

*family*

A D V O C A C Y

PO Box 502  
Epping NSW 1710

305/16-18 Cambridge St  
Epping NSW 2121

Phone: (02) 9869 0866  
Facsimile: (02) 9869 0722

Record

325

File Number

10292

Author: Gerver, Joan

Title: A grandparent's view

Original source: DSA Newsletter

Resource type: Written

Publication Date: 01/05/85

Publisher Info: DSA

**Abstract**

A grandparent relates how she came to terms with the news that her grandchild, born in another country, has Down Syndrome. She advises other grandparents to obtain up-to-date written information and to talk to others who are familiar with Down Syndrome. She received positive support from family and friends and was able to enjoy and love her grandchild during her visits, and to delight in his milestones. **Keyword: Families**

# **A GRANDPARENT'S** **VIEW**

*Reprinted from 'Children Today' which is published by the Office of Human Development Services, Department of Health and Human Services, Independence Ave., S.W., Washington, D.C. 20201. The article was written by Joan M. Gerver.*

Anticipating the arrival of a first grandchild is a special experience. Our initial joy when our son telephoned to announce the birth of his son was followed two days later by despair and depression, when he called again to tell us that the baby had Down syndrome. An alert paediatrician had suspected what the obstetrician and nurse had missed. Several characteristics were present, an X-ray showed a displacement in the hip joint (characteristic of the syndrome), and chromosomal tests confirmed the diagnosis of Trisomy 21.

The only associations I had toward Down syndrome were negative. I recalled a protesting child making unrecognisable sounds, being pulled by an exhausted mother in a playground. Scenes from Letchworth Village - a state institution for the "feeble-minded" where I had spent several days during my clinical internship in the 1940s- emerged from the recesses of memory: hydrocephalics, unable to lift their grossly disproportionate heads; mildly retarded women feeding profoundly retarded inmates; rows of adult-size cribs housing a population of idiots and imbeciles, as they were labelled then. It was such a grotesque world that I pushed it far back in the depths of memory, preferring to work with the gifted, or at least those of normal intelligence.

Now it was here, in my family, knocking at the door of my heart. Emotions flooded me. Elizabeth Kubler-Ross has described the stages that one goes through when confronting imminent death. Here, too, one may experience anger, denial (mistaken diagnosis - maybe those features that typify Down syndrome are only a throwback to some ancestor?) and a kind of bargaining or rationalisation (since the parents are gifted, retardation will mean the baby is merely normal) as one attempts to deal with unexpected tragedy.

Amid all of this inner turmoil, there was concern over my son and daughter-in-law, compounded by the fact that they were living literally halfway around the world from us. After a week of crying, I pulled myself together. The situation existed, the baby was real, what could and should be done?

For me, the first step was to get information. There was never any hesitation in telling relatives, friends, even colleagues. Their responses were positive and supportive. They provided newspaper clippings, popular magazine articles

---

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

accurate information seems to be an early reaction to the diagnosis, and the need to be up-to-date on the latest research is continuous.

Our local public library has a good selection of books, and I was fortunate in my initial choice: *Children of Dreams, Children of Hope* by Raymundo Veras (Henry Regnery, 1975). I say "fortunate" because the book expressed great hope for what could be done with children formerly given up as "hopeless". The author, a Brazilian physician, described his personal encounter with discouraging professionals after his son's tragic accident and how, through persistence, patience and hope, the child made remarkable strides. Even though the methods of patterning he advocated are not applicable and do not work for everyone the underlying theme of hope provided an emotional and cognitive set that was, and continues to be, extremely helpful.

I also searched for material in the professional journals and current medical and psychological texts. (Some still use the term Mongoloid!)

My first advice to other grandparents would be to start with a hopeful book. One couple, faced with a similar need to acquire "instant information", told me of their visit to a small local library in the area where they were vacationing when the news arrived that their grandchild was born with Down syndrome. The only available books referred to Mongolism as hopeless and advocated institutionalisation as the only recourse. The initial impact of this obsolete information was negative and only exacerbated the conflict, especially when there was no rejection of the baby by the family.

In addition to the desire for accurate information - a cognitive need - I wanted to meet and talk with others who were affected by Down syndrome, and I especially wanted to see babies with the disorder. A friend who was a social worker told me of an organisation that visited new mothers of Down syndrome infants in the hospital. Another friend gave me the name of a social worker connected with a medical institution serving our area. A series of telephone calls - networking - provided the names of the Parents' Assistance Committee for Down syndrome liaison persons in our county. Both were parents of children with the disorder.

I will never forget the warmth and understanding that permeated my initial contacts with Barbara Levitz and Emily Kingsley ... Barbara offered me the opportunity to speak with other grandparents (her own parents) since my concern also involved my children - the parents of our new grandchild. Emily volunteered to bring her son, Jason, to our house, so I could see a real, live, functioning child with Down syndrome. I did want to see the child, but I wanted to see him in his own home, on his territory.

My 23 year-old daughter offered to come with me, and I, who rarely ventured on the road after dark, drove on unfamiliar highways at night to reach the Kingsley's home. The motivation to see and learn overcame my fear and discomfort. Finding unknown strengths in oneself is another thing one experiences. When you have to do something, you go ahead and do it. One rises to the demands of the situation of the moment.

We were welcomed into the house, and a little boy insisted on hanging our coats in the closet. Although he was a trifle clumsy, he knew what to do for visitors. We were amazed. We had expected to find a living vegetable; instead, we spent an enjoyable time with an alert youngster.

The anticipation and fear of the unknown are worse than the reality. Seeing and being with a Down syndrome child assuaged our dread of the unknown. The problems were real, but they were tangible, and it is easier to cope with the known.

I would [tell] tell other new grandparents to look - feel - handle - a child with Down syndrome as soon as possible. If one is geographically close, once can see the new grandchild, but if the baby is miles away, as in our case, get in touch with a support group and visit a child with the disorder living at home.

I eventually met my new grandson - three visits to Hawaii in two years, once with my daughter and twice with my husband - always laden with presents and warm wishes from our friends to the baby and his parents. My first glimpse of the baby was after an exhausting 12-hour plane trip. My son and his wife were waiting at our hotel, carrying a tiny, embryonic-looking creature. Their love for their baby was obvious, and soon we were involved with watching his responses and reactions. The first 24 hours of each visit were depressing and sad for me, partly due to the long intervals between visits. But after being with the baby and observing him closely, we saw evidence of curiosity and experimentation. The depression was replaced with delight and pride in his accomplishments.

I would urge grandparents to accept that fact that their grandchild will develop in a different time frame, using a different clock. This is not easy; one cannot refrain from ever comparing, or wishing "What if...?" It is normal to have such thoughts, as long as they don't immobilise you, or keep you from loving and enjoying the child that is, not the child he might have been.

What else can grandparents of a Down syndrome child do? Some of the same things a grandparent would do for any new parents. Offer them respite, if possible, a few hours "off" to go to a movie - or services, such as help with shopping and cooking. Give them "another pair of arms," as one grandfather described it. The help might also be financial, if you are able to give and they are willing to receive. If nothing else, there is always a need for psychological support. We have rejoiced with each new milestone our grandson has attained and showed our concern over problems that arise.

Realising the importance of early intensive stimulation in raising Down syndrome children at home, we have made and bought things we felt would be helpful in his development - records, books, puppets, talking clocks, a sturdy wagon, puzzles, an anatomically correct boy doll, a shirt with his name across the front.

The rewards are unexpected. They occur when he gives us a sweet smile of recognition, or spontaneously "sings" several verses of a school song using sign language, or recognises words printed on cards.

Despite some similarities in physical characteristics of Down syndrome children, it is important for grandparents to realise that each child will be different physically and mentally and should be treated as an individual with different strengths and weaknesses. By developing a positive and hopeful outlook, grandparents can do much to encourage their grandchild to reach his or her full potential, whatever it may be.