




East Anglia's
Children's Hospices

Here To Support You

A guide to help you in the
transition into adulthood

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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



The Mental Capacity Act – decision making when approaching adulthood

Before children reach the age of 16 the law assumes that they're unable to make decisions for themselves, and that parents/guardians will generally make decisions for them on their behalf. This means that parents will routinely be asked to make decisions around issues such as the type of social care support to be provided to their disabled child, or whether proposed medical treatment should be given to their child.

As children develop and mature, they generally become more able to participate in decision-making and start to make their own decisions, including about their own care and support. This is reflected in the provisions of the Mental Capacity Act 2005 (MCA), which applies to individuals in England and Wales who are aged 16 or over. The MCA refers to 'children' (under the age of 16), 'young persons' (aged 16 or 17), and 'adults' (aged 18 or over). The MCA says that it must be assumed that young people and adults are able to make decisions for themselves, with support as needed, unless evidence shows that they lack the capacity to do so.

If there are concerns about whether a young person or adult has capacity to make a certain decision, a capacity assessment should be carried out. Capacity is assessed on a "decision specific" basis. The law says that people have capacity if they can do all of the following:

- Understand the relevant information
- Retain the information relevant to the decision
- Use and weigh that information in reaching a decision
- Communicate their decision.

If you or your adult child is assessed as lacking capacity to make a certain decision themselves, a 'best interests' decision will need to be taken. Sometimes these decisions are taken informally, although if a "big" decision needs to be made such as where somebody should live, a formal best interests decision is normally recorded, after consultation with relevant parties.

Even where the person doesn't have capacity to make a decision themselves, the process must, as far as possible, involve them. People involved in the care and support of the young person should also be consulted. This enables them to take into account the known wishes and feelings of the person, as well as any values or beliefs they may have that could influence the decision.



Lasting Power of Attorneys and Deputyship

When an adult lacks capacity, many parents and family members worry about how to best look after them and make decisions on their behalf.

A Lasting Power of Attorney (LPA) is a document that can be signed by any adult, giving authority to another adult(s) to make decisions on their behalf, either in relation to financial matters, or health and welfare matters, in the event that they lose capacity to make such decisions for themselves. The LPA needs to be registered

with the Office of the Public Guardian in order to be valid. However an LPA will only be valid if the adult in question had capacity to understand and sign the document at the time it was executed.

If the adult already lacks capacity, then they cannot sign an LPA. So the alternative is to apply directly to the Court of Protection, to become that person's deputy. You can apply to be a deputy to manage somebody's property and affairs, or health and welfare, or both. The role of a deputy is to act in the best interests of the person who lacks capacity, and to "step into the shoes" of the person who lacks capacity and make decisions on their behalf. It doesn't give the deputy more power than the individual themselves would have had, if they had capacity.

Deputies are monitored by the Court of Protection to ensure that they act in the best interests of the individual. Financial deputies are required to file financial information each year to show that they are managing the person's affairs in their best interests.

Many family members feel that applying for deputyship gives them better control over their loved one's affairs, and helps to give them authority to make complex decisions on their behalf if and when they arise.

The forms for deputyship can be found online, and a court fee is payable to the court when the application is issued. Court of Protection solicitors are able to offer support with the applications if necessary.



Access to education post-16

Young people in England must remain in school until the last day of the school year in which they turn 16 (usually the end of school year 11). They are then required to continue in education or training until at least their 18th birthday, this could be through:

- Full-time education (such as school, college or home education)
- Work-based learning (such as an apprenticeship or traineeship)
- Part-time education or training, if they are employed, self-employed or volunteering for more than 20 hours a week.

Local authorities have a duty to ensure that suitable education is provided to children of statutory school age. For children who are too unwell to attend school, even for short periods, this could involve home education or education in alternative or specialist settings. Where children or young people have additional needs, the local authority must ensure those needs are met. Schools and colleges are also under specific duties to make reasonable adjustments to accommodate and educate children and adults with additional needs.

Young people who have an Education, Health and Care Plan (EHCP), might remain in education or training, free of charge, until they are 25 if it's agreed that it would be beneficial for them to do so and necessary in order to meet their identified special educational needs. Whilst there is no automatic right to have an EHCP until the age of 25, this is often justified where somebody has complex needs and requires ongoing or additional support, for example help with adjusting to life as an adult and learning necessary life skills.

The drafting of an EHCP is very important as the provision that is outlined in an EHCP will provide the young person with specific legal rights to access that support. It's important that provision in an EHCP is as specific and quantified as possible. An annual review should take place each year, and following each annual review a right of appeal to the First Tier Tribunal for Special Educational Needs arises. A right of appeal also arises if the local authority decides to cease an EHCP, or decides not to carry out an EHC needs assessment or issue an EHCP at all.

For students with an EHCP, discussions about post-16 options must form part of the focus of and discussions at their annual review meeting in Year 9. Local authorities must also ensure that the EHCP review every year thereafter includes a focus on preparing for adulthood. Preparing for adulthood covers support to prepare for higher education and/or employment, support to prepare for independent living, support in maintaining good health in adult life and support in participating in society.



Social care support

Until children reach the age of 18, any social care support they require is funded by the local authority under the provisions of either the Children Act 1989 or the Chronically Sick and Disabled Persons Act 1970.

However when a young person turns 18, any social care provision they require is funded by the local authority under the provisions of the Care Act 2014.

The Care Act provides that a local authority should carry out an assessment before somebody turns 18, to ensure they have support in place once they turn 18, where it's anticipated that the person is going to have needs for care and support as an adult. If a local authority fails to do this, it will still need to continue providing

funding for social care support under the Children Act 1989 until it has completed the new assessment. This is to ensure there is no “gap” in provision.

Under the Care Act, an adult is entitled to a care assessment where it “appears” that they have needs for care and support. Once an assessment is completed, the local authority will carry out an eligibility assessment and determine if those needs are eligible for support. The eligibility criteria are set out comprehensively in the legislation.

The local authority is under a direct duty to meet any eligible needs that are identified in the assessment. This could include funding support for care at home, for respite support, and for some aids and equipment.

Local authorities must consider how to promote the person’s wellbeing when carrying out the care assessment and putting the care plan in place. Local authorities are entitled to charge a contribution towards the costs of providing such services but must carry out a lawful financial assessment.

Carers of adults are also entitled to carers’ assessments and carers’ support plans. Again, the threshold for these assessments is purposely low – the carer only needs to “appear” to have needs for support in order to be eligible for a carer’s assessment.

For adults with very complex needs, it might be determined that they have a “primary health care need” because of the complexity, unpredictability, intensity, or nature of their overall needs. This would make them eligible for something called “Continuing Healthcare” which means that the NHS would be responsible for funding their care package. In order to determine eligibility for Continuing Healthcare an assessment called a Decision Support Tool would be carried out.

The main difference between being eligible for local authority and NHS funded support is that the NHS isn’t entitled to charge for any contribution towards the care and services it provides, so any care plans funded under Continuing Healthcare come at no additional charge.



Deprivation of liberty

If a young person or adult lacks capacity to consent to their care and support arrangements, they might be “deprived of their liberty” if they are under constant supervision and control, and are not free to leave. The care package must be supervised or funded by the State in order for the person to be officially deprived of their liberty. Examples of deprivation of liberty could include somebody being provided with 24 hour care or supervision, even if that is for their own safety and in their best interests.

The Deprivation of Liberty Safeguards (DoLS) are rules in the Mental Capacity Act, to safeguard adults who lack capacity. They ensure that people who cannot consent to their care arrangements are protected if they're deprived of their liberty. If they're in a care home or hospital, the care home or hospital must ask the local authority to "authorise" the restrictions that are in place.

The arrangements are then assessed to check they are necessary, proportionate and in the person's best interests. The local authority would then issue a "standard authorisation", which can remain in place for a maximum of 12 months before being reviewed.

If a standard authorisation is put in place, one key safeguard is that the individual in question has someone appointed with legal powers to represent them. They are called the Relevant Person's Representative, and can be a family member, friend, carer, or sometimes a paid professional representative. If the individual in question doesn't have family or friends who are able to speak for them, in certain circumstances they'll also have access to an Independent Mental Capacity Advocate (IMCA) who'll work with and support the person who lacks capacity to find out their views, wishes and feelings, as far as is possible, and involve them in the decision-making process.

The individual has a right to challenge the deprivation of liberty in the Court of Protection and can access non-means tested legal aid to do so.

It should be noted that the "standard authorisation" process only applies to adults who are 18 or over in a care home or hospital setting. For young people aged 16 or 17, or those who are cared for in other types of settings such as supported living, the local authority would need to apply directly to the Court of Protection for an order to authorise the arrangements. This process is in place to ensure that people aren't unfairly restricted and to ensure their human rights are respected.

Please note that the DoLS system is currently under review and a new system called the "Liberty Protection Safeguards" is likely to be implemented in the next year.

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

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

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This information relates to the law and procedures in England and Wales. All information included within this booklet is correct at time of print: February 2020.

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