

Living with Huntington's disease

Scientists throughout the world are working hard to find effective treatments to slow down or stop the advance of Huntington's disease. While there is no cure at present, there are many things you can do to live positively with Huntington's disease despite the challenges it brings.

It's important for us all to have a healthy lifestyle, however this is especially important if you have Huntington's disease.

1. Eat a healthy diet

Good nutrition is vital for health and wellbeing. This means eating a balanced diet to provide the body with all the energy and nutrients it needs. Weight loss is common in Huntington's disease and as you develop more symptoms, you may need a higher calorie diet to maintain your weight. This can be challenging and your dietitian and HD Specialist will give advice about how to make sure you are getting enough calories while maintaining as healthy a diet as possible. For more information, see our factsheet 'Nutrition in Huntington's disease'.

2. Regular physical activity

Staying active and doing things you enjoy can help you cope, whether you have the disease yourself or are caring for someone with the disease. Research shows that keeping active is beneficial in Huntington's disease, and exercise is a great way to manage anxiety and stress. That could be going to the gym, a daily walk or even doing some housework! You will find exercise ideas you can do in your own in our Mobility factsheet.

3. Reduce stress

Stress can make symptoms of Huntington's disease worse and impact your quality of life. Lifestyle or practical changes to reduce stress include ensuring you get enough sleep, making time for relaxation, listening to music or working your way through a 'to do' list of things you have been putting off. You might consider talking to your employer so that small changes can be put in place to make work more manageable. Or you can reduce financial worries by making sure you are accessing the correct benefits. Consider areas in your life that are stressful, then you can start to take appropriate steps. Our HD Specialists">HD Specialists and Financial Wellbeing Officers will give advice and support in these areas.

4. Exercise your brain

It's just as important to keep your mind active too. Brain training is a good way of practising your thinking skills, keeping them active so you can maintain them for longer. It can be anything from playing a computer game to doing a crossword or chatting to friends. Researchers are looking at specific brain training exercises for Huntington's disease, but for now there are lots of general brain training apps available.

5. Look after your mental health

Mental health symptoms such as depression and anxiety are common in Huntington's disease. The good news, however, is that they can be treated, just like they are in people who don't have Huntington's disease. If your mood is low or you are becoming anxious and irritable, it is important to speak to someone, such as your HD Specialist or GP. Medication may be required to help you feel better. Psychology and counselling may also be helpful. For more information, see our Mental Health factsheet.

6. Develop a support system

At times you may feel like avoiding people or be reluctant to share your thoughts and feelings. This can leave you feeling isolated. If you are able to talk to someone openly about how you are feeling then you are likely to feel a sense of relief. Try to find a friend or family member you can confide in and remember there are also professional services you can access. Your HD Specialist will provide emotional support and can signpost you to other services. These may include counselling, befriending services and telephone

helplines. It may help to meet other people living with Huntington's disease and your HD Specialist can let you know if there are a support group in your area.

7. Accept help

If you have symptoms of Huntington's disease, there is a lot that can be done to help you manage them so that you can enjoy a good quality of life. Accepting support in the early stages enables you to become familiar with the range of professionals involved in helping you to develop positive strategies for living with Huntington's disease. It also means you are more likely to continue accepting support as your condition progresses. You can get more information on who can help from our factsheet 'Professionals involved in your care'.

8. Hope for the future

You may have days where you feel less optimistic about the future and worry about yourself and your family. This is completely normal when living with a serious medical condition such as Huntington's disease. It may help you to feel more in control if you talk about planning for the future (see our Planning for the Future factsheet). It is also worth keeping in mind the huge progress that scientists and researchers are making in the Huntington's disease field. Keep up to date with latest research news at www.hdbuzz.org

Useful links

Contact a Scottish Huntington's Association HD Specialist

Scottish Huntington's Association Financial Wellbeing Service

National and Regional Care Frameworks for Huntington's disease

Scottish Huntington's Association Youth Service

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