



The NHS and caring for a disabled child - Wales

Information for families

Wales

Incorporating **The Lady Hoare Trust**

Introduction

Caring for a disabled child can involve dealing with almost the full spectrum of public services - local education authorities, social services, the benefits agency, and the National Health Service (NHS). All families will come into contact with the NHS at some point but if your child has a disability or health condition, you may use different parts of the NHS or have more frequent contact with health professionals. This factsheet is designed as a guide to the health service and explains how to find information on your child's condition and the roles of the professionals you may come into contact with. We also explain your rights, your child's rights and what options you might have if, for whatever reason, you are unhappy with any aspect of the NHS and how it's organised.

The information in this factsheet is for families using the NHS in Wales only. Families in England, Scotland and Northern Ireland should ring the Contact a Family free helpline on Tel: 0808 808 3555 for further information.

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The structure of the NHS in Wales

The NHS in Wales is organised differently to its English counterpart.

The National Assembly for Wales is responsible for all health policy decisions and for allocating funds to the NHS in Wales.

How does the National Assembly and Welsh Assembly government affect the NHS in Wales?

In short, the National Assembly is responsible for all health policy decisions and for allocating funding. The Welsh Assembly minister for health is responsible to the National Assembly for the NHS in Wales.

The NHS Wales Department of the Welsh Assembly government is made up of

civil servants who have responsibility for strategic leadership and policy implementation across Wales. They also advise the minister for health on securing and allocating health resources and oversee the implementation of government policies.

Local Health Boards (LHBs)

There are 22 local health boards in Wales, each one assessing the health needs of a particular area. They cover the same geographical area as a local authority and work with them to produce health, social care and wellbeing strategies. LHBs answer to the Welsh Assembly minister for health. They are responsible for managing and commissioning things like GP services, dentists and opticians

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(known as primary healthcare) and community healthcare services (like health visitors and district nurses).

Powys LHB is unique in that, as well as commissioning community healthcare services, it also has responsibility for delivering them. In all other areas of Wales, community healthcare services are delivered by NHS trusts.

NHS trusts

Most healthcare services provided by NHS trusts are commissioned by other bodies. Services at local and district general hospitals (known as secondary healthcare) are commissioned by Secondary Care Commissioning Groups (SCCGs). Highly specialised healthcare services, usually delivered at specialist centres (known as tertiary healthcare),

are commissioned by Health Commission Wales (Specialist Services) (HCW(SS)).

There are 14 NHS trusts in Wales. As well as providing community healthcare services, most are responsible for providing secondary and tertiary healthcare (that is, they run hospitals and deliver healthcare services within the hospital setting). The Welsh Ambulance Services NHS trust provides ambulance and patient transport facilities right across Wales.

Health Commission Wales (Specialist Services)

Health Commission Wales (Specialist Services) (HCW(SS)) is an executive agency of the Welsh Assembly government. It provides advice and guidance to NHS Wales on

commissioning healthcare services. Where a highly specialised healthcare service (known as a tertiary service) is required, HCW(SS) will commission NHS trusts to provide it.

Community Health Councils (CHCs)

Community health councils are independent bodies set up to reflect public views on health services and provide information and support to those who are using health services and the complaints procedure.

Community health councils are statutory bodies which represent the interest of the public and patients. There are currently 20 community health councils in Wales. Where members of the public have complaints about or problems with the NHS which cannot be resolved by their local LHB or NHS Trust, their local CHC can provide help and advice.

National Institute for Health and Clinical Excellence (NICE)

NICE provides national guidance on the promotion of good health and the prevention and treatment of ill health in England and Wales. It produces guidance on the use of new and existing medicines and treatments and on the appropriate care and treatment of people with specific conditions.

The National Public Health Service for Wales (NPHS)

The National Public Health Service for Wales (NPHS) provides resources, expertise, information and advice to enable the Welsh Assembly government, Health Commission Wales, local health boards, local authorities and NHS trusts

to discharge their statutory public health functions. The NPHS:

- provides each LHB with a public health director and a local public health team
- brings together existing expertise from across Wales to develop specialist services to improve the health and wellbeing of the people of Wales and reduce inequalities in health. The aim is to protect against existing, new and emerging diseases and health threats and contribute to improvement in health and social care services
- oversees the Infection and Communicable Disease Service (ICDS) which supports all agencies involved in communicable disease management, prevention and control in Wales.

For further information about the structure of the NHS in Wales, please contact our Wales office or NHS Direct (contact details on page 25).

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Who's who in the NHS?

You may come into contact with many different professionals within the NHS – general practitioners (GPs), health visitors, audiologists, consultants,

paediatricians, physiotherapists and speech and language therapists to name but a few. The following table explains the roles of some of the health professionals you are likely to encounter.

Job title	What they do	How will you be referred to this service?	Who is responsible for this service?
General practitioner (GP)	<ul style="list-style-type: none"> • First point of contact if your child is unwell • also responsible for services such as prescriptions and vaccinations • referrals to other health services. 	You will need to be registered with a GP surgery.	GP practices in Wales provide services under contract to local health boards.
Community paediatrician	<ul style="list-style-type: none"> • Ongoing care for children with long term medical conditions, neurodisability and social and emotional problems • some specialise in a particular aspect of children's healthcare such as treating children with social and emotional problems or behavioural problems. 	Referrals are made by GPs, hospital paediatricians, health visitors, school nurses, educational psychologists.	Usually based at children's centres. Employed by NHS trusts.

Hospital paediatricians (also known as consultants or specialists)	<ul style="list-style-type: none"> • Hospital based medical care for children • some specialise in a particular aspect of children's healthcare such as heart conditions or breathing problems. 	Referral is usually via your GP, although sometimes it is via another consultant.	Based in hospitals and employed by NHS trusts.
Midwife	<ul style="list-style-type: none"> • Provides care for a woman and her baby throughout her pregnancy • helps with the birth of the baby • continues to care for the mother and newborn baby for at least ten days after birth. 	A GP will refer a woman to a midwife during the early stages of her pregnancy.	Based in hospitals. Employed by NHS trusts.
Health visitor	<ul style="list-style-type: none"> • Provides advice and support for the parents of babies in their home setting. 	Referral will normally follow automatically after the birth of a child.	Based in children's centres or GP surgeries. Employed by NHS trusts.
Special needs health visitor	<ul style="list-style-type: none"> • Provides practical advice and support about living at home with a child with an ongoing medical condition or disability. 	Referral is usually via a community paediatrician or a GP.	Based in children's centres or GP surgeries. Employed by NHS trusts.

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Job title	What they do	How will you be referred to this service?	Who is responsible for this service?
Specialist nurse	<ul style="list-style-type: none"> Provides support, advice and information for patients with a particular health condition or disability (such as diabetes). 	Referral is usually via a hospital paediatrician.	Usually hospital based, but often visit homes and schools. Employed by NHS trusts.
Community children's nurse	<ul style="list-style-type: none"> Provides ongoing home based nursing care for children provides families with support and education about children's medical conditions and needs helps co-ordinate care with other agencies. 	Referral is usually via your GP, community or hospital paediatrician.	Usually based at children's centres or GP surgeries. Employed by NHS trusts.
Speech and language therapist	<ul style="list-style-type: none"> Works with children who have difficulties communicating, eating, drinking and swallowing. 	Referral is usually via a community or hospital paediatrician or your GP.	Based in hospitals, children's centres and sometimes schools. Employed by NHS trusts.
Occupational therapist	<ul style="list-style-type: none"> Provides support and advice for children and parents on tasks like washing and getting dressed helps with home adaptations or getting specialist equipment. 	Referral is usually via a community or hospital paediatrician or your GP.	Based in hospitals and children's centres but can make home visits. Employed by NHS trusts.

Physiotherapist	<ul style="list-style-type: none"> Provides treatment, advice and support to help improve mobility and movement. 	Referral is usually via a community or hospital paediatrician or your GP.	Based in hospitals and children's centres. Employed by NHS trusts.
Dietitian	<ul style="list-style-type: none"> Works with children with feeding/eating problems (including those fed via a tube) and those who have special dietary needs involved in the dietary management and treatment of disease. 	Referral is via a GP or community or hospital paediatrician.	Based in hospitals or children's centres. Employed by NHS trusts.
Portage worker	<ul style="list-style-type: none"> Provides a service for pre-school children with developmental difficulties to help with language, motor skills and movement. 	Referral can be via your GP, community or hospital paediatrician, physiotherapist, occupational therapist, speech and language therapist or health visitor.	Usually employed by the local authority. They are office based (sometimes at local schools) but usually work in the patient's home.
Audiologist	<ul style="list-style-type: none"> Identifies and assesses hearing and/or balance disorders recommends and provides rehabilitation and management. 	Referral is via a GP or community or hospital paediatrician.	Usually based in hospitals or children's centres.

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Getting information about your child's condition or treatment

You may want further information about your child's condition or disability. Contact a Family produces a wide range of family friendly information on specific conditions and syndromes, available online at Web: <http://www.cafamily.org.uk> or by ringing the Contact a Family free helpline on Tel: 0808 808 3555.

Great Ormond Street Hospital also produces more than 300 jargon free factsheets for families on a wide range of conditions, treatments and tests. These factsheets are available online at Web: http://gosh.nhs.uk/gosh_families

Finding information on the internet

Many people use the internet as a source

of medical information. Contact a Family also produces a short guide to 'Finding medical information on the internet' which aims to help families judge if a website provides relevant, quality information. You can get a free copy of this leaflet via our free helpline on Tel: 0808 808 3555.

Unsure about treatment?

If you're not sure about the role of any health professional, or the purpose of any treatment or test, ask the person who referred you.

"It's important to look at the child not the condition. The same condition might mean varying disabilities in different children."

Cathy

Patients' rights

The main purpose of the NHS is to provide a universal healthcare service for all, based on clinical need and not on an individual's ability to pay. This section looks specifically at what rights individuals have when using the NHS.

GPs

GPs are often the first point of contact if you or your child is unwell. Your GP surgery provides a wide range of family health services including:

- advice on health problems
- examinations and treatment
- prescriptions for medicine
- referrals to other health services
- vaccinations.

How do I register my child with a GP?

Every individual living lawfully and on a settled basis in the UK has a right to be registered with a local GP surgery. If the surgery of your choice is able to add you to their patient list you will be asked to complete the registration forms. It is useful to take your medical card when registering with a new GP.

When you have completed the forms, your medical records will be transferred to your new surgery and you will be sent a new medical card.

Most parents prefer to register their child with their own GP or at the same surgery. Each child has to be registered separately regardless of age. If you are registering a baby, take the FP58 form given to you

by the registrar of births. You should then be issued a medical card after you have registered your baby.

What if my local surgery refuses to register my child?

If a surgery refuses to accept you or your child it must have reasonable grounds for doing so and provide the reasons in writing. There are a number of reasons why you may not be able to register with your chosen GP. For example, the practice may be full or you may live too far away. If this is the case, simply choose another GP in your local area.

If you have difficulty registering with a GP you can contact your local business service centre and ask for 'contractor services' (see 'Useful organisations' at the end of this guide). Alternatively call NHS Direct Wales on Tel: 0845 4647.

Can I change my GP?

You have the right to change your GP at any time without having to give a reason to the new surgery or your old GP. The process of finding a new GP is similar to registering with a surgery. If you have a problem with your GP or surgery, it is often worth discussing it with your GP or the practice manager before deciding to change GPs. A new practice does have the right to refuse if you live outside of their practice area or if they're not accepting new patients at that time. If you have difficulty in changing your GP, you should contact your local business services centre (see 'Useful organisations')

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at the end of this guide) or NHS Direct Wales on Tel: 0845 4647.

Consulting your GP

If your child is ill you should see the GP at the surgery. However, if your child is too ill to visit the surgery you can ask the GP to visit you at home. You should contact your surgery as early as possible if you want to arrange a home visit. Your practice should explain their criteria but, ultimately, you can't insist on a home visit. Generally, a home visit will only be available if a GP feels that a patient's medical condition warrants it.

What if I need to consult the GP when the surgery is closed?

If you or your child needs to see a GP out of normal surgery hours, you will still need to telephone the surgery and listen to the recorded message which should direct you to the out of hours service covering your practice.

Dentists

Dental practices can take private and NHS patients and most take both.

How do I access a dentist?

In Wales, patients are no longer required to be registered with a dentist. Patients can continue to see their usual dentist who can choose to keep a list of regular patients. To find a dentist in your area, you can use the 'Search for a dentist' facility on NHS Direct Wales at Web: <http://www.nhsdirect.wales.nhs.uk> Or call NHS Direct Wales on Tel: 0845 4647 and speak to an adviser. You can then contact the practice to see if they can make you an appointment or



include you on their patient list.

At the outset your dentist will agree with you whether your treatment will be under the NHS or private, or a mixture of both. If you are not sure at any time, do not hesitate to ask your dentist or receptionist.

What do I do if I need treatment in an emergency when the surgery is closed?

If you or your child has a dental emergency out of normal surgery hours call the dental surgery you normally use and an answerphone message will give you a local number you can ring to get clinical advice, and treatment when necessary.

Who is entitled to free NHS dental treatment?

NHS dental treatment is free for:

- women who are pregnant when treatment starts or who have had a baby in the last 12 months. You need to take a MatB1 certificate or NHS prescription maternity exemption certificate to your dentist as proof. You can get these from your GP or from a registered midwife using form FW8
- children and young people under 18 and full time students under 19 years of age
- anyone receiving Income Support, income-based Jobseeker's Allowance or Pension Credit (guarantee credit) and their partners
- anyone named on a Tax Credit NHS Exemption Certificate
- anyone named on an NHS HC2 certificate for full help with health costs.

In Wales, young people under 25 years of age are entitled to free NHS dental examinations. For further information see the section on 'NHS charges'.

Community dental services (CDS)

Community dental services provide treatment for people who may not otherwise seek or receive dental care, such as people with learning disabilities, older housebound people, people with mental or physical health problems or other disabling conditions which prevent them from visiting a dentist. They can also visit schools to carry out dental inspections of children.

To find out how to access your community dental service contact your

GP, local health board or NHS Direct Wales, Tel: 0845 4647.

NHS charges

Most NHS treatment is free to the majority of people who live in the UK. However, there are charges for some services such as dental treatment and sight tests.

The following section explains who is exempt from these charges or qualifies for some help.

Prescriptions, wigs and appliances

Pharmacies in Wales will not charge for dispensing prescriptions as long as they are written by a GP in Wales.

No charges are made for wigs and appliances issued under the NHS in Wales.

Children and young people

Dental treatment is free for children and young people under 18 or full-time students under 19 years of age.

Young people under 25 years of age are entitled to free NHS dental examinations.

All children and young people under 16 and young people aged 16, 17 or 18 who are in full-time education are entitled to free NHS sight tests and vouchers towards the cost of glasses or contact lenses.

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Families on a low income

If you or your partner are getting Income Support, Pension Credit (guarantee credit), income-based Jobseeker's Allowance or if you are named on or entitled to an NHS Tax Credit Exemption Certificate:

- you will not have to pay for sight tests and NHS dental treatment
- you will be entitled to NHS vouchers toward the cost of glasses and contact lenses
- you can claim a refund of essential travel costs to receive NHS treatment under the care of a consultant
- if you need someone to travel with you to hospital for medical reasons, you can get their travel costs paid as well.

If you are not getting any of the benefits listed above, you could still be entitled

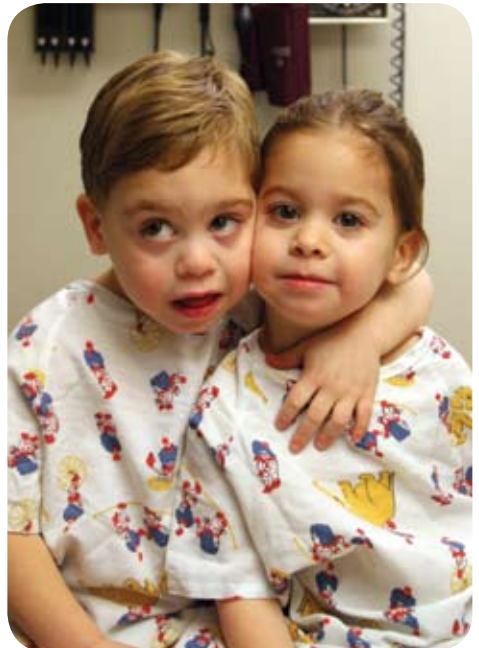
to help through the NHS low income scheme. You need to complete form HC1 which you can get from your local office of the Department for Work and Pensions or Jobcentre Plus. Most social security offices and NHS hospitals and some GP surgeries, dentists and opticians will have a stock. You can also ring the customer enquiry line on Tel: 0845 850 1166 and ask for a copy (call this number too if you need help filling in the form).

You can fill in this form at any time and do not need to wait until you need treatment. You will be sent a certificate telling you how much, if anything you will need to pay toward health costs. If you have already paid health costs and think that you are entitled to claim them back, form HC1 will tell you what to do.

Overseas visitors

If you do not normally live in the UK or have been living outside of the UK for more than three months you may be required to pay for any treatment you receive. This is regardless of whether you are a British citizen or if you have lived or worked here in the past. The hospital providing the treatment is responsible for deciding who is entitled to receive free hospital treatment.

For further information about overseas visitors and people who have recently moved to the UK and access to healthcare, ring the Contact a Family free helpline on Tel: 0808 808 3555.



How do I claim help with travel costs to and from hospital?

You can claim help with travel costs to and from hospital for NHS treatment when escorting your child. Usually you can get a refund of your fares directly from the hospital on the day if you produce proof that you are in receipt of one of the benefits mentioned above or have completed form HC1 and have been sent a certificate of entitlement to help with health costs.

If you are in receipt of Income Support, income-based Jobseeker's Allowance or Pension Credit you can apply for a Community Care Grant to visit a person in hospital. This is a discretionary payment from the Social Fund at your local Jobcentre Plus office or Pension Service. Ring our free helpline on Tel: 0808 808 3555 for further information.

Consent to treatment

Before a medical practitioner can examine or treat your child, they need consent. The way consent is asked for partly depends on what the medical practitioner plans to do. If a GP wishes to look in your child's throat they will ask your child to open their mouth. You may then encourage a younger child to open their mouth or an older child may open their mouth of their own accord. This is usually enough to demonstrate that they and you have given consent. If your child requires an operation, you or they will be asked to sign a form agreeing to treatment and therefore giving consent.

New laws on decision making for adults

The Mental Capacity Act 2005 came into force during 2007. This legislation governs decision-making on behalf of adults, where they lose mental capacity at some point in their lives or where the incapacitating condition has been present since birth. For more information about the procedures and principles of decision making for adults who lack capacity visit

Web: <http://tinyurl.com/8l7dv> or ring the Contact a Family free helpline on Tel: 0808 808 3555.

Adults

Patients over the age of 18 are usually regarded as competent to decide their own treatment. However some adults, such as adults with learning disabilities, may be unable to give their consent. No one can formally give consent on behalf of an adult who cannot give consent but a doctor may still give treatment if this would be in the patient's best interest. Relatives or friends may also be consulted. Where a patient lacks capacity to consent, certain medical procedures, such as sterilisation for contraceptive purposes, should only be carried out with the agreement of a court.

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Young people aged 16 or over but under 18

Young people aged 16 or over but under 18 can give independent consent to their own treatment. In this situation it isn't necessary to obtain the consent of a parent or guardian. However, if the young person is incapable of giving their consent, for example a young person who is severely disabled, the person with parental responsibility will usually be able to give consent for them.

Children under 16

Children under 16 can give consent to medical treatment provided they have demonstrated they have sufficient capacity to decide. This is dependent on their ability to understand what is involved in making the decision. There isn't a general test to assess this capacity and each case should be assessed based on the individual circumstances. If a child under 16, who has sufficient understanding, refuses treatment,

treatment can still be given with parental or guardian's consent, or by a court order. When a child under 16 is not able to give their informed consent, a person with parental responsibility may give consent for the child.

Refusing consent for a child under 16

If a parent or guardian or child refuses to give consent for treatment which a doctor thinks is necessary, the course of action a doctor will take depends on how urgently the treatment is required. The doctor may obtain a court order if a child's life is in danger. If the child's life is not in danger, the doctor will ask the local authority for a care and protection order so the doctor can give consent instead of the parent or guardian. The NHS trust can also obtain a court order. If a parent fails to provide medical help for a child, or unreasonably refuses to allow treatment, they could be prosecuted for neglect.

When a child under 16 is not able to give their informed consent, a person with parental responsibility may give consent for the child.

Who has parental responsibility?

Parental responsibility is a legal concept that consists of the rights, duties, powers, responsibilities and authority that most parents have in respect of their children.

Mothers automatically have parental responsibility for their children.

Fathers have parental responsibility if they were married to the mother when the child was conceived or born, or if they were married later.

Gay and lesbian couples who have children

From December 2005 the Civil Partnership Act enables gay and lesbian couples to ensure both partners can have legal rights and responsibilities in respect of any children they have. For more information about the Act and what it means visit Stonewall at Web: <http://www.stonewall.org.uk> or ring the Contact a Family free helpline on Tel: 0808 808 3555.

Unmarried fathers, since 1st December 2003, have automatic parental responsibility for their children if they have jointly registered the birth of their child with the mother. If a child was born before 1st December 2003 the child's birth can be re-registered jointly with the child's mother and the father will then have parental responsibility. Unmarried fathers can also acquire parental responsibility either through entering a parental responsibility agreement with the mother, through a parental responsibility order made by a court, if he is appointed guardian or if he marries the child's mother.

Mothers and fathers who are married but separate or divorce do not lose parental responsibility.

Other people with an interest in the child's upbringing, such as grandparents and step-parents, may acquire parental responsibility. For further information on parental responsibility and consent to treatment, ring the Contact a Family free helpline on Tel: 0808 808 3555.

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Looking at your child's health records

Generally, it is presumed that a child or young person aged 12 or over has sufficient age and maturity to exercise their rights under the Data Protection Act 1998 (the law governing how personal records about individuals should be managed).

Parents do not have an automatic right to see their child's records (except educational records). If a child or young person is capable of understanding the nature of any application to see their records, their consent must be sought before giving you access - or the request must be deemed to be in the interest of the child or young person. As a child gets older, it's likely that evidence of the child's agreement will be required before

The Informing Healthcare Programme

Nearly all GPs and hospitals use computers to keep records about their patients, but these computers frequently cannot exchange information. The Informing Healthcare Programme is a ten year project funded by the Welsh Assembly government. Amongst its goals are:

- the creation of a single computer based individual health record for each patient which can be accessed by professionals looking after the patient in any healthcare

setting;

- the creation of a computer based library which will allow professionals to access an electronic library of best practice and treatment;
- the creation of a secure system which will allow patients to see their own health records.

The system is still being developed and it is likely to be several years before it is fully operational. If you would like more information, go to Web: <http://www.wales.nhs.uk/ihc> or call Contact a Family Wales on Tel: 029 2039 6624.

a parent can see the records. It may be suggested that the child makes a request for the record themselves.

When a request to see records may be refused

If the health practitioner feels a child is not capable of understanding the nature of the application and feels it is not in the patient's best interest to let the parent access the record, they are entitled to deny a parent's request to see it.

What can I do if I am refused access to my child's health records?

If you have been refused access to your child's records, you can make a complaint to the record holder. Similarly, you can make a complaint if you have seen the records but are unhappy with the content, for example if you believe it is inaccurate or out of date. The record holder will try to resolve the complaint.

If you are still dissatisfied after making a complaint to the record holder, you can make a complaint to the information commissioner (see Useful Organisations for contact details).

National Service Framework

National Service Framework for Children, Young People and Maternity Services

National Service Frameworks (NSFs) set national standards and identify key treatments and services for particular groups of people. The 'National Service Framework for Children, Young People and Maternity Services in Wales' (The Children's NSF) is a 10 year programme from the Welsh Assembly government which aims to ensure that there are high quality services to keep all children and young people as healthy as possible and safe from harm.

It is mainly about healthcare and social services, but it also looks at other things such as education, transport, housing and leisure because these services can affect the health and wellbeing of children and young people. There are six standards dealing with different aspects of service provision, namely: 'Key actions universal to all children', 'Maternity services', 'Children and young people with mental health problems', 'Disabled children and young people', 'Children and young people in special circumstances' and 'Acute and chronic illness and injury'.

For further information about the Children's NSF in Wales visit

Web: <http://www.wales.nhs.uk/nhs> or ring Contact a Family Wales on
Tel: 029 2039 6624.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

What do I do if I would like a second opinion?

You can request a second opinion (also known as a further opinion) if you are not satisfied with the advice you have received or the treatment that has been offered to you by your GP, consultant or other medical practitioner. A medical practitioner may also ask for a further opinion from colleagues when a case is unusually complex or difficult.

You have no legal right to a second opinion. However, a request for a second opinion is rarely refused unless there is sufficient reason or the request is not considered necessary. You can't insist on seeing a particular expert but you shouldn't be referred to someone you don't wish to see. The responsibility for finding a suitable medical practitioner to provide a second opinion rests with the referring GP but you can also make a request for a second opinion to the medical practitioner who provided the initial advice. You should try to discuss



your reasons for wanting a second opinion with the first medical practitioner in case it's an issue that can be resolved without a second opinion.

Waiting for a second opinion

A second opinion isn't usually considered a priority case and you may find that you have to wait some time for an appointment. It could also mean having to travel to a different hospital.

Disagreement over treatment options

In some cases medical practitioners may feel so strongly that a certain treatment is in the best interests of a child that they ask a court to decide.

If a young person under 18 refuses treatment, a person with parental responsibility or medical staff may seek a court order to override them. In both of these situations seek specialist legal advice.

Waiting times in Wales

In Wales, the Waiting Times Information Service provides information about hospital waiting times to help doctors and patients make informed choices at the time of referral. For more information visit: Web: <http://tinyurl.com/2hvgub>

From March 2007, nobody in Wales should wait over eight months for their inpatient or daycase treatment. The maximum total waiting time from GP referral to treatment will be six months by 31st December 2009, including waiting times for diagnostic tests. Anyone in Wales who is already waiting or likely to

“When we were in the hospital we kept watching the bleeps on the monitor. The nurse came in and said don't worry about looking at the monitor so much, the child is here on the bed.”

David

wait over the maximum target inpatient or daycase waiting time will be offered the opportunity of having their consultant-led treatment at another hospital, inside or outside Wales. This is known as the 'second offer scheme'.

What to do if you're unhappy about any aspect of the NHS

Unfortunately, sometimes things go wrong. If you are unhappy with any service or treatment you or your child has received from the NHS you can make a complaint using the NHS complaints procedure.

Where to start

If you have a complaint you should first speak to the staff concerned or the person in charge of providing the service

you are concerned about. They may be able to resolve your concerns straight away without the need for a formal complaint.

If you don't want to talk to the professional involved, you can contact the complaints manager in the NHS trust (if your complaint is about hospital or community services) or the local health board (if your complaint is about GPs, dentists, pharmacists or opticians). All NHS organisations in Wales must have a complaints manager. NHS trusts and local health boards will employ complaints managers, but at GPs' or dental surgeries this is likely to be one of the senior practitioners.

You can make a complaint verbally or in writing (e-mail or letter).

Who can make a complaint?

A complaint can be made by a patient or former patient. In a situation where a patient is unable to make a complaint themselves, for example children, someone else, such as a parent, can make a complaint on their behalf.

How soon must I make a formal complaint?

The NHS complaints procedure will investigate complaints that are:

- made within six months of the event
- made within six months of realising there are grounds for a complaint

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(this must still be within 12 months of the date of the incident).

There is discretion to ignore the time limit where it would be unreasonable to expect the complaint to have been made in the time, for example because of trauma or grief. However, it must still be possible to investigate the complaint. You must always give full details of why you didn't make a complaint within the time limits.

Local resolution

The first stage of the complaints procedure is local resolution. A formal complaint must be acknowledged in writing within two working days. You should receive a written reply within 20 days of making your complaint.

Sometimes it can take more than 20 days to deal with a complaint, particularly if it is complicated. In this case, the person dealing with your complaint should keep you informed of their progress.

Independent review

If, after making a complaint, you are unhappy with the response you have received, you can ask for it to be considered for an independent review by the Independent Complaints Secretariat (see 'Useful organisations' at the end of this guide). You must request the review within 28 days of the date of the letter informing you of the outcome of local resolution.

Your request for an independent review must be acknowledged in two working days and you will be asked to provide



a written statement which explains why you want to continue your complaint. This must be sent within 28 days of making a request for an independent review. If you need help in preparing your written statement, please contact your local community health council.

The outcome of a review

An independent reviewer, together with a lay advisor and, if necessary, a clinical advisor will consider what action may resolve the complaint. They may decide that there is something more that can be done locally, or they may decide that an independent review panel should be set up. You will be informed of the reviewer's decision within 28 days of the reviewer

Help with making a complaint

You can ask your local community health council for help and advice in making a complaint. The Board of Community Health Councils in Wales can put you in touch with your local community health council, contact Tel: 0845 644 7814 or visit Web: <http://www.patienthelp.wales.nhs.uk>

The Welsh Assembly government and NHS Wales have also produced a leaflet 'Complaints about NHS treatment and care' which is a guide to making a complaint about the NHS in Wales. You can obtain copies from the Welsh Assembly government at Web: <http://www.wales.gov.uk/nhscomplaints> or get in touch with Contact a Family Wales on Tel: 029 2039 6624.

receiving your written statement.

An independent review panel

If it is decided that an independent review panel should be asked to investigate the complaint, the panel will look at the complaint in the way it feels most appropriate but it will speak to all parties involved. The results of the examination of the complaint will be sent to you, the NHS body (NHS trust, GP practice etc), the local health board, NHS Performance Quality and Regulation Division and the local community health council.

The panel can make recommendations, but it is up to the local health board or NHS trust to decide what, if any, further action will be taken. The chief executive of the local health board or NHS trust will write to you within 20 working days of receiving the report. The letter may include an apology, what action is being taken and/or an ex-gratia payment (a payment from a moral obligation rather than a legal obligation).

Ombudsman

If you feel that your complaint hasn't been resolved by the Independent Review Secretariat, and the treatment or care you are making a complaint about took place after 1st April 2006, you can take your complaint to the Public Services Ombudsman for Wales (see 'Useful organisations' at the end of this factsheet.

The ombudsman does not have to investigate your complaint, but will

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

normally do so unless it appears that it is unfounded or trivial.

If you ask the ombudsman to investigate your complaint, you cannot later ask for an independent review, even if the ombudsman decides not to take it on.

If the ombudsman decides to accept your complaint, following an investigation, a report will be produced and the ombudsman will tell the NHS organisation what it should do to resolve the situation.

Judicial review

If you disagree with the final decision under the NHS complaints procedure, it may be possible to seek a judicial review. A judicial review is a procedure which allows a court of law to challenge a decision made by public bodies.

Clinical negligence

Clinical negligence is the legal term used to describe a medical accident where a patient has been harmed because a doctor or other healthcare professional has not given the proper standard of care.

If you or your child has been a victim of a medical accident, you may want to consider possible courses of action once your health care needs have been met. It is important to remember that taking legal action is only about getting compensation and other things like an apology may be more important to you. Once you start a legal claim you may not be able to take another course of action.

If you are considering taking legal action, get specialist advice. Action against Medical Accidents (AvMA) can provide further information on possible courses of action, advise you of your rights and put you in contact with a specialist solicitor. See 'Useful organisations' on page 25 for their contact details.



Useful Organisations

Action against Medical Accidents (AvMA)

Tel: 0845 123 23 52 (Mon-Fri, 10am-5pm)

Web: <http://www.avma.org.uk>

e-mail: advice@avma.org.uk

Benefits Enquiry Line

Tel: 0800 88 22 00

Board of Community Health Councils in Wales

Tel: 0845 644 7814

Web: <http://www.wales.nhs.uk/chc>

e-mail: enquiries@waleschc.org.uk

Business Services Centre - Mid & West Region (Swansea)

Tel: 01792 458066

Business Services Centre - South East Region (Pontypool)

Tel: 01495 332000

Business Services Centre - North Wales Region (Mold)

Tel: 01352 700227

Contact a Family Wales

Tel: 029 2039 6624

Web: <http://www.cafamily.org.uk/wales>

e-mail: wales.office@cafamily.org.uk

Health Commission Wales

Tel: 029 2080 7575

Web: <http://tinyurl.com/yv7xkg>

e-mail: hcw.enquiries@wales.gsi.gov.uk

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Health of Wales Information Service (HOWIS)

Web: <http://www.wales.nhs.uk>

Healthcare Inspectorate Wales

Tel: 029 2092 8850

Web: <http://www.hiw.org.uk>

e-mail: hiw@wales.gsi.gov.uk

Information Commissioner's Office

Tel: 029 2044 8044

Web: <http://www.ico.gov.uk>

e-mail: wales@ico.gsi.gov.uk

Independent Complaints Secretariat, Mid and West Wales

Tel: 01874 712 748

Independent Complaints Secretariat, North Wales

Tel: 01352 700 227

Independent Complaints Secretariat, South Wales

Tel: 029 2040 2262

National Institute for Health and Clinical Excellence (NICE)

Tel: 020 7067 5800

Web: <http://www.nice.org.uk>

e-mail: nice@nice.org.uk

NHS Direct Wales

Tel: 0845 46 47

Web: <http://www.nhsdirect.wales.nhs.uk>

Patient's Association

Tel: 0845 608 4455

Web: <http://www.patients-association.org.uk>

e-mail: mailbox@patients-association.com



Public Services Ombudsman for Wales

Tel: 01656 641 150

Web: <http://www.ombudsman-wales.org.uk>

e-mail: ask@ombudsman-wales.org.uk

Welsh Assembly Government

Web: <http://www.wales.gov.uk>

Tel: 0845 010 3300 (English)

Tel: 0845 010 4400 (Welsh)

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Getting in contact with us

Free helpline for parents and families

0808 808 3555

Textphone

0808 808 3556

Open Mon–Fri, 10am–4pm;

Mon, 5.30–7.30pm

Access to over 100 languages

www.cafamily.org.uk
www.makingcontact.org

Contact a Family Head Office:

209-211 City Road, London EC1V 1JN

Tel **020 7608 8700**

Fax **020 7608 8701**

Email **info@cafamily.org.uk**

Web **www.cafamily.org.uk**



Language Line
services

Other information booklets available

This guide is one of a series produced for parents and groups concerned with the care of disabled children. A full list of Contact a Family publications is available on request or can be downloaded from our website www.cafamily.org.uk

- Concerned about your child? (UK)
- Understanding your child's behaviour (UK)
- The tax credits guide (UK)
- Working (UK)
- Disabled children's services in England and Wales (England & Wales)
- Dealing with Debt (England & Wales)
- Special Educational Needs (Wales)

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