

Realising you have - or might have - HD

What is in this fact sheet

- Tips and hints for this stage
- Coping styles and stages in making changes
- Stages of change
- Asking doctors questions
- Tips and hints for family and friends
- Sources for further information

Key points from this fact sheet

- Take time when you get a diagnosis or a genetic test. You can come back later and ask questions about it and what it means when you are ready
- Remember that other people might need time to take things in and cope with change in different ways
- There are tips on asking doctors questions and coping with change

Tips and hints for this stage

Take your time when you get the diagnosis. Don't think you have to ask everything all at once. Go back to the HD Specialist or your doctor and ask your questions when you are ready.

Don't try to tackle every aspect of living with HD at once. Take your time. Cope with one thing at a time.

Have someone you are close to who you can talk to about HD.

- It's good to be able to talk about how you feel about it.
- It always helps to have someone with whom you can talk over your options on anything.
- They can also tell you if you do begin to behave differently or seem to be having problems with something that you might not have noticed.

Think about how you tell your partner and tell other members of your family.

- Ask the HD Specialist or the staff at the Genetics Unit for advice on how to tell people, especially your family.
- Use material that SHA has produced, and check out material written for young people as this is a lot less technical: Talking to children about HD and Information for teenagers, which are both available on the website (hdscotland.org/hd-routes).
- Remember that other people may need to hear about HD several times before they take it all in. So don't get annoyed if they don't remember what you've told them or if they get a bit muddled at first.
- Tell them about this web site or talk about the other sections of Information and resources on the site, so they can check things out for themselves.
- Take time to think about the implications for other people as well as for you – for example, when someone young gets a genetic test and that takes away their parent's right not to know whether they have the HD gene.

Start building up photographs and other ways of reminding yourself about what is good in life.

Coping styles and stages in making changes

Everyone has a different approach to coping with a big life change like getting a diagnosis of HD.

- Some people react to the news in a similar way to having a bereavement.
- Some people cope by learning all there is about their condition.
- Others cope by getting on with the rest of their lives and putting this new part to the background.
- In time, we often adapt to the change and find the balance that lets us get the support we need for HD and have as good a life as we can.

- For someone with HD, the changes can include where we live and the type of work we do.
- It can also be about how we look out for our symptoms and keep well.
- Making a big change in our lives doesn't come all at once. We do it in stages.
- One of the stages is just thinking about it – getting used to the idea that you may have to make a change in your life.
- Other stages are what happens next – trying things out and coping with setbacks as well as when things go well.
- Everyone makes changes in their lives at their own pace. What is right for you may not be right for the people around you.

More information when you want it

The SHA website and the Youth Project website have good information which is useful when you are telling other people about HD.

Asking doctors questions

These are the steps that many people find helpful when they want to ask about their own situation at any time.

- Take some time to think about what you want to know or get changed around with your own treatment or support.
- If you have questions about your condition or treatment, make a list.
- Arrange to talk to your doctor or to someone else who can help.
- You do not have to wait for a clinic or GP appointment that is already arranged if you want to see someone sooner.
- Get some help if you find it hard to remember what the doctor tells you.
- Find ways to explain to the doctor how you manage your condition.

More information when you want it

There is a longer note on Asking Doctors Questions on the website.

Tips and hints for family and friends

- Remind the person with HD that you care about them and will help, whatever happens.
- Give them time to take things in and move at their own pace.
- If you find you want to move at a different pace, explain this, but try to find other ways to deal with this. For example, you can go and find out more about HD and keep it to yourself until the person with HD is ready to read it. Or you can let off steam in the gym while they seem to be going on as before.
- Use this fact sheet to help you list the questions you have about HD and living with it.
- Think about ways you are adjusting to the news about HD, and also about how the person with HD is adjusting. You may need to learn to allow each other to move at a different pace or to cope in different ways.
- Offer to help with the practical side of things – such as going with the person to the doctor and other appointments. Having someone else to drive and find the parking space can make a stressful situation a lot more manageable, as well as the emotional support a person gets from someone who cares about them.
- At the same time, don't feel upset if the person with HD says they prefer to do things on their own, or to talk to someone else.
- Think about the ways the person with HD can go on helping you. Relationships are based on reciprocity – we help each other but do it in different ways. For many people, having aspects of their life that are the same as before and where they are still making a contribution are really important during a period of change and when other things are out of their control.
- Get advice and support for yourself. One source is the Carers' Centres that are linked to the Princess Royal Trust for Carers.
- If you are at risk of HD, think about what support and advice you need for yourself.
- Remember that you can get in touch with the HD Specialists and use the information on the SHA website too.

Sources of Further Information

The Health Rights Information Scotland project is funded by the Scottish Government and is based at the Scottish Consumer Council. It is here to help everyone in Scotland to be able to ask questions about their care and be involved in their own treatment and care in the way that they want to.

There is further information about where to get support at care.hdscotland.org/finding-out-if-you-have-symptoms-of-hd