Contact a Family – not just a red book!

This article considers the place of the charity *Contact a Family* as a major provider of information and support to families caring for a child with any kind of disability or additional support need. It examines parents' needs for access to good quality information and outlines the ways in which *Contact a Family* can provide this both for the parents and the professionals who support them. The role of the paediatric project – *Parents and Paediatricians Together* – is also described and the ways in which this new initiative between the Royal College of Paediatrics and Child Health (RCPCH) and *Contact a Family* can facilitate the parent-professional partnership.

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Key points

Wilson A.K. (2006) Contact a Family – not just a red book! *Infant* 2(4): 142-45.

1. Families are more likely to cope better when they are well-informed.
2. It is essential to present information in different ways and through a variety of media.
3. Contact with other parents can often significantly reduce parents' feelings of isolation.
4. The parent-professional relationship is at the centre of the parents' coping mechanism.

What's in a name?

Contact a Family is synonymous in very many professionals' minds with the *Contact a Family Directory: Specific Conditions, Rare Disorders and UK Family Support Groups* which has been described as the organisation's flagship or more simply as '*The Red Book*'. In any event it holds a unique position in the affections of paediatric professionals up and down the country as a lifeline in the ever-growing labyrinth of medical conditions.

> "The *Contact a Family Directory* is a huge instant resource for the lay public and medical experts alike. It is a great benefit to medicine."
>
> *Professor Finbarr Cotter, Professor of Experimental Haematology, St Bartholomew's Hospital, London*

The *Contact a Family Directory*

Containing over 400 entries covering some 1,000 different conditions with brief medical descriptions, inheritance patterns, prenatal diagnosis and any relevant support groups, the directory represents a unique resource for parents and professionals when looking for up-to-date, reliable information concerning rare disorders. The medical texts provided in *The Contact a Family Directory* are written for non-specialist, multidisciplinary professionals involved with families and individuals. They are also designed to provide accessible information for the families themselves.

Contact a Family also maintains a database of a considerable number of specific conditions and rare disorders in addition to the ones listed in the directory, so that even if an individual is looking for a particular condition for which there is no entry, it is still worth contacting the charity.

Professionals are also likely to identify the organisation with a means of putting families in touch with each other for mutual support and the sharing of information. In fact, as demonstrated overleaf, the organisation does much more than its name suggests, although it retains at its core the essential aims of information giving and support to families caring for a child with a disability.

> "It has been reassuring to have someone else looking and finding things out for us."
>
> *Parent*

Starting points

The organisation began life as a community-based initiative in Wandsworth in London in the early 1970s. The main aims of the project were very much about providing support for the whole family, covering all types of disabilities and with the empowerment of families at the centre of its work and this is still the case today.

Interestingly, and perhaps significantly for the *Parents and Paediatricians Together* project, one of its chief supporters has been Professor David Hall (ex-president of the RCPCH). He is very aware of the potential impact of bad news on parents but equally cognisant of the difficulties for professionals confronting this situation when he says:

> "Conveying difficult news to parents is just as much of an art form as doing an operation and it's just as important to be self-critical."

Contact a Family did not become an independently registered charity until 1979. Since then it has gone from strength to strength to become well-known as a leading provider of quality information and support, not only to families but, just as importantly, to the professionals who support them. It is the only UK-wide organisation, operating through 14 offices across the country, which provides support and help for families of children with *any* disorder or chronic health condition.

The information gap

Over the last 25 years, many studies in journals and Government policy documents have emphasised parents' need for information and support and it would be redundant to rehearse these again here. Rather more important is the way in which professionals and other organisations actually manage to provide this help. The need for information is still as much an imperative now as it was then and this is demonstrated in many of the recent policy documents such as the NSF.

It has long been recognised that the provision of guidance and good-quality information can empower parents and assist them in the process of adjusting emotionally to their child's condition, physically allow them to access services and benefits and thus improve their overall management of their child's situation.

Different people need to access information in different ways and it is as important to provide written information as it is to communicate verbally. In fact the two go hand in hand and the former reinforces the latter. Parents regularly report that they forget what has been said after a consultation and that anxiety and their perceived lack of knowledge etc., all conspire against their retaining the mass of essential information. Studies reporting parents' views recommend that professionals provide written summaries of what has been said. Alongside the need for different media is the ongoing, all-encompassing need for sustained information throughout the child's life.

> Information provision is not a one-off event – it has to be a 'process' during the patient journey from pre-diagnosis on-going into adult life. The need for information never goes away, and information needs vary at different parts of the patient journey.
>
> *Children's National Service Framework – Ill Child EWG – Long term conditions subgroup report*

This has been aptly described as three-dimensional information which will be quickly and easily accessible (thus reducing the effort on already strained parents); available in more detail for those who are at a different stage; and ongoing when they return to their communities.

FIGURE 1 Seen through a glass darkly. *www.johnbirdsall.co.uk*

How *Contact a Family* helps parents

Learning that a baby or a child has a particular condition or disability is always going to be a traumatic experience no matter how sensitively the initial communication is handled. It may be helpful here to imagine a family in a neonatal setting, perhaps already on the NICU because there are concerns about their baby. The birth of a baby where everything goes *well* is a profoundly emotional and earth-shattering experience – how much more so then when, for any one of a number of reasons, things do not go as planned? (**FIGURE 1**)

Once a concern has been raised parents sense that all is not well, even when professionals are not in a position to state with any certainty, the precise nature of their concerns. Even pre-diagnosis, help and support can be accessed through *Contact a Family's* freephone helpline where a team is on hand to give advice and support and answer any query, no matter how specific an issue is. Perhaps more importantly in this situation staff can just lend a listening ear. The helpline is often the first port of call for families, and parents are able to phone free for as long and as often as their case demands.

> "I've been contacting *Contact a Family* for about 4-5 years now. Sometimes I just need to talk to someone who understands. They always seem to have time – no-one else does. Thanks for the helpline. I really, really need it. Even if they don't have a magic wand to sort out education and social services, it helps to talk to someone who understands, it helps keep me sane."
>
> *Parent*

The *Contact a Family* helpline could be described as a one-stop shop staffed by a team of specially trained parent advisors who can give advice on a wide range of issues both general and specific. This includes anything from information on the baby's medical condition (if the diagnosis is known) to benefit and employment rights and help with transport costs, for example if a family need to spend a prolonged period in a hospital setting perhaps far from their home.

No matter how well the professional is able to communicate the diagnosis or additional concerns in the case of a baby already diagnosed, at some point parents will find themselves alone, wondering and doubting and sometimes unable to remember what it was that the consultant had explained so clearly to them earlier that day (**FIGURE 2**). A call to the helpline will enable them to discuss their worries or arrange a time for the advisor to call them back. If appropriate and relevant there are also a number of other organisations

FIGURE 2 Playing the waiting game.
www.johnbirdsall.co.uk

which the advisor may direct parents to:

- BLISS – the charity supporting premature or sick babies (www.bliss.org.uk/)
- SOFT – a family support organisation for Trisomy 13/18 and related disorders (www.soft.org.uk)
- Baby Breathe Easy – a network of support groups for parents and carers of children from 0-5 years, who have recurring respiratory problems. www.lunguk.org/baby-breathe-easy.asp
- ACT – Association for children with life-threatening or terminal conditions and their families (www.act.org.uk)

Once there is a diagnosis or the professionals are able to say what they may be considering, parents can access the *Contact a Family Directory* for more information on their child's condition and for details of any national family support groups which may exist. Parents may decide that if their child's condition is rare (of the 15,000 babies born with a disability every year, 1,200 are diagnosed with a rare condition) they would find the support of other parents coping with a similar condition helpful. There are four ways in which they can make contact with others for mutual support and information, thus reducing the isolation so often experienced:

- Getting in touch with a national specific condition group
- Face to face in a local generic parents group
- Via the new web-based family linking service which allows parents to chat to other families across the UK and the rest of the world by email (www.makingcontact.org)
- Families who do not have access to the internet or find it difficult to pay the charge for the online service, can access it manually through the *Contact a Family* freephone helpline.

In addition to this support around the child's condition, there is also a network of Local Area Volunteer Representatives, (themselves all parents of a child with additional support needs) and Family Workers who can provide information and support at a more local level.

Some parents may prefer the medium of the printed word, in which case they are able to access *Contact a Family's* website (www.cafamily.org.uk) where they will find a wealth of factsheets. Much of this information is available not only in different formats, e.g. tape, but some can also be read in translated versions in several minority ethnic languages. It is important to remember that *Contact a Family* can reach out to families whose first language is not English, through the helpline which has access to interpreters in over 100 languages via Language Line.

In keeping with *Contact a Family's* commitment to supporting the whole family there are a range of factsheets focusing on specific family members, for example *Relationships, Grandparents and Siblings*. It pays to also check out the Dads' Zone which contains tips from other fathers on how they have coped, as well as useful links to other sites which may be of interest.

> "My questions were answered clearly and sympathetically … a very positive experience at the time as I was feeling very concerned. It was cheering to know that there is a support network available. My daughter doesn't feel the need for this at present, but in my efforts to support her I am grateful for possible backup."
>
> *Grandparent*

Parents and Paediatricians Together Project

The provision of information and the importance of good communication are both at the heart of this exciting three-year UK-wide project carried out in partnership with the RCPCH and funded by the Big Lottery. This work is coordinated and implemented by five paediatric project officers covering England, Wales, Scotland, Ireland and London. The roots of the Parents and Paediatricians Together (PPT) Project lie in three main areas:

- policy at government and health service level
- parents' views
- a perceived information gap

Government documents and NHS policy emphasise the responsibility of all healthcare professionals to ensure that families have adequate information about their child's condition and available services. This imperative, coupled with the results of *Contact a Family's* own family survey, where 90% of parents questioned stated they would like their health professional to give them more information and 84% would welcome the opportunity to become involved in the shaping and developing of child health services, has been one of the driving forces behind the project. The survey also revealed a gap in the number of families the organisation is able to help. It is estimated that 28,000 children are born or diagnosed each year with a disability. If *Contact a Family* only manages to reach around 20-30% then 70-80% or up to 22,000 families will have unclear sources of support and may not receive the right information at the time when they most need it.

The project's first aim is to try to close this gap by encouraging paediatricians and health professionals to put every parent whose child is born or diagnosed with a disability or rare disorder in touch with *Contact a Family* as a source of information and support. At this critical point in their lives, it will give every parent and family access to the advice, support and information they need to meet the challenges of looking after their disabled child, which will set them on a positive course for the future. Hopefully it will also mean that more families have a constructive experience of dealing with paediatric services.

Secondly, the project is designed to promote the participation agenda – or patient focus public involvement as it is sometimes known – by opening up new opportunities for parents of disabled children to influence paediatric and child health services across the UK, by creating new frameworks for cooperation between parents and paediatricians. The aim is to encourage a lot more families of disabled children to become directly involved in developing and influencing local child health services.

Supporting professionals

It is hoped that in the course of reading this article health professionals will have gained sufficient insight into the work of *Contact a Family* to encourage them to signpost parents and carers to the organisation, so that they can access the range of help and support they need.

In addition to encouraging healthcare professionals to put families in touch with the organisation, the PPT project aims to assist by providing a wide range of family-accessible information for display in units and clinics, e.g. helpline posters, helpline cards, leaflets (e.g. *Finding Medical Information on the Internet*), sample factsheets and of course the directory). A great deal of this is free or downloadable from the *Contact a Family* website. Some of the longer reports and studies, e.g. *Relationships – No Time for Us*, do carry a small charge and details of these are available from the publications list. Families, however, will not always pick up information from displays so personal recommendation from health professionals becomes extremely important. Parents in fact are found to prefer the personal, face-to-face setting when receiving information, but the extra responsibility this can place on professionals should never be underestimated.

In addition to providing information for health professionals to give to families, the organisation has a wealth of material specifically tailored to help the professionals in their supporting role. All of the resources mentioned above in the section on supporting families are also available for professionals to use. Thus the directory can provide an invaluable tool for checking out the patterns of inheritance or immunisation, for example, as well as providing essential medical information on conditions and associated national support groups.

It should be borne in mind that just as the helpline can be a lifeline for parents it is equally accessible to professionals and can for example enable them to access the additional database of 2000 +/- rare conditions lying behind the directory. In addition a parent advisor on the helpline team acts as a Welfare Rights Specialist who can be linked to families to answer queries about benefits.

Resources

Website

There is a dedicated page for professionals detailing the wealth of resources available and giving direct access to factsheets, reports and packs designed specifically for professionals.

Of specific interest in this setting are *Genetics, Living without a Diagnosis* and *Specific Disorders and your Child's Behaviour (A parent's guide to behavioural phenotypes)* and other publications on absolutely any aspect of caring for a child with a disability.

Packs

The *Support Pack for Health Professionals* is a resource intended for all health professionals working with families of disabled children including ultrasonographers, obstetricians, midwives, neonatologists, neonatal nurses, paediatricians, health visitors and specialist nurses. Its aim is to highlight parents' needs for accessible information and appropriate support at significant times from pregnancy to pre-school. All information is based on consultation with health professionals, parents and the voluntary sector and on current guidelines for good practice. It has already proved to be an invaluable resource for professionals working in the neonatal and early paediatric settings and contains the following 10 topics:

- Prenatal diagnosis
- Options following a prenatal diagnosis
- Death *in utero*
- Information sharing in neonatal units
- Care and support at home
- Hospital care – the role of the health visitor
- Referral to a genetics clinic
- Support for fathers, siblings and grand-parents
- Good practice in sharing news
- *Contact a Family* and other sources of information

It has recently been updated to include a section on the Early Support Programme in England and several relevant organisations in the other three nations.

New publication

Contact a Family has also recently published the *New Rare Eye Conditions Directory* which is modelled on the same high standards as the original one. The organisation places great importance on the provision of up-to-date accurate information and to this end each entry is either written or endorsed by a medical expert.

Conclusion

Care of a child affected by a chronic medical condition, rare disorder or other disability takes the combined efforts of all staff involved and not least the parents themselves with whom the day-to-day responsibility lies. Just as contact with other families in a similar situation can go a long way to alleviating feelings of isolation, so too can the availability of good quality relevant information and perhaps most important of all, the comfort afforded by an empathetic supportive professional.

Only by working in partnership can *Parents and Paediatricians Together* provide the best possible services for families and in the best possible interests of the children they care for.

Contact a Family

www.cafamily.org.uk
Freephone helpline 0808 808 3555
Mon-Fri 10am-4pm
Mon evening 7.30-9.30pm
Textphone 0808 808 3556
www.cafamily.org.uk/helpline.html