

An Alphabet of Helpful Hints: G is for Grandparents

Peter Limbrick with Don Meyer and Jenni Thomas



For those of us who support children with disabilities and special needs, grandparents are just about emerging from the shadows or, from their point of view perhaps, reclaiming the light. I remember my great surprise as a teacher in the 1980s, meeting parents of babies and pre-school children and learning that there was no formal recognition from health, education and social services that parents might need emotional support. Since then, particularly after the publication of *Together From The Start** in 2003, there has been an attempt to be more family-centred and this has brought focus, first on parents and then on siblings. Now perhaps it is time for grandparents to come into their own.

I have a little awareness and I will share it for what it is worth, but to do the subject justice I have recruited

the help of two grandparents and of Don Meyer who works to support grandparents in USA and gives some observations below. The first grandparent is Ray Murray who has kindly written a separate article for this issue of IQJ entitled *Issues for practitioners in supporting grandparents*. The second grandparent is Jenni Thomas who writes below of her fairly recent experience of becoming grandmother to Dominic. (Jenni is author of another article in this issue entitled *The Helping Relationship with Parents of Babies who have Limited or Uncertain Life Expectancy*.)

In One Hundred Hours we were privileged to offer support to a few families in which the parent or parents of the infant with disabilities had been categorised in their school days as having learning difficulties. In all cases there was a loving, concerned and very hard-working grandmother, and sometimes also a grandfather, holding everything together and taking on the battle to get some level of effective support in place for the young family and the infant. My heart went out to these grandparents because I could easily recognise that they had struggled enough already and now deserved a bit of peace. When the mother of the infant was a single parent, I wondered if this was a realisation of a lifetime's fear and anxiety of her parents, now grandparents.

I have run groups for grandparents that were designed to give space for thoughts, feelings and emotions – just as many of us do for parents. At one group I remember having very contrasting attitudes from grandparents. One grandmother was devoting her whole life now to her daughter with the disabled infant – to the extent that she was exhausted, could not sleep and was neglecting herself and her partner terribly. Another set of grandparents had consciously decided to stay very much in the background, to leave the young family to live their own lives and to make sure they, as pensioners, could now enjoy the retirement their lifetime of labours has earned them.

It was interesting that the feeling of the larger group was that the first grandmother needed to find some way to get herself off the treadmill. Most grandparents present, as you would expect, fell between these two extremes. I reminded myself of the lesson I had learned many times from parents – that it is not my place to judge, and that I will not know what sort of grandparent I will make until it happens to me.

I learned another thing too. Many grandparents who live near enough to the young family might be excellent providers of short breaks if they had enough training and support in the care of their grandchild to overcome their anxiety and feelings of not being up to the job.

Over to Don Meyer of Seattle...

I suffered for him – for what he might have been, should have been. I resented what his birth had done to my lovely daughter.

A grandparent

Compared to the birth of a healthy child, the birth of a grandchild with a disability can be disturbingly different. It is different, first of all, in its meaning. An event that normally reassures the grandparent with the certainty that the future will be carried on by the new infant instead introduces uncertainty about what lies ahead for the family.

It is also different in the emotions it evokes. Parents and relatives experience different degrees of grief, denial, sadness, or anger. While family members' reactions to a child's disability have many similarities, each family member also has concerns unique to that member's role. Grandparents frequently express a dual hurt, not only for their grandchild who is disabled, but also for their child, whom they may see as burdened for life.

Grandparents, whose fondest wish is for their children's happiness, often express deep sadness when they are unable to help their children and, with their children, must face a problem that will not go away and that cannot be easily fixed. Sometimes, perhaps to avoid the pain of reality, grandparents will deny a grandchild's problem (*There's nothing wrong with him.*), trivialize it (*He'll grow out of it.*), or entertain cure fantasies. Other grandparents will withdraw and be unable to look at, touch, spend time with, or even mention the name of the grandchild with special needs.

Grandparents who have difficulty accepting a child's disability can add to the burden of the child's parents, who then face the task of helping others cope; the denial or rejection a relative expresses may create problems for the disabled child's siblings, who are influenced by adult role models. These conflicts then

reverberate throughout the family system. As one sibling described her experiences:

We go to visit my grandparents, and they don't talk to my sister (who has autism). They'll talk to the rest of us, but they don't talk to her. We'll get in the car to go home and she'll cry and ask, 'Why don't they ever talk to me?'

A family's value system can compound a grandparent's grief. A grandfather who is an educated professional who has instilled in his family the importance of intellectual and academic achievement may suffer a poignant loss when he learns that his only grandson will be unable to follow in the family footsteps.

Outdated and inaccurate information can also exacerbate a grandparent's grief. If a grandmother's ideas about the potential for people with disabilities were formed, for instance, in the 1950s, then she may have low expectations for what her grandchild can achieve. She may even advise institutionalization for the grandchild, and she may have never heard of early intervention or vocational programs for children with disabilities.

These views can not only cause pain for grandparents but can also greatly complicate the stresses already experienced by parents during the time following their child's diagnosis. Rather than being able to turn to their own parents for support – a traditional source – parents may find that the child's grandparents themselves need their support and assurance. A grandparent's denial of a child's disability can be devastating to a parent who is already struggling with the reality of the diagnosis. Unwanted and illogical advice about institutionalization or cures can be difficult to disregard when offered by one's own parents.

Grandparents who have opportunities to learn about disabilities and share their unique joys and concerns with others in a similar situation are more likely to provide their children and grandchildren with meaningful emotional and practical support.

However, to be an effective supporter, grandparents must first have their own needs and concerns addressed. Like most parents, grandparents, prior to the grandchild's diagnosis, are often unfamiliar with information and services pertaining to disabilities. And grandparents, unlike parents who attend clinic visits, IEP (Individual Education Plan) meetings, and parent groups, have fewer opportunities to obtain helpful information. Often grandparents' only resource is their children, who may be reluctant to convey stressful information, or who may not have the time to provide adequate explanations. Grandparents who attended our pilot Grandparent Workshops at the University of Washington told us that getting up-to-date informa-

tion from someone who was not a family member calmed many of their fears and gave them hope for their families.

They also told us that the opportunity to discuss their hopes and fears about their families with other grandparents allowed them to put their own experiences into a broader perspective. They were grateful for an opportunity to learn what other grandparents did to effectively support their children and grandchildren.

Don Meyer is the director of the Sibling Support Project in Seattle, Washington and is the creator of the Sibshop model. His most recent book is *Thicker than Water: Essays by adult siblings of people with disabilities* (Woodbine House). He conducts workshops internationally on the joys and concerns of siblings, fathers, and grandparents of people who have disabilities and has trained local providers on the Sibshop model leading to the creation of more than 260 Sibshops worldwide. www.siblingsupport.org

My special Dominic by Jenni Thomas

Orchard Road Shopping Centre in Singapore was where I learnt I was soon to be a granny again. Another little premature grandchild was on its way, my lovely daughter-in-law was 27 weeks pregnant. The last time she had only been 24 weeks and tiny Annabelle lived for only an hour.

Before Annabelle, I had been fortunate enough to be with my son and daughter-in-law when Estelle was delivered, a normal full-term baby girl. Nothing prepares you for the shock of an early labour. Being at Annabelle's birth in the hospital where I had worked on the Special Care Baby Unit for more than 30 years was an experience I cannot find the words to describe. Now here we were again. The anxiety was all consuming and yet I needed to be realistically positive for my son. I longed with everything in me to jump onto a flight home so I could be there when this new precious child was born. But I was committed to provide bereavement skills training for the doctors and nurses attending the workshop I was to facilitate. My son was able to drop everything and get a flight home from America. I longed to catch a flight to be there for the emergency section I knew they would do to safely deliver this baby. A good friend and consultant obstetrician was there at the hospital and she kindly phoned me to explain the situation and reassure me.

Dominic Tennant Thomas came into this world on 15th March 2006 '*weighing just two and a half pounds!*' It was two days before I could fly home. I went straight to the Neonatal Unit (not a Unit I already knew). However, I was immediately made to feel welcome. The Sister who had been his special nurse from birth was

there and as soon as we met I felt the tears well up. She and I had worked together previously for many years and she was the very best nurse I knew.

My daughter-in-law, Lucy, was sitting with Dominic who was in an incubator. When I first saw him my heart felt like it missed a beat – he looked such a good colour and was not being ventilated. He was just so sweet. I also felt a deep-seated fear for his future as he was by no means out of the woods. When I got into my car later I was weeping with joy and yet found it difficult to believe he was going to survive. I knew I was doing what vulnerable parents had spoken to me about over the years, holding back just in case he died – even though I knew I should not, that I would love him whatever was to happen.

My anxiety extended to my son, Darren, and Lucy. How would they survive if Dom died? They had already been through so much loss. I was aware of how very positive they were and how very different I was feeling. They were so hopeful and I was so scared. My instinct was to help at home with Estelle – that was one thing I could actually do to help, look after Dominic's big sister. I felt protective towards her and a deep sadness for her because this was not how having a sibling was meant to be. Estelle would not be 4 until August yet she had already experienced having a sister born early who had not come home with Mummy.



Dominic in the Neonatal Unit

Lucy was in hospital for weeks and then went back every day to be with Dom, as he was now called. Estelle really missed her Mummy who was constantly on the breast pump getting the best food for Estelle's brother. I remember Darren holding Dom, his tiny head against his Daddy's hairy chest. Lucy managed brilliantly and, after 4 weeks, Dom breastfed. It was another 3 months before he came home, during which time there were a few ups and downs – but nothing serious. It was the coming home I was very nervous about as new premature babies are more at risk from cot death.

Once home the hard work began. Darren and Lucy were exhausted with the worry of him. I knew premature babies were harder work but I was not prepared for how upsetting it was to watch my own grandson turning blue with screaming because of colic. He and I had many nights bonding as I would hold him upright tucked into my pyjamas terrified that I would fall asleep.

The screaming continued until hernias were diagnosed – and then the dreadful journey back to hospital for an operation. At this time my heart went out to my son, such a capable caring young man. But he could do nothing to make things better for the wife he loved or his baby and he became uncharacteristically on edge with us all. For example, requests to wash hands became an obsession. If he asked me once, he asked me a million times, *'Have you washed your hands Mum?'* and *'Have you washed your hands?'* And me a neonatal nurse!



Proud grandmother with Dominic

As the months went by and as Dom became more adorable every day, the silent concern I had for his development grew. Dom showed no signs of wanting to move or sit up although he was unbelievably contented and happy, loved his food and smiled at everyone. He was heavy because he was not mobile and this became ever more noticeable. As his wonderful parents and other grandparents took each new

hurdle in their stride, I had to keep telling myself to stop worrying and just enjoy my precious grandson. Nothing was ever a big drama for his Mummy and Daddy. I was aware that I was looking for the problems. They were not. They helped me to see they were just so pleased to have him whatever his difficulties or future.

Dom had to wear glasses before he was a year old. His little head tilted to the right and he had to have a huge amount of physiotherapy every day. He had to wear different contraptions to help his posture and wore AFOs (ankle foot orthotics) on his legs. He was confirmed as having mild cerebral palsy and we were told there was much we could all do to help Dom reach his potential.

Long before he was 20 months old Dom's command of language was magical. He spoke beautifully, putting whole sentences together and he loved making us laugh. In this particular skill he seemed to be well advanced and he continues to use it to delight the whole family! Now he is three and a half and happily settled into a local nursery school in Palo Alto, San Francisco where they tell us he is the kindest, sweetest, cutest little fella they have ever had. And to boot he at last uses the potty! Dom is a tactile chap who loves a massage. He is hugely affectionate and has always been happiest having a cuddle.

Recently he has become frustrated and angry because of the constraints his little body puts on him, but thankfully he can express himself and has a family who understands. What he has not been unable to do physically he has made up for verbally! He loves swimming and a rough-and-tumble with his Dad – although Dom is generally cautious and a bit fearful of physical stuff. But that is not surprising as he falls easily and his balance is poor. I find myself having to hold back from protecting him all the time. I struggle with knowing that there will be disappointments and hurts for Dom in his life as a child with cerebral palsy.

I took him to the park the other day and a very small girl ran quickly past him up the steps on the slide. He looked amazed and then when it happened a second time Dom looked upset and tried to stop her, *'Please please don't go in front of me.'* She looked amused and ran ahead again. Dom cried and said to me, *'Ra Ra, she didn't take any notice. I want to go home now.'* He asked me to carry him down the steps. He did not want to slide anymore and took a while to get his cheery self back again. It was emotional and painful for both of us. I felt sad I could not protect him but reminded myself there is not a soul who has met him who does not love him.

Ra RaDominic's Granny Jenni Thomas.
25/10/09

* *Together from the Start – Practical guidance for professionals working with disabled children (birth to third birthday) and their families.* 2003. DfES (now DCSF) and DoH in England.

Cartoon © Martina Jirankova-Limbrick – first published in PNR magazine