

## Young onset Parkinson's disease

A person who is diagnosed with Parkinson's under the age of 50 is said to have young onset Parkinson's disease (YOPD). Receiving a YOPD diagnosis can be overwhelming, however, it's important to remember that you are not alone. Research indicates that YOPD is more likely to have genetic causes than late onset Parkinson's, but its symptoms are more likely to progress slower. As with late onset Parkinson's, these symptoms can be managed with medical treatment and a healthy lifestyle. We will explain more about YOPD and how living with Parkinson's has different challenges when you are younger.

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### What is young onset Parkinson's Disease?

Your risk of developing Parkinson's disease increases with age, but it can affect younger people too. If you are between the ages of 21 and 50, and you've been diagnosed with Parkinson's disease, you have what is called young (or early) onset Parkinson's disease (YOPD).

Worldwide, YOPD accounts for an average of five in 100 cases of Parkinson's, but up to one in 20 people with Parkinson's first experience symptoms when they're under 50 years of age. In even rarer cases, Parkinson's can occur in young people under the age of 20 – this is called juvenile Parkinson's disease.

Studies show that YOPD is more likely to be caused by genetic factors than late onset Parkinson's disease. One in five people with YOPD has a genetic mutation compared to less than one in 10 people diagnosed at an older age.

If you have been diagnosed with YOPD, you may be concerned about passing on the same genes to your children. While it is possible for a parent to pass on the genes to their children, it is not likely. Most people have what is called "idiopathic" Parkinson's, meaning the cause is unknown.

## Does young onset Parkinson's disease have different symptoms?

It is hard to say because Parkinson's symptoms vary from person to person, whatever age you are. Your symptoms are individual to you. But overall, YOPD has similar symptoms as late onset Parkinson's disease but with some subtle differences.



For example, you are more likely to have involuntary muscle contractions and cramping (dystonia) as an early symptom. These can affect different parts of your body including your legs and feet, and your hands.

You are also more likely to develop involuntary muscle movements (dyskinesia) than older people with PD. This is because they are a long-term side effect of taking a common medication called levodopa.

On the brighter side, due to the fact that you are younger, your body is naturally more resilient and you are less likely to have other chronic health conditions. This means that the progression of Parkinson's is likely to be slower than if you were older, and your risk of cognitive (brain) problems, such as dementia and memory issues, is also lower.

## Being diagnosed with young onset Parkinson's disease

Getting a Parkinson's diagnosis at a younger age may take longer. It can feel frustrating and confusing to have to see so many doctors and have lots of different tests before being diagnosed. This is because doctors may initially think your symptoms are caused by conditions that are more common in your age group, such as arthritis or sports injuries.

Being told you have Parkinson's disease is difficult whatever your age, but if you are younger, it could be more challenging particularly around balancing your work and family life.

This is why speaking about your diagnosis with your family and people you trust around you can help you take back some control of the situation. If the people around you understand that your symptoms are as a result of a physical



disease, it could clear up some stigma and hostility you could potentially face. You could also <u>check out our support page</u> for details of organisations that may be able to provide support.

# What are the treatment options for young onset Parkinson's disease?

Treatments for YOPD are usually the same as for late onset PD, although there may be a difference in which medication you are prescribed and when you are prescribed it.

Depending on where you live, you also may be offered surgical procedures, such as deep brain stimulation or new medicines that are generally not an option for older people.

Before deciding on treatment, your doctor should explain the benefits and drawbacks of different approaches and work out what can help to relieve your individual symptoms.

For example, some younger patients decide not to take levodopa just after they've been diagnosed because of concerns about dyskinesias.

Whatever care plan you receive, you should have regular appointments with your healthcare provider to monitor your condition.



### Coming to terms with YOPD

Coming to terms with a diagnosis of Parkinson's at a younger age may seem difficult. There are a wide range of emotions to deal with when you are diagnosed with YOPD. The emotional pressures that come with receiving a life-changing diagnosis and how it will impact your personal life, your family and work, may make you more prone to long-term anxiety and depression.

You may have issues and concerns that are very different to someone who is older. For example, you may worry about how your diagnosis will affect new relationships, having a baby or caring for your children. Or you may be thinking about how you can continue in your job or progress with your career or worry about money. These are all legitimate concerns but accepting your diagnosis and finding ways to make the most of life can be very rewarding and give you a sense of fulfilment.

Getting help early on and maintaining a healthy lifestyle like regular <u>exercise</u> can help you manage your <u>symptoms</u> and <u>mental health</u>.

Opening up to others, whether it is family, friends or other people with the condition, is also important. Also, when you feel ready, it can help to think ahead and plan for changes in your life. Making small changes to your life or your living arrangements can help you take back some control of your condition.

Building a strong network of loved ones who you can trust and who understand your condition can help you feel less overwhelmed. And there is lots of <u>help</u> and <u>information</u> available that can help you feel less alone.



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