

Supporting parents who have a child with additional needs

When you have a child or children with additional needs, you have to look at life in a way you may not choose or want to accept.

Parents often tell us that they feel so alone, misunderstood and confused when they are presented with the diagnosis. However, if we do not find a way to look at our situation in a positive way, we are in danger of missing what we really have.



Understanding our emotions

As parents of a child or children with additional needs we go through a roller-coaster of emotions. We experience the feelings of shattered dreams for the child we hoped for, we experience the emotion of guilt; “is it my fault?”, “Could I have prevented this?”, “Have I sourced the best medical help?”

Then there is the feeling of helplessness; “Why can’t I make them better?” “Take away the pain?” “Stop the endless hospital procedures?” And there is also the feeling of: “I can’t cope anymore,” “Nobody understands the pain I am going through.” What you have to understand is that you are not alone, these emotions are normal, and you can have the means to share your feelings through the Care for the Family telephone support network.

Understanding acceptance

Rob Parsons, Care for the Family’s founder and Executive Chairman, regularly talks to parents about the joys and challenges of living with teenagers. Amongst his humour and many words of wisdom, one phrase in particular stands out:

“One of the greatest gifts we can give our children is acceptance.”

This is true for all our children, but when we first learn that our child has an additional need, it can be tempting to wish they were different and to want them to be like other children. It may take time to fully accept our child as he or she is. But when we do, we will hopefully find a **depth of relationship** that surprises us and helps us to gain a different perspective on life.

Acceptance tells our child that we love them for **who they are**, not what they achieve or how they look. They need to know that while we may not always like what they do, we still love them unconditionally and **accept them as they are**.

Shattered dreams: One father's story...

When we start a family, we have hopes and dreams for our child, and certain expectations of what family life will be like.

One father wrote to Care for the Family about life with his 11-year-old autistic son and 8-year-old daughter with galactosaemia (an eating disorder). He wrote of struggles he and his wife have faced and their shattered dreams as a family.

Here are some of the questions they asked themselves, and some of the thoughts they've had about their particular situation...

"Why do both our children have something wrong with them?"

"Although we were unaware that we were both carriers of our daughter's genetic disorder, we feel in some way 'responsible' for her condition."

"When your children are born you have some expectations for them in terms of schooling, work and perhaps starting their own family in time. At the

moment, we certainly have to consider 'another way' because our son can barely read; we cannot let him play outside by himself (he wanders off, has hit people and others may take advantage of him); employment prospects are limited; and he may never be able to live independently. We have yet to tell our daughter that it is unlikely that she will be able to have children."

"We face criticism from people, either for not disciplining our son (yes, he is naughty, but sometimes he's just distressed/confused), or for being 'picky' about our daughter's food (but it is vital that we keep to her diet)."

"Situations like this put marriages under a lot of stress."

"One child's disability has an impact on the other child, limiting where you can go and things you can do as a family."

"We accept that there are no answers, but we are grateful to friends, Social Services, and organisations like Care for the Family for offering support and understanding."

How to VALUE your child

Here are some great ideas to help you let **all** your children know how much you value them. When so much of our time and energy is spent looking after our child with special needs, it is perhaps especially important to ensure that our other children also know that they are precious and accepted.

Validate them. Children can tell whether you think they're important or not by how seriously you take them. If they come to you with a problem, give them your full attention while they talk to you, no matter how small you think the problem is. Pay particular attention - and listen carefully - to your other children's concerns about their brother or sister who has special needs.

Avoid comparisons. Don't compare your child to their friends or siblings. It can undermine their confidence and knock their self-esteem. Instead, affirm something that is unique about them.

Listen to them. Remember to look at your child while they talk - listen with your eyes. Give them your full attention.

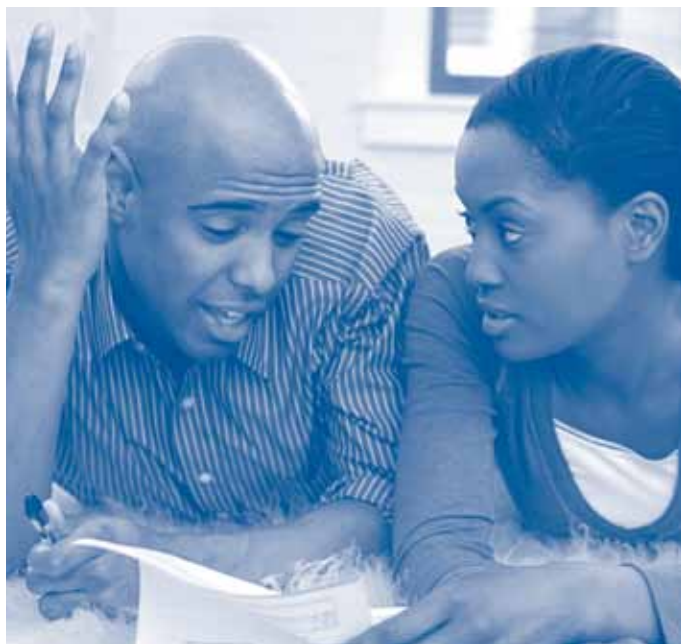
Understand the power of praise. Catch your child doing something right - and tell them. To a child, praise can be like rain in a desert.

Enter into their world. Spending time with a child tells them you value them. Join in their games. Talk about what interests them. Watch their choice of TV shows together.



Understanding the pressures on couple relationships

Having a child or children with additional needs can put tremendous pressure on parents' relationship with one another. Sometimes one partner will go into denial, then sometimes the relationship breaks down because they feel they cannot share their feelings, or even begin to blame their partner for their child's condition.



Justine Devenney, the Head of Policy and Dissemination at One Plus One, a leading UK relationship research charity, shares the results of some of their research into couple relationships for the website Thecoupleconnection.net:

“One of our target audiences was parents of disabled children. Back in 2008, One Plus One had just published a literature review entitled ‘Growing together or drifting apart? Children with disabilities and their parents’ relationship’ (Glenn, 2007) which found that couples caring for a child with a disability were at a greater risk of relationship problems and divorce.

Moreover a growing body of research evidence shows that a child's behaviour can be affected by the way their parents relate to each other.

Parents caring for a child with a disability face a number of pressures. These include: managing traditional gender roles; lack of time for one another; dealing with the grief over the loss of the ‘hoped’ for child; adjusting to changes associated with the child's growing up; and significant financial pressures.

Our review found that a really important factor in dealing with these various pressures was the couple's **coping style** – *the way a couple supports each other as well as their ability to handle the pressures and circumstances of parenting.*”

For more information on One Plus One or to find out how you can be helped in your relationship, visit www.thecoupleconnection.net

Where to go for help

Care for the Family's parent support for additional needs:

If you're in a relationship it can be helpful to share your feelings with your partner. If you find this too difficult, or you are a single parent and do not have anyone to talk to, then remember **we are here for you**. **Care for the Family** provides a telephone befriending service for parents who have a child with additional needs.

If you would like to talk to someone who understands your situation, please call **(029) 2081 0800** and we will put you in touch with one of our befrienders. Befrienders are not counsellors, but will informally share from their own personal experience of being part of a family where someone has additional needs.

Other places to find help:

When your child is diagnosed with an additional need, you may have questions about their condition. There is a whole range of organisations that you can contact to source the best answers to your particular questions.

Here are some suggestions that you might find helpful:

Contact the organisation that is specific to your child's condition for example:

National Autistic Society (www.autism.org.uk)

ME Association (www.meassociation.org.uk)

Cerebra (www.cerebra.org.uk)

Contact your local *Citizen Advice Bureau* for help about benefits. Web: www.citizensadvice.org.uk

Contact a Family is a nationwide organization that offers help with financial issues.

Web: www.cafamily.org.uk

Tel: 0808 808 3555

Through the Roof is a charity that helps churches to be more user friendly towards those with additional needs.

Web: www.throughtheroof.org

Tel: 01372 749955