

CHAPTER 2

Survival strategies



As you've no doubt gathered by now, the road ahead may be bumpy at times. Getting the best for your disabled child sometimes takes a lot of effort, but it can be done. This chapter focuses on our top survival strategies for maintaining your sanity and getting what you think is best for your child. Some of them relate to getting help from professionals, others are more personal, perhaps relating to the stability of the family or your own well-being. Amaze also produces fact sheets that may help: a general one about official letters and meetings, one about school meetings and another on health appointments, so call us for a copy of any of these.

HANDLING ALL YOUR MEETINGS

All parents have this worry: 'Am I doing the best by my children?' It's even worse when you know if you don't get the best for your child they're not going to get anywhere on their own. The following tips should help you to manage your dealings with professionals and allay those fears to some extent.

Write it down!

- **Get a notebook or diary;** you wouldn't believe how much information you start to collect.
- **Note the date of any telephone calls you make and any letters you receive,** and keep copies of anything you send.
- **Take notes of every conversation** - if you can quote details of a previous conversation it can refresh a befuddled memory.
- **Make use of email** if you can.
- **Start a file** where you keep copies of all the letters and reports you get about your child.

On the phone:

- **Make sure you're talking to the right person,** or persist until you get hold of them; don't be put off by someone being hard to get, note down when they'll be back and call them on time.
- **Try to be patient,** no-one else is as emotionally involved as you are, but be prepared to be firm if necessary.
- **Always be friendly to receptionists and secretaries** and let them know how much you appreciate their help.
- **Get to know who's who** in the place you're calling and go to the top if you need to.
- **Try to be specific,** sort out your thoughts before you ring.

At appointments:

- **Take someone with you for support**, and get them to take notes.
- **Ask the professional if you can have copies of any notes taken.**
- **Don't be afraid to ask questions**, especially if you don't understand what has been said. If you're still confused, ask again.
- If English is not your first language, **ask for an interpreter.**
- **Be prepared for clinics running late** and take activities to occupy your child or ask if your child can be seen before others who are more able to wait.
- **Choose who is present** and say no if onlookers might make you or your child feel uncomfortable.
- **Have faith in your own experience of your child**, you know your child better than anyone else.

When you're presenting your case, like at social services, sometimes you can just get so upset, because you're going through all the worst things, aren't you? Trying to explain to somebody what it's like, it can be really upsetting...

And afterwards:

- **Follow up appointments with questions in writing** or by email if you think of them later on.
- **Ask when you can expect replies to requests** - make a note in your diary and follow it up if you haven't heard by then.
- **Make sure you meet deadlines**; it's in your interests to think ahead.
- **Make sure professionals know if you're unclear or unhappy about anything**, a brief word or telephone call may be all that is needed to sort things out.
- **Let people know in writing if things start to go badly wrong**; don't wait until you're at crisis point.

- **Don't feel bad about changing specialists** if you don't get on or feel their approach is wrong for you or your child.

I complained to the consultant about the way I was treated in hospital. I wrote this great long letter, and I was so impressed with myself afterwards, because all the grievances came out, and I thought 'Oh God, she's never going to speak to me again'. But I sent it off, and she was excellent, and it never happened again...

LOOKING AFTER YOURSELVES

I found that you just do everything. Everything that came: 'Yes, she'll do that, oh yes, we'll go to that, yes, we'll do that'. I tried to carry on doing everything and then I couldn't manage, really. But then it needed someone else to come in and say 'It's all right, actually, you don't have to do all these things, and Alex will be perfectly fine if she doesn't do these things'... I felt she needed so much input.

Looking after your child

- **Remember that not every minute of your child's time has to be filled** with something educational/useful, do things you both enjoy without feeling guilty.
- **Get any information on your child's condition that you can**; national organisations can give support, advice, and perhaps information on the latest research into your child's condition.
- **Ask your support group to help.** Remember, they've heard it, seen it, and been there. They may be able to go to meetings or reviews with you, or write letters of support for you. Use them.
- **Explore financial help** and don't feel embarrassed about asking for it. Remember, not all benefits are means tested.
- **Ask other parents about their experiences**, they will often be your best source of information.

- **Teach your child to be as independent as possible**, it will make your life easier in the long run.

Rose is good now, she takes her own medicine, and she has done for two years, because she was on such frequent doses. Looking ahead, the only way to get through it was to teach her to do what she could as a normal thing, every day.

Looking after the whole family

- **Try to do things as a family** - it's easy to concentrate too much on your 'special' child and get the balance wrong.
- **In the early days or during a crisis, appoint someone outside the immediate family to be the contact person for news**, to pass on messages or let people know when they can visit.
- **Don't be afraid to take the phone off the hook** and enjoy what peace and quiet you can.

It's looking ahead at a strategy that is not going to crack any one of you up - you can't have a weekly routine that's going to leave you exhausted.

Looking after you

- **Don't be ashamed to say 'I can't do this any more'**, ask for help when you need it.
- **Find someone who'll listen and take you seriously**, not necessarily a qualified person, just someone you get on with and trust.
- **Be selfish** - if you go under everyone will suffer. Put yourself first for once.
- **Find ways of pampering yourself** - maybe have a massage or some reflexology. It needn't be expensive. The Carers' Card, run by Amaze in partnership with the local council and the Carers Centre, offers lots of discounts and deals on

activities across the city that aim to improve the health and wellbeing of carers. Read more in our chapter on Leisure or contact the Carers Centre to see what's on offer at the moment.

- **Be prepared to deal with well-meaning but insensitive comments sometimes**, even from family and close friends. In time, you'll find you get better at hearing what people mean to say.
- **Make sure any groups you join are supportive** - if you come home feeling worse it's not worth it.
- **Have an interest outside the family**, like work/sport/a hobby. Having somewhere to go where you're treated the same as anyone else puts things back into perspective.

I play sport - that's my stress relief. I think it's essential, and nobody asks you how your child is - I'm a person! It keeps your mind and body together.

Being listened to - that's really important, to have people around who are prepared to listen.

GETTING SUPPORT FROM OTHER PARENTS

Finding out that your child has special needs may be very painful. Even now, sometimes years after we first heard the news, many of us still relive and remember everything that happened at that time. Our children are all very different, but the one thing we all have in common is that we all needed to talk about what had happened. For some of us, having a supportive family was enough. Some of us by chance met someone who was a marvellous shoulder to cry on. Others, often at the suggestion of a health visitor or other professional, were pointed in the direction of a parent support group.

Groups for specific conditions

It's useful for a parent to meet another parent who's got a child that's a bit further down the line...

Especially in the early days, many of us found that joining a parent-to-parent support group specifically for our child's condition was a life-saver. If your child has just been diagnosed and you're frightened of what might lie ahead, meeting a parent with an older child with similar needs to yours can make you feel you will be able to manage. People with children who have similar needs can be a great source of support and information, and they may also become good friends.

That's what I found the most helpful - that other couples had gone through the same things as me, and you know they're still around - sometimes you tend to think you are the only person that this has ever happened to.

There is a regular parent-led autistic spectrum support group called mASCot which meets monthly at Emmaus in Portslade. T21 is a Brighton group for parents of children with Down's syndrome and their families and the Dyspraxia Foundation also has a local support group that meets regularly in Hove. Amaze has details of many other support groups for specific conditions, both local and national, on our website. Or you can look at the national and local contacts at the back on this book.

Parent-led general support

There are a number of regular support groups in Brighton and Hove for parents of children with additional needs. Sweet Peas parent and toddler group takes place on Friday afternoons at Tarner Children's Centre on Ivory Place. Brighton Pebbles is a group for families with disabled children aged 4 to 14. Kaleidoscope is a group specifically for parents of children with physical disabilities. There are two Kaleidoscope groups: Little

Wheels is for 0-8s and Wheels is for 8-16s. Little Darlings is another group for parents and children aged 0 -10 with any additional needs. Link Up is a social group for families of children with SEN in mainstream schools. You can find the contact details for all these groups at the back of this handbook.

What I found most important was finding the right person on your wavelength, who you actually can get on with as a person and has got the added thing of having an appropriate special needs child. I was lucky - I had this girl down the road, but she's moved now, and I really miss her.

Amaze runs a regular 'Parents with Teens' group for any parent with a child who is 13 upwards. It's a chance for parents to get together and discuss things that are important to them. Check our website for latest event details.

Nationally, Contact a Family operates an online forum at www.makingcontact.org. The forum enables families affected by disability to make contact safely online and talk about issues that affect them

Community support groups

There may be parent groups in your area that are not specifically for parents of children with special needs. For example, single parents or parents from minority ethnic groups may benefit from support that takes account of their particular needs. The Black and Minority Ethnic Community Partnership is there to provide support and information to people from different ethnic backgrounds. If you are a single parent, Gingerbread and Single Parents Information Network (SPIN) may be able to put you in touch with other parents in similar circumstances. If your child is lesbian, gay, bisexual or transgender, Allsorts has lots of resources and a parent group that meets regularly.

Working Families may be another useful organisation. They produce a factsheet, 'Waving Not Drowning', for parents trying to combine paid work with caring for children with disabilities.

GETTING SUPPORT FROM PROFESSIONALS

There are many local and national organisations that can offer information and support to parent carers. Some cater for certain disability groups; others are for anyone who may be caring for a child with additional needs.

General support

Amaze's helpline is there to give advice and support to parent carers about any issues that affect them. We can send you our publications or offer you practical one-to-one support with education issues and claims for benefits like Disability Living Allowance. We also run courses and hold regular meetings for parents of teenagers. Or we may just be a listening ear in times of trouble.

Other important local sources of information and advice for parent carers are The Fed Centre for Independent Living, the Carers Centre and the council's Family Information Service. Contact a Family is a national organisation which offers help for parents of disabled children. They produce information sheets on a variety of topics, a quarterly magazine and a directory with information about specific conditions.

If you have a child who is under five, many of the services you will need to use are located in your local Children's Centre. These include health visitors, advice on child development, support for additional needs, speech and language therapists, family support, early education and childcare. There are six main Children's Centres in Brighton and Hove: Conway Court and Hangleton Park in Hove, Moulsecoomb, North Portslade,

Roundabout in Whitehawk and Turner Children's Centre at Ivory Place. Smaller gateway children's centres also provide information and advice and have services visiting periodically. These smaller centres serve a local area and are based in schools, libraries or community venues.

Family Lives is a national charity that offers help and support to anyone caring for children. They have lots of information on their website, arranged according to your child's age or around particular issues like bullying, work or relationships.

Find the contact details for all these organisations in the 'Useful contacts' section at the back of this book.

At certain times, however, you may need more specific support.

DEPRESSION

Being a parent carer can be extremely stressful so it's not surprising that many of us experience depression at one time or another. It can be very hard to admit you're not coping, quite apart from dealing with the guilt you might feel at not always being happy with the hand life has dealt you. But you don't need to suffer in silence. Apart from your friends or your GP, there are some other places that offer you the space to talk, and this can often make the difference between coping and not coping. Sharing your problems will relieve some of the pressure and help build your resilience to cope with future demands more easily.

The ability to speak to someone you know will listen and know what you're talking about - that's the most important thing for us, to be listened to and to be taken seriously. I know if we didn't have that we wouldn't survive.... it literally keeps our family together.

Local counselling services

If you think you'd benefit from a place where you could talk openly with one person about how having a child with special needs is affecting you, you could think about counselling. Some of us have used a trained counsellor when our child was first diagnosed or much later, but we had to ask for it - counselling isn't offered routinely.

People think you're coping, and you're not. People think because you're not falling apart all the time and going round in shrouds of grey, they think everything's fine and hunky-dory.

There are various kinds of services available in this area. Help may be short or longer term, it may be free or involve payment. If your mental health is at risk you should talk to your GP about talking therapies available from the NHS. But the following are all counselling services that particularly understand the issues around parenting a child with additional needs:

The **Seaside View counselling service** is a free service for parents whose children have complex needs and a learning disability and are being seen by one of the practitioners at Seaside View Child Development Centre. Call the counselling service on 01273 265787. They may also offer mindfulness groups.

The **Parental Support Counselling Service (PSCS)** provides low cost counselling by qualified counsellors, to parents, siblings and carers of a child or young person with a disability or special need. There is a small charge of between £5 and £20 and the counsellor will discuss this with you in advance. Find their contacts details at the back of this book.

The **Fed Centre for Independent Living** offers a counselling service for disabled people and their parents or carers. The

initial 50 minute assessment is free and subsequent sessions cost between £5 and £20. No one will be turned away due to an inability to pay. Call them on 01273 296747.

Relate can sometimes offer free counselling to carers including parent carers. To check if this is currently available contact the Carers Centre first.

Chestnut Tree House provides counselling for parents of children who are using their services for children with life limiting conditions.

Families Plus is a counselling service run by Sussex Central YMCA as part of the Dialogue Centre. Their services are sometimes free but usually means tested. Call them on 01273 320530 or email dialogue@sussexcentralymca.org.uk.

Sometimes, other organisations offer counselling or therapeutic groups for parent carers. Contact our helpline for the most up to date information.

RELATIONSHIP DIFFICULTIES

It would be dishonest of us not to say that sadly, having a child with special needs can lead to much unhappiness between parents, and even the breakdown of their relationship. Sometimes it's because it's so hard to spend time together away from the children. Maybe one partner has to devote so much energy to dealing with appointments, therapies and so on that the other partner feels left out, or chooses to stay uninformed of what's going on.

The flip side of that is that some of us found the opposite effect; that as a couple we were brought closer together.

Relationship counselling

If you're beginning to worry that your relationship is in trouble, there are organisations that can offer support and a place to let off steam, for example, RELATE. Contact a Family produce an excellent guide called 'Relationships and caring for a disabled child'. It was created in association with One to One, a leading relationships research charity and covers topics like maintaining intimacy, managing differences and what to do when relationships break down. Call them for a copy or download it from www.cafamily.org.uk.

We've found weekends away absolutely essential. We save up, we go to a hotel. The Link family have Jane, and somebody else has to have the others.

Family work

Most of us have found that having a child with special needs creates stresses and strains within the whole family. Sometimes getting help which focuses on the needs of everyone in the family can be helpful.

Your family could be referred to the Child and Adolescent Mental Health Service (CAMHS) to see if you could get family therapy. Families are usually referred to CAMHS by a professional such as a GP or social worker.

Brighton & Hove Children's Services can offer support to families in crisis. Your local children's centre (for under 5s) or your child's school should organise a CAF meeting to get this underway, but you can also contact MASH, the Multi-Agency Safeguarding Hub, on 01273 295920.

Safety Net's Families Team work with East Brighton families with children age 4-11. They offer support to parents, individual children or the whole family on issues such as relationships,

schooling, managing children's behaviour and bullying. They work in partnership with families building on their strengths and the resources of the family and their community. Call 01273 419725 to find out more.

Dialogue Families Plus is the name of a counselling and mediation service run by Sussex Central YMCA for children, young people and their families. They offer a safe space and time out to think about solutions which may help improve your family's well-being. To find out more, call 01273 320530.

The Dialogue Linx Family Support project also offers a range of flexible support through some schools in Brighton and Hove. The service, in essence, aims to help families rebound from tough times. They work with parent carers, children and young people, individually and in themed groups, encouraging the development of community support networks and groups. For further information, call 01273 320500.

DEALING WITH BEHAVIOUR ISSUES

Most parents will have times when they worry about their child's behaviour or their own parenting. As people often say, kids don't come with an instruction manual and this can feel doubly true if your child has special needs. Some of our children have conditions that make them more likely to have behaviour problems. Even needs that are not directly related to behaviour can have an impact; children that are struggling with learning or communicating will often express this by acting up. In fact this is sometimes the first clue there is a real problem.

Lots of parents will also experience other people criticising their parenting or judging them and their child because of their behaviour. This can be from those close to us, members of the public or even professionals we see about our child. We may

find it hard to work out ourselves what is 'normal' bad behaviour and what is down to our child's special needs.

I find I am treading a fine line. I feel awful that I was too hard on him when he was little because I didn't know he had those extra needs and I thought he just wasn't trying. But I don't want to let him get away with things just because he has a label now. I've got to help him learn that some things aren't OK. So every day I am picking my battles, pushing on some stuff but trying to be realistic and kind too. And then you have to try not to take it all personally of course.

There are things that help with behaviour that are worth everyone trying. Here are our tips for getting to grips with this issue and getting more help if necessary.

Things you can do about behaviour

- **Don't waste energy blaming yourself.** Put your energy into helping your child with their behaviour instead. If you are sure your child has special needs don't be fobbed off by people who tell you it is all down to your parenting. Keep looking for answers. But this is not a reason not to do everything you can to help your child with their behaviour too.
- **The principles of good parenting are the same for all children:** love, attention, fun and discipline that is firm but fair. But making changes with behaviour can take longer when your child has additional needs. Be patient and persistent. Think about what is reasonable to expect at your child's age and developmental stage. You may have to take small steps or focus on just one or two issues at a time. Act the part of the calm, in control parent even if you don't feel like this on the inside. And remind yourself on the tough days that giving in to your child is not being kind, helping them learn and grow is kinder.

- **Remember the basics.** All children behave worse when they are hungry, thirsty, uncomfortable or tired and they can't always tell us directly. Sometimes tricky behaviour may tell us other things too, for example that our child is anxious or scared or finds a task or situation difficult. If your child doesn't communicate verbally you'll need to be extra alert to this.
- **Be clear with your child about what they need to do to be 'good' in any situation.** Think about how you tell them what to do. Are you clear? Keep instructions short and simple. Do you get close to them and get their attention? Give them enough time to take in what you say. Would a sign or picture help? Some children benefit from visual timetables.
- **Have some simple family rules that apply to everyone, parents included.** It can help to put them positively, e.g. 'speak nicely to each other' rather than 'no shouting'. Involve the whole family in choosing these rules. You could draw pictures or write them out together to stick them up in the house.
- **Reward the behaviour you want to see more of.** This sounds obvious but often we ignore good behaviour and give lots of attention to the less good. Catch them getting things right and tell them so. Work out what your child finds rewarding and use that. This doesn't mean a trip to Disneyland! It could be an extra bedtime story or their favourite DVD. Praise and attention are best for most children but some disabled children don't respond strongly to these and need more concrete rewards.
- **Keep them busy at home and out and about.** Have plenty of appropriate things for your child to do and things up your sleeve for problem moments like when the phone rings. Some children behave much better if they get a bit more exercise. Activities that make your child feel successful or like they belong to something are worth their weight in gold. See the chapter 'Social and leisure activities'. Be

prepared to keep trying things to find what works for your child.

- **Plan ahead. If you know they will find a situation tricky make sure you have a snack and something to do.** Can you plan a reward on the way home if they behave well? Lots of children find change (big and small) difficult. Think about how to warn them that a favourite activity must end or that their normal routine will be disrupted.
- **React quickly, firmly and consistently to problem behaviour.** Use consequences that you know you can and will follow through. It can work better to actually take away a toy for five minutes than threaten to take it for five days. Focus on the behaviour as the problem not the child and avoid saying things that are hurtful rather than helpful. Aim to use responses that help children learn to do better in future e.g to calm themselves. Angry responses like shouting can seem to solve things in the short term but bring more problems in the long term. That's why people may suggest to you ideas like reward charts and time out. These can really work and it helps to find out how to do them most effectively.

Where to get more behaviour help and advice

- **Make use of any parenting advice on offer.** For younger children try your local Children's Centre. Websites like Family Lives and Netmums have information and the chance to ask other parents for ideas. There are some great books on parenting and some about behaviour and specific needs such as ADHD or ASC. Try the library. ParentChannel.TV is a website with a series of short videos you can watch on line that cover parenting from toddlers to teens. Lots of parents have watched Super Nanny. Some of her approach is over-simplified to make it fit a TV programme, but again the website has more detail. Share ideas with your child's school or pre-school about what works at home and at school. Find out who is best to ask. It

could be the SENCO or class teacher or perhaps someone else in school such as a learning mentor. If you are in contact with family support services or community CAMHS workers try them for advice.

- **Find out about parenting courses such as Triple P on offer locally.** The Parenting Team page on the Brighton and Hove council website links to a list of current courses. Nearly all the strategies covered by these courses will apply to your child even though they have additional needs. Amaze runs Triple P parenting courses that are especially for parents of children with special needs. Call our helpline to see if there is one coming up or visit the events page of our website for latest information. You can also download a leaflet all about courses for parent carers on the Training and Support page of our website. Other courses like Insiders' Guides at Amaze and Time Out for Special Needs and Time Out for ASC at Seaside View are not all about behaviour but can still help. Just talking to other parents who face similar issues about behaviour can make a difference.
- **If your child is at a special school, you can ask the school for advice.** They have a lot of expertise in managing children's behaviour and sometimes run advice sessions for parents where they work to share this expertise. If your child has learning difficulties and challenging behaviour you can get specialist support and advice from the CAMHS Learning Disability team located at Seaside View and The Aldrington Centre, Hove. This may include one to one advice at home. Call 01273 718680 to find out more.

One of the hardest things to cope with can be the lack of understanding from people we meet, especially when our child has an invisible disability. Some parents find it helps them to have a sentence they always use to explain that their child has special needs, something like 'I know his behaviour is unusual. It is part of his special needs'.

Finally, no-one should struggle on alone with behaviour and parenting worries. This is one area where it important not to be embarrassed to ask others for ideas and support.

BEREAVEMENT

Some parents may live for years with the knowledge that one day their child will die. Some of you may have already lived through that.

When a child dies or is terminally ill, it is a desperately sad and sensitive time for parents, siblings, other family members and close friends. Other people don't know what to say and, being afraid of saying the wrong thing, they often say nothing at all. Those of us who have lost a child, however, often want to talk about him or her - we long for people to mention their name and share memories and stories. Frequently our lives have been very closely involved with our child's physical and medical care and suddenly this has all stopped. There's a huge gap. Some of us found it invaluable to talk with other parents who had had the same experience, or just someone who could understand our feelings.

Professional support for bereavement

For parents in this situation, there are a number of sources of support that may prove useful. Child Bereavement UK runs a confidential support and information line that gives help and guidance to bereaved families. Their website also offers lots of literature and resources and an online forum that enables parents to share their experiences. For parents who have lost a child, the Child Death Helpline, run by bereaved parents from Great Ormond Street Hospital, provides home visits, a befriending service and a booklist. The Compassionate Friends and CRUSE support both bereaved parents and other family members and CRUSE have a local service in Brighton.

Practicalities

As if coping with grief itself wasn't enough, there are funeral arrangements to sort out as well. Funeral directors don't charge for their services for babies' and children's funerals, and a number of them provide extra support for families who have lost a child. There's a lot of sensitive and practical advice about funerals on the website of the Child Bereavement Charity (www.childbereavement.org.uk) or you can call their helpline on 0800 02 888 40 for specific information. The Bereavement Advice Centre can also give advice and support about all the practical issues to manage when someone dies. Visit their website at www.bereavementadvice.org or call 0800 634 9494.

For details of any of the organisations mentioned in this chapter see the 'Useful contacts' at the end of this book. Or if you have questions about any of the things we mention, just call our helpline.