

RELATIONSHIPS & CARING FOR A DISABLED CHILD



INFORMATION FOR PARENTS OF DISABLED CHILDREN



*“Prioritise your
relationship – no
one else is going to
do it for you!”*

Parent carer

CONTENTS

INTRODUCTION	5
WHY RELATIONSHIPS MATTER	6
LOOKING AFTER YOUR RELATIONSHIP	7
RECOGNISING EACH OTHER'S ROLE AND WAYS OF COPING	10
INTIMACY	12
BUILDING FOR THE FUTURE	13
THE WHOLE FAMILY	14
NETWORKS OF SUPPORT	16
MANAGING DIFFERENCES	21
CHILDREN AND CONFLICT	24
RELATIONSHIP ADVICE AND COUNSELLING	26
RELATIONSHIPS UNDER PRESSURE	28
COPING WITH STRESS	34
DOMESTIC VIOLENCE	38
IF THINGS BREAK DOWN	41
RELATIONSHIP BREAKDOWN AND THE LAW	43
USEFUL ORGANISATIONS	48



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.

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. It 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 Click, a mobile-friendly website on dealing with relationships issues.

"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."

Parent carer

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.

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.

“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.”

Parent carer

LOOKING AFTER YOUR RELATIONSHIP

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.

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!

“Remember that the partner you married has feelings too – tell them you've heard them. Remember why you married them.”

Parent carer

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

Parent carer

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'.

"Often we would suffer from outbursts of emotion, a natural process when feelings that had been suppressed become unbearable! I recognise today that we went through a grieving process, a 'coping bravely' process, even a healing process as a family, and on our own.

Parent carer

"Keeping talking to each other and not bottling up our feelings – put the other person's needs and feelings first."

Parent carer

"Being truthful about what we really think about our situation helps us understand each other."

Parent carer



RECOGNISING EACH OTHER'S ROLE & 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.

*“One parent in our relationship is the investigator/
explorer/questioner/driving force, and the other keeps
the ‘home fires burning’/brings perspective to ideas
that can be outlandish/brings balance.”*

Parent carer

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 longer 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 18).



Relate has advice for couples on managing your relationship at www.relate.org.uk

"We are stronger because we know that we have to get on with it – we try to respect each other, learn from each other, laugh at one another and love one another. Oh, and on the odd occasion that we get a good night's sleep we do all the above!"

Parent carer

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.

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 advice and counselling on page 26 for more information.

"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!"
Parent carer

"When our child is looked after we spend quality time together."
Parent carer

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 'Getting a break' on page 19 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.”

Parent carer

“Taking time to be with yourself and your partner can re-establish relationships that are buried under doctors' appointments, being told what they can't do, and hopes and disappointments of life.”

Parent carer

THE WHOLE FAMILY

As well as setting time aside to spend as a couple, set time aside to spend as a family with activities for all as well. 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.



Check your local authority website for details of local leisure activities. Our free guide to **Holidays, play and leisure** is available free from our website or helpline **0808 808 3555**.

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.



Our free **Siblings** guide has information and advice for helping siblings:
www.contact.org.uk/siblings-guide



“It helped to know that I’m not alone with a disabled brother or sister.”
Sibling

NETWORKS OF SUPPORT

THE EXTENDED FAMILY

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

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. It isn't always easy for family members to know what to do or when to step in and offer help. 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"
Grandparent

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

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

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.

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



You might want to order our free guide for **Grandparents**, written with grandparents: www.contact.org.uk/grandparents-guide

“You need a sense of humour –if anyone else says we’ve been ‘chosen’, I’ll be up for murder!”

Parent carer

“Find time for yourselves. Grab any help you can get!”

Parent carer

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

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



Our helpline has details of local support groups, or you can look on your local authority website. If your child has a rare condition and there is no existing group, we may still be able to help

0808 808 3555 helpline@contact.org.uk

GETTING A BREAK

Short breaks (previously called ‘respite care’) are any service provided by your local authority or a voluntary agency which ensures a disabled child or adult is cared for while their main carer has a break. This may include regular overnight stays with another family (sometimes known as ‘family linking schemes’).

Most breaks are arranged by social services – a department within your local authority. Usually, social services will need to assess your child and 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 short breaks visit our website

www.contact.org.uk/short-breaks

“I finally felt like a person – I had the feeling that I belonged in a community, with others in similar situations. It boosted my confidence and I feel as though my life has been saved from the despair and exclusion I have felt.”

Parent carer

“Short breaks make it possible for my partner and me to reconnect and remember why we got together in the first place, before caring for our children became the overwhelming focus of our family life.”

Parent carer



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 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 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.

TOP TIPS FOR MANAGING DIFFERENCES

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

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. Remember the warmth, the fun, the closeness.
- **Each of you will be under pressure, but are there small ways you can support one another – emotionally or physically?** Often just a small change can make a big difference.
- **Try to 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.
- **Be realistic.** It's tempting to think that our partner should be the one who can solve all our problems – after all, that is the fairy tale. But this can put even more strain on a relationship. Be realistic, and make sure you have lots of support from friends and family too.

CHILDREN & 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 even greater strain on the relationship between parents.

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.

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.

“Taking time to be with yourself, your partner and your other children can re-establish relationships that are buried under doctors’ appointments, being told what they can’t do, and the hopes and disappointments of life.”

Parent carer

HELPING CHILDREN AFFECTED BY CONFLICT

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. Children's behaviour might become challenging, and they might become withdrawn and depressed. You can help by bearing in mind some of these suggestions.

- **Try and make sure your children see you making up, and, if possible, resolving the problem** if you do find yourself caught up in an argument in front of the children. 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, let them know that you made things up with your partner and everything is ok.
- **Stay united with your partner on discipline** if possible.
- **Reassure children that they aren't to blame** for an argument.
- **Don't try and get children to take sides.** 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.
- **Be sensitive to any changes in your child's behaviour** if you and your partner are going through a bad patch. 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.
- **Consider seeking outside help** if conflict feels like a serious problem.

RELATIONSHIP ADVICE & COUNSELLING

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.

Sometimes a partner may not want to talk to a counsellor. But that doesn't mean you can't get support for yourself – in fact it may be even more important to do so!



To find services in your area, search for 'relationship counselling' on the NHS website: www.nhs.uk or call our free helpline on **0808 808 3555** helpline@contact.org.uk

“Having someone independent to talk to, unload on, discuss feelings of guilt and so on, without being judged and not having to put a brave face on the whole time – I can't tell you how much it helped.”

Parent carer

“We needed some kind of family counselling – out of the home, a few months after diagnosis, and at pressure points along the way. 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.”

Parent carer



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. 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.

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

Parent carer

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

Parent carer

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 some, 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.

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.”

Parent carer

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.***



Our website also has information on making the transition back to work easier: www.contact.org.uk/work-childcare

CHILDCARE & 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 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 our free helpline.



Our guide to ***Accessing Free Childcare for two-to-four-year-olds*** has information about your rights to childcare and how to challenge if you're refused a place www.contact.org.uk/childcare-guide. Corum Family and Childcare also have a guide at www.familyandchildcaretrust.org

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.



For more information on direct payments visit our website
www.contact.org.uk/direct-payments

“It would be nice to have time with my husband as one of us is normally involved in caring to give the other a break. Good reliable childcare would allow us peace of mind to enjoy our rare time together without worrying about our son. We will keep fighting for it!”

Parent carer

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.

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.

Some parents find parenting programmes a helpful source of support and information. To find out more, talk to a professional who's supporting, or to the school. You can also call our free 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.



Understanding your child's behaviour is our practical guide for parents and includes sources of specialist information, advice and support.

www.contact.org.uk/parent-guide-behaviour



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

“You have to fight for everything for your child – it’s wearing and takes its toll on relationships”

Parent carer

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.

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.

"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."

Parent carer

"Our child brought us closer together. We had to be strong [but] it's a hell of a strain – it takes you to your limit sometimes."

Parent carer

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.

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

Parent carer

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.



You can also see our guide to ***Aids, equipment and adaptations*** for more information about making your home accessible

www.contact.org.uk/aids-equipment-adaptations

TIPS TO REDUCE STRESS

- **Plan your time.** Trying to cram in too much will end up making you feel stressed when you do not achieve everything.
- **Reduce your to-do list.** Try delegating tasks or, if they are really not essential, cross them off your list altogether!
- **Just say no.** Know your limits and stick to them.
- **Avoid people who stress you out.** If you know a person touches all your buttons, limit the time you spend with them.
- **Take control of your environment.** If trips to the shops are really difficult, can you shop online instead?
- **Be more assertive.** If someone calls and you only have five minutes, tell them and be firm when the time is up.
- **Be positive.** If something goes wrong, try to find a more positive way to view it. Try to focus on the five things that worked today, not the one that didn't.
- **Learn how to let go of anger** - and forgive others.

- **Take notice of the world around you and what you are feeling.** Reflecting on the day will help you appreciate what matters to you.

LOOKING AFTER YOURSELF

- **Keep active.** Exercise is proven to improve mental wellbeing and can be as simple as a walk around the block or dancing to a song on the radio.
- **Eat healthily.** Try to have your five a day and eat breakfast. Cutting down on caffeine can help, and eating with the family can reduce stress for some.
- **Make sure you get enough sleep.**
- **Keep learning.** Set yourself a challenge you will enjoy achieving - learning something new will make you more confident as well as being fun.
- **Make time to regularly do something for yourself.** Just ten minutes every day or an hour or two every week can really help.

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.

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 page 49 which you may find helpful if you are experiencing or at risk of domestic violence. You can also call our free helpline:

0808 808 3555 helpline@contact.org.uk

“My partner is not physically violent but he verbally bullies me because he cannot cope with the situation and cannot cope with the demands placed upon us by having two disabled children”

Parent carer

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.

Some refuges are specifically for women from particular ethnic or cultural backgrounds, for example Black, Asian or South American women. 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 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.



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.

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.***

“The relationship was the first thing to be kicked into touch when we were living in crisis and turmoil.”

Parent carer

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.

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.

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 College of Mediators (see page 48).

“Our disabled child is very close to me but he has a bond with his dad too. He sees his dad on a Saturday – we both love him very much.”

Parent carer

RELATIONSHIP BREAKDOWN & 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.



Visit the government website to find out about legal aid:
www.gov.uk/legal-aid

“We split up when she was only a few months old. If they (health service) had had some sessions for dads in the evenings, he would maybe have found it easier to cope, to talk to someone else and maybe the marriage would not have ended.”

Parent carer

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.



The Citizens Advice Bureau website has more information
www.citizensadvice.org.uk



CHILD MAINTENANCE

Child maintenance is the money a parent pays towards their child's upbringing. All parents have a responsibility to support their child financially. Child maintenance is usually regular amounts of money paid to the parent who cares for the child most of the time from the other parent.

You and your ex-partner may be able to arrange child maintenance yourself if you are able to agree the amount and how to receive the payments. This is called a 'family-based arrangement'. A family-based arrangement is a private way to sort out child maintenance. Parents arrange everything themselves and no-one else has to be involved.

If you can't agree child maintenance yourselves, you can contact Child Maintenance Options for help.



Further information on child maintenance, including guidance on payments is at www.cmoptions.org where you can also find Child Maintenance Options.

"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."

Parent carer

SUPPORTING CHILDREN THROUGH SEPARATION

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.

- **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. 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.
- **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.
- **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.

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.



Our website has information about benefits and financial information, including a benefits calculator you can use find out what benefits you may be entitled to www.contact.org.uk/benefits-financial-help

We can also put you in touch with a specialist benefits adviser on our helpline **0800 808 3555** helpline@contact.org.uk

*“I am a single parent, and we are a close family.
Support from family and friends keeps me going. I
am determined to provide the best for my children.”*
Parent carer

USEFUL ORGANISATIONS

ALCOHOL AND DRUG USE

Al-Anon Family Groups UK & Eire

Support to anyone whose life is, or has been, affected by someone else's drinking.

Helpline: 0800 0086 811

www.al-anonuk.org.uk

Alcoholics Anonymous

Support for people who are having trouble with their drinking, or if drinking has reached the point of where it worries them.

Helpline: 0800 917 7650

www.alcoholics-anonymous.org.uk

Families Anonymous

For families and friends concerned about the use of drugs.

Helpline: 020 7498 4680

www.famanon.org.uk

National Association for Children of Alcoholics

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

Helpline: 0800 358 3456

www.nacoa.org.uk

Alcohol Change UK

Information and advice on alcohol misuse. Drinkline helpline for people concerned about their own drinking or someone else's.

Drinkline: 0300 123 1110

www.alcoholchange.org.uk

Turning Point

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

www.turning-point.co.uk

BEHAVIOUR ISSUES

College of Mediators

Information and how to find your local mediation services.

Tel: 0845 65 85 258

www.collegeofmediators.co.uk

Challenging Behaviour Foundation

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

Tel: 0300 666 0126

www.thecbf.org.uk

YoungMinds

Information for children and young people on emotional wellbeing and mental health, and for their parents.

Parents helpline: 0808 802 5544
www.youngminds.org.uk

The British Association for Counselling and Psychotherapy

Directory of accredited counsellors in your area.

Tel: 01455 883 300
www.bacp.co.uk

The Mental Health Foundation

Information on mental health issues for the general public.
www.mentalhealth.org.uk

Mind

Information and support for mental health in England and Wales, including tips for everyday living and an online community. Also provides legal information on, for example, mental capacity.

Infoline: 0300 123 3393
Legal Line: 0300 466 6463
www.mind.org.uk

DOMESTIC VIOLENCE

If you are in immediate danger, call 999.

Women's Aid

Confidential support and advice for women and children experiencing domestic violence, plus information on what to do if you're worried about someone else, and how to cover your tracks online.

Tel: 0808 2000 247 (24 hour)
www.womensaid.org.uk

ManKind

Confidential help and information to male victims of domestic violence.

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

DEBT

The National Debtline

Free, specialised money advice if you are struggling to manage. Free downloadable guide to managing finances.

Tel: 0808 808 4000
www.nationaldebtline.org

Citizens Advice

Free, confidential and independent advice about your rights.

www.citizensadvice.org.uk

DIVORCE AND SEPARATION

Gingerbread

Practical advice for those in the process of, or thinking about, splitting up, plus advice for single parents.

Tel: 0808 802 0925

www.gingerbread.org.uk

One Parent Families Scotland

Advice and information, plus local family support services.

Helpline: 0808 801 0323

www.opfs.org.uk

College of Mediators

For details of local family mediation services.

Tel: 0845 65 85 258

www.collegeofmediators.co.uk

GAY AND LESBIAN FAMILIES

Pink Parents UK

Information for lesbian, gay, bisexual and transgender families.

www.pinkparents.org.uk

HOUSING

Shelter

Advice on housing rights, and signposting to housing advice in the UK nations.

www.shelter.org.uk

PARENTING

Family Lives

Support for anyone parenting a child.

Advice, forums, parenting courses.

Helpline: 0808 800 2222

<http://familylives.org.uk>

RELATIONSHIP SUPPORT

Relationships Scotland

Advice on parenting apart, relationship counselling, sex therapy, family mediation, and support face-to-face.

InfoLine: 0345 119 2020

www.relationships-scotland.org.uk

Relate

Advice, relationship counselling, sex therapy, workshops, mediation and support either face-to-face, by phone, email or online. You will have to pay for any telephone or web counselling.

www.relate.org.uk

Marriage Care

Relationships counselling for all.

Counsellors are unpaid professionals who give their time freely. A contribution is requested, but no one is turned away because of an inability to pay. Operate at local centres across England and Wales.

Tel: 0800 389 3801

www.marriagecare.org.uk

WORKING

Working families

Advice and information for working parents and carers and their employers to help find a better balance between responsibilities at home and work.

Helpline: 0300 012 0312

www.workingfamilies.org.uk

“We are stronger because we know what is best for our child and her love and laughter carries us through. If she can get on with it, then so can we.”


Parent Carer


“Faith, love, grace, compassion... all these are present and manifest and we are close and love each other and feel fortunate too – but it’s still a hard journey to face.”


Parent Carer


GET IN CONTACT


Contact's Freephone helpline advisers can help you with any question you have about life with a disabled child – from getting a diagnosis for you child, the services and benefits you might be entitled to, to help in the early years for new parents and support when your child is at school or college. We can also put you in touch with support groups in your area.


 0808 808 3555

 info@contact.org.uk

 www.contact.org.uk

 twitter.com/contactfamilies

 facebook.com/contactfamilies

 youtube.com/contactfamilies

Contact Head Office
209–211 City Road
London EC1V 1JN



We are Contact, the charity for families with disabled children.

We understand that life with a disabled child brings unique challenges, and we exist to help families feel valued, supported, confident and informed.

We support families with the best possible guidance and information. We bring families together to support each other.