

Family reactions

Chapter 2 from *Deaf ability not disability: a guide for parents of hearing impaired children*

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There is no correct or incorrect reaction to being told that your child has a permanent hearing loss. There is a flood of emotion which must neither be dammed up nor allowed to sweep you away. No one can predict how any particular family will react; this depends on many factors. As a deaf adult Hilary was in the position of understanding what deafness meant; to her it was the norm, yet this did not mean that the formal diagnosis of her son as being profoundly deaf was a completely worry-free period:

They decided to do brainstem on him at the hospital. After the test I was told he had no response at all; this upset me greatly. Deep down I knew he was deaf but to be stone deaf was extremely rare. I was completely taken aback... The peripatetic teacher came round that evening to talk about hearing aids and my first reaction was immediately 'no'. I couldn't see that putting a hearing aid on a four-month old baby would help, especially when I was told he had no response. To say I was a bit upset was an understatement. It was Fiona's playgroup leader who had the most helpful advice. She said, 'Never mind, you are the best person to help him, having gone through the experience yourself.' Everyone else had said they were sorry but I knew then she was right, it was up to me to help him as best as I could.

As a teacher of the deaf Wendy has faced the other end of the problem:

Parents are upset, devastated and often aggressive; this is to be expected. They are full of questions which are impossible to answer. When will our child learn to speak? What sort of school will he go to? and so on. They are in a very vulnerable position. It is important for them to see you in a positive light but not as the 'source of all knowledge about deafness', no one is that. Some parents want to rush into action and try anything and everything straight away, others are numb and unable to take anything in at all. Families need time, support and advice so they can make informed decisions about their child. They do not need pushing, converting to a particular approach or to be 'carried around' by professionals who are keen to be invaluable.

To the majority of parents deafness is something they know little about. When they are told their child is deaf they are faced with a totally unknown quantity. The child whom they know better than any other person is suddenly labelled with something which is completely foreign to them. The hearing test can be worrying to parents, and a negative result is often devastating:

Brainstem – I remember thinking it sounded awful, what on earth were they going to do to her? They explained she'd have to be put to sleep and have things stuck on her head – I couldn't cope at all. My husband

took the day off to go to the hospital. There were a lot of children being tested and they were all fine, no problems. We were last. They came out and said she was profoundly deaf – I didn't hear those words. I was so shocked, I just felt ignorant. I said 'Oh you mean she'll have to wear deaf aids?' 'No', they said, 'hearing aids.' I felt so stupid, I didn't know anything about deafness. It was all arranged, we were given an appointment the next day, a bus route, times and so on. It was all too much. I felt so awful. They asked me if I'd realised she was deaf, hadn't I banged doors or shouted or anything? I think I would have liked a little time just to let it sink in – to have someone to chat to, not appointments and official people. (Mother of a profoundly deaf girl.)

It is natural for parents to want their children to be happy and healthy, and to live a full life, so diagnosis of a hearing loss is inevitably a shock. Parents no longer know what to expect. Here are a number of extracts from parents' accounts which illustrate painful but normal reactions.

I can remember very clearly the absolute devastation. I thought of the simple deaf person who couldn't talk. I saw other little girls chattering together and thought my daughter will never do that. I didn't think she would ever learn to talk.

I was upset when she was diagnosed because it was something I knew nothing about. (Parent's comments about their severely deaf daughter.)

I spent my time in tears just being sad for what was lost and for not understanding Sofie's problem sooner. (Mother of a deafened child.)

When I found out my child was deaf, I cried. I couldn't believe it. I was angry too but I didn't know who with. Then once I got used to the idea I was angry with everyone who kept saying 'no he can't be'. (A deaf mother of a deaf son.)

I just felt grief, I couldn't believe it was true. I spent hours walking around the house with earplugs in trying to imagine what life would be like for him. (Grandmother of a partially hearing child.)

It was a strange time; three or four weeks before we'd had a little boy, now we had an officially deaf child. (Mother of a son who had meningitis.)

Families need to regain control, to balance the situation and to start making some practical adjustments. The whole family is affected by the diagnosis of a specific problem, brothers and sisters, grandparents and neighbours. A sense of panic at not knowing what to do or expect, or of sinking under a mass of advice can easily force parents into a position where they do not know what to do – so they do nothing.

When we were first told Christopher was deaf, I watched my daughter turn from being a happy young wife and mother into a bitter tormented girl. She would not accept that her child was deaf for a long time. When she did at last come to terms with the situation she coped marvellously by expecting Christopher to behave like a hearing child. I have nothing but admiration for my daughter and her husband. (Christopher is partially hearing.)

I felt as if I was the only person in the world who this happened to, the only one who had to struggle to cope. (A mother whose daughter has a dual handicap.)

I tried to be practical and not let it complicate my life, I cried too. A few weeks later all the negative aspects kept coming into my mind. (Mother of a profoundly deaf son.)

It was very important after swimming around in a grey area for so long – we were going to make the decision. We would look at everything, decide what we wanted for our son then put all our energy into it. (Parents of a child deafened by meningitis.)

Parents often feel very isolated, particularly in the early stages. In many cases it is the mother who receives the majority of professional advice and opinion; this puts all the stress of decision making on the mother and in some cases results not only in tension but also in the apportioning of blame:

My husband works away so when Lee was diagnosed as being deaf, I had to tell his parents and they've always blamed me, as if it is my fault. It caused a huge rift which is still there. My husband blames me because I took Lee to be tested!

If you only ever have visits from the teacher of the deaf at times when only one parent can be present because of work, ask if you can arrange to have a chat with all of you together occasionally. Ask if there are evening meetings for parents, contact your local branch of the National Deaf Children's Society, ask to be put in contact with the Social Worker for the Deaf who will be a sympathetic listener, and remember that the peripatetic teacher of the deaf is there to support and advise you too.

Sometimes the feeling of isolation is the result of physical isolation, but in other cases the professionals who should be offering support fail in their duties, with unforgiveable results:

We needed support, information, advice, the chance to talk things over; instead we struggled, we blamed ourselves and we all suffered. (A family with four children with hearing losses where all were diagnosed very late.)

Through all the emotional turmoil it is easy for parents to become distracted and to forget that whilst their child has a hearing loss, he is in every other way the same child. The special smile he gives you, his favourite toy, splashing in the bath, throwing his half-finished meal across the kitchen, fear of the dog or delight at balloons—none of these reactions will be changed because of a label of deafness. To a child who is born deaf, deafness is accepted, it is what he knows. It can be very difficult for him to understand the looks of worry, sorrow and anger on his parents' faces. He is not aware of what he has done wrong; like all children he simply wants to be accepted.

We could not accept he was deaf, then someone showed us how he had adapted: if he could see the teacher's face he was fine'(parent of severely deaf son).

Children who are deafened face a harder task but show their ability to change and get on with life: Justin was the one who adapted, we found it a lot harder (Justin was deafened by meningitis);

I don't think she knows she's deaf, she needed time to adjust to her hearing aids but now there are no problems (parents of a girl deafened at the age of two).

It is easy for any parent to mistake difficult behaviour in a young child as reaction to his hearing loss rather than being normal development. Most two-year-olds have temper tantrums at the most inconvenient times. A determined three-year-old may hold out for what he wants for hours. Sit down strikes, scribbling on the wallpaper, snipping new trousers to see if the scissors work or emptying the contents of the fridge on to the kitchen floor are activities enjoyed by many young children, if not by their parents. Deafness does not cause bad behaviour and it should not be used as an excuse for bad behaviour. The nine-year-old who throws a temper tantrum because he cannot have some sweets, and is excused because he is deaf, is a sad child. The parents have overcompensated for his deafness by allowing him his own way; he manipulates the situation to ensure that he gets what he wants. Life is much harder if you do not know how to behave; people will forgive

many things, but rudeness is not one of them. When faced with these situations, as all parents are, simply ask yourself 'Would I let a hearing child do that?' If the answer is 'No', then it is 'no' for any child. All children make mistakes and learn from them, it helps them to grow. Parents' natural protective role towards their children can be difficult to break but all children have eventually to learn to be independent; the longer you put this off the harder it becomes for all concerned.

I always feel I want to keep Christopher on a lead even though he is now six, in case he takes off into any danger and I can't reach him in time. (A grandparent's comments.)

At first we were overprotective, watching her like a hawk, grumbling at her parents for allowing her to play outside, until one day our son-in-law told us we can't cage her in like an animal. She is a normal healthy girl who can't hear. She loves to be with other children and plays very well and other children have accepted her as one of them. (A common reaction felt by grandparents.)

We know it's important to treat Michael normally, he is almost twenty-two! We do worry, it's like suddenly having a younger child again. I think of all kinds of ridiculous situations, like train crashes and panic, how would he know which way to go if he couldn't hear people shouting. I know it is stupid but I can't help it. (Michael was deafened by meningitis as an adult.)

All children bring their share of joy and laughter, of worry and sadness, and a deaf child is no different. This may seem hard to believe at first but the case studies that are included in the second section of this book may help you to accept this. We hope so. Brothers and sisters are in a very difficult position. The need to find out about things such as hearing aids and lipreading, as well as attending clinic and the visit of your peripatetic teacher all focus attention away from the rest of the family. Hearing impaired children do have some special needs but in emphasising these, and the major role parents play, it is necessary to stress that all family members have their own special needs. It is very easy for brothers and sisters to be excluded, even though this is not done in an intentional way, but creeps in unnoticed. The hearing impaired child needs to be in a position to see to lipread, to be near so he can use his hearing aids, to have things explained clearly and then repeated if necessary. But hearing brothers and sisters need just as much love and reassurance that your time is also available to them, that their strengths and weaknesses are acceptable because they are individuals. The fact that they can hear normally does not mean they will be successful at everything, understand everything or always be understanding and helpful. It is not always easy.

All the children need support and help and we tried to give all the children an equal amount of attention, as far as we could. We are a family and we do things together and enjoy it. We've all got different limitations. (This mother has three children, one of whom is severely deaf and has spinabifida.)

Treating any member of the family as special tends only to store up problems which reappear later:

Angela was handicapped and handicapped people had special status. As far as I was concerned Angela was my sister who happened to be deaf, but my grandfather saw my teasing as taking advantage of her disability. I wasn't allowed to have a normal teasing relationship with my sister. This all seemed very unjust. (Sister of a severely deaf girl.)

Many of the parents we spoke to felt pressured by grandparents, whose reactions varied from complete denial of any problem and refusal to accept the hearing aids, to constant interference and criticism of what was going on. One grandmother's own comment helps to shed light on this sensitive area:

I think the most important thing to remember is that any grandparent is not only worrying about their grandchild, they are also worrying about their child. The more you know the more support you can give, but it is important to support rather than interfere or criticise.

Grandparents' concern for their own children can easily lead them into very similar emotions to those of the parents about their deaf child. All those involved need simply to be a family together, to have time to adjust and think. Hilary's own words are a thoughtful reminder of the pressures that teachers can unwittingly exert on families:

I really enjoyed Fiona when she was a baby but somehow with Iain I didn't have the time. I always had appointments to go somewhere or someone coming to see me. I was constantly told what I should be doing, nothing could just happen, every little thing had to be planned out. I think I was mentally exhausted when Iain started school.

Many parents are in the position of never having met a deaf person. They associate the word 'deafness' with a highly negative image: the words 'deaf-and-dumb' always seem to come to mind. Our feeling is that the following comments illustrate the value there is in parents meeting deaf adults and realising that they are as varied as hearing adults. They too may be employed or unemployed, drive a car, get married, own a house, have children and generally get on with life.

I found it hard to believe, then I thought she'd be a deaf child but she'll be able to hear later and just go deaf when she was old – like people often do. Even now, when I know she is profoundly deaf and she will always be, there is a little voice somewhere in my head saying perhaps she will hear again. None of my friends or family believed she was deaf. (Mother of a profoundly deaf child.)

The involvement of an adult deaf person is a good idea, it would help the children to realise that they are always going to be deaf. (Parent of four deaf children.)

A paediatrician's advice to one family was their turning point, after which they were at last able to take decisions after months of helplessness: 'You have a normal little deaf boy here – just go and get on with your lives.' This doctor gave the parents faith in themselves as parents; he reminded them that their little boy was first and foremost a child, and only secondarily did he happen to be deaf. A mother whose son is multiply handicapped in addition to being severely deaf wrote this; her aims are those common to all parents:

He knows he is different but I think he realises his importance, he is there for a reason. The reality is he is deaf in a hearing world so we try to give him every advantage that will make him confident and have some self-esteem. We are not I think, over-indulgent, we just try our best to make him dependent and responsible.



deafnessatbirth.org.uk

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