Meningitis Research Foundation

Meningitis now

Social work and community support

As a result of meningitis or septicaemia we know that people's lives and family circumstances can change in many different ways. If you are caring for a child who has been disabled by meningitis and septicaemia you may have to spend lots of time helping your child with bathing, moving around, eating, toileting or with communication. You may have new responsibilities like giving medication, using technical equipment or doing physiotherapy or other therapies with your child. Or you may need to spend more time supervising your child to keep them safe. These sorts of issues can have a huge impact on the day to day functioning of a family.

It important to be aware that support is available to your family and your child from your local council.

Your local council can provide help if you have a disabled child, including:

- short break services
- holiday play schemes
- care at home
- some aids and adaptations
- financial help (e.g. money towards travel costs for hospital visits)

Your council has a duty to provide services to "children in need" under the Children Act 1989. According to this act a disabled child would be considered a "child in need". Some services are free of charge - the council might ask you to contribute towards others.

If you think your child may qualify, contact the social services department.

A social worker will then talk to you about the needs of your family, including:

- health
- social care
- education

This is called a **'needs assessment'**.

Families are sometimes reluctant to get involved with social services at first because of the perception that social services are for 'problem families' or bad parents. Social services do help families with social problems and deal with child protection, but they are there for all children in need. While health services should look after your child's medical problems, many families with children disabled by meningitis and septicaemia have found that having a social service assessment is key to getting the support they need for everyday living. If you are still concerned about involving social services, you may wish to ask your local council to put you in touch with an advocacy service.

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Numbers within the text that appear as subscripts like this [1] correspond with numbered references listed at the end of this fact sheet.

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Getting an assessment for your child

Most families with a child disabled by meningitis and septicaemia who needs help are referred to social services by a health professional involved in their child's care; however this is not always the case. You are entitled to contact your local council for an assessment of your child's needs.

Councils use certain criteria to assess whether a child is "in need" and qualifies for an assessment under the Children Act. They must make a decision on whether your child will be assessed within one working day of receiving the request for an assessment[1]. If your local council decides not to assess your child, you can ask them to provide the reasons for this decision. If you still feel that your child should be assessed you can make a complaint.

Who does the assessment?

Assessments are carried out by social workers. A social worker's role is to give support so that service users can help themselves. They maintain professional relationships with service users, acting as guides, advocates or critical friends.

Qualified social work professionals are often supported by social work assistants and other social care professionals such as Family Support Workers. Social work involves engaging not only with clients themselves, but also their families, friends and other organisations including local authority (LA) departments and schools.

What the assessment involves

If your child is to be assessed, the initial assessment should be carried out within seven working days of when the request for an assessment was made[1]. Social services will assess the needs of the family as a whole and should take into account:

- The family's background and culture
- Your own views and preferences (for example consideration of whether you need to work, participate in training, leisure and other activities)
- The needs of any other children you have

The assessment is not a test of your parenting skills. It should be a sensitive look at any difficulties your family has, with a view to considering what support or services are needed.

Each council will have a set of eligibility criteria. If your child's needs meet these criteria the council has a duty to arrange certain support services. In some circumstances the outcome of the first assessment will be that a more detailed core assessment should take place. A core assessment will almost certainly involve other agencies (such as health professionals or educational professionals). These individuals will provide specialist knowledge or advice to social services or undertake specialist assessments. A core assessment should be completed within 35 working days of the initial assessment ending[1].

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A care plan will be drawn up to specify the services that will be provided to best meet your child's needs.

A care plan should:

- outline specific goals for your child
- be realistic and avoid vague statements of good intent
- be drawn up in agreement with your child where possible and key family members
- be reasonable and have timescales that are not too short or unachievable
- not be dependent on resources that are known to be scarce or unavailable
- focus on your child even though the wider family may get help as part of the plan
- be based on the findings from the assessment
- state when and how the plan will be reviewed (your child's needs will change over time)

Carer's assessment

You may find that your child's assessment carried out under the Children Act meets all your needs as the carer, but if that is not the case you can ask for a separate assessment of your own. A carer's assessment gives you the opportunity to talk to a social care professional about what could make caring easier for you and what help and support is available. It is not an assessment of your ability to care and you do not have to pay for the assessment.

You have a right to a separate carer's assessment under the Carers (Recognition and Service) Act 1995 and the Carers and Disabled Children Act 2000 if you are providing care on a regular and substantial basis. Government guidance suggests that parents who have disabled children do provide regular and substantial care[2].

Put your request in writing to social services and explain which aspects of your own needs as a carer have not been dealt with during any assessment under the Children Act. If they refuse to carry out a separate assessment, you may choose to make a complaint.

Support available

Special equipment and home adaptations

Some children need special equipment to help them carry out normal day to day tasks, such as washing, dressing and getting around the home. The LA can arrange for adaptations to the home or additional facilities for greater safety, independence, comfort and convenience. A Disabled Facilities Grant may be available to you, which can fund necessary changes to your home to improve access to rooms and facilities e.g. widening doors, installing ramps, a stair lift or a downstairs bathroom.

A **Disabled Facilities Grant** will not affect any benefits that you're getting, but the amount you are rewarded will depend on your income and savings, and you may need to pay towards the cost of the work to the property.

Disabled children under 18 can get a grant without their parents' income being taken into account. Contact your local council for more information.

Equipment to meet medical needs, such as wheelchairs will generally be provided by the NHS.

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Mobility and assistance with travel

You may be entitled to concessions on public transport, be eligible for a blue badge or lease a car with the **Motability Scheme**. The national **Blue Badge Scheme** is for people who are blind or unable to walk, and entitles them to park close to the facilities and services they need to use, to improve their lifestyle, independence and freedom of choice. The Motability Scheme can help you lease a car if your child is aged 3 or over and is entitled to either the higher rate of the mobility component of Disability Living Allowance or the enhanced mobility component of Personal Independence Payment.

Short break services – provide disabled children and young people with an opportunity to spend time away from their parents or primary carers, relaxing and having fun with their friends. Short breaks can include day, evening, overnight, weekend and holiday activities.

Holiday play schemes
Your local council's Family Information Service should be able to provide a directory of suitable schemes which may be run by schools, private or voluntary organisations,

Home help – help from paid care workers who will provide practical support (such as helping your child dress, putting them to bed, sitting with your child to give you a break etc).

Learning disability support
Your child's health, education and social care should all be considered when assessing their needs. Supporting your child in school should form part of the care plan, if you have one. **The Parent Partnership Service** at your local council can give impartial advice about special educational needs. You can also read our fact sheet 'Education, your child's rights' for further information.

Additional financial support
There is a wide range of disability-related financial support, including, Child Tax Credits, Disability Living Allowance or Personal Independence Payment and Carer's Allowance. See our **Disability Benefits factsheet** for more information.

Direct Payments – As a parent or carer you can choose to receive a direct payment rather than having social care services directly provided by the LA. A direct payment is money the council can give you to buy the services or equipment that you, or your child needs. You spend the money on getting the support that meets the needs of your family, such as employing personal care assistants, buying in care assistants from an agency or buying equipment. You can have a direct payment for all the support, or for part of it, and you need to be aware that direct payments may not cover the total cost of the service you require so you may need to contribute financially.

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Complaints

If you wish to make a complaint about any aspect of the assessment process you should do this within 12 months either in writing or verbally to the complaints manager in your local council. Confirmation or receipt of your complaint will be sent within 3 working days and the council must respond fully within six months unless a different timeframe has been discussed and agreed with you. If you are still not satisfied with the response then you can contact your local government ombudsman who investigates complaints about local councils.

If you have any questions or wish to discuss anything in this factsheet in more detail, please contact us.

Useful online information

http://www.nhs.uk/CarersDirect/guide/assessments/

https://www.gov.uk/help-for-disabled-child/overview

http://www.carers.org/

http://www.carersuk.org/

References

1. Department of Health, Framework for the assessment of children in need and their families. 2000.
2. Department of Health, Carers and Disabled Children Act 2000: carers and people with parental responsibility for disabled children: practice guidance. 2000.

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