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Huntington's disease

Huntington's disease is an inherited condition that affects the nervous system. It causes problems with movement, memory, and concentration.

There are treatments that can help with some of the symptoms, but there is no cure. Huntington's slowly gets worse over a number of years and eventually leads to death.

If you are affected by Huntington's, you can use our information to talk to your doctor about the treatments available and planning for the future.

What is Huntington's disease?

If you've got Huntington's disease, a part of your brain stops working properly. This affects the nervous system, causing problems with movement, memory, speech, and concentration.

Huntington's is an **inherited** condition. About half of people with a parent with Huntington's will go on to develop it. It is not infectious. You can't catch Huntington's from someone else or pass it on like a virus or a bacterial infection.

Symptoms can start at any age, but it's usually between the ages of 30 and 50.

There is no cure for Huntington's. The symptoms slowly get worse over time, and most people die from it about 20 years after they first have symptoms.

Men and women are equally likely to get it. But it's much more common in people of white, northern European descent than in people of most other ethnic groups.

What are the symptoms?

The symptoms of Huntington's affect people in three main ways. These are:

- Thinking and memory: the medical term is **cognitive impairment**
- Changes in **behaviour**, and
- Problems with movement. Doctors call these **motor symptoms**.

Cognitive impairment symptoms

Symptoms that affect thinking and memory are often some of the earliest symptoms of Huntington's. They include:

- Problems with concentration. For example, you may notice that your work is suffering
- Anxiety about work, and not caring about your work as much as you used to
- Needing help from family or friends with things that you used to be in charge of, and
- Making poor decisions when you need to concentrate. For example, you may be more likely to have a car accident.

Behaviour symptoms

Huntington's can affect someone's behaviour in many ways, including:

- Being irritable
- Being impulsive. For example, you may make quick decisions without thinking much about them
- Not paying attention to how you look, or to personal hygiene
- Personality changes. For example, someone's friends and relatives may notice changes in their habits and interests.

Problems with movement (motor symptoms)

Huntington's affects the nerves and the muscles that they control. This can lead to symptoms including:

- Twitching and jerking movements that you can't control. Doctors call this **chorea**
- Seeming restless and unable to stop moving
- Problems with coordination
- Moving slowly. For example, walking more slowly than you used to, and stiff muscles that don't relax.

People with Huntington's often develop **depression**. It's not clear whether this is a symptom of the changes in the brain that Huntington's causes, or whether it's a reaction to having the condition.

If you see your doctor with symptoms similar to those of Huntington's, your doctor will ask you if you know whether either of your parents had the condition.

It may be possible to have **genetic testing** to find out if you have inherited Huntington's. But other tests and scans are not always needed, especially at first.

Being diagnosed with Huntington's can be hard to deal with. You may want time to think about it before making any treatment decisions.

And you may want to think about having counselling to help you cope. Your doctor may be able to help in arranging this.

What treatments are available?

Unfortunately there is no cure for Huntington's. And, while there are treatments that can help with some of the symptoms, there are none for the condition itself.

But this is likely to change as we find out more about the condition. For example, there is currently a lot of research into how to stop the Huntington's gene from causing problems. These treatments are some years away, but they should offer hope for the future.

The medicines currently used to help people with Huntington's can have **side effects** in some people. Your doctor should talk to you about them, and about what to do if they happen.

For example, you may be able to switch to a different medicine or dose. But don't just put up with them.

Depression

Depression and **anxiety** are common in people with Huntington's. But treatments such as medicines and counselling can help.

Counselling for depression linked to Huntington's is different from counselling for depression from other causes. It focuses on issues that concern the person and their carers. For example, you may learn about:

- How Huntington's can affect your behaviour and your thoughts, and
- What you can reasonably expect from yourself, and how your carers can help.

Obsessive-compulsive behaviours

Many people with Huntington's develop some types of obsessive-compulsive behaviours. For example, they may want to stick to rigid routines or to wash their hands a lot.

Some people develop new interests that they become obsessed with and anxious about.

Of course, there's nothing wrong with having routines or new interests. But if these cause anxiety and other problems, there are **medicines** that can help someone to relax and be less obsessive.

You can talk to your doctor about whether medicines like these would be suitable for you.

A talking treatment called **cognitive behaviour therapy (CBT)** can also help people to understand the changes in their behaviour and deal with them.

Behaviour and mood problems

Problems with behaviour and mood can get worse as Huntington's gets worse over time. For example, some people have problems with:

- Being irritable
- Mood swings

- Aggression, and
- Outbursts of bad temper. Some people with Huntington's sometimes become physically and verbally abusive.

Several types of medicine have been found to help with these symptoms, including:

- Antidepressants
- Mood stabilisers, and
- Antipsychotics.

Antipsychotic medicines may sound like an alarming treatment. But these medicines are often used to treat conditions other than psychosis. For example, they often just help people to feel calmer and less anxious.

These medicines aren't suitable for everyone. For example, some people find that they make their mood worse. So it may take a while to find out which medicines are most suitable for an individual.

Problems with movement

Symptoms such as twitching and jerking can be difficult to treat, partly because the medicines that can help can make some of the other symptoms of Huntington's worse. For example, they can affect your mood, concentration, and coordination.

So it can take time to find something that helps you without causing other problems.

Physiotherapy can help with some of these problems. Your doctor may be able to help you find a suitable therapist.

Pregnancy and medicines

Medicines called **valproates** are sometimes used to help with some of the symptoms of Huntington's.

If you are a woman or girl of childbearing age, you should **not become pregnant** while taking medicines that contain valproates. Valproates cause severe birth defects.

If you need to take these medicines, your doctor should discuss them with you carefully and help you to make a **pregnancy-prevention plan**.

What to expect in the future

If you have relatives with Huntington's, you can have a blood test to tell whether you have the Huntington's gene. You don't have to have the test, and many people prefer not to.

If you decide to have the test, your doctor may first refer you to a **genetic counsellor**, who can discuss with you the pros and cons of having the test.

While many symptoms of Huntington's, such as depression and mood changes, can be helped with medicine and therapy, the condition is not curable and it is eventually fatal.

Most people live for about 20 years after diagnosis, but the symptoms will get worse over time. This means that it's a good idea to try to look ahead and plan as well as you can.

For example, you may be able to keep doing things like working, driving, and cooking for yourself for years. But it's a good idea to think about putting plans in place for when you can't.

But there's no need to rush most decisions. Huntington's usually gets worse slowly, over a number of years. There is usually time to take in the news of your diagnosis and immediate treatment needs before dealing with the stress of making longer-term plans.

After your diagnosis, your doctor will probably want to check on you every three to six months. But you should see them more often if you feel you need to.

When you see your doctor they will check on what things you are still able to do for yourself, for example, how you are coping with work, and whether your treatments are helping.

They will also want to check on your **mental health**. Depression is a common problem in people with Huntington's, and your doctor will want to do whatever is possible to help.

Over time, long-term **complications** of Huntington's get noticeably worse. For example, most people lose weight, have trouble swallowing, and struggle to do many things for themselves.

Support for carers

People with Huntington's will need a lot of care at some point. Caring for someone with the condition can be difficult and demanding.

Support for carers of people with Huntington's should be a part of the care someone receives, and your doctor should be aware of this each time they see you.

Support groups can offer many kinds of help, including practical information about **financial and community support**.

For example, in the UK, the Huntington's Disease Associatio (hda.org.uk) is a vital resource for many people. The International Huntington Association (huntington-disease.org) is another well-known organisation that helps many people.

Your doctor may be able to help you find support in your area, or you can search online.

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