

Record

311

File Number

10278

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Title: The diagnosis

Original source: Cooinda Family Support Group Newsletter

Resource type: Written

Publication Date: 01/11/92

Publisher Info: -

**Abstract**

This story highlights the pressures and difficulties parents face when they are given the choice of carrying a pregnancy to term or terminating it. It is written by a parent who has three children who have degenerative disability, each of whom brought happiness and joy to their lives. She feels professional advice is geared towards terminating the pregnancy when there is knowledge of a disability, and that there should be a lot more information provided about services and supports which are available to such children and their families.

**Keywords: Attitudes, Ethics, Families**



At the age of seven months, our daughter Jade was quite delayed in her motor development. She had not learnt to roll over, let alone any of the other delightful skills babies of her age usually develop, like sitting up, crawling, holding on to things etc. Socially, she was a delightful, bubbly child enjoying being part of everyone's life. She just didn't DO anything.

X-rays showed a spinal curvature and bilateral dislocated hips. Boy, what a relief! The next three months Jade spent in a plaster. This was followed by one month in a splint all day, except for an hour at bath times, and then another three months, just at night. All in all, the seven months of treatment passed slowly. At the end of this time, I was about four months pregnant with my second child and Jade had now learnt to roll over extremely well and could sit up for about thirty seconds. We thought she was very clever, but for a fifteen month old, she was still very much behind.

We were referred to a neurologist. Blood and urine samples were taken and tested, X-rays were taken of her entire body and a CAT scan performed. I don't recall us every receiving the results. It was decided to wait until after my baby was born, to do any final testing which would hopefully present a definite diagnosis.

At one of my prenatal checkups, during the following three months, I discovered that my GP had the results of some of the tests Jade had had. The result of her CAT scan showed patches of cerebral atrophy. The doctor

confirmed my worst fears, my little girl was going to be mentally retarded.

Being abnormal, or subnormal, in my childhood, was really not very acceptable. There was always a bit of fear or pity felt for people who were like that, but never acceptance. We were certainly never allowed to play with children who were "like that". So over the next few months, my feelings tended to be full of shame and low self esteem. I had produced a defective child. Somehow, that made me feel less than acceptable myself.

I made enquiries and found out about a special playgroup for handicapped children in Katoomba. I started to take Jade and began stimulation therapy exercises with her at home. They weren't all that hard, but I was always so tired. Being pregnant and being concerned about Jade, and just not knowing anything, was very difficult.

I don't remember feeling concerned about my second baby. Twenty-four hours after she was born, I was home again. I had become very protective of Jade and felt nobody could look after her the way I could.

Protecting myself from being hurt again became the order of the day. I had decided not to love Tegan just in case she had the same thing wrong with her as Jade. Unfortunately for me, and fortunately for her, or perhaps the other way around, she was a very colicky baby. After so much contact with her, due to her being colicky, my heart melted and I fell in love with her about the third or fourth day after I got home from hospital with her.

Institutionalisation is an option. Boy, are things that bad? Hang on! Sorry, that's not really an option for us. What about stimulation therapy? Well, if you can teach them skills that will lessen your workload, by all means, go ahead, but . . . Alright, if the kids are as sick as you say they are, just how long are they going to live? Well, they will be very lucky to reach their teens. Teens, ten to fifteen years, hey, that's miles away, they're only two and bit years and six months old. Lots of things can happen in that time. What about treatment? Lots of treatments have been tried, but they've either failed or, are even now, in the very early stages of experimentation.

We have two beautiful little girls, the apples of our eyes, who have a death sentence hanging over their heads (and ours), so what do we do now? Institutionalisation is out, experimental treatments are out, stimulation therapy is in, treatment of infections etc, as they occur is in, hope is in, life is in. Quality of life, that is, because there sure as heck isn't going to be much quantity.

In the beginning, lots of decisions were made as a matter of course, without even much thought or discussions, they were just made because that was what had to be done at the time. Then they were often made by me alone, as my husband felt that because I had the medical background, I was better qualified to make these decisions. This became difficult later on when I felt trapped by those same decisions. I began resenting having to be responsible for everything. They were both our daughters, not just mine. By this stage, I needed help with, or confirmation of, or just plain taking over, of the dr

Another referral, to a paediatrician this time. The neurologist had judged Jade's problem not to be in his field of expertise. Initial examination of Tegan showed her to be unaffected. Further testing was to be done: first some time to consult some other colleagues and then arrangements were made for the girls to be admitted into hospital for those tests.

**DISBELIEF!! SHATTERED!! CONFUSION!!** How can this doctor be talking about our little girls? The words he's using, I'm sure they don't describe our daughters. It's one thing to have an answer as to why Jade is not progressing, but to say that both girls are the same and use words like stunted growth, recurrent ear and chest infections, heart abnormalities, enlarged liver and spleen, hearing and sight problems, unstable joints, clawed hand, limited movement in all their joints, progressive physical and intellectual developmental delay and shortened life expectancy. Progressive degeneration; the words just reverberated over and over in my mind.

For children with this disease, death usually occurs from pneumonia or congestive cardiac failure. Children with their problem don't usually walk, talk, become toilet trained, have many independent living skills, such as feeding etc, or go to a "normal" school. This all sounds a bit much. I don't know if I can cope with this. I don't know if I want to cope with this. I knew there was a problem and that possibly Tegan may be affected as well, but he's describing a nightmare.

O.K. what options do we have?

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making being carried out. My husband felt unable to do this because he hadn't had any practice in this area.

So, here we were, married barely two and a half years, two daughters, both suffering rare genetic disorders, with a life span of ten to fifteen years, maybe, discovering that life was full of pain, and people who couldn't or wouldn't help, that's how we felt. A new learning process was beginning to emerge for both of us. Priorities were changing, life was taking on a whole new meaning. The next few years would be full of more pain, joy and a whole range of other emotions, options and choices.

Looking back now, I can see the bereavement process, each of us was going through. And not just us either, but our extended families and friends too. And the most difficult part about so many people grieving at the same time, is that rarely two people are at the same stage of grief at the same time. In our case, this led to many conflicts, between ourselves and between us and some of the members in our families. There has been much pain experienced during this time too, of rejection, of resentment, of anger felt by us and others. In some instances, we turned to each other for comfort and support, in other instances we turned to other people.

#### THE DECISION

There has been three occasions on which I have had to consider terminating the pregnancy of a fetus, which may or may not have been abnormal. But the question has never been; Will I terminate this pregnancy? or, Will I keep the baby? My line of questioning went more

like; What will happen if I continue with this pregnancy? Are the resources to meet my needs available to support me in whatever decision I make? Each time, my PAST EXPERIENCES, my CIRCUMSTANCES, my SUPPORT SYSTEMS, my FAITH and my ATTITUDES have been different, therefore my decision each time has been different also. Apart from the questions, which were always very practical, because that's the kind of person I am, there were also the consideration of other people to be made. What is their needs? feelings? reactions? etc. The first time was when I was twenty-one. I was sharing a flat with a girlfriend from home, two country girls, living in the big city. Life was, for the first time in a long time, free from tensions and high expectations. I was able to live my own life, make my own decisions and mistakes and come and go as I pleased.

Before moving to Sydney, my marriage, of seven months, to an abusive alcoholic husband had just ended. I began a relationship with a married man. It felt safe. Because he was married, there would be little chance of him trying to tie me down. The relationship suited me.

The trauma of my recent separation was judged to be the cause of recurrent bouts of persistent cystitis. Tests were ordered and carried out. Later, it was discovered that I was pregnant and that these tests had been carried out in the first few days after conception. This very likely meant that my baby would be deformed.

The child I was pregnant with was the result of my affair. The father couldn't and/or wouldn't support me. I felt I had no one to whom I could go for help

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or support. I believed that what I was doing was wrong but I felt I had no other choice.

My father died of cancer one week before my baby was terminated, his father died from a heart attack in the week following. My mother was not coping and still had four children at home to look after. I could just imagine her response if I turned up with an illegitimate child, handicapped to boot. My life was in a mess. I was in debt, confused, lonely and afraid. I felt there was nothing else I could do. My pregnancy was terminated.

The second time was my pregnancy with the twins. I was married and had two beautiful little girls, both affected with a rare genetic disorder which, we had learnt from medical literature obtained through our doctor, had a life span of between five and six years, not the ten to fifteen years we first believed.

We discussed the idea of having more children off and on from the time the girls were diagnosed. We knew the options; no more children, artificial insemination by a donor, fostering, adoption or have our own children and take the one in four risk that they would be affected like the girls. We chose to have our own.

Unbeknown to each other, we both began to pray. Lord, please don't let this baby be affected. Neither of us was a Christian, but in some way though I

guess we just felt that there was only one way we could cope with this. This article is made available by the Institute for Family Advocacy & Leadership Development and cannot be used except for the sole purpose of research and study

outcome of this pregnancy. Him. We just hope He would, and in our favour.

It was necessary to be sure of my dates so that an amniocentesis could be performed at exactly the right time. So, it was a BIG shock to discover, at eleven weeks gestation, that we had not one, but two babies to consider when deciding whether or not we would terminate a pregnancy with an affected fetus.

Our praying began to change. We hadn't anticipated twins. Was it too late to change the plea? My husband started praying, Lord, make them both O.K. But I was a bit more practical, and wanted all avenues to be covered. I prayed, Lord, if it's not your will to make both babies normal, then give me one normal child and the strength to cope with the other.

Everything regarding the amniocentesis was pretty clinical. Unreal is probably a better description. Here we were, talking about these two babies as though they were a couple of disposable items, where, if we didn't like them or we weren't happy with the way they were, we could just give them back or throw them away.

The amniocentesis was performed at almost seventeen weeks into the pregnancy. Four weeks to wait for the results. We had decided that if both babies were affected, we would terminate the pregnancy; if one of the babies was normal, we would not terminate the pregnancy, as one "normal" child was more than we had at present.

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The next four weeks were the longest on record. Every scenario that could possibly be thought about, went through my mind. What if this? What if that? but then again, etc etc etc. I felt the babies moving and kicking every day while we waited. It was hard not to think of them already as ours and living with us and all of us being one big happy family.

Then one week before the results were due, I knew I couldn't go through with it. It didn't matter if both babies were affected, I couldn't terminate. We were coping with two, we could cope with four. I tried to share my feelings with my husband and it was then that I realised from his response, that he didn't understand what a termination meant at that stage of pregnancy.

I remember feeling very lonely and alone at this time. It was as if I was being punished for being bad and rebellious and I felt that everyone was against me for putting "them" through the pain "they" were feeling. It was like I was the culprit. How dare I. Nobody seemed to realise that all the feelings of anger, hurt, frustration, fear, pain they were feeling, were the same feelings I had. And that all the arguments, both for and against having more children, were the same ones I had gone over and over, in my mind time and time again.

God! I can't cope with this on my own. I feel so desperate and scared.

What a great relief when the results of the amniocentesis showed one normal baby and a baby they were almost certain was also normal, but

couldn't guarantee it. The pressure was off. We would have two "normal" babies, it was more of a hope than a certainty. Our hopes were dashed when the twins were born and one was in fact affected.

The third time a decision was to be made, as to whether to terminate or not was with my last three pregnancies (all of which were unplanned by us). Because my husband and I had become Christians following the birth of our twins, we chose to put our faith and trust in God we had come to know and trust. We believed that He, knowing what was in our best interests, and wanting only the best for us, would provide for the needs we had. The first two pregnancies ended in miscarriage. The third pregnancy produced a normal, healthy boy. The waiting was, at time, very difficult. Our faith certainly got put to the test.

Throughout the decision making process, a lot of emotional energy was spent in what seemed like a great battle to decide on the "right" choice. More pressure came, when more people were involved, either consciously or unconsciously, in that decision making process.

The "pain" felt, was, I think, often caused, not because of the emotions felt, e.g. anger, fear, etc, but because of there not being any clear and definite "right" decision to make, too many options and yet not enough information about the available resources. That uncertainty or pain was also felt by those associated with that decision making process or us making that decision. This more often than not, would lead to reactions from us or other which caused more pain.

## AFTERWARDS

When we choose to continue or terminate a pregnancy containing a defective child, there is a price we have to pay, be it physical, emotional, social or spiritual. Each of us has had to decide which cost we are willing to be responsible for.

That cost gets paid in the "afterwards" and sometimes that "afterwards" seems to go on for such a long time. There is the near afterwards, the far afterwards and the bit in the middle. And each "afterwards" brings its own kind of learning, sometimes easy, sometimes hard.

At the time of my termination, I was working in the maternity wing of a public hospital. After my termination, I remember the ache I felt. When I woke up from the anaesthetic, I was crying uncontrollably and continued for quite a long time. My world was full of loss at that time. My dad was gone, my grandfather and now my baby. Why? That was the question I had to all the areas of my life. Why did I marry a man who was an abusive alcoholic? Why did my marriage have to break up? Why did my body have to react because of my separation in the way it did? Why couldn't I think straight? Why did I take up with a married man? Why did I have to lose my baby?

I remembered the date my baby was due. I wondered what he/she would have been like. Working in the Maternity Ward sometimes helped, sometimes hurt. But at least, you could get to cuddle other babies.

**What I remember most about the afterwards of the twins was the work.**

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Four babies. None could walk. None talked very well. None was toilet trained. They all needed to be fed, one way or another. There was always somewhere to go, someone to see, something to do. All those nappies, YUK. Even to think of it now, I don't wish for those days back. But I know, I wouldn't be the person I am today if it weren't for those days.

As time went along, what I remember are the battles, both the people and to get the things my children needed. Not being the most tactful person around, I had, and probably still have, a tendency to speak first and think later. But I'd get a notion in my head that I wanted something and I wouldn't be happy until I got it. Sometimes this was very productive, the Lithgow Early Intervention Program and the relationships we have established with the professionals who care for us and our children are just two examples of that productivity.

On the negative side, there have been times when no matter what my motive, whether it be purely selfish or whether it be for the benefit of all and sundry, if the other person or persons I was battling with, wouldn't work with me then it became a battle and the ones that ultimately lost out, were the children. In these instances, I've often had to take a step backwards to find out just what my motives were, and decide whether it was worth the hassle. In one such instance, we actually decided to cut our losses and move to another town.

In my mind I have a paradox. I want what's going to happen to hurry up and happen. At times, I actually "want" my children to die. There are other



areas of my life I want to take up and get on with. At the same time my heart cools from the thought of losing yet again.

My children are going to die, but then aren't we all, but my thought is not to give up and let them die but to stand up for them, while we have them, so that they can have available to them the requirements that will enable them to reach their maximum potential, whatever that may be. And in the mean time, if they should die, nothing will have been in vain. Other children will benefit from whatever we achieve and I know that I will have done my best. And that's all any of us can ever hope for.

The future is relative to where one is standing in one's walk along life's path. At the moment, I'm in the future of my life, five to ten years ago. The way one faces their future is, I believe, dependent upon the wisdom one has acquired throughout the life experiences preceding that future.

Today, I still face the prospect of losing three of my five children and while they are alive, I face many experiences, both good and bad, that will occur as part of their lives.

My children have now outlived their expected life span of five to six years. It's possible we may have our ten to fifteen years with them after all. This ultimately means, that decisions which we thought we would not have to make for them, we will.

Because the disability our children suffer is of a progressive nature and will

eventually lead to gradual deterioration, we are faced with both the physical and emotional pressures that brings. Much lifting and carrying occurs each day, on and off chairs, in and out of wheelchairs, the bath, cars etc, and on the emotional side, each time we are faced with a "loss" or think of what's to come we have to "work" through that too.

Sometimes, life is very difficult, unpleasant. Experiences bring their own kind of pain. Difficult or unpleasant relationships with family, friends, professionals or even the general public can lead to a person wanting to just curl up and not be a part of life. On the other hand, it can have the opposite effect of making a fighter of a person, who, in the past, never seemed to have any fight in them, in effect, making a lion out of a lamb.

In my nature, I have probably become one of the "lions" mentioned. I have become more outspoken on issues I previously had no interest in. The pain and trauma experienced by other couples and families with disabled children cause me to become concerned at the lack of resources available to assist in the area of disability. Support, information, educational and vocational services are just a few areas where resources are sadly lacking.

The thing is though, if parents and carers with children with disabilities are not adequately supported, in one way or another, then the services, which are deficient, are never going to be provided, because these people, who have a vested interest in the provision of these services, aren't going to be equipped to fight for the services they need.

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Each of us become the person we are, through the choices we make. My husband and I have grown in many areas and now also experience better decision making ability than we did in the past. This has developed through being surrounded by some very loving and supportive family members and friends.

I still experience much pain as part of the grieving process that I face associated with the loss of my three "normal" children and the dreams and aspirations I associated with them. Each time any of my children lose a skill which we have painstakingly taught them, I grieve some more. When they die, I will grieve a whole lot more. It would seem, from what I've said, that all I do is grieve. This is far from the truth. I have many happy, joyful moments with my children. More than I would have had, if we had chosen to eliminate these children from our lives.

At a seminar I attended in May this year, one of the speakers said, "People aren't destroyed because of the trials and tribulations they face in their lives. They are destroyed because they believe nobody cares about them as they go through those trials and tribulations". My prayer for today is, that out of the meeting here today, people will know that other people truly "care" about them as they go through the trials and tribulations they face, in determining whether or not to terminate a pregnancy which may contain a child affected by an abnormality of what ever type or degree.

In my life, the decisions my husband and I make are based on the

teachings in the bible. Jesus "cares" for us though His Word and the love and fellowship we have with other Christians. We still make mistakes, but we have the assurance of God's love and forgiveness.

As I said earlier, what ever choice we make concerning a pregnancy of a child with a disability, there is a cost to pay. The decision to continue or terminate is one of the hardest, I believe, any woman, with or without her partner, will ever make. That decision can be made a little more bearable when the "whole" picture is presented.

The first time I had to make the choice about whether to continue my pregnancy or not, nobody told me what was or was not available to help me cope with a disabled child. The talk was geared in such a way as to encourage me to terminate. When my husband and I were given the choice of whether or not to continue my pregnancy with the twins, our daughters had already been born. We were already aware of many services which were available for the care of children and adults like ours. Again, not once did anyone talk about "and if you decide to continue, . . .". Perhaps this may be another area which can be addressed in a support group, so that when a decision is made, it is an even more informed decision.