

about specialist recreational activities for your child or young person. There are also lot of websites offering specialist play equipment for children with disabilities. The following organisations can provide further support in this area:

Disabled Living Foundation
Tel: **0845 130 9177**
Web: **www.dlf.org.uk**

Smart Play Network (Scotland)
Tel: **0131 664 2746**
Web: **www.smartplaynetwork.org**
Run a range of play projects and offer services directly to children and families. Also, help and support toy libraries and play projects in Scotland to deliver quality services for children and families.

Can I buy second hand equipment?

Lots of people sell equipment on and it is usually in good condition. It can be a lot cheaper than buying new equipment. You can also buy second hand toys and lights for sensory rooms. To find out more about second hand equipment please contact the organisations listed below:

Disabled Living Foundation
Tel: **0845 130 9177**
Web: **www.dlf.org.uk**

Disability Equipment Register
Tel: **01454 318 818**
Web: **www.disabilityequipment.org.uk**

Mobility Market
www.themobilitymarket.co.uk

The Furniture Reuse Network
www.frn.org.uk

Where can we get financial help for equipment?

The Family Fund gives grants to low-income families to meet the additional needs of caring for a severely disabled child. In England and Wales, the age limit of children and young people

they can help is aged 17 and under. The Fund will not help with costs that are the responsibility of the Local Authority or health services.

Family Fund
Tel: **0845 130 45 42**
Web: **www.familyfund.org.uk**

Online service to help people access information on all benefits and grants available to them from both statutory and voluntary organisations in the UK.

Turn2us
Web: **www.turn2us.org.uk**
Freephone: **0808 802 2000**

The BDFA can also provide information about grant-giving trusts and other possible sources of help. We run our own Small Grant Scheme and you can apply for up to £500, for example, to pay for a larger capacity washing machine. This may be necessary if there is a need to frequently wash large amounts of bedding for someone who is incontinent.

It can also help with utility bills such as heating or telephone. This can give families peace of mind to enable them to maintain a constant temperature for the person they care for or to keep in contact with health professionals when caring for someone at home. If a person is in hospital some distance from home we can help with the cost of travel and subsistence to provide support at this stressful time. Children or young people with Batten disease often have access to a stimulating sensory environment and equipment when they attend school, respite care or day care but very few have these facilities at home. Our funding can help provide these at home.

Where do I get help with benefits and tax credits?

The BDFA have produced a leaflet about which benefits you may be entitled to claim. There are many different benefits and which ones you receive may depend on your household income. To find out more please visit **www.gov.uk** where you will be able to find out more about all the benefits. You could also contact your local Citizens Advice Bureau or the BDFA on: **0800 046 9832**.

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Edited by Harriet Lunneman with contributions from Andrea West and support from Bluepepper Designs.
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BDFA, The Old Library, 4 Boundary Road, Farnborough, Hants. GU14 6SF
Freephone Helpline: **0800 046 9832** Email: **support@bdfa-uk.org.uk** Website: **www.bdfa-uk.org.uk**

Equipment

This leaflet was designed to answer some of your questions about what the equipment needs will be for a child or young person living with a diagnosis of an NCL disease. The BDFA Support and Advocacy Partner is available to answer any questions you might have concerning the information in this leaflet. They can be contacted on **support@bdfa-uk.org.uk** or **0800 046 9832**.

What sort of specialist equipment may my child need?

Children and young people living with a diagnosis of an NCL will need various pieces of specialist equipment throughout their lives. Supporting a child or young person who has a diagnosis of an NCL can often be assisted through the use of specialist aids, equipment and/or adaptations to the home and other environments. For some parents, being able to access the right equipment may also enhance their son or daughter's independence in certain aspects of their lives. These items are likely to include specialist seating, buggies, wheelchairs, bathing and toileting aids, hoisting equipment and a specialist bed and mattress. Professionals will play a key role in ensuring that these and other items are provided in a timely manner following proper assessment of the individual's needs.

Changes to the home environment are likely be required to enable the family to appropriately care for a child or young person with an NCL disease. These may include installing ramps, widening doorways and providing suitable floor surfaces. A purpose-built wet room with a specialist bath or shower is commonly needed and various other aspects may require consideration.

There are grants and funds available to ensure that the work involved is affordable. An occupational therapist will consult on all aspects of adaptations and assist the family in undertaking this process. However, many of the items available can be incredibly



expensive with an almost overwhelming range of options. This leaflet provides information on ways you may be able to source equipment through statutory and charitable services along with recommendations of who to ask for specialist advice.

Who provides the equipment?

Both the NHS and your Local Authority can provide specialist equipment for your child or young person. The NHS usually funds equipment needed for your child's or young person's medical needs, such as specialist beds, incontinence pads and mobility equipment. The Local Authority should provide equipment for daily living. These are items such as hoists, adaptations to the home and equipment needed for personal care.

Current legislation for all UK countries states 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.

This often means providing equipment as well as other forms of practical help. In your area there may be a local agreement which clarifies who is responsible for different types of equipment.

You should be able to use your child's or young person's Direct Payments to pay for equipment and you may not have to pay tax on some items. For further information on items which you may be able to obtain tax free please contact:

HMRC on **0845 302 0203**.

How is the equipment provided?

If your social worker has already been to visit you at your home they may have already spoken to you about the equipment your child or young person may need. They should ask what your needs are as a carer so that you can get the right equipment to help you too. The social worker may ask an occupational therapist (OT) to visit your home to discuss your needs and your child's or young person's needs further. They may then contact your GP or the community nursing team if they feel you also need equipment that will need to be sourced by the local health authority.

All items should be provided free and you may be able to choose which items you would like, after a discussion with the team who are sourcing your equipment. The Local Authority can provide equipment for daily living or a minor house adaptation as long as it is less than £1000.

Children and young people with a diagnosis of NCL may need different equipment at different stages of their disease progression. Your equipment should be reviewed regularly, but if it is not you will just need to give your social worker or community nursing team a call and ask for different equipment. If they would like to know more about your son or daughter's NCL diagnosis they can contact the BDFA Support and Advocacy Partner for more information.

What should I do if I am not satisfied with the equipment provision?

If you are unhappy with the Local Authority's assessment of your needs then you will need to speak to your social worker who will tell you how to make a formal complaint. You may find it helpful to contact a local disability or carer's organisation to help you form the complaint. The BDFA can also support you when making complaints.

If you are unhappy with the NHS provision you will need to speak to the person responsible for your assessment again. They will then be able to give you more information if you would like to take the complaint further.

Can my child or young person receive visual aids?

Low vision aids along with more complex aids can be provided by the NHS. You will need to make an appointment at the hospital's Eye Service to discuss which aids your child or young person could receive.

Blind Children UK can provide information for you and your family about your child's or young person's visual impairment. They will be able to tell you about all the technology which is available to support your son or daughter. Their advice will be independent and they will listen to your needs before suggesting which equipment they feel would be most appropriate. They may even be able to provide you with a grant for the equipment.

Blind Children UK: **0800 781 1444**
www.blindchildrenuk.org

Can my child receive help with communication aids?

A speech and language therapist should be able to support you in regards to your child's or young person's speech. For young people with a diagnosis of Juvenile Batten disease they may be able to give you ways in which you can help your son or daughter maintain their speech for a while longer. They should be able to discuss alternative ways of communication for your son or daughter when they have lost their speech.

For children with Infantile and Late Infantile Batten disease your speech and language therapist should be able to support you and your family to find ways of communicating with your child, even if this is non verbal. Makaton or body signing may be

suggested or your speech and language therapist may suggest some types of technology which can be used.

Speech and Language Therapy is often an educational provision and will be something which is worked on a lot in school. If you have any concerns you should be able to speak to your child's or young person's class teacher or the speech and language therapist directly.

Will my child or young person receive incontinence pads?

Incontinence pads will be provided by your local health authority. However these may not be supplied until your child is 4 years old. The number provided also fluctuates greatly depending on the area in which you live. Some local health authorities provide 3 pads per day and some will provide up to 5. Sadly this may mean that you may have to spend some money on incontinence pads if your local health authority will not provide the amount you need.

The NHS may also provide bedding protection but you would need to ask your community nursing team about this. Sometimes it is possible to be provided with free incontinence pads before the age of 4 but this will need to be discussed with the community nursing team.

You may have to wash your child's or young person's bedding more often than normal and this can take its toll on water bills and your washing machine. If your water is metered you may be eligible for money off your bills. Contact the BDFA for more information about this. You may also be eligible for the Local Authority's Laundry Service. They will arrange to wash your child's or young person's bedding for you. However, please note not all Local Authorities provide this service.

The BDFA also runs a Small Grant Scheme for families of children with a diagnosis of NCL. You can apply for up to £500 to help with the cost of replacing household equipment which you use frequently to support your child or young person. The scheme covers many other things too. Please contact the BDFA Support and Advocacy Worker for more information on the Small Grant Scheme.

The following organisations can offer support and advice on continence issues:

ERIC (Education and Resources for Improving Childhood Continence)
Helpline: **0845 370 8008**
Web: **www.eric.org.uk**

The Bladder and Bowel Foundation
Tel: **01536 533255**
Nurse helpline: **0845 345 0165**
Web: **www.bladderandbowelfoundation.org**



What help can I receive for my child's or young person's mobility issues?

All walking aids or wheelchairs will be provided free of charge by the NHS. However these may differ depending on where you live as certain types of chair may not be available. If you live in England you may be able to use the wheelchair voucher scheme. This allows you to pay for a more expensive wheelchair if you are not happy with the basic one which Wheelchair Services will pay for.

Your child or young person may already have a physiotherapist. If they don't, you can ask your GP to be referred to one at your local hospital. They will assess your child's or young person's needs to see which mobility equipment would be best suited to their needs.

If your child is still able to independently walk then you may want to ask for a walker to be provided before a wheelchair is provided as this may help them maintain their independence for a while longer. This will include extras such as cushions, arm rests and trays. They will also help provide a suitable work chair for your child or young person to access their school curriculum. They also provide specialist children's buggies.

Wheelchair Services should assess your child or young person and provide them with a wheelchair which will meet their needs as well as being comfortable and supportive. In Wales the Artificial Limb and Appliance Service (ALAS) are responsible for providing a wheelchair. Your OT or physiotherapist should be able to refer you to Wheelchair Services.

Wheelchair Services are responsible for the maintenance of the wheelchair provided no damage is caused by misuse of the chair. You will be given the number of the repairer when you collect the wheelchair.

If you are not happy with the service you should ask Wheelchair Services how to complain and follow their procedure. You may want to contact a local disability or carer's organisation to help you do this. The BDFA will also be able to help you.

Here are a few other organisations who may be able to help you:

Whizz-Kidz
Tel: **020 7233 6600**
Web: **www.whizz-kidz.org.uk**
Whizz-Kidz can provide essential mobility equipment for children up to 18 that is not available from the NHS.

Go Kids Go! (Association of Wheelchair Children)
Tel: **01482 887163**
Web: **www.wheelchairchildren.org.uk**

What about my child's equipment needs at school?

Local Authorities or the school may supply certain specialist equipment that a child or young person needs for education purposes. The school should be able to arrange for an occupational therapist (OT) to assess your child and may provide aids for use in school and at home. You should contact the Head Teacher or SENCO for further information.

If your child has a Statement, then details of specific equipment required to help your child at school should be included. If you have concerns about your child's needs, then these should be raised with the school.

In Scotland, a child's co-ordinated support plan should detail any equipment necessary to meet a child's educational needs.

What toys and recreational activities are available for my child or young person?

It is important for your child or young person to be encouraged to play with toys and to participate in recreational activities. It is crucial that all children, whatever their abilities, are given the opportunity to play and access leisure facilities.

A paediatric occupational therapist may be able to assist you in finding toys to suit your child's needs. Their school should also have an idea of what their favourite toys are and may be able to help you source these. If you speak to your son or daughter's teacher they may be able to give you ideas for sensory activities you could do with your child or young person at home. There is lots of information online about how to make your own sensory toys or how to provide activities. You can even find information on how to make your own sensory room at home. If you turn a room into a sensory room you may be eligible for a council tax reduction, provided no one sleeps in that room.

Toy libraries are usually free for children who are on DLA or access portage services and speech and language services. You can borrow toys from the libraries and they have a range of sensory toys and equipment for you to use. You can then try out toys before you buy them to see how your child or young person will respond to them. Toy libraries also run their own play sessions and can signpost you to other play sessions or leisure activities which your child and young person may be interested in.

Your Local Authority may be able to provide you with information