

The contents have been written by parents of Wolf Hirschhorn Syndrome children with the aim of sharing our Blue Days and Golden Advice with other parents. Out thanks to everyone who took the time to share these thoughts with us.

BLUE DAYS

When your child is born, you have hopes, dreams and great expectations for that child. You imagine what **YOU** will teach him and all the wonderful places that you will one day visit and show him.

However, when you are told that your beautiful baby you patiently waited and planned for is disabled, it is something that you can't quite believe. Every parent's worst fear - the fact that their child has many problems that no doctor and no amount of money will ever put right has happened and that it has happened to you not to someone else.

At first you feel extremely isolated. Nobody that you know has a disabled child. All your friends and family have healthy children and there is nobody to cope with your new emotions. One half of you naturally loves and adores this much wanted beautiful child but the other half of you hates him for not having lived up to your expectations.

When you have a child, you have a great need to meet parents who, like you, have had these emotions and who know how you feel. You no longer want to be isolated but part of the human race again. You realise eventually that because your child has problems, he doesn't have the rights as a normal human being. Not only is he robbed of being able to walk, talk, think etc., but also he has no automatic rights to the basic forms of education that he so desperately needs. If you want your child to have portage, hydrotherapy etc., you must fight your way through endless red tape. Local authorities unfortunately keep the priorities of disabled children at the bottom of the agenda, any allowances your child is legally entitled to are begrudgingly handed over to you at the end of another long battle.

Being the mother of a disabled child, I must say that my life has altered in ways that I could never have imagined. At 16 months of age my baby doesn't toddle about, babbling, "mum, mum, mum" or "dad, dad, dad" and he doesn't touch things that he shouldn't. In fact, he lies on the floor because he can't sit up. Each week we attend a playgroup for support and it is a place I know that my baby will get the kind of care and attention he needs.

He has physiotherapy, portage and hydrotherapy each week and in between these activities, we fit in numerous visits to three different hospitals

when we have appointments. Sometimes there are the unscheduled emergency visits when he has a convulsion, or is ill for one reason or another.

I must admit, we have very happy times but we also have days when things do get too much to deal with.

Being parents of a disabled child is not the option that my husband and I would have chosen had we been given the choice, but as we are, we make the most of what we have and enjoy every precious day that we have with our baby because love, as the song says, changes everything.

On finding out our first long awaited child was born with Wolf Hirschhorn Syndrome, my husband and I felt that our world had come to an end. We both grieved for the child we thought we were going to have and came to terms with the child we did have. My feelings were so mixed up and confused, I lived day by day, making myself believe that it wasn't true and that my daughter would be fine and all the doctors had got it completely wrong!! I suffered from bad depression and it took me 8 months before I could talk to anyone about my daughter.

I was worried in the early days that we could lose her, so it was difficult to build a bond with her. Even the littlest task like taking her out or to the clinic was so painful, people commenting on how tiny she was and her failure to put on weight. Nine years ago little was known about Wolf Syndrome and talking to other parents of children with Wolf Syndrome was so important, knowing you are not the only one in the world with these problems is a comfort. I can remember saying, "if only she would feed, things wouldn't be so bad". Nobody knows those feelings like another parent. To an outsider, it's only a little thing, but unless you've been there it's one hell of a problem!

Her first seizure at the age of 14 months was terrible. The feelings I had at not being able to do anything to help her, the feelings of being out of control, seeing my daughter going through this, and on admittance to hospital seeing what they did to her - to say the least I was distraught! None of the medical staff knew anything about Wolf Hirschhorn Syndrome, I must have tried to explain 5 times in an hour and when you are upset it's not an easy task...

I think the most painful aspect for any parent about Wolf Hirschhorn Syndrome is the fact that it cannot be cured. In most cases it just happened. At the very beginning, in fact, at conception, and that the baby you've been carrying round for nine months is imperfect, abnormal, may not survive

even. It is not the baby you've been hoping for and yet it is her: a time for celebration - it is an emotional blend of happiness and great sadness, and one of the hardest things I have ever had to come to terms with,

When our daughter was discharged from hospital, the doctor said "take her home and love her while she is here". On reflection that didn't give us any hope for the future and it clouded a moment that should have been full of joy.

One of my worst moments was when our son had his first big fit. It was as if it wasn't him but someone else. I ran around the house with him, not knowing what to do next. In the end I just phoned an ambulance and the ambulance men took over. He was taken to hospital and they calmed him down.

I feel that when my son does get admitted into hospital, he is treated as a second-class citizen. He was desperately ill, in his own room, and at 1 am we were asked to leave the room for another child and we were just left on the ward.

Our worst moment has been when, after 4 years without any fits and 2 ½ years off medication our daughter had a 7 ½ hour fit in the middle of her 10th Birthday Party. She definitely knows how to communicate her worries and feelings.

We were told that our daughter would have "severe learning difficulties" on a Sunday night at the end of a two-week holiday. My worst moment was returning to work the next morning to be congratulated on the birth of my daughter (she was two weeks old).

The feeling of desperation when my daughter has to go into hospital and I feel she is not getting the care and attention she requires and deserves.

Our worst moment was when our son needed prolonged blood tests every half an hour and they took blood from his head. Up until then he had been very calm about this, but since, he hates anyone touching his head for any reason. This could have been avoided if doctors and nurses had more patience and understanding and did not take the view that if he can't communicate back he has no understanding or feelings.

Being told by the Genetic Counsellor that our daughter "would not amount to be very much, be a happy child who would spend most of her time in a

bean bag". Also taking her to hospital for operations, waiting whilst she had these and then seeing her in intensive care.

Our worst moments were trying to explain to our parents about our son's handicap. What made matters worse was the difficulty in getting one set of parents to come to terms with the fact that they have a handicapped grandchild.

The fact that Nana will never acknowledge her when we are out, she will never walk alongside her wheelchair.

We couldn't leave her, she had to be right beside us or else she screamed and screamed. When we brought her home from hospital the staff told us to take each day at a time and being told she would never do anything.

During the first year of our daughter's life, I prayed on many occasions that she would die, releasing me from the emotional hell that I was experiencing in trying to come to terms with life with a child with special needs. The process was that of grieving - grief for the child whose life I had projected into the future but who had "died" at birth.

At the same time as trying to cope with grief, I was being drained by the demands of looking after the child that I did get and who gave nothing back in return for all the effort that we put in. I felt hate, anger and helplessness at times, intermingled with compassion for this little, damaged person it was my lot to look after and I felt a terrible apprehensive guilt at my desire for my daughter to die. I knew that these feelings were part of the process of coming to terms with things but I needed reassurance that this was so. I mentioned my feelings to our paediatrician who told me that he had had similar emotions after the birth of a handicapped child of his own.

Our daughter I now regard as one of the best and most meaningful things in my life and the warmth and happiness of her personality makes, in retrospect, all the early pain worthwhile.

His first fit - any fit. We hadn't been told that our son could possibly have fits, therefore, his first one was totally unexpected. When we realised that he was unwell, we rushed to the hospital. He was nine months old, he looked so small and the fit seemed uncontrollable for a long

time. We couldn't lose him now; we had all been through so much.

After a few days the effects of the drugs wore off but his left side was weak. It took several months for him to regain his strength and now, many years later, I feel that his left side is still slightly weak. Fits and illnesses always put him back but given time he recovers and regains his capabilities. I now keep medication in the form of suppositories at home for him to bring him out of a fit. Before I had these I felt helpless.

We were very upset when we were told that our son needed an operation. The thought of the anaesthetic frightened us. He had been unwell for several months and no one seemed to know what was wrong. If only he had been able to tell us where it hurt and how bad it was, then perhaps diagnosis would have been quicker. I felt that I should have known that his increasing bouts of sickness were more than tummy bugs.

He had the operation, having his gallbladder and a testicle removed. He was very brave and we were nervous wrecks. He recovered quickly and fully - thank heavens! The staff were wonderful; doctors explained everything to us and nurses were gentle and efficient.

Birthdays can sometimes bring on a `what might have been feeling`.

GOLDEN ADVICE

Don't harbour negative feelings; they're natural and understandable. Don't feel guilty.

I felt that it was essential to find out as much information as possible as soon as a diagnosis of my daughter's condition was made. Although we cannot speak highly enough of the Consultant at the hospital, he was only able to provide a brief textbook description of Wolf Hirschhorn Syndrome. Our initial telephone discussion with the Founder of the Support Group left us with no illusions about the future and helped us start coming to terms with it immediately.

You may feel that this is the blackest day - but it's not! There's going to be a tough road ahead, but you'll ride it and find that you'll be amazed at the love, care and support that your child brings you and vice versa. Life is what you make it. You can sit there and feel sorry for yourself - which doesn't help anybody, least of all yourself. Or you

can grab the bull by the horns and try to be more positive.

You will get your bad days where you'll probably cry and feel very sorry for yourself, your family, your child etc... but it's surprising where the strength comes from to carry on and make the most of your life. Yes, you have a handicapped child - Yes, you've become a handicapped family but there are so many things we can do now that we no longer need to be handicapped families, as such. With hard work, care, patience and above all love, it's surprising what we can do.

Keept a diary - at first when this was suggested to me I wasn't too keen but accepted the diary. I found that pouring my feelings onto paper was very therapeutic, noting small achievements and emotional hurdles we had overcome. At low points I look back and realise that we have overcome many hurdles and that our daughter has achieved wonders.

Contact other parents when you feel ready. Another parent told us that her child had enjoyed rough play from an early age. Until that point we had been treating our daughter very, very gently. When we changed our approach her response was fantastic, she giggled for the first time.

At the end of the day, parents know best. I firmly believe this now and would argue with anyone who tried to tell me otherwise.

We have always encouraged our son to work. We firmly believe that the more you put in, the more you'll get out. It is not easy and we doubt if it will ever get any easier. Some doctors have told us that we really should not be doing any exercises with him because of his heart condition. We feel that we cannot live our lives wrapping him up in cotton wool; none of us know what's in store for us, so let us make the most of life and enjoy it.

Look at your child as an individual with his/her own personality and characteristics. They are only hampered by Wolf Hirschhorn Syndrome not taken over by it.

In the immediate stages after you have been given your child's diagnosis, it helps if you are `selfish`. Try not to worry about how other friends and family are coping. Give `time` for yourself, your partner and your child.

However difficult, try to take time for yourselves away from your child, it is easy to think that because your child is handicapped nobody else can look after them. Treat your child like any other because "what is normal?".

The best advice I would give to somebody is to have contact with people in the same position, to talk and to ask for advice. I gave up a long time ago listening to the `professionals`. Enjoy your child; they will develop at their own speed and when they are ready. I spent a lot of my time in the early years pushing my daughter to achieve things but I strongly feel when they are good and ready they will eventually achieve these milestones. She has a smile for everyone, is a happy and lively little girl, and a smile and a cuddle from my daughter means so much to me, they are very loveable and very special children.

To remember that they are a person first and have a handicap second. That they can give and accept love.

You don't have to be a `super mum` and always cope. The one thing that one of the Meetings showed me was that we did not have to struggle to force our daughter to chew. It was more important that she ate and was well and happy.

When your baby is diagnosed with Wolf Hirschhorn Syndrome it is probably the greatest shock that you will ever experience. Enjoy your baby because they will not stay a baby forever. It's surprising how time flies and your baby will grow before you have realised it. Try not to wallow in self-pity for too long. Enjoy your baby.

When you talk about your child try to begin with the positive things about him/her,

Be proud of yourself and your family. You are doing your best to cope with a situation that you would never have believed you could.

Please make an effort to ensure that siblings lead the same life that they would have if their brother or sister had not been handicapped. Often this means planning ahead and isn't always easy but it will help towards a happier family life.

Oviously essential life sustaining things have to be done daily for the children but we are often advised to do this, try that, to help them. However family life is important as well and if that means for a while the non-essential programme has to be left, don't feel guilty.