



East Anglia's
Children's Hospices

Here To Support You

A guide for parents on
different areas of law

We support families and care for children and young people with life-threatening conditions across Cambridgeshire, Essex, Norfolk and Suffolk. Our family-centred approach includes specialist nursing care, symptom management support, short breaks, wellbeing activities, therapies and counselling; all meeting the individual needs of the child, young person and whole family.

We offer a family-centred, needs-led approach to care, ensuring all of the needs of the children and young people we care for are met. This includes their psychological, physical, emotional, social or spiritual needs. We do understand that depending on the circumstances there may be broader practical and legal issues that can cause concerns to a family, some of which are not immediately obvious.

This guide has been prepared with support from the law firm, Irwin Mitchell, for young people during the transition into adulthood and their parents to offer legal advice for issues that may arise around this time. A number of areas have been covered and these include:

1. The Mental Capacity Act – decision making when approaching adulthood
2. Lasting Power of Attorneys and Deputyship
3. Access to education post-16
4. Social care support
5. Deprivation of liberty



Disability Rights - Care and Support

Unless your child's needs are very complex, any social care support is usually funded by the local authority.

Local authorities should carry out a care assessment for any "child in need" in its local area upon request - and this threshold is deliberately low. Where needs are identified, provision can then be made available to a child under the terms of the Children Act 1989 or under the Chronically Sick and Disabled Persons Act 1970.

Some children who have complex healthcare needs might also be eligible for continuing care from NHS services. This generally means that both the NHS and the local authority pay towards the costs of meeting the child's care needs. One of these bodies will take the lead in managing the care package.

Either way, it's important for parents to know that statutory bodies are under specific duties to ensure they provide adequate support to meet the needs of disabled children and their family. Your local social services department is usually the best place to go at first, in order to request a care assessment for your child. You can find details of how to make a request for an assessment by looking at the Local Offer your local authority should have on its website. Once the care assessment is complete, a care plan should be put in place that meets any identified needs. The types of support could include aids and equipment, respite or short breaks, and personal care within the home. It could also include specific support for parent carers.

If you are not happy with the provision you receive from the local authority or NHS services, you can seek to challenge the assessment and the funding granted to ensure that your child is provided with the services to which they are entitled, either by filing a complaint, or by seeking legal advice.

Support services your child may be entitled to include:

- Community care services – helping you and your child get all the care and support they need to live as independently as possible
- Continuing healthcare – ensuring they receive the care they need where they have more complex health needs
- Adaptations to the family home, and access to additional aids and equipment.



Education

Schools are under a legal duty to ensure they meet the needs of children in their schools. This includes direct legal responsibilities such as making reasonable adjustments for disabled children.

Local authorities are also under a duty to ensure that children in their area receive a suitable education. Under this duty they must ensure, for example, those children with a long term health condition can access education in alternative settings where necessary.

For children with a learning difficulty which calls for additional provision to be made available to them than would otherwise normally be available in school, Education, Health and Care (EHC) plans are often put in place. EHC plans enable children up to the age of 25, who are in education, to receive a complete package of support if they require it. This could include speech and language therapy, physiotherapy, and occupational therapy. A parent is able to request an EHC needs assessment by directly writing to the local authority – details of how to make this request should be available on the local authority's website.

If a local authority refuses to carry out an assessment, or refuses to issue an EHC plan, these decisions carry a right of appeal. Parents can go to the First Tier Tribunal for Special Educational Needs within 2 months of the decision being made, or within 1 month of the date of their mediation certificate. Parents are required to contact a mediation advisor before lodging an appeal, although there is no requirement to actually mediate.

Children with an EHC plan have direct legal rights. For example any of the provision listed in Section F of an EHC plan (special education provision) must be provided by a local authority. Similarly any healthcare provision listed in Section G of an EHC plan (healthcare provision) must be funded by the CCG. EHC plans should therefore be drafted carefully to ensure the provision is specific and enforceable.

Annual reviews should take place every year, and if a parent is unhappy with the contents of an EHC plan, or if the local authority refuses to amend an EHC plan following an annual review, a right of appeal also arises.

In addition to legal provisions around EHC plans, schools must also ensure they do not discriminate against children with disabilities, and claims for discrimination can also be brought to the First Tier Tribunal.



Medical negligence and birth injuries

Fortunately medical treatment in the UK is generally of a high standard - poor decision making and medical accidents are rare.

However there are occasions where children are not provided with medical care of an acceptable standard, either during or after their birth, which can leave children and their families to cope with lifelong disabilities and ongoing complex care needs. Families naturally want answers and the comfort that lessons have been learnt and mistakes in the future will be avoided for other families.

It may be that the hospital poorly managed the pregnancy or your child's birth, failed to reach a correct diagnosis in time or delayed commencing the necessary treatment. Or it could be that your GP failed to pick up the early stages of a condition and delayed your child's referral to hospital for treatment, which led to a worsening of their symptoms and potentially permanent injury or death in some cases.

Ante-natal errors - despite highly advanced scans, medical professionals can miss or even misdiagnose problems with an unborn baby. Errors made at this stage can have devastating consequences. Including misdiagnosed miscarriage, severe unexpected birth conditions and even stillbirth.

Errors during the birth - concerns can arise from damage caused by medical instruments, anaesthetics, inadequate monitoring of the baby's heart beat and poor management of the labour. The injuries which might result following these concerns include cerebral palsy, brachial palsy (Erb's Palsy), brain injury, facial paralysis, spinal injuries or fractured bones.

Whatever the circumstances of your child's treatment, the legal investigation process requires information to be gathered, which will usually involve obtaining medical records and seeking independent evidence from expert medical practitioners. This would be taken care of by your specialist medical negligence solicitor.

Compensation is not a windfall but rather a way of providing your child with financial support in relation to on-going care needs, specialist aids, equipment and educational and rehabilitation needs. If your child receives ongoing treatment with the hospital or clinicians where the negligence occurred, this should not stop you from investigating a claim as the hospital and clinicians continue to have a duty of care to provide the best treatment and support.



Employment rights for parents

When you are caring for a child suffering from a life threatening condition or have suffered bereavement it may be difficult to cope with your workload. You may find that your job becomes too stressful for you to deal with or that you're unable to return to work. Many employers will be very supportive when an employee suffers bereavement or has carer responsibilities.

Employers have a duty to make reasonable adjustments to working practices to accommodate their employees. This means, in practical terms, that:

- A person shouldn't be refused employment simply because they have carer responsibilities
- An employee should usually be allowed time off work to attend medical appointments relating to their child's treatment
- An employee should be allowed to take reasonable time off work as a result of the death of a dependant.

Employers must also make reasonable adjustments to the workplace to accommodate their employees - these could be changes to workstations, premises or working hours. If these adjustments are not made, then the employer must be able to justify that they wouldn't be reasonable (e.g. because they wouldn't be practicable or would be too disruptive).

Parents of children under the age of six or disabled children under the age of 18 have the right to apply to their employer to work more flexibly. The request can cover hours of work, times of work and place of work and may include requests for different patterns of work, including:

- Flexi-time
- Home working
- Term-time working
- Shift working
- Self-rostering
- Annualised hours.

The request must be made in writing and the employer has a statutory duty to consider the request seriously and to refuse it only if there are clear business grounds for doing so. Employees making applications for flexible working have the right to be accompanied at a meeting by a fellow employee.

Contact us today, we're here to support you and your family, whatever the outcome.

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W: each.org.uk

For advice or assistance with any legal matters raised in this guide, please contact Irwin Mitchell:

T: 0800 023 2233

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This information relates to the law and procedures in England and Wales. All information included within this booklet is correct as of August 2020.

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