

(12) Parents: Help from social work services

Parents looking after a child with epilepsy often feel isolated and on their own, and will be reluctant to ask for help outside their immediate circle of family and friends.

If your child has complex epilepsy it can be helpful to get a social worker involved early. This can often open doors to further services and support. A social worker can alert you to any help and financial assistance your family may be entitled to.

Section 23 assessment

Section 23 of the Children (Scotland) Act 1995 gives you the right to ask your local authority to carry out an assessment if you feel your child needs additional support. This can be for specialist equipment, financial help, or even short-term breaks.

To request a section 23 assessment, call your local social work department and ask for the Children with Disabilities Team. Some local authorities have a different name for these teams. Always follow up your call with a letter. This should clearly state

- your name and address
- * the members of your family
- * a short description of your child's disability
- what kind of extra help you think you need
- if you need this help urgently

An assessment should be carried out within a reasonable time. What is reasonable will depend on how urgent your request for help is. Your social work department will need to inform you of the reason for any unexpected delays. If it takes too long for a social worker to be allocated to your family, you can make a formal complaint.

helpline: 0808 800 2200 text: 07786 209 501 email: contact@epilepsyscotland.org.uk



During the assessment

You should be given a leaflet about the assessment in advance so that you can prepare yourself for the visit. Make a list of any questions you have before the visit. Some parents find it helpful to have someone else with them for moral and practical support.

A social worker or occupational therapist will visit the family at home looking at how epilepsy affects a child, their parents, siblings and the wider family on a day to day basis. This includes how a child manages in the home with daily tasks like eating and sleeping, and how a child is getting on in school and in the general community.

The social worker is expected to be sensitive to a family's religious and cultural needs as well as anything which is important to a family and make this part of their assessment. Both the parent / guardian's views and the child's views must be taken into account as far as this is 'reasonable and practical'.

After the assessment

A resource allocation team or team by similar name makes the decision. This team is usually made up of social work staff, health professionals, a voluntary sector and parent representative. The team may assess a child as being 'in need' of services, or they may decide that there is no need and will close the case. If you disagree with the outcome of the assessment, you can appeal.

The kind of support and services you can expect includes:

- practical help in your home
- * specially adapted equipment
- * a short break for you or your whole family

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- Befriender this is a one to one relationship with a child. The befriending agency agrees with a parent beforehand what activities the child might like to do, for example go fishing, climbing, shopping and when this is to take place. The number of hours can vary, but it is generally around three hours per week.
- Specific clubs or schools these take place outside of school hours or may even be part of an after-school club. Some groups run over the long school holidays.
- * Overnight stays this can be either within a unit specifically for children with disabilities or with a family with specialist interest and training in disabilities.
- Residential schools these are usually set up specifically for children with complex disabilities. Residential stays might be from Monday to Friday or last the whole term time.

A local authority may, however, not have the funds to provide all the services a child needs. They will often use 'eligibility criteria', which allow them to prioritise services for those that need them most. This can mean that a child may be refused some services because they simply do not meet the eligibility criteria. Ask for a clear reason for the refusal, and if appropriate, challenge it through their complaints procedure.

Carer's assessment

Under the Community Care and Health (Scotland) Act 2002, as a parent / carer you are also entitled to ask for your own assessment for support from your local authority. Every time a family's circumstances change, a carer can ask to be reassessed. For more information visit www.carersuk.org or phone the Carers UK advice line on 0808 808 7777.

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