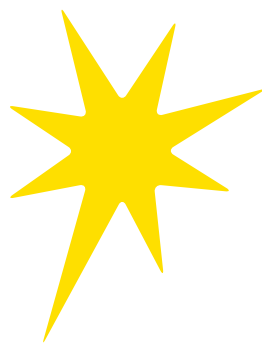




# Decision Making, Confidentiality & Sharing Information

A Guide for Parents



# Working wonders for children with brain conditions

Families where a child has a brain condition face challenges every day. Just to learn, play, make friends and experience the world can feel difficult, even impossible. But we don't believe there's any challenge that can't be overcome.

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Thank you.

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# Introduction

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This guide has been prepared for parents of disabled children and young people 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 capacity, i.e. 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.

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').

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 it is considered that 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. For example, if it is considered that your child, who is aged over 16, needs to go into hospital, your child's consent will be sufficient, unless your child does not have capacity to make this decision.

If there are concerns that your child lacks capacity to make certain decisions, an assessment of their capacity should be undertaken in accordance with the **Mental Capacity Act 2005** and the Code of Practice that accompanies this Act. (The Resources section provides details on where to find more information on this Act and its Code of Practice).

If your child is assessed as lacking the capacity to make certain decisions, the **Mental Capacity Act 2005** allows acts and decisions concerning their care and treatment to be taken if 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. 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 and will not be able to make decisions on your child's behalf. However, if your child is not able to make such decisions then you should be involved in deciding what is in their 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 has the capacity to consent to such matters, for example medical treatment.

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 the 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.)
- 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.



# 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 considered to be '**Gillick competent**' will be able to consent to decisions. In relation to medical treatment this means that if your child is able 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, such treatment can be given with your consent, as a person with '**parental responsibility**'. 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 considered to lack the maturity to make the treatment decision, in which case 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. The Department of Health (Seeking consent: working with children, 2001) states that 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 are also advised that:

- 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 a child or young person's refusal can be overridden in circumstances in which, without the treatment, the child or young person is likely to die or to suffer severe permanent injury. 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 lacks the necessary mental capacity to decide on whether or not information should be shared with you, then a 'best interests' decision as to whether it should be shared with you must be taken.

The starting point for such a 'best interests' decision will be that it is in general in a child's best interests that their parents have access to this information.

### 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 21).



# 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 1998 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.

The request should be complied with within the relevant timescale. This is usually 40 days, but the Department of Health's Guidance for Access to Health Records Requests, considers that health bodies should respond within 21 days. You may be asked to submit a fee (for social care agencies this is a maximum of £10, for health, the maximum is £50).

However, 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/>

If the record holder refuses to grant access to your child's records you could make an application to the County Court or apply to the Information Commissioner. (Further information on such applications, and general information on seeking access to personal records can be obtained from the Information Commissioner's Office (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.

If you apply to see your child's personal records and the record holder questions whether they can provide this information to you, you will need to explain that either:

- your child is able to understand the nature of the request and has authorised you to apply on his/her behalf,

or

- 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 does not have sufficient understanding to have access to his/her personal records because s/he lacks the maturity, or the capacity, to understand the information that is likely to be contained in the records.

If your child applies to see his/her records, the record holder may ask whether your child has sufficient maturity to understand their right to

see their records and make this request. If this happens, in considering whether your child is able to make this request, it might be helpful to consider the following points:

- The Information Commissioner states that the child will need to be 'able to understand (in broad terms)' what it means to make such a request and 'how to interpret the information they receive as a result of doing so'. (Information Commissioner's Office, "*Subject access code of practice - Dealing with requests from individuals for personal information*", Feb 2014).
- A child or young person, who has the capacity to understand and make their own decisions, may give (or refuse) consent to sharing information.
- Where your child is aged 16 or over s/he is presumed to have capacity to make decisions for him/herself unless evidence suggests otherwise (see the discussion on the Mental Capacity Act 2005 at Q.1 above).

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 (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 (details are provided in the Resources section on page 18 below).

## 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.

The Department of Health advises in Guidance for Access to Health Records Requests, that where this happens with health records the amendment should 'clearly display the correction whilst ensuring that the original information is still legible. An explanation for the correction should also be added'.

If the professionals concerned do not agree that the information is inaccurate, ask that a statement that you do not agree with this aspect



# 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. For further information see Department of Health, Reference guide to consent for examination or treatment, 2nd edition 2009, page 33 (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. 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 Department of Health, Reference guide to consent for examination or treatment, 2nd edition 2009, page 36, paragraph 22 (link provided in the Resources 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,

[www.carersuk.org](http://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

An independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals.

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

### 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.

<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.

[www.publiclawproject.org.uk](http://www.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/>

Department of Health, *Guidance for Access to Health Records Requests*, 2010

<https://www.nhs.uk/chq/Documents/Guidance%20for%20Access%20to%20Health%20Records%20Requests.pdf>

Information Commissioner's Office, *Subject Access Code of Practice: Dealing with requests from individuals for personal information*, February 2014.

[https://icosearch.ico.org.uk/s/search.html?query=Subject+Access+Code+of+Practice%3A+Dealing+with+requests+from+individuals+for+personal+information&collection=ico-meta&profile=\\_default](https://icosearch.ico.org.uk/s/search.html?query=Subject+Access+Code+of+Practice%3A+Dealing+with+requests+from+individuals+for+personal+information&collection=ico-meta&profile=_default)

## Confidentiality

Department of Health, *Confidentiality: NHS Code of Practice*, November 2003

<https://www.gov.uk/government/publications/confidentiality-nhs-code-of-practice>

Department of Health, *Guidance for Access for Health Records Requests*, 2010

<https://www.nhs.uk/chq/Documents/Guidance%20for%20Access%20to%20Health%20Records%20Requests.pdf>

Department of Health, *Mental Health Act 1983: Code of Practice, Chapter 19*, April 2015

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

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>

HM Government, *Information Sharing: advice for practitioners providing safeguarding services*, March 2015

<https://www.gov.uk/government/publications/safeguarding-practitioners-information-sharing-advice>

Royal College of Psychiatrists, *Carers and Confidentiality in Mental Health*

<http://www.rcpsych.ac.uk/healthadvice/partnersincarecampaign/carersandconfidentiality.aspx>

Welsh Assembly Government, *Confidentiality: Code of Practice for Health and Social Care in Wales*, August 2005

[www.wales.nhs.uk/sites3/documents/950/codeofpractice.pdf](http://www.wales.nhs.uk/sites3/documents/950/codeofpractice.pdf)

## Consent to medical treatment

Department of Health, *Mental Health Act 1983: Code of Practice, Chapter 19*, April 2015

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

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

[http://webarchive.nationalarchives.gov.uk/20100306110611/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4067204.pdf](http://webarchive.nationalarchives.gov.uk/20100306110611/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4067204.pdf)

General Medical Council, *Consent guidance: patients and doctors making decisions together*

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

## Mental health

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/living-with-mental-illness/mental-health-laws>

## Mental Capacity Act

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

<https://www.gov.uk/government/collections/mental-capacity-act-making-decisions>

## Sharing information

Department of Health, *Mental Health Act 1983: Code of Practice, Chapter 19*, April 2015

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

HM Government, *Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children*, March 2015

<https://www.gov.uk/government/publications/working-together-to-safeguard-children--2>

HM Government, *Information Sharing: advice for practitioners providing safeguarding services*, March 2015

<https://www.gov.uk/government/publications/safeguarding-practitioners-information-sharing-advice>

## Further information and guidance

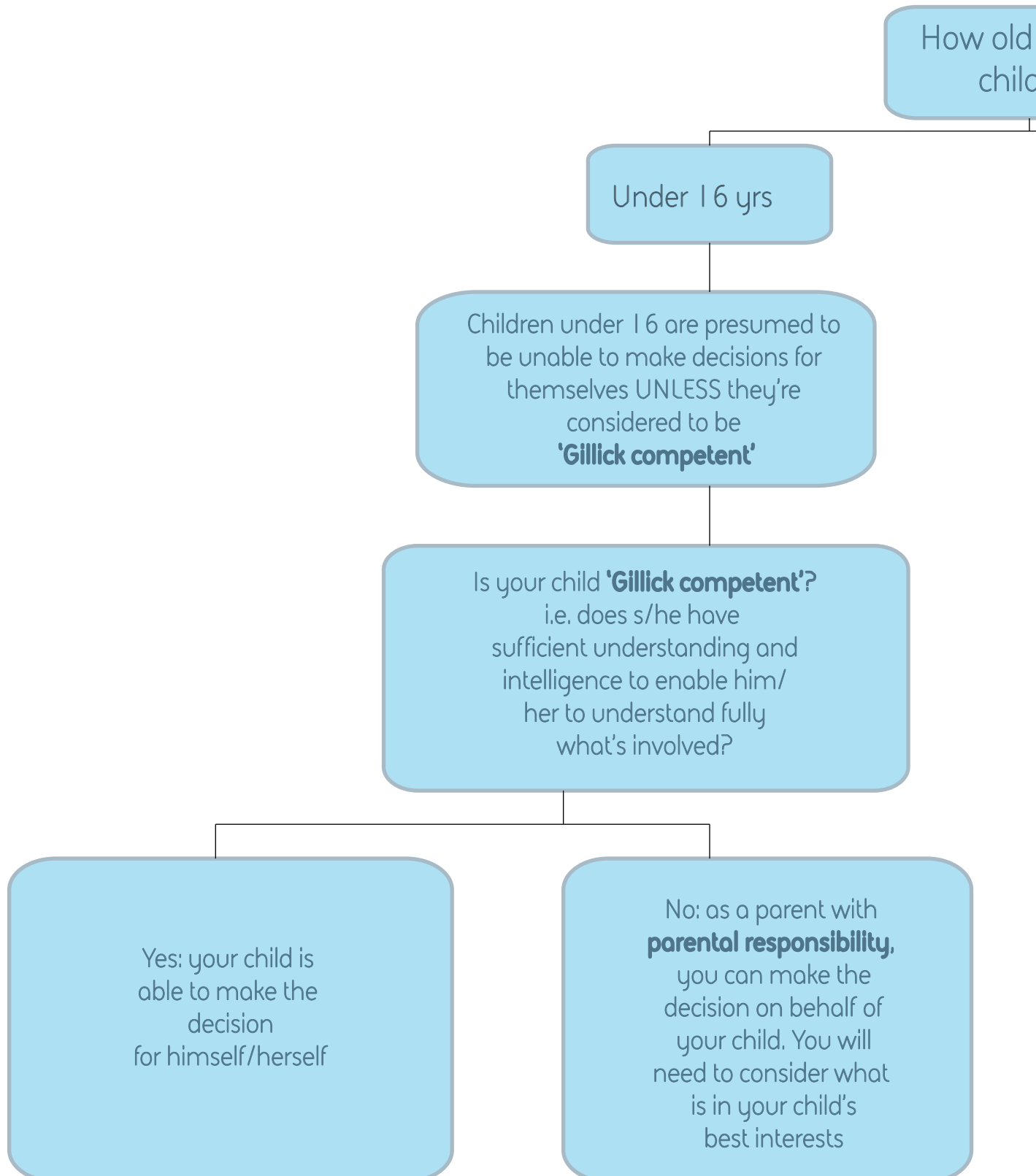
For information on other topics such as social care, please refer to the Parent Guides available on Cerebra's website:

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



# Who makes decisions about my child's care?

This flowchart is for illustration purposes only—please refer to the rest of the guide for more details. See the glossary for definitions of the phrases highlighted in **bold**.



is your  
child?

16 or 17 yrs

Young people aged 16 and 17 are presumed to be able to make decisions for themselves UNLESS it is established that they lack capacity

Does your child have capacity to make his/her own decision? S/he may need to be assessed by a professional with expertise in working with children and young people in accordance with the **Mental Capacity Act 2005**

Yes: your child can make the decision for himself/herself

No: decisions can be taken by practitioners involved in your child's care if they are in your child's 'best interests', in accordance with the **Mental Capacity Act 2005**. You should be involved in deciding what is in your child's best interests





## Information about the author

Camilla Parker is a legal and policy consultant, specialising in the areas of mental health, disability and human rights. She has written, presented and trained extensively on issues relevant to these areas. Camilla was the main author of *The Legal Aspects of the Care and Treatment of Children and Young People with Mental Disorder: A Guide for Professionals*, (DH/National Institute for Mental Health in England, January 2009) and worked as a consultant for the Department of Health on the revision of the children and young people's chapter in the Mental Health Act 1983 Code of Practice (2015). She is a member of the Law Society's Mental Health and Disability Committee.

## Information about the reviewers

Carys Hughes joined Cerebra in April 2014 as project co-ordinator for the Legal Entitlements and Problem-Solving (LEAP) Project. The Project team is led by Professor Luke Clements at Leeds University and aims to provide legal support to families who are experiencing difficulties in accessing health, social care and other services. Part of Carys' role is to assess requests and manage referrals made to the scheme. Having qualified as a solicitor in private practice in 2002, Carys spent 11 years in a complaints-handling role at a local authority before joining Cerebra. Carys' legal background and experience in the public sector have given her a useful perspective on how the Project can develop effective ways of helping families overcome problems in accessing services.

Derek Tilley is currently working as part of the Cerebra Research Team and is the father of a young lady who happens to have Down's syndrome. As a result of his dealings with public services he has had a long interest in supporting parents with disabled children access their legal entitlements. Firstly, in the area of special educational needs with IPSEA and SNAP Cymru Parent Partnership Services before moving into the area of direct payments with Diverse Cymru. During this period Derek served as a third sector representative on the Cardiff Disabled Children's Strategy Development Group and the Cardiff Autism Strategy Development Group. He recently successfully completed an MSc in Social Science Research Methods at Cardiff University and is carrying out a PhD under the supervision of Professor Luke Clements of Leeds University exploring issues related to the reoccurring problems parents of disabled children have obtaining their rights from the education, health and social services.

The findings of this report are those of the author, not necessarily those of Cerebra.

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# Working wonders for children with brain conditions

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