

People to help you

What is in this fact sheet

- Tips and hints for everyone
- Tips and hints for the early stages
- Tips and hints for later stages
- Tips and hints for families and friends

Key points for this fact sheet

- There are services that will help you when you need more support
- There are also lots of ordinary services that will help you

Tips and hints for everyone

There are several types of people who can help you. They all bring different skills and strengths, so you'll probably use a combination of people at various times and situations.

- Family and friends are often a great source of help
- Services – people who provide help with health care and symptoms, social care services, housing services, money advice services and so on.
- All the ordinary services that people pay for, such as shops and tradesmen.
- There are people to help you if you get hassled or are at risk – Police, social work, Employment Rights and Money Advice etc.

There are health care and social care services that are based in the community. You get access to these through your GP or through the social work department at the local authority. They are there to help everyone who needs extra support because they have a disability or a health problem.

There have been recent changes to the way that people access support from social services. Councils now have to offer self-directed support to everyone. There are four options:

- Direct payments (money paid to you for the purpose of buying and arranging your own care (this can be with someone's help).
- An individual budget, where you are allocated a pot of money to get support, but this is organised for you by Social Work.
- Traditional model of support where a social worker will work with you to assess your needs and then organise services.
- The fourth option is a mixture of any of the first three options.

You can get more information about these options from:

www.selfdirectedsupportscotland.org.uk

Tips and hints for the early stages

Check what help you can get through SHA. You may live in an area that has a Specialist Advisor and/or a Family Group. But even if you don't, you can still get advice and use the website and newsletters and other information. And the Youth Project is a great source of information and help too. There is also a National Financial Wellbeing Service that gives advice on maximising your income, managing debt and planning for the future.

SHA is in the process of developing a National Framework for Huntington's Disease (care.hdscotland.org). At the time of writing, the National Framework is live and will help you see all the services that you should be receiving. During 2017, Regional Frameworks for each area of Scotland will be developed.

You can also get in touch with the Genetics Unit that did the test for you. Ask what help is available for people in your area who have HD. They may have told you about it at the time, but just go back when you are ready and take time to get all the details you need.

At the beginning it can feel that there are lots of staff with job titles you've not heard of before. Get into the habit of asking each person what they do – what their job is, who they work for, what skills they have in their role, and how they can help you.

Keep some of the information about HD with you when you are in touch with various services, as not everyone will know about HD. Also, if you are looking well at the moment they may not immediately understand why you are trying to anticipate something that will happen in a few years.

SHA produces a Road Map (<http://hdscotland.org/hd-road-map/>) which can help you write your own care plan. This can be very useful in meetings with health or social care staff.

Think about the confidentiality thing. The staff who are looking after you must respect your confidentiality. That means they cannot tell other people – including your relatives – unless you specifically tell them that you want them to do this and it is ok. Even the family doctor can't tell the other people who are also her patients. So you might want to discuss with your GP or the HD Specialist if you want them to help you tell other people about the diagnosis or about later developments.

Remember that the ordinary sources of help are there, and you can build up a good relationship with the people there. For example, if you get help from staff at the local supermarket or use the on-line ordering services, you may not need to ask for extra help with getting shopping when you are tired.

Tips and hints for later stages

If you feel you are finding some things difficult, ask for a Social Work Community Care Assessment. List out the things you find are problems and any ideas you have about what would help. The SHA's Road Map can be helpful here (<http://hdscotland.org/hd-road-map/>). Don't worry about coming up with solutions for everything – there will be options that you don't know about.

Have a list of names and phone numbers of people who are good at helping. Keep it somewhere that is easy to see. Or put the numbers into your phone and use the speed dial numbers. Or better still, do both. Include people like your GP and the SHA team as well as neighbours and friends.

Get to know the people who can come quickly if you need some extra help with something practical or to talk to. You may not ever need them but it's good to know they are there. It's like a 24 hour emergency plumber, but for living with HD rather than your kitchen getting flooded – although it's good to hold onto a good plumber too.

Don't assume that the staff you deal with even in health services and social care will know all about HD, or that they are in touch with HD Specialists at SHA. They might not. And even staff who know all about the genetics side may not know that much about living day to day with HD. Ask people what training and experience they have and encourage them to get in touch with SHA.

Tips and hints for families and friends

Think about what you and other people close to the person with HD can do to support and encourage them.

Be realistic. Think and talk about what happens if you are unwell, or have more commitments at work, and so can do less than before.

Find out about the practical supports that are available for everyone, such as supermarkets that do home delivery for shopping.

Also find out about the social care services that are available where the person with HD lives. Get a contact number for the social work team in case you ever need it in a hurry.