



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, different expectations about their child, and cope with significant emotional, social, physical and financial pressures. Many parents find these experiences bring them together and make their relationship stronger, as in the case of some of the parents who took part in a Contact a Family survey:

"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."

But some couples are overwhelmed by the experience and struggle to stay together. This guide offers information and ideas to parents of disabled children about looking after their family relationships. It has been developed from the experience of over 2000 parents who took part in a survey about how their relationship has been affected by caring for a disabled child, and the expertise of One Plus One, a research charity that looks at relationships and families and how they can be supported.

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	10
Children and conflict	12
Relationship advice and counselling	13
Domestic violence	13
The whole family	14
Networks of support	16
Relationships under pressure	18
If things break down	24
Useful resources	27
Useful organisations	27



find out what parents need to help them in their 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, 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 couple relationship and caring for a disabled child brought together the range of evidence on the subject.

Looking at surveys, it found that couples caring for a child with a disability are at greater risk of marital problems and divorce. It recorded the pressures that can overwhelm parents' relationships, including: 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 financial pressures.

One important factor is coping style, which affects parent's ability to draw support from one another and their ability to handle the pressures and circumstances of their caring responsibilities. The research showed that supportive spouses protect one another from the parenting stresses and risk of depression associated with caring for a child with a disability.

You can download a copy of this research, 'Growing together or drifting apart', at Web: <http://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 our relationships are an important part of

keeping us healthy; reducing 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 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 similar issues, hopefully this guide will help you to strengthen and build on the support you need in your own relationships. Many of the tips and suggestions in it have been put together from what parents with disabled children have told us.



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



"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.

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, 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'.

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.

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://www.theparentconnection.org.uk>

Keep communicating!

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 and hopes and needs. Each of you needs to know the other has heard those things – that means really listening – listening to the words and the feelings that underlie them.

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

Recognising each other's role and ways of coping

Sharing the care

Research shows that mothers often take on the main responsibility for a child's physical care and home care. 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 others' contributions. If you are out to work all day, you can help your partner by showing an interest in and an understanding of their day 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 the 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.

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).

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



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. 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

Building in 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 time aside to spend 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.

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**

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

The same old argument

For most couples, it is the same old arguments that keep cropping up again and again. If that is you, keep a sense of humour and try and work out a way of

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

dealing with it. If it always ends up in a slanging match, at least agree to put the subject on hold for the time being and discuss it another time.



Positives can cancel out the negatives

People who are good communicators are often good at managing their differences. After all, arguing is a form of communication. If you aren't good at managing your differences, try to understand the feelings underneath. Rows are often just the symptom that we feel our partner isn't supporting us or that they're not 'there for us'.

If there are lots of other times when you show affection, warmth, enthusiasm and humour towards each other, these can make up for the times when you fall out. So too can thinking the best of our partner and overlooking or accepting their failings or hurtful behaviour or comments.

Tips for managing differences

All 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 10-15 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.

For all couples there will be the same old sticking points that you never resolve. They are unique to you and your relationship. Learn to live with them - and have a sense of humour!

Remember that what a row seems to be about is often not the real, underlying problem - try to work out the real cause of the upset and address that.

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**

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 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 worsening behaviour. In turn, children's difficult behaviour can put an even greater strain on the relationship between parents. Be wary of falling into unhappy

Children and conflict

Children can be particularly troubled when you are arguing 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. They might react by becoming difficult or challenging or they might become withdrawn and depressed. You can help by bearing in mind some of these suggestions:

- don't try and hide conflict behind closed doors. 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 them 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.

cycles of criticism and withdrawal. If you feel stuck, look at some of the tips in this factsheet, 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 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 a Family freephone helpline, Tel: 0808 808 3555.

If you are worried about your relationship there are many websites and books you can look at and you can find more relationship advice at, for example
Web: <http://www.oneplusone.org.uk>
and Web: <http://www.relate.org.uk>

Relationship counselling can help you with your relationship difficulties.

Domestic violence

In our survey around 1 in 10 respondents indicated that they had experienced domestic violence since having a disabled child. The survey does not tell us the identity of victim or abuser, or whether the violence involved the birth parents, a reconstituted family, or even other family members. However, crime statistics do tell us that in the overwhelming majority of cases, the victims of domestic violence are women. Sometimes that violence is directed towards children, other family members and friends.

Recognising an abusive relationship

Women may be subject to a wide range of manipulative and controlling behaviours by a partner. This may happen once every so often or on a frequent and regular basis. Every situation and every relationship is unique, but abuse is always about power and control.

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

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

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 page 29 which you may find helpful if you are in a situation with 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.

There are over 250 refuges in England, Scotland, Wales and Northern Ireland - you can choose to travel as far away from, or stay as near to your home town as you wish. Some refuges have space for many women and children, and some refuges are small houses. Some refuges are specifically for women from particular ethnic or cultural backgrounds - for example Black, Asian or South American women - and some refuges 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, but you're not alone. Although research shows that it is mainly women, this doesn't mean that

men don't suffer too. 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 a Family 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.

"Finding a balance between the disabled and non-disabled world - which having a second child allowed. Letting the two develop their own relationship."

For more information about leisure activities ring the Contact a Family helpline for a copy of the 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 certain times to spend with siblings, e.g. bedtime, cinema once a month. Organise short-term care for important events such as sports days and sometimes put the needs of siblings first 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 difficulties. Come to terms yourself with your child's disability and 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 difficulties 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 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, e.g. 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 alright 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 a Family also publishes a 'Siblings' guide.



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 term breaks" (sometimes called "respite care") is the general 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. For example 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 information about getting a break call the Contact a Family helpline and ask for a copy of the guide 'Disabled Children's Services (England and Wales)' or 'Assessments and Services in Scotland.'

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."

"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.



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

"The grandparents have their other grandchildren to stay but we are avoided and not invited to family 'dos'."

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.

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

Sometimes there won't be a support group for your child's specific condition, but there will be a local multi-disability 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 who understand the strains that having a disabled child can put on a relationship.

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 Web: <http://www.makingcontact.org> - our internet based 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 on your child's condition, and share what you have learned 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 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. For detailed advice on the full range of benefits you should phone our free helpline, Tel: 0808 808 3555. We employ a welfare rights specialist who can advise on any aspect of claiming benefits and tax credits. We also produce a free factsheet 'Benefits, Tax Credits and other financial help.' Our helpline can also provide details of charitable trusts that may be willing to offer some financial assistance.

Challenging behaviour

Many parents whose children have behavioural problems 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 badly behaved, or imply that the problems are all due to bad parenting. This often occurs in the period before your child receives a firm diagnosis.

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

If you're already feeling vulnerable, it's all too easy to believe that other people's criticisms are valid, and to turn these feelings of guilt 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 behavioural problems, children's behavioural problems are minimized.

Even if your anxieties do not turn to blame, dealing with difficult behaviour places a real strain on you and your relationship. It might help to avoid criticizing one another's handling of difficult behaviour, and to be supportive of the main carer, where one of you has taken on that role. 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 (Web: <http://www.surestart.gov.uk>) or ring Contact a Family's helpline on Tel: 0808 808 3555.

It is also worth addressing any problems, particularly high levels of acrimonious and unresolved conflict, in the relationship, as children may become troubled, and develop challenging behaviour, as a response.

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

The work, care, life balance

For some of the parents who took part in our survey, being able to go to work was a major boost to the relationship they had with their partner. It allowed for a break from the family situation, 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, 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 could find. 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 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, work can be seen as 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

Employment legislation, effective from 2003, has given most working parents new rights, with enhanced rights for parents of disabled children. Such rights may enable working parents of disabled children to have more time to spend with their children and each other. For example, it should now be easier for a working parent to have more opportunity to accompany a partner who is a full time carer to hospital appointments.

The employment rights include:

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

These, and other rights, are discussed in more detail in our employment guide 'Working'. Roles and relationships in the family may change over time and non-working parents may want to return to work. The employment guide also contains information on benefits available to make the transition back into work.

Childcare and other care for children

Many families struggle to find appropriate childcare. The Childcare Act (2006) places a requirement on local authorities to provide good quality childcare for families caring for a disabled child. It is hoped that this will increase existing provision. In England, Wales and Scotland help with finding suitable childcare can be obtained from the local children's information service, Web: <http://www.nacis.org.uk/contactcis> In Northern Ireland families can call Employers for Childcare Tel: 0800 028 3008 (Mon-Fri, 10am-1pm).

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

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

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



someone to look after a child after school. In exceptional circumstances direct payments can be used to pay a close relative and may be a way of receiving and acknowledging help given by someone who has a close relationship with you and your child. Our factsheets on disabled children's services and assessments contain information about direct payments.

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.

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.

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 describe periods of stress or depression at some time or 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 the relationship. For some who took part in our survey it played a significant part in their relationship coming to an end.

"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 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. These are listed at the end of this factsheet.

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 a Family helpline for a free copy of the guide 'Aids, equipment and adaptations'.

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

If things break down

This next section looks specifically at some of the legal and practical issues that parents may face if the relationship has broken down completely and one partner has now moved 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 25) 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 couples, having to maintain contact with one another and sort out

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.

Children often go through stages of loss and grief, and denial is a common response. 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.

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, Web: <http://www.marriedornot.org.uk> for more information about the legal differences in parental rights and responsibilities when married or unmarried.

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 their relationship 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. 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, details for whom are on page 29.

Relationship breakdown and the law

Couples 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,

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

the most common being divorce. If both parties agree to divorce (i.e. 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 defended, 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 – although at the time of writing the government is reviewing whether this will be available in future.

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. Child support is administered by the Child Support Agency (CSA), which can calculate how much is due and set up payment arrangements through the CSA.

A parent with day-to-day care of a child will have little option but to agree to a CSA assessment if they claim benefits like Income Support (otherwise they may lose benefits). Other people can ask CSA to make an assessment, including a non-resident parent (NRP) and, in Scotland, although in limited circumstances, a child can also apply. The CSA can only consider



applications for child support in respect of children under 16 years, or under 19 years if he or she is still in full-time non-advanced education.

The assessment is complex and may cause a lot of upset between you and your former partner. Also, you may find that interim payments may be required while an assessment is carried out and these can be disputed when the level of child support maintenance is finally agreed. A local CAB can help with these issues and advise on how to challenge the assessment if you are unhappy with the outcome. Details for who to contact about child support are at the back of this factsheet. The government is deciding whether to change these rules for the future, so call the CAB if you have any concerns about this.

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 a Family helpline. The helpline can also put you in touch with a specialist benefits adviser.

Useful resources

Finding a place to live

Shelter, 88 Old Street, London EC1V 9HU
Tel: 020 7505 4699
Price: £0.55
Web: <http://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.

Over the top behaviour: in the under 10s.

Web: <http://www.familyandparenting.org>
Or send a 2nd class stamp and A4 envelope to:
NFPI, 430 Highgate Studios,
53-79 Highgate Road,
London NW5 1TL
Tel: 020 7424 3460

Looks at the differences between normal misbehaviour and where there might be more serious problems.

The Parent Connection

Web: <http://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.

Splitting up - the guide for lone parents on divorce & separation

One Parent Families,
255 Kentish Town Road,
London NW5 2LX
Tel: 020 7428 5400
Price: £3.50
Web: <http://www.oneparentfamilies.org.uk>

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

Useful Organisations

Alcohol and drug use

Al-Anon Family Groups UK & Eire
61 Great Dover Street, London SE1 4YF
Tel: 020 7403 0888
Web: <http://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. Alateen is part of the Al-Anon fellowship and is for young people, aged twelve to twenty, who are affected by someone else's drinking.

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

Alcohol Concern

64 Leman St, London E1 8EU

Tel: 020 7264 0510

Web: <http://www.alcoholconcern.org.uk>

Alcohol Concern acts as the national umbrella body for 500 local agencies across the UK tackling alcohol-related harm and offering help to the families and friends of those with alcohol-related problems.

Alcoholics Anonymous

PO Box 10, 10 Toft Green, York YO1 7NJ

Tel: 0845 769 7555

Web: <http://www.alcoholics-anonymous.org.uk>

A fellowship of men and women who share their experience, strength and hope with each other that they may solve their common problem and help others to recover from alcoholism.

Families Anonymous

Doddington & Rollo Community Association, Charlotte Despard Avenue, Battersea, London SW11 5HD

Tel: 0845 1200 660

Web: <http://www.famanon.org.uk>

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

National Association for Children of Alcoholics

PO Box 64, Fishponds, Bristol BS16 2UH

Tel: 0800 358 3456

Web: <http://www.nacoa.org.uk>

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

Behaviour problems

Challenging Behaviour Foundation

c/o The Old Courthouse, New Road Avenue, Chatham, Kent ME4 6BE

Tel: 01634 838 739

Web: <http://www.challengingbehaviour.org.uk>

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

Counselling and mental health

The British Association for Counselling and Psychotherapy (BACP)

Tel: 0870 443 5252

Web: <http://www.bacp.co.uk>

Can provide a list of accredited counsellors in your area.

The Mental Health Foundation

9th Floor, Sea Containers House, 20

Upper Ground, London SE1 9QB

Tel: 020 7803 1101,

Web: <http://www.mentalhealth.org.uk>

Information on mental health issues.

Mind

15-19 Broadway, London E15 4BQ

Tel: 0845 766 0163

Web: <http://www.mind.org.uk>

Mental health charity in England and Wales

Turning Point

Standon House, 21 Mansell Street,

London E1 8AA

Tel: 020 7481 7600

Web: <http://www.turning-point.co.uk>

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

Domestic violence

Everyman Project

1a Waterlow Road, London N19 5NJ

Tel: 020 7263 8884 (Tue-Wed, 6:30-9pm)

Web: <http://www.everymanproject.co.uk>

For men behaving violently who want to change and others concerned about this issue. Operate a national helpline.

Mankind

Tel: 01823 334 244

Web: <http://www.mankind.org.uk>

Supports male victims of domestic violence, as well as helping all callers regardless of sex, race or sexual orientation. Call the helpline for up-to-date information about availability. Also have a referral system for single men and men with children fleeing domestic violence.

Women's Aid

PO Box 391, Bristol BS99 7WS

Tel: 0808 2000 247 (24hrs)

Web: <http://www.womensaid.org.uk>

e-mail: helpline@womensaid.org.uk

A national charity working to end domestic violence against women and children. The 24 hour National Domestic Violence Helpline, provides support, information and a listening ear to women experiencing (or who have experienced) domestic violence.

Debt

The National Debtline

Tel: 0808 808 4000 (Mon-Fri, 9am-9pm & Sat 9:30am-1pm)

Web: <http://www.nationaldebtline.co.uk>

Offers specialised money advice if you are struggling to manage.

Divorce and separation

The Child Support Agency

Tel: 08457 133 133 (Mon-Fri, 8am-8pm & Sat 9am-5pm).

Textphone: 08457 138 924

Web: <http://www.csa.gov.uk>

Operates a national helpline.

United Kingdom College of Family Mediators

Alexander House, Telephone Avenue, Bristol BS1 4BS

Tel: 0117 904 7223

Web: <http://www.ukcfm.co.uk>

For details of local family mediation services.

Gay and lesbian families

Pink Parents UK

The D'Arcy Lainey Foundation, PO BOX 417, Oldham OL2 7WT

Tel: 08701 273274

Web: <http://www.pinkparents.org.uk>

A national organisation offering support to lesbian, gay, bisexual and transgender families.

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

Housing

Shelterline

Tel: 0808 800 4444 (24hrs).

Web: <http://www.shelter.org.uk>

For advice on your housing rights and options.

Parenting

Parentline Plus

520 Highgate Studios,

53-79 Highgate Road,

London, NW5 1TL

Tel: 0808 800 2222 (24hrs)

Web: <http://www.parentlineplus.org.uk>

Parentline Plus is a UK charity which 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

Relate Scotland,

18 York Place, Edinburgh EH1 3EP

Tel: 0845 119 6088

Web: <http://www.relatescotland.org.uk>

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

Relate

Herbert Gray College, Little Church Street,
Rugby CV21 3AP

Tel: 0845 456 1310

Web: <http://www.relate.org.uk>

Web: <http://www.relate.org.uk/sexproblems>

Offers advice, relationship counselling, sex therapy, workshops, mediation and support either face-to-face or by telephone.

One Plus One

1 Benjamin Street, London EC1M 5QG

Tel: 020 7553 9530

Web: <http://www.oneplusone.org.uk>

One Plus One puts relationship research into practice. They aim to strengthen and support couple and family relationships through research, information and training practitioners working with families.

Marriage Care

1 Blythe Mews, Blythe Road,

London W14 0NW

Tel: 0845 660 6000

Web: <http://www.marriagecare.org.uk>

Marriage care helps people prepare for, achieve and sustain successful marriages and to support them should their marriage break down.

Respite care

Shared Care Network

Units 63-66 Easton Business Centre, Felix
Road, Bristol BS5 0HE

Tel. 0117 941 5361

Web: <http://www.sharedcarenetwork.org.uk>

Promoting family-based short breaks for disabled children and young people.

Working

Waving not Drowning Project

Working Families, 1-3 Berry Street, London
EC1V 0AA

Tel: 020 7253 7243 (Wed-Fri, 9.30am-
1pm & 2-4.30pm)

Web: <http://www.workingfamilies.org.uk>

Has an established network for working parents of disabled children focusing on issues around combining paid work and parenting.

This factsheet was produced in partnership between Contact a Family and One Plus One. It was revised and updated by Jenny Reynolds on behalf of One Plus One. The original factsheet was written by Mark Robertson for Contact a Family with the help of Relate.

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

Getting in contact with us

Free helpline for parents and families

0808 808 3555

Textphone

0808 808 3556

Open Mon–Fri, 10am–4pm;

Mon, 5.30–7.30pm

Access to over 100 languages

www.cafamily.org.uk
www.makingcontact.org

Contact a Family Head Office:

209-211 City Road, London EC1V 1JN

Tel **020 7608 8700**

Fax **020 7608 8701**

Email **info@cafamily.org.uk**

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



Other information booklets available

This factsheet is one of a series produced for parents and groups concerned with the care of disabled children. A full list of Contact a Family publications is available on request or can be downloaded from our website www.cafamily.org.uk

- Benefits, tax credits and other financial help (UK)
- Holidays, play and leisure (UK)
- Siblings (UK)
- Grandparents (UK)
- Fathers (UK)
- Working (UK)
- Disabled children's services in England and Wales (England & Wales)



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