

Acceptance

Many forms of intellectual disability also have linked physical disabilities or challenging behaviours that demand a lot of time, attention and skill to cope with. Very soon you may find you move into a new phase of coping -

DOING - not feeling

This coping stage can give you space to get used to the idea that no miracles are going to occur and this is the way life is likely to be for a long time. But it can also be the time when you bury unexpressed grief. Buried grief will come out eventually.

Your losses

Parents of intellectually disabled children lose a lot that parents of normal children don't ever experience as loss.

Your losses could include realising that -

- ◆ your child may never read or write
- ◆ Your child may never communicate
- ◆ You may never be free of caring for your child until the child dies
- ◆ You cannot look forward to retirement
- ◆ Finding the right care for your child is just about impossible
- ◆ You will always have to buy expert child-care (not just the 15year old down the road)
- ◆ Family outings or holidays have become logistical nightmares

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- ◆ Time for yourselves as a couple or individuals is almost impossible
- ◆ Your couple relationship is falling apart

As your child grows

Each normal childhood milestone is likely to bring you fresh grief. These could include significant birthdays or the time when other children are joining clubs or sports teams.

Leaving Home

There are many reasons why your intellectually disabled child might leave home. You might -

- ◆ Choose to have go into specialised care
- ◆ Choose to have them live in a foster family
- ◆ Choose to share care with another family so you can have regular breaks
- ◆ Become so ill or old you cannot cope any longer

Whatever reason, expect another onset of grief. You may experience sadness, disappointment, guilt, fear, shame, anger, depression, tiredness, emptiness. This is perfectly natural—you now have time to grieve. Our Web Page discusses some of these emotions in more depth.

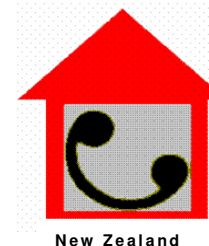
Visit our Web Page at
www.rescarenz.com

Rescare's Information Leaflet 2.3.22

Let's
Talk about
feelings

What about YOUR feelings ?

When a child with an intellectual disability is born into a family, or a child becomes intellectually disabled through illness, there is a huge amount of grief for each family member. Acknowledging and accepting it is part of the process of coping with the extra demands of living with a person with an intellectual disability



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Your feelings are perfectly OK because they are YOUR feelings

First feelings

Normal pregnancies usually result in a child who will grow and develop and eventually take charge of their own lives. When a child who has an intellectual disability arrives none of these expectations can be taken for granted.

No matter how your family member became intellectually disabled your first feelings will be ones of shock and disbelief.

You may feel -

- ◆ Numb or sick in the stomach
- ◆ Angry at the doctor who first told you
- ◆ In absolute denial about disability.
- ◆ Constantly weepy
- ◆ Angry at friends or family members who try to comfort you with positive words.
- ◆ Ashamed
- ◆ Guilty about any remembered possible (or impossible) cause of disability.
- ◆ Angry and betrayed by your god or religion
- ◆ Really “high” or positive about the future
- ◆ Terribly possessive about your child
- ◆ Unable to function normally

All these reactions and many more are absolutely NORMAL reactions to learning you have a child with an intellectual disability.

They are part of a grief process you must go through in order to cope with the huge disappointment that your child will not grow up to fulfil the possibilities you dreamed of for them.

Important
Don't tell yourself, or let anyone else
tell you, how you SHOULD be
feeling
Your feelings are perfectly OK
Because they are YOUR
feelings
Experience them, express them and
move through them

Friends and family reactions

The reactions of friends and family are often the most difficult to handle. They too are going through a process of grief, They may have shared events of your pregnancy and were ready to celebrate with you. Now they don't know what to say or how to act.

They may make remarks like -

“Well at least you've got two healthy children ”

“At least you're young enough to try again “

These are hard to take because you will be coming to terms with your child's disability and will be bonding with him or her. You may feel your baby is really precious and any insinuation that she or he is not equally lovable or valuable as any other child will be hard to take.

Friends or family members may-

- ◆ suddenly avoid you
- ◆ treat you like you are unable to operate normally
- ◆ tip-toe round you and close down any conversation about what has happened.
- ◆ become quite distraught themselves so you feel you have to comfort them
- ◆ be wonderfully supportive and just listen
- ◆ become “experts” on intellectual disability
- ◆ inundate you with articles, books, information about other disabled children
- ◆ quietly try to learn how to care for your child so that they can relieve you occasionally
- ◆ keep praising you for how well you cope even when you feel like screaming
- ◆ they may even deny that anything is wrong with your child and point out incidents that show how “normal” they are.

Some of these reactions may be just what you need at the time. Other reactions will enrage you.

Every grieving process is different and there are no rules on what is “best”