



Huntington's  
Disease  
Association

# **Huntington's disease: A carer's guide**

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# Introduction

If you help somebody with Huntington's disease manage their daily life you may be acting as a carer. If you are looking after members of your own family you may not consider yourself to be a carer, as you are first and foremost a sibling, parent, partner, or child of the person with Huntington's.

Naturally, as the disease progresses the person with Huntington's will need more and more support, and your caring role could increase. Being a carer can become difficult, tiring and stressful, and may have an impact on your relationships.

Due to the genetic nature of the disease, you may have previously cared for other family members with Huntington's, and may even be at risk of the disease yourself.

How you feel about your carer role is entirely dependent on your circumstances. Acting as a carer can take its toll, emotionally and physically.

Being a carer is demanding and can be isolating. It is important that you take time to look after yourself. It is not uncommon for a carer to wait until they reach breaking point before seeking help.

Asking for support can be tough, but you should see your own well-being as just as important as that of your loved one. After all, it is easier to care for someone else when you are taking care of yourself.

Carers UK estimate that currently 6.5 million people in the UK act as carers. These people may be supporting a loved one who is older, disabled or seriously ill. Connecting with other carers can help you feel less alone, and can be a great way to share advice and support.

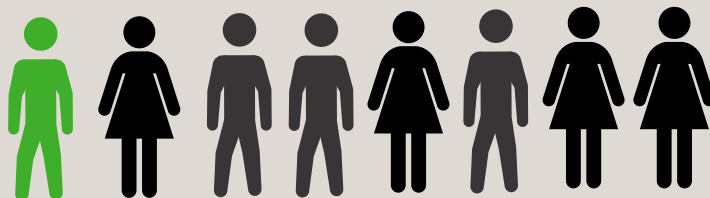
Carers can connect with each other in person or online. There are also various kinds of practical support that you can apply for.

This guide is aimed specifically at people who are caring for a person with Huntington's disease.

Further carer support and free guides can be found at:

 [www.carersuk.org](http://www.carersuk.org)

**6.5 million  
carers in the  
UK**



**That's 1 in every 8 adults**



# Support from the Huntington's Disease Association


## **Specialist Huntington's Disease Advisers (SHDAs)**

Our Specialist Huntington's Disease Advisers have a background in health or social care and are knowledgeable about Huntington's disease.

They operate throughout England and Wales and support both the person with Huntington's and the carer.

You may want to contact one of our advisers if you are struggling and need help. They can give you advice on accessing other support services, or simply act as somebody to talk to.

To get in touch with your local Huntington's Disease Adviser, contact us at:

 0151 331 5444

 [info@hda.org.uk](mailto:info@hda.org.uk)

*"I found it really hard to make the first phone call to the Huntington's Disease Association. I was caring for my mother and was struggling with feelings of failure. I felt completely stuck and powerless and other agencies had not been interested or couldn't help. I needed help for myself, as well as my mother, and the Specialist Huntington's disease adviser was amazing."*

*She understood right away and over time we worked out how to move forward, and there was a huge sense of relief.*

*The Huntington's Disease Association provide so much more than this support; it's a safe haven for when things are tough. I would encourage everyone to make the first call, sooner, rather than later."*

## **Website**

Our website offers practical information and sources of help and support. It also has information about events and activities that you can attend and get involved in. Our website can be found at:

 [www.hda.org.uk](http://www.hda.org.uk)

## **Branches and support groups**

It can really help to meet people who know what you're going through. Many people find comfort in meeting others who face similar challenges as they can relate to each other's experiences.

There are Huntington's Disease Association branches and support groups all over the country which are run by volunteers who have a link to Huntington's. These volunteers strive to meet all the complex needs of the people who use their service. Groups meet for a mixture of social activities, information sessions, fundraising and awareness raising – and always a good chat.

Further information about local branches and support groups can be found on our website.

## Message board

We have an online message board for people to share support, information and ideas. This is a great service if you are unable to attend groups and events, or for if you wish to remain anonymous. The message board can be found at:

 [hdmessageboard.com](http://hdmessageboard.com)

## Membership

Huntington's Disease Association membership is free for people with Huntington's and their families and it is easy to join. If you become a member you'll receive a bi-annual newsletter with up-to-date information on events and research. To become a member of the Huntington's Disease Association either give us a call or visit our website for a membership form and return to our central office at:

Huntington's Disease Association  
Liverpool Science Park, IC1  
131 Mount Pleasant  
Liverpool  
L3 5TF

## Events

Each year at the Huntington's Disease Association we run a number of events to provide useful advice, support and guidance to people affected by Huntington's disease.

We hold an annual family weekend. The weekend is made up of talks and workshops, and is not only informative, but can give you the chance to meet others in similar situations to yourself.

There are also local carers events held each year, providing further opportunity to meet others caring for loved ones with Huntington's, share experiences together and learn of useful resources to help you in your caring role.

Further information about our national and local events can be found on our website.

*"The family weekend is great...it is lovely to meet people who understand what I am experiencing. There is a great feeling of belonging and a common cause."*



# Support from other organisations



## Local Council / Social Services

If you are acting as a carer you may be eligible for support from your local council. This can come in the form of finances to help with the ease of care or to cover the cost of respite. Respite can come in the form of alternative care that would allow you some time off.

Local authorities have a legal obligation to offer you a carer's assessment if you request one, or are in need of support. The assessment determines whether you meet criteria that make you eligible for extra support from the local council.

If you're found to be eligible for extra support the council will contact you to discuss what help may be available. Contact with one of our Specialist Huntington's Disease Advisers can be helpful during a process such as this.

During a carer's assessment social services will assess the person you are caring for, and will consider the level of personal care that they generally need. They take into account aspects like whether the person needs help when washing, dressing, shopping, housework, and going to the toilet, before deciding whether external help may be required.

If it is decided that a person requires extra help then a financial assessment is carried out, and a decision is made regarding whether assistance can be given with finances.

The majority of people are expected to contribute towards at least some of the costs, as there are certain benefits that they could be claiming. Additional information on benefits that may be relevant to you can be found later on in this guide and also through the charities Carers UK and Age UK.

Should you wish to have a home assessment carried out by an occupational therapist you can arrange this via the social worker or GP of the person you care for. During these assessments it is decided whether adaptations to the person's home could be helpful, such as the addition of grab rails, home care alarms or seating in the bath.

People with Huntington's who are entitled to financial assistance may be offered direct payments by their social worker. This allows them to arrange their own care services.

Social workers are generally a great source of knowledge when it comes to topics such as benefits, funding, care packages, residential and nursing homes, and respite services.

## **General Practitioners (GPs)**

GPs, or doctors, can support you with any health problems you may be having, including issues with mental health, and stress related illnesses. They can also help with the needs of the person you are caring for.

A GP will record that you are a carer on your medical records and many GP practices hold a 'Carers Register'. If you're on the Carers Register the GP can try to offer more convenient appointment times, or home visits. They can also arrange for prescriptions to go straight to a local pharmacy or to be delivered to your home.

You may want to consider getting a flu jab, to protect yourself, and the person you care for, and a GP is able to arrange this.

A GP can also act as a bridge to other appropriate health and support services. They are able to make referrals to counselling services, social services, and other local services that could provide help.

It is always best to visit a GP as soon as a problem crops up, instead of letting it get out of hand.

## **Counsellors**

A counsellor can help you deal with worries and stresses that you may be facing. A list of local counselling and psychotherapy services can be found on the British Association for Counselling and Psychotherapy (BACP) website:

 [www.bacp.co.uk](http://www.bacp.co.uk)

Your GP can refer you for counselling on the NHS.

## **Care centres**

There are carers centres across the country set up specifically to offer support and advice to people in a caring role. Some centres run support groups, which can give you the opportunity to meet people in a similar situation to yourself and to offer mutual support.

Some carers centres offer training for people wishing to learn more about their carer role. The centres also offer assistance with applying for grants and benefits.

The Carers Trust website has a search facility to help find local carers centres. More information can be found at:

 [www.carers.org/section/help-advice](http://www.carers.org/section/help-advice)

Local authorities can also direct you towards the nearest carers centre.



## Help in an emergency

Being the main carer for someone with Huntington's is a lot of responsibility, and you may be concerned about who would take over your role if something happens to you.

Carers UK has accessible advice on how best to plan for an emergency.

Some areas have an emergency card scheme managed by the local council or carers centre. This would involve you carrying a card with the local scheme's telephone number and your own unique identification number. You are then able to contact the local scheme in the event of an emergency. These schemes usually offer a 24-hour response service. An operator will be able to look up an emergency plan and arrange replacement care where needed.

Local carers organisations should be able to advise whether a scheme operates in your area.

### *Advice for if you find yourself in a crisis*

Occasionally a relationship may change in a way that leaves the carer feeling physically, emotionally or mentally abused. This may make it incredibly difficult to cope with. There are no easy answers, but it is important that you think about your own safety, and that of any dependents you may have.

Having a plan in place should the worst happen is very important. This can mean that if a difficult situation arises in the future it is a little easier for you to handle.

Planning may include considering the best way to react in a variety of different situations, including a crisis.

It can help to have a record of certain phone numbers, put these into your mobile phone. Keeping a list of numbers of your friends, family and colleagues who can help could prove invaluable. Keeping a list of emergency numbers in your mobile phone, including the police, domestic violence agencies, a local GP, a social worker, any children's schools, mental health crisis team and legal aid, such as a solicitor could also be vital to your safety.

You should be aware of the National Domestic Violence helpline, which is free to call and operates 24-hours a day.

You may also want to ensure that your children know how to call the emergency services in the event of an emergency, and are able to recite your address and telephone number.

It may also be worthwhile to ask your neighbours to stay vigilant and to call the emergency services should they suspect something is wrong. A neighbour may also be willing to keep hold of an emergency bag for you.

An emergency fund can come in handy should you need to buy any bus or train tickets. Any keys should be kept in a safe place that you can access easily if needed. Your mobile phone should be kept charged and close to hand.

Should you feel that you are at risk from a partner you should head away from any immediate danger, try to avoid the kitchen or garage where there may be implements and tools which could be used as weapons, and avoid rooms with only one exit or where you could be shut in a cupboard or other small space. You may need to leave your home all together.

Friends and family can be a great means of support in difficult decisions, and talking the situation through with people who are trusted could help.

You must remember to prioritise your own safety and that of your children. Leaving an abusive partner can be a long and difficult process. Having a plan in place doesn't come with any obligation to leave or to involve the authorities, but makes it a lot easier should you choose to do either of these things.

### Emergency contact numbers

In an emergency:	999
National Domestic Violence Line:	0808 200 0247
Women's Aid:	0800 085 2654
Men's Advice Line:	0808 801 0327

### Other resources

The government website also has information on domestic abuse and how to report it:

 [www.gov.uk/guidance/domestic-abuse-how-to-get-help](https://www.gov.uk/guidance/domestic-abuse-how-to-get-help)

# Respite



You may find it helpful to have regular breaks. A lot of people find respite, such as using a day centre two or three times a week, to be helpful. In addition, having a longer respite break once or twice a year can give you, and the person you are caring for, something to look forward to.

*"I have seen a big improvement in my husband's mood since he started going to a weekly group. It has really helped me to cope as I have a morning to myself once a week to get my hair done, visit friends or just sit on my own in peace. When he comes back we have lots to talk about and the break does us both good."*

Although awareness is improving, Huntington's is a rare illness, so not all respite services will have experience of looking after someone with Huntington's. Our Specialist Huntington's Disease Advisers (SHDAs) can make contact with respite services and provide information, advice, or training. Most social workers can advise you on how best to arrange a respite service. Respite options that may be available include:

## **Sitting services**

This service involves somebody visiting the home for a couple of hours a week so that you are able to have a short break.

## **Day centres**

They can vary greatly in the services they provide and the people who attend. They can offer a range of activities for people with Huntington's and some can assist with transport.

## **Care homes**

After a carer's assessment the person you care for may qualify for time in a care home or specialist holiday centre so that you can take a longer break. There are certain trusts that can offer financial support to aid with this, but in some cases you may have to pay for the whole stay.

## **Holidays with help**

There are a number of options for the person you care for to have a holiday with help, either with you or independently.





## Care homes

Many people with Huntington's will eventually move into a care home. This may be an incredibly difficult time for you. You may feel guilt, relief, or worry. Being prepared for this situation may make things easier for everyone involved.

*"It was such a hard decision to make when dad moved into a care home, but we just knew that mum wasn't coping anymore. We all felt guilty at first, but we realised with time that he was really happy in the home and that the staff were lovely. When we visited it was real quality time that we could spend together."*

### Choosing a care home

All care homes are different, so it may take time for you to find the best home for the person you care for. Local authorities can assess the person's needs and sometimes assist with fees.

Considering the wants and needs of the person going into a care home, and balancing this with what's available, is important when deciding which care home to choose.

First of all you'll need to choose what kind of home would be best. Homes vary in what they can offer, and it is important that you find out what level of care is included in the fees, how they could increase, and what services may cost extra.

## **Residential care homes**

These are for people who find it hard to manage alone and need help with personal care. Personal care can include washing, bathing, dressing, and going to the toilet. Some residential care homes can cope with people who are incontinent. Although residential care homes will provide help for residents who fall ill, they can't usually give long term, full nursing care. Access to community nurses is available if required.

## **Nursing homes**

These are for people who also need skilled nursing care and cannot be cared for in the community by their GP or community nurses. Qualified nursing staff are available 24 hours a day.

## **Dual-registered homes**

Some homes can give the types of care offered by both residential care homes and nursing homes. The main advantage of these is that there is no need to move if nursing needs increase. It's important to find out how the home defines 'nursing care' as this may mean paying a higher fee.

## **Care home fees**

Everyone is entitled to an assessment on whether they qualify for help towards services. This assessment is carried out by the local authority and will be means tested on the person with Huntington's assets, savings, and income.

One of the most important things you should consider when choosing residential or nursing care is what you can afford. Whilst you may be able to afford the fees to begin with, the money could run out. If financial help is needed later on the person with Huntington's will need to already have had an assessment by their local social services department.

## **NHS continuing healthcare**

If the person with Huntington's has a lot of medical needs they may meet the criteria for fully funded NHS care. This means that their care needs will be paid for by the NHS rather than by the person themselves and social services.

This is known as NHS continuing healthcare, or continuing care. It is a package of care that is arranged and funded solely by the NHS for people who are not in hospital and have been assessed as having a 'primary health need'.

Further information about NHS continuing healthcare is available at:



[www.nhs.uk/Conditions/social-care-and-support-guide/Pages/nhs-continuing-care.aspx](http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/nhs-continuing-care.aspx)

## **NHS funded nursing care**

A person living in a residential care home or nursing home, who is not eligible for NHS continuing healthcare, may still be eligible for NHS-funded nursing care.

This is nursing care provided in a care home by a registered nurse. The NHS will pay a flat rate contribution directly to the care home towards the cost of the nursing care.

The person with Huntington's may be eligible for NHS-funded nursing care if:

- They are not eligible for NHS continuing healthcare but have been assessed as needing care from a registered nurse.
- They live in a care home registered to provide nursing care.

Further information about NHS funded nursing care is available at:

 [www.nhs.uk/chq/Pages/what-is-nhs-funded-nursing-care.aspx](http://www.nhs.uk/chq/Pages/what-is-nhs-funded-nursing-care.aspx)

## **Seeking advice about care homes**

Your local Specialist Huntington's Disease Adviser will be able to advise on any care homes that are experienced in caring for someone with Huntington's. Different environments will suit different people and it is worth checking out as many options as possible. Some local care homes may not have had a resident with Huntington's before, but may feel that they still have the skills to care for someone with Huntington's.

The Care Quality Commission website features ratings of different care homes:

 [www.cqc.org.uk](http://www.cqc.org.uk)

## **First steps**

Most care homes have brochures which give details about the facilities, number of rooms, and pricing options, as well as outlining the home's aims and objectives. It is important to find out if there is a waiting list and, if so, how long the average waiting time is. Some homes offer a trial stay of a month or so.

After viewing the brochure you may want to visit the home a few times, at different times of the week to see if the residents seem happy and well cared for. Speak to the person in charge, as well as the staff, residents, and relatives of residents to find out their views on the home.

## Care home checklist

The following list is of things that you should consider when visiting a care home:

- ✓ The location, and how convenient it is for you to visit.
- ✓ The fees, what's included, and what could cost extra.
- ✓ What plans or packages are available and what kind of care they include.
- ✓ If facilities like chiropody, physiotherapy, incontinence pads or sheets, and toiletries are included, or if they cost extra.
- ✓ Whether insurance for the person's possessions is included or needs purchasing separately.
- ✓ How often fees are raised.
- ✓ Which GPs attend the home and whether it is possible for the person with Huntington's to continue seeing their own GP.
- ✓ If there are arrangements in place should the person with Huntington's go away on holiday or for a hospital stay, and how this affects the fees.

- ✓ What kind of assistance the care home provides should a resident pass away, and how long fees would need to be paid for.
- ✓ Specific terms included in the contract and whether it covers reasons that the resident may need to leave.
- ✓ Whether there is a notice period involved should the resident need to leave.
- ✓ Staffing levels and how this compares to the numbers of residents.
- ✓ Whether staff members are trained to deal with specific conditions that may be relevant.
- ✓ If the staff treat the residents with dignity and respect.
- ✓ If the building is clean, accessible and well maintained.
- ✓ If there is an accessible outdoor area or garden.
- ✓ If the resident's rooms have en-suite bathrooms and appropriate equipment.
- ✓ If the rooms have emergency alarms.
- ✓ If residents are allowed to decorate or personalise their rooms.
- ✓ How much freedom residents have regarding their schedules.

- ✓ What the meals are like and if dietary needs are taken seriously.
- ✓ Rules regarding visitors and if they are able to stay overnight or for meals.
- ✓ If there is any kind of residents' committee.
- ✓ If any leisure or social activities are organised, in or out of the home.
- ✓ Are residents allowed to take their pets or are their pets allowed to visit.

Further advice and information is available at:

Care Quality Commission (England):  [www.cqc.org.uk](http://www.cqc.org.uk)

Healthcare Inspectorate (Wales):  [www.hiw.org.uk](http://www.hiw.org.uk)





## Emotional support

There are thousands of people across the UK caring for people with Huntington's, and who are trying to cope with the challenge of this role and the changing nature of the relationship that they have with that person.

Access to a range of emotional support can be invaluable to you. Support can come from friends and family both inside and outside of the Huntington's and carer communities. Some people find emotional support from online forums, telephone helplines such as Carers UK or from contact with our Specialist HD Advisers and local Huntington's disease branches and support groups.

There are also services set up specifically to help support children and young people such as our Huntington's disease Youth Engagement Service (HDYES) and young carers groups.

To find out more about emotional support in your local area contact us on:

-  0151 331 5444
-  [info@hda.org.uk](mailto:info@hda.org.uk)

*"It was our daughters who found the Huntington's Disease Association online and contacted our local adviser who visited us, organised a quicker consultant*



*appointment and pointed us towards useful resources. She was kind, knowledgeable, human and practical, and has continued to be an amazing, pro-active support ever since. She made us feel that we are not alone and we have her support for as long as we need it. She also linked us with other families affected by Huntington's for mutual support."*



# Talking about Huntington's

You may find it difficult to talk to other people about caring for someone with Huntington's. Most people haven't heard of it and won't know the symptoms or understand how it might affect you and the person you care for.

When you are telling somebody about Huntington's, making the distinction between the physical changes, behavioural changes, and changes to mood and memory may help in their understanding.

When somebody has a better understanding of your situation they may be better placed to offer help or advice. It may help you to direct them to informative websites, such as our Huntington's Disease Association website:

 [www.hda.org.uk](http://www.hda.org.uk)


Some of your friends or family members may be good listeners. Others may be keen to do something more practical, like assisting in making arrangements. It is best if you are direct with friends and family members, and ask for help where needed.

The advantage of seeking advice from other carers and people with experience of Huntington's is that they should be able to empathise with you and won't need you to explain as much to them. This is when it may make sense for you to utilise sources of support such as online communities, message boards, events, and our local Huntington's Disease Association branches and support groups.

Many people find it helps to talk to others who have been in a similar situation and as a carer you may find it helpful to talk to other carers. People become carers for many different reasons, but what led to this may not matter. Whilst you are in a caring role, caring is a huge part of your life.

Alternatively, you may find it therapeutic to socialise with people outside of the Huntington's community in order to give yourself time to focus on other things.

Carers UK runs a helpline offering advice, information and support. They also host an online forum where you can share experiences or ask questions to other carers.

 0808 808 7777

 [www.carersuk.org](http://www.carersuk.org)



## Other professionals that can help

A person with Huntington's may benefit from referral to and support from a number of professionals.

### **Occupational therapist**

An occupational therapist can advise on the best way to make certain tasks easier and can recommend specialist equipment that could make things more manageable. This equipment may range from small items, such as adapted cutlery, to large items, such as specialised beds and chairs. Occupational therapists can also offer advice around adaptations to a property, for example converting a bathroom into a wet room. The occupational therapist can also advise on how to access funding for this equipment. More information can be found at:

 [www.gov.uk/disabled-facilities-grants](http://www.gov.uk/disabled-facilities-grants)

### **Physiotherapist**

Physiotherapy can be accessed through a GP referral and may involve practicing exercises that address certain physical challenges. These exercises can help improve core strength which in turn can improve balance. A physiotherapist can also recommend walking aids and can arrange for the provision of a wheelchair where necessary.

## **Speech and language therapist**

A speech and language therapist can be accessed by referral from a GP and can address communication problems and issues with swallowing, as well as offering some aids and adaptation that may help.

## **Dietitian**

Advice from a dietitian is accessible through a GP referral. A dietitian can advise on the best way to maintain a healthy and nutritious diet. It is important to note that a person with Huntington's will have additional dietary needs compared to someone without the disease.



# Financial support

You may at some point find yourself worrying about finances. Researching what grants and benefits are available can help to reduce some of this stress.

If you have never claimed benefits before, it may feel overwhelming to think about this, but it is your right to apply.

Some benefits are means tested, which means you or the person you care for will be financially assessed. This means your income and savings are taken into account to work out how much you are entitled to receive. You may receive benefits as a carer or the person you care for may receive benefits.

## Benefits available

### Attendance Allowance (AA)

For people aged 65 and over to help with extra costs if they have care needs.

### Carer's Allowance

For carers who provide care for 35 hours or more a week to support someone receiving Attendance Allowance, Disability Living Allowance or Personal Independence Payment.

## **Carer's Credit**

If you are of working age and your caring role creates gaps in your work history, this credit protects your National Insurance.

## **Carer's Premium**

If you can't get Carer's Allowance because you are being paid another benefit that overlaps with it, you can still get an extra amount known as the Carer's Premium if you meet all the criteria for Carer's Allowance. You must still make a claim for Carer's Allowance to qualify.

## **Council Tax Benefit**

For anyone on a low income who needs help to pay their Council Tax bill. Council Tax Benefit is means tested.

## **Council Tax Reduction**

Available if you live in a larger property because the disability of the person you support requires an extra bathroom or kitchen, or a room mainly for their use. It also applies if internal spaces or doorways have been widened for wheelchair access.

## **Housing Benefit**

To help with the cost of rent if you are on a low income, whether you are working or not. This is means tested.

## **Disability Living Allowance (DLA)**

This used to be the main benefit for people with disabilities under 65, to help with extra costs from care or mobility needs. New claims now have to be made for the replacement benefit called Personal Independence Payment (PIP). Anyone under 65 who is already claiming Disability Living Allowance will be contacted at some point to let them know when their DLA will end and to make a new claim for PIP. Anyone over 65 will be able to retain their DLA award.

## Employment Support Allowance (ESA)

For anyone whose ability to work is limited by ill-health or disability. Where enough National Insurance has been paid, contribution-based ESA may be awarded, which is not means tested. If not, income based ESA may be available, which is means tested.

## Personal Independence Payment (PIP)

This is the main benefit for people with disabilities under 65, to help with extra costs from care or mobility needs. This is replacing Disabled Living Allowance. There is a useful guide to PIP available on our website, with useful tips to help when making an application:

 [www.hda.org.uk](http://www.hda.org.uk)

## Universal Credit

For people on a low income whether they are working or not. This new benefit is replacing six other benefits - Jobseeker's Allowance, Housing Benefit, Working Tax Credit, Child Tax Credit, Employment and Support Allowance and Income Support. Universal Credit is only available in certain areas of England and Wales, but is gradually being introduced across the UK.

If you are responsible for a child or young person, you may qualify for Child Tax Credit. If you work and receive a low income, you may qualify for Working Tax Credit. You can often get both types of tax credits.

## Disabled Facilities Grant (DFG)

A local authority grant to help towards the cost of adaptations or installations at home, to enable someone with disabilities to continue living there. A DFG can take a long time to agree and arrange, so it is important to plan ahead rather than waiting until point of need. DFGs are means tested.



## Further advice

A useful website that can help identify what you're entitled to and how to claim is Turn2Us:

 [www.turn2us.org.uk](http://www.turn2us.org.uk)

Carers UK have also produced a guide 'looking after someone' that provides useful information about financial support. It can be downloaded from their website:

 [www.carersuk.org/help-and-advice/get-resources/looking-after-someone](http://www.carersuk.org/help-and-advice/get-resources/looking-after-someone)

Our Huntington's Disease Advisers can also advise you on local grants that may be available to you.



# Out and about

The following items and schemes may be available to you or the person you care for:

## **Radar Keys**

These are universal keys that enable access to locked disabled toilets around the country. The keys are relatively cheap to purchase and can be purchased either from your local authority or from the Disability Rights UK shop at:

 [www.disabilityrightsuk.org/shop](http://www.disabilityrightsuk.org/shop)

## **Disabled person's railcard**

This card enables someone with a disability to purchase rail tickets with 1/3 discount. More information can be found at:

 [www.disabledpersons-railcard.co.uk](http://www.disabledpersons-railcard.co.uk)

## **Concessionary travel passes**

This pass enables someone with a disability to travel for free, or at a reduced rate. These are generally administered by the local authority. Contact your local authority for further details.

## **CEA card**

This card enables a person who is accompanying a disabled person to a participating cinema to receive a complimentary ticket. The card is available to people in receipt of certain benefits. More information can be found at:



[www.ceacard.co.uk](http://www.ceacard.co.uk)

## **Blue Badge scheme**

The Blue Badge scheme means that a person with Huntington's can park closer to their destination if they have mobility problems. More information can be found at:





















[www.gov.uk/apply-blue-badge](http://www.gov.uk/apply-blue-badge)



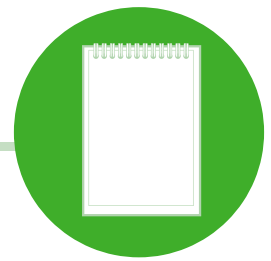
# Resource library

The following charities, organisations and public bodies have been mentioned throughout this guide. Their details have been summarised and grouped below for easy reference.

Organisation	Contact details	Support
<b>Huntington's Disease Association</b>	0151 331 5444 info@hda.org.uk www.hda.org.uk	<ul style="list-style-type: none"><li>Advice</li><li>Support resources</li><li>Online forum</li></ul>
<b>Carers UK</b>	0808 808 7777 info@carersuk.org www.carersuk.org	<ul style="list-style-type: none"><li>Advice</li><li>Support resources</li><li>Online forum</li></ul>
<b>Carers Trust</b>	Local telephone list info@carers.org www.carers.org	<ul style="list-style-type: none"><li>Advice</li><li>Support resources</li><li>Online forum</li></ul>
<b>Age UK</b>	0800 678 1602 contact@ageuk.org.uk www.ageuk.org.uk	<ul style="list-style-type: none"><li>Advice</li><li>Support resources</li></ul>
<b>NHS UK</b>	Local telephone list www.nhs.uk	<ul style="list-style-type: none"><li>Advice</li><li>Medical services</li><li>Referrals</li></ul>
<b>GOV UK</b>	Local telephone list www.gov.uk	<ul style="list-style-type: none"><li>Advice</li><li>Local services</li><li>Financial support</li></ul>

<b>Care Quality Commission (CQC)</b>	0300 061 6161 Web contact form <a href="http://www.cqc.org.uk">www.cqc.org.uk</a>	 Information  Local care homes  Care regulation
<b>Healthcare Inspectorate Wales</b>	0300 062 8163 <a href="mailto:hiw@gov.wales">hiw@gov.wales</a> <a href="http://www.hiw.org.uk">www.hiw.org.uk</a>	 Information  Local care homes  Care regulation
<b>Turn2Us</b>	<a href="http://www.turn2us.org.uk">www.turn2us.org.uk</a>	 Financial advice
<b>Disabled Rights UK</b>	Various helplines <a href="http://www.disabledrightsuk.org">www.disabledrightsuk.org</a>	 Advice  Support resources
<b>British Association for Counselling and psychotherapy</b>	0145 588 3300 <a href="mailto:bacp@bacp.co.uk">bacp@bacp.co.uk</a> <a href="http://www.bacp.co.uk">www.bacp.co.uk</a>	 Advice  Local services
<b>Emergency services</b>	999	 Medical  Crime  Fire
<b>NHS 111</b>	111	 Non emergency medical advice
<b>National Domestic Violence line</b>	0808 200 0247	 Advice  Support  Local services

# Notes





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## Get in touch

For advice and support  
or to speak to a  
Specialist Huntington's  
Disease Adviser

email **info@hda.org.uk**

phone **0151 331 5444**

**www.hda.org.uk**

 @hda\_tweeting

 @hdauk

 @hdauk

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## Huntington's Disease Association

Suite 24,  
Liverpool Science Park IC1,  
131 Mount Pleasant,  
Liverpool, L3 5TF

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