

**contact a family**



Parents and Paediatricians Together Project

## **Promoting self care: Information for families**

A report for child health professionals on the role of information in self care for parents and young people

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## Introduction

This report describes the role of information in promoting self care for families of children with long term conditions. It explains how information helps and where reliable sources of information can be found.

There are three types of information families might need:<sup>1</sup>

- **Medical:** This includes not only medical information about the child's condition, but also around caring for the child.
- **Welfare:** If the child's medical condition has a major impact on their daily life, then parents will also need access to welfare information, to help them find out about social support for their child and themselves.
- **Psychosocial:** Parents also benefit from information that helps them cope and adjust emotionally.

**Young people** need information, in a simple and clear format, that will help them understand their medical condition and know how to look after themselves. They also benefit from psychosocial information that helps them deal with the effect their condition has on their school and social life.<sup>2</sup>

Information is best provided verbally, and backed up by written information. It needs to be offered as an ongoing process, as people's information needs change over time.

**Transition** occurs when the young person is moving from one service to another. Transitions commonly experienced by families include transition from hospital to home, from one geographical area to another, beginning primary school, moving to secondary school and moving from children's service to adult (health, education, social care). Extra information is often needed to support the families at these times. The transition from child to adult services can be particularly difficult, as so many changes happen simultaneously.

## Medical information

It helps if families know the **name** of their child's diagnosed medical condition, and how it will affect the child. Finding out more about the medical condition is important for both the parent and young person in promoting self care. Medical professionals can use different names for describing the same condition, or give families the name of symptoms rather than the name of the underlying disorder. This can hinder families from finding out more about the condition, through their own research and through support groups e.g. a family who is told their child has a pervasive developmental disorder, might not link this to autism, and therefore not contact the

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National Autistic Society, which can provide useful information to help them care for their child.

Families can also benefit from having information which helps them judge whether medical information found on the internet is reliable, as well as being provided with a few reliable online sources of medical information.<sup>3</sup> The internet leaflet provided by Contact a Family meets this need (see <http://www.cafamily.org.uk/paptinfo.html>).

Living without a diagnosis, or not knowing what the long term prognosis is, can prohibit families from accessing support and adjusting to their situation. When the diagnosis is uncertain, or when it is not possible to give a definite prognosis, some indication of the worst and best case scenario is helpful for families to understand what the future might hold and plan for it.

Families also need information on:

**Management and interventions** - to care for the child's medical needs. This includes medical interventions, monitoring the condition, recognising and responding to symptoms and knowing how and when to seek assistance from a health professional.

**Self care - diet / exercise** - attention to lifestyle is particularly important for certain medical conditions. Families might need information about diet, exercise, how to avoid aggravating the child's medical condition and how to minimise the risk of complications.

**Promoting the child's development** - parents might need to learn how to encourage their child's development in particular areas, such as communication, and mobility.

**Supporting child's learning and behaviour** - If the condition impacts on the child's learning or behaviour, parents might need information to help them manage this including advice around sleeping, eating and toilet training.

**Managing physical consequences** - If the child's condition affects their mobility, parents need information about using equipment, so they are able to lift or carry them whilst avoiding injury to the child or themselves. They might also need information about getting aids and equipment and dealing with incontinence.

**Information to give to other professionals** - Schools and other professionals working with the child might need information about the child's medical condition, to help them provide appropriate support. This information might be given to the school by the parent, or through direct contact from the health professional. Difficulties can arise around communicating between health and school, particularly when there is uncertainty on who is responsible for taking the lead.<sup>4</sup>

## **Welfare information**

If the child's medical condition has a major impact on their daily life parents will also need access to welfare information to help them access social support for their child and themselves.

### **How does a medical condition impact on family life?**

Parents can spend much more time than other parents looking after their child either because they require a lot of daily care such as help with dressing, feeding and toileting or they have frequent hospital visits, medical interventions and frequent absences from school.<sup>5,6</sup>

This can often prevent one parent from working, with financial consequences for the whole family. The cost of raising a child with a long term medical condition or disability can be three times greater than that of bringing up a healthy child. Research shows that over 50% of families with disabled children live close to or below the poverty line.<sup>7</sup> These families need information about all the financial benefits they may be able to claim and other sources of financial help i.e. grants.

Parents often become exhausted with caring for their child, especially if the condition impacts on their sleep. Specific behaviour traits are associated with certain medical conditions. Challenging behaviour is not only draining on parents' energy but can also be extremely isolating. Friends stop coming to see them and their child's behaviour prevents them from going out.<sup>8</sup> These families will benefit from respite services and short break schemes.

If the child's condition affects their ability to do school work, or attend school, then the child could need extra support or special allowances at school to take account of this. These families need information about any educational support they are entitled to and how to apply for it. This can include additional support so they can attend nursery, school or university, allowances when taking public exams to allow for their medical needs and concessions in entry requirements for getting into university /college.

The child's medical condition can impact on the family's social life. Parents can feel unable to go out and leave their child unless they are confident the person left caring for the child can manage their medical needs. This can place a strain on marital relationships, leave parents socially isolated and sometimes one parent has no role apart from looking after the child. Marital relationships do break under the strain of caring for a child who is disabled or has a chronic medical condition, leaving one parent caring for the child on their own.<sup>9</sup>

The young person's medical condition might prevent them from having as many opportunities to socialise with other young people their age as their peers. This can be because their condition prevents them from joining in with school and out of school activities. If they have to travel some distance to a school that can support

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their additional needs, they have less opportunity to make friends with youngsters living locally to them.

If the parents' time is taken up in caring for one child, this can prevent them from taking siblings to leisure activities outside the home. It can also be difficult to find activities the entire family can enjoy together, both the ill or disabled child and healthy siblings. These social activities are important for children's development as well as their mental well being.<sup>10</sup> These families need information about local organisations that can provide babysitting services with medically trained staff, as well as holidays and leisure schemes their children can take part in.

If parents are continuously stressed, tired and exhausted, then they are more likely to develop health problems, both physical and psychological. Providing social support to the family can prevent breakdowns occurring, as well as improve the overall quality of family life.

### **Problems accessing welfare information**

Social support such as short breaks, blue badges and babysitting services are often advertised as being for families with 'disabled children'. Families of children with long term medical conditions often do not think of their child as disabled.

The legal definition of disability is

*'any person who has a physical or mental impairment or long-term health condition, which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.'*<sup>11</sup>

The 2007 British Social Attitudes Survey<sup>12</sup> shows that the majority of the public, when referring to 'disabled people', focus on physical impairments and would not consider people with long term medical conditions or mental illness as being disabled. So even if families hear about these benefits they do not realise they are eligible for them.

Most parents of children with long term medical conditions never see a social worker, who usually only get involved if the family need to access support services such as respite or direct payments. If families find out they can claim DLA they often have no assistance from social services, find the claim process difficult and do not find out what else they are entitled to claim.<sup>1</sup>

For finance alone, parents might be eligible to claim Disability Living Allowance (DLA) for their child, family tax credits, housing benefits, road tax exemptions, hospital fares, income support, council tax benefits, carers allowance, as well as get help from the Family Fund. These are provided by different agencies and organisations, including voluntary organisations. Professionals are sometimes only aware of what their own agency offers. Families often do not find out about all they are entitled to.<sup>7</sup>

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Children can miss out on educational opportunities because their family are not aware of what support is available or how to access it, and educational staff are not aware of the individual child's needs.<sup>4</sup>

There is a mass of information, both medical and welfare, for families to absorb, which can be daunting. Research shows that parents can get overwhelmed if they are given too much information and this can add to their stress. It is best to give families small amounts of information about what is available, and where to go for more detailed information should they need it.<sup>13</sup>

As the child grows older and their personal circumstance change, a family's information needs also change. They need to be informed of which agencies they can approach if they need help in the future.

### **Psychosocial information**

Psychosocial information is information that helps the family cope and adjust emotionally.

#### **Delivering difficult news**

Research tells us that how the diagnosis is delivered affects how well families subsequently cope. The Right from the Start template produced by Scope ([www.scope.org.uk/earlyyears](http://www.scope.org.uk/earlyyears)) provides a good practice framework for professionals on delivering difficult news. As well as delivering the news in a sensitive way, in an appropriate place, the template mentions the need to provide families with information.<sup>14</sup>

*'They (parents) want, and have a right to, full information about the services and benefits available... conveyed in a manner which recognises their lack of familiarity with systems and procedures that are complex and potentially daunting.'*

Anne Leonard, 1994 <sup>14</sup>

It is known that families on hearing a diagnosis can undergo various emotions, including shock, denial, anger, guilt and loss. Searching for more information about the child's medical condition is a common reaction and a way of coping for many parents.<sup>15</sup>

Having accurate information on the condition and prognosis helps parents <sup>1</sup>

- 1) Come to terms with understanding how the condition will affect their child
- 2) Understand why it has happened and perhaps stop blaming them self
- 3) Adjust expectations, for themselves as well as their child
- 4) Take control and plan their future

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Where the prognosis is uncertain parents say they prefer to be given the worst and best scenario, so they can have some understanding of what might lie ahead.

Without information parents can be left feeling overwhelmed, anxious how they will cope and worried about their future.<sup>13</sup>

If provided with information, parents know where they can find out more about their child's medical condition, how to best support them and access help for themselves and their child. This reduces some of their stress, helps them become confident in their ability to manage the situation, able to plan for the future and take back control of their lives. As the child grows older the family's information and support needs are likely to change. Families need to know where to go for more information and support when this occurs.<sup>16</sup>

There is also the need for parents (and other siblings), to have the opportunity to think about and talk through what they will tell other family and friends and how to cope with their reactions. For example, many parents find it difficult when their child is stared at in the supermarket. Brothers and sisters may also need support to discuss or role play what they might tell their peers. This can be provided by groups that support siblings.

### **Contact with other parents and groups**

Research tells us that parents usually find voluntary organisations and other parents their most useful source of information.<sup>17-21</sup>

Through their newsletters or websites national condition support groups often provide a forum through which parents can share solutions to specific problems associated with their child's medical conditions, such as managing school, going on holiday or finding suitable equipment. Even if their children have different medical conditions, parents often face similar problems. Parents often learn about local services and how to access them from other parents, local to where they live. Seeing one family access services can spur others to apply. Many families of children with long term conditions talk about feeling isolated from the rest of society and that people do not understand how their lives are affected. Contact with other families can reduce feelings of isolation and being alone.<sup>22-23</sup>

It also provides a new network through which they can support each other, which helps them feel them more valued by others in turn and promotes self esteem.<sup>8,24-26</sup>

*'I finally felt like a person. I had the feeling that I belonged in a community with others in similar situations'* **(Parent)**

*'Knowing we aren't alone in experiencing this stuff makes it much easier to bear, breaking that sense of isolation and otherness.'* **(Parent)**<sup>3</sup>

## Information for young people

The information needs of young people with long term medical conditions include not only medical information, so they can manage their daily life but also information that helps them deal with the impact having a long term medical condition has on their life. Young people look to health professionals to provide them with medical information.

In Beresford's and Sloper's study<sup>2</sup> on the Information needs of chronically ill or physically disabled children and adolescents, young people were asked to say what they want when seeing a doctor. Their answers are shown in Box 1.

### **Box 1: When we see our doctor we want....**

- choice about who else is present
- continuity of contact with one doctor
- our doctors to be interested in us and not just the condition
- to be asked questions
- our doctors to talk to us, not our parents
- the opportunity to ask questions
- the language used to be understandable
- to be treated with respect
- to be made to feel comfortable and not rushed
- to have the choice about whether we see a male or female doctor <sup>2</sup>

Medical information for young people needs to be available in a language that is understandable to them and presented in an accessible way. Different versions should be available for different age groups.<sup>16</sup> Many young people say that 'real life' histories are helpful to them as well as information and advice.

However young people do not always want to be told everything e.g. those with life threatening conditions do not always want to know about their prognosis and health at the end stages of their condition. Avoiding information can be their way of coping.

Young people also need psycho-social information, which helps them deal with the situations and emotions that are the result of having a medical condition. This can include living with the physical symptoms, dealing with school, friend and parents, managing social situations and planning for the future. Many find being able to share experiences with other young people who have the same condition helpful. Many of the voluntary organisations provide both written information, with real life stories, as well as the opportunity to network with others like themselves.

## Transition to adult services

At adolescence the young person is moving from children's services to adult services in health, education and social care.

Before becoming independent of their family the young person needs to understand how their medical condition affects them, how to manage their medication and how to care for themselves. They need to be able to monitor their own health and know when and how to seek help. The young person also needs to become confident in seeing health professionals on their own.

Young people might need additional information about the impact taking alcohol and drugs might have on their medical condition. They could also want advice on sex, family planning and know whether their condition affects their ability to have a family. They also need to know how their condition will impact on their ability to study, go to university or enter employment. Where the prognosis is uncertain it is very difficult for them to plan a future.

If the young person has a statement of educational need or is known to social services then a multi-agency transition plan should be initiated around the age of 14. Many young people do not have a statement or are known to social services but still need information to help them understand the options available to them once they leave school. This includes educational opportunities, help available to them in securing employment and support so they can live independently of their parents. At this time any financial benefits that the parents have been claiming need now to be claimed by the young person.

This can be a very stressful time, with changes happening in all aspects of the young person's life. At this time families need information to help them understand the opportunities available for the young person and how to access them.

## **National Service Framework – information**

The National Service Framework for Children, Young People and Maternity Services<sup>27</sup> for England recognises information as important for families. All of the standards refer to information for families and says parents and young people should be provided with:

- Written information about their illness or condition and treatment interventions in appropriate format
- Information about relevant support groups and voluntary organisations that might help
- Be provided with contact with other families with similar problems

## **The RCPCH and Contact a Family – Parents and Paediatricians Together**

In 2004 the Royal College of Paediatrics and Child Health began a three year project called 'parents and paediatricians together'. The aim of this partnership work was to support health professionals in providing information to families. Over the course of the project various information material was developed which health professionals can give to families.

Contact a Family is the only UK wide charity that supports all families of children who have a disability or long term medical condition. Contact a Family can provide all three types of information: medical information, welfare and psychosocial, as well as signposting to other organisations who can provide more specialist information.

### **Medical information**

The Contact a Family Directory of Specific Conditions, Rare Disorders and UK Family Support Groups contains entries covering over 1000 long term conditions affecting both children and adults. All entries have been written or endorsed by a leading UK medical expert and each entry is updated every three years. This information is widely used by medical professionals, but is also useful for professionals working with the child, such as teachers and social workers. The directory can be found online at <http://www.cafamily.org.uk/dirworks.html> and printed and CD versions can be purchased. Each directory entry contains a two page summary about the condition, which can be printed or photocopied and handed out to the family. Many health professionals do this when delivering the diagnosis, so families have a little information to take away with them.

At the bottom of each entry there are details of a condition support group. Medical information especially that found on the internet is not always reliable.

The support groups can be a useful source of reliable information. They can provide information, written in simple language about the child's specific medical condition and information on wider care issues, such as diet, exercise, activities that promote the child's development and getting help with managing the physical consequences of the child's condition. Many of the support groups also provide useful information for professionals supporting patients with that condition. The support groups in the Contact a Family directory are given guidance on ensuring any medical information given out is first endorsed by an appropriate medical expert. The groups receive information from Contact a Family, who in turn receive newsletters from the groups. This dialogue means the contact details within the directory are kept up to date on an ongoing basis.

Contact a Family have additional information about certain rare conditions that do not appear in the directory and will assist health professionals in tracking down medical information for any condition.

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Contact a Family can also provide generic information useful for families covering a wide range of conditions. These are listed in Box 2:

**Welfare and psychosocial information** Contact a Family can help by providing families with information on any aspect of supporting a child with a disability or long term medical condition. Their publication 'When your child has additional needs' informs parents newly diagnosed about the different services available. They also have many fact sheets which give information on accessing various types of support, such as financial, education and aids and equipment. These publications can be downloaded from the web or ordered free of charge via the Contact a Family freephone helpline. The helpline advisers can also provide qualified advice to families and provide details of what is available in a family's local area, including statutory and voluntary organisations and details of local parent support groups. These support groups tend to be multi-disability but do give families the opportunity to meet others facing similar problems.

They also have national offices in Scotland, Wales and Northern Ireland, regional offices in the North of England and the West Midlands and project offices in various parts of London who provide local support to families. They also have family support workers in various parts of the UK who can provide one to one support to families as well as a network of parent volunteers.

A table of other sources of medical, welfare and psychosocial information is shown in Box 3.

### **Box 2: Contact a Family – Factsheets relevant to wide range of medical conditions**

**About diagnosis** - explains the processes that can be involved in reaching a diagnosis, why this can be a lengthy process, answers common questions parents have and describes what might help parents cope

**Developmental delay / Concerned about your child** - describes the different health professionals who might help if a child has developmental delay and encourages parents to seek advice

**Feeding /eating** - explains the problems that can occur for disabled children and gives hints on managing mealtimes

**Internet: searching the internet for medical information** - provides advice to parents when searching for medical information on the internet to help them judge whether it is reliable

**Sleep: Improving your child's sleep** - provides advice on encouraging good sleep habits in children, breaking bad habits and information about where to go for further help

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**Toilet training** - provides information to aid families of disabled children when toilet training their child

**Understanding your child's behaviour** - helps parents understand the reason behind their child's challenging behaviour and find strategies to deal with it

The fact sheets on sleep, feeding/eating and toilet training are also available in some other languages.

### **Box 3 - Sources of information**

#### **Medical**

**The Contact a Family Directory** of Specific Conditions, Rare Disorders and UK Family Support Groups contains information on over 1,000 long term conditions affecting both children and adults. It provides a short summary of each condition, and details of national condition support groups, which can be sources of more detailed patient information and support.

Helpline: 0808 808 3555

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

**Early Support** is a government initiative to support services for families with young disabled children. Early Support has developed a range of information material for families of children aged 0-5, covering a range of disabilities and conditions. This material can be downloaded from the web and printed versions can be ordered in England.

Tel: 0845 602 2260 Web: <http://www.earlysupport.org.uk>

**Great Ormond Street & Institute of Child Health** provide more than 300 factsheets suitable for parents and young people covering a wide range of conditions, treatments and medications.

Web: [http://www.gosh.nhs.uk/gosh\\_families](http://www.gosh.nhs.uk/gosh_families)

**NHS Direct** provides an encyclopaedia of common conditions with patient information, and links to other sources of information.

Helpline 0845 4647

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

#### **ACT: The Association for Children's Palliative Care**

ACT is a UK-registered charity which works with professionals in supporting families whose child has a life threatening or life limiting condition

Helpline: 0845 108 2201

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

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**AFASIC** is a charity for children and young people affected by speech, language and communication impairments, their families and professionals working with them.

Helpline 0845 3 55 55 77

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

**The Challenging Behavior Foundation** provides various factsheets for families of children who are severely disabled and who display extremely challenging behaviour.

Tel: 01634 838739

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

**ERIC (Education and Resources for Improving Childhood Continence)** runs a helpline and produces information to support families of children who are incontinent.

Helpline: 0845 370 8008

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

**The Genetic Interest Group** has information sheets for patients, including explanations about inheritance patterns, chromosome problems, genetic testing and genetic appointments. Most of their leaflets are downloadable from their website.

Tel: 020 7704 3141 to order documents which have no online option.

Web: [http://www.gig.org.uk/eurogentest\\_patientleaflets.htm](http://www.gig.org.uk/eurogentest_patientleaflets.htm)

**ICAN** is a charity providing information to parents and professionals living or working with a child with speech and language difficulties.

Tel: 0845 225 4071

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

## **Welfare**

**Contact a Family** is a UK charity providing advice, information and support to the parents of all disabled children no matter what their disability or health condition.

Helpline: 0808 808 3555

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

Tel: 0845 602 2260 Web: <http://www.earlysupport.org.uk>

**Early Support** is a government initiative to support services for families with young disabled children. Their background information files explain the help that families might be eligible for regarding finance, childcare, education and social services.

Tel: 0845 602 2260 Web: <http://www.earlysupport.org.uk>

**Children's Information Services** help families find suitable childcare, and should provide details of other sources of support in their local area. Details of local children information services can be found on the website below. The Helpline shown is for England only.

Helpline: 0800 2 346346 Web: <http://www.childcarelink.gov.uk>

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**The Disabled Living Foundation** provides information and advice to people on finding and choosing all types of equipment.

Helpline: 0845 130 9177

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

**KIDS** provides play and leisure opportunities through a network of regional branches.

Tel: 020 7359 3635

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

**Parent Partnership Schemes** are statutory services that offer information, advice and support for parents of children and young people with special educational needs (SEN). Details of local parent partnership can be found at:

Tel: 020 7843 6058

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

**Shared Care Network** promotes family-based short breaks for disabled children across the UK and helps families find providers of short break schemes in their local area.

Tel: 0117 941 5361 Web: <http://www.sharedcarenetwork.org.uk>

**Sibs** is a charity supporting people who grow up with a brother or sister with chronic illness, special needs or disability.

Tel: 01535 645453

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

**WhizzKidz** is a national charity providing information, advice and wheelchair training as well as customised wheelchairs, tricycles and other specialised mobility equipment.

Tel: 020 7233 6600

Web: <http://www.whizz-kidz.org.uk>

## Information for young people

**Children First for Health (CFfH)** is a web-based, child-centred health and hospital resource, supporting teenagers, children from five years of age and their families. It provides comprehensive and age-appropriate health information from the UK's leading medical experts and paediatricians.

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

**SKILL** is a UK charity providing advice to young disabled people on applying to college, getting financial assistance, examination arrangements, disclosing disability and looking for work.

Helpline: 0800 328 5050

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

**Transition Information Network** has web-based information on all aspects of the transition process and signposts to further resources. They produce 'My Future

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Choices', a magazine for disabled young people and others interested in the transition process.

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

**Youthhealthtalk.org** is a web-based contains a collection of interviews with young people about their experiences of health or illness. They identify the issues, questions and problems that matter to young people.

Web: <http://www.youthhealthtalk.org>

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