



Informing, Empowering and Changing Lives Training Conference 2014

Supporting parents with a new-born baby with Down's Syndrome

Compiled by Claire Fisher, with contributions by the parents of WDDSSG

Hearing the diagnosis of Down's syndrome affects every parent in a different way. Good support in the first few days after birth and beyond is essential to help the parents understand the news they have received. We asked the parents of the Wakefield and District Down's Syndrome Support Group what support they had received in those early days, what had worked well and what hadn't. Below is a guide on how to support someone who has recently had a child with Down's syndrome. All the views reflected below have come from parents in the Wakefield area.



Say congratulations

It is really important to say the same things to the parents of a baby with Down's syndrome as you would to any other new parents. It is essential to say "Congratulations", or "Isn't he cute?" Not all parents in our group heard these words from the professionals when their babies were born. Assumptions were wrongly made about how the parents would feel about their baby. A simple congratulations can go a long way to reassuring a parent that their baby is welcome in the world and something to be celebrated.

"We would have loved to have heard the words congratulations, even the ward photographer was told by the midwives not to bother us as we wouldn't want any pics"

Please do not pity the parents of a baby with Down's syndrome. We want people to celebrate with us the arrival of our baby and not feel sad for us. We want the balloons and the footprints and the family photos and other things that will remind us of our babies' first day. Be positive about the arrival of the baby. Focus on how well mum did in her labour, on how cute the baby is, on how much she looks like her dad. It is this positive normal attitude which will help the parents focus more on the baby being their child, and less on the diagnosis.

"I was starting to get fed up with people telling me how well I was coping under the circumstances. I kept thinking 'What's the problem? I have a lovely baby.'"

Do your research about Down's syndrome first

From a new parent point of view it is really important for professionals coming into contact with a family to have up to date and factually correct information about Down's syndrome. We need to know that you are there to support us and help us care for our babies, and not learning something new. It is also important to get your facts right. Please do not offer an opinion on the level of the child's learning difficulty, as there is no way to know until later in life, and it cannot be determined by facial features or health problems at birth.



“One health visitor said to me that we would be “on the learning curve together” about Down's syndrome. This wasn't terribly helpful, I wanted professionals that had experience of disability, especially as a first time mum”

Find out first-hand about Down's syndrome

It can be helpful for new parents to hear about what people with Down's syndrome can achieve. Reading the books and the leaflets often highlight the problems people with Down's syndrome may face. We would advise the professionals to spend time with people with Down's syndrome so they are able to reassure families as they have first-hand experience of Down's syndrome. Being able to tell a positive story about a teenager or adult with Down's syndrome can go a long way to helping parents see a positive future.



“I would advise professionals to step out of their professional contact with families with a child with Down's syndrome and spend time seeing how life is further down the line. Come and meet my teenager – this way they would be able to reassure families with confidence and experience”

If you do not know anyone with Down's syndrome then please get in touch with WDDSSG if you would like to know more. We will be able to put you in touch with families of children with Down's syndrome of a variety of ages and enable you to get this first-hand experience.

Give the family reliable information on Down's syndrome



One of our families' biggest concerns about the early days was the lack of factual information about Down's syndrome they were given. The hospitals may not have given the family the information appropriate to their needs. Understanding Down's syndrome is the key to coming to terms with the diagnosis. Each family will need a different amount of information and some will require more detail than others. It is important that a family knows where to go to search for information and reliable websites. Families should be reminded that although children with Down's syndrome may have similar traits, they will develop according to their genes which are mainly from their parents. No book will tell them what their child will or will not do, nor who they will become.

“We were ok, the worst was the lack of information at the hospital, the out of date leaflets and to be honest the worry of telling people.”

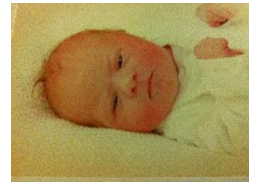
Find someone with a child with Down's syndrome for the parents to talk to

Many of our parents have said that meeting other families with children with Down's syndrome has been really helpful for them, and for some even a turning point in accepting the diagnosis. Try to make sure you have the telephone number of someone who has a child with Down's syndrome before you meet the family. Take with you

the contact details of WDDSSG so you can pass them on to the family. Our website always has an up to date telephone number on for new parents to get in contact with us.

“I wanted to meet a family who had a child with Down’s syndrome and I visited someone who I went to school with, who lived in the next village. From there onwards we moved forwards.”

New parent contacts are essential at this point and are a lifeline potentially for some parents. It may be that you need to organise someone from the local support group to come out and see the family as the family may not want to make the contact themselves. It can be so reassuring to watch other children with Down’s syndrome play and interact, to see them walk, talk, and sing. This can often be the start of the healing process for those who need it.



“We had a visit from the Health Visitor within a few days, who organised for someone from the local Down’s syndrome support group to come out and see us. I have to say, I probably didn’t want to see her beforehand, but it was a good move to see a real life child with Down’s syndrome”

Parents need support before the diagnosis is confirmed

For some, there may be a period between concerns being expressed by the paediatricians and the results of the blood test confirming Down’s syndrome. Many of our parents struggled in this period especially if they were no longer in the hospital. They have been told that their child probably has Down’s syndrome and are going through a wide range of emotions, but professionals are not offering the support that is needed, because the diagnosis has not been confirmed. Parents need support at this time as if they have had the diagnosis confirmed.



Don’t offer false hope in this in-between time. It is unhelpful. Parents will have started the process of accepting and it is not in their best interests to start doubting the paediatrician because the baby doesn’t look enough like it has Down’s syndrome. It is best to be clear with the parents about the expectation of the results of the blood test.

“We were in the limbo period between birth and diagnosis when a young doctor looked for some of the physical signs and said she wasn’t sure if our baby had Down’s syndrome. At this stage, a couple of days in, we had started the process of accepting and didn’t need to be given this false hope”

Offer emotional support

It is really important in these early days to offer the right emotional support to parents. Some parents will be devastated by the news of the diagnosis and others won’t seem to mind. Other parents might be more concerned with the pressing health needs of the baby, and Down’s syndrome is something to be dealt with at a later date. Delivering a diagnosis can be hard for the professionals and many do not get it right. Some parents may still be angry or upset about the way the news was delivered to them. One of our parents even diagnosed her child with Down’s syndrome before the doctors had even looked at her. With such a variety of emotions and experiences of parents it is vital that professionals listen to parents and react to what they say rather than making assumptions.



"I felt upset that I had not produced the expected 'perfect child' but decided it didn't matter what the diagnosis was, he was mine to look after and I would do my very best for him."

"I immediately fell into protective mode – I then had two clear but long term worries. Will me and my wife be able to enjoy our retirement? What will happen to him when we are not here? I don't know why I had such far away concerns but I do now know that me and my wife will be free to enjoy our retirement and that our son will be fine when we are gone."

"Something inside of me gave me inner strength and I knew as soon as I was told I had to protect this child and do everything to make her succeed in life."

"We were devastated, but the Down's syndrome wasn't the major issue – the heart problems were much more significant. We always said if we had to worry about the Down's syndrome, she'd have survived the heart operation, which she very nearly didn't, so we were glad to get there, in a bizarre way."

"The midwife held my hand and waited, expecting me to breakdown. I just asked her to hand my son back to me and when she did I started to put him back to feed again. It was obvious she didn't know what to say. I just looked at her and said (and I truly meant) "I'm fine, honestly, he's here, he's mine, he's gorgeous.""

"My partner on the other hand took the news very badly and was devastated."

"Being told my baby had Down's syndrome was the start of the biggest roller-coaster of my life. Thankfully we had a private room, because we cried and cried."

"We were so thrilled to get pregnant – we'd tried unsuccessfully for two and half years, so she was a miracle to us, and we quickly reconfigured our perception to the fact that she was the one that was tough enough to survive. We just felt so lucky that we didn't mind if she wasn't 'perfect'."

"We were both just so in shock at becoming new parents that the DS news didn't seem to be all that overwhelming at the time."

Many of our parents have thought things in this initial stage that you would never normally dream of thinking about, just after the birth of a baby. Some parents have, for a split second, considered leaving their baby in the hospital. Parents need to know that they shouldn't worry or be ashamed about any thoughts that enter their head. All these thoughts are natural and understandable.

Parents may need to be reminded to enjoy the baby for who they are. Many parents only see the diagnosis of Down's syndrome and struggle to see their wonderful child. It is helpful to remind them of how gorgeous their child is and help them see the wonderful individual they have created.



Encourage parents to do what they need to do to come to terms with the diagnosis. Visitors may need to wait until the family are able to deal with the news. It is important that the family get the support they need at this time and do not need extra stresses put on them. The parents should be allowed to try to feed the baby by either bottle or breast, as they have chosen. It is possible for babies with Down's syndrome to successfully breastfeed, and parents should not be encouraged to bottle feed just because of the diagnosis. Neither should parents feel pressurised into breastfeeding at this time. As long as the baby is putting on an adequate amount of weight, parents should be supported in whatever their decision on how to feed their baby.



Offer practical advice

Parents often find things easier when they feel they are doing something to help their child. Early referrals to the physiotherapists, occupational therapists, Portage, and speech and language therapists will help parents to feel proactive in helping their child. Encourage parents to do normal baby things. The first year is a time for them to enjoy their baby and they may need help to do this.

“The play therapist told us from 0-3 were very crucial years and the best thing you can do is stimulate, stimulate, stimulate which I immediately started doing”