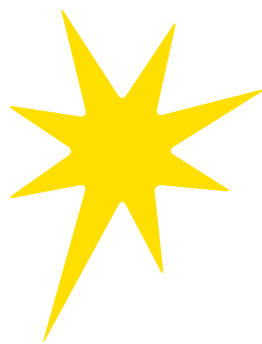




# Decision Making, Confidentiality & Sharing Information

A Guide for Parents



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# Introduction

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This guide has been prepared for parents of disabled children and young people aged under 18 to provide an overview of the law and policy relevant to decision-making in health and social care, including the duty of confidentiality and sharing information. This is an important area because parents are likely to find that their role in decision-making about their child's care and support changes as their child gets older. Health and social care professionals will start to encourage disabled children and young people to take an active part in planning and reviewing their own care and support.

Parents who have been closely involved in their child's health and social care might find this change of approach difficult, especially if the reasons for their reduced involvement are not explained to them. This guide explains the main issues relating to decision-making through a series of questions and answers.

A guide such as this can only provide a summary of the issues involved. It can only give general information and is no substitute for specialist advice on specific issues. Accordingly, the Resources section (see page 18) contains information on where to get further help and assistance and gives details of useful guidance, as well as links for other relevant Cerebra publications. A Glossary of commonly used terms – these are highlighted in **purple** in the text – is provided on page 17.

This guide covers the following areas:

- Making decisions in health and social care
- Consent to medical treatment
- Confidentiality
- Sharing information
- Access to personal records (health and social care records).

# Making decisions in health and social care

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## Q.1 Who makes decisions about my child's care?

This will depend on the age of your child and your child's ability to make decisions for him or herself.

As a parent with 'parental responsibility' you should be involved in decision-making in relation to the care and support of your child. However, the extent of your involvement is likely to change as your child gets older. This is because parents of young children who are not able to make decisions for themselves will make the decisions on behalf of their children, but as children develop and mature, they will generally become more able to participate in decision-making and to start to make their own decisions about their care and support. Such consideration as to whether a parent can make a particular decision on behalf of their child is sometimes referred to as the 'scope of parental responsibility'.

As your child gets older, health and social care professionals should help your child to understand their health and/or social care needs and encourage your child to take an active part in decision-making. Increasingly, wherever possible, health and social care professionals will want to talk to your child directly about their health and social care needs and what care plan to put in place. This is an important aspect of preparing your child for adulthood, which, if your child has continuing health and/or social care needs, will include a move from services and support that are focused on children to services that address the needs of adults. (This process is known as 'transition').

As explained below, the law regulating how a person's ability to make decisions is assessed differs between those aged under 16 and those who are aged 16 or over. However, in all cases:

- Your child's ability to decide must be assessed in relation to the particular decision at the time that decision needs to be made.
- Your child may lack the ability to make some decisions, such as to consent to a surgical operation, but be able to make other decisions, such as agree to a dental examination.

### If your child is under 16 years of age

Before children reach the age of 16, the law assumes that they are not able to make decisions for themselves. In such cases you will be asked to make decisions on behalf of your child, such as what type of social care support is to be provided or whether proposed medical treatment should be given to your child. Parents making decisions on behalf of their child are expected to make decisions in the best interest of their child.

However, in some cases, a child may be considered to have the necessary maturity and understanding to make the decision in question for him or herself. Where a child is considered to be able to make the particular decision, s/he might be referred to as being 'Gillick competent'. For example, if your child needs to go into hospital and your child is considered to be competent to make this decision, your child's consent will be sufficient to authorise his/her admission to hospital.

### If your child is 16 or 17 years old

Once your child reaches the age of 16, health and social care professionals and other practitioners providing care and support to your child will work on the basis that your child is able to make decisions for him/herself, unless this is shown not to be the case.

This is because the [Mental Capacity Act 2005](#) applies to people aged 16 and over. Under this Act, people are assumed to have capacity unless evidence shows otherwise. This means, for example, if your child is aged over 16 and needs to go into hospital, your child's consent will be sufficient, unless your child lacks the capacity to make this decision.

If there are concerns that your child is unable to make a particular decision, an assessment of their capacity to make that decision should be undertaken in accordance with the [Mental Capacity Act 2005](#) and the Code of Practice that accompanies this Act. (For details on where to find more information see the Resources section below).

If your child is assessed as lacking the capacity to make certain decisions about their care and treatment, the [Mental Capacity Act 2005](#) allows such decisions to be made on your child's behalf, provided they are in your child's 'best interests'. Where this happens, you should be involved in deciding what is in your child's best interests. This is because the Mental Capacity Act 2005 sets out factors to be considered when deciding what is in a person's best interests, which includes seeking the views of carers and anyone interested in the person's welfare (i.e. parents). The Act makes clear that such consultation must take place unless it would be impracticable or inappropriate to do so (likely to be rare).

In some cases, you may be asked to make the decision concerning your child on the basis that s/he is not able to do so. The decisions taken must be in your child's best interests.

### If your child is aged 18 or over

Once your child reaches the age of 18 you will no longer have parental responsibility. However, if your adult child lacks the capacity to make certain decisions about his/her care and treatment, such decisions can be made on their behalf under the Mental Capacity Act 2005, with all such decisions being made in your child's best interests. In some circumstances you may be making such decisions (e.g. as your child's primary carer). As noted above, if others are making such decisions, then you should be involved in deciding what is your adult child's best interests in accordance with the requirements of the [Mental Capacity Act 2005](#).

### Where your child has fluctuating capacity

If your child has fluctuating capacity (for example, due to periodic, profound depression), social and health care professionals should plan for the times during which your child is not able to make decisions for him/herself.

They can do so by negotiating advance agreements with your child when s/he is able to make such decisions, for example, the actions taken if your child becomes very distressed.

Although these are not legally binding, such agreements are helpful in developing trust and understanding between your child and the care team. They will also help to ensure that your child's wishes and preferences are taken into account even during periods in which your child may not be able to express them.

### Involving you and your child in decision-making

Planning and reviewing your child's care and support will involve numerous and wide-ranging decisions. You may find that your child is able to make some of these decisions, but not others. However, even if your decision-making role lessens because your child is able to make more decisions for him/herself, you should continue to be involved in the decisions about your child's care (save for exceptional circumstances discussed in Q.4 below). In cases where your child is not able to make

decisions, your child's views should still (of course) be taken into account. It is important to remember:

- Your views, as well as those of your child, are central to the decisions that are made about your child's care and support.
- The importance of involving children and young people in their care planning, often referred to as 'person-centred planning,' is underpinned by legislation, such as the Children Act 1989 which highlights the importance of ascertaining the wishes and feelings of a 'child in need' before providing services to that child.
- You and your child should receive the information and support that you need to make decisions about your child's treatment, care and support. (For example, the needs of children who rely on communication equipment or who use non-verbal communication such as sign language should be addressed so that they are not excluded from the decision-making process). (For further information on the duty to make such 'reasonable adjustments, see the Resources section on page 18)
- Even with young children, health and social care practitioners should seek to encourage children to take part in decisions about their care and support.
- Even when your child reaches adulthood at the age of 18, if your child lives with you, or lives independently but you provide care and support to your child, it will be essential that you have the necessary information to be able to continue in your caring role.

## The provision of mental health care

The law relating to the care and treatment of children and young people with mental health problems is complex and beyond the scope of this guide. The Resources section provides links to information on this area.

## Deprivation of Liberty

There may be circumstances in which it is thought necessary to place certain restrictions on your child in order to keep your child safe and provide your child with the care and support that s/he needs. Where such restrictions go beyond the kind of restrictions that would normally be placed on a non-disabled child of the same age as your child, those providing care for your child must consider whether your child is being deprived of his or her liberty.

A finding that the care your child is receiving falls within the legal term of 'deprivation of liberty' is not a criticism of you, your child or the health/ social care professionals caring for your child. However, it does mean that those seeking to place such restrictions on your child must ensure that they have the legal authority to do so. They will therefore need to apply to the court for an order authorising the deprivation of liberty. In doing so they will need to show that the restrictions are necessary and the least restrictive means of caring for your child.

The circumstances in which a deprivation of liberty arises is complex and an area of developing law, so beyond the scope of this guidance. Links to further information on deprivation of liberty and the procedures for authorising a deprivation of liberty are included in the Resources section.

If you are concerned about the restrictions being placed on your child, you should raise this with your child's care team and ask for the care plan to be reviewed in the light of your concerns.

# Consent to medical treatment

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## Q.2 How are decisions about my child's medical treatment made?

As with other decisions, this will depend on the age of your child and your child's ability to make the decision. Consent should be obtained for each aspect of your child's treatment. Even where you, or your child, give your consent to the proposed treatment, you can withdraw your consent if you later change your mind.

In cases where your child is not able to make treatment decisions, it will still be important to involve your child as much as possible in the discussions about their medical treatment and other aspects of their health care.

### If your child is under 16 years of age

As discussed above (Q.1), although the starting point for children under the age of 16 is that they are not able to make decisions for themselves, children who are '**Gillick competent**' will be able to consent to the proposed action (e.g. admission to hospital). In relation to medical treatment this means that if your child is competent to decide about whether to consent to the medical treatment being proposed, the health professionals should seek your child's consent. The question whether your child is able to make the particular treatment decision will need to be assessed in the light of the seriousness and complexity of the treatment being proposed.

If your child is competent to make the decision, your child's consent to the treatment will be sufficient authority for the health professionals to provide that medical treatment. However, it is still good practice for health professionals to involve you in the discussions unless your child asks that you are not included (for further information see Q.4).

If your child is not competent to make the treatment decision, as a person with '**parental responsibility**', you may be asked to give consent on your child's behalf. In deciding whether to agree to the treatment or not, you will need to consider whether the treatment is in your child's best interests.

### If your child is 16 or 17 years old

The starting point for health professionals involved in the care and treatment of 16 and 17 year olds is that these young people can consent to their own treatment, unless they are shown not to be able to do so. Accordingly, unless your child is assessed as being unable to consent to the treatment being proposed, s/he can authorise the treatment.

Even though your child's consent will be sufficient authority for the treatment to be given, health professionals should encourage your child to involve you in the discussions about the treatment.

If your child lacks capacity under the **Mental Capacity Act 2005** (see Q.1 above) to decide about the proposed treatment, the treatment can be given if it is considered to be in their best interests. You should be consulted on what is in your child's best interests.

There may be cases in which your child is unable to make the treatment decision for reasons other than lacking capacity under the Mental Capacity Act 2005. For example, the decision might involve lots of new information which your child is finding difficult to absorb, despite steps to enable him/her to do so. In such cases, because you have parental responsibility for your child, you may be asked to make the decision on behalf of your child and in your child's best interests.



## Information to help you and your child make treatment decisions

You and your child should be given sufficient information to decide whether to consent to, or refuse, the proposed treatment. Such information will need to include:

- the benefits and risks of the proposed treatment;
- what the treatment will involve;
- the implications of not having the treatment;
- what alternatives may be available;
- what the practical effects of having or not having the treatment will be on the lives of you and your child.

Health professionals should also take into account the following points:

- The provision of information should be given in a form that the person can understand and the health professional should check the child's understanding.
- This will involve 'explaining what is proposed in language which is suited to the child's age and abilities, using pictures, toys and play activity where appropriate and drawing on the skills of specialist colleagues'.
- For disabled children, particular care should be taken to provide information in a suitable form, for example interpreters for hearing impaired children and appropriate materials for children with learning disabilities. In addition, specialist colleagues 'may be able to act as facilitators or advocates where children have particular needs'.

## Q.3 What if there are disagreements on whether the treatment should be given?

In some cases disagreements on whether treatment should be given arise between the health professionals caring for children and the parents and/or child. They can also arise between the parents of the child. Such situations can be very stressful and may give rise to complex legal issues. If they arise it would be important to seek legal advice without delay.

### Where you and the health professionals disagree

Usually, if your consent is required and you do not agree with the treatment being proposed, the treatment will not be given to your child. However, in extreme cases, where the health professionals are concerned that your child may die, or suffer serious permanent injury without this treatment, they may apply to the court so that the court can decide whether the treatment should be given.

### Where you and others with parental responsibility disagree

If you disagree with your child's other parent (who shares **parental responsibility** with you) on whether the treatment should be given, the health professionals involved will seek to reach a consensus, failing which they will need to decide on whether it is appropriate to give treatment despite one parent's opposition to the treatment being given.

This is because the consent of one person with **parental responsibility** for a child will usually be sufficient for the treatment to be given to the child, for example a GP could provide treatment to a child on the basis of the consent of the child's mother, without the need to contact the child's father. However, if one parent objects to the treatment being given, health professionals may conclude that

the question of whether to treat should be decided by the courts, particularly in cases involving serious or complex treatment.

### Where you and your child disagree on the treatment

As noted above, the consent of your child will be sufficient authority for the treatment to be given, if your child is able to decide whether or not to have the treatment proposed and then consents to this treatment. In such cases, your child's refusal of treatment will usually be respected as well. However, if there are likely to be grave consequences for your child if the treatment is not given, an application to the court can be made, asking the court to decide whether treatment can be given.

This is because the courts have held that the refusal of a child or young person aged under 18 years can be overridden in circumstances in which, without the treatment, that child or young person is likely to die or to suffer severe permanent injury. Life-saving emergency treatment can be given if there is no time to seek authorisation from the court.



# Confidentiality

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## Q.4 How does the duty of confidentiality affect my involvement with my child's care?

As your child gets older you may find that questions arise as to whether you should be involved in the discussions and decisions about your child's care.

For example, as they develop and mature, it is common for children and young people to prefer to discuss personal matters with health, social care and other professionals without their parents being present.

Furthermore, sometimes the starting point for professionals working with young people nearing adulthood is that parents will not be involved unless the young person specifically requests this.

Where your child has given personal information to health and social care professionals, with the understanding that such information will not be shared with others, these professionals will be under a duty to keep such information confidential.

This is known as the 'duty of confidentiality'. If your child is able to make decisions about the use and disclosure of information that s/he has given in confidence, your child's views on who should, or should not, be given such information should be respected in the same way as an adult's request for confidentiality.

Such personal information may only be disclosed without your child's consent in limited circumstances, for example to prevent serious harm to your child. (See Q.1 above for how your child's ability to make this decision will be assessed.)

If you are informed that you are not to be involved in decisions about your child's care, you might find it helpful to consider the following points:

### Establishing the reasons why your child does not want you to have certain information

- If your child does not wish you to be involved in decisions about his/her care then every effort should be made to understand the reasons for this.
- In some cases it may be that your child is happy for you to be given relevant information and be involved in some aspects of care, but not others. If this is the case, this should be made clear in your child's care plan.

### If your child wishes you to continue to be involved

- If your child is happy for you to continue to be involved in the decision-making about their care and support, then this should be respected. In such cases you should ask that your child's wish for you to be involved is recorded in their care plan.

### Your views are still important

- Your role as a parent of a disabled child should never be ignored.
- You should not be excluded from decisions that are likely to impact upon you and the rest of your family.
- Even if your child does not want you to be given personal information, this does not prevent you

from giving information to those providing care and support to your child. This is particularly important if you are continuing to provide care and support to your child.

- If your child is unable to decide on whether their personal information should be shared with you, this will be possible if it's in your child's 'best interests' to do so. It will usually be in a child's 'best interests' to share such information with their parents.

### Discussing the impact of your non-involvement

- If you are concerned that the lack of certain information will prevent you from providing adequate care, you should inform your child's care team and ask that the care plan be reviewed to take account of your concerns. (For further information on health and social care planning, see Cerebra's Parent Guide on Social Care. Details of Cerebra's Parent Guides are listed in the Resources section on page 20).



# Sharing information

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## Q.5 Will health and social care agencies share information about my child with each other?

Your child may be receiving care and support from a number of different health and social care agencies, for example, from your local authority's children's services, your GP and the local NHS Trust, as well as from other agencies, such as your child's school. It is likely that they will want to share information about your child.

This is because government policies and guidance emphasise that these bodies should work together in order to provide appropriate care and support. In order to co-operate effectively, these agencies will need to share information, including personal information about your child's health, social care and other needs.

Sharing information will be particularly important during the period when your child is nearing the age of 18 and preparing to move from children's services to adult services.

## Q.6 Should my child and I be consulted before personal information is shared?

The need to share information should be discussed with you and your child when you first have contact with the service. You should be told what information will be shared and why this is necessary, who will see the information and how the information will be used.

Personal information should only be shared without the consent of you or your child in limited circumstances, for example to protect children from significant harm, to protect adults from serious harm, or to promote the welfare of children or prevent crime and disorder.

You might find it helpful to consider the points about sharing information set out below:

- If you are unsure as to which individuals (or in the case of a multi-agency service, which agencies) are to be given personal information about your child, or why it is necessary for this to happen, you should ask for this to be explained.
- Those seeking consent to information being shared will need to ascertain whether this is something that your child can consent to, or whether your consent, as a parent with '**parental responsibility**' should be obtained. As discussed under Q.1 above, young people aged 16 and over will be presumed to be able to make this decision unless evidence suggests otherwise.
- If your child is considered able to decide about sharing of information, your child should be encouraged to discuss this with you. However, if your child consents, this will be sufficient for the information to be shared, even if you disagree.
- If your child is considered not to be able to decide about sharing information, your consent will be sought, but your child should still be encouraged to give their views. Your consent will be sufficient authority for the information being shared. However, if you have separated from your child's other parent, practitioners will need to decide whose consent to seek; this will usually be the parent with whom your child resides.
- If personal information about your child has been shared without consent, you should ask for an

explanation for disclosing the information. If you are not happy with the response you may wish to obtain legal advice. The Resources section at page 18 provides details of organisations that may be able to refer you to appropriate legal advisers.

Health and social care services should have written policies on sharing information. If you would like further information, ask to see copies of this document.



# Access to health and social records

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## Q.7 Can I see my child's health and social care records?

You or your child can apply to have access to your child's health or social care records by applying in writing to the organisation that holds the records (referred to below as 'the record holder') that you wish to see. Under the Data Protection Act 2018 individuals have the right to see information that is held about them. Accordingly, NHS bodies and local authorities are expected to put in place arrangements so that individuals can exercise their right to see their health and social care records. You can request this information in writing (e.g. by email) or verbally (in which case you should make a note of who you spoke to and when you made your request).

Usually the request should be complied with within one month and free of charge. You may be asked to provide proof of identity. In some circumstances the timescale could be extended for another two months, for example if your request is complex. You can only be charged a fee (to cover reasonable administrative costs) if you request further copies of your child's information or your request is 'manifestly unfounded or excessive'. If you are asked to pay a fee you should ask the organisation to justify this in writing.

There are some exemptions to the duty to disclose information. For example, if your child's records contain information about someone else and that person has not consented to the disclosure, this part of the record will not be made available to you. If some information is not to be disclosed, you should be informed of this in writing, with reasons for the non-disclosure. A template letter for seeking access to personal records is available to download from <https://www.cerebra.org.uk/help-and-information/legal-help/precedent-letters/england/>

The Information Commissioner's Office (ICO) provides helpful guidance on what to do if you are unhappy with the record holder's response or they do not reply. (See: <https://ico.org.uk/for-the-public/official-information/what-to-do-if-you-are-dissatisfied-with-the-response/>) Further information on access to personal records can be obtained from the ICO (see the Resources section at page 18 for details.)

## Q.8 Who should apply to see my child's health and social care records?

As with general decision-making, this will depend on the age of your child and your child's ability to make this particular decision.

This is because the personal information held about your child by health, social care and other agencies is confidential to your child. Guidance issued to health and social care bodies reminds these agencies that the right to see such records belongs to the child, although parents may be able to exercise this right on behalf of their child.

This means that before giving you access to your child's personal records, the record holder must be satisfied that they can disclose this information to you without breaching their duty of confidentiality to your child.

Accordingly, if you apply to see your child's personal records, the record holder may ask some questions to check that they can provide this information to you. You will need to explain which of the following apply:

- Your child is able to understand the nature of the request and has authorised you to apply on his/her behalf. Guidance issued by the Information Commissioner's Office states that when making such a request (known as a 'subject access request' (SAR)), or authorising someone else to do so on their behalf, 'what matters is that the child is able to understand (in broad terms) what it means to make a SAR and how to interpret the information they receive'.
- Your child is not able to understand the nature of the request and you are making the request on your child's behalf, in their best interests. For example, you may consider that your child is unable to request access to their personal records because they would not understand the information that is likely to be contained in the records.

If your child applies to see his/her records, the Information Commissioner's Office (ICO) states that the record holder should consider whether your child is mature enough to understand their rights and if they are, the record holder 'should usually respond directly to the child'.

If aged 16 or over, your child will be presumed to have capacity to make their own decisions unless evidence suggests otherwise (see the discussion on the Mental Capacity Act 2005 at Q.1 above). Although there is no such presumption for children aged under 16, the ICO suggests that 'a reasonable starting point' would be that a child aged 12 or more has sufficient understanding of their right of access, unless the contrary is shown. (See the Resources section on page 18 for details of ICO guidance).

If your child is able to make decisions about the use of their personal information, they will be able to give or refuse consent to the sharing of such information (exceptions to this are noted in Q.6).

## Q.9 What can we do if the records are inaccurate?

If you or your child consider that your child's personal records include information that is incorrect, you should raise this with the relevant health or social care professional (e.g. your child's GP if the inaccuracy is contained in the records held by the GP). If it is agreed that the record is inaccurate then the information should be amended. Guidance issued by NHS England states that the correction should be made 'as soon as practically possible, but in any event within one month'.

If the professionals concerned do not agree that the information is inaccurate, ask that a statement that you do not agree with this aspect of your child's records is included in these records.

If you are not happy about the outcome of your discussions you can make a complaint to the relevant local authority or NHS body (see Q.10 below). Information on how to do so should be available on the relevant organisation's website, usually the complaint will need to be made within one year of the incident which gave rise to your complaint. You could also contact the Information Commissioner's Office who may be able to help (see Q.10 below).

## Q.10 What can we do if we have concerns about the way my child's personal information has been handled?

If you are not happy about the way in which your child's personal information has been used you can make a complaint. The Information Commissioner's Office (ICO) provides a guide on how to complain to the relevant organisation as well as when you can make a complaint to the ICO. (Details are provided in the Resources section on page 18 below).



# Glossary

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## Gillick competent

This term is used to describe a child who has sufficient understanding and intelligence to understand the particular decision being considered, for example the provision of medication for an illness, so he/she can consent to his/ her own treatment. There is no specific age when a child becomes competent – this will depend on the kind of decision being proposed, for example a child may be competent to agree to having a dental check-up but not be competent to agree to heart surgery.

The Mental Health Act 1983: Code of Practice, 2015, (paragraph 19.36) sets out some suggested questions for determining whether a child is competent which ask about the child's understanding, retention and use of the information relevant to the decision (see the link provided in the Resources section below).

## Mental Capacity Act 2005

The Mental Capacity Act 2005 provides the legal framework for making decisions on behalf of individuals aged 16 or over who lack capacity to make such decisions for themselves. To lack capacity under this Act, a person must be: a) unable to make the particular decision at the time it needs to be made (often referred to as the 'functional element' and b) the person's inability to make that decision is 'because of an impairment of, or disturbance in, the functioning of the mind or brain' (often referred to as the 'diagnostic element'). Determining whether a person is unable to make the decision entails consideration of their ability to: understand the information relevant to the decision, retain that information, use or weigh that information to arrive at a decision and communicate their decision. The Mental Capacity Act 2005 provides that 'acts in connection' with the person's care and treatment can be taken in the person's 'best interests'. In order to determine what might be in the person's best interests those involved in caring for the person (such as their parents) should be consulted. For further information see the Resources section below.

## Parental responsibility

This is a term defined in section 3 of the Children Act 1989 as 'the rights, duties, powers, responsibilities and authority which by law a parent has in relation to a child and his property'. Those working with children will need to ascertain who has 'parental responsibility'. This will be particularly important when the child is not able to make decisions about his or her care or treatment, as in those circumstances a person with parental responsibility may be able to make that decision on behalf of the child.

Usually both parents will have parental responsibility, but unmarried fathers will need to take steps to acquire parental responsibility. In some cases, parental responsibility may be shared with others, for example when the child or young person is subject to a care order, the Local Authority will share parental responsibility with the parents (if both have parental responsibility). For further information see Parental rights and responsibilities: <https://www.gov.uk/parental-rights-responsibilities>

## Scope of Parental Responsibility

This is a term that is sometimes used when considering whether a person with parental responsibility can authorise actions or decisions to be taken on behalf of their child, for example, whether that person can consent to their child's medical treatment. Factors taken into account include the invasiveness of the proposed treatment or care and the views of the child. Another relevant factor would be if one person with parental responsibility disagreed with the action being proposed. For further information, see Mental Health Act 1983: Code of Practice, 2015, paragraphs 19.41 - 19.42 (the link is provided in the Resource section below).

# Resources

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## Useful organisations

### Carers UK

A charity set up to help people who care for family or friends. Its work includes providing information and advice about caring.

<https://www.carersuk.org/>

### Citizens Advice Bureau

A source of advice and support if you want to complain about the NHS, social services or Local Authorities.

[www.citizensadvice.org.uk/](http://www.citizensadvice.org.uk/)

### Contact

Provides support, information and advice to families of disabled children.

<https://contact.org.uk/>

### Information Commissioner's Office (ICO)

An independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals. The ICO provides a range of information, including how to request copies of personal information from organisations by such as local authorities and NHS bodies and how to make a complaint if you are unhappy about the way in which an organisation has handled personal information.

<https://ico.org.uk/for-the-public/>

### Local Government Ombudsman

Looks at complaints about councils (Local Authorities) and some other authorities and organisations in England, including education admissions appeal panels and adult social care providers (such as care homes and home care providers). It is a free service. The website provides guidance on making a complaint.

<https://www.lgo.org.uk/make-a-complaint>

### Parliamentary and Health Service Ombudsman

Considers complaints that government departments, a range of other public bodies in the UK and the NHS in England, have not acted properly or fairly or have provided a poor service

<https://www.ombudsman.org.uk/>

### Public Law Project (PLP)

This is an independent, national legal charity which aims to improve access to public law remedies for those whose access is restricted by poverty, discrimination or other similar barriers. Its website includes a guide to making a complaint.

<https://publiclawproject.org.uk>

## Public Services Ombudsman for Wales

Has legal powers to look into complaints about public services in Wales.

<https://www.ombudsman.wales/>

## Access to public records

Cerebra's template letter requesting personal information held about you or your child (including medical records held by your child's GP and records held by children's services about your child).

<https://cerebra.org.uk/download/we-want-to-see-the-personal-information-that-the-council-health-body-holds-about-us/>

Detailed guidance on the right to access can be found at:

<https://ico.org.uk/media/for-organisations/uk-gdpr-guidance-and-resources/individual-rights/right-of-access-1-0.pdf>

## Confidentiality

HM Government, *Information Sharing: advice for practitioners providing safeguarding services, for children, young people, parents and carers*, May 2024

[https://assets.publishing.service.gov.uk/media/66320b06c084007696fca731/Info\\_sharing\\_advice\\_content\\_May\\_2024.pdf](https://assets.publishing.service.gov.uk/media/66320b06c084007696fca731/Info_sharing_advice_content_May_2024.pdf)

Mind, *Accessing my personal information*

<https://www.mind.org.uk/information-support/legal-rights/accessing-my-personal-information/overview/>

NHS England *A Guide to Confidentiality in Health and Social Care*, September 2013

<https://digital.nhs.uk/data-and-information/looking-after-information/data-security-and-information-governance/codes-of-practice-for-handling-information-in-health-and-care/a-guide-to-confidentiality-in-health-and-social-care>

NHS England, *Amending patient and service user records*, January 2022

<https://transform.england.nhs.uk/information-governance/guidance/amending-patient-and-service-user-records/>

## Consent to medical treatment

Department of Health, *Reference guide to consent for examination or treatment*, 2nd edition 2009

<https://www.gov.uk/government/publications/reference-guide-to-consent-for-examination-or-treatment-second-edition>

Department of Health, *Seeking consent: working with children*, 2001 (this has now been archived but remains a useful document)

[https://dera.ioe.ac.uk/id/eprint/9286/1/dh\\_4067204.pdf](https://dera.ioe.ac.uk/id/eprint/9286/1/dh_4067204.pdf)

General Medical Council, *Decision-making and consent*

[http://www.gmc-uk.org/guidance/ethical\\_guidance/consent\\_guidance\\_index.asp](http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_index.asp)

General Medical Council 0–18 years: guidance for all doctors

<https://www.gmc-uk.org/professional-standards/professional-standards-for-doctors/0-18-years>

## Deprivation of Liberty

Law Society, *Understanding when someone is deprived of their liberty* (March 2024)

<https://www.lawsociety.org.uk/topics/private-client/deprivation-of-liberty-safeguards-a-practical-guide>

Nuffield Family Justice Observatory, *Deprivation of Liberty: Legal Mechanisms* (2022)

[https://www.nuffieldfjo.org.uk/wp-content/uploads/2022/02/nfjo\\_briefing\\_DoL\\_final\\_20220203.pdf](https://www.nuffieldfjo.org.uk/wp-content/uploads/2022/02/nfjo_briefing_DoL_final_20220203.pdf)

## Mental Capacity Act 2005

A range of booklets on the Mental Capacity Act 2005 can be found here:

<https://www.gov.uk/government/collections/>

## Mental health

Department of Health, Mental Health Act 1983: Code of Practice, April 2015

<https://www.gov.uk/government/publications/code-of-practice-mental-health-act-1983>

A range of information on legal rights can be found at:

### Mind

<https://www.mind.org.uk/information-support/legal-rights/>

### Rethink

<https://www.rethink.org/advice-and-information/rights-restrictions/mental-health-laws/>

## Reasonable Adjustments

NHS England, Reasonable adjustments

<https://www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments/#:~:text=Reasonable%20adjustments%20can%20be%20things,their%20GP%20surgery%20or%20hospital>

Public Health England *Reasonable adjustments: a legal duty* (2020)

<https://www.gov.uk/government/publications/reasonable-adjustments-a-legal-duty/reasonable-adjustments-a-legal-duty>

## Further information and guidance

For information on other topics such as social care, please refer to the Parent Guides available on Cerebra's website:

<http://www.cerebra.org.uk/help-and-information/guides-for-parents/>

See also 'Decision-making the legal framework' in Disabled Children a legal Handbook (eds Luke Clements and Steve Broach Legal Action Group, (2019, 3rd edition); available at:

<https://councilfordisabledchildren.org.uk/resources/all-resources/filter/inclusion-send/disabled-children-legal-handbook-3rd-edition>



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# Working wonders for children with brain conditions

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