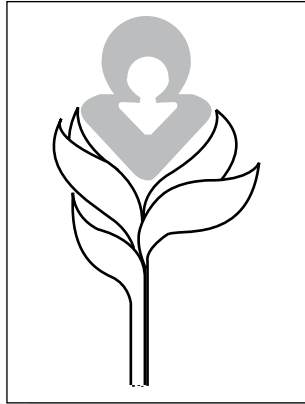


Huntington's Disease Association



Advice on Seating, Equipment and Adaptations

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 will be provided on the basis of a professional assessment of your needs. This assessment will not just look at your possible need of equipment, it should also look at your possible need for the whole range of community care services.

Do note that if your need is urgent, you can 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.

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 (see Appendix 1). 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.

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, all personal and health care professionals may be able to give help and advice – eg an occupational therapist, a physiotherapist, a district nurse, a health visitor, a general practitioner or an HDA Regional Care 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.

There are three types of provision:

- Equipment
- Laundry Service
- Disposal of Waste

How can you get help?

Your local PCT 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 PCT 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 PCT, 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 obtain laundry service?

If a laundry service is available in your area it will normally be run by the local social services department and probably attached to the Personal Care Service.

A laundry service may collect soiled sheets, bedding, clothes or nappies and return them laundered. It should be available to those too ill or disabled to manage laundry, as well as to people who are incontinent. Ask your social service department or your local PCT for details. If you find the receptionist does not know whether a laundry service exists or not ask to speak to Customer Service.

How can you dispose of waste?

If the PCT refuse disposal service should 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. This service can sometimes be arranged through your local PCT, but is generally provided by your local authority's Environmental Health Department.

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.

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

NB: 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. For example, Kirton Healthcare have special forms for use when purchasing any of their equipment for people with a disability.

Suppliers of chairs, beds and other equipment

AIDS AND ADAPTATIONS

Sitting

Careflex	0800 0186440 enquiries@careflex.co.uk
Kirton Healthcare Group	01440 705352 info@kirtonhealthcare.demon.co.uk

Sleeping

Geniecare Safesides	01903 733377 www.geniecare.com
Collage Trading Co. The Cocoon Bock, electric bed with tumble mattress goes flat to floor	01282 602100 0049(0)5246 9205 0 www.bock.net

Bathing and Showering

Genie Portable Shower Shower Cradle 900 Special Warwick	01903 733377 01257 425438
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Smoking

R & N Engineering Smoking Aids	01474 823 771
Hospital Aids Northampton Smoking Apron, lap cover	01604 586501 www.hospitalaids.co.uk
Aremco Apron, Ashcatcher, Smoking Aid	01622 858502

Eating and Drinking Communicating

Speakability 020 7261 9572
www.speakability.org.uk

Mobility

Crelling Harnesses
for Disabled Ltd (Seatbelts) 01253 852298
Chiltern Medical
Sling for Hoist 0869 246470
Disabled Drivers Association 01508 489 449

Protective Gear

Remploy Orthotics
Protective Headgear 0870 6090600
British Epilepsy Association
(could give advice re this) 0808 800 5050

Medical Alerts

Meditag 0121 2001616
Medalert 0800 581 420
S.O.S. Talisman 0208 554 5579

General

Ways and Means 0845 606 0911
Homecraft Chester-care 01623 722337
Care Shop 0845 600 1204
OT Stores 08705 275 274
www.otstores.co.uk 0845 2607061
NRS 0845 121 8111
www.nrs-uk.co.uk
Oneoff Design Problems REMAP 01732 883 818

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

Tel: 020 789 6111

Helpline number: 0870 603 9177

The Continence Foundation will provide advice on all aspects of incontinence.

The Continence Foundation

Helpline: 020 7831 9831

Monday-Friday 2pm-7pm

Appendix 1

How can the Act be enforced?

Wherever possible problems should be resolved locally, perhaps with the aid of a local councillor. Social services departments must have a complaints procedure and an explanatory leaflet. Information about this should be provided with the case assessment. Ask their 'Complaints Unit' for a copy.

Complaints

The procedure has three stages: informal problem solving, formal registration, and review. If you cannot resolve the problem informally, send the authority a written complaint, telling them that you wish to register this as a formal complaint. A social worker can write this for you if necessary. That 'registers' your complaint. You must get a reply within 28 days of the authority's receipt of your registered complaint, you should get an explanation of the current position, with a full response coming within three months.

Reviews – If you cannot resolve a complaint informally, or are unhappy with the authority's full response to your registered complaint, you can ask for a review within 28 days of the date the local authority tells you the result of their consideration of your complaint.

The review panel consists of three people; at least one person must be independent of the authority. Its hearing must take place within 28 days of the date the local authority received your request for a review. You will be given at least 10 days notice, in writing, of the time and place of the hearing. You can be accompanied by someone who may speak on your behalf – curiously, this person cannot be a lawyer acting in his or her professional capacity!

The review panel must record its recommendations within 24 hours of the hearing and notify you in writing. Their letter should explain the reasons for their recommendations. Your local authority then has 28 days to decide what action, if any, to take in the light of the review panel's recommendations. They must tell you what they decide.

Your next step

If, after going through this complaints procedure, the authority continues, in your opinion, to be acting unlawfully, or wholly unreasonably, it is possible to refer the council to the Secretary of State for Health. Alternatively, you may be able to use a procedure called 'Judicial Review'. You must act quickly. Contact your local law centre or a legal aid solicitor.

Appendix 2

The 'Disability Rights Handbook'

gives all the latest information on benefits and services for the disabled, covering: Disability Living Allowance, Income Support, Housing Benefit, Social Fund, Community Care, Benefits in Hospital, Incapacity Benefit, Benefits in Care Homes, Disability Working Allowance, Pensions, Lists of Addresses (Law Centres, Disabled Living Centres etc.,) and more.

A copy can be obtained from:

**Publications
Disability Alliance
88-94 Wentworth Street
London E1 7SA
Telephone 020 7247 8776**

Fact sheets available from the HDA:

1. All about the Huntington's Disease Association
2. General Information about Huntington's Disease
3. Predictive Testing for Huntington's Disease
4. Talking to Children about Huntington's Disease
5. Information for Teenagers
6. Eating and Swallowing Difficulties
7. Huntington's Disease and Diet
8. The Importance of Dental Care
9. Communication Skills
10. Behavioural Problems
11. Sexual Problems
12. Huntington's Disease and the Law
13. Huntington's Disease and Driving
14. Advice on Life Assurance, Pensions, Mortgages etc.
15. Seating, Equipment and Adaptations
16. Checklist for Choosing a Care Home
17. Advance Directive or "Living Will"

Booklets

Huntington's Disease in the Family (1997)

A booklet produced for young children

For a publication order form, membership form, details of our Regional Care Advisers and local Branches and Groups, please telephone or write to:

Huntington's Disease Association

Neurosupport Centre, Norton Street, Liverpool L3 8LR

Tel: +44 (0)151 298 3298 Fax: +44 (0)151 298 9440

Email: info@hda.org.uk Web: www.hda.org.uk