



Huntington's Disease Association

Huntington's disease

A Carer's Guide

Fact Sheet

A Carer's Guide

BEING A CARER

Many people who care for a member of their family don't see themselves as a 'carer' but as a son, daughter, partner or parent to the person with Huntington's disease (HD). However, across England and Wales there are thousands of people caring for people with HD and trying to cope with the changing nature of the relationship they have with that person.

Caring for someone with HD can be incredibly difficult, tiring and stressful. People with HD present with physical, emotional and cognitive problems but the variation in the symptoms is great and no two people present the same way. What sets HD apart from many other illnesses is its genetic nature; carers may have cared for others in the family with the same disease and may be at risk themselves.

How you feel about your caring role will vary greatly depending on your individual circumstances, but all carers are likely to find that there are times when they struggle practically and emotionally.

Many people describe feelings of frustration, fear of the future, resentment, anxiety, guilt, anger, loneliness and depression (carers UK, 2007). People often find it helpful if they can meet other people in a similar situation and realise that they are not alone in having these feelings. As a carer it is important that you have access to support for the person with HD and for yourself; by doing this you can try and stop these feelings getting out of control.

SUPPORT FOR YOU

How you feel about being a carer will depend on your individual circumstances, while the role can be rewarding, all carers are likely to have times when they struggle practically and emotionally. A lot of people you encounter, including professionals, are unlikely to know much about HD and therefore struggle to understand what you are going through, which can be very frustrating. People often find that friends and even family members struggle to understand the disease and especially the changes which people might have to their behaviour. It's important that you find a

form of support that suits you; this might be support that is specific to HD, or general support (most likely a mixture of both).

Support from the HDA

The HDA Regional Care Advisory Service – There are HDA Specialist HD Advisers (SHDA's) across the country, the SHDA's all have backgrounds in either health or social care; they are there to support you and the person you are caring for. This could be just having someone to chat to and off-load, or it could be helping you to access other support if you don't know how to do this or where to look. You can find your local SHDA by looking on the website www.hda.org.uk or calling the HDA Head office T: 0151 331 5444 (E: info@hda.org.uk).

HDA Youth Engagement Service – The service is for any young person who is aged 11-22 living in a family affected by HD. The support that we can provide is completely up to you. We can provide support with talking to school or college, introducing you to young carer's projects and even provide a non-judgemental ear to listen to you if you just need someone to talk to. You can access the service either by referral through your local Specialist HD Adviser (SHDA), or directly, by contacting our Specialist Youth Worker at the HDA head office on 0151 705 3460, or email adam.cho@hda.org.uk

HDA Branches And Support Groups – The HDA has branches and support groups across the country; these are run by volunteers who have a link to HD. They all evolve in their own way and form to meet the needs of the people who use them. Branches are slightly more formal than support groups as they have a committee, but the main aim of both branches and support groups is to come together with people who understand your situation. Once again contact details of any local branches or groups are available by calling the HDA Head Office T: 0151 331 5444 (E: info@hda.org.uk).

HDA Message Board – the HDA also has an online message board where you can find support from people in similar situations. This is a great way of getting support if you find it difficult to get to a group or if you feel you would prefer to remain anonymous. You can access the message board via the HDA website www.hda.org.uk.

HDA Membership – The HDA has free membership for people with HD, their friends and families. By subscribing you will receive a twice yearly newsletter to keep you up to date with HDA events and research. Contact the HDA Head Office (T: 0151 331 5444) if you wish to become a member.

HDA Annual Events – The HDA runs annual events which are there for people with HD, their carers and children to get involved in. Each year there is a ‘family conference’ which runs alongside the Annual General Meeting; this is a good way of meeting other people who have a link to HD and learning more about the disease. The HDA currently runs 3 summer camps for children who have HD in the family; these are activity based fun weekends allowing both children and parents to have a break. The HDA also holds an annual family weekend for children who have juvenile HD and their families. There is also an annual conference for young people (18-35) with HD in the family. For further details of any of these events contact the HDA Head Office (T: 0151 331 5444).

General Support

Carers Centres – Carers centres are available across the country and the support offered varies depending on where you live (support could include days out, advice on benefits and form filling, complementary therapies, support groups, courses about caring, training on back care etc). Find your local carers agency by visiting www.carersuk.org or in the local phone book.

GP / Health Services – It is important that you look after your own health. It is important to tell your GP that you are a carer; they will find it easier to provide you with the right care you need if they know that you are under the extra strain of this role. Many GP practices hold a ‘carers register’ to help carers e.g. by offering more appropriate appointment times. Your GP should be the gateway to other health services and they can refer to social services. They should be able to offer advice and support on issues relevant to your caring role. Your GP should also be able to arrange for you to have a free flu jab. This is important not only to maintain your own health but to ensure that the person you are caring for is not put at risk of infection. Try to visit your GP with problems before they get out of

control. Be open with your doctor about how you are feeling so he/she can make the best decision about your care.

HAVING A BREAK

In order to function as a carer you need to have time to have a break from your caring duties and 're-charge your batteries'. A lot of people find that regular respite (e.g. using a day centre 2 or 3 times a week) helps from week to week and having a longer respite break once or twice a year gives both the carer and the person with HD something to look forward to. Although awareness is improving, HD remains a very rare illness so services may not have experience of looking after other people with HD. You could ask your SHDA to make contact with them and provide information, advice or training.

Sitting Services – This would involve someone who could come and sit with the person you care for in your own home, normally for a couple of hours a week, so you have the chance to have a short break. Your Social Worker should be able to advise you on the services and nominate you for schemes in your area such as Carers Trust (www.carers.org).

Day Centres – Day centres vary greatly in the services they provide and in the client group who attend. They can offer suitable activities for people with HD and some have their own transport. It is worth considering different day centres in your area to see which one would suit the person you care for the best. Some day centres will be free of charge and others will require a financial contribution. Your Social Worker should be able to advise you on day centres in your local area.

Respite Breaks In A Care Home – A carers' assessment should highlight whether you are entitled to respite breaks from your caring role. This is normally a chance for the person you care for to have a week or two in a care home (or specialist holiday centre) so you have a break from caring. You will be means tested for this and may have to pay the whole amount of a respite break or make a contribution towards it. Often people like to use a home which has specialist knowledge of HD and your Specialist HD Adviser will be able to advise if there are such homes in your area.

Holidays With Help – There are a number of options for people with disabilities to have a holiday with help; either by themselves or with their

partner or carer. 'Holidays for all' has a number of options
www.holidaysforall.org.uk

HELP WITH GETTING AROUND

Having highlighted the importance of getting breaks from the day-to-day caring role, either away from the person you care for or by doing other things together, the practicalities of getting out and about needn't be a barrier to independence.

There are a number of schemes to help you and the person you care for get around more easily.

Private Travel:

The Motability Scheme – leases cars, powered wheelchairs and scooters to disabled people who are in receipt of specific benefits
www.motability.co.uk

Car Tax Exemption – If your car is primarily used for the person with HD then you should be able to claim car tax exemption see www.gov.uk

Blue Badge – The Blue Badge provides a range of parking concessions to people with severe mobility problems. Contact your local council for their application procedure. People with a Blue Badge are able to apply for exemption from the London Congestion charge, and application forms can be downloaded from www.tfl.gov.uk or 0845 900 1234.

Public Transport:

Disabled Persons Railcard -If the person you care for has difficulty travelling by train they may be entitled to a disabled person's railcard. They and an adult companion who is travelling with them will be entitled to 1/3 off most train journeys. www.disabledpersons-railcard.co.uk T: 0845 605 0525.

Help At Stations – help should be available at stations for people with a disability but you will need to book this in advance, call the train company you are travelling with. Further details can be obtained through National Rail Enquiries, on T: 08457 484 950, or email: www.nationalrail.co.uk.

Local Bus Pass – People who are seen to have an ‘eligible disability’ are entitled to free local (off peak) travel on local buses, contact your local council for more information.

Taxicard – some areas have taxicard schemes whereby some disabled people are entitled to cheaper taxi journeys. Contact your local council to see if there is a scheme in your area.

Dial – A – Ride: Most councils have a scheme such as dial-a-ride where a specialist mini-bus will transport people to their destinations. The schemes run differently across the country – contact your local council for more details.

Concessions:

Sometimes concessions are available to a carer accompanying someone with HD e.g. free cinema tickets and event tickets are available at many venues. Always ask at the time of booking if any concessions apply and mention any special needs such as wheelchair access. Most establishments welcome disabled visitors and appreciate advance notice so they can assist as far as possible.

Disabled Toilets:

Disabled toilet facilities are required by law in many places. Use schemes such as RADAR key to make accessing facilities easier. www.radar-shop.org.uk

FINANCIAL HELP

As a carer of someone with HD, you are likely to have cut down or given up work; income will have dropped and often costs go up, for example if you are spending more on food or laundry. The benefits system is very complex and constantly changing so it is important to get help in accessing what is available to you and the person you care for.

You can get advice on benefits from:

Carers Line T: 0808 808 7777 or carers UK www.carersuk.org

Local Carers Centres

Local Citizens Advice Bureau

Disability organisations / welfare rights teams in your area

There is other financial assistance that you may be able to claim alongside your benefits. The following list is not exhaustive but highlights some of the schemes in place to help reduce the financial burdens on you and your household.

Reductions in council tax

Help with healthcare costs including free prescriptions for those who are affected by HD and unable to leave the home 'without the help of another person' (Form FP92A applies).

Help with heating costs

Grants if you need to adapt your home

There are several charities that offer small grants for people in financial hardship

CARING AND WORKING

Working while caring can become very difficult and having an understanding employer can make a big difference. You do not have to tell your employer that you are a carer and you might want to check your company's policies on carers before you start discussing the issue. You do have rights as an employee and your employer should be able to advise you on flexible working, emergency time off and any other policies.

If you are thinking of leaving work Carers UK provide useful information which might help your decision. www.carersuk.org T: 0808 808 7777.

HELP WITH CARE

Caring for people with HD can be incredibly stressful due to the cognitive changes which people experience. By knowing a little more about how the person with HD feels it can help you understand why they might behave in

a certain way. The information below was written by a carer, it is their understanding of what it means to have HD based on the person they care for, and other people they have met. This handout is often given out to paid carers as a quick reference guide to thinking about having HD.

One of the best ways of coping is talking to other people who have been in a similar situation and finding out the coping strategies they used. The information below was written by the same carer, it is a list of tips that can be useful when caring. Again this is often given to paid carers as a quick reference guide.

PRACTICAL HELP WITH CARE

All carers need support with the care they provide. You could contact Social Services to get practical help. In order to assess the sort of assistance you need they should carry out an assessment of the person you care for and a separate assessment of your needs. You can find the number for Social Services from the telephone book, by looking for your council online or by asking your GP to refer you.

When Social Services assess the person you care for they will look at what help they need with personal care (such as washing/dressing or going to the toilet) and whether external help is needed with this. If the person needs help with personal care they may also be entitled to help with the shopping and housework.

A financial assessment will be carried out and a decision made as to whether you have to pay the full cost of care or a contribution towards it (most people are expected to make some contribution as benefits can be used for this).

The Social Worker or the GP can also arrange for a home assessment by an Occupational Therapist to see if adaptations could help e.g. grab rails / a seat for the bath, a home care alarm etc.

Direct Payments Scheme – If you are entitled to financial assistance towards your care, your Social Worker may offer you the option of Direct Payments. Direct Payments allow you to arrange your own care services.

This does give you more flexibility (e.g. more choice in who you employ) but also gives you more responsibility (e.g. paperwork and arranging insurance).

Emergency Care - Social Services should be able to give you a telephone number for their out of hours emergency services.

Nursing Care - If the person you care for has nursing needs then the NHS may contribute towards the cost of their care or pay the full costs. If the person you care for is living in a care home, the managers should be able to assist you in contacting the local Primary Care Trust and asking them to make an assessment of the nursing needs.

Private Care - You can arrange home care privately; for details of agencies contact the UK Home Care Association (UKHCA), www.ukhca.co.uk T: 020 8288 5291.

HEALTH AND SOCIAL CARE PROFESSIONALS WHO MIGHT BE INVOLVED

HD is a complex disease, therefore over the course of the disease you will come into contact with many professionals. Sometimes it is difficult to know to ask for these services if you don't know they exist; the list below may be useful. It is recommended that these professionals are involved as early as possible. If you have a Health Care Professional involved who doesn't know a lot about HD you can ask your Specialist HD Adviser to contact them who can give information, advice and training.

Family Doctor – The GP can help with Health problems of both yourself and the person you care for and also refer onto other health services, such as Physiotherapy or Speech and Language Therapy.

Specialist Clinics – There are a number of specialist clinics for HD across the country, which can be accessed through a GP referral. Your local SHDA will be able to advise you of any clinics in your area.

Genetics Services – There are genetics clinics across the country, some of them linked to the Specialist HD clinics.

Dietician – A Dietician will assess a person's nutritional needs. Many individuals with HD require a high calorific intake to maintain their body weight. The Dietician can offer help and advice on maintaining an adequate and nourishing diet. This may include information on ways to increase calorific intake without increasing the amount of food intake.

Speech And Language Therapist – A Speech and Language Therapist can advise on swallowing and ways to assist communication.

Occupational Therapist – Occupational Therapists can advise on equipment or alterations to the individual's home, specialist seating and bathing equipment.

Physiotherapist – The Physiotherapist will show the individual with HD and the family how to keep as active as possible to maintain muscle strength and minimise potential problems of falling. They will also give advice on moving and handling.

Mental Health Services – Specialist mental health workers can include Community Psychiatric Nurses, Counsellors and Psychologists. They provide people with opportunities to talk through issues and difficulties that may arise and find better ways of coping.

Social Services – Social Workers can advise and help on many social and care issues such as sources of information on benefits and funding, care packages, respite services, residential and nursing homes.

Continence Nurses – The Continence Nurse can offer advice to yourself and the person with HD on all issues regarding bladder and bowel problems.

Admiral Nurses – Admiral Nurses, who specialise in dementia, work in the community with people with dementia and their families and carers. www.fordementia.org.uk T: 0845 257 9406.

District Nurses – District Nurses visit people in their own homes, or in residential homes for their nursing needs. They can offer advice on generic health issues and administer basic treatments in the home.

Dental Services – It is very important for those with HD to maintain a high degree of oral hygiene. Some areas offer home (domiciliary) visits to keep regular checks on dental health.

Search for one close to you at www.nhs.uk

Opticians – In the event of it being difficult to get somebody to the opticians some opticians offer a home visit service. Your GP may have a list.

Bereavement Services – Bereavement services should be available through your GP or your local hospice. There are also bereavement charities such as Cruse Bereavement, www.crusebereavementcare.org.uk Helpline 0844 477 9400.

Hospice Services – Hospice services vary across the country, some offer inpatient stays or day facilities. They may be able to help with pain management and often offer services such as bereavement counselling and complementary therapies for carers.

Counsellors – Local counselling services can be found on the British Association for Counselling and Psychotherapy (BACP) website. www.bacp.co.uk; you can also ask your GP to refer you for counselling.

WHAT HAPPENS WHEN PEOPLE GO INTO LONG TERM CARE?

There may come a time when it is more appropriate for the person you care for to move into a long term care facility (residential or nursing home). The HDA provide a fact sheet on choosing a care home and your Social Worker should be able to assist you in finding a suitable placement, they will carry out a financial assessment to see if you will need to pay for or contribute towards the cost of long term care. Your SHDA can suggest any specialist homes which might be appropriate.

This can be an incredibly difficult time especially as most people have been spending so much time with the person they care for. However, people often report that while the quantity of time they spend with their loved one is less, the quality of time is much more.

CARING FOR A CHILD WITH JUVENILE HD

Juvenile Huntington's disease (JHD) refers to anyone who develops signs or symptoms of HD before they are 20 years old. It is a relatively rare condition and only about 5% of people affected with JHD will develop symptoms this young. This can make it quite an isolating experience for everyone involved, and particularly the carer who is often the child's parent or close relative. The person caring for a child with JHD may well be caring for (or recently have cared for) the child's parent with HD or other family members as well.

In many ways, the issues that affect carers of young people with JHD are very similar to those caring for adults with HD and the advice in the other sections in this leaflet will be relevant to any carer of someone with JHD. However, carers of people with JHD also often say that caring for your child is different, because of their age, their relationship to you and because JHD is much rarer than adult-onset HD.

Since JHD is rarer than adult-onset HD, it can be difficult to meet other people in a similar situation. Some carers of young people with JHD use on-line message boards or chat rooms to meet other people throughout the world. The HDA also run a family weekend once a year for young people with JHD and their families. Further information can be found through the JHD pages on the HDA website (www.hda.org.uk) or through the HDA's Care Adviser for JHD.

There are some additional sources of practical / financial assistance for those who develop HD at a younger age, as some services / charities particularly focus on younger people. A useful source of advice on these is Contact a Family (www.cafamily.org.uk). The HDA website also has a 'useful websites' page specifically for JHD (www.hda.org.uk).

There are a number of children's wish charities that can arrange special trips or holidays for children or young people with JHD. They all have different criteria, and some can also accept those with JHD who are older (up to the age of 21). Organising a special trip or holiday can give the young person and their family something to look forward to.

Because of their age, many of the young people with JHD will, at some point, be attending a school or college. Many schools and colleges are happy to support the young person for a long time and look for ways to overcome the challenges that may occur, but may appreciate information, advice and training to help them do this from the Specialist HD Adviser or Care Adviser for JHD.

Children's Hospices can also provide a lot of support to young people with JHD and their carers. They can often provide respite, specialist advice and family support. There are some hospices that also offer services to those who are a bit older. Although there are not many of these, new services are currently being planned and opened.

Fact sheets available from the Huntington's Disease Association:

- General information about Huntington's Disease and the Huntington's Disease Association
- Predictive Testing for Huntington's Disease
- Talking to Children about Huntington's Disease
- Information for Teenagers
- Eating and Swallowing Difficulties
- Huntington's Disease and Diet
- The Importance of Dental Care
- Communication Skills
- Behavioural Problems
- Sexual Problems
- Huntington's Disease and the Law
- Huntington's Disease and Driving
- Advice on Life Assurance, Pensions, Mortgages etc.
- Seating Equipment and Adaptations
- Checklist for Choosing a Care Home
- Advance Decision to Refuse Treatment (ADRT)
- A Carers Guide
- A Young Adults Guide
- Challenging Behaviour in Juvenile Huntington's Disease
- A Brief Guide to Juvenile Huntington's Disease for Children's Hospices and Palliative Care Service
- A Young Person with Juvenile Huntington's Disease at School

All fact sheets can be downloaded free of charge from our website www.hda.org.uk or ordered from Head Office.

For a publication price list/order form, membership form, details of our Specialist HD Advisers and local Branches and Groups, please call Head Office on:

Tel: 0151 331 5444 or Email: info@hda.org.uk

Huntington's Disease Association
Suite 24, Liverpool Science Park, IC1, 131 Mount Pleasant, Liverpool L3 5TF
Tel: 0151 331 5444 Web: www.hda.org.uk Email: info@hda.org.uk
Registered charity no. 296453