

Support if you are a caregiver

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Support if you are a caregiver

Caring for someone with Huntington's Disease (HD) can be intense, emotional and stressful. Many people who care often do not realise the support they are providing is care and therefore do not always refer to themselves as a carer. However, no matter how big or how small your caring role is, it is important to make time to look after yourself too. There are also many rewarding parts to caring however, if a carer becomes exhausted and drained the impact can be devastating.

There are many resources available to ease some of the pressure of caring. Please take some time to look over them as it is important to find a style of support that will work for you. Some people prefer HD-specific support, others would rather access more general carers services – or maybe a combination of both!

HD Specialist Services

HD Specialists are available in most areas of Scotland. Their role can be from emotional support and a chance to off-load or chat to more formal support and assessment. Many Health and Social Care Professionals may not have prior experience of supporting someone with HD. The HD Specialists can support them by providing training or an understanding of how things are for both yourself and the person with HD that you care for.

To contact your local HD Specialist please visit www.hdscotland.org or call Head Office on **0141 848 0308** for more information.

SHAyp

Specialist Youth Advisers are available Scotland-wide for any young adults who are living in a family affected by HD. The SHAyp life staff can offer practical and emotional support for young carers amongst many other things. For more information on how SHAyp Life may help you please visit www.hdscotland.org/shayp-home or call **0141 556 2136** for more information.

Carers Assessment

Anyone who provides regular care in Scotland is entitled to a free assessment from their local Social Work Office. This is an opportunity to discuss your caring role, how it impacts on your days and what support might make life easier for you or the person you care for. This is different from the Community Care Assessment the person with HD will be offered. If you would like further information please contact your local Social Work office, or alternatively, you could speak to your HD Specialist to make this referral on your behalf.

Getting a break

It is important to have the opportunity to 'get away from it all' at times and recharge your batteries. This may be booking a holiday with the person you care for or perhaps it may mean taking a break from your caring role completely, known as respite.

Taking a holiday together

There are now several options available for those who enjoy holidaying together though need to ensure properties are accessible to meet their needs. It can feel daunting when visiting places you may not have been before, especially if you need to ensure access for wheelchair or for someone with mobility issues.

www.disabledgo.com has information on hotels, self-catering, cafes, museums etc. which have disabled access throughout the UK.

SHA Short Breaks Grant Fund

The charity provides grants of up to £500 to enable families living with Huntington's disease to have a break. Grants are available to people living with the symptoms of the condition, carers and young people. To apply for a grant, contact your local HD Specialist Service.

Other sources of information

Carers Trust Scotland:

www.carers.org/scotland

The Carers Trust website is a comprehensive resource with many fact sheets and guides for caring. These include information about respite care, managing to balance work and care, taking care of yourself, money advice and legal advice (power of attorney, guardianship). There are local carers centres throughout Scotland – to find your local centre please visit [HERE](#) These centres are able to offer training in topics such as first aid, budgeting and finances and moving and handling.

Carers Scotland:

www.carersuk.org/scotland

The Carers Scotland website also offers many fact sheets and guides for caring. These include information about respite care, managing to balance work and care, taking care of yourself, money advice and legal advice (power of attorney, guardianship). Scotland-wide they offer a selection of training opportunities, updates on policy and campaigning. There is a carers advocacy service in South West Glasgow area.

Care inspection reports:

www.careinspectorate.com

You can check, up-to-date care inspection reports for care homes.

Respite Break:

www.carers.org

At times, you may feel you need a break from your caring role and this may take the form of additional care at home or a residential break in a care home. Your local Social Work office can provide details about the local arrangements for this. You can contact them directly or ask your HD Specialist to make this referral on your behalf. This can be a difficult decision to make, however emotional support and practical information can be provided by your HD Specialist to help this be as smooth an experience as possible.