement disorders specialist with expertise in this condition. Patients may respond to some extent to levodopa. Evaluation and treatment of respiratory, bulbar and autonomic features is important.

Managing the condition

It's crucial that younger people with Parkinson's are given information from diagnosis onwards about managing the potential impact of their condition and medication on their work and life in general.

It's likely that younger people with Parkinson's will be living with the condition for decades. This long-term perspective on treatment and support needs to be incorporated into delivering a diagnosis.

⁷ Fanciulli A, Wenning GK (2015) 'Multiple-system atrophy' *New England Journal of Medicine* [dx.doi.org/10.1056/NEJMra1311488](https://doi.org/10.1056/NEJMra1311488)

⁸ *Ibid*

In service provision, thought should be given to the appropriateness of and alternatives to elderly medicine clinics and older people's services.

Where possible, service providers should also consider appointment times for younger people who are still working.

Genetic support

Younger people with Parkinson's are more likely to have the Parkinson's-associated genetic mutation PARK2 (parkin), and in rarer cases PINK1, PARK7 (DJ-1), than those who develop the condition later in life. Genetic diagnostic testing can be arranged.

Those with a family history and no identified gene, and those with a diagnosed genetic cause who have questions regarding family risk etc can be referred to genetic services.

Patients may wish to take part in genetic studies. See the [Research](#) section for signposting.

Due to increased frequency of family history, a younger person with Parkinson's may already have greater insight into the progression of Parkinson's, which can compound the psychological and emotional impact of diagnosis.

► Information about genetic testing: parkinsons.org.uk/information-and-support/does-parkinsons-run-families

Medical management

There are distinctive features of young-onset Parkinson's, some of which need to be given extra attention when assessing the potential benefits and harms of the different Parkinson's drugs.

- An increased rate of dystonia at onset and during treatment⁹
- An increased rate of dyskinesia in response to levodopa treatment¹⁰
- Increased likelihood of impulsive compulsive disorders in response to levodopa treatment
- A lower rate of dementia¹¹
- Risk of poor emotional wellbeing and depression¹²

Suggested treatment strategies to navigate these features include:

- avoiding high initial doses of levodopa, to ensure dyskinesia is not precipitated prematurely
- when discussing dyskinesia and medication, being aware that there is evidence that people with Parkinson's who experience dyskinesia find it less of a concern than other symptoms, compared to those who have not experienced dyskinesia¹³

⁹ Wickremaratchi et al (2011) 'The motor phenotype of Parkinson's disease in relation to age at onset', *Movement Disorders* doi.org/10.1002/Mds.23469

¹⁰ *Ibid*

¹¹ Parkinson's UK (2016) Younger people with Parkinson's survey

¹² *Ibid*

¹³ W Hung, S et al (2010) 'Patient perception of dyskinesia in Parkinson's disease' *Journal of Neurology, Neurosurgery, and Psychiatry* [10.1136/jnnp.2009.173286](https://doi.org/10.1136/jnnp.2009.173286)

- accurately diagnosing and treating depression to maintain good quality of life
- checking thoroughly for impulsive compulsive disorders risk factors and symptoms

► UK Parkinson's Excellence Network impulsive and compulsive behaviour resources:

- [Monitoring and information tool](#)
- [Education film for consultants](#)
- [Education film for nurses](#)

Neuroprotection

Neuroprotection and slowing disease progression are particularly important for younger people with Parkinson's, who potentially have longer to live with the condition. Exercise may slow the progression of symptoms.

There is no conclusive evidence that any medication (eg rasagiline and exenatide) or other substances (eg caffeine and cannabis) have neuroprotective properties in people with Parkinson's. However, clinical trials are investigating the neuroprotective properties of a range of repurposed and novel therapeutics.¹⁴

Deep brain stimulation

The EARLYSTIM trial has demonstrated a clinical benefit for deep brain stimulation (DBS) in patients with early motor complications.¹⁵

Younger people with Parkinson's are considered good candidates for DBS procedures because:

- they are more likely to be suitable surgical candidates (healthy apart from Parkinson's) when symptoms progress, necessitating DBS
- age is a risk factor for dementia in Parkinson's, so patients with early onset Parkinson's are less likely to have cognitive impairment¹⁶
- they tend to get behavioural side effects from Parkinson's medications, which can be stopped/reduced as a result of DBS

Subtle personality changes can occur with DBS (usually resulting from stimulation of the limbic part of the subthalamic nucleus). However, these should be reversible by adjusting the stimulation parameters.

Self-management

As for all patients, education about self-management is critical. This is particularly true for people with young-onset Parkinson's, who may live with the condition for many decades.

¹⁴ Athauda et al (2017) 'Exenatide once weekly versus placebo in Parkinson's disease: a randomised, double-blind, placebo-controlled trial' *The Lancet* thelancet.com/journals/lancet/article/PIIS0140-6736%2817%2931585-4/fulltext

¹⁵ EarlySTIM study group (2013) 'Neurostimulation for Parkinson's disease with early motor complications' *New England Journal of Medicine* ncbi.nlm.nih.gov/pubmed/23406026

¹⁶ EY Uc et al (2009) 'Incidence of and risk factors for cognitive impairment in an early Parkinson disease clinical trial cohort' *Neurology* 10.1212/WNL.0b013e3181bf992f

To facilitate self-management, primary and secondary care providers need to proactively signpost to available services, information and support.

This includes making people with young-onset Parkinson's aware of all aspects of a multidisciplinary service before, not when, relevant symptoms arise.

Exercise

For people of any age with Parkinson's, exercise is particularly important in optimising long-term function.

Evidence shows that 2.5 hours of exercise a week keeps people more fit and healthy, and is feasible in people with Parkinson's.¹⁷

The [Parkinson's Exercise Framework](#) can be used to help people with Parkinson's choose exercise styles that are right for them and their symptoms.

The Framework has been developed with people with Parkinson's, expert physiotherapists and exercise professionals. It includes key messages for professionals and examples of exercises.

- ▶ Exercise information for people with Parkinson's: parkinsons.org.uk/information-and-support/exercise

Mental health

Younger people with Parkinson's are at risk of depression, which is linked to a poor overall quality-of-life score.¹⁸ Accurate diagnosis and treatment of depression in younger people with Parkinson's is needed at the time of diagnosis and throughout Parkinson's management to maintain a good quality of life.

The All-Party Parliamentary Group for Parkinson's has made several recommendations on improving mental health services for people with Parkinson's who experience anxiety and depression.

- ▶ Read the [Mental health matters too](#) report and recommendations.

Connecting to other younger people

Younger people with Parkinson's have identified peer support and someone to talk as important. Many feel that the sense of confusion, isolation and loss they experienced would have been mitigated by having someone in a similar position to talk to.¹⁴

Signposting to relevant support and organisations can contribute to the wellbeing of younger people diagnosed with the condition.

- ▶ More information and links can be found at parkinsons.org.uk/information-and-support/younger-people-parkinsons

¹⁷ Schenkman et al (2018) 'Effect of High-Intensity Treadmill Exercise on Motor Symptoms in Patients With De Novo Parkinson Disease' *JAMA Neurology* europepmc.org/abstract/med/29228079

¹⁸ Knipe et al (2011) 'Quality of life in young- compared with late-onset Parkinson's disease' *Movement Disorders* www.ncbi.nlm.nih.gov/pubmed/21574185

Relationships, friends and family

Talking about Parkinson's

Many younger people affected by Parkinson's experience difficulties in telling others about their diagnosis due to fear of stigma, discrimination or embarrassment.¹⁹

Younger people may need advice on how to approach conversations about their diagnosis with friends, parents, children, and at work.

- ▶ Information is available from Parkinson's UK on telling people about Parkinson's, including workplace conversations: parkinsons.org.uk/information-and-support/talking-people-about-parkinsons

Younger people with Parkinson's may have children or teenagers that they need to explain their diagnosis to, and may find the following information helpful.

- ▶ Explaining Parkinson's to children: parkinsons.org.uk/information-and-support/talking-children-and-teenagers
- ▶ Children's books for 3- to 7-year-olds: parkinsons.org.uk/information-and-support/childrens-books
- ▶ A guide for teenagers who have a relative with Parkinson's: parkinsons.org.uk/information-and-support/guide-parkinsons-teenagers
- ▶ A short film on the importance of parents and teachers understanding Parkinson's and its impact on the children affected: <http://www.parkinsons.org.uk/professionals/resources/short-film-teachers-listen-my-thoughts>

Relationships and sex

For younger people, it can be particularly important to acknowledge and discuss the potential impact of a Parkinson's diagnosis on current and future relationships.

Some people with Parkinson's say that the condition made their relationships stronger, but others find that Parkinson's does negatively affect their relationships, and this can happen at any stage of the condition.

- ▶ Information on how Parkinson's can affect existing relationships: parkinsons.org.uk/information-and-support/being-relationship

This page also signposts to resources on relationship counselling, including links to [Relate](#) and how to access private counselling from the [British Association for Counselling and Psychotherapy](#).

- ▶ Information on relationships for single people: parkinsons.org.uk/information-and-support/forming-new-relationships

It's important to acknowledge the potential for people with Parkinson's to experience sexual problems. This can be due to the physical effects of the condition and emotional issues, such as

¹⁹ Parkinson's UK (2016) Younger people with Parkinson's survey

low mood or depression. Patients may also experience hypersexuality – impulsive compulsive behaviour linked to dopamine agonists and levodopa.

- ▶ Detailed information on sex and Parkinson's: parkinsons.org.uk/information-and-support/sex-and-parkinsons

Pregnancy

Those working with younger people with Parkinson's should be ready to discuss issues around pregnancy and post-natal care.

As pregnancy in Parkinson's is relatively rare, there is a lack of evidence about the effects of Parkinson's on pregnancy or the effect pregnancy might have on Parkinson's symptoms.

Many of the changes that happen with pregnancy are also symptoms of Parkinson's. So having Parkinson's while pregnant can make issues such as changes in centre of gravity, slowing down, tiredness, morning sickness and disturbed sleep more profound.

A recent review²⁰ of pregnancy and Parkinson's has summarised that:

- about half of women with Parkinson's experience worsening of symptoms during pregnancy
- Parkinson's medications reduce the worsening of symptoms in only a third of pregnant women with Parkinson's
- women with Parkinson's do not have higher rates of birth or foetal complications
- levodopa has the most use and safety data to recommend its use during pregnancy
- amantadine should be avoided in women trying to conceive and those who become pregnant

- ▶ More information on pregnancy and Parkinson's: parkinsons.org.uk/information-and-support/pregnancy-and-parkinsons

Work, finances, driving and legal

Many younger people may want to know how to find support to continue working, and information about their rights around workplace discrimination.²¹

By law, an employer must make 'reasonable adjustments' to overcome any problems caused by Parkinson's.²²

Information is available to help people make informed decisions about their working life. This includes their legal rights in the workplace and advice on occupational health.

- ▶ parkinsons.org.uk/information-and-support/work-and-parkinsons

²⁰ Seier and Hiller (2017) 'Parkinson's disease and pregnancy: An updated review' *Parkinsonism & Related Disorders* [prd-journal.com/article/S1353-8020\(17\)30173-6/fulltext](https://doi.org/10.1016/j.parkpdis.2017.03.017)

²¹ Parkinson's UK (2016) Younger people with Parkinson's survey

²² Equality Act 2010 [gov.uk/rights-disabled-person/employment](https://www.gov.uk/rights-disabled-person/employment)

- ▶ Citizens advice can offer support on work-related issues and more: citizensadvice.org.uk

If a younger person with Parkinson's can't work, or if their ability to work is limited because of the condition, there is financial support available.

- ▶ Medical sickness benefit: parkinsons.org.uk/information-and-support/benefits-if-you-cant-work-due-illness-or-disability
- ▶ The Money Advice Service can give free advice on things such as mortgages, borrowing money and insurance: moneyadviceservice.org.uk
- ▶ Parkinson's UK [employment and benefits advisers](#) can provide help to access a range of financial support, including benefits and prepaid certificates for prescriptions.

People with Parkinson's need to be made aware of their obligation to tell the DVLA or DVA about their diagnosis.

There should also be a discussion on how the progression of their condition may affect their ability to drive. Ongoing conversations about this issue are important, particularly when someone relies on being able to drive for their work.

- ▶ Information about contacting the DVLA/DVA: parkinsons.org.uk/information-and-support/telling-dvla-or-dva

Research

There is now a strong evidence base in many areas of treatment and care for younger people with Parkinson's. But there are still topics where evidence specific to young-onset Parkinson's is lacking, owing to the smaller number of people with the condition in this age group and their exclusion from many therapeutic trials. Increasing the evidence base remains important.

Because of the higher prevalence of genetic mutations in younger people with Parkinson's, this group is more likely to be eligible for trials based on the genotype of their condition.

Several studies are attempting to identify the genetic contribution to early-onset Parkinson's, including [Tracking Parkinson's](#) and the [Parkinson's Families Project](#).

- ▶ Information about taking part in research trials for all ages, both national, regional and home based, can be found at parkinsons.org.uk/research/take-part-research

Frequently asked questions

Questions that clinicians may face from younger people with Parkinson's

What is my life expectancy?

Most people's life expectancy won't change much because of Parkinson's.

Some of the more advanced symptoms can lead to increased disability and poor health, but it may take decades for a younger person with Parkinson's to develop advanced symptoms.

Will I be able to have children?

There is no evidence that Parkinson's affects fertility or poses any additional risk to pregnancy.

- ▶ There is more information on pregnancy and Parkinson's in this statement and on the Parkinson's UK website: parkinsons.org.uk/information-and-support/pregnancy-and-parkinsons

Can I have children after deep brain stimulation?

Research into this is limited, but in one study, all participants' pregnancies and births were normal, and their Parkinson's symptoms were well controlled. In two cases, the women experienced local discomfort when the cable stretched as parts of the body grew larger.²³

Will my children get Parkinson's?

It's rare for people to pass on Parkinson's directly to their children. However, there is likely to be an inherited susceptibility, much as there is for other conditions such as heart disease or diabetes.

In some cases, it's possible for family members of people with Parkinson's to have a predictive test to see if they carry a Parkinson's genetic risk factor. This will usually happen with support and counselling from genetics service.

- ▶ parkinsons.org.uk/information-and-support/does-parkinsons-run-families

Will I be able to live alone?

Many people with Parkinson's live alone and manage very well. There are various aspects to consider, including social and emotional support, as well as physical needs.

- ▶ parkinsons.org.uk/information-and-support/living-alone

Will I be able to work?

If symptoms and treatment are carefully managed and with plenty of support, it's possible to continue working for many years, depending on the job and how symptoms progress.

²³ Scelzo, E et al (2015). 'Deep brain stimulation during pregnancy and delivery: Experience from a series of 'DBS babies'' *Frontiers in Neurology* [10.3389/fneur.2015.00191](https://doi.org/10.3389/fneur.2015.00191)

Information is available to help people make informed decisions about their working life, including what their legal rights are in the workplace, and advice on occupational health.

- ▶ parkinsons.org.uk/information-and-support/work-and-parkinsons

What about alternative or complementary therapies?

There is no conclusive evidence that any alternative therapies (eg metal chelation) or supplements influence the progression or symptom management of Parkinson's.

- ▶ More information for patients about vitamin supplements and diet is available at parkinsons.org.uk/information-and-support/diet

Can cannabis help with Parkinson's?

Cannabinoids or medical cannabis are not licensed for the management of Parkinson's symptoms in the UK.

More research is needed to assess the potential benefits of cannabinoids for people with Parkinson's.

- ▶ There is a [Parkinson's UK blog](#), aimed at a public audience, covering the evidence around cannabis and cannabinoids and Parkinson's, as well as the legal status of both.

How can I still live my life with Parkinson's?

Lots of people with Parkinson's feel that one of the most important things to do is make plans, such as setting personal goals and making positive life changes to help achieve targets.

- ▶ Parkinson's UK has information on planning life around Parkinson's parkinsons.org.uk/information-and-support/plan-life-around-your-parkinsons

Acknowledgements

Our thanks go to the following contributors, who generously shared their extensive expertise to inform this comprehensive and evidence-based resource.

Dr Camille Carroll, Associate Professor and Honorary Consultant Neurologist at the University of Plymouth

Dr Thomas Foltynie, Consultant Neurologist and Professor of Neurology at the National Hospital for Neurology and Neurosurgery, UCLH

Dr Donald Grosset, Consultant Neurologist at the Institute of Neurological Sciences at Glasgow's Queen Elizabeth University Hospital and Honorary Professor in Neurology at the University of Glasgow

Prof Huw Morris, Consultant Neurologist and Professor of Clinical Neuroscience at the Royal Free Hospital and Professor of Clinical Neurosciences, Clinical and Movement Neurosciences at UCL Queen Square Institute of Neurology

Miriam Parry, Senior Parkinson's Nurse Specialist at King's College London

We'd also like to thank the Younger Parkinson's Alliance for spearheading and shaping this statement. Formed by people who were diagnosed early in life, the Alliance shines a light on the needs of younger people with the condition and takes steps to ensure these are met – by healthcare professionals and society in general.