

# Practical Support and information when a disabled child needs medical care

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Contact a Family Scotland

[www.cafamily.org.uk/Scotland](http://www.cafamily.org.uk/Scotland)

## Who Contact a Family helps

We support parents and carers across Scotland whose children have a

- physical disability
- learning disability
- disabling medical condition
- rare condition
- behavioural problem
- life threatening condition
- mental health issues

Families with children and young people aged up to 18 years old or older if they have not transitioned into adult services

## Who Contact a Family helps

‘Just the name was frightening enough but to hear the prognosis was devastating. We could not ask questions as our emotions had taken over so we were invited back at a later date. During this time our child’s walking had deteriorated and his speech was getting slower to the point where you felt like finishing sentences off for him.’ **Parent**

‘I have just been told my child has Aspergers – I don’t know what to do.’ **Parent**

‘We walked out of the hospital feeling stunned and alone... I think I went through a period of mourning, you mourn for the child you thought you had, and the one you want to have.’ **Parent**

“At one stage we seemed to be meeting a new professional every week. My son found it very difficult to go anywhere new so I would have to cope with a distressed toddler at the same time as trying to tell my story.

They all asked the same questions ... I seriously thought of putting it all on tape and saying, Here you are, listen to that .”

# Emotional Impact

- Grief
- Fear
- Guilt
- Anger
- Emotional Exhaustion
- Relief



## **Information and communication problems we have learned from listening to parents and carers**

### **Parents**

- Don't know what support exists or where to look for it
- Expect a professional to tell them
- Are overwhelmed with too much information

### **Professionals**

- Assume someone else has provided the information
- Knowledgeable of own speciality

Childcare

Equipment  
and  
adaptations

Finance  
and  
benefits

Transport  
and  
mobility

Health  
services

Leisure



Education/  
transition

Support  
groups

**Areas families might need  
support with**  
Where would you signpost  
families to for support?

Social  
services

Parenting/  
relationships

Employment

# What information we provide

## Medical Information


- A-Z directory of around 440 conditions online
- details of national and local support groups
- medically-verified
- 'lay-appropriate'

The screenshot shows the website interface for 'Pallister-Killian syndrome'. At the top, there is a navigation bar with the 'contact a family' logo, regional links (Scotland, Wales, Northern Ireland), 'Media enquiries', 'makingcontact', and a 'Donate to us' button. A search bar is also present. Below the navigation bar, there are several menu categories: 'Home', 'What we do', 'Medical information' (which is highlighted), 'Know your rights', 'Advice and support', 'Get involved', and 'Professionals'. Under 'Medical information', there are sub-links: 'A-Z conditions', 'Finding reliable medical information', 'All about genetics', 'Our medical advisory panel', and 'Medical words'. The main content area is titled 'Pallister-Killian syndrome' with a 'Go back a step' button. There is a 'Print' icon and a 'Background' section. The background section contains a paragraph of text explaining the condition. Below this is a 'Credits' section with a paragraph of text. A red box highlights the question 'What are the symptoms?'. Below this, there is a list of main features including hypotonia, distinctive appearance, streaks, developmental delay, learning difficulties, speech delay, epilepsy, and sparse hair. There are also expandable sections for 'How is it diagnosed?', 'How is it treated?', 'Inheritance patterns and prenatal diagnosis', and 'Is there support?'. On the right side, there are three promotional boxes: 'Benefits and you - get what you're entitled to!', 'Benefits and tax credits', and 'Find out about our wide range of services for families'. At the bottom right, there are social media icons for Facebook and Twitter.



# What information we provide when,

- Diagnosis can take time
- Developmental delay often not explained to families
- Getting support without a diagnosis, or for a rare condition, can be difficult




**contact** a family  
for families with disabled children

Developmental delay

Information for families  
UK

Incorporating The Lady Hoare Trust



**contact** a family  
for families with disabled children

Living without a diagnosis

Information for families  
UK

Incorporating The Lady Hoare Trust



**contact** a family  
for families with disabled children

Living with a rare condition


Information for families  
UK

Incorporating The Lady Hoare Trust

## What information we provide when,

Being a parent can be more  
'challenging'


It helps to give parents information  
early on, **before** problems become  
entrenched



**contact a family**  
for families with disabled children

**Helping your child's sleep**  
Information for parents of disabled children


Parents & Paediatricians together  
Contact a family working with The Royal College of Paediatricians and Child Health



**contact a family**  
for families with disabled children

**Feeding and eating**  
Information for parents of disabled children

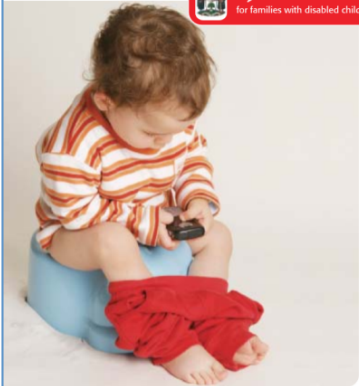
Parents & Paediatricians together  
Contact a family working with The Royal College of Paediatricians and Child Health



**contact a family**  
for families with disabled children

**Understanding your child's behaviour**  
Information for families

Incorporating The Lady Moore Trust  
UK



**contact a family**  
for families with disabled children

**Potty/toilet training**  
Information for parents of disabled children

Parents & Paediatricians together  
Contact a family working with The Royal College of Paediatricians and Child Health

## Other information


### Making GP practices more welcoming

Explores the consequences if disabled children are seen in A&E

Explains why families of disabled children find it difficult to visit their GP

Makes practical suggestions for GP practices, to make it easier for disabled children to visit their GP.

[www.cafamily.org.uk/healthprofessionals](http://www.cafamily.org.uk/healthprofessionals)



**contact a family**  
for families with disabled children

**Making GP practices more welcoming**

Information for GP practice teams

## Supporting disabled children and young people

Health service that disabled children might need

Issues that disabled children frequently present with and who can support them

Why early intervention is important

Information that GPs can provide to families

[www.cafamily.org.uk/healthprofessionals](http://www.cafamily.org.uk/healthprofessionals)

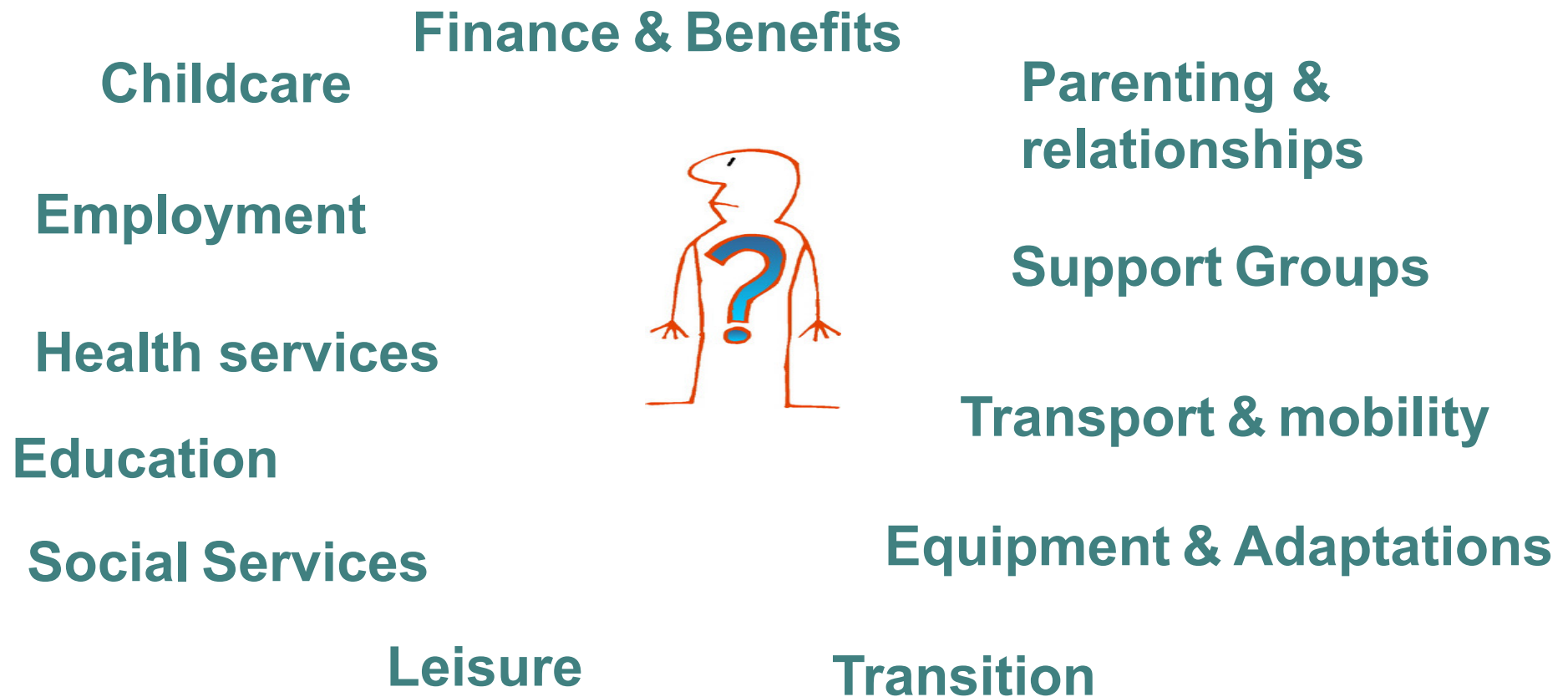
## Other information



**GP practice guide: supporting disabled children and young people**

Information for Health Professionals

## Information we can provide and support we can signpost parents and professionals to



## An enquiry

Family with a child on the autistic spectrum and has developed scoliosis on the spine and needs to go into The Royal Sick Kids in Edinburgh. Mum phoned and didn't know what support they could get and she was worried how they would travel from Orkney and accompany their child. After discussion with CAF adviser found out they;

- Needed support in preparation for the visit – pre-admission visit information
- Access to overnight accommodation and travel expenses – provided with sources of funding (trusts, foundations) for one off grants and how to access them e.g. support letter from healthcare professional or social worker
- Information on visiting their child out with visiting hours and
- Other organisations that could support them before, during and after their visit

## How Contact a Family helps



0808 808 3555

**UK Help Line** – includes interpreter service / finance, benefits and welfare specialist parent advisers

Email: [Helpline@cafamily.org.uk](mailto:Helpline@cafamily.org.uk)

Web: [www.cafamily.org.uk](http://www.cafamily.org.uk)



0131 659 2930

**Scotland office information service** – take enquiries via phone and email, provide e-bulletin for parents and professionals, events, workshops, information on support groups, family linking

Email: [scotland.office@cafamily.org.uk](mailto:scotland.office@cafamily.org.uk)

Web: [www.cafamily.org.uk/Scotland](http://www.cafamily.org.uk/Scotland)

## How Contact a Family helps

### Telephone helpline

Our parent advisers are available from Monday to Friday, 9.30am to 5.00pm on our freephone helpline 0808 808 3555.

- Telephone confidential advice lines
- A call back service for in depth advice, complex queries, benefits checks
- Helpline has access to interpreters in 170 languages
- Offers online information and support by email, Facebook and Twitter

We are members of The Helplines Association (THA) and the helpline is accredited to their quality standard.



## How Contact a Family helps



Online information on the web [www.cafamily.org.uk](http://www.cafamily.org.uk)

## How Contact a Family helps

**National Condition groups** – condition specific information

**Local Parent Support** – different conditions, similar problems

**Making contact** – rare conditions

Contact with other families

- reduce feelings of isolation
- share information and strategies
- network of support
- feel valued

## How Contact a Family helps

### How Parent Support groups help parents

*'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 )

## **And finally.... to ensure families get the practical support they need**

### **Professionals**

- to be proactive in providing information
- to signpost families to relevant local services/organisations
- to link closely with other professionals
- to listen to parents and also the child where appropriate
- not assume someone else is providing information.

### **Parents**

- to know where to go to get up-to-date information, as they need it
- to be able to access information in a variety of locations
- to be able to access information in a variety of formats including print, online and 1 to1
- to know who to ask for the information they may need
- to be signposted to the right information source
- to be supported in finding information
- to not assume professionals know all about the information that is out there
- to link in with parent groups/forums as they are often good sources of information.

Thank You, any questions?

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