

3. Loss and Grief

1. **The time of initial (definite) diagnosis, can be a time of huge stress, that can “shatter” the whole family, (including the extended family,) or “bowl them over”**

In his book *Special Children, Challenged Parents*, Robert Naseef, says: “*The dream of a perfect child can die a painful death. If you have a child with a disability, you certainly want compassionate words. But moreover, you just want it all to go away; and it won't.*”¹

Julia Anderson, the wife of former deputy Prime Minister, John Anderson recently described the discovery that they were going to have a baby with Downs Syndrome:

I just had my breath taken away. It was like being punched in the stomach. Awful. Shock, a shock, because you don't - I guess, especially being our fifth, I just assumed that I was having a perfect baby. It's a mourning process, but I think that as you go through that mourning of the loss of your perfect child, you re-orientate to the fact that he's still a child, he's still a person. He's got his own little life. It's just the loss of that perfection that we seek so often in this society. So it's realigning your ideals, I suppose, to come into line with the fact that he is still of great worth. He's still a little human, still a little person that's going to be born.

[Later on in the interview John Anderson says] ... *it's an imperfect world and it will never be otherwise this side of the grave.*

*JULIA ANDERSON: But having said that, I think that you shouldn't underestimate the joy, too, the joy that can be brought through those sorts of situations, too. We're very quick to look at the negative and look at the downsides and the scary bits, as a parent of a child that might have some disabilities, but they can bring such joy and wealth to your family as well.*²

Charlotte Thompson³, talks about the intense pain and grief, and some of the different emotions parents may feel, at the time of the initial diagnosis. For some it is like a rollercoaster of emotions and reactions, including anger, grief, numbness, denial, hysteria, rejection, and guilt, or just keeping quiet, but all leaving you wondering how you will survive. There is no “normal” way to react to such earth shattering news.

She goes on to say, a first step in surviving successfully is to “...*acknowledge and accept the unfamiliar and painful feelings that may overwhelm you many times during each day after you receive your child's diagnosis.*” (p. 3.)

¹ Pages 15-16, Naseef, R., (2001) *Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a disability*, (Revised Edition.) Baltimore, Maryland: Paul H. Brookes Publishing Co.

² Denton, A. (2006) *Enough Rope* ABC Television, Interview Transcript: Retrieved from <http://www.abc.net.au/tv/enoughrope/transcripts/s1627424.htm> 18th May 2006

³ In chapter 1, Thompson, C., (2000) *Raising a handicapped child: a helpful guide for parents of the physically disabled*. New York: Oxford University Press.

While acknowledging each person's circumstances are different, Charlotte Thompson suggests the following, especially if this is the first time you have really needed to grieve;

First, consciously set aside a specific time to let yourself feel the grief fully.

Second, allow yourself to share your grief with someone—a close friend, your minister, priest, rabbi, or counsellor.

Third, give yourself permission to let things go for a while, to be less organized, less productive, even a little less compassionate for others.

Fourth, find a quiet place for yourself to feel the grief—a special corner in your house or garden, a chapel, church, park or private place.

Fifth, avoid as much noise as possible during this time so you can tune in to what you feel. Let yourself really feel the grief. Don't just pay lip service to it.

Sixth, look for some records or tapes—especially “relaxation tapes” often found in record stores – to help you relax and unwind. (p. 5-6.)

2. The experience of loss and grief associated with a child with a physical disability, although having some similarities to a bereavement, is not the same because it is ongoing and repeated

The loss and grief related to the diagnosis of a physical disability is usually on-going (or chronic) and different to dealing with say a bereavement, which is a specific event at a specific point in time. One man has described the experience as “a gaping wound that will not heal”.⁴

The grief related to raising a child with a disability has been called “on-going Grief” or “non-finite loss” because, unlike bereavement, it is a cycle or pattern. One counselling textbook⁵ has referred to it as “...losses that are contingent on development; the passage of time; and on a lack of synchrony with hopes, wishes, ideals and expectations.” The same authors refer to how dealing with grief overall means making adjustments to how you look at the world, in particular in relation to the “subject” of the grief. Or how various things you had taken for granted are no longer the case, and how this type of non-finite loss and on-going grief will challenge your “comfort zone” or view of the world.

They talk of feelings going in “cycles”, that come and go, in no particular order, and how “there is an inescapable feeling of being unsettled, and of incompleteness in grieving non-finite loss.” (p. 163) they refer to the following cycles;

⁴ An unnamed father at p. 28, Bruce, E. J. (2000) Grief, trauma and parenting children with disability: cycles of disenfranchisement. Grief Matters v.3 no.2 winter: 27-31.

⁵ Page 7., Bruce, E.J. & Schulz, C. (2001) Non-finite Loss and Grief: A Psychoeducational Approach Eastgardens, New South Wales: MacLennan + Petty.

Cycle 1: Themes of Shock. Like thinking: “This can’t be happening”. A response to the fact that the person’s taken-for-granted world has been rocked to the core.

Cycle 2: Themes of Protest/Demand. A typical response may be along the lines of “Why did this happen?” It can also be a case of feeling like you are lost in a maze, with no way out.

Cycle 3: Themes of Defiance. Sometimes this can be a case of thinking “I can fix this!” Sometimes it may be believed this will be achieved by recovering, (from the “cause”) by rehabilitation, while the threat may be acknowledged at one level, it is not, at a deeper psychological level.

Cycle 4: Themes of Resignation and Despair. This can include feelings of anxiety and despair, helplessness and anger, and be typified by a response like, “I recognise I can’t go back to the previous state of affairs.” Or “I really appreciate each day now.”

Cycle 5: Themes of Integration. A case of merging the old and new views of the world, while also having underlying anxiety, fear and sadness as the threat continues. A typical comment may be “I could have done without this – but it has taught me what my strengths are.”

It’s worth restating that these are not “stages” to go through, from *Shock* to *Integration*, but feelings that will come and go, time and again, in no particular order much like the ebb and flow of waves on a shore.

3. Because the diagnosis of a disability is so far outside the “normal” experiences of a parent, it can (in some rare cases,) trigger Post Traumatic Stress Disorder

Therefore, it is important (regardless of how well you think you are coping) to have an appointment (*at least* at the time of initial diagnosis) with a counsellor to help with coping and give you some ideas about how to adjust to the news.

An Australian researcher⁶ writes about *Post Traumatic Stress Disorder*,⁷ (PTSD) grief, and the need for validation of emotions, and how “shell shocked” parents try to come to terms with the diagnosis.

Also, how over time it becomes the “unspoken drama” parents get tired of telling others about and the parents also feel their friends get tired of hearing about. She goes on to talk about the need to validate the trauma and grief, and how without help and support, parents can become “burnt out”, when they need to deal with their child’s own grief.

Research has shown that counselling, (group, individual or family) may be helpful in dealing with the various aspects of the care giving role⁸. For those living outside the

⁶ Bruce, E., (2000) Grief, Trauma and parenting children with disability: Cycles of disenchantment, Grief Matters pp 27- 31

⁷ An *American Psychological Association*, glossary describes: “**Posttraumatic stress disorder (PTSD)** [as] An anxiety disorder characterized by the persistent reexperience of traumatic events through distressing recollections, dreams, hallucinations, or dissociative flashbacks; [and it] develops in response to rapes, life-threatening events, severe injuries, and natural disasters.” [Retrieved from <http://www.psychologymatters.org/glossary.html#p> 10th April 2006]

metropolitan area, or not able to have one to one counselling, there are telephone and email counselling services provided by organisations like *Carer's WA*.⁹

Some indicators that you should seek professional help in relation to this issue can be found in the *Australian Psychological Society*, Tip Sheet for “*Managing traumatic stress symptoms and stressful events*” where they say:

When to seek professional assistance

Traumatic stress often leads to sudden changes in our patterns of daily living and the experience of unusually strong emotional reactions. You should seek professional assistance if you:

- are unable to handle the intense feelings or physical sensations
- continue to feel numb and empty and do not have normal feelings
- feel your emotions are not returning to normal after approximately three to four weeks following the incident
- continue to have physical symptoms
- continue to have disturbed sleep and/ or nightmares
- have no person or group with whom you can share your feelings and emotions
- find relationships with friends, family and colleagues seem to be suffering as a result of the trauma
- are becoming accident prone and are increasing the use of alcohol or drugs.¹⁰

4. Sometimes it can take up to 6 years to get a diagnosis, and with degenerative conditions there is also the constant change for the worse, therefore the grief experience is not the same as that for a death, and needs to be dealt with differently

In looking at the responses of fathers to the death of a child with a disability, some American researchers¹¹ noted how sometimes the diagnosis of disability took a while;

The process of diagnosis was not always clear. Some fathers went through a more gradual unfolding over several months or even years to understand the extent of their child's disability or to find a diagnosis. Rob describes the gradual learning as something “that just sends waves of fear through you.” While believing he had a healthy baby and enjoying the early period of raising a child, he was also identifying problems at a more gradual pace. “Finding out” was neither marked by a dramatic moment of diagnosis or obvious impairment. The men's response to the diagnosis ranged from, “I was very, very angry,” “Why me? Why is this happening to me?” “I went to bed and just cried and cried” to a strong sense that things like this just don't happen to “families like us.”
(p. 644)

⁸ Schofield, Bloch, Herrman, Murphy, Nankervis & Sing, (1998) cited in Studman, Roberts, Hay, & Kane (N.D.) Development and Evaluation of a Program Designed to Facilitate Family Adaptation in Families with a Child who has a Disability.

⁹ Go to <http://www.carerswa.asn.au/> for more information.

¹⁰ http://www.psychology.org.au/publications/tip_sheets/12.5_6.asp

¹¹ Wood, J., & Milo, E. (2001) Fathers' Grief When a Disabled Child Dies. *Death Studies*, 25, 635-661.

Terry DeRocher Lerma¹² writes both as a parent of a child with a disability, and someone who has worked in health care provision and notes how as parents:

Many of us reach providers' offices with some combination of three basic emotional responses: defensiveness/suspicion, exhaustion and/or dependence. [She suggests health care workers should] Probe carefully for the emotional underpinnings of the reactions you see. Your understanding of, and respect for, my experience as a Parent will allow you to approach me in a manner that is respectful and helpful to me and my family. We need, after all, to see you as an ally. We don't need to see you as yet another insensitive cog in the service delivery system, nor as a powerful, benevolent being capable of meeting all of our needs, but as a partner with whom we can safely share our fears, grief, elation with both major and small successes, anger and hope for our own and our Child's future. As a Parent, this is what I need from you, even when you "don't have all the answers". As a provider, I much prefer to play the role of partner, contributing to the well-being of Parents and their Children, to that of a benevolent, omniscient expert, destined to disappoint those for whom I assume responsibility. (p.11)

5. There is a need for adjustment (for parents) to issues about the need to move from looking for a "cure" to dealing with "maintenance" and the ongoing grief

"Every day, one of the most trying challenges is accepting and just being with a child who has a disability or special need."¹³

Joining up with support groups for parents of children with a disability (whether face to face or on-line) and meeting and discussing issues with other parents about the trials and tribulations of this epic journey, may assist in the transition from "looking for a cure" to dealing with the day to day living experiences.

6. In the case of degenerative conditions, there is the need to make the most of the time available, and set achievable goals

This may mean setting in place plans for realistic and achievable goals which might be something like one or more of the following "practical" goals;

- a.) To learn to touch type;
- b.) Learning another language (to assist in travel plans as suggested below, apart from the intellectual challenge);
- c.) Complete a TAFE or University qualification, in an area of interest;
- d.) Create a website;

¹² DeRocher Lerma, T., (2004) *CDIP Update: Life in the Trenches: A Provider's View of Raising a Child with Disabilities*. [American Psychological Society] Division 22 Newsletter: (31) 2.

¹³ Naseef, Robert, (2001) Special children, challenged parents: the struggles and rewards of raising a child with a disability (Revised Edition.) Baltimore: Ill., Paul H Brookes Publishing Company.

- e.) Self-publish written reflections on life, with the particular physical disability;
- f.) Learn to play a keyboard instrument;
- g.) Design a better or improved wheelchair, or mobility aid;
- h.) Become involved in some sort of community based organisation (not necessarily disability related,) for example *Toastmasters*¹⁴, (public speaking) or one of the “service” organisations:
- i.) Become a motivational speaker;

Other goals may include travel related plans,¹⁵ for example;

- a.) Seeing the sun set at Cable Beach (Broome), Uluru, The Taj Mahal, or the Pyramids in Egypt;
- b.) Viewing wildlife in their natural environment in an African Game park, or sea life through a glass bottomed boat on the Great Barrier Reef;
- c.) Going to *Disneyland*, or *Movie World on the Gold Coast*;
- d.) Cruising down the Murray, Amazon, Danube, Mississippi, or Nile, River’s;
- e.) Circumnavigating Uluru, (perhaps in stages) in a self-powered, or electric wheelchair;
- f.) Travelling across some of the “landmark” bridges in a wheelchair, e.g. Sydney Harbour, Golden Gate (San Francisco), Brooklyn (New York) Tower Bridge (London);
- g.) Going to an interstate or overseas concert (Rock, R & B, Jazz, or classical etc) of a particular or favourite performer or group (again, Rock, Classical, Jazz, you name it);
- h.) Participation in, or attendance at some sort of “major event” e.g. Mardi Gras in Rio, (or the Gay and Lesbian one in Sydney), the Special Olympics, Cricket at Lords, or the MCG, a major tennis or golf event, the Football/Rugby/Soccer Grand final, there are numerous possibilities;

7. The discovery by parent’s that their child has a disability may place additional strains on their relationship above and beyond those usually associated with raising a child without a disability;

In writing about gender differences in bereavement, Catherine Sanders¹⁶ notes that men will grieve differently to women.

¹⁴ See www.toastmasters.org for fore information.

¹⁵ Admittedly, apart from logistical issues, these may require financial assistance from some sort of charity, or fundraising activity, by the family and friends.

¹⁶ Sanders, C., (1998) Gender Differences in Bereavement Expression Across the Life Span. In Doka, K., & Davidson, J. (Eds.) *Living with Grief: Who We Are How We Grieve* (pp131-132). Philadelphia, PA: Hospice Foundation of America.

Recognising these differences may assist in helping your partner deal with loss, and understand why you may deal with grief in different ways to your partner, Sanders refers to previous research to note these differences.

This is summarised in the table on the next page.

Grieving for Men	Women
<ol style="list-style-type: none"> 1. Feelings are limited or toned down; 2. Thinking precedes and often dominates feeling; 3. The focus is on problem-solving rather than expression of feelings; 4. The outward expression of feelings often involves anger and/or guilt; 5. Internal adjustments to the loss are usually expressed through activity; 6. Intense feelings may only be expressed privately; there is a general reluctance to discuss these with others; 7. Intense grief is usually expressed immediately after the loss, often during post death rituals. 	<ol style="list-style-type: none"> 1. Can express anguish in tears and laments; 2. Are socialized to be nurturing and empathic; 3. Are not afraid to express grief; 4. Seek support; 5. Have difficulty expressing anger; 6. Are prone to guilty feelings; 7. Are caregivers to friends and family; 8. Are keepers of the family circle;
<p>(Martin & Doka, 1996, cited at p. 125, Sanders 1998)</p>	<p>(Sanders, 1995, cited at p. 128, in Sanders, 1998.)</p>

It is also advisable to consider some of the strategies and suggestions elsewhere in this resource, about nurturing and caring for the primary relationship between parents.

8. There will probably be a need for help and support for parents, children (including classmates) and families, and others in the school community related to the loss of function, and for end of life issues (i.e. for degenerative conditions);

Children and young people in the education system, both with physical disability and their peers, may well need assistance to deal with the grief they feel in relation to this situation, or that of the child with a physical disability.

In the school setting, there are a number of categories of people who may be affected by grief related to the child with a disability, they include;

- The child themselves;
- Their classroom peers;
- Other students within the school system;
- Teachers and other adults within the school system;

As noted in the *Rocky Bay L.I.N.C.K.S.* resource:

It is inevitable that other school children, or the child with a neuromuscular condition themselves, will ask questions about the condition. Responses should be age appropriate, and it is important to discuss with the parents how much information they want divulged. A child with a neuromuscular condition may not know of all of the implications of their condition.¹⁷

Other options include working with the school psychologist, or chaplain, apart from consultation with the parents of the child about how they wish to deal with the situation, and based on their circumstances, including the child's wishes, what they feel it is appropriate to do.

Looking at the following section on "My Grief Rights" may give young people some guidelines to help them deal with some of the issues related to grief.

¹⁷ p.25, Rocky Bay Inc., Information for the Whole School (2005) [L.I.N.C.K.S.].

Resources:

accessibility.com.au - the disability information resource.

Australian Psychological Society:

"Managing traumatic stress symptoms and stressful events An APS Tip Sheet"
http://www.psychology.org.au/publications/tip_sheets/12.5_6.asp

Carers WA <http://www.carerswa.asn.au/>

255 Walcott Street Phone: (08) 9444 5922 Fax: (08) 9444 8966
North Perth 24hr Carer Counselling Line: 1800 007 332
WA 6006

Emerging Horizons <http://candy-charles.com/> [***Emerging Horizons*** is a consumer oriented magazine about accessible travel. *Emerging Horizons'* primary focus is travel for people with mobility disabilities"]

Information on Disability - Equipment Access Services Inc. <http://www.ideas.org.au/>

Kids Helpline www.kidshelp.com.au phone 1800 55 1800, or email via the website.

National Association of Loss and Grief www.nalag.org.au

Transitions Abroad <http://www.transitionsabroad.com/listings/travel/disability/index.shtml>
[Disability Travel Resources and Information.]

Wolfelt, A. Healing a child's grieving heart: 100 practical ideas for families, friends & caregivers Fort Collins, CO: Companion Press. [ISBN: 1879651289]

