

CHAPTER I

Finding out what's wrong



We've put this handbook together for you because we've all had stressful times in coming to terms with what's happened to our children. Though we're quite a large group of parents, none of us felt exactly the same when we realised something was wrong with our child. Some of us tried for a long time to kid ourselves that there was nothing wrong; others tried really hard to convince their doctor or health visitor that there was a problem. Many of us felt completely devastated to start with, then somehow angry. Why us? Did we do something wrong? Could we have done anything to prevent it? Why wasn't it picked up during my pregnancy? And yes, we all felt bereft: 'This isn't the child I expected', however much we love the child we got.

To me, it was like someone had died, and it takes a long time to come to terms and to be rational about it afterwards.

Many of us felt crushingly guilty at some of the thoughts that went through our heads: 'I don't want this child. I won't be able to cope. I don't want to have to cope'. We want you to know that whatever you're feeling at this moment - anger, despair, fear or overwhelming protectiveness - somebody has been there before.

I was frantically making out that it was going to be all right, although I really knew that there was something wrong...I was fighting it all along.

WHERE IT ALL BEGINS

Some of us know there's likely to be something wrong before our child is born; some of us find out during the early years; some of us may be told about particular problems when we foster or adopt and a lot of us find out once our child starts school.

You may have concerns yourself or a professional may pick them up. Usually the first person you talk to about the problem will be your health visitor, GP, or someone at your child's nursery or school. They may then refer you to one of the specialist health services at the Seaside View Child Development Centre, CAMHS (Child and Adolescent Mental

Health Service) or the Royal Alexandra Children's Hospital. You can read more about these centres in the 'Health' chapter.

But however and wherever the problems are first picked up, it's rarely going to be a neat and tidy moment of revelation – 'he has X and you should do Y'. In fact, many children with special needs never get a specific diagnosis. Their needs may be too complex, or their symptoms don't fit a pattern, or there may simply be no identifiable reason for the child's condition.

You may more often be at the beginning of a frustrating ongoing process of trying to work out what's wrong and what you need to do.

WHEN YOU GET A DIAGNOSIS

Many of us thought that getting a diagnosis for our child would be like getting the answer to our problems. We didn't realise that having a specific diagnosis would come with its own set of pros and cons.

We were shocked when we eventually got a diagnosis, which we weren't expecting to be serious.

For example, some of us found that having a specific diagnosis for our children meant they were not eligible for certain schools, or for services that we thought were appropriate. Also, if you get a diagnosis, your child is automatically labelled and there may be no expectation of ability.

On the other hand, some of us found that having a specific diagnosis was very helpful because we could start to read up on the condition, join relevant local or national organisations, find out about latest research and, perhaps most importantly, meet other parents in the same boat as us.

Amaze publishes a range of fact sheets about specific disabilities or conditions such as autism, Down syndrome and ADHD. The fact sheets give you essential information about a particular condition and signpost you to the local services and organisations that can help. They also include reliable sources where you can do more research. Download our fact sheets at www.amazebrighton.org.uk/resources/publications/fact-sheets or call our helpline for copies.

We know that finding out what's wrong is one of the most stressful times for a parent, so we've thought about some of the strategies that helped us cope with this difficult time.

Strategies for coping with diagnosis

It can be worth thinking about what you can do to make better sense of what you are finding out about your child.

You have the right to expect to be given information in a respectful and sensitive way, delivered by specially trained staff.

- If you are expecting news, take someone with you for support
- Don't worry unnecessarily; make a list of questions you want to ask and take this with you. Ask about anything that is worrying you
- Ask if you don't understand what has been said and don't be rushed, take time to think

- Ask what will happen next, who you can speak to regularly for advice and where you can get more information
- Professionals cannot always tell you how things will turn out
- Sharing news with other significant people in your life can be really tough, so ask for help
- Talk about how you are feeling with the rest of the family but avoid blaming each other
- Remember they are the same child they were the day before
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Sometimes parents want medical diagnoses confirmed. Usually this is not because they don't trust the doctor, but simply that they need to feel absolutely sure that they have explored every possible avenue on their child's behalf. Some doctors are very sympathetic towards these feelings. Your child's GP or consultant may be willing to refer you to a different consultant for another opinion, but they don't have to do this if they don't agree that it's necessary.

Parents who can afford to might choose to approach consultants on a private basis. Private health care is very expensive and it is not at all easy to discover for yourself who is an expert in any particular condition. You may be able to get advice about these matters from The Patients' Association, the Care Quality Commission or Healthwatch.

Whatever your child's diagnosis, talking to someone who understands can really help. Amaze's Face 2 Face Befriending service offers emotional support to parents of children with additional needs at any difficult time, but particularly at the time of diagnosis. Call our helpline on 01273 772289 to ask about Face 2 Face befriending or email amandam@amazebrighton.org.uk. We'll tell you about lots of other support services in the next chapter.

If your child has a specific condition, the relevant local or national support group may be able to provide advice or help. Some of the larger national organisations have medical experts of their own or websites with lots of resources. And Contact a Family holds details of even some of the rarer conditions.

Local groups like T21 and mASCot are great places to meet parents of children with Down's syndrome and autistic spectrum condition respectively. There may be different approaches that other families have found, or a different angle on the problem you are facing, or it may just help to talk with parents who have had to face similar situations or make the same tricky decisions.

You can find the details of these local and national groups (and many more) in the Useful contacts at the back of this book or on Amaze's website in the Useful Contacts directory.

WHEN YOU DON'T GET A DIAGNOSIS

I expected them to be able to tell me what was wrong and they didn't, they couldn't, as it were, so that was a bit of a shock. It shakes your faith a bit, doesn't it?

Some of us will never get a concrete explanation of our child's special needs. Some will get vague diagnostic labels like 'global development delay', which can suddenly transform into a 'developmental disorder'. Some will find that they'll start off being told their child has one thing, only to be told they have another in later years.

Furthermore, without a concrete diagnosis, professionals can find it very difficult to give you answers to those difficult questions about the future: 'Where will my child be in ten

years' time?', or 'Will he grow out of it?' And it's not just the dealings with professionals that are more problematic. Without a label, family and friends can find it more difficult to accept there is a problem and to give you the support you need. And if the diagnosis changes, they need to assimilate this too.

These states of 'not knowing' or 'all change' can be a huge emotional struggle for families, as can the strain of pushing and pushing for a proper explanation. For many parents it's a battle worth fighting. Though a diagnosis is not the Holy Grail, you should trust your instincts; if you sense something's wrong with your child, keep pursuing things to get answers or, more importantly, get the right support for your child. On the other hand, some of us may just need to learn to think of our children as a bit quirky or eccentric or fragile and stop searching for the perfect explanation.

Here are some key things to remember when struggling with not having a diagnosis.

Strategies for coping with not getting a diagnosis

- Focus on what's really important – namely working out what help your child needs, not what label they have.
- Find an explanation that works for you. You might not be able to tell friends 'my child has such and such condition' but perhaps you can say something like 'his instincts are not like other children's' or 'she has difficulties with understanding social situations'.
- Just because you don't have a diagnosis, that doesn't mean you're not right to be concerned and to ask for help for your child.
- Access all the help you can as early as possible. Even if your child does grow out of their difficulties this will help them in the meantime and if they don't, you'll be glad you acted quickly.
- You don't need a diagnosis to get all sorts of extra help for your child, for example extra support at school or DLA – so ask for it.
- Sometimes you will need evidence about your child's needs or difficulties but that's not the same as a diagnosis. For example, for claiming DLA you will need some confirmation from other people that your child needs extra help but this doesn't mean a specific diagnosis is necessary.
- Watch for change, monitor your child's progress. They might not have met the clinical criteria for a particular diagnosis at three, but if they're still demonstrating certain behaviours at seven, they may now be diagnosed.
- Call Amaze. Our helpline advisers will give you advice and support whether your child has a diagnosis or not.

• Amaze produces a fact sheet called 'Living without a diagnosis'. Download it at www.amazebrighton.org.uk/resources/publications/fact-sheets

I was totally devastated when he got a diagnosis of autism aged 7, after years of being told he had 'speech and language delay'. I really believed he would just grow out of it – I think I used the lack of diagnosis as an excuse not to face up to the severity of his difficulties. I wish now I had accessed more help at an earlier stage.

'LOOKED AFTER' CHILDREN

Adopting and fostering children with additional needs throws up a unique set of experiences and problems. Sometimes you will get a lot of information before you become a family, sometimes not much at all. Maybe you'll have a rosy idea that it will all be OK once your son or daughter is in your home and the social workers have gone away. Then,

when it doesn't quite work out like that and the social workers really have disappeared, it can be hard and you can feel suddenly abandoned.

You can feel like you've got an extra set of uncertainties with an adopted child, because you probably don't know anything about the birth parents' medical histories, any genetic conditions, what blood group your child is or even if they have any allergies. And when someone asks you what they were like as a baby, you simply don't know.

The majority of fostered and adopted children will have some sort of attachment difficulties. Asking for help with this does not mean you are not being a good parent. Likewise, many fostered and adopted children will have other special needs and these can be difficult to diagnose or sometimes missed because you are busy dealing with the behavioural and other issues that your new child has. But don't be fobbed off. If you know something else is wrong, pursue it with your GP, child's school or health visitor. And don't forget, the fact that you may be getting a fostering and adoption allowance does not mean you can't claim disability benefits for your child like DLA.

We thought our health visitor was OK, although she didn't understand a lot of my child's problems were down to his poor start in life before we had him, so sometimes we felt unfairly judged. Then we got a new health visitor who had read up about issues to do with adopted children, and if she didn't know she was eager to listen to us, which made us feel valued.

If you need support, obviously you can talk to Amaze and all the other organisations we discuss in this book. However, there are certain agencies or organisations that are specifically for adoptive parents or foster carers.

Brighton and Hove's Adoption team runs a weekly 'drop in' for adopters and children under five and various support groups for adopters and children of different ages. There is also a lesbian and gay adopters and foster carers group run by the parent carers themselves. The Adoption team also runs social events for parents and children, workshops for Brighton and Hove adopters and a Parenting Programme specifically for adopters, in partnership with After Adoption. These are all featured in a bi-annual newsletter. Adopters may also be entitled to an adoption support assessment.

If you are interested in any of these groups or services, or have any queries about the support available, email the Adoption Support Services Adviser on Adoption.SupportHelpline@brighton-hove.gov.uk or ask for the adoption duty worker on 01273 295444. You can also visit the Adoption team's website at www.adoptioninbrightonandhove.org.uk and Facebook page at www.facebook.com/BrightonAdoption.

Adoption UK is a national charity run by and for adopters. It provides advice, support and training on all aspects of adoption and adoptive parenting (www.adoptionuk.org.uk). BAAF (British Association for Adoption and Fostering - www.baaf.co.uk) is another national charity that may offer some useful services and information. After Adoption (www.afteradoption.org.uk) is for those who have been adopted or birth families and New Family Social (www.newfamilysocial.co.uk) is run by and for lesbian, gay, bisexual and transgender adopters and foster carers.

You suddenly have to become an expert in certain things, like attachment, behavioural problems, loss ... and you have to learn the terminology to understand what everyone's talking about, especially the

social workers. At one meeting I went to, my new health visitor assumed I worked as a social worker because I could talk knowledgeably about all the terms they used!

PROGNOSIS – THE NEVER ENDING STORY

As we said at the start of this chapter, lots of parents find that understanding their child's particular needs is less of a lightbulb moment and more of an ongoing saga. For example, you may start out being told they have one thing only to be told it's something completely different a few years later. Or you may just acquire additional labels going forward. Still more will find themselves forever trying to get their heads round a vague collection of learning difficulties and development delays for which they never get a satisfying explanation.

Although I was unprepared and felt uncertain ... I was relieved to find he was as loveable as my other children.

Whatever your story, we aim to support you at times of change or discovery through our helpline or through our Face 2 Face Befriending service.

FINDING OUT MORE

Amaze's helpline is there for you to discuss any of your concerns around diagnosis or not getting a diagnosis. The helpline advisers have access to a lot of information or will do research for you to try and find the information you need. They will put you in touch with groups or services that might help. But perhaps most importantly, they will happily be a shoulder to cry on when times are tough. See the telephone number and opening times on the back cover.

These days many of us will use the internet to search for relevant websites that can enlighten us about our child's special needs. We may even have used them when we were trying to work out what was wrong. Contact a Family or certain NHS websites may be useful for this kind of information gathering.

If your child receives a specific diagnosis, you will find that many of the most common conditions have local parent organisations or certainly national organisations where you can get more information. Check the contact details at the back of this book.

If your child has a rare condition it may be more difficult to get the information you need. We produce a fact sheet called 'Rare syndromes' which you can download from the Resources area of our website. Contact a Family produces a comprehensive directory of specific conditions and syndromes with details of their family support networks. You can find this on their website at www.cafamily.org.uk/medical-information/conditions. You may also be able to get information and advice from Unique and SWAN, organisations that aim to link families who have children with rare chromosome disorders or undiagnosed genetic conditions. Contact a Family also co-ordinates a contact network for parents whose children have a rare condition or no specific diagnosis. Find the contact details for all these organisations in the 'Useful contacts' section of this handbook.