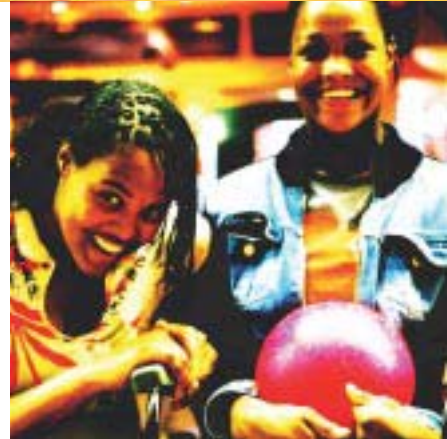


# making **contact**



family  
**linking**  
scheme



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

# making contact

**There are over 770,000 disabled children and young people in the UK. Every day around 75 children are born or diagnosed with a disability or health problem. You may feel very isolated and anxious when you are told for the first time that your child has a disability. The isolation can be particularly acute if your child has a rare disorder.**

*'It was so frustrating not being able to talk to another mother whose child had the same condition so we could share things, the way you do if your child gets measles.'*

*Mother, Northern Ireland.*

**Contact a Family is a UK wide charity which aims to put parents in touch with each other in a variety of ways. Families want different levels of contact at different times. Some may want to meet up in groups, others prefer a one off phone call and others like to chat with other families via email. Can we help you to make contact?**

*'Finding other mums to talk to, share feelings with and laugh and cry with has helped me so much'*

*Mother, Wales.*

## UK wide support groups

There are a large number of UK support groups linked to a specific condition. These range from huge organisations that the general public will be familiar with such as MENCAP, which supports families whose children have a Learning Disability and SCOPE, supporting families affected by Cerebral Palsy, to small informal groups with only a handful of members.

Contact a Family has information about large, well known charities as well as hundreds of smaller groups across the UK which support families affected by very rare disorders.

You may not have heard of Williams Syndrome which is a rare metabolic disease, but there is a national support group, the Williams Syndrome Foundation, which offers contact and support through a network of regional groups. It has a twice yearly newsletter and is in touch with over 900 families. There are many groups of a similar size, for other disorders, offering similar services and support.

Many groups produce detailed information factsheets about the disorder or syndrome and can link you with other families in a variety of ways, for example through contact lists, local networks or requests for contacts in their newsletters.

For some conditions smaller groups may exist, often run from a parent's own home, which offer support to a handful of families by telephone, letter or email. These groups still cover the UK and may have a meeting once a year where affected families can get together.

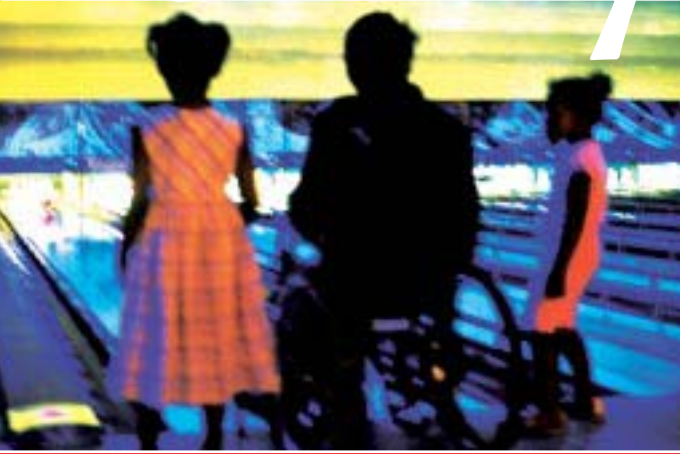
Because many of the smaller national groups are run from the home of an affected family, and with little or no funding, it can be hard to find out about them. You may have been told by professionals involved in your child's care that they know of no such group. Even if you have been told you have little chance of making contact with others don't be put off, as you may find that there IS a group.

To find out whether there is a UK wide support group, you should call the Contact a Family helpline on freephone 0808 808 3555. Alternatively, you can email [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk) or visit the Contact a Family website [www.cafamily.org.uk](http://www.cafamily.org.uk), which contains our *Contact a Family Directory of Specific Conditions, Rare Disorders and UK Family Support Groups*.

The parent advisers on the helpline can also give you medical information about your child's condition and advise you on practical matters such as claiming benefits, education rights and getting help from social services. Even if your child's condition is not listed in the *Contact a Family Directory of Specific Conditions, Rare Disorders and UK Family Support Groups*, our Parent Advisers will be able to find out information about it for you.

They can also give you information about the support group Syndromes Without a Name (SWAN) which provides support to families whose children are undiagnosed.

# family linking



## If there is no UK wide support group for my child's condition what are my options?

### Is there a local support group?

*'We use a local group of special needs families, who are excellent.'*

*Father, Essex*

Many areas in the UK have a local parents' support group where families of children with all kinds of disabilities come together for mutual support and contact. If your child has a rare disorder, it is unlikely that another child will have the same condition, but you will almost certainly find that a lot of the issues you face will be the same. Local groups also have the advantage of meeting regularly and locally, the added benefit of local knowledge and sometimes arrange trips or outings as a group.

Contact a Family's local, regional and nation offices have links with numerous groups in the areas they cover and can put you in touch. They can also offer support to parents at any stage of starting or developing a local group, by phone or in person. These offices are all listed at the end of this booklet.

If you live in an area not covered by one of these offices and you would like to find out about local groups in your area, call the Contact a Family freephone helpline on 0808 808 3555 or email [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk). The parent advisers will help you make local contacts.

In a number of areas, we have volunteer local area representatives: all are parents of disabled children and are familiar with local services and sources of support. Any regional or national office or our UK wide freephone helpline will tell you if there is an area representative for your area.

We also have a free booklet 'Starting a local group' which covers topics such as getting started, holding an open meeting and reviewing progress. This is available from any Contact a Family office.

### Could you start a UK wide group?

Most national support groups start because a parent, just like you, decides that they would like to speak to others in the same situation. No special knowledge is required, you do not need lots of money and Contact a Family will support you every step of the way.

The Contact a Family Rare Disorder Groups Development Officer will talk you through the process and help you with practical arrangements. It may be that you decide to have a one off telephone conference where other affected families across the UK call into a group telephone call from their own homes. We can arrange and pay for the initial telephone conference, help to find other affected families and our groups' worker will help you by running the telephone conference if you would like. If you would like to talk this over informally, call the Contact a Family switchboard on 020 7608 8700 and ask to speak to the Rare Disorder Groups Development Officer.

For helpful information about starting a group, look at the Group Action Pack on the 'Publications' section of our website [www.cafamily.org.uk](http://www.cafamily.org.uk) or from Contact a Family on 020 7608 8700.

# scheme



## One to one linking

National groups may offer to link individual families with one another in various ways e.g. they may have a contact list, or link parents through their local networks. Alternatively, they may link families by suggesting that a parent put a contact request in their newsletter. However, where no support group exists, or where groups for whatever reason may not be able to offer a linking service, Contact a Family will try to find you a one to one link.

If you are a parent or carer of a child with a specific condition or rare disorder, Contact a Family will make every effort to link you with another family according to individual circumstances. In order to do this, you can either

- cut out and complete the form in this booklet with as much detail as possible and one of our parent advisers will contact you to make sure we understand what you are looking for or
- telephone our freephone helpline (0808 808 3555, between 10am & 4pm Monday to Friday). One of our parent advisers will go through a form with you and it will then be sent to you for your signature and return.

It is important to point out that as we may have heard from only a small number of families of children with the same rare condition as your child, we may not be able to meet your specific requirements (e.g. same geographical area, same or similar age of child). Also children can be affected quite differently by the same condition. Other parents that we link you with may come from a different cultural background to you and have a different level of understanding of their child's disability. Some parents may only want a one-off contact, others may wish to continue to keep in touch – there is no obligation on either party to do so.

*'Thank you for your support and help in arranging contact between me and Liz with whom I could share issues around similar experiences. After you wrote to me in October, I received a letter from Liz and since then we have written and phoned one another on a fairly regular basis. As you predicted, we do have a lot in common and this link has been of great benefit to us both. I really did feel all alone – it was amazing to find another family who are so kind and understanding.'*

*Mother, Midlands*



Arranging an individual link can often take some time – we may have to explore a number of avenues and we may not get an immediate response from families. If we are not able to link you at the time of registering your details with us, please do not think we have forgotten you! We will keep your details on file for linking for at least 3 years but please do contact us at any time during that period to update us about your child or your contact details (or to ask for further information or advice from us). For extremely rare conditions we may not have been able to link over that time - if this is the case it would help us if you let us know you are still looking to make contact with other parents.

Don't let this put you off!! Many parents tell us that having the opportunity to share experiences relating to their child's condition has been of great benefit and certainly helped to lessen their feelings of isolation.

The information you give us will be held in the strictest confidence and will only be used for the purpose of the Family Linking Scheme. Your details will not be passed on to another family without a Parent Adviser getting in contact with you first. At this point we will check with you whether there are any changes to your or your child's circumstances.

You are not obliged to link with any families that we contact you about in the future – we are very aware of the stresses and pressures that many families are under and we do not in any way want to add to this. Whatever the reason, whether we have contacted you at a difficult time or you are not sure about whether it is a suitable link for you, please be honest and just say no!! If at any time you tell us you no longer wish to be considered for any linking this will not mean you will be excluded from using the scheme in the future.

## Other options for making contact

- ☞ Contact a Family is in the process of designing an email linking service via our own website, rather like those sites which offer to link up old school friends, or former work colleagues. The other family will not be given your email address, but instead you may correspond in complete anonymity via the Contact a Family website. Visit the Contact a Family website at [www.cafamily.org.uk](http://www.cafamily.org.uk) click on 'what's new' and register for our general email bulletin. You will then be informed as soon as the service is up and running.
- ☞ There are other ways of making contact such as penfriend schemes for disabled children and their siblings.

**If you would like to know anything more about any of these options or would like to talk through your situation with our parent advisers, please do get in touch with us.**

**Helpline**

**0808 808 3555**

Monday to Friday 10am to 4pm

**Textphone for deaf parents**

**0808 808 3556**

Monday to Friday 10am to 4pm

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

**Fax 020 7608 8701**

**Write to us at 209-211 City Road, London, EC1V 1JN**

**Contact our nation, regional or local offices – details on back cover**

---

Your name

---

Your postal address

---

---

County/Borough

---

Your telephone number

---

Mobile telephone number

---

Email address

---

---

Your child's name

---

Child's date of birth

---

Boy or girl?

---

Your child's disability

---

Please tell us a little about how your child is affected i.e. what features of the condition does your child have. It would also be helpful if you would indicate the degree of severity (where known) e.g. moderate learning disability, profound hearing loss, partially-sighted)

---

---

---

---

---

Please tell us a little more about your family (these questions are optional and are designed to help us find a family similar to your own, where possible)

---

Single parent? Yes/No    Other children? Yes/No (Please let us know their ages)

---

Do the other children have any disabilities? Yes/No (If yes, please describe these)

---

---

If there is anything in particular that you are looking for in a link family, please tell us in the space below (for example, if you are looking specifically for a dad, grandparent or a single parent family, or a family with a child of the same sex as your child)

---

---

---

---

---

---

---

*continued over*

*continued*

---

Area of link

---

If we cannot link you with a family in your area (which may be likely in the case of a rare disorder) are you willing to have contact with a family from

---

Anywhere in the UK?    Yes/No                      Abroad?    Yes/No

---

Age range preferred?

---

How would you prefer to be contacted by other parents?

---

Telephone    Yes/No                      Letter    Yes/No                      Email    Yes/No

---

Have you registered on our [www.makingcontact.org](http://www.makingcontact.org) website? Yes/No

Having your story on [www.makingcontact.org](http://www.makingcontact.org) will maximise the chance of finding a link family for you. No-one outside Contact a Family will be able to access your contact details and links will be made via the helpline. You will be known by an anonymous "user name". If you don't have access to the internet, would you like your details to be entered into our website [www.makingcontact.org](http://www.makingcontact.org) so that others can contact you? Yes/No

If "Yes", what user name would you like us to register you under?

---

It may be some time before we can find a possible link for you. Do feel free to come back to us at any time if there are any changes that you think we should know. In any case, we will not give your details to another parent without checking with you first.

Please sign below to confirm that the information is accurate, you are happy for us to hold this information on file and to contact you again in the future.

---

Signed

Date

---

Please return this form to  
**FREEPOST Contact a Family, FREEPOST LON8801, London, EC1B 1EE.**  
No stamp is needed.

FOR CONTACT A FAMILY USE ONLY

---

Parent adviser

---

Registered on [makingcontact.org](http://makingcontact.org)                      H     V     Username

---

Match found    Match family contacted

---

Response received    Accept/decline

---

Link family notified

---

# OFFICE ADDRESSES

## NATIONAL

### UK OFFICE

Contact a Family  
209-211 City Road  
London EC1V 1JN  
Tel 020 7608 8700  
Fax 020 7608 8701  
Helpline 0808 808 3555 or  
Textphone 0808 808 3556  
Freephone for parents and families  
(10am-4pm, Mon-Fri)  
e-mail: [info@cafamily.org.uk](mailto:info@cafamily.org.uk)

### NORTHERN IRELAND

Contact a Family Northern Ireland  
Bridge Community Centre  
50 Railway Street  
Lisburn BT28 1XP  
Tel/Fax 028 9262 7552  
e-mail: [nireland@cafamily.org.uk](mailto:nireland@cafamily.org.uk)

### SCOTLAND

Contact a Family Scotland  
Norton Park  
57 Albion Road  
Edinburgh EH7 5QY  
Tel (0131) 475 2608  
Fax (0131) 475 2609  
e-mail: [scotland@cafamily.org.uk](mailto:scotland@cafamily.org.uk)

### WALES/CYMRU

Contact a Family Cymru  
The Exchange Building  
Mount Stuart Square  
Cardiff  
CF10 5EB  
Tel 029 2049 8001  
Fax 029 2049 5001  
e-mail: [wales@cafamily.org.uk](mailto:wales@cafamily.org.uk)

## REGIONAL

### North East England

Contact a Family North East England  
The Dene Centre  
Castle Farm Road  
Newcastle upon Tyne  
NE3 1PH  
Tel/Fax 0191 213 6300  
e-mail: [northeast@cafamily.org.uk](mailto:northeast@cafamily.org.uk)

### North West England

Contact a Family North West England  
6th Floor, St. James House  
Pendleton Way  
Salford M6 5FW  
Tel (0161) 743 0700  
Fax (0161) 743 0711  
e-mail: [northwest@cafamily.org.uk](mailto:northwest@cafamily.org.uk)

### West Midlands

Contact a Family West Midlands  
Prospect Hall  
12 College Walk  
Selly Oak  
Birmingham B29 6LE  
Tel 0121 415 4624  
Fax 0121 415 4922  
e-mail: [westmids@cafamily.org.uk](mailto:westmids@cafamily.org.uk)

We do not have staffed offices in the following regions at present.

### Yorkshire and the Humber

### East Midlands

### East of England

### South East England

### South West England

However, we have several contacts covering these areas, so please use our UK office for more information.

## COMMUNITY PROJECTS

### Ealing

Tel 020 8810 8151  
e-mail: [ealing@cafamily.org.uk](mailto:ealing@cafamily.org.uk)

### Lambeth

Tel 020 8671 7665  
e-mail: [lambeth@cafamily.org.uk](mailto:lambeth@cafamily.org.uk)

### Lewisham

Tel. (020) 7635 6333  
e-mail: [lewisham@cafamily.org.uk](mailto:lewisham@cafamily.org.uk)

### Southall

Tel 020 8571 6381

### Southwark

Tel 020 7277 4436  
e-mail: [southwark@cafamily.org.uk](mailto:southwark@cafamily.org.uk)

### Sutton and Merton

Tel 020 8640 5525  
e-mail: [sutton@cafamily.org.uk](mailto:sutton@cafamily.org.uk)

### Wandsworth

Tel 020 8947 5260  
e-mail: [wandsworth@cafamily.org.uk](mailto:wandsworth@cafamily.org.uk)

We thank the Parenting Fund for the production of this leaflet.

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