

Support for carers

“It isn’t just about the complex symptoms or huge financial challenges. It isn’t just the many years during which you may be a carer, or the possibility of caring for more than one family member during your lifetime. It isn’t just the sadness, grief and sorrow of gradually losing the person you care for. It isn’t just the worry about children living with the genetic condition or the isolation that can come with Huntington’s disease. It is ALL of these things.”
(Quote from a family carer)

Being a carer for someone with Huntington’s disease can be very challenging. Because of this, it is important to look after yourself as well as the person you care for. This factsheet will look at what help is available to support you in your caring role.

1. The Carers (Scotland) Act 2016

This gives all adult and young carers in Scotland the right to a personalised plan to identify what is important to them and to offer support in meeting these needs. For adult carers this is called an Adult Carer Support Plan and for young carers it is called a Young Adult Statement.

2. Respite

It may help to have regular breaks from your caring role. For example, the person you care for may be able to visit a day centre a few days a week or someone might come in and sit with them for a few hours. In addition, having a longer respite break can give you and the person you care for something to look forward to.

To find out how to get your own carer’s plan, or to discuss respite, you can contact your local [social work department](#) or [carer centre](#).

3. Local carer centres

Carer centres are independent charities that can offer:

- Information and advice on things such as benefits, training, short breaks, support services and advocacy
- Emotional support to allow you to talk with trained staff, volunteers and other carers who understand your situation
- Community consultation, giving carers a unified voice to influence local, regional and national decision making
- Activities for yourself including breaks, time out from caring and relaxation therapies

4. Finances

Caring for someone may lead to money worries, especially if your caring role means you have had to give up work. You may be able to get help to increase your income, such as Carer's Allowance or a Young Carer Grant. Our [Financial Wellbeing Officers](#) provide advice on issues such as benefits, debts and energy.

5. Emergency Planning

Many carers worry about what will happen to the person they care for in an emergency. It is a good idea to have a plan in place for this type of situation. This is called an emergency plan. You can write your own plan or use one of the templates available, such as the [Emergency Planning Toolkit for Carers](#).

It is useful to talk to friends, family and support networks about the role they could play in an emergency and share the plan with them. This can provide peace of mind for you and the person you care for. It will also ensure that the relevant people have the necessary information to step into your role temporarily or identify resources when informal networks can't be relied upon.

6. HD Specialists

[Scottish Huntington's Association](#) HD Specialists have expertise in working with individuals and families impacted by Huntington's disease. They help with issues such as symptom management and provide emotional support for carers. Your HD Specialist can meet you at home or in another place of your choice. This can be with or without the person you care for. Your HD Specialist can also give you information on any carers' support groups that may be running in your area.

7. Supporting young carers

The [Scottish Huntington's Association Youth Service](#) provides advice and support for young carers and, if you wish, will introduce you to other young people who are in a similar situation.

8. Looking after yourself

Carers often neglect their own health and wellbeing because they are so busy caring for and thinking about others. They often have little free time and stop doing the things they enjoy. Eating well and exercise can also fall by the wayside. However, it's really important to look after your own physical and mental health. Doing things you enjoy and having time to relax can make it easier to cope when things are difficult. Talking about how you feel can also help, and there is support available if you find it difficult to talk to friends and family. It's also important to speak to your HD Specialist or GP if you feel your mood is low or you are struggling to cope.

Useful links

[Carers UK - Scotland](#)

[Carer information - Scotland](#)

[Breathing Space](#)

[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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Updated January 2022