



HUNTINGTON'S DISEASE ASSOCIATION NORTHERN IRELAND

Families at the heart of all that we do

A Carer's Guide to HD

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. However, across Northern Ireland there are hundreds 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. 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 forms of support that suits you; this might be support that is specific to HD, or general support for carers or most likely a mixture of both.

It is important that you look after your own health and 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.

You Time

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. Ask your social worker for more information and if you do not have a social worker ask your GP to make a referral to social services on your behalf.

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](#).

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 HDANI Support Worker can advise you of homes in Northern Ireland with experience of HD or we can arrange training for staff in any home you have been matched with.

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.

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.

Patient Transport Service

Northern Ireland Ambulance Service provides non-emergency patient transport services across the province. This enables patients, usually vulnerable and dependent upon us, to get to routine appointments at hospitals and treatment centres throughout Northern Ireland. This service is not available to everyone attending appointments; there must be a medical need for transport. If you think you may require ambulance transport to take you to hospital, please contact your Doctor once you have received your appointment. Your Doctor will then assess your medical need and decide if you require ambulance transport.

Community Transport Association

Call 028 9094 1661 to find out if there are any community transport schemes in your area.

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.radarshop.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](tel:08088087777) or [carers UK www.carersuk.org](http://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 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 Revised January 2015 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 trust 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.

Your social worker can provide advice about benefits or you could contact Advice NI for information.

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.

Considering Long Term Care away from Home

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). 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. HDANI 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.

Contacts

Support from HDANI

HDANI have a small but dedicated team of Support Workers who 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 and services that may help.

HDANI run monthly [support groups](#) with counsellors which provide an opportunity to share experiences and vent in safe space.

You can also speak to HDANI about arranging one to one counselling and we do this either through our own counsellors if there is availability in your area or via GP or community counselling organisations where we will provide information and training about HD to help improve the counsellors understanding of your situation.

There are also courses provided free of charge throughout the year in Northern Ireland in the areas of Mental Health First Aid, Managing Aggression and other relevant areas. Contact [HDANI](#) for further information.

You may also find support through engaging in online discussion groups and you will find some examples of these on our [website](#).

If your GP, or any health or social care professional has limited knowledge or HD you should invite them to [contact us](#) for further information of training or visit our [professional resources](#) section on our website.

Non HD Support for Carers

Carers centres are available across the province 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 [Carers Trust](#).

CAUSE

Founded in 1995, CAUSE is a unique peer-led regional charity offering services to families, partners and friends across Northern Ireland caring for a loved one who has experienced serious mental illness. CAUSE is run by carers for carers which gives us an organisation a true peer-led ethos and belief in the power of connecting with other people who have shared similar experiences of caring.

Helpline: 0845 603 0291

Womens Aid

Offer specialist services for women, children & young people who have experienced domestic violence.

Helpline: 0808 802 1414

Men's Advice Line

MAL are a team of skilled professionals offering practical advice, information and emotional support to male victims of domestic violence, as well as to concerned friends and family and frontline workers.

Helpline: 0808 801 0327

Health and Care Professionals you may need

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 HDANI 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 acts as a gateway to other health and social care services. If you have a HD Specialist nurse in your Trust area they can be an immense source of knowledge, information and support.

Specialist Clinics

There is a specialist clinic for HD at the Belfast City Hospital be accessed through a GP referral. Any patient with HD in Northern Ireland can seek a referral through their GP to Dr Seamus Kearney, Familial Movement Disorder Clinic (HD Clinic) at Belfast City Hospital and they will be added to the waiting list for an appointment however currently (Sept 16) only those patients in the Belfast or South Eastern Trust will have access to the specialist HD nursing service.

Genetics Services

The Regional Genetics Service is based at the City Hospital in Belfast and there are other outpatient services throughout Northern Ireland.

Genetic Outpatient Clinics take place in a number of hospitals and clinics across Northern Ireland, listed below. As not all clinic settings have access to the full range of clinical facilities, patients may be required to attend in Belfast or one of the hospital settings :

In Belfast:

- Belfast City Hospital
- Royal Belfast Hospital for Sick Children
- Royal Jubilee Maternity Hospital
- Knockbreda Health and Well-Being Care Centre
- Action Cancer House, Belfast
- Ulster Hospital, Dundonald

Regionally:

- Altnagelvin Area Hospital
- Antrim Area Hospital
- Banbridge Health Centre
- Bridgeview Clinic, Londonderry
- Causeway Hospital, Coleraine
- Craigavon Area Hospital
- South West Acute Hospital, Enniskillen

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.

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 visits to keep regular checks on dental health.

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 who provide information and support across the province.

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](#) you can also ask your GP to refer you for counselling or speak to HDANI about possible services.

It is important to remember that while HD may be a huge part of your life many other people will never have heard of it. You should not be surprised to find that even the health and social care professionals you turn to for help may have limited knowledge and understanding of HD. It is only one of thousands of disease and conditions they will encounter and they simply cannot be experts at them all. This can be frustrating but you should try to be patient and work together.

If your GP, or any health or social care professional has limited knowledge or HD you should invite them to [contact us](#) for further information of training or visit our [professional resources](#) section on our website.

We can provide in-house training or keep them up to date about any training events we are holding throughout the year. They can also subscribe to our e-zine or newsletter.