



Promoting self care

Information for families

Parents & Paediatricians together

UK

Introduction

This leaflet outlines the type of information families with disabled children, including children with long term conditions, might need, along with useful sources of information.

Providing information can help parents become more knowledgeable and confident in managing their child's condition and the consequences it has on daily life.

If health professionals don't provide information, parents can be left unable to provide appropriate care to their child, and feeling anxious, isolated and unsupported. This can impact on the whole family's health and well being.

Young people need information in a suitable format that helps them learn about their medical condition, start to take responsibility for looking after themselves and deal with the effect their condition has on their school and social life.

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Research tells us that how information is provided can impact on how patients cope, including their compliance with treatment, making adjustments to lifestyle and accessing care for their wider support needs.

Additional information can be needed when a young person is moving from one service to another, for example hospital to home, geographical area or school. The transition from child to adult services can be particularly difficult and there is evidence that some young people with long term conditions suffer irreversible damage to their health after disengaging with health after transition to adult services.

Families often don't get information they need because professionals assume they already have the information from other people. It's estimated that only 1 in 13 families of disabled children get support from social services. Parents of children with long term medical conditions don't always think of their child as being 'disabled' so often don't find out about additional support they're entitled to.

The National Service Framework for Children and Young People and Maternity Services

for England recognises information as important for families. Their standards say parents and young people should be provided with:

- **medical information** like medical condition and treatment interventions;
- **welfare information** like relevant support groups and organisations that might help;
- **psychosocial information** which helps families cope and adjust emotionally.

"One of the nurses at the hospital said, 'I assume you're getting DLA, and we said 'What's that then?'"

Parent

Medical Information:

Around diagnosis

Parents need to know when it is appropriate to seek advice from health professionals and know what support is available if their child develops problems.

It helps for parents to understand that sometimes it can take a long time to reach a diagnosis. If this happens they can still seek additional help and support for their child and their care needs, without having to wait for a named diagnosis.

If it's suspected that the child has a genetic condition, then families need information to help them understand what that means, its implications for future children and how genetic counselling can help.



Families can initially react with various emotions on hearing the diagnosis. This means they might not be able to take in all the information provided in the appointment. Families often look on the internet for medical information.

Providing families with sources to go to for information and advice can help them gain a better understanding, find answers to questions they forgot to ask and prevent families from being misled by unreliable sources of information.

This not only means the patient is better informed at future consultations but can save medical practitioners time having to explain away bad information and address patients' unsubstantiated concerns.

"Every time we saw the doctor he would simply say 'we will have to wait and see.'"

Parent

Information for families around diagnosis

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.

The following leaflets/factsheets can be downloaded or ordered from their helpline:

- **Concerned about your child** encourages families to seek advice if they have concerns around their child's development and describes the different health professionals who might help.
- **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.
- **Finding medical information on the internet** gives guidance to families searching the internet for medical information as well as reliable sources of information.

Helpline: 0808 808 3555

Web: <http://www.cafamily.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_patient_leaflets.htm

Medical condition, interventions and lifestyle

The parent and young person need to find out about the medical condition and how it will impact on their lives.

Families also need information about medical interventions, managing symptoms and when to seek assistance from a health professional.

Families might also benefit from information about diet, exercise, and healthy living to minimise the risk of aggravating the condition.

National condition support groups can be a good source of information.

Professionals like teachers and social workers involved with the family will also benefit from understanding how the condition can affect the child.

"I was given the name of a syndrome on a torn piece of paper and told to look on the internet but not to believe everything I am told."

Parent



Information for families about medical conditions

The Contact a Family Directory of Specific Conditions, Rare Disorders and UK Family Support Groups contains entries covering over 1,000 long term conditions affecting both children and adults.

All entries have been written or endorsed by leading UK medical experts and are updated every three years. They provide a short summary of each condition, and details of national condition support groups, which can be sources of more detailed patient information and support.

Parents can access the Directory online or call the helpline for medical information and a general information pack.

Helpline: 0808 808 3555
Web: <http://www.cafamily.org.uk>

Early Support Programme is a government initiative to support services for families with young disabled children. It provides information for parents on certain conditions including Autistic Spectrum Disorders, Cerebral Palsy, Deafness, Down syndrome, Learning Disability, multi-sensory impairment, speech and language difficulties and visual impairment. Their information material can be ordered in England, or downloaded from their website.

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

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 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>

Supporting learning and behaviour

Parents might need to learn how to encourage their child's development in particular areas, such as communication, learning, and behaviour.

Long term medical conditions can impact on the child's development and learning. Some conditions have associated behaviour phenotypes, for example Fragile X, or Autism.

Parents might need additional information on how to support their child's development and behaviour.

"Lack of sleep causes rows and stress."

Parent



Information for families – supporting learning and behaviour

Early Support is a government initiative to support services for families with young disabled children. It provides material that helps families support their child's development including:

- monitoring protocol for deaf babies and children;
- Early Support Developmental journal for babies and children with Down syndrome;
- Early Support Developmental journal for babies and children with visual impairment.

Tel: 0845 602 2260

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

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

Tel: 0845 3 55 55 77

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

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>

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.

The following leaflets/factsheets can be downloaded or ordered from the helpline:

- Feeding and eating;
- Helping your child's sleep;
- Potty/toilet training;
- Understanding your child's behaviour.

Helpline: 0808 808 3555

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

Mobility and incontinence

If the child's condition affects their mobility, parents might need information to help them get aids and equipment. This could be through a referral to an occupational therapist or social worker.

There are also numerous charities that can help families find appropriate equipment and funding for it. The Contact a Family helpline can provide details of these.

Parents might also need training to help them learn how to handle their child safely, avoiding injury to the child and themselves.

Parents might also need information to help them deal with their child's incontinence. They might be entitled to practical assistance from the local continence service. Contact your PCT for details of your local service.



"My daughter has Prada Willi syndrome, and because of the way she walks, she needs new trainers almost once a month. Affording that has been a worry."

Parent

Information for families on mobility and incontinence

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.

The following factsheets can be downloaded or ordered from the helpline:

- **Aids, equipment and adaptations** gives information on families' rights and where to obtain special equipment, and how to adapt your home.
- **Potty/toilet training** gives information to help parents of disabled children when toilet training their children.

Helpline: 0808 808 3555
Web: <http://www.cafamily.org.uk>

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>

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>

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>



Welfare information: relevant support groups and organisations that might help

If the child's medical condition has a major impact on daily life, then without support parents can become stressed, tired and exhausted. They are then 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. Families might need information to help them access the following:

Social support

Financial assistance If the child's medical condition impacts on parents' ability to work, or causes them additional expenses, then families need information about sources of financial help.

Childcare It can be difficult for parents of children with long term medical conditions to find appropriate childcare. Parents will need information about how to access suitable childcare and help with the additional costs involved.

Pre-school Children can miss out on taking part in early educational experiences such as playschools and nurseries because of concerns that the staff can't meet their additional support needs.

Education If the child's condition affects their ability to do school work, or attend school then families need information about available educational support and how to apply for it.

Leisure and social activities A long term medical condition can prevent young people from taking part in out-of-school activities and make it difficult for families to find holiday activities suitable for all the children. Information about holidays and leisure schemes their children can access helps.

Respite services and short break schemes If caring for the child disrupts sleep, family life or is very time consuming, families might need to know about support services providing short breaks or respite available in their area.

Siblings and family relationships If one child in the family needs a huge amount of help and support, this can have a negative impact on other family members including siblings. The additional pressures can sometimes put considerable strain on relationships. It helps if families are told about local support that might help including activities for siblings and counselling services.

Information for families on social support

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>

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. They have factsheets giving advice on support available including finance, employment rights, childcare, education, leisure activities and relationships. Factsheets can be downloaded or ordered from the helpline.

Helpline: 0808 808 3555

Web: <http://www.cafamily.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's information services can be found on the website below.

Helpline: 0800 2346346 (England only)

Web: <http://www.childcarelink.gov.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>

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

Tel: 020 7359 3635

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

Social workers might be able to provide practical help and support for the child and family. This can include short breaks, nursery provision, aids and equipment and home help. Families can ask their local authority children with disabilities teams to carry out an assessment to find out what help they are entitled to.

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>

Contact with other families

Research tells us that parents often find other parents their most useful source of information. Through their newsletters or websites, national condition support groups provide a forum through which parents can share solutions to specific problems associated with their child's medical conditions. Parents often face similar problems even if their children have different medical conditions. Many families of children with long term conditions talk about feeling isolated from the rest of society and of people not understanding how their lives are affected. Contact with other families can reduce feelings of isolation and being alone and provide them with a new network of support and information.

"I finally felt like a person, I had the feeling that I belonged in a community; with others in similar situations."

Parent



Information to help families make contact with others

Contact a Family can help parents make contact with others like themselves. They have details of both national and local support groups for parents with disabled children.

Where the child has a rare condition and there is no support group, Contact a Family can help families to make direct contact with others across the UK. Parents should call the helpline in the first instance.

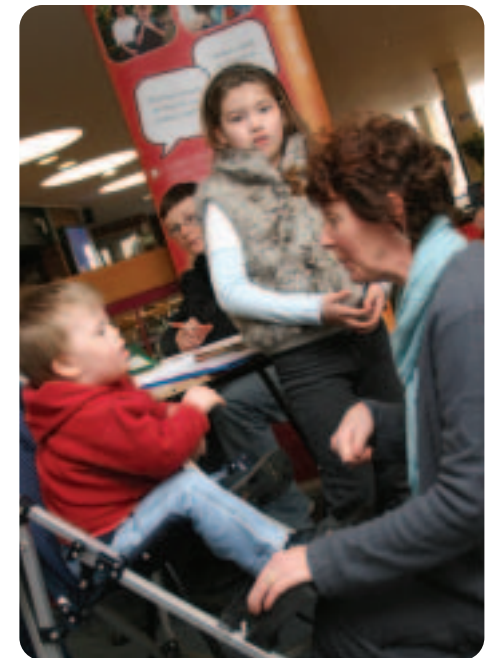
Helpline: 0808 808 3555

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

Children's Information Services should be able to provide details of sources of support in the local area. Details of local children's information services can be found on the website below.

Helpline: 0800 2346346 (England only)
0800 2 346346

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



Information for young people

Young people with long term conditions not only need medical information, so they can manage their condition, but also information to help them deal with the impact that having a long term condition has on their life. They need this presented to them in an accessible way and in language that is understandable to them.

Many young people say that 'real life' stories are helpful to them as well as information and advice.

However young people don't always want to be told everything. Those with life threatening conditions sometimes don't want to think about their prognosis and health at the end stages of their condition. Avoiding information can be their way of coping.

Young people also benefit from information to help them deal with the emotions and situations they face as a 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 national condition support groups provide both written information, with real life stories as well as the opportunity to network with others like themselves.



Information for young people and families

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>

Youthhealthtalk.org is a web-based 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>

The Contact a Family Directory of Specific Conditions, Rare Disorders and UK Family Support Groups gives details of national condition support groups, which can be sources of more detailed patient information and support. Parents can find out about local or national support groups by calling the helpline.

Families can access the Directory online five times each month for free, otherwise there's a fee for professionals for unlimited use.

Tel: 020 7608 8700

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



Transition to adult services

At adolescence, the young person is not only moving into adulthood but also moving from children services to adult services. This can be taking place in health, education and social care.

To be independent of their family the young person needs to understand how their medical condition affects them, how to manage their medication, how to care for themselves, to be able to monitor their own health and know when and how to seek help.

The young person also needs to be confident in seeing health professionals on their own.

Young people might need additional information, such as the impact taking alcohol and drugs might have for someone with their specific condition, or whether they will be able to have children of their own.



They also need to know how their condition will impact on their ability to study, go to university or enter employment and what support is available.

Any financial benefits that the parents have been claiming may also now need 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. Families require information to help them understand what opportunities are available for the young person and how to access them.

"It is like finding yourself stepping off the edge of a cliff and discovering there is no safety net."

Parent

Information for families

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. They have various factsheets which can be downloaded or ordered from the helpline.

- **Transition** explains to parents the processes that take place and signposts them to more detailed information;
- **Growing up: sex and relationships** are three information packs, one each for young people, parents and teachers

Helpline: 0808 808 3555

Web: <http://www.cafamily.org.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 Choices', a magazine for disabled young people and others interested in the transition process.

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



Background to this leaflet

In 2004 the Royal College of Paediatrics and Child Health (RCPCH), working with Contact a Family, began a three year project called 'Parents and Paediatricians Together'. The aim was to support health professionals in providing information to families with children who have a long term health condition or disability. This booklet has been written for health professionals, to help identify the type of information families might need to promote self care, and provide them with reliable information to give to their patients.

A more detailed research-referenced report supporting this booklet can be downloaded from both the RCPCH website at Web: <http://www.rcpch.ac.uk/publications> and Contact a Family's website at Web: <http://www.cafamily.org.uk/papt>

Thank you to the Department of Health for help in funding this leaflet and all those who helped in developing it.

Written by Sheila Davies,
Paediatric Project Officer (England)

Local contacts – health

Please record useful local contact information here:

Community dentist service

Name Tel

Address

.....

Incontinence service

Name Tel

Address

.....

Occupational therapy

Name Tel

Address

.....

Physiotherapy

Name Tel

Address

.....

Speech and language therapy

Name Tel

Address

.....

Nurses/health visitors

Name Tel

Address

.....

Name Tel

Address

.....

Name Tel

Address

.....

Local contacts – social support

Please record useful local contact information here:

Children’s information service

Name Tel

Address

.....

Parent partnership

Name Tel

Address

.....

Social workers (children’s team)

Name Tel

Address

.....

Other useful contacts

Name Tel

Address

.....

Name Tel

Address

.....

Name Tel

Address

.....

Name Tel

Address

.....

Getting in contact with us

Free helpline for parents and families
0808 808 3555

Textphone

0808 808 3556

Open Mon-Fri, 10am-4pm;

Mon, 5.30pm-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**

Textphone **0808 808 3556**

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

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



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Other information booklets available

The following Contact a Family publications might be of particular interest to health professionals:

Support pack for health professionals provides information on best practice when communicating with and supporting parents at significant times, from pregnancy to pre-school. Contact us for a free paper copy.

About families with disabled children is a guide which highlights some of the issues that are part of a parent's daily experience of dealing with a disabled child and also details key legislation. Contact us for a free paper copy.

The Contact a Family Directory of Specific Conditions, Rare Disorders and UK Family Support Groups can be ordered in paperback, on CD-ROM or you can register for unlimited access via the internet. Tel 020 7608 8700 for more details.

Although great care has been taken in the compilation and preparation of this information booklet to ensure accuracy, Contact a Family cannot take any responsibility for any errors or omissions.