



Parkinson's  
Disease Society

## Juvenile Parkinson's

### **What is the difference between juvenile Parkinson's and other types of Parkinson's?**

Juvenile Parkinson's is a form of Parkinson's disease that affects children and young people under the age of 20. Like other forms of Parkinson's, it is a neurological disorder that manifests itself as rigidity or stiffness, resting tremors and difficulties with initiating movements. There is also a range of non-motor symptoms.

### **How quickly will juvenile Parkinson's progress? Will my symptoms change when I am 30?**

As with other types of Parkinson's, juvenile Parkinson's is a very individual condition with each person experiencing different symptoms. Not everyone experiences all the symptoms and there is no set progression for the condition. As with other types of Parkinson's, it is impossible to predict how someone's symptoms will develop and the rate at which the condition will progress.

In order to ensure that people with juvenile Parkinson's maintain a high quality of life for as long as possible, healthcare professionals need to work in partnership with patients and families to establish drug and therapy regimens that control the symptoms as effectively as possible. It is also important to get the emotional support needed to cope with being diagnosed with a long-term neurological condition at such a young age.

### **Can anyone get juvenile Parkinson's?**

The prevalence of juvenile Parkinson's is unknown, but it is much more rare for someone to be diagnosed with Parkinson's under the age of 20 than for someone to be diagnosed in their 50s or 60s.

### **Who are the experts in this condition?**

Unfortunately, the Parkinson's Disease Society (PDS) is unable to refer people to a specific expert. As juvenile Parkinson's is so rare, neurologists with expertise in treating children may only have had experience of treating very small numbers of patients with juvenile Parkinson's, if any at all.

However, we recommend that if a member of your family has juvenile Parkinson's and is under 18 they should ask to be referred to a neurologist with expertise in treating children.

If someone is diagnosed at 18 or over, they could see an adult neurologist.

### **Can people with juvenile Parkinson's have deep brain stimulation?**

We have heard that deep brain stimulation (DBS) has been performed on people with juvenile Parkinson's, but the numbers treated have been very small.

DBS is not a cure. If successful, DBS can reduce tremor or dyskinesia. It is an effective way of treating symptoms in some people with Parkinson's, but it doesn't cure the underlying condition, so most people who have had the surgery will still have to continue with some medication.

DBS is not suitable for all people with Parkinson's. Usually, only patients who have benefited from levodopa therapy and have symptoms that aren't adequately controlled by medication can be considered for the surgery.

In addition, clinicians need to take other things into account, such as people's ability to deal emotionally with major surgery, their expected growth rates, and the expected number of operations that would be needed to reinsert the chest unit during the course of their lifetime.



**Parkinson's**  
Disease Society

If people want to be considered for DBS, they need to speak to their specialist.

### **Can you put me in touch with other families with juvenile Parkinson's?**

The PDS is looking into ways it could link people with juvenile Parkinson's together. However, as juvenile Parkinson's is relatively rare, we do not know of many families with the condition.

### **Have you got the latest research?**

At present, research suggests that up to 5% (ie. 5 in every 100 people with Parkinson's) may have a genetic cause. The remaining 95% are considered 'idiopathic', i.e. of no known cause. These figures may change as research into the cause of Parkinson's progresses.

### **Does taking illegal drugs like cannabis and ecstasy help control the symptoms of Parkinson's?**

The PDS does not support the use of any illegal drugs or drug treatments. These can be very harmful and could potentially do further damage to the dopamine nerves.

People with Parkinson's should always use medications that have been prescribed to them by specialists in Parkinson's, such as their neurologist, geriatrician or Parkinson's Disease Nurse Specialist. With increased choice of Parkinson's treatments, it is becoming easier to establish a drug regime that fits with an individual's lifestyle and clinical needs.

People with Parkinson's can make use of therapies, – for example conductive education and other forms of exercise, such as yoga – to help control their symptoms. How beneficial these therapies are varies from individual to individual. But we do know that, for example, physiotherapy can make a real difference to someone's movement and independence, and occupational therapy can help people remain as independent as possible and feel safer at home.

.....  
**Parkinson's Disease Society**

215 Vauxhall Bridge Road, London SW1V 1EJ, UK

**Tel:** 020 7931 8080 **Textphone:** 0800 111 4204 **Fax:** 020 7233 9908

**Helpline:** 0808 800 0303 (The Helpline is a confidential service.)

Calls are free from UK landlines and some mobile networks)

**Email:** enquiries@parkinsons.org.uk **Website:** www.parkinsons.org.uk

© Parkinson's Disease Society of the United Kingdom (2008)

Charity registered in England and Wales No. 258197 and in Scotland No. SC037554.

A company limited by guarantee. Registered No. 948776 (London)

Registered office: 215 Vauxhall Bridge Road, London SW1V 1EJ

Revised October 2008

To obtain any PDS resource, please go online to [www.parkinsons.org.uk](http://www.parkinsons.org.uk) or contact Sharward Services Ltd, the appointed PDS Distribution House, at Westerfield Business Centre, Main Road, Westerfield, Ipswich, Suffolk IP6 9AB, tel: 01473 212115, fax: 01473 212114, email: [pds@sharward.co.uk](mailto:pds@sharward.co.uk)