



Disability Rights and Benefits

England version

Contents

Living with meningitis and septicaemia

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Table Summary

Financial Support

| Benefit | Abbrev | Means Tested | Affected by Savings & Income | Individual/Carer | NI | Taxable | Restrictions | Administered |
|--------------------------------|--------|---|------------------------------|--|-----|---|--|----------------------------------|
| Disability Living Allowance | DLA | no | no | individual | no | no | under 65 | DWP |
| Carer's allowance | CA | no | yes | carer | no | yes | at least 35hrs a week caring | DWP |
| Direct payments | | Dependent on benefits claimed | | both | no | no | over 16 and disabled or carer; or older person | Local authority |
| Attendance allowance | AA | no | no | individual | no | no | over 65 – can be affected by other benefits | DWP |
| Disabled Facilities Grants | | yes (for adults) | yes | owner/tenant | no | no | main residence | Local authority |
| Energy efficient grants | | Dependent on disability or income related benefits received | | individual | no | no | main residence | Local authority |
| Family fund | | yes | yes | carer of child | no | no | claimant must be over 18 | family fund under DoH guidelines |
| Working tax credit | WTC | yes | yes | individual/carers | no | no | over 16 and working at least 16hrs a week | HMRC |
| Child tax credit | CTC | yes | yes | carer of person under 19 still in full time ed | no | no | claimant must be over 16 | HMRC |
| Disabled student allowance | | no | no | individual | no | no | subject to criteria including type of course and immigration status | Student finance |
| Statutory Sick Pay | SSP | no | no | individual | no | yes | max 28 weeks if you are over 16 and employed or self employed, earning at least the lower earnings limit | employer |
| Employment & support allowance | ESA | yes | no | individual | yes | yes - but only if you've paid a certain level of NI contributions | 16 or over, unable to work due to health or disability, under pensionable age, not receiving SSP | DWP |
| Income Support | IS | yes | yes | all | no | no | over 16, work less than 16 hours | DWP |
| Housing benefit | HB | yes | yes | family/individual | no | no | Need to be personally liable for paying rent, or caring for a person in receipt of other benefits | Local authority |
| Council Tax Benefit | CTB | yes | yes | family/individual | no | no | Need to be personally liable for paying council tax or caring for a person in receipt of other benefits | Local authority |
| Local Housing Allowance | LHA | yes | yes | family/individual | no | no | need to be personally liable for paying rent and council tax | Local authority |
| Job Seeker's Allowance | JSA | may be affected by earnings or pensions | no | carer/individual | yes | yes | To qualify you need to be unemployed or not working more than 16 hrs per week, available for and actively seeking work. Other restrictions apply | Jobcentre Plus |

DWP - Department of Work and Pensions HMRC - HM Revenue & Customs

Living with meningitis and septicaemia

If you have experienced meningitis and/or septicaemia your life may have changed forever. If you are living with the after effects, or caring for someone affected, you may have to deal with any number of physical and mental disabilities.

The after effects of meningitis and septicaemia can have an impact on your whole family, not just the person who had it. Adapting to this life change may be emotionally, physically and financially exhausting. There may be a lot for you to take on at this stage, so this document is here to help you navigate some of the resources, both financial as well as medical, that can go some way to making your lives easier.

It is not always possible to predict the outcome of these illnesses. That is why anyone who recovers from meningitis or septicaemia should have at least one follow-up appointment to look for evidence of any immediate or potential long-term complications, and resulting need for follow-up care. Some people have more subtle effects that can cause difficulties later on, and may need help from their GP or health visitor to access specialist care and rehabilitation services.

However, help is at hand! We may be able to answer your enquiry ourselves, or we can signpost you to the relevant professionals, agencies or organisations to assist with your specific needs.

MRF also has over 15,000 Members and supporters with personal experience of the diseases. Many have first-hand experience of negotiating the benefits and services system as a result, and have shared information and advice with us.

This resource is for guidance only. Entitlement to benefits, services and equipment, and the providers of these and the laws governing entitlement to them can change. The need for these services is key when completing applications and assessments. This information was accurate at time of going to press in May 2010.



"We are delighted MRF have produced this simple and accessible information on disability rights and benefits. Following Lydia's illness, we were at a loss for where to start seeking information about equipment and benefits to which she might be entitled. We found the whole process daunting, time consuming, lengthy, lots of form filling and/or telephone calls, which was very frustrating. This resource is a great starting point for families who find themselves in a similar situation." Jodie Cross.

Lydia contracted Hib meningitis and septicaemia in November 2003 at the age of two, resulting in bilateral amputations below the knees and permanent hearing loss at high-pitched frequencies.

Lydia's parents are able to claim **Disability Living Allowance** and **Carer's Allowance**. They also have a **Blue Badge** for their car but were unaware until recently that they did not have to pay car tax due to Lydia's disabilities. Lydia is receiving some **extra help at school** with her maths and writing.

Financial support

The benefits system

The benefits system is complex. You may be entitled to a range of financial help. The pressures of looking after a child or adult after meningitis and septicaemia can be challenging, without the added stress of trying to navigate the benefits system to better understand what you may be eligible for.

The key point to remember when filling out application forms is that you must strongly demonstrate your need (or your child's or family's need) for these services.

There are two types of benefits:

- **Means-tested** – dependent on income and savings (and those of your partner). These are always non-contributory (you can claim these even if you have not paid National Insurance contributions)

- **Non means tested** – can be either contributory (these are based on contributions you have made to the National Insurance scheme) or non-contributory.

There is a guide for disabled people, those with health conditions, and their carers (DHC IJP), which includes details of financial and practical support available. There are also leaflets that give details of specific benefits, available at your local Department of Work and Pensions or download them here: www.jobcentreplus.gov.uk/jcp/customers/leaflets_and_guides/

Further information can be found on www.direct.gov.uk/en/MoneyTaxAndBenefits/index.htm

If you would like to talk through the process of claiming and of the benefits listed here, for assistance and support please call the MRF helpline team during normal office hours on **Free**one 080 8800 3344.

Disability Living Allowance (DLA)

DLA is paid in addition to other benefits and can lead to further benefits such as Income Support, Housing Benefit and Working Tax Credit or Child Tax Credit. It can be claimed whether you work or not and is not affected by savings or income.

It is paid in recognition of the individual needing care, not the carer or parent. What matters is your disability and the help you need. You don't need to have someone looking after you to qualify for DLA.

It is tax free and you don't need to have paid National Insurance contributions.

DLA has two components:

- **Care Component** – for help with personal care needs, paid at three levels. The level of benefit to which you are entitled will be made through an assessment carried out by the social care team;

■ **Mobility Component** – to help those who have difficulty walking, paid at two levels.

You can receive either or both depending on your circumstances.

Age limits – there is no lower limit for DLA care component, but for the mobility component it is age three years. You can get DLA if you are making your first claim before your 65th birthday.

How to claim

- Call the Benefit Enquiry Line 0800 882200. They will send you a claim form and your claim can be backdated to the date of your call
- Claim online or print a claim form at www.direct.gov.uk/disability-dla
- Contact your local Jobcentre Plus or social security office for a DLA1 Claim Pack.

Citizens Advice Bureau (CAB) <http://www.citizensadvice.org.uk/index.htm> can be helpful when dealing with these benefits.

The interaction between DLA & other benefits is complex, in these cases specialist advice should be sought.

“Once we were in receipt of Disability Living Allowance for Edward, it acted as a gateway for other types of benefits to which he was entitled. We are pleased that the Foundation has taken this step towards helping families through this process.”

Steve Bright

Edward contracted group Y meningococcal septicaemia February 2007 with resulting amputations of his arms and legs. Edward’s parents have received a lot of support from their local community.



Carer's Allowance (CA)

To be able to claim Carer's Allowance (CA) you must be caring for a child or adult who receives DLA at the middle or highest rate of the care component, or is in receipt of Attendance Allowance (AA). See below for AA.

You do not have to be related to or live with a disabled person to claim CA. You can get CA even if you have never worked. You may also be entitled to home responsibilities protection and income support as a carer. CA is not means tested but it is taxable.

To qualify you must regularly spend at least 35 hours a week caring for a person. If you work, you must not earn more than a specified amount, and you must be over 16 and not in full time education.

Only one person can receive CA for looking after the same person i.e. if both parents are caring for a child only one may claim CA.

If you receive CA, the person you are caring for will lose their entitlement to the severe disability premium (if applicable). As it may impact upon other benefits it is important to seek specialist advice.

Claims can be backdated for up to three months if applicable.

How to claim

For an application pack:

- Call the Benefit Enquiry Line 0800 882200
- Contact your local Jobcentre Plus
- Claim online or print a claim form from www.direct.gov.uk/carers-ca



"When Theo came home from hospital, I had to come to terms with having a different baby to the one that went into hospital. Life was going to be different and I would need help caring for Theo. Carer's Allowance is one of the types of benefits to which Theo is entitled."

Jo Kirwin

Theo contracted pneumococcal meningitis aged four months in November 2004. As a result, Theo suffered severe brain damage and is profoundly deaf. He has bilateral cochlear implants and special educational needs. His movement is limited and he needs regular physiotherapy. His mum trained in baby yoga and yoga for children with special needs to help with his physical development. Looking after Theo is a 24 hour-a-day commitment. His parents have realised that it is essential to seek out any help available. Theo and his family are entitled to **Disability Living Allowance, Carer's Allowance and Direct Payments.**

Direct Payments

Cash payments are made to a patient/carer who has been assessed as needing services, in lieu of social service provisions.

The aim is to give more flexibility in how services are provided. By giving individuals money in lieu of services, people have greater choice and control, and are able to make their own decisions about how their care is delivered.

Further information at <http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/Directpayments/index.htm>

Attendance Allowance (AA)

For people aged 65 or over who have difficulty looking after themselves. It is based on the amount of care you need. You do not need to have a carer to claim this benefit. You must have needed care for at least six months to qualify and it is paid at two rates:

- **Lower** – for people who need help during the day **or** night
- **Higher** – for people who need help both during the day **and** night.

How to claim

AA is not means tested and you can claim if you are working. You do not need to pay National Insurance contributions to claim. Any other benefits claimed will not be affected and you may also be eligible for another benefit such as Pension Credit.

For an application pack:

- Call the Benefit Enquiry Line 0800 882200
- Contact your local Jobcentre Plus or social care office
- Go online to www.direct.gov.uk/disability

Disabled Facilities Grants

A Disabled Facilities Grant is a local council grant of up to £30,000 to help towards the cost of adapting your home to enable you to continue to live there. It may be used for adaptations to help the disabled person enter and leave the home or garden or rooms within the home, to make use of bathing facilities and toilet, to enable the person to prepare and cook food, or to improve the heating if necessary.

Disabled facilities grants are available for people of any age. For adults they are means-tested but not for a disabled child or young person.

Disabled facilities grants are administered by the local authority housing department, which you

should contact for an application form. See Disabled Facilities Grants – how to apply http://www.direct.gov.uk/en/DisabledPeople/HomeAndHousingOptions/YourHome/DG_10018283

Occupational therapists assess needs on behalf of local councils.

Blue Badge Scheme

This scheme of parking concessions is designed to help people with severe mobility problems.

Having a badge allows you to park:

- without charge or time limit at on-street parking meters and in 'Pay and Display' bays
- without time limit in streets where otherwise waiting is allowed for only limited periods
- for a maximum of three hours on single or double yellow lines.

Congestion charge exemption is also available in Central London to badge holders for an initial £10 administration fee. Apply to the Congestion Charging Office (call 0845 900 1234 or visit www.cclondon.com).

You qualify for the Blue Badge Scheme if you are two years of age or older and:

- receive the higher rate mobility component of disability living allowance or mobility supplement, or
- are registered blind.

You may qualify if you are two years of age or older and:

- drive regularly and have a severe disability in both arms so that you are unable to operate, or have considerable difficulty in operating, all or some types of parking meter, or
- have a permanent and substantial disability which causes inability to walk or have considerable difficulty in walking.

A child under two years of age may also qualify if they need permanent access to bulky medical equipment or need to be in continuous reach of a car due to the likely need for urgent medical help.

If you get the higher rate mobility component of disability living allowance (DLA) you can also apply for exemption from road tax.

For more information contact Mobilise on 01508 489449 or the Blue Badge Network on 01384 257001.

Motability

Motability is a charity that offers two schemes: contract hire and hire purchase. Both schemes offer cars, including those adapted to carry a wheelchair or mobility scooter. You can apply to Motability for help with the initial deposit, adaptations or for additional discretionary help.

- For enquiries about the Motability Car Scheme call 0845 456 4566
- For enquiries about the Motability Wheelchair and Scooter Scheme call 0845 607 6260
- To enquire about the network of accredited mobility centres call 0800 559 3636 or visit www.mobility-centres.org.uk

See also Motorbility.com



“Andrew contracted pneumococcal meningitis at eight months. He was in a coma for three weeks and not expected to survive. He did pull through, however the meningitis had taken its toll. Andrew was left with severe physical and mental disabilities.

At the age of seven he has started to walk, although not unaided. He cannot speak or use his right side. He has vision problems, epilepsy, hydrocephalus and has severe learning difficulties.

*Andrew attends a special school, which he loves. Thanks to a **Disabled Facilities Grant** my house has been adapted to help me care for Andrew – with facilities such as a wet room, a ramp to the front door and extra wide doors.*

*Andrew receives **Disabled Living Allowance** and I receive **Carer's Allowance**. As I am unable to work, the portion of **Child Tax Credits** I receive for Andrew is also doubled. I use the “help with getting around” portion of the **Disabled Living Allowance** to lease a car from **Motorbility** that has been adapted so Andrew can travel in his wheelchair. The **Motorbility** scheme is often misunderstood, and is assumed that I have a free car. This is not the case. It costs £46 per week to lease this car with a deposit of £6,000 for the lease over five years. Luckily I was able to get a grant to help me otherwise I would not have been able to afford it. We also have a disabled parking badge (**Blue Badge**).*

I would love to be able to work, but I simply cannot. There is no provision for after school or holiday clubs for children as disabled as Andrew. Plus attending all his hospital appointments requires a great deal of my time and commitment.”

Shirley Carmichael

Energy Efficient Grants

Under the Warm Front Grant scheme, help is available towards improvements in insulation, room and water heating for disabled people, families with children who receive a qualifying benefit or tax credit, and to people aged 60+ who receive a means-tested benefit.

Call Freephone 0800 3162805 for more details.

Family Fund

The Family Fund is a charity that can help pay for specific items to help relieve stress from caring for a child under 16 who has a severe disability, for families on a low income. It cannot be used for items that are the responsibility of the local authority, but can be used for things that make life easier and more enjoyable for the disabled child and their family, such as play equipment, laundry equipment, driving lessons, computers, holidays and hospital visits. Visit www.familyfund.org.uk

Working Tax Credit (WTC)

Working Tax Credit (WTC) is a payment made to working people on low income to top up their earnings.

WTC can be claimed by single people, couples, parents and people without children. It is also paid to working people with a physical or mental disability that puts them at a disadvantage in getting a job.

WTC can also help with payments towards the costs of childcare. It is means-tested and you must be aged 16 or over and working at least 16 hours a week.

It is made up of different elements (reasons/circumstances/factors) to suit various circumstances, which include a lone parent element, a disability element, a childcare element and a 50+ element.

If you do not have children and do not receive a disability element or 50+ element, you or your partner must be over 25 and working at least 30 hours per week to enable you to claim.

You may still be able to claim WTC for up to 28 weeks if you are off work due to illness.

How to claim

- Call the Tax Credits Helpline on 0845 300 3900 or textphone 0845 300 3909
- Contact your local HM Revenue and Customs (HMRC) Enquiry Centre, your local Jobcentre Plus or social security office
- For more information, see www.hmrc.gov.uk

Child Tax Credit (CTC)

This is a payment made to parents and carers of children or young people still in education. You do not have to be working to claim CTC.

CTC is means-tested and the person claiming must be 16 or over. You or your partner must be responsible for a child under 16 or a young person aged 16-19 in full time education who normally lives with you.

The amount you can claim is influenced by several factors. These include the family element (reasons/circumstances/factors) and the child element for each child in the family. There are extra amounts that can be claimed for children with disabilities.

How to claim

- Call the Tax Credits Helpline on 0845 300 3900 or textphone 0845 300 3909
- Contact your local HMRC Enquiry Centre, your local Jobcentre Plus or social security office
- For more information, see www.hmrc.gov.uk

Disabled Students' Allowance

Disabled Students' Allowances are grants to help meet extra course costs students can face as a result of a disability or specific learning difficulty. They are paid on top of the standard student finance package, and don't have to be paid back. Check eligibility and what grants can be claimed at http://www.direct.gov.uk/en/DisabledPeople/EducationAndTraining/HigherEducation/DG_10034898

Proof of disability will be required from a medical professional or by diagnostic assessment which will need to be paid for. However, you may receive help from the Access to Learning Fund http://www.direct.gov.uk/en/EducationAndLearning/UniversityAndHigherEducation/StudentFinance/Extrahelp/DG_171615

Statutory Sick Pay (SSP)

Many employers have an employee sickness pay scheme. However, when this runs out or if the employer does not have a scheme you will need to claim SSP. It does not cover the first four days of sickness leave.

SSP is paid to employees by their employer for up to 28 weeks in any period of sickness lasting for four or more days. You must earn at least the lower earnings limit.

Unemployed or self-employed people are not covered by SSP. If you are not eligible for SSP, you may be able to claim Employment and Support Allowance.

How to claim

You must notify your employer you are off sick and you may be asked for evidence that you are incapable of working. The self-certificate form SC2 is available from a GP surgery or HMRC (HM Revenue & Customs office (tax office)) if your employer doesn't have a form. After this you will need to give your employer a sickness certificate from your doctor or hospital doctor (if applicable).

SSP is paid for a maximum of 28 weeks either in one time period or linked to another (separated by eight weeks or less each time).

If you are still sick at the start of the 23rd week of your period of entitlement to SSP and are likely to remain sick beyond the 28th week, you will need to claim Employment Support Allowance (ESA).

Employment and Support Allowance (ESA)

In October 2008 Incapacity Benefit and Income Support were replaced by Employment and Support Allowance (ESA).

During the first 13 weeks of the claim, the 'assessment phase' ESA is paid at a lower rate. Following assessment, claimants are placed into one of two groups depending on their level of disability, which will determine the level of ESA they receive and whether or not the claimant is expected to participate in 'work related' activity.

Other benefits can be paid on top, including Disability Living Allowance (DLA), Attendance Allowance (AA), and Working Tax Credit (WTC).

How to claim

- Call the Jobcentre Plus claim line 0800 055 6688 (textphone 0800 0230 4888). They will go through the form over the phone, complete it and send to you to sign and return
- To claim online go to www.dwp.gov.uk/eservice

Income Support (IS)

This is a means-tested or income-related benefit to provide for basic living expenses. It does not depend on your National Insurance contributions. It can be paid on its own or in addition to other benefits or earnings. Income Support is replaced by Pension Credit if you are over 60. If you have children, their basic living expenses can be met by claiming Child Tax Credit.

IS is for people who are not required to sign on for work.

It can help towards mortgage interest payments and certain other housing costs. If you get IS you may also get housing benefit and council tax benefit.

IS may also entitle you to free prescriptions and dental treatment, housing grants, help from the social fund, help with fares to the hospital and free school meals.

How to claim

- Call the Jobcentre Plus claim line 0800 055 6688 (textphone 0800 0230 4888). They will go through the form over the phone, complete it and send to you to sign and return
- Download an AI claim form from www.dwp.gov.uk/advisers/claimforms

You may be asked to provide supporting documents within one month of the date you first notified the Jobcentre Plus of your intention to claim.

Housing Benefit and Council Tax Benefit (HB & CTB) running concurrently with Local Housing Allowance (LHA)

The general rule to claim HB, CTB and LHA is that you must be personally liable to pay the rent and council tax on your home.

To get your benefit backdated (maximum of three months) you must apply in writing.

In some areas, you may be able to claim LHA instead of HB if you are a private tenant on a low income. The amount you receive depends on the area you live in, who lives with you, your household income and savings. If your rent is higher than the amount awarded you may need to make up the difference. If your rent is lower than LHA you can keep the difference and this will not affect other benefits you receive.

How to claim HB, CTB and LHA

When you claim IS (Income support) or JSA (Job Seeker's Allowance) you will also be given a form for HB and CTB. This is usually called HCTB1. If you complete it over the phone it should be sent to you to check. Most authorities have a standard claim form. Local authorities accept claims for HB/CTB by telephone or online.

For further information contact your local council offices or see:

http://www.dwp.gov.uk/lifeevent/benefits/housing_benefit.asp

http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/On_a_low_income/DG_10018926

Job Seeker's Allowance (JSA)

To qualify you need to be unemployed and available for and actively seeking work.

People who are incapable of working should claim Employment and Support Allowance.

How to claim

Call the national claim number 0800 055 6688 (textphone 0800 0234888). Call centre staff will take your details, tell you if you seem to be entitled to JSA or any other benefit and book an appointment for you to see a financial assessor and a personal adviser. These interviews will take place at your local Jobcentre Plus office, normally within a week. The call centre will send you claim forms or 'customer statements' – a print out of the information you provided on the phone, which you should take to the interview.

Health benefits

For help with the cost of:

- NHS prescription charges
- Free NHS dental treatment
- Fares to hospital
- Sight tests and glasses.

You qualify automatically if you (or your partner) receive income related ESA, IS, JSA or pension credit. Please call the MRF helpline on 080 8800 3344 to talk through the eligibility of receiving these benefits.

References

Disability Rights Handbook, 34th Edition 2009-2010.

Other websites which may be helpful:

<http://www.turn2us.org.uk/>

<http://www.citizensadvice.org.uk/>

Services equipment and education for people with disabilities from meningitis and septicaemia

Meningitis and septicaemia can alter your life in many ways. While most people make a full recovery – with no permanent disabilities – others are not so fortunate. The need for specialist follow-up care, services and equipment is often apparent – even before hospital discharge – and may be prolonged or even life-long.

Meningitis Research Foundation has more than 20 years experience of patterns of recovery and can offer help and reassurance. If you, your child or family member have been affected, please call our 24 hour **Freefone** helpline 080 8800 3344 (UK). The helpline:

- Offers a listening ear and support to anyone affected
- Answers your questions and provides information
- Helps you navigate the disability rights and benefits system
- Puts you in touch with telephone befrienders who have been through a similar experience.

Hearing loss: aids, implants and communication support

Hearing loss is amongst the most common and well-known after effects of meningitis. It is especially common after pneumococcal and neonatal meningitis. Anyone recovering from any form of bacterial meningitis or from meningococcal septicaemia should have a hearing test as soon as possible, usually before discharge from hospital, but certainly within four weeks of being well enough to be tested.

See page 9, www.baap.org.uk/Quality_Standards_in_Paediatric_Audiology_Guidelines.pdf

Should any hearing loss be detected there are a variety of services available:

Hearing Tests: Hearing tests are usually arranged by the hospital, but if a test is not offered it is important to ask for one. Most people will have several hearing tests to determine what sort of device they need.

Hearing aids: Digital hearing aids are now fitted routinely on the NHS. These are available on prescription from an ear, nose and throat consultant in audiological medicine, or by referral from a GP to an audiology department.

Cochlear implants: Rapid assessment for cochlear implants is vital for anyone with profound or very severe hearing loss, otherwise bone may grow in the inner ear (ossification), compromising successful implantation.

A cochlear implant is a bionic ear, surgically implanted to restore hearing to a person too severely deaf to benefit from hearing aids. Bilateral cochlear implants (implants in both ears) are recommended for all children who need implants, and for adults who need implants and are blind or have other disabilities that increase their reliance on hearing.

See www.nice.org.uk/nicemedia/pdf/TAI66QRG.pdf

Communication support: Deaf people are entitled to communication support for job interviews, medical appointments or training courses. In addition, support comes in the form of British Sign Language (BSL) interpreters, deafblind interpreters, lipspeakers, notetakers and speech-to-text reporters (palantypists).

See www.direct.gov.uk/en/DisabledPeople/Everydaylifeandaccess/Everydayaccess/DG_10037996

In England, all families of children who are deaf or disabled should receive a Family Support Pack from the Early Support programme. Download at www.earlysupport.org

Speech and language therapy

Meningitis can cause hearing loss, neurological damage or both, with resulting speech, language and communication problems. A speech and language therapist can help with communication and the development or restoration of speech.

Speech and language therapists may also help with neurological damage that causes problems with eating, drinking or swallowing. They work in clinics, health centres, schools and hospitals, and will try to see children in the most appropriate setting, which may be at home or at school.

If verbal communication is not an option, other methods of communication such as sign language, symbol speech or a communication aid can be used.

If you think you or your child need(s) a speech and language therapist and this was not provided on discharge from hospital, you can ask your GP, child's teacher, health visitor or nursery teacher, to refer you. In many areas there is often a shortage of speech and language therapists, so it is important to know that you can also refer yourself or your child directly by contacting your local speech and language therapy service through your primary care trust.

There is often a waiting list for speech and language therapy appointments, but you might be able to move things faster by getting in touch with your NHS Trust to remind them of your case.

When obtaining a Statement of Special Educational Needs for a child who is deaf, make sure speech and language therapy is specified under special educational provision.

For more information visit:

<http://www.ican.org.uk/talkingpoint/>

http://www.rcslt.org/speech_and_language_therapy/how_to_find_an_slt/howtofind

Prosthetics

People with amputations due to septicaemia often undergo a more difficult healing process to those who require amputations for other reasons. It can result in continuing problems which can mean there is a delay before prosthetics can be fitted. While you are in hospital you will be under the care of a multi-disciplinary team which could include orthopaedic surgeons, plastic surgeons, physio and occupational therapists; each of whom will work to optimise mobility and day-to-day functions.

Your consultant will refer you to your nearest Disablement Services Centre or Limb Centre where the process can begin.

Each limb needs to be individually made and fitted for each patient and so, within the first month, more than one prosthesis may be required to ensure a good fit, as the residual limb can change shape. Children will require regular replacements as they grow.

When choosing an artificial limb, it is important to consider what you're expecting it to achieve, and to be explicit and aspirational about sports and recreation as well as work requirements. Training on use should also be received.

See <http://www.limblossinformationcentre.com/rehabilitation/>

<http://www.limbless-association.org/pages/amputee-information-centre-faqs.html>

In some instances Primary Care Trusts (PCTs) will agree for NHS funding to be put towards privately-sourced prosthetics but this is not true of all PCTs. In other cases family and friends fundraise to purchase specialised prosthetics privately.

Physiotherapy

Many people affected by meningitis and septicaemia will need physiotherapy while in hospital and after discharge to help with rehabilitation, which may be due to problems with bone, muscle and skin following septicaemia, or neurological damage.

Physiotherapists work in hospitals, community day centres and may visit at home. They massage and manipulate bones and muscles and introduce exercises to develop or restore physical function.

They work closely with other healthcare professionals including occupational therapists and orthotists.

Occupational therapy

Occupational therapist (OTs) enable disabled people to carry out the activities of everyday life, using therapeutic techniques, adaptations to the home or other surroundings and specialist equipment including motability. These activities could include simple functions like sitting, eating and washing.

They work alongside physiotherapists and are part of the health service, and social services. They work out of hospitals, schools and special units.

In the first instance a referral is needed from a doctor to access physiotherapy and occupational therapy.

Wheelchairs

Wheelchairs (manual and electric) are supplied and maintained free of charge to a disabled person whose need is permanent. This is through NHS Wheelchair Services, see:

www.wheelchairmanagers.nhs.uk/services.asp

The way services are organised and provided varies but the basic process is:

- referral to a local NHS Wheelchair Service
- assessment of need
- discussion of timescales and funding options
- provision of wheelchair and training
- arrangement of maintenance and repair plan.

People can be referred to a service by a hospital, doctor, consultant or occupational therapist, and some services allow self-referral. The minimum age for referral is generally 30 months, but younger children with postural needs will be considered if they cannot be safely seated in a standard buggy. Each service has its own eligibility criteria.

The assessment for a wheelchair considers:

- the nature and level of disability
- the person's lifestyle and needs
- the person's ability to use any particular type of wheelchair
- all the situations in which a wheelchair may be used – at school, using transport, social and recreational activities.

Consequently, it is important to aim high and be positive about the activities you/your child expect(s) to undertake using a wheelchair and the level of independence desired.

NHS trusts in England have a voucher scheme. Users can personally add to the voucher in order to buy a more expensive wheelchair. See www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/Equipment/DG_10038381

You may be unable to use the voucher to get a powered wheelchair but could use the Motability scheme to hire or purchase an electric wheelchair.

NHS wheelchair services are significantly under resourced, with long waiting times and restrictive eligibility criteria. It is important to be clear and explicit about what you need.

If you have applied and cannot get funding, or if you were applying for a child and could not get the kind of chair needed, then charities such as Whizz-Kidz may be able to help. For details of charities that fund children's wheelchairs and other equipment visit

<http://www.livingmadeeasy.org.uk/scenario.php?csid=172>

There is also a range of specialist mobility equipment for disabled children such as standing frames, scooter boards, swivel walkers and many others, see http://www.dlf.org.uk/sites/default/files/Choosing_childrens_mobility_equipment_sponsored.pdf

For information on the options available for adult wheelchairs see

<http://www.wheelchairusers.org.uk/index.html>

www.mobilitytrust.org.uk



Aaron Phipps contracted meningococcal septicaemia aged 15 in 1999. He has had both legs amputated below the knee and lost the tips of most of his fingers.

He works full time and is also a keen sportsman: he completed the London Marathon for MRF in 2008 and also races competitively and plays rugby.

"Seeking the right equipment to enhance independence was, and still is, really important to me. This resource is a first step to identifying where that help may be available."

Special Education Needs (SEN)

Meningitis can cause a range of disabilities, including moderate to severe learning difficulties, more subtle concentration and memory problems and physical disabilities that affect a person's ability to carry out normal day-to-day activities. Many children affected by meningitis will need more educational help than other children and there is help available for them.

The term Special Educational Needs (SEN) is used to describe children who find it much harder to learn than most children of the same age, or who have physical or behavioural disabilities that make school more difficult for them.

The education departments within local authorities (often still called Local Education Authorities, or LEAs, although LEAs were amalgamated into Children's Services under the 2004 Children Act) write statements for children who need the most help, after parents and professionals have agreed the nature of a child's difficulties and have decided what extra help is needed.

By law, local authorities, schools, government-funded nurseries/other early education settings and agencies who help them – including health and social services – must have regard to the government's Special Educational Needs Code of Practice. For a copy of the SEN Code go to http://www.teachernet.gov.uk/_doc/3724/SENCodeOfPractice.pdf

Not all children with special educational needs have a statement. The SEN Code recommends that children with special educational needs, but less serious difficulties, should be given extra help by the school through either School Action or School Action Plus (or Early Years Action or Early Years Action Plus in pre-school). However, you do not have to wait until your child has had help through Action Plus before getting a statement. Many children are affected by meningitis in the first months or years of life, and it may be clear well before school age that your child will need extra help.

Local authorities have a duty to identify any child who may have special educational needs, but children must be referred to them for this to happen.

How to get an SEN statement:

I. Statutory assessment

- This is carried out to help the local authority decide what extra help your child needs
- You can make a request to your local authority or your child may be referred to the local authority by a professional, eg. health visitor, social worker, or by the school or nursery they attend
- Even if the health authority or social services has referred your child to the local authority, it is important to request an assessment yourself. This not only ensures that you see all the reports and information about your child, puts you in a better position to request meetings and arrange extra reports, but helps you keep track of deadlines. It is important to note if the request comes from a health professional you have no right of appeal if the local authority refuses to assess your child
- Whomever asks for the assessment, it is a good idea to request one yourself as it may avoid some delay. You can request an assessment even if the school has already requested one

- If the school asks for the assessment, you do have the right of appeal. You have the right to request an assessment even if the school does not agree that it is necessary
- In the first instance, talk to your child's pre-school or class teacher to find out about help available within the school. There should be a designated person called The Special Educational Needs Coordinator (SENCO) who coordinates the necessary help
- It is a good idea to find out as much as you can about possible schools for your child at an early stage even if your child is not in school or pre-school
- The charity SCOPE has a factsheet on getting a statutory SEN assessment, including useful points to look for when checking schools:
www.scope.org.uk/information/factsheets/statementing.html

Also see: [http://www.teachernet.gov.uk/_doc/3755/4163_A5_SEN_GUIDE_WEB\[4\].pdf](http://www.teachernet.gov.uk/_doc/3755/4163_A5_SEN_GUIDE_WEB[4].pdf)

How to go about making a request:

- Explain what help your child is getting at school or nursery if applicable and why this is not enough
- Write a report on your child's needs and difficulties
- The Early Support booklet on Statutory Assessment provides template letter for requesting a statement and a checklist that will help you to prepare your report: <http://www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/earlysupport/resources/informationsharing/booklets/booklets/> and click on Statutory Assessment
- Also include any reports you may have from doctors or teachers to support your request, and a list of professionals who have worked with your child who can be consulted by the local authority
- Then send this, with a letter requesting an assessment for special educational needs to the Education department of your Local Authority.

What happens next:

- Once the local authority gets your letter requesting an assessment, it has six weeks to investigate whether there is a need for a formal assessment
- You should receive a response explaining how they will make the decision, who they will ask for advice and details of Parent Partnership services.

What is Parent Partnership?

- You may find it helpful to contact your local Parent Partnership group for support, advice and information, see www.parentpartnership.org.uk
- Among other things, Parent Partnership services can provide access to an Independent Parental Supporter (IPS) if you want one. Your IPS can tell you about local arrangements, help you make

your report, attend meetings with you, go through letters and reports with you and tell you about any other agencies offering support with benefits or childcare.

I've heard nothing – what now?

- If you don't hear from the local authority you can write to remind them that the six-week period started when they received your first letter. It is important to keep a copy of all letters and documentation and to follow up any telephone calls with a letter summarising your conversation.

Outcomes:

- **The local authority does not agree to make a formal assessment**, in which case you can appeal to the First-tier Tribunal (Special Educational Needs and Disability) as long as you or the school requested the statutory assessment. The local authority must tell you the time limits for an appeal. If the Tribunal agrees with you, they can order the local authority to assess your child. See <http://www.sendist.gov.uk/>. The Independent Panel for Special Education Advice produces a detailed 'Refusal to Assess' advice pack for parents who want to appeal, see <http://www.ipsea.org.uk/>
- **The local authority agrees to make a formal assessment.** To confirm their agreement, they will send you an information pack with time-scales, an outline of the assessment process and details of special needs services in your area. They will then ask for advice and opinions about your child's educational difficulties from anybody who has a caring role in your child's life: from you, their school, educational psychologists, doctor or social services. This is so they can get a clear picture of your child's needs
- If you can provide them with a list of people you want them to consult about your child, this will help, and do ask to be sent all the advice and opinions they receive
- Also it's worth asking to be informed of all assessments so you can attend. You are entitled to attend any interview (medical or other) during the assessment. You know your child best so this is important, and it gives you a chance to ask the assessor (usually an educational psychologist or therapist) what they have found out, what specific resources or help they think your child needs and how his/her education will be affected. If you write down the answers, you can compare the findings with the report the assessor makes to the local authority
- The local authority has ten weeks to carry out the assessment. If however the additional requested information is not provided within six weeks, it may take longer.

After the assessment the local authority has two weeks to EITHER

- Send you a Note in Lieu, explaining why they will not make a statement and how your child's needs should be met in school or in other ways. At this point they will explain your right to appeal. If this happens you can appeal to the First-tier Tribunal (Special Educational Needs and Disability), see above.

OR

- Send you a proposed (or draft) statement with copies of the advice and assessment reports they have received
- At this stage, it's worth checking that the reports agree with your notes, and that the proposed statement agrees with the reports. If you don't agree with a report, you can request a meeting with the assessor, and can take your IPS or another representative with you. You can also arrange for additional reports if need be
- You have just 15 days to register an objection to the proposed statement with the local authority
- After this you will receive a final statement. Again, you have 15 days to register an objection with the local authority after receiving the final statement, but two months to register a complaint with the Tribunal if you are not happy with the statement.

The Statement of Special Educational Needs

- It is important to check the proposed statement very carefully to ensure that you are happy with the detailed description of your child's needs and the provision which should be made to meet those needs
- Watch out for vague language that doesn't make it clear what help your child should get. Also, make sure that your child's needs and provision for those needs are set out in Parts 2 and 3 of the Statement (including eg speech and language therapy, if needed)
- The local authority must, by law, make sure that educational help listed in Part 3 is given to your child. This is not the case for non-educational help listed in Part 6. The Advisory Centre for Education produces a very helpful Getting the Statement Right booklet that covers checking the statement, negotiating with the local authority, mediation, and appeals. See <http://www.ace-ed.org.uk/Resources/ACE/advice%20booklets/Getting-Statement-Right-Nov09LR.pdf>

Annual Review

- If your child receives an SEN Statement, the local authority must review it at least annually to see how your child is getting on and whether the statement needs to be amended
- The annual review meeting is usually held at the child's school
- You should receive copies of all reports and assessments that will be used in the review at least two weeks before the meeting
- Network81 produces a comprehensive leaflet about the annual review, see [www.network81.org/files/Green%20Leaflet%20\(for%20web\).pdf](http://www.network81.org/files/Green%20Leaflet%20(for%20web).pdf)

For more information and advice about Special Educational Needs consult:

SEN toolkit: www.teachernet.gov.uk/wholeschool/sen/teacherlearningassistant/toolkit/

SEN guidance for parents www.teachernet.gov.uk/docbank/index.cfm?id=3755

SEN Quality Standards <http://www.teachernet.gov.uk/docbank/index.cfm?id=12896>

www.direct.gov.uk/en/Parents/Schoolslearninganddevelopment/SpecialEducationalNeeds/DG_4000835

Getting a statement

"Jamie was two and half years old when we knew he would need specialist schooling. We decided to begin looking at schools then so we could ascertain the best one for his needs as he is profoundly deaf and cochlear implants have not been successful. We had already begun to explore British Sign Language so Jamie would be able to communicate, but we were very surprised by the resistance we had from the council and other service providers to support our choice for him to be educated in a BSL environment.

We learnt very quickly that to get a statement and access to the right educational services we would have to fight. It was important for me to do all my research before filling in any forms. Using statements like 'must have' and 'needs to have' rather than 'would benefit from' was key to our success. Also getting an independent assessment to support our own assessment strengthened our case.

"What I would advise any parent is do your homework and find out everything about the process of statementing before you begin. Find out who will be responsible for making the decisions on your child's case, when they will meet to review the case, whether this will give you enough time to appeal (if required), and speak to them beforehand if you can. Make sure you know what you want for your child and do not let anyone else convince you otherwise."

To talk to other parents about Special Educational Needs and statementing, visit http://www.mumsnet.com/Talk/special_educational_needs/

Portage

Portage is a home-visiting educational service for pre-school children with special educational needs, which is usually provided by local education authorities. The aim is to support development of a child's play, communication and relationships.

Portage also gives parents the practical help they need to share their child's learning and help with their child's day-to-day learning and activities.

A Portage worker may be a teacher, speech therapist, nursery nurse, parent or volunteer with relevant experience.

You can find your local portage team on <http://www.portage.org.uk/map.php>

Further sources of help and information

British Society of Rehabilitation Medicine

<http://www.bsrm.co.uk/ClinicalGuidance/ClinicalGuidance.htm>

<http://www.bsrm.co.uk/ClinicalGuidance/StandardsMapping-Final.pdf>

Department for children schools and families. Every Child Matters. Background information booklets

<http://www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/earllysupport/resources/informationsharing/booklets/booklets/>

Directgov. Health and social care professionals you may meet

http://www.direct.gov.uk/en/CaringForSomeone/CaringForADisabledChild/DG_10027150

Disabled Living Foundation (DLF)

DLF is a charity that helps the public and healthcare professionals find out about daily living equipment and assistive technology. www.dlf.org.uk

KIDS

KIDS is a charity that works with disabled children, young people and their families.

www.kids.org.uk/information/100347/our_work/

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Meningitis Research Foundation

MRF has more than 20 years experience of patterns of recovery. If you, your child or a family member has been affected by meningitis or septicaemia, please call our 24 hour **Free**phone helpline. We can:

- offer a listening ear and support to anyone affected
- answer your questions and provide information
- help you navigate the disability rights and benefits system
- put you in touch with telephone befrienders who have been through similar experiences.

080 8800 3344 (UK)

Email helpline@meningitis.org

www.meningitis.org



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