



**Huntington's
Disease
Association**

Huntington's disease

**Advice on seating, equipment and
adaptations**

Assessment of need

Under the Chronically Sick and Disabled Persons Act 1970, local authorities have a statutory responsibility to arrange for the provision of equipment and adaptations to the home that will help people maintain their independence and continue living in their own homes. 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.

If your need is urgent, you may get help without waiting for a formal assessment.

Although, since April 1993, the local authorities are the lead community care agency, the health service retains all its functions and responsibilities.

Equipment, aids and adaptations may be provided by your local health or social care department, depending on assessment.

If the process of assessing your needs suggests to the local authority that you may also need the services of another agency, such as the NHS, they will inform that agency and invite them to participate in the

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

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 or by the NHS is generally considered to be on long-term loan. It will usually be an occupational therapist (OT) 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 local HDA Specialist HD Adviser.

Nursing equipment

Health authorities, including NHS 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
- 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 drawsheets 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 are 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.

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

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.

Suppliers of chairs, beds and other equipment

Seating

Careflex

Phone: 0800 018 6440
sales@careflex.co.uk

Kirton Healthcare Group

Phone: 0800 212 709
info@kirtonhealthcare.co.uk

Sleeping

Geniecare Safesides

Phone: 01903 733 377
www.geniecare.com

Orthodocs*

Phone: 0800 064 5521 / 02891 821 934
www.orthodocs.co.uk

Non-entrapment cocoon, limb and other pressure relieving cushioning. Details available from Orthodocs

Carebase

Phone: 01765 600 453

www.carebase.net

Electric bed with tumble mattress goes flat to floor
Details can be obtained by contacting Carebase

Smoking

R & N Engineering Smoking Aids

01474 823 771

Hospital Aids Northampton

Smoking Apron, lap cover

Phone: 01604 586 501

sales@hospitalaids.co.uk

www.hospitalaids.co.uk.

Aremco

Smoking Apron, Ashcatcher

Phone: 01622 858 502

Communicating

Speakability

Phone: 0808 808 9572

www.speakability.org.uk

Mobility

Crelling Harnesses (Seatbelts)

Phone: 01253 852 298

Slings for hoist, available from:

Workincare Ltd (slings for hoists)

Phone: 08450 533 035

info@workincare.com

Disabled Motoring UK

Phone: 01508 489 449

Protective Gear

Remploy Orthotics and Remploy Protective Headgear

Phone: 0870 609 0600

Epilepsy Action

Phone: 0808 800 5050

(for advice regarding protective gear)

Medical Alerts

Meditag

Phone: 0121 200 1616

www.medi-tag.co.uk

MedicAlert Foundation

Phone: 0800 581 420

www.medicalert.org.uk

S.O.S. Talisman

Phone: 0208 554 5579

www.sostalisman.co.uk

Other products/support services

Ways and Means

Phone: 0845 606 0911

Care Shop

Phone: 0845 600 1204

www.careshop.co.uk

website for business sales orders only – but clients could look at products required. Patients/carers to phone to place orders.

OT Stores

Phone: 08705 275 274

www.otstores.co.uk

NRS (Nottingham Rehab Supplies)

Phone: 0845 121 8110

www.nrs-uk.co.uk

REMAP (One-off design problems)

Phone: 0845 130 0456

www.remap.org.uk

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

380/384 Harrow Road

London W9 2HU

Helpline: 0870 603 9177

The Bladder & Bowel Foundation - will provide advice on all aspects of incontinence.

Phone: 0845 345 0165 (24 Hour Helpline)

Leave a message and they operate a call-back service

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
- A young adult's guide
- 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
- Challenging behaviour in Juvenile Huntington's disease
- A brief guide to Juvenile Huntington's disease for children's hospices and palliative care services
- A teacher's guide
- 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 by phone 0151 331 5444 or email info@hda.org.uk

For a publication price list/order form, membership form, details of our Specialist Huntington's disease Advisers and local Branches and Support Groups, please phone 0151 331 5444 or email info@hda.org.uk

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