



Your legal rights

*A short guide for parents and carers
of young people with complex needs
and disabilities.*

About Young Epilepsy

Young Epilepsy is the national charity working exclusively on behalf of children and young people with epilepsy.

With over 100 years expertise it provides world class diagnosis, assessment and rehabilitation for children and young people with epilepsy. It has a unique blend of specialist services including a school, college and residential services providing education and healthcare for children and young people with epilepsy, autism and other neurological conditions. The charity provides a range of support and information for parents, children and young people and training for professionals. It campaigns for better access to, and quality of, health and education services.

About this booklet

Having a child with a serious health condition or long-term complex needs can present a number of challenges that you were not expecting or were unprepared for. This informative booklet will give you an overview of the legal issues which may affect your family as a result of your child's condition(s).



I have a child with additional needs to care for, what are my rights as an employee?



If your child is under the age of 18, you can make a flexible working request to your employer to try to accommodate your child's care needs. This gives you the ability to ask to change the hours or times you work, or to work from a different location, i.e. home.

- In order to make a formal flexible working request, you must:
 - be an employee, not an agency worker
 - have been employed for at least 26 weeks when the request is made
 - not have made another request to work flexibly in the last 12 months.
- Although you do not automatically have the right to be allowed to work flexibly, your employer must give proper consideration to your request. It may only be refused if you are ineligible to make it, or for a number of prescribed statutory reasons.
- If your employer unreasonably refuses your request, then you could potentially have claims for failure to follow both flexible working and sex discrimination legislation.

I am not happy
with my child's
NHS medical care,
what do I do?



- In the first instance, speak with the health professional to see if matters can be resolved directly. It's important to complain as soon as possible, unless in exceptional circumstances.
- The next stage is a formal complaint in writing; all NHS organisations will have a complaints manager. You should receive a written response.
- If you are still unhappy then go to the local Clinical Commissioning Group (for GP and dental services) or NHS England/Scotland/Wales/Northern Ireland (Hospital Trusts). Otherwise the Parliamentary and Health Service Ombudsman can assist further.
- The Patient Advice and Liaison Service (PALS) is available in most hospitals to help. Local authorities have a statutory duty to commission independent advocacy services.
- If you believe your child may have been injured as a result of medical negligence, you may wish to contact a specialist clinical negligence solicitor for advice.

How can I help my child manage his money?

- If your child is under 18, you can open a bank account which is jointly held between the parents and the child.
- If your child has a physical disability that limits his ability to sign or use a Chip and Pin device, many banks have policies in place to ensure funds can still be accessed, such as making a mark instead of signing.
- If your child has capacity to make his own decisions and understands his own finances, he will be able to make a Lasting Power of Attorney at the age of 18. This will enable someone else to deal with his finances for him, for example when he has a hospital stay.
- If your child does not have capacity and they have a larger amount of money, i.e. an inheritance, an application can be made to the Court of Protection in

England and Wales, the Office of the Public Guardian (Scotland) or the Office of Care and Protection in Northern Ireland for a Deputy or similar to be appointed to manage these funds.

- If your child does not have capacity and he only has small amounts of money to manage, it may be too costly for a Deputy to be appointed. A benefits appointee can deal with any benefits he is entitled to which means the need for a Deputy could be avoided.



I've heard about trusts for children and disabled people, are they just for tax avoidance?



- A trust can be set up as a part of a will to deal with inheritance for the children. It can also be established, during the parents' lifetime, to provide for the children and allow them some independence.
- Special rules exist for trusts set up by parents for their children and for trusts set up for those who are classed as disabled.
- The special rules for people who are classed as disabled apply to anyone who is receiving the disability living allowance care component, at the middle or higher rate.
- The terms for paying out income or capital can be decided when the trust is set up, or decided by the trustees, on an ongoing basis. These terms can help to provide for the child throughout the child's life.
- A trust can also be used to protect money received in compensation for any injuries the child may have received, and to protect the child's right to means tested benefits.

What can I do to ensure my child is provided for after I die?

- The best way to ensure your child is provided for is to make a will. If you die without making a will, your money may not go to the people you want it to.
- When making a will, you may need to consider your child's age and their ability to manage any money they may receive.
- You may also need to think about the impact any inheritance they receive may have on their entitlement to benefits.
- Get professional advice from a solicitor who can consider your personal circumstances, and advise you on how to achieve what you want and ensure your child is provided for after you are no longer here.



We are separating, what do I do regarding my disabled child?

- Try to agree access arrangements. Legally a parent with parental responsibility cannot be stopped from having contact with their child unless a Court orders this. If you can't agree, try using a free mediation service for families on low incomes.



- Contact the disability team in your local authority and ask for a re-assessment of your circumstances. Disabled children are classed as 'children in need' in most cases, which means you may be entitled to support, whether that is practical, emotional or financial.
- Check whether you are entitled to any benefits. Both parents are legally responsible for financially supporting their child. If one parent does not have day-to-day care of the child, child support maintenance may need to be paid. This can either be mutually agreed or an arrangement can be set up by the Child Maintenance Service/Child Support Agency.
- If you are in receipt of any benefits or tax credits, notify them of your change of circumstances immediately. Failure to do so could incur a fine.
- Your local Citizens Advice Bureau will be able to help you find a solicitor, or agencies, who can assist in sorting out eligibility to benefits.
- Get support for yourself. Ask your GP about services in your area.

My child will shortly turn 18 and I've heard that as a parent I will no longer be involved in decisions about her care and treatment. Is this right?



- At the age of 18, everyone is presumed to be able to make their own decisions unless it can be shown otherwise.
- If your child isn't able to make her own decisions then any decisions made for her must be in her best interests.
- The decision maker, e.g. a doctor, should consider all the relevant circumstances, the views and wishes of that person, and the views of other people who are close to that person.
- If you feel your views are not being taken into account, speak to those involved and make a formal complaint through their complaints procedure.
- If this does not resolve the issues an application can be made to the Court of Protection in England and Wales or the Office of the Public Guardian (Scotland) for a specific decision or the appointment of a Deputy to make decisions for them. In Northern Ireland there is currently no equivalent legislation.

Useful contacts

Young Epilepsy Helpline

www.youngpilepsy.org.uk

Email: helpline@youngpilepsy.org.uk

Tel: 01342 831342

Text: 07860 023 789

Health

- NHS England: Tel: 0300 311 2233
www.england.nhs.uk
- NHS Scotland: www.scot.nhs.uk
- NHS Wales: www.wales.nhs.uk
- NHS Northern Ireland: www.hscni.net
- Patient Advice and Liaison Service. Find your nearest PALS office on NHS Choices website, www.nhs.uk

Ombudsman

- Health Ombudsman England:
Tel: 0345 015 4033
www.ombudsman.org.uk
- Public Service Ombudsman Wales:
Tel: 0300 790 0203
www.ombudsman-wales.org.uk

- Scottish Public Service Ombudsman:
Tel: 0800 377 7330
www.spsso.org.uk
- Ombudsman Northern Ireland:
Tel: 02890 233 821
www.ni-ombudsman.org.uk

Employment advisory service

- ACAS: Tel: 08457 47 47 47
www.acas.org.uk

Financial advisory services

- Court of Protection:
Tel: 0300 456 4600
www.gov.uk/court-of-protection
- Office of the Public Guardian:
Tel: 0300 456 0300
www.gov.uk/office-of-public-guardian
- Child Support Agency:
www.gov.uk/child-support-agency
- Child Maintenance Agency:
www.gov.uk/child-maintenance
- Child Tax Credit:
www.gov.uk/child-tax-credit/overview

General advisory services

- Citizens Advice Bureau:
Tel: 0844 848 7919
www.citizensadvice.org.uk

With thanks to Withy King for their kind support in the production of this booklet.



Withy King is a law firm offering a full range of legal services.

www.withyking.co.uk

0800 923 2073



Check out our Facebook page:

facebook.com/youngpilepsy



Follow our tweets:

twitter.com/youngpilepsy



Watch us on YouTube:

youtube.com/youngpilepsy



Download our FREE app:

youngpilepsy.org.uk/app

Young Epilepsy

St Piers Lane, Lingfield, Surrey, RH7 6PW

Tel: 01342 832243

Fax: 01342 834639

Email: info@youngpilepsy.org.uk

youngpilepsy.org.uk

Young Epilepsy is the operating name of The National Centre for Young People with Epilepsy.

© Young Epilepsy 2014 Registered Charity No 311877 (England and Wales)

Publication No. 305