



Relationships and caring for a disabled child

Information for families

UK

Incorporating **The Lady Hoare Trust**

Introduction

Relationships matter. When they work well, they are a vital source of support and protection against life's stresses and strains. All relationships go through periods of change and challenge. Parents caring for a disabled child have to adjust to new roles, and may have different expectations about their child. They also have to cope with significant emotional, social, physical and financial pressures. Many parents find these experiences bring them closer together and make their relationship stronger, as in the case of some of the parents who feature in our report *What makes my family stronger* (Contact, 2009).

"Neither my husband nor I can imagine life without the other – neither of us could cope with the children without the other's help. There is a bond between us that can never be shared by anyone else."

Some couples, though, are overwhelmed by the experience and struggle to stay together. This guide offers information and ideas to parents of disabled children to help looking after their family relationships. The original guide was developed with help from over 2,000 parents who took part in a survey about how their relationship has been affected by caring for a disabled child, and One Plus One, the UK's leading relationships research charity and creators of thecoupleconnection.net.

Contents

Background to this guide.....	4
Looking after your relationship	6
Recognising each other's role and ways of coping	7
Intimacy.....	8
Building for the future.....	8
Managing differences.....	9
Children and conflict.....	11
Relationship advice and counselling.....	12
Domestic violence.....	13
The whole family	14
Networks of support.....	15
Relationships under pressure.....	18
If things break down.....	23
Relationship breakdown and the law.....	24
Useful resources	26
Useful organisations	27



Background to this guide

Contact's survey of over 2,000 parents asked them how caring for a disabled child had affected their relationship with their partner. Parents in all sorts of circumstances responded: mums and dads in relationships; those caring alone or who had formed a new relationship, and gay and lesbian couples with children. One Plus One also published a report, *Growing Together or Drifting Apart? Children with disabilities and their parents' relationship*. The Report was based on research into what parent carers of disabled children need to help them support family relationships.

What parents said

Parents who responded to our survey described feelings of isolation; struggling to come to terms with the news of a child's disability; a lack of time for themselves and each other; problems balancing work and caring; increased financial worries; a lack of support and

understanding from professionals and the wider family network; a lack of suitable services and having to fight for those that are available.

"Any difficulties between my husband and I are exacerbated by the additional stress and time lost to caring for a disabled child. Neither of us gets enough time and attention for us as individuals and neither of us has the capacity to give more to the other. There is a great deal of resentment. He resents that I don't spend as much time with our disabled child as he does, and I resent that he doesn't recognise the colossal effort I put into co-ordinating schedules, visiting school and fighting continuous battles to get what our son needs."

Ultimately, for some couples, such challenges were a huge factor in a relationship coming to an end.

"The break up of my marriage was as a direct result of giving birth to a disabled child. But I consider this to have been a good thing in the long run. In my view a disabled child in the family strengthens a good marriage but shows up flaws in a way nothing else would in a bad marriage."

Pressures on parents' relationships

The research review conducted by One Plus One into the relationship of couples caring for a disabled child brought together the range of evidence available on the subject.

Looking at the survey results, it was found that couples caring for a child with a disability are at greater risk of relationship issues leading to separation.

In my view, having a disabled child in the family strengthens a good marriage but shows up flaws in a way nothing else would in a bad marriage."

It recorded the pressures that can overwhelm parents' relationships, including: heterosexual couples adapting to traditional gender roles; lack of time for one another; dealing with the grief over the loss of the 'hoped' for baby; adjusting to changes associated with the child's growing up; and significant additional financial pressures.

One important factor is how different coping styles affects parents' ability to draw support from one another and handle the pressures and circumstances of caring responsibilities. The research showed that supportive couples protect one another from the stresses and risk of depression associated with caring for a disabled child.

You can download a copy of the report, *Growing together or drifting apart*, at www.oneplusone.org.uk

Why relationships matter

It is hard to underestimate how important relationships are. When a relationship is working well, it can make you feel happy, safe and secure. It can also protect you from some of the stresses of caring for

a disabled child, including the risk of depression. In fact, research shows that a supportive relationship is an important part of keeping us healthy and may reduce the chances of developing poor physical and mental health.

Children also benefit when parents get on well. They are likely to feel more secure, do better at school, and are less likely to develop additional emotional or behavioural problems. Disabled children with high care needs do better when their parents get on because their parents are more able to focus on their care.

This guide

If you are experiencing issues with your partner, hopefully this guide will help you to strengthen and build your relationship and help you find support,



Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**



if you need it. Many of the tips and suggestions in this guide have been put together from what parents with disabled children have told us.

Looking after your relationship

All relationships go through good times and bad times. Managing the bad times well is an important part of creating a strong, lasting relationship. The next section looks at things you can do. You can find more information about managing life as a couple and as parents on One Plus One's dedicated website <http://thecoupleconnection.net>

Talking and listening

Your relationship relies on each of you knowing how the other feels, which means taking time to talk about feelings, thoughts, concerns, hopes and needs.

Each of you needs to know the other has heard them. That means really listening to each other – listening to the words and understanding the feelings that underlie them.

"Keeping talking to each other and not bottling up our feelings – being truthful about what we really think about our situation."

When your partner shares their feelings with you, don't judge them, do listen and try to understand. Recognise your differences. Try not to make assumptions about what your partner is thinking and try and be as open with your partner as you can be. Look at where you might be able to make changes that might make things better. Keep communicating!

Saying it well

Research has found that the way you express your feelings is very important. Couples who avoid saying every critical thought and who can raise problems gently are consistently the happiest. When there are potential disagreements,

Your relationship relies on each of you knowing how the other feels, which means taking time to talk about feelings, thoughts, concerns, hopes and needs.

When your partner shares their feelings with you, don't judge them, do listen and try to understand. Recognise your differences.

you're more likely to see eye to eye if you pause a moment and resist going on the attack straight away. But try not to bottle up feelings; you will probably end up feeling resentful and explode when you reach the 'last straw'.

Recognising each other's role and ways of coping

Sharing the care

Research shows that, in couples, mothers often take on the main responsibility for a child's physical and home care. Heterosexual couples can find themselves in relationships divided along traditional roles where they had previously shared breadwinner and home-maker responsibilities. Many couples are happy with this division of labour, but it can cause tensions for some. One way to avoid these tensions is to recognise each other's contributions. If you are out at work all day, you can help your partner by showing an interest in, and an understanding of, their work at home.

If there is conflict over who does what, find ways to share the work – avoid nagging people to do jobs, instead make

sharing tasks part of everyone's daily routine, adults and children.

Make arrangements to cope with the practical aspects of your family's daily life, troubleshoot problems in advance – this will help keep some of the pressures and stresses off your relationship.

Think about how you both cope with problems

Recognise that you may have different coping styles. Some people cope by focusing on a problem and finding solutions or strategies to improve the situation. Other people focus on finding ways to feel better about a situation by reinterpreting it, distancing themselves, or even denying or avoiding it. Partners can find these differences frustrating. Recognising and acknowledging feelings is important. Finding ways to reduce stress, and focussing on how to improve the problems you face is likely to bring long term gains for both of you.



Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Talking to other parents caring for a child with the same condition can help. Sharing practical solutions to shared experiences is a valuable source of support that many parents get from talking to others who've been there too (see 'Contact with other parents' on page 17 for more information about the different ways this is possible).

Intimacy

Touch is important and caring gestures keep you close as a couple. Touch on a daily basis – a squeeze of the arm, a touch on the shoulder, a kiss.

Sex is an important part of a relationship – but tiredness, or complete exhaustion, will take its toll. This is a common experience for parents, especially those caring for young or disabled children. Stress or worry can also affect your sex drive. Talk through your needs and agree on how you want your sex life to be. Remember your needs from sex might be different from your partner; women often want to be sexual when they feel desired and safe, men may want sex to feel loved and intimate. Many couples also have sex less frequently after they have been together a while, but this does not mean they are not happy with their sexual relationship.

"I found it helpful to meet with and talk to other mums in the same situation – finding their sex lives are also non-existent due to sleep problems!"

Lots of people find problems with sex don't last long. Where a problem does last then speaking with a relationship counsellor can help. See 'Relationship



information and support' in the 'Useful organisations' section on page 30 for more information.

Building for the future

Making time

It sounds strange, but your relationship will benefit if you each set some time aside for yourself. This is not an indulgent luxury but valuable time to recharge your batteries. Let others know when your time is – it might be a long bath, or out walking the dog.

Set aside time as a couple, too. You don't have to go out, it might be one evening a week when the children are in bed – but agree in advance you will spend the time together, not doing jobs. If this sounds impossible then it is probably most important of all! Also, be sure you've explored all opportunities for help and services that would make finding time for

you and your relationship possible. See the box 'Getting a break' on page 16 for more information on this sort of practical help.

Managing differences

When we choose a partner, we are attracted both by their similarities to us and by their differences. Similarity means we can share interests for the future and understand where each other is coming from. Differences can be exciting and bring new things to the relationship. But differences can also become troubling. Discussing difficulties and differences is

Set aside time as a couple. You don't have to go out but agree in advance you will spend the time together, not doing jobs.

Digging deeper

Just as each of you needs looking after, so does your relationship. These are some ideas for how you might build up your relationship. See what might work for you. If you find it difficult to express yourself to your partner you could think about inviting a trusted friend or professional to talk with you both.

- Spend some time thinking about your expectations and how things have turned out. For most people, life will not be as they imagined. What about the future? Share your expectations and hopes and dreams.
- Think about when you first met. What attracted you to each other? Hold on to those memories. And reinforce them – remember good

times – moving in together, holidays, family events, nights out together. Remember the warmth, the fun, the closeness.

- Each of you will be under pressure, but are there small ways you can show support for one another – emotionally or physically? Often just a small change can make a big difference.
- Try and think the best of one another – grant each other the benefit of the doubt wherever possible.
- Seek out support wherever you can. When parents are coping with the care of a disabled child as well as the financial and other pressures that go with it, they need as much support as they can find.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

an important element of managing them, especially when they stir up difficult and sometimes hard-to-understand feelings.

The same old arguments?

For many couples, the same arguments keep cropping up again and again. If this is happening to you and your partner, try to keep a sense of humour and to try and work out a way of dealing with it. If you often end up in a slanging match, at least agree to put the subject on hold for the time being and discuss it another time.

Rows can be a sign that we feel our partner isn't supporting us, or that they're not 'there for us'. But arguing is a form of communication. People who are good communicators are often good at

Discussing difficulties and differences is an important element of managing them, especially when they stir up difficult and hard to understand feelings.

managing their differences. If you aren't good at managing your differences, try to understand the emotions underneath.



If you and your partner often share affection, warmth, and humour, then you will be able to handle your disagreements more easily when you fall out. So too can thinking the best of our partner and looking for the positive things about our relationship.

Children and conflict

Your relationship and parenting

How we get on with each other not only affects us and our relationships, it affects

how we parent. Fathers sometimes find it more difficult to be involved in parenting when they are not getting on well with their partner. Mothers can feel unsupported and become critical of the care a father offers, causing him to withdraw even further.

Difficulties between partners can leave children feeling vulnerable and anxious, which can result in the child developing behaviour that challenges. In turn, children's difficult behaviour can put an

Tips for managing differences

Most couples argue and it is normal not to agree on everything. Be prepared to compromise – you want a win-win situation for both partners – not one the victor and one the loser.

Set aside time to talk about a disagreement or conflict. Give each other 10 to 15 minutes to explain the point without interruptions and without criticism. If you get worked up and can't see a way of sorting something out, why not agree to disagree? Set aside some time later (and a time limit) to explore what you can't agree on.

Remember that what a row seems to be about is often not the real, underlying cause. Try to work out the real reason for the upset and address

what, if anything, can be done to change it.

Judging, accusing and criticising are damaging to a relationship and you'll have to work hard to put things right if rows become damaging or acrimonious.

Try not to drag out old disputes or argue a point for longer than is necessary. A good rule is to keep it to under an hour, agreeing to talk at another time if the issue remains unresolved.

Try not to argue after drinking or act aggressively or shout. And always stop arguing and go to a separate place if it appears to either of you that an argument may escalate into violence.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

even greater strain on the relationship between parents. Be wary of falling into unhappy cycles of criticism and withdrawal. If you feel stuck, look at some of the tips in this guide, or look to get some outside help.

Relationship advice and counselling

"In the end, a local charity provided us with counselling and I'm sure that is the main reason we are still together as a family."

You might consider talking to a relationship counsellor – they will explore

Children and conflict

Children can be particularly troubled when you are shouting a lot, when you show real contempt for your partner, when things are left unresolved, when there is a strained atmosphere, or where arguments involve the children. Children's behaviour might become challenging, and they might become withdrawn and depressed. You can help by bearing in mind some of these suggestions.

- Children are sensitive to an atmosphere and know when things are not right. Research has shown that even infants under one are troubled by unhealthy parental conflict.
- If you do find yourself caught up in an argument in front of the children, try and make sure they also see you making up, and, if possible, resolving the problem. The humour, apologies and understanding that can come at the end of an argument provide a helpful model that children can use in their own lives. If children don't see things resolved or if arguments don't end smoothly, let them know that you made things up with your partner and everything is ok.
- Reassure children that they aren't to blame for an argument.
- Don't try and get children to take sides, and don't lavish lots of attention on them because things with your partner aren't working out well. Instead, take time to listen to what they are thinking and help them to explain how they are feeling.
- If possible, stay united with your partner on discipline.
- If you and your partner are going through a bad patch be sensitive to any changes in your child's behaviour. Have they become more withdrawn, started acting up, or are finding it hard to settle in school?
- Think about how you argue and what you argue about. Choose a good time to talk, not when your partner has just walked through the door or when one of you is in the middle of something.
- If conflict feels like a serious problem consider seeking outside help.

with you the issues in your relationship and help you make changes. You will have regular sessions that can be face-to-face or by telephone. The counsellor will listen to both of you, and will not take sides. The counsellor will respect your ideas about your relationship, as well as suggesting some others.

Whether you are married, living together, straight or gay, separated, divorced or single, relationship counselling can help you to deal with your relationship difficulties. For details of counselling services in your area, ring the Contact freephone helpline on 0808 808 3555.

Domestic violence

In our survey, around one in 10 parent carers said that they had experienced domestic violence since having a disabled child. The survey does not tell us the identity of the victim or abuser, or whether the violence involved the birth parents, an adopted family, or others. However, crime statistics do tell us that in the overwhelming majority of cases, the victims of domestic violence are women. Sometimes violence is also directed towards children, other family members and friends.

If you are worried about your relationship, there are many websites where you can find advice, for example, www.relate.org.uk, www.oneplusone.org.uk and www.marriagecare.org.uk

Recognising an abusive relationship

Women, especially, may be subject to a wide range of manipulative and controlling behaviours by a partner. Research and experience suggests complex patterns of domestic abuse including 'situational violence', where people respond violently to stressful situations, and where there is no controlling behaviour taking place by either partner in the relationship.¹ These incidents of violence can be very infrequent or happen just once.

Every situation and every relationship is unique. The organisation Women's Aid produces some very helpful information about different behaviours to help you recognise if you, or someone you know, are in an abusive relationship. This includes examples of physical violence (punching, slapping, hitting, biting, pinching, kicking, pulling hair out, pushing, shoving, burning, strangling, raping) and verbal abuse (shouting, mocking, accusing, name calling, verbally threatening).

We have included some helplines and support services on pages 28-29 which you may find helpful if you are experiencing or at risk of domestic violence.

Refuges

A refuge is a safe house where women who are experiencing domestic abuse can live free from violence. If you have children, you can take them with you. Refuge addresses are confidential.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Some refugees are specifically for women from particular ethnic or cultural backgrounds, for example Black, Asian or South American women. Some refugees have disabled access and workers who can assist women and children who have additional needs.

Men who are victims of domestic violence

If you are a man who is experiencing domestic violence you may feel as if you're the only one in this situation, but you're not alone. It may be hard to admit to yourself and to others that this is happening to you but it's not your fault and you can get help.

Men have exactly the same rights as women to be safe in their own homes. All statutory services (such as the Police, housing department and social services), have a duty to provide services to all – male or female. Local and emergency numbers will be in your local telephone directory. Also, many local support organisations provide services for both men and women who have been affected by domestic violence. For details of local support organisations ring the Contact helpline. There are more contact details for support services at the back of this guide.

The whole family

As well as setting time aside to spend as a couple, also set time aside to spend as a family with activities for all. What children most want from their parents is their time – and this can be in short supply! Make sure you set time aside to

spend with all your children – everyone will benefit.

For information about leisure activities, call our freephone helpline and ask for a copy of our guide *Holidays, play and leisure* and details of local information services.

Siblings

Here are just a few tips from other parents on dealing with common issues around siblings of disabled children:

- **Limited time and attention for other children?** Protect time to spend with siblings, for example, bedtime, or an outing once a month. Organise short-term care for important events, such as sports days. Put the needs of siblings first sometimes and let them choose what to do.
- **Why them and not me?** Emphasise that no-one is to blame for their brother's or sister's condition. Encourage siblings to see their brother or sister as a person with similarities and differences to themselves.
- **Worry about bringing friends home?** Talk over how to explain a brother's or sister's condition to friends. Occasionally, invite friends round when the disabled child is away and don't expect siblings to always include the disabled child in their play or activities.
- **Stressful situations at home?** Encourage siblings to develop their own social life. A lock on a bedroom door or cupboard can ensure privacy and avoid possessions being damaged. Get

professional advice about caring tasks and handling difficult behaviour in which siblings can be included. Try to keep the family's sense of humour.

- **Restrictions on family activities?** Try to find family activities that everyone can enjoy; for example, swimming, picnics. See if there are holiday schemes the sibling or disabled child can take part in, and use help from family or friends with the disabled child or siblings.
- **Guilt about being angry with a disabled brother or sister?** Make it clear that it's all right to be angry sometimes – strong feelings are part of any close relationship. Share some of your own mixed feelings at times. Sometimes siblings may want to talk to someone outside the family.
- **Embarrassment about a brother or sister in public?** Realise that all relatives can be embarrassing, especially parents. Find social situations where the whole family is accepted. If old enough, split up for a while when out together.

Contact also publishes a *Siblings* guide you can download from our website, or call our freephone helpline for a copy.

Networks of support

The extended family

Support and understanding from other family members can be a lifeline for some parents during difficult periods. Practical support can create time to be together or take time apart. Emotional support can help you feel understood and more able to cope.

"Having a supportive extended family nearby [helped our relationship]. When our child was younger, we would only leave him with close family members who understood his needs."

For some parents the wider family network, especially grandparents, can be a huge source of practical help. But many parents feel disappointed by the support they receive from grandparents or others. Sometimes it tails off, or they are simply not supportive.

Here are some quotes from grandparents, describing their feelings when they heard the news that their grandchild had a disability:

"It was hard coping and fighting, if only I was ten years younger."



Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Getting a break

Practical services might be available to give you the chance of a real break and to make time for you and your relationship. 'Short breaks' (previously called 'respite care') is the term used to describe any service provided by your local authority, or a voluntary agency, which ensures a disabled child or adult is cared for while the main carer has a break. This may, for example, include regular overnight stays with another family, (sometimes known as 'family linking schemes').

Most breaks are arranged by social services – the department within your

local authority, which is responsible for providing help to meet the needs of disabled children and adults. Usually, social services will need to assess your child and the family's needs before services can be arranged but getting a break can prove to be a lifeline for some relationships.

For more information about getting a break, call our freephone helpline on 0808 808 3555 and ask for a copy of our guide *Disabled Children's Services* (England) or *Disabled Children's Services* (Scotland).

"Hard to know how to support my daughter and husband – tried to give them space."

"It was a double whammy – concerned for the child's parents but also worried about the child."

As some of these quotes suggest, it isn't always easy for family members to know what to do or when to step in and offer help. Sometimes, it may feel like you need to support them. At times you may not share the same views on parenting or sensitive issues like growing up and disability.

"It's not worth letting her spend a night at her grandmother's, because she changes the sleep pattern and it takes us up to five days to get her back the way she needs to be."

A consistent approach is often very important, particularly for children with learning disabilities or behavioural problems. This doesn't have to mean that other family members can't contribute, even if only in small ways. Don't wait until help is offered – ask, and be specific about what would help you.

If your relationship with your own parents has always been difficult, having a disabled child is unlikely to improve it. Families also told us that there are times when they have been hurt by extended family and friends' words and behaviour, even if it was unintended.

"The grandparents have their other grandchildren to stay but we are avoided and not invited to family get-togethers."

The key might be in honest and open discussion with your parents about the

issues. Our guide *Grandparents* goes into more depth on this subject.

Contact with other parents

Almost invariably, parents of disabled children say that at one time or another they have experienced feelings of isolation. Some parents find it helpful to chat to other parents who have gone through similar experiences. Many medical conditions that affect children (including some very rare ones) have a national support group, usually run by parents of a child with the condition. They are an invaluable source of support and advice, especially when it feels as if nobody else understands what you're going through.

Sometimes there won't be a support group for your child's specific condition, but there will often be a local support group for parents of children with any kind of disability. You'll meet other parents who have experienced the same feelings of isolation that you have and



Support and understanding from other family members can be a lifeline for some parents during difficult periods.

who understand the strains that having a disabled child can put on relationships.

Call our helpline for details of national and local support groups for families caring for a disabled child. If your child has a rare condition for which there is no existing network of parents, our helpline will try to link you on a one-to-one basis with other parents caring for a child with the same condition. If you have access to the internet you may wish to visit www.makingcontact.org – our free online linking scheme.

For many couples, the initial period when their child has just been diagnosed with a disability is the most trying time of all. To reduce the uncertainty and fear of the unknown, try and find out as much information as possible about your child's condition and share what you learn with each other. Get as much support as you can from all the sources mentioned above, and from the healthcare team looking after your child. Sometimes just

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

getting a firm diagnosis can take a long time, but don't let that stop you seeking help in the meantime.

Relationships under pressure

Parents in our survey identified particular issues that put them and their relationship under pressure. All families struggle with these issues at different phases in their lives, but families caring for a disabled child have an extra dose of these concerns.

Financial worries

In any relationship, money worries can be a huge problem. The additional costs of caring for a disabled child, perhaps having given up work too, for many parents means an extra strain on a relationship.

"It is still difficult with hospital costs, our son has had many operations so my husband has had much unpaid leave."

"Money is a continuous worry and this puts us under added strain."

Making sure you claim all the benefits you are entitled to can help ease some of the other pressures on family life. We produce a range of guides on benefits and grants, including our general guide to benefits, our tax credits guide and a guide to benefits for young disabled people turning 16. For detailed advice, phone our free helpline on 0808 808 3555. We have a welfare rights specialist who can advise on any aspect of claiming benefits and tax credits. Our helpline can also tell you about charitable

trusts that may offer some financial assistance.

Behaviour that challenges

Many parents whose children have behaviour issues linked to their medical condition talk of the frustration and hurt they feel when friends, teachers, health care professionals and others dismiss their child as simply being badly behaved, or imply that their child's behaviour is due to bad parenting.

"My Dad thought our child was just naughty and we argued over this."

If you're already feeling vulnerable, it's all too easy to be affected other people's criticisms, and to take out your feelings on to your partner. It is helpful if you can recognise when this is happening, and avoid blaming each other. Remind yourselves that you're in this together. Research shows that where parents can take a positive attitude towards their child's disability and work together in dealing with behaviour that challenges, children's behaviour often becomes less challenging.

Even if your anxieties do not turn to blame, dealing with behaviour that challenges places a real strain on you and your relationship. It might help to avoid criticising one another's handling of your child's behaviour and to be supportive of the main carer, where one of you has taken on that role.

Understanding your child's behaviour, Contact's practical guide, includes sources of specialist information, advice and support. Parents can call our freephone



helpline and we will send you a copy.

Some parents find parenting programmes a helpful source of support and information. To find out more, talk to your health visitor, local children's centre. You can also call our freephone helpline on 0808 808 3555.

It is also worth addressing any problems – particularly if you and your partner are rowing a lot and there is unresolved conflict in the relationship – as children may become troubled, and develop behaviour that challenges, as a response.

The work, care, life balance

For some of the parents who took part in our survey, being able to go to work was also a major boost to the relationship they had with their partner. Working can be a break from the family, give you outside interests, other friendships, increased personal confidence, and the opportunity to talk about different experiences with your partner beyond the

day-to-day family issues.

For a few, balancing work with the responsibilities of caring for children and running a family home left them with no free time to devote to themselves or their relationship, or simply too exhausted to enjoy any free time they might have. This may be particularly difficult during school holidays when children are at home full-time.

"For thirteen years we have had disturbed and relatively little sleep. Our eldest, fortunately still small in stature, spends half the night in between us in our bed or she doesn't go back to sleep when she wakes at 2am. During holidays, I am accustomed to taking the children out during the day and then working in the office all night when [my

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

partner] gets home. By the end of a school holiday, I am completely zombie-like with no chance to recover."

Parents have told us the main obstacles to working include the unpredictable nature of some conditions, difficulties getting time off for hospital appointments, a lack of understanding from employers and problems finding suitable childcare.

We know from listening to parents that sometimes a working parent feels excluded from daytime appointments and unable to provide support to a partner who cares full time, while a parent left at home may feel resentful and isolated. However, working can be essential to minimise a family's financial difficulties.

"My wife is there at meetings and appointments and makes all the decisions. Then, because of work, I am accused of not being there to help make the decisions."



"I come home tired. Then I have to face caring and I have a stressed partner to deal with."

Employment rights

As a working parent, you may have a legal right to request time off in certain circumstances. You may also be able to ask for a change to your working week to help you juggle your work and caring responsibilities. Such rights may enable working parents of disabled children to have more time to spend with their children and each other. These employment rights include:

- the right to ask to work flexibly
- parental leave
- time off for emergencies relating to a dependant
- paternity leave.

See our *Fathers* guide (pages 11–14) for more on employment rights, including paternity leave, parental leave, adoption leave.

Roles and relationships in the family may change over time and parents who had stopped working may want to return to work. Call our freephone helpline on 0808 808 3555 for more information on employment rights and benefits available to make the transition back into work.

Childcare and other care for children

Despite local authorities having a responsibility to ensure the provision of good quality childcare, many families caring for a disabled child still struggle to find appropriate childcare.

In England, Wales and Scotland help with finding suitable childcare can be obtained from the National Association of Family

Sometimes a working parent feels excluded from daytime appointments, while a parent left at home may feel resentful and isolated.

Information Services,
www.daycaretrust.org.uk/nafis

In Northern Ireland, families can call Employers for Childcare for advice on 0800 028 6538.

In certain circumstances it may be possible to get help with childcare costs via working tax credits. For further information telephone the Contact helpline.

Across the UK, it may be possible to use direct payments to arrange childcare. Through the direct payments scheme, local authorities can give cash payments rather than a service. For example, this can enable working parents to employ someone to look after a child after school. Direct payments can even be used to pay a close relative, although only in exceptional circumstances if they share your household. In Scotland payments to close relatives are only considered in exceptional circumstances even if they live elsewhere. Using direct payments in this way can be a way of receiving and acknowledging help given by someone who has a close relationship with you and

your child. Our guide on direct payments has more detailed information.

Coping with stress

Stress affects millions of people in the UK every year. It can be brought about by major life events like moving house or bereavement, or by a stream of less serious difficulties, such as the day-to-day pressures of bringing up a child. For parents of a disabled child, there are the additional pressures – the constant battle for services, attending meeting after meeting, or the struggle to meet extra financial costs.

Problems in your relationship can also create stress-related health problems. Experiencing stress for short bursts is a healthy way to respond to difficult situations but excessive or prolonged stress can cause illness. You might experience physical symptoms – headaches, nausea, indigestion, palpitations, and/or perspire more.

Stress might encourage feelings of anxiety, fear, anger, frustration, and depression. You may find your behaviour changes too – perhaps you are more irritable or tearful, affecting how you interact with others (including your partner), and it may interfere with your sleep patterns or sex life.

The vast majority of parents caring for a disabled child experience periods of stress or depression at some time or

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

another. Most link this directly to the additional pressures of caring for a disabled child.

"It's not because the child is disturbing you, but what goes on inside your head. You worry about the future."

How a couple copes with a very difficult time in their lives is often seen as an important factor in determining how a relationship develops. It can make a relationship stronger, bringing a couple closer together.

For those couples who don't cope well during stressful times, it can have a negative impact on their relationship. For some who took part in our survey it played a significant part in their relationship coming to an end.

Stress affects millions of people in the UK every year. It can be brought about by major life events like moving house or bereavement, or by a stream of less serious difficulties, such as the day-to-day pressures of bringing up a child.

"It would have helped if I hadn't been so depressed when I first had my child. If I'd been as strong and coped like I do now, I probably wouldn't be on my own with my son now. It could have helped if I'd listened to my ex partner more but at the time I was too stressed and depressed."

"Any difficulties between my husband and I are exacerbated by the additional stress and time lost to caring for a disabled child."

A number of organisations produce a range of helpful information on coping with stress, feelings of anxiety and depression. There are contact details for some of them at the end of this guide.

Alcohol and drug abuse

People use drugs for a variety of reasons, but for most it is about changing the way they feel. It might be to feel relaxed, to forget about problems, to increase self confidence, or simply to feel good. It may involve taking illegal drugs or abusing legal drugs such as prescription medications or alcohol. Using drugs in this way can become harmful, for example when it begins to affect a person's ability to cope with difficult situations, causes damage to their health, or leads to destructive behaviour which affects the individual and their relationships with those close to them.

If you are worried that you or your partner may have an alcohol or drug related problem you can discuss this with your GP. Also, there are a number of organisations that may be able to help and some are listed at the end of this guide.

Housing

Unsuitable or inadequate housing can have a huge impact on all aspects of family life, and will often put a considerable strain on personal relationships within the household. For advice about any kind of housing problem, look at the back of this guide for places to contact.

For information about getting help to adapt your home to meet the needs of a disabled person ring the Contact helpline for a free copy of the guide *Aids, equipment and adaptations*.

If things break down

This section looks at some of the legal and practical issues that parents may face if their relationship breaks down and one partner moves out of the family home.

Maintaining contact with children

No longer living under the same roof as your children will inevitably affect the level of contact you have with them and it will usually be necessary to agree contact arrangements with your former partner. Legally, a person with parental responsibility cannot be denied contact with their child without the intervention of the courts. Of course, it will usually be best if both parents can discuss and agree appropriate arrangements informally.

Perhaps a trial period can be agreed and the arrangements reconsidered at a later date. Where an agreement can't be made, it may be necessary to consider professional family mediation, (see page 24), and getting legal advice. Children generally find it helpful to say what

arrangements they would like to be in place, whilst being reassured that they are not responsible for making final decisions or having to choose between parents.

Communicating with your ex

For some parents, having to maintain contact with one another and sort out arrangements for the children can be a huge strain. These are some tips to help you communicate with your ex and protect your children from any fallout from the separation:

- avoid blaming yourself or your partner
- agree not to let your own relationship issues get into the discussion
- create some rules together about how best to manage meetings
- continue at another time if you feel discussions sliding into tricky waters
- don't communicate with your partner through your child
- focus on child-related issues; it can help keep your dialogue clear and to the point
- work on a parenting plan together
- don't argue with your partner about the children in front of them. This will only increase their sense of guilt and blame about the break up.

Family mediation

Family mediation services help any couple separating or divorcing/dissolving to resolve disputes and reach their own decisions on specific issues, particularly matters involving the children of a relationship. They can also help with disputes around finance and property.

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

Although often helpful, mediation is not a substitute for legal advice. Services vary from area to area and there may be a fee (although legal aid might be available). Information about family mediators is available from the United Kingdom College of Family Mediators (see page 28).

Relationship breakdown and the law

Parents who were cohabiting, or are married but do not wish to formally end the relationship, including civil partners, might need legal advice if no agreement can be reached on issues concerning children, property and money. There are several ways to end a marriage legally, the most common being divorce. If both

parties agree to divorce (that is, it is 'undefended'), a solicitor will not usually be needed and a local Citizens Advice Bureau (CAB) should be able to help with the petition. If a divorce is contested, or there are other issues in dispute concerning children, money or property, then it will be necessary to consult a solicitor. The same applies to civil partners wishing to formally end their relationship (this is sometimes called 'dissolution' rather than 'divorce').

A local CAB should be able to help you locate a solicitor in your area and advise you about any legal aid which might be available to help with the costs.

Supporting children

Helping your child through a period of separation or divorce is challenging as you come to terms with your own feelings. But research shows there are things you can do that can help.

Keeping children informed about what is happening will help to prevent them blaming themselves and worrying unnecessarily. You can help children feel more secure by helping them to express their feelings, letting them know that you understand how they feel, and making sure they feel they can ask questions if they want to, will help.

Children often feel a great sense of loss and letting them grieve is an important part of helping them to deal with the

situation and to move on to accept the changes in their family relationships. They may also express anger towards you, whilst this can be hurtful, try not to take it too personally as it can be a sign they are finding it hard to cope.

Denial is also a common response. A child will naturally have hopes and fantasies about the family, such as wanting you all to be reunited. Talking about these feelings, without raising false hopes, will help your child to move on.

Avoid criticising your ex-partner in front of the children. It can be very upsetting for them and leave them feeling forced to take sides.

Parental responsibility

The law presumes married parents both have parental responsibility. Unmarried mothers have parental responsibility but not all unmarried fathers do. Unmarried fathers can acquire parental responsibility, for example by entering into a parental responsibility agreement with the mother. A civil partner or member of a same-sex couple can acquire parental

responsibility in a similar way. Call your local CAB if you would like more information, or visit One Plus One's specialist website www.marriedornot.org.uk for more information about the legal differences in parental rights and responsibilities when couples are either married or unmarried.

Community Legal Advice
Helpline: 0845 345 4345
www.communitylegaladvice.org.uk

This website offers free, confidential and independent legal advice for residents of England and Wales.

Child support

Both a child's parents (biological or adoptive) are legally responsible for his or her financial support. If one of the parents does not have day-to-day care of the child, s/he may be liable to pay child support maintenance.

There are two main options for arranging child support:

- a private agreement between you and the other parent, or
- an arrangement that is set up by the Child Support Agency (CSA) (called a statutory agreement).

In December 2012, the government introduced a new agency called the Child Maintenance Service (CMS) and a third scheme called the 2012 Child Maintenance Scheme. This is currently

open to only a limited number of people, the government intend to widen the scheme but has not said when. Eventually, there will be a fee to apply to the 2012 Scheme, but at the moment no fees are charged. There's no charge for using the other schemes.

Applications for statutory child maintenance should be made to the CSA which will refer applications to the CMS as appropriate. The CSA and the CMS can calculate how much is due and set up arrangements for the collection of payments.

Since 2008, parents with day-to-day care of a child who receive certain benefits such as Income Support have been able to choose between using the CSA or not. The Child Maintenance Options service provides information to parents on the choices available.

Child Maintenance Options

Tel: 0800 988 0988

Freephone helpline: **0808 808 3555**
Web: **www.cafamily.org.uk**

(Mon-Fri 8am-8pm; Sat 9am-4pm)
www.cmoptions.org

In Northern Ireland – Child Maintenance Choices

Tel: 0800 028 7439
www.nidirect.gov.uk/choices

Anyone who wishes to set up a statutory agreement for child support rather than a private arrangement should contact the Child Maintenance Options or the CSA's national enquiry line, see page 29.

The CSA can only consider applications for child support in respect of children under 16 years, or under 20 years if he or she is still in full-time non-advanced education.

Benefits and tax credits when a relationship has ended

If you are in receipt of benefits or tax credits you may need to seek advice immediately following the break-up of a relationship. This is because some benefits are assessed and paid for the whole family, and a change in the family circumstances like a person leaving the family home will affect entitlement. With tax credits you risk a fine if you do not stop claiming when you stop being part of a couple (you might be able to claim again as a single claimant). The benefit and tax credits system also recognises gay and lesbian couples who live together whether or not you have registered as civil partners. For more information about benefits and tax credits ring the Contact helpline. The helpline can also put you in touch with a specialist benefits adviser.



Useful resources

Finding a place to live, a guide to housing options – download this guide on the Shelter website www.shelter.org.uk

This guide gives information about finding a place to live in England and Wales. It explains how to get temporary accommodation in an emergency and how to find a more permanent home.

A guide to childcare for disabled children

This guide aims to set out what should be available and will take you through your childcare options. There are tips on choosing the right childcare, guidance on what support your local authority should offer and the financial help available for childcare costs for disabled children. Useful contacts and sources of further information are also provided at the end of the guide.

If you are a parent you can ask for a free copy of this publication by emailing: publications@daycaretrust.org.uk.

Understanding your child's behaviour, Contact's practical guide to help families, includes sources of specialist information, advice and support. Parents can call our

freephone helpline and we will send you a copy.

The Parent Connection

www.theparentconnection.org.uk

A website created by One Plus One, the Parent Connection aims to encourage you to think about the importance of your relationship with your child's other parent, whether or not you are still together, and the impact this has on your child.

Useful organisations

Alcohol and drug use

Al-Anon Family Groups UK & Eire

Tel: 020 7403 0888

www.al-anonuk.org.uk

Al-Anon Family Groups provide understanding, strength and hope to anyone whose life is, or has been, affected by someone else's drinking.

Alcohol Concern

Tel: 0800 917 8282

www.alcoholconcern.org.uk

The national agency on alcohol misuse.

Alcoholics Anonymous

Tel: 0845 769 7555

www.alcoholics-anonymous.org.uk

Men and women share their experience, strength and hope that they may solve their common problem and help others to recover from alcoholism.

Families Anonymous

Helpline: 020 7498 4680 or

0845 1200 660 (the second number is cheaper from a landline outside London, but more expensive from a mobile).

www.famanon.org.uk

For families and friends concerned about the use of drugs or related behavioural problems.

National Association for Children of Alcoholics

Tel: 0800 358 3456

www.nacoa.org.uk

Supports children growing up in families where one or both parents suffer from alcoholism, or similar addictive problems.

Turning Point

Tel: 020 7481 7600 (for you)

Tel: 020 7481 7600 (for family and friends)

www.turning-point.co.uk



Freephone helpline: **0808 808 3555**

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

Charity with services for adults across England and Wales working in the areas of drugs and alcohol misuse, mental health and learning disability.

Behaviour issues

Challenging Behaviour Foundation

Tel: 0845 602 7885
www.thecbf.org.uk

Supports families with children with severe learning disabilities and associated challenging behaviour.

YoungMinds

Tel: 0808 8002 5544
www.youngminds.org.uk

Aim to help improve emotional wellbeing and mental health of children and young people and to empower their parents.

Counselling and mental health

The British Association for Counselling and Psychotherapy (BACP)

Tel: 01455 883300
www.bacp.co.uk

Can provide a list of accredited counsellors in your area.

College of Mediators

Tel: 0845 65 85 258
www.collegeofmediators.co.uk

Offer information on local mediation services.

The Mental Health Foundation incorporating the Foundation for People with Learning Disabilities

Tel: 08457 90 90 90
www.mentalhealth.org.uk

Information on mental health issues.

Mind infoLine

Tel: 0300 123 3393
Email: info@mind.org.uk
www.mind.org.uk

Mental health charity in England and Wales

Domestic violence

If you are in immediate danger, call 999.

Women's Aid

Tel: 0808 2000 247 (24 hour)
www.ndvh.org.uk
Email: helpline@womensaid.org.uk

A national charity working to end domestic violence against women and children.

Broken Rainbow UK

Tel: 0300 999 5428
www.broken-rainbow.org.uk
Email: help@broken-rainbow.org.uk

Support for lesbian, gay, bisexual and transgender (LGBT) people experiencing domestic violence.

ManKind

Tel: 01823 334 244
www.mankind.org.uk

A charity providing help and information to male victims of domestic abuse and domestic violence.

Debt

The National Debtline

Tel: 0808 808 4000

Offers specialised money advice if you are struggling to manage.

Debt Action NI

www.debtaction-ni.net

Tel: 0800 917 4706

Email: debt@adviceni.net

Divorce and separation

The Child Support Agency (CSA)

Tel: 0845 713 3133

www.gov.uk/child-support-agency

Families in Northern Ireland, can get advice from **Child Maintenance Choices**

Tel: 0800 028 7439

<http://preview.tinyurl.com/cz7kuae>

Gingerbread

Tel: 0808 802 0925

www.gingerbread.org.uk

Offers information and practical advice for those in the process of, or thinking about, splitting up or divorcing.

theparentconnection.org.uk

www.theparentconnection.org.uk

Created by One Plus One, this website aims to help parents who are going through separation or struggling with issues associated with parenting after parting. The website has resources, access to mediators and a forum.

United Kingdom College of Family Mediators

Tel: 0845 65 85 258

www.collegeofmediators.co.uk

For details of local, family mediation services.

Gay and lesbian families

Pink Parents UK

Email: info@pinkparents.org.uk

www.pinkparents.org.uk

Information for lesbian, gay, bisexual and transgender families.

Housing

Shelter

Tel: 0808 800 4444

www.shelter.org.uk

Advice on housing rights in England.

Shelter Scotland

Tel: 0808 800 4444

<http://scotland.shelter.org.uk>

Advice on housing in Scotland

Housing Rights Service Northern Ireland

www.housingadviceni.org

Independent advice on housing in Northern Ireland with information and links to local support.

Parenting

Family Lives

Tel: 0808 800 2222

<http://familylives.org.uk>

Freephone helpline: **0808 808 3555**

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

Offers support to anyone parenting a child. Runs a freephone helpline, courses for parents, develops innovative projects and provides a range of information.

Relationship information and support

Relationships Scotland

Tel: 0845 119 2020

www.relationships-scotland.org.uk

Offers advice, relationship counselling, sex therapy, consultations and support face-to-face, by phone and website.

Relate

Tel: 0300 100 1234

www.relate.org.uk

Offers advice, relationship counselling, sex therapy, workshops, mediation and support either face-to-face, by telephone, email or online via their website.

One Plus One

Email: admin@thecoupleconnection.net

www.thecoupleconnection.net

One Plus One puts relationship research into practice. Their free web-based service has been designed to help couples strengthen their relationship and includes articles and exercises specifically to help couples who have a child with additional needs.

Marriage Care

Tel: 0845 660 6000

www.marriagecare.org.uk

Marriage Care offers relationships counselling to all. Their counsellors are unpaid professionals who give their time freely. Marriage Care do not charge a

fixed fee, but contributions towards their services are requested. No one is turned away because of an inability to pay. Marriage Care operate at local centres across England and Wales.

Short breaks

Shared Breaks Network

Tel: 0117 941 5361

www.sharedbreaksnetwork.org.uk

Information and advice on short breaks for disabled children and young people.

Working

Waving not Drowning Project

Tel: 020 7017 0072

www.workingfamilies.org.uk

Waving not Drowning is a project run by Janet Mearns for Working Families aimed at supporting working parents of disabled children and adults. Waving not Drowning focuses on issues around combining paid work and parenting.

Reference

1. Johnson, Michael P. *A Typology of Domestic Violence: Intimate Terrorism, Violent Resistance, and Situational Couple Violence* (Boston: Northeastern University Press, 2008).

This guide has been revised with help from parents, as well as Debbie Butler of Marriage Care and Jenny Reynolds on behalf of One Plus One. The original guide was written by Mark Robertson for Contact with the help of Relate.

Social networking

Contact is on Facebook and Twitter. Join us at:

Facebook

www.facebook.com/contactfamilies

Twitter

twitter.com/contactfamilies

Podcasts

You can download podcasts from our website at:
www.contact.org.uk/news/podcasts.html

iTunes users can listen to our podcasts at: <http://bit.ly/96EVT>

Videos

You can watch videos on our YouTube channel at:
www.youtube.com/contactfamilies

Freephone helpline: **0808 808 3555**
Web: **www.contact.org.uk**

Getting in contact with us

Free helpline for parents and families

0808 808 3555

Open Mon–Fri, 9.30am–5pm

Access to over 170 languages

www.contact.org.uk

0808 808 3555

Contact Head Office:

209–211 City Road, London EC1V 1JN

Tel **020 7608 8700**

Fax **020 7608 8701**

Email **info@contact.org.uk**

Web **www.contact.org.uk**

Other information booklets available

This guide is one of a series produced for parents and groups concerned with the care of disabled children. Our guides include:

- Tax credits
- Holidays, play and leisure (UK)
- Siblings (UK)
- Grandparents (UK)
- Fathers (UK)
- Disabled children's services (England)

Contact's publications can be downloaded from our website www.contact.org.uk

Parents can call our freephone helpline and ask for a copy of any of our guides.

Registered Office: 209–211 City Road,
London EC1V 1JN
Registered Charity Number: 284912
Charity registered in Scotland No. SC039169
Company limited by guarantee
Registered in England and Wales No. 1633333
VAT Registration No. GB 749 3846 82

® Contact is a registered trade mark
Although great care has been taken in the
compilation and preparation of this guide
to ensure accuracy, Contact cannot take any
responsibility for any errors or omissions.



MIX
Paper

FSC FSC® C011842

Order code i21