



HUNTINGTON'S
DISEASE ASSOCIATION
NORTHERN IRELAND

Families at the heart of all that we do

Seating, Equipment and Adaptations for HD

Assessment of Need

Section 2 of the Chronically Sick and Disabled Persons Act 1970 (England & Wales), and the equivalent legislation for Scotland and Northern Ireland, state that a local authority (LA) has a duty to provide practical assistance and additional facilities for the greater safety, comfort or convenience of people who are assessed as needing them.

If you live in a residential home, you may also get help. Any equipment and adaptations may be provided on the basis of a professional assessment of your needs. This assessment will not just look at your need of equipment; it should also look at your possible need for the whole range of community care services. Equipment, aids and adaptations may be provided by your local health or social care department, depending on assessment.

If it is clear that you will need help from several sources, the assessment should be a joint one. You, and your carer, should also be involved in the needs assessment. Once the assessment is complete, there should be a written record kept. If you are refused services, you can ask to see a copy of this. If you disagree with it, then you can use the local authority's complaints procedure, you can ask for this or look on their website. If you are going to be provided with services, the local authority will usually give you and your carer a written care plan. It may also set out any arrangements for reviewing your care plan.

Items to promote independence

Suitable adapted or specialised equipment is a key factor in enabling someone to live as independently as possible. The range of items is wide so don't buy anything without getting expert advice and, if possible, using the equipment on a trial basis to see if it really will work for you. Equipment provided by local authorities is generally considered to be on long-term loan. It will usually be an occupational therapist or physiotherapist that will assess your needs.

Items for daily living include items to make it easier to use the toilet, to wash, to dress, use cooking facilities etc., for example, handrails next to the bath and toilet, raised toilet seats, widened doorways, a bathroom on the ground floor etc.

A social worker in your social services department may be the best person to turn to initially for advice and help. However, other professionals may be able to give help and advice – e.g. an occupational therapist, a physiotherapist, a district nurse, a health visitor, a general practitioner or your HDANI support worker.

Nursing equipment

Health Trusts as part of their community health services, may provide nursing equipment such as special beds, commodes, urinals, incontinence pads etc some items may serve a dual purpose – for nursing care and for daily living. So some health and social service authorities have a jointly agreed procedure to determine who supplies which particular item.

In the first instance, apply for any item via your GP, district nurse, health visitor, continence adviser, occupational therapist or social worker.

Services to help with incontinence

Many disabled people have trouble either occasionally or regularly with incontinence, which can be costly besides causing a lot of extra work. What help is available and how it is administered will vary from one area to another. Seek advice on the management of incontinence from a continence nurse adviser or district nurse, and through your GP practice.

There are three types of provision: Equipment, Laundry Service and Disposal of Waste

How can you get help?

Your local commissioning group has the power to supply, free of charge, aids and equipment to help in nursing sick and disabled people at home and in residential care. These may include the loan of a commode and bed linen, the supply of incontinence pads, protective pants, inter liners, disposable draw sheets and bedpans, nappy rolls etc.

It is up to your local commissioning group to decide on the quantity of items, such as pads, and some, indeed, decide not to supply any at all.

Protective pants and pads are not available on prescription. If you cannot get an item through your local commissioning group, you can buy it privately either from chemists (a limited range) or more generally through specialist mail order firms. Body worn urinary appliances can be prescribed by GPs, but take the prescription to a chemist or surgical supplier providing a skilled fitting service. Appliances supplied 'over the counter' are unlikely to be satisfactory.

How can you dispose of waste?

This service is generally provided by your local authority's Environmental Health Department and will collect soiled incontinence pads, dressings and other nursing waste which cannot be disposed of normally and which arises from the care of a sick or disabled person at home.

Seating and Other Equipment

Seating

Sitting is often a major problem for people with Huntington's disease, as the person frequently has a tendency to slip out of a conventional chair because of the twisting and arching movements regularly seen.

There are no hard and fast rules about suitable chairs for people with Huntington's disease but there are guidelines which should be considered before deciding upon a particular chair.

In some cases, different chairs may be required at different stages of the illness.

The main aim of the chair should be to promote good support and encourage the correct posture and body alignment from the earliest to the final stages of the disease.

People should always have an assessment by an occupational therapist even if they are buying it themselves.

What to consider before deciding on a chair:

- ☐ Firstly the height of the seat and angle of the seat to the back of the chair are two essential points to consider.
- ☐ The front of the seat should be higher than the back so that when the person is sitting the knees are higher than the hips. The angle caused by the difference in height will have to vary according to the individual and type of chair.
- ☐ The angle can be adjusted by using either wedge shaped cushions or a chair which is specifically designed to meet this requirement.
- ☐ The height at the front of the seat must allow the user to sit with his or her feet resting comfortably on the floor, without causing undue pressure on the back of the thighs, and be deep enough to support without putting pressure on the back of the knees.
- ☐ To prevent the person adopting an abnormal sitting position, the seat should be narrow enough to support and secure the angle of the hip joint but allow for ease in getting out of the chair. The back of the chair must be high enough to provide support for the head, neck, shoulders and back.

Recliner chairs

For the person who tends to sleep in a chair during the daytime, a recliner chair with adjustable back and strong footrest may be considered. However, the hip angle needs to be maintained if involuntary hip extension (which causes the person to slide out of a chair) is to be avoided.

The arms of the chair should project far enough forward to assist the person when getting in or out of the chair. For comfort, support and safety reasons filled in sides are recommended.

It is preferable to adjust the angle of the seat rather than tilting the chair backwards as a means of restraint. The tilting action of the chair can cause the person to become disorientated and limit their communication.

Before you purchase a chair we recommend that you seek advice from a professional person such as an occupational therapist; through social services or your doctor.

Don't buy a chair until the user is satisfied with it. Most makers and suppliers be happy to visit and give advice on the most suitable chair from their range.

A correctly angled seat and back can often overcome the problems encountered. Harnesses should be avoided if at all possible. If a harness has to be used because all other methods of maintaining posture have failed and the person becomes a danger to him/herself, then the correct harness must be used. Before using a harness we strongly recommend you seek professional advice.

HDANI have a limited supply of specialist chairs for loan once your occupational therapist has deemed them suitable.

Wheelchairs

Under the National Health Service, wheelchairs are supplied and maintained free of charge to a disabled person whose need for such a chair is permanent.

If you need a wheelchair, contact your GP or hospital consultant first. He/she will complete the application form and send it to the Wheelchair Service Centre who will supply the wheelchair (after an occupational therapist has assessed you, if necessary).

VAT Exemption

If you do have to buy equipment privately you should be aware that any special equipment (irrespective of cost) purchased for people with disabilities can be VAT exempt. Please mention this at the time of purchase. You will be asked to fill in a VAT exemption form.

Contacts

Your first point of contact should be your GP for a referral to an occupational therapist who will conduct an assessment including an assessment of the living environment whether it be the home or a care facility. They will have access to all of the information about specific equipment, aids and grants for home adaptations.

If you wish would like information about possible equipment the Disabled Living Foundation will provide practical information and advice on all aspects of disability, especially equipment and problems of daily living. They have an extensive database of equipment and will utilise it to find the appropriate product for your need.

Disabled Living Foundation

DLF is a national charity providing impartial advice, information and training on independent living since 1969. Helpline number: 0870 603 9177

The Bladder & Bowel Foundation

The Bladder & Bowel Foundation will provide advice on all aspects of incontinence. 24 Hour Helpline: 0845 345 0165 (leave a message and they operate a call-back service)