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■ ABOUT THE AUTHOR

Liz Crowe graduated with a Bachelor of Social Work from James Cook University in 1992. She worked initially in Mental Health at a Day Therapy Centre (1993 -1995) later working in general hospital work. These experiences led to a long term interest in issues of grief and loss and working with families in crisis. Since 1995 Liz has worked at the Royal Children's Hospital in Brisbane where she has specialised and developed a passion for working with children and neonates with life limiting conditions, their families and communities, particularly in the areas of grief, loss, crisis and adaption. In 1999-2000 she was employed by Queensland Health to conduct a comprehensive Statewide needs analysis of families and service providers caring for children with non-malignant life limiting conditions. Her passion unabated, Liz continues to work in this area both in a clinical and educational role while raising a young family.

■ BACKGROUND

The first paediatric palliative care project funded by Queensland Health and initiated by the Royal Children's Hospital and Health Services District [RCH&HSD] commenced in 1998. This initial project identified the needs of health professionals and families caring for children with progressive malignant disease. This led to the development of a handbook called 'A Practical Guide to Paediatric Oncology Palliative Care', written for health professionals. A follow up book for parents and families has more recently been developed.

In 1999, Liz Crowe, Social Worker at the Royal Children's Hospital, was seconded by Queensland Health to undertake an extensive needs analysis looking into the requirements of families with children suffering from non-malignant, life-limiting illnesses: 'The Statewide Paediatric Palliative Care Education and Community Awareness Project'. Working with a steering committee from the [RCH&HSD] comprising of Dr Helen Irving, Dr Jim McGill, Tim Rogers and Michele Noyes, Liz Crowe completed the project in 2000. Amongst the project report's recommendations, education and training for health care professionals was highlighted, particularly in regard to working with children with life-limiting conditions in the area of loss, grief and bereavement. This became one of the unit's strategic priorities.

To this end, in August 2003, a three-day paediatric loss and grief training workshop was held in Bundaberg, Queensland, for professionals involved in the support of children with life-limiting illness and their families. The Centre for Palliative Care Research and Education [CPCRE] was contracted to manage the project, which also included the development of an educational resource for professionals and/or parents caring for children with life-limiting illness.

Dr Judith Murray, a well-respected leader in the area of Loss and Grief, developed an innovative program with the assistance of Liz Crowe. The workshop was well attended by representatives from health, education, disability, and pastoral care sectors. At the end of the workshop participants were asked by Liz and Judith to identify key areas of loss and grief thought to be essential for inclusion in an educational resource. This booklet, 'When children have a life-limiting illness: questions and answers around loss and grief', written by Liz Crowe, is the result.

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■ INTRODUCTION

It has only been in the last decade that research, education and information on paediatric palliative care and children with chronic conditions has come to the attention of researchers and the general population. Mainstream palliative care services and research identify people and children with malignancies as their target population despite the many people – especially children and young people – who die of other conditions. Issues for families and children living with life-limiting conditions and chronic conditions differ in many ways from the issues of families impacted by cancer and leukaemia.

These differences include:

- The longevity and chronic nature of the illness
- The complexity of many of the life-limiting conditions such as intellectual and physical disabilities
- The genetic nature of many of the conditions which can render more than one family member affected with the same condition
- The condition will cause premature death
- There is no cure available for any of these conditions
- Conditions will be diagnosed in childhood

Such differences are important to acknowledge in order for us to understand the unique needs of these children and their families.

■ WHAT IS THE PURPOSE OF THIS BOOKLET?

Who is it for?

This booklet has been designed for parents, health care professionals, teachers, respite care workers, grandparents and anyone whose lives are impacted by a life-limiting condition.

Care has been taken so that whether you are a parent, a carer, a doctor, nurse, teacher, educator or allied health professional you will easily be able to understand the language used in this booklet.

How can it be used?

Each section starts with a question. If a person has a specific question he or she can forward directly to that section. The booklet does not need to be read from start to finish to make sense. Rather, this booklet can be put down and picked up whenever you need to!

■ WHAT DO ALL THESE WORDS MEAN?

Before we get started we will go through what some of the terms and definitions mean so that we are all talking the same language.

The Conditions

- An acute condition is one that comes on quickly, and has a beginning, middle and an end. The outcome could be recovery or some state of permanent damage that affects the individual's capacity to function as he or she did before.
- A chronic condition is one where the outcome is an ongoing state of disruption to a person's "normal" life. If left unchecked, the ability of the person to live normally is limited in some way. It may be that the person can be enabled to function normally, but has to take extra steps to do so.
- Some chronic illnesses have acute flare-ups. These episodes are termed acute on chronic. So a child with cystic fibrosis has a long term chronic illness but may have an "acute on chronic" flare up when he or she develops a chest infection as a result of a flu.

What is a Life-limiting Condition?

There is still much debate about what constitutes a life-limiting condition. Below are some of the current definitions:

- Conditions for which there is currently no cure and the condition is likely to lead to a child dying prematurely (Sutherland, 1994);
- Any chronic condition (longer than three months) developed in childhood that without major intervention is likely to result in premature death (Lenton 1997);
- Recognition and diagnosis of the condition must occur before the age of 16 years. There is no cure for the condition and a likelihood that the child will die prematurely as a young person (25 years or under), (Crowe, 2000).

What are some examples of Life-limiting Conditions?

- Cystic Fibrosis
- Muscular disorders (eg Muscular Dystrophy or Muscular Atrophies)
- Congenital abnormalities
- Neurodegenerative and neurological conditions
- Metabolic conditions (eg: Mucopolysaccharides)
- Organ failure (eg: kidney or heart disease)
- Severe multiple disabilities: this is a controversial category, even though many children and young adults with severe intellectual and physical disabilities can die prematurely as a result of complications through respiratory illness (particularly pneumonia) or as a result of surgery.

■ WHAT DOES 'LOSS AND GRIEF' ACTUALLY MEAN?

What are some of the definitions for loss and grief?

- **John Lennon sang**, "Life is what happens to us while we are making other plans."
- **Change** is one significant aspect of life, which can occur very unexpectedly. It can also be a change that we are aware of but still do not want to have happen (eg: moving house).
- **Loss** can be described as that sense that all is not well. It "is produced by an event which is perceived to be negative by the individuals involved and results in long-term changes to one's social situations, relationships, or cognitions" (Miller & Omarzu, 1998);
- **Grief**
 - is the reaction to loss;
 - is the emotional response to loss: the complex amalgam of painful affects including sadness, anger, helplessness, guilt, despair (Raphael, 1984);
 - incorporates diverse psychological (cognitive, social-behavioural) and physical (physiological-somatic) manifestations (Stroebe, Hansson & Schut, 2001);
- **Mourning** describes the psychological processes that occur in bereavement; the processes whereby the bereaved person gradually undoes the psychological bonds that bound him or her to the deceased (Raphael, 1984). This is the slow process of recognising what has been lost and how our lives will now be different without that person; and,
- **Suffering** refers to the width of the gap between the reality of 'what is' and 'what is desired'.

Doesn't someone have to die in order for us to experience loss and grief?

Definitely not. We will all experience loss and grief in our lives at some stage. Loss and grief can happen for us in many different circumstances.

When can we experience loss and grief?

Individuals can face loss and grief in a variety of circumstances. Loss and grief are very individual and a complete list would be impossible to construct. Below are just some examples when you could experience loss and grief:

- Death
- Relationship breakdown – marriage or otherwise
- Unemployment
- Disability
- Business or farm loss

- When a child leaves home
- Abuse
- Ageing
- Illness
- Living with a terminal or chronic illness
- Having to move
- Loss of libido

What are some of the losses that families living with life-limiting conditions and disability may face?

Here are some of the losses that may be faced:

- The loss of the perfect child you dreamed about but did not have;
- The constant wanting or thinking of “what if” throughout your child’s life;
- The losses of living with the reality of your child’s disability or condition;
- The loss of the opportunity to just have a normal parenting role (eg: not having to give medications, do physiotherapy; not having to understand medical terms, the loss of time just to have fun);
- The loss of normality when your child does not make milestones or get to participate in ‘normal’ developmental activities such as starting school, getting married; and,
- The loss of family time as you once knew it; that you no longer have the life your family had prior to having a child with a life-limiting condition or disability.

It is so vital to understand that grieving these losses does NOT mean you do not love your child. This is a normal part of grieving and adjusting to living with a precious child with special needs.

Why is it important to understand loss and grief?

Grieving is a normal and natural response to any loss. When we grieve, other people (family, friends, and work colleagues) can feel uncomfortable with our reactions simply because they feel powerless to help. They may suggest that what we are doing is “not normal”, that we are “depressed” or that we “need medication” or to “seek help”. In some instances this advice may be useful, but for most of us, reactions such as tears, anger, insomnia or poor concentration are just a natural reactions to our loss. It is important for us to be confident in what is and isn’t normal so that we can judge for ourselves when we need outside assistance.

What is a ‘normal’ reaction to loss and grief?

Loss and our reactions to loss in the form of grief are very INDIVIDUAL. It is rare that two people will experience any loss in the same way. How intense and severe our grief will be depends on how severe the loss is for us and what meaning we attach to

this loss. Whoever you were prior to your loss will determine in many ways the way you cope with the loss. If you have always been extremely outgoing and chatty, then you may find great relief in constantly talking about your experience. Sharing it with others and asking opinions and advice may feel right for you. However if you are normally a very private and introverted sort of person you may withdraw and prefer to read about losses in a book.

There is no right or wrong way to grieve. There are no clear steps or paths that can be prescribed to stop having these feelings.

What are some things that can shape the way we experience grief and loss?

Losses rarely exist in isolation:

From an early age we all experience loss and grief on either a small or large scale. For example, finding out that Santa isn't real or losing a grandparent or moving schools can shake a child's world. This previous experience may shape the way you deal with the recent loss. We know that when a person experiences a new loss he or she may often re-experience previous grief.

This means when people experience a new loss (eg: the birth of a child with Cystic Fibrosis), the new loss may bring back feelings and a sense of helplessness they may have experienced when their grandmother died, or when they were unemployed for several months. Again this is normal. People often have good intentions in telling us that "time heals all wounds". We know this is not the case. Rather than getting over loss, loss becomes a part of who we are. What people learn to do is to live with the loss, or integrate the loss, or make some sense of the loss so that they can continue to live their lives. By remaining part of us, it doesn't mean that we are destined to be sad about a loss all our lives. It just means that it is part of who we are, and is part of the life experiences that shape us as the people we are today.

Culture:

Different cultures deal with loss and grief in a variety of ways. These different ways can shape how we cope with loss and grief as individuals. In some cultures loss and grief are experienced very publicly, with wailing and crying out, whilst other cultures may see this as disrespectful to their ancestors or religious beliefs. In some cultures illness or disability is viewed in a much more fearful or negative way than in other cultures.

Family background:

The way we have grown up and what we have learnt from our families with respect to the ways to manage our grief will play a large part in how we cope with loss and grief. This can be a difficult aspect for a couple and "in-laws" when both families want to deal with the loss in completely different ways.

Gender:

There are some major differences (cultural, sociological and biological) in how men and women can experience loss and grief. There is more on this later.

What else do we know about the effects of loss on people?

Loss and grief is said to threaten our sense of control and mastery. We all have things in our life that we take for granted. Most of our lives continue with routine, predictability, and the certainty of daily events, people and the immediate future. We make assumptions about our world.

An example: Most of us wake in the morning and assume our day will unfold in a certain way just like it always does. "I will wake, have breakfast whilst watching TV and then have a shower before going to work."

After a loss or grief event, we can start to doubt even our most basic of routines. It can feel like everything is under threat or changing. We can feel that the world as we once knew it will never be there again. And the reality is that it never will be exactly the same again. That world as we knew it is gone. In our grieving we learn to live in a new world.

One person's experience of loss and grief:

One of the best analogies I have ever heard to describe loss was from a woman whose husband had been killed suddenly and tragically in a work related accident. She described her experience in this way:

"Initially the death of my husband was like a severe burn. It hurt 24 hours a day. No matter what I did or tried to do the pain was raw and with me. Even when I tried to sleep or was asleep, I was conscious of the pain. There was no relief from it.

"After several months it got to a stage where it wasn't so consistent but just like with a severe burn a simple 'knock' could make the pain and the wound as red and raw and painful as before. This could happen when someone mentioned his name or when our favourite TV show came on. I had no control of it. It would feel like I was back at square one.

"After about a year, I could have times when things felt almost normal again. Though it was a new type of normal. I was definitely a different person now in many ways. It was like the burn had been grafted. So it was painful to look at, think about or touch but there were times when I could do the things I used to and not be reminded of it. As the years have gone by the scar has remained and I have learnt to live with that. There are times such as Christmas, birthdays and anniversaries when I am so conscious of my scars and I take precautions to protect it and nurse it. Or to look at it and reflect on it. I might even still cry about it. The scar will always be with me. I have learnt to live with it. It's not as red and painful as it once was, but I am always aware that it exists."

This example highlights how intense loss and grief can be. This intensity of grief is to be expected and does not mean that something is now 'wrong' with us.

Are there stages of grief?

In the 1980s and early 1990s, there was a lot of talk about the stages of grief from a lot of grief experts. This discussion led many people to believe that there were steps or stages of grief and once you went through these, you could 'accept' your loss and simply move on with your life. Many people who experience loss try to achieve these steps quickly in the hope that life will 'go back to normal'. Unfortunately the research on steps and stages was not quite correct.

It is true that during periods of grief and loss it is normal to have a number of feelings. Emotions such as disbelief, anger, denial and guilt are all normal and part of grieving but rather than be 'steps' or 'stages' most people report revisiting these emotions sometimes again and again. For those people who move on from emotions such as anger and disbelief he or she frequently say that they never get to a stage where they 'accept' what has happened to disrupt their lives so dramatically. Rather they work out a way to build the loss into their lives. Like the story of the 'scar' above the loss never really goes away but you can learn to live, love and work around it. Grief can have a habit of re-emerging in times of stress or when we experience a new loss or grief experience. The old 'wounds' will be more profound if we never really gave ourselves the opportunity to grieve the first loss the first time around!

■ FREQUENT QUESTIONS FAMILIES MAY HAVE

What are other families who have children with similar health problems experiencing?

Sixty-three families were interviewed in 1999-2000 about their lives when living with a child or children with life-limiting conditions. Out of these interviews, a number of very clear themes emerged as being common amongst all the families. Below are the most common themes and issues for these families.

The most common themes and issues for families living with children with life-limiting conditions

- Parental disappointment with the way the diagnosis had been given.
- Difficulties experienced for the family due to the high levels of physical care required by the children.
- Nighttime disturbance and sleep deprivation having a major impact on family life, quality of life and physical health.

- The significant impact the child/children's illness had on the couple's relationship – be it positive or negative.
- The significant impact the diagnosis had on the family's ability to still participate normally in a fulfilling social life.
- The significant impact the child/children's diagnosis had had on the well siblings in the family.
- The impact the illness was having in the normal function and activities of the child who had the condition.
- The incidence of depression, suicidal thoughts and substance abuse in the parents who were interviewed. Half of all the parents interviewed believed they had suffered or were suffering from depression. Fifteen percent of parents had thought about suicide though no one had acted on these feelings. Eleven percent of families openly admitted to abusing substances (such as alcohol) as a means of coping with the stress and grief of having a child with a life-limiting condition.
- Thirty percent of all the parents stated that caring for a child with a life-limiting condition had created significant mental and physical health problems for themselves as the primary carer. Issues included back and neck injuries, migraines, ulcers, and having to delay surgery and other important medical/dental appointments for themselves due to a lack of respite care.
- The need for quality counselling and support from an experienced and consistent person was identified. Eighty percent of parents stated they had never had counselling.
- Families identified financial assistance as the greatest area of need when caring for a child or children with a life-limiting condition.
- Employment opportunities were found to be greatly limited for both parents when there is a child with a life-limiting condition in the home.
- Respite care was highlighted as the second greatest area of need for these families. Families wanted more respite care as well as greater quality and consistency with respite care. They stated they needed respite care to be more flexible with the greatest need being night time and weekend respite care.
- A major issue for families was the lack of co-ordinated care that was being given to their child or children. Parents complained of the difficulty of trying to negotiate their way through a complex system of forms, government departments as well as numerous community organisations. Parents stated that they found themselves having to try and manage their own case through all these complexities, which added to their stress.
- Many parents expressed their concerns for what would happen to their children in the future. They worried about their ongoing ability to care for their child or children in the future, as the children grew to become heavier and harder to manage physically, and they as parents became less agile. Parents also worried about who could care for their children if they became ill, died or were injured. Parents were also worried about leaving the paediatric health system to enter the adult system.

■ COMMON FAMILY ISSUES AND SUGGESTIONS TO HELP DEAL WITH THEM

Why have your family and friends abandoned you when you need them most?

People tend to feel extremely uncomfortable when any one cries, grieves or is distressed. If that person loves you they may want to simply 'fix' the situation, or make it stop, or go away because this will make them feel better. No one likes to watch anyone they care about suffer. When we are grieving or sad, we are suffering, even though this suffering is normal. Some common experiences of families when they are experiencing loss, grief and perhaps bereavement include:

- Most families and friends will simply not know what to do and may avoid contact with you for fear of "saying the wrong thing" or upsetting you. Remember prior to this happening to you, you may have fallen into this category so try to be gentle with them.
- People are terrified that they will make you cry. They do not realise that you probably would be crying whether they were there or not! Some people will try and crack jokes or avoid the subject in an effort to not see you cry!
- Some people may think that it would be too difficult to invite you to social functions as you may feel overwhelmed, out of place or not want to discuss what is happening for you.
- You may have some people who will not tell you when they are pregnant or if they have had a new baby as they think that you will not cope with their 'healthy' baby.
- Some families will be amazing and will do everything possible to assist you with your precious child and new lives.

How can you help your family and friends understand what it is you need?

The main thing to remember is that even though your family and friends may be doing all the wrong things and making you feel isolated and alone, they probably have good intentions.

Here are some strategies that may help when dealing with unsupportive or avoidant family and friends:

- Ring them and let them know what it is you need. Lots of people can cope with practical tasks. They like to be given jobs or tasks as a means of being helpful. Suggest they drop around a meal or just pop in for a coffee.
- Ring them and tell them how alone you feel. Let them know you are upset but that what they do or don't say is not responsible for your sadness. Let them know that it

is very hard to know what the 'right' thing to say is and you don't expect them to be magicians and solve all your problems or fix your feelings or emotions. Let them know that what you need is a parent, a friend, a neighbour, a cuddle, a beer, a laugh – whatever it is you need from them and whatever your relationship has been prior to this experience.

- Give them some guidelines as to what you and your family do need and want! For example: "We've eaten 16 lasagnas in the last week so please no more food – but my husband and I would love an hour to ourselves to go for a walk. Could you please watch the kids?"
- Give them some printed material on the condition, on grief and loss or on whatever it is you would like them to learn about. This can be done in a way that is tactful and helpful. This gives them the power to read it in their own time and space.
- Let them know what your greatest fears and anxieties are. Let them know what will be a crisis for you (e.g. the first blood test or first admission to hospital) so that when these events happen they have the chance to respond.
- Tell them that you are still you and that it is really important that they recognise this. Let them know that you do not want to now just be "the parent of a child with a disability". Get them to help you remember that amongst all the pressure that you still love to read a good book, dance, be creative or have a good time on a Friday night.

As in any crisis there will be people who disappoint you with their response, but perhaps with time they will come around. If you do lose contact with people, try not to let it make you despondent. Relationships change with need and there will be friends, some old and some new, who will do the right thing. The people who end up being your major support may surprise you!

If there is a genetic component to this illness, why is your family ignoring you?

There is often a genetic component to many of the life-limiting conditions. This fact can intensify feelings of guilt and grief for all members of the family. Unfortunately most people are at a loss as to what to say or do when people are grieving, stressed or just plain sad. When a condition or illness is directly related to our genes it can mean that many will carry a level of guilt (even though they may not be aware of these feelings) from grandparents, to in-laws, great aunts and uncles. Many people do not know what to do or how to cope with this level of guilt or responsibility. It is common when there is a genetic component to a condition that this complicates the grief issues for the extended family.

Grandparents, aunts and uncles can feel guilty that "their" genes have been responsible for inflicting a condition on a precious and much wanted child. Because of this guilt, fear and anger families can respond in ways that are unhelpful to you.

This can be the result, even though realistically **it is no-one's fault**. Often what family members and friends will do when they feel uncomfortable is avoid us, trivialise the situation or say something that is completely unhelpful. Genetic links to many illnesses and understanding many of these conditions is quite recent. Hence many grandparents may have been led to believe that the four brothers and sisters they had who died at an early age died from 'pneumonia'. This will cause them a great deal of concern and may raise their own grief issues that they have worked hard to bury!

Other typical responses from your family

These may include:

- Some members of the family may avoid contact with you because they believe if they don't see you they won't have to think about it and confront what is happening
- Some members of the family particularly if they are having or are planning on having children themselves may avoid you because they do not want to be confronted by the condition and the statistics that they and their children may also be affected
- Some members of the family despite being presented with the facts will insist that the condition has come from the other side of the marriage, "the in-laws" because they certainly don't have any illness in their family
- Other family members report their families being fantastic. They tell stories of having a planned family get together or BBQ where they talk about the condition. Give out information and discuss the implications for everyone. And generally feel well supported.

Remember that genetic counsellors are available to everyone through Queensland Health for free of charge. Their services include extended family members! General emotional counselling may also be available to extended family members through the hospital or community health social worker.

Why does your neighbour who has a child with cancer appear to be getting more support and acknowledgement than you are?

When someone gets cancer, everyone shudders because it is their greatest fear that someone they know and love may be touched by cancer one day. When someone you know gets Muscular Dystrophy most people will say "What the hell is that?"

As one mother stated:

"When someone hears of a child being diagnosed with cancer or leukaemia their immediate reaction is "oh my God that poor family". When people hear that a family has a genetic disorder their attitude is more like "It's something in the family."

This does not mean that people are uncaring. Rather, because they are unaware of what the condition entails, they may simply not know what to do or understand the significant impact that it has on both the children and their parents. It can also be confusing to family and friends to know what to offer when your baby actually “looks fine”. It is hard for people to appreciate the level of stress and concern parents will constantly feel and experience when their child has a life-limiting condition. Many conditions are degenerative so people may be confused as to how and if the condition will impact your lives.

In discussions with many extended family members and friends people talk about their confusion as to what to say. They don't want to ‘depress’ the family when they have such a long journey ahead of them with a life-limiting condition so they try to minimise and stay positive.

People may initially gather and be supportive but as the years go by many may not know how to sustain this support. They may be unsure whether or not to keep bringing up the issue particularly if the child is currently in good health. Again it may be helpful for you to take the lead and initiate the conversation around the condition or keep people informed as to what is happening and what you need from them.

If a family is diagnosed with a child with cancer they will experience many of the same loss and grief issues as those impacted by life-limiting conditions. The difference is that in most cases (definitely not all) when the child is diagnosed treatment, surgery and hospitalisation will all occur quite quickly (Cancer is an acute condition). So the reality of what is happening for that family will be obvious to everyone. The battle for survival will commence immediately giving members of the community clear clues as to what may be needed. If you spoke with people who were touched by cancer most would have similar stories of being ignored or let down by certain family members and friends. Again we need to be reminded that most people are very uncomfortable with grief and loss and find it difficult to respond no matter how much they may love and care for the person being affected.

Why do men and women talk and grieve so differently?

First let us recognise that this is a fact. The differences between men and women are very real and not just isolated to your marriage, relationship or family. There are a number of biological and social reasons why men and women grieve differently. However, do not forget that personality will also play a part!

It is important to acknowledge that in times of grief, loss and crisis people are still who they are. If you are normally a quiet and reserved sort of person this will filter how you express yourself at this time. If you are normally very outgoing and love to talk through issues you are likely to still do this even in a crisis.

When looking at a person in grief, loss or trauma it is also important to see them in context of:

- social and cultural backgrounds;
- family backgrounds;
- socioeconomic status;
- their previous life experience and skills they have developed in managing other times of crises e.g. death of a grandmother, unemployment; and,
- their role (or their perceived role) is within the family.

Remember some men do cry and some women can read road maps!

What are the biological differences between men and women and how does this affect the way we communicate?

In making statements about sex differences, it is VERY important to remember that these are general trends between the sexes. There are NO hard and fast rules about particular individuals. Both males and females have a mix of feminine and masculine qualities.

Men and women's brains are different in structure. The neural structure of the brain can result in men finding it harder to put language around what they are feeling. In contrast, women generally have a brain structure that allows them to talk more easily about how they are feeling – much to the distress of their male partners!

If we look through evolution and the way men and women's roles have developed it can give us a stronger understanding as to why we communicate the way that we do.

How do some men respond to grief and crisis?

'The Fight or Flight Response'

Since the beginning of time, men have been the hunters and protectors of our societies, be it in prehistoric times or in times of World Wars. Despite whatever fears or atrocities that they have been confronted with, men have had the task of getting on with the job in order for societies to eat and survive! A crying caveman facing a saber tooth tiger with only a spear would have not achieved much. If men had sobbed in the trenches huddled together, talking through the issues in World Wars, we would have had very different outcomes. As part of the defence mechanisms for these situations men have developed a 'fight or flight' response as part of their physiology. In times of crisis, hormones pour through their bodies and they will either **stay and fight it out or run for the hills**.

Men's brains tend to see them prefer to evaluate and react from a logical viewpoint and attempt to problem solve issues rather than evaluate and experience them. Some

women can find this frustrating, as they want to ‘talk and feel’. However, it is this mechanism that allows men to be able to filter situations and even switch off to them so that they can still go and function at work despite problems at home. Think of how often following an argument, the woman will go to bed tossing and turning on the issues while the man can simply switch off and be snoring in seconds.

It is VERY IMPORTANT however that we do not assume that just because there is an absence of tears and men continue on with their activities of daily life that they are not grieving deeply or are not impacted by the situation. They are simply doing it differently!

How do some women respond to grief and crisis?

‘Tend and Befriend’

In times of stress and crisis, women may also use a fight and flight response. However research is indicating that women can also be comforted and seek support or structure through ‘tending and befriending’.

What does to ‘tend’ mean? Women in times of grief and crisis may deliberately tend to the house, tend to the children; tend to throw themselves into voluntary work, tend to the child with the condition with extreme vigour etc as a means of coping. How many women will scrub the house when something is on their mind?

Women also have a habit of ‘befriending’. This means in times of crisis women may have a strong desire to be with their friends, sisters, mothers and other women so they can talk and grieve freely. Most women will actively seek out other women they love to talk too. Women will meet for a coffee or tea to be with other women. They may actively and sometimes deliberately pick these times to not only talk but to cry and grieve and be angry because they know it is a safe place to do so. Women usually have larger and more supportive networks to meet with friends and be comforted.

While some men also have very supportive networks of friends, many Australian men unfortunately may have many mates but no male friends with whom they would feel comfortable to cry.

When we understand these two very different approaches between men and women it is easy to see how conflict can arise between the sexes during times when people are already very stressed and lonely.

What do men find really unhelpful when they are distressed?

When a man is sad/angry/grieving he may want to retreat into himself (flight) or involve himself heavily in a task so he can either address the problem or distract himself. This is how he is coping. It makes sense to him and feels better than just

experiencing the emotion. So the following situations and comments are usually not only unhelpful to men but may be a source of eventual conflict:

- Having your female partner follow you from room to room in the house saying “you obviously need to talk, so what’s wrong?”
- “What are you thinking?”
- “Tell me what you are feeling?”
- “What you need is a good cry!”
- “You’re just like your father - completely unemotional!”
- “Have you told your friends and the people at work what is going on? Why not?”
- “Don’t you care what is happening to your family?”

What do women find really unhelpful when they are distressed?

Unlike men, women will often feel very comforted simply by talking out loud about the situation (not necessarily getting advice or practical solutions – just talking). Women may simply feel better just for listening to a sad song and sobbing through it. So some examples of what is unhelpful to women when they are distressed are comments like:

- “Crying doesn’t fix or solve things”
- “Are you crying again?”
- “Pull yourself together, that’s not going to help anyone”
- “If it is too hard to be at home, go back to work”
- “You need to move on and get over this”
- “Let’s just work with the reality of the situation and solve the problem”
- “Why do you have to tell everyone our business?”

Apart from the physical differences in the brain, what else makes men and women talk so differently?

Studies have shown that right from childhood (particularly in previous generations) little boys are discouraged from crying and expressing feelings, while little girls are given lots of attention and affection when they are upset.

How often do you hear in your own life where a little boy will be called “sooky” or “gay” if he cries about an accident or incident? Little boys are often told to be brave when they have hurt themselves, while a little girl will receive a cuddle and a bandaid? This all plays a part in how we then react as adults.

Boy’s toys and activities tend to focus on action, movement and distraction. For example, it is difficult to talk or express feelings while playing football or with a Tonka truck.

Girls on the other hand often have toys such as tea parties, dollies, playing dress-ups and so on, that actually encourage them to practise their talking skills with others or foster a sense of nurturing and caring.

Traditionally, men have been taught from childhood to act “like a man” – contain emotions and take control/ take charge of a situation. Women have alternatively been taught from childhood that emotional expression and talking is acceptable.

What are some of the theories behind the differences between men and women?

Gilbert (2002) believes that women’s grief is “social and emotional grief”. This means that women are encouraged by others to share their grief with family and friends. That tears and outbursts on these occasions will not only be tolerated but also expected and women will usually receive the friendship and support they require.

In stark contrast, men’s grief tends to be “cognitive and solitary”. This means that men think about their grief (cognitive) but do not necessarily share their sadness and pain with anyone (solitary)."

Cook (1983) found that when men are confronted with grief that effort is made to manage and control emotions of grief, the use of reason and reflection to work through their emotions and try to make sense of their loss, the use of involvement in other activities including work as forms of distraction, self isolation during periods of intense unhappiness and the helping of others in managing their grief.

In times of grief there are some common differences between dads' and mums' reactions

It is important not to stereotype all men and all women. Some men are very emotional and able to express themselves in times of grief, while some women may deliberately isolate themselves and be silent. Also a strong reminder that just because dads may isolate themselves and not outwardly grieve, this does NOT mean that they are not really distressed and devastated about what is going on.

- Dads appear to avoid going through the grieving (that is, emotional) process more than mothers do. They tend to be less willing to talk about the loss and to experience a less intense grief that is integrated more quickly than mother's grief (especially with babies – maternal bond closer).
- Dads tend to take on a managerial role, intellectualise their emotions, increase their involvement outside the home and express a strong desire for future children.
- Dads appear to control their emotions, suppress their feelings and use more denial more than mothers do.
- Dads limit their show of grief to a greater extent than mothers, feeling that they need to be strong for their partners.

- Interestingly, a dad's stoicism may not be seen by their partners as strength; rather, it may be seen as coldness and evidence that he does/did not truly love the child and mothers report anger at the father's lack of expression.
- Mothers are seen to express more sorrow, depression and guilt, while fathers indicate that they feel more anger, fear and loss of control.
- Mothers express their feelings early after loss and reach out for social support, seeking help from their social group, friends, or family.
- Husbands and wives have exhibited different interpretations of appropriate gender role behaviour in grieving, with men more likely to speak of performing their role as "man of the family", to engage in avoidant coping behaviours, to focus on and feel overburdened by their partner's needs, and to speak of their lack of a male support system. Women have been more likely to perceive their grief as their right, and to look for ways to support their husband's limited emotional expression.

Why may some men apply to do overtime as soon as a new diagnosis is given?

This may appear to be a funny question, but it is something that may affect many families. Many mothers have noted that after a diagnosis of a life-limiting condition some fathers may apply for more overtime. Mothers may worry that this is dad's way of avoiding the situation. Dads may report that they are working such hours because they believe the family will need more money to cope with the increased financial needs of having a child with a life-limiting condition. This may be part of a dad's way of problem solving an issue. It is important that mums and dads sit down and discuss what is the family's highest priority at that time – more money or to have dad at home.

Sex, Loss and Grief

It's a subject many of us do not feel comfortable to talk about, yet it's very important and can be the source of great conflict between couples. Let's talk about sex....

It is important to have a topic on sex when discussing life-limiting conditions because men and women may have different intimacy and sexual needs during times of stress, crisis, loss and grief. We need to try and understand these differences so we do not interrupt the actions of our partner as uncaring and rejection. It is also very important to note when we are discussing this topic that exhaustion can greatly affect libido. If you have a child who is not sleeping well or at all or your stress and anxiety is keeping you up at night, than this may greatly impact your desire and drive for sex.

Do men and women have different sexual needs during times of grief and loss?

Men and women can have very different intimacy needs.

Sex is the act of sexual intercourse and sexual activity. Intimacy is about having a very close and personal relationship with someone. Intimacy is feeling a connectedness with another person that may or may not involve sex. Intimacy can be simply about touching, holding hands and talking about personal issues.

REMEMBER: sex and intimacy are the same thing for many people.

What are the differences between men and women when it comes to intimacy?

For women intimacy often means having opportunities to talk about events and share ideas with their partner.

For men, on the other hand, intimacy can be emotional and social, sexual and recreational.

Sexual intimacy may be associated with **yearning for comfort by women** (they want a cuddle) while **men may find comfort in sexual intimacy** (a cuddle is an invitation for sexual intimacy). They also express a sense of being stigmatized by their wife for wanting sexual intimacy.

Put simply it often equates to this:

- **Women generally need intimacy** (cuddling, talking, understanding and affection) to feel they want to have sex with their partner.
- **Men generally need sex** in order to feel safe and secure and close to their partners so that they can create intimacy and space for later cuddling, talking, understanding and affection.

Herein lies the problem. Recognising these issues within the relationship can often assist in a negotiation and arrangement that will work for both men and women.

Why are some days so much harder than others?

We can all have times when we are distracted from our grief or when we feel strong enough to put it to the side for a while. There are multiple factors that can make raw pain from the grief feel as fresh as it did in the first few months. Here are a few of those factors:

- Sleep deprivation: apart from just making us feel tired sleep deprivation can affect our self-esteem, perception of the world and ourselves. When we are tired or exhausted our defenses are down and we are more vulnerable to the world.
- Additional stress or new stress can make what we are already coping with more overwhelming than other times.
- Isolation.

Why do you find joyous occasions and milestones so difficult?

Occasions such as:

- Christmas and Easter;
- Birthdays;
- Start of the school year;
- Having other children of the same age start school, graduate from school;
- Participation in school formals, plays and carnivals;
- Marriages and births.

These events are all occasions that families with healthy children take for granted. For you and your family these occasions can be a cause of great sadness and concern. You may find yourself devastated that your child will never unwrap his or her own present and squeal with delight at the gift inside. You may feel angry or distressed that he or she will never go on a date or be asked to go to the school formal. These events may simply be a reminder of the fragility of your child's health and the risk that they may never live to experience them or they will experience each of these events with a chronic condition.

Birthdays and milestones can be difficult, as you may have had hopes that your child would improve in skills or health between birthdays and this may not have happened. As each milestone passes without your child reaching the achievement, there may be a daily reminder of your child's disability.

What other crisis periods do you need to be aware of?

Some families report that the events listed below can often trigger a new crisis for them or a new grief reaction just when they felt they were doing well.

1. Admission to hospital.

In her study of families impacted by cystic fibrosis, Myra Bluebond-Langner (1996) found that most parents put the condition and all the implications of the condition to the back of their mind when ever they can. She used the analogy of our brains being like a filing cabinet. We have all the information in there but we put files on death, serious illness, and the possibility of disability to the very back of the filing cabinet simply as a self-defense mechanism. This allows parents to get on with the daily activities of life and enjoy the child/children for whom they are. They effectively allow the condition to take a backseat. When a child actually becomes sick, loses a skill or is admitted to hospital, parents/siblings/the child/ friends etc are forced to accept the whole reality of the situation. This can lead to a crisis.

2. Failure to participate or meet a milestone.

Everything may be going along fine in your household and then all of a sudden the neighbour's child who is the same age as your child starts 'normal' school and you fall in a heap. This is distressing but normal. It is inevitable that when you have a

child with a life-limiting condition that you will occasionally find yourself drawing comparisons between your child and healthy children you know. It may be sadness and a new 'loss' that your child may never walk. It may be the loss for you that your friend will get to send his or her child to school without having to worry about wheelchairs and seizures. You may feel angry that you will never get to dress your daughter up in a wedding gown or simply the fear that he or she will not live that long. Such loss may trigger a new set of grief and loss reactions and is definitely a crisis. However, even though others may not recognise the 'new' loss

3. Being unable to attend an event.

If your child requires intensive care from you it may prevent you from doing the things that you used to love to do. This can spark a crisis for you, your family and friends. This may happen every time you are unable to accept an invitation. Again this is part of the ongoing sense of loss and grief you may experience.

■ CHRONIC SORROW

When we look at all of the above issues it demonstrates how the issues for families living with a life-limiting condition differ from families coping with other serious illnesses. Understanding this long-term grief reaction is important and can be explained by the term "*chronic sorrow*".

What is chronic sorrow?

- Chronic sorrow is long-term sadness that accompanies ongoing loss and that sometimes comes to the fore, and sometimes will sit on the periphery of the consciousness (Olshansky, 1962).
- It is recognised with chronic sorrow that the loss has no definite endpoint. Losses keep occurring over time.
- Lindgren and colleagues (1992) state that the sadness may progress and intensify years after the initial diagnosis and loss.
- Chronic sorrow differs from grief associated with bereavement (Teel, 1991).
- Chronic sorrow is described as a recurring process of grieving. The intensity of this sorrow varies from time to time, from situation to situation and from one family member to another. It can be understood as a normal and emotional response associated with chronic or life threatening illness and disability.
- Because chronic sorrow exists over a long period of time, the term encompasses not only sadness but also a person's ability to have happiness, joy and satisfaction with the situation even though the underlying sadness remains.

Put simply, chronic sorrow exists when people have long term involvement with a loved one who is chronically ill or disabled and the situation continually causes periods of sadness and loss, as well as joy and satisfaction.

How does chronic sorrow differ from other grief and loss?

When someone dies, or loses a job or encounters many of the other grief and loss situations, it is obvious to everyone what has been lost. As tragic as the loss may be when someone dies people usually know what they had and valued in that relationship and what the loss entails. While the loss may be profound and alter that person's life and approach to life, bereaved people still have the opportunity to incorporate this experience into their lives and try and start living a different life. With chronic sorrow the losses are ongoing until death. It can be difficult for others to recognise the ongoing sorrow. Friends and family may be supportive when they first hear a newborn child has severe and life-threatening cerebral palsy. They may not recognise that a diagnosis that the child will never eat food orally is a new loss. That the child will not walk is a new loss. It may be very hard for others to understand what has been lost.

With chronic sorrow there will be a primary loss e.g. The diagnosis that their child has a life-limiting condition. Then there will be multiple secondary losses (e.g. your child being unable to walk, or having to give up your job to become a fulltime carer).

What are some of the major differences between chronic sorrow and bereavement grief (death)?

Given that chronic sorrow is associated with people with chronic illness, life-limiting illness and disability, the sense of loss and grief is often ongoing for decades. People have to incorporate this situation into every aspect of their lives.

Unlike the situation when someone dies, people who experience chronic sorrow when a loved one is impacted by chronic illness or disability can have a variety of feelings ranging from happiness and satisfaction with their situation through to intense pain and sadness.

After a death people have the chance to reinvest in a world without the deceased. In contrast when living with chronic sorrow, people are constantly aware of the person and the many reminders of loss involved in loving and caring for him or her.

What are some of the differences between chronic sorrow and prolonged grief (grief that lasts a long time)?

Within the situation of chronic sorrow people are living and reacting to a range and a multitude of losses over a period of time. There may never be a resolution to these losses. Because the situation of loving and caring for a person with a life-limiting condition or disability may go on for years, people have to adjust or live with these experiences and get on with the activities of daily life, such as caring for their child, looking after the household and returning to work.

When some people have been grieving a long time, it is usually in reaction to a single loss, such as a death of a family member. They may find their daily life is affected and they are unable to function with day to day activities

Is chronic sorrow really depression?

Absolutely not! It is also not “not coping”. People caring for loved ones with chronic conditions and disabilities are often asked to manage extraordinary circumstances, with too little support over many years often without appropriate respite or break periods. Nobody could manage to do this for someone they love and not be profoundly impacted every now and then!

It is important to note that chronic sorrow is not prolonged grief or depression (Lindgren et al, 1992). However chronic sorrow and prolonged grief that finds no relief and makes a person feel trapped, may indeed lead to hopelessness and depression.

Why do you need to understand chronic sorrow?

- It's important to accept that chronic sorrow is a natural reaction to a long-term event, that has many losses, and that we have a right to feel sad about each of these losses.
- With chronic sorrow it can be difficult to accept the situation as it is constantly changing and requiring new management. It is possible to learn ways of adapting to each new situation
- If we understand chronic sorrow and how it affects us it can give us a greater opportunity to understand the situation we are in, ourselves and the rest of the family who is living in the same situation.

Why is an understanding of chronic sorrow so important to your relationships and family life?

Chronic sorrow means that in living or loving a person with a chronic condition or disability there will be periods of joy and satisfaction and periods of extreme sadness and dissatisfaction. The problem is that no-one can say how you will feel on a particular day, or how your partner or your children will feel.

It can be hard on relationships when someone is feeling good on a particular day while someone else is feeling particularly sad and alone. Normal family dynamics are tricky enough without the added burden of chronic sorrow!

For example if Mum has just worked really hard to feel good about life and then Dad hits rock bottom this may cause conflict and isolation for both parties. If there are children involved and living in the household, people's emotions and needs may vary from day to day.

Families may benefit from working out a system where everyone can be aware how everyone else is feeling on a particular day without necessarily communicating this verbally. Creating a system that worked for you and your family may enable people to be supported if this is what they want or at least have some acknowledgement of their feelings.

When does chronic sorrow stop?

Chronic sorrow is profound and ongoing in nature. Chronic sorrow may only end for families when death occurs. Then chronic sorrow becomes grief and bereavement. However, for others faced with chronic sorrow, they come to an uncomfortable, but yet strangely liberating, sense of knowing chronic sorrow so well that its impact is lessened on their ability to live their lives in a fulfilling manner. What they define as fulfilling may have changed though!

Is chronic sorrow a bad thing?

While it is terrible that anyone should have to experience chronic sorrow it is not really a 'bad thing'. Chronic sorrow allows families to keep adapting to the constantly changing situation with which they have to live with. It allows families to have periods where they can experience joy and happiness and satisfaction with the way that life is going. Chronic sorrow is not only about the sad things but also about having periods (and they can be extended periods lasting months or years) where people are simply happy with their lives.

CHILDREN, DEVELOPMENT AND LOSS

Some important things to consider when you talk to kids about loss

- Children of different ages and maturity levels will understand the situation of loss and its implications in different ways.
- When explaining issues of loss to a child it must be tailored to suit the cognitive (thinking) and emotional development of that child. It must suit the personality of that child. As a parent or carer you will be able to decide the best way.
- Children's understandings of a situation of loss may change over time and their need to re-explore earlier losses may occur as they develop. An example of this is a child who has a sibling die when they are 18 months may not appreciate this loss until they are six and then will feel quite sad about the loss and have a need to talk about it over and over.

What do you tell the kids?

This is a very common question for parents struggling with any major event in the context of the family. Previous generations had believed that children did not

experience grief, loss or even pain the same as adults. This is now known to be untrue! Children experience things just the same as adults- the only difference may be that they do not have the language (words) or maturity or experiences to let us know how they feel or what they feel about it.

Should you even tell the kids?

Yes! You cannot keep a secret of this magnitude from them forever. It is far better for them to hear from you directly in a safe and supportive environment than for them to overhear it from someone else or to have some kid yell at them in the school ground “ your baby sister is a spastic and can’t even walk!” Things like this do happen. If you set up a code of secrecy in your family your children may just adopt that code. They may hide from you their anxiety, sadness and distress. They may not tell you if they are getting bullied or are having nightmares.

By not telling them you unfortunately will not be ‘protecting them’ which is the good intention of many wonderful parents. Instead it will be excluding them from sharing in a family experience and perhaps make things much more difficult for them down the track.

Remember that up until the 1900s, children were constantly surrounded by death and loss in the family. Talking about loss, grief and even death is much harder for adults than it is for children.

How much will having a child with a life-limiting condition upset and impact upon your other kids?

This is a difficult question to answer because each child is so individual, just like adults' reactions will vary. Some of the things that may influence how kids will react may include:

- Their relationship to the person with the life-limiting condition.
- How other family members are responding and reacting.
- Their developmental level. More importantly than age is what your child is like as a person and their maturity levels. Some six-year-olds may understand what ‘death’ is or what a ‘disability’ is whereas someone else’s 14-year-old child may have difficulty in understanding what these terms mean.
- What you tell them. If kids have a clear knowledge or all the information on the situation it may give them a sense of control over the situation. If kids are only given little pieces of information and then they hear snippets when you are on the phone or from Aunties whispering they may start to form their own (often wrong) story of what is going on. This usually frightens them far more than the truth.

Is it bad to let your kids see you cry? Won't it scare them?

Crying is a normal part of human emotions. When adults cry in front of children and explain why they are crying it will make sense to kids and it will not be a frightening experience. It will teach your children that crying and talking is healthy. It will make them feel confident to cry and share their feelings with you. When adults put on a 'brave front' for kids, kids usually know. There have been many times when kids have confided in their counsellors/doctors or teachers that they hear mum and dad cry and night and that frightens them because they worry it is something they have done wrong during the day. Hiding of emotion rarely works as children know something is wrong and often wrongly conclude that what ever is going on in the house is far worse than the reality simply because they have huge and colourful imaginations. If children know there is a problem in the house but are unsure of the cause they may also be greatly concerned that they have done something wrong or are no longer loved. Finding out the new baby has cystic fibrosis is probably a lot less scary than thinking Daddy is dying like so and so's Granddad or that your parents are divorcing. Children can only draw from their own experiences. This is how they make sense of the world.

If you are crying in front of your children gather them in close for a cuddle and a talk. When you are able to speak, tell them exactly why you are crying.

"Mummy/Daddy is crying because the doctor told us that the baby has ... This makes me sad and worried because we wanted the baby to be healthy like you. It makes us very sad that the baby has to stay in hospital and have tests because we would like to bring them home. It is no-one's fault that the baby has... It just sometimes happens that way."

Even if you are crying or sobbing so hard that you are finding it difficult to talk, gather your child to you for a cuddle. Try to say that you are finding it hard to talk at the moment because you are so sad that but they shouldn't be afraid of this. If someone else is with you encourage him or her to do the talking for you as long as it is honest and direct.

How do you talk to kids about this serious and upsetting stuff?

- Keep it simple and really honest.
- The number one thing is to talk to your children in a direct, open, clear, gentle and loving way. Let them know that there are no wrong questions. That you are always available to talk.
- It is really important that children are kept up to date with important things that are happening for their loved ones. If something happens to someone they love and children have been left in the 'dark' about the situation they may find it more difficult to adapt and cope. They may also become distrusting of other relationships and information in the future. Children have very vivid imaginations and they will often fill in gaps with their own stories, which may be more frightening than the reality.

Should you use the proper names of the diagnosis or just tell them that their brother or sister is sick?

It is very important to use the proper medical terminology and language. This will avoid confusion for the children down the track. It is amazing how even very young children (two years and above) will be very comfortable to talk easily about medical diagnoses and treatment in the correct language.

Children can form an understanding of what is happening if you say things like -

“Your brother has Duchenne Muscular Dystrophy which will affect the muscles in his body as he grows and he will need to go into a wheelchair one day because the muscles in his legs won’t be able to hold him up to walk”.

If you just tell the children that “their brother is sick” and then they watch him have to have a battery of tests and watch him physically decline, they may become frightened of general sickness, colds and earaches because it might ‘make their legs stop working’.

Using the right words stops other children from worrying that they can “catch” things off their sibling. It makes it easier to explain it to other children and sometimes adults.

■ WHAT ARE SOME OF THE REACTIONS YOU MAY SEE IN YOUR KIDS IF THEY ARE EXPERIENCING LOSS?

Many of these reactions are very similar to that of adults. Children usually have less opportunity to talk through these issues with someone. They also find it more difficult to have the language and maturity to understand where these emotions are coming from. They may not associate these feelings with the current loss event. Even being able to tell them that they are having these feelings because of what is happening in the house or with their sibling etc may be a huge relief.

There will be a wide variety in children’s reactions to loss and grief including:

Immediate reactions

These may include:

Shock and disbelief:

They may just pretend its not happening and go about their lives as normal. They may tell you huge imaginary tales to replace the reality of what is happening in their lives.

Distress and protest:

They may be visibly and verbally upset and distressed. Lots of crying and needing to be comforted. They may need to be with people who make them feel secure 24 hours a day which can be very difficult for parents and other carers who are trying to do their own grieving.

Apathy:

They may not be particularly interested or caring about the situation, demanding that their lives continue as usual.

Continue as if nothing has happened:

This is not necessarily denial. For example, for some children the birth of a critically ill newborn baby may not impact on them as long as they are able to maintain their usual routine. For example, Dad is still home at night to read them a bed time tale, Nanny picks them up from daycare as normal, and all their toys are still there to play with.

Later common reactions

These may include:

Anxiety:

Fears that their every day lives are no longer stable or secure. They may fear change in all aspects of their lives and generally lose confidence.

Sleep disturbance:

Night terrors, nightmares, finding it difficult to go off to sleep. Wanting to sleep with someone at night.

Fear of sleep and of the dark**Sadness and longing:**

Wanting for things to return to the way they were prior to the loss event. Talking a lot about the past.

Anger and acting out:

Again if children are feeling awful but do not know what the cause of their pain is or what to do about it they may revert to anger and acting out. These children need lots of patience and support to help work through the issues. If it becomes extreme or a problem it may help to seek counselling with a person experienced in these issues.

Guilt, self reproach and blaming:

If a child had been jealous of a new sibling, reluctant about a new pregnancy or had simply been a 'normal, self absorbed child or teenager' they may feel that they have in some way contributed to the current situation simply because they had such thoughts.

Problems at school:

Socially or academically.

Physical complaints:

This is very common. Children seeking comfort or nurturing will often do so through physical complaints. Siblings may also subconsciously note that the child who has a life-limiting condition gets to see lots of specialists and receives loads of attention from adults. They will not differentiate between good attention and 'bad' attention (e.g. needles, tests, hospitalisations) so physical complaints can seem like a good way of seeking adult attention.

Bedwetting:

Even if a child has been toilet trained for years in times of stress, crisis and uncertainty for children bedwetting can reappear. Punishment for this is not advised as the bedwetting is a sign of anxiety and punishment may only increase the problem.

Clinging to parents and family:

In times of crisis children may feel that there are no longer solid foundations and truths that they can believe in. They may be very anxious that something could happen to mum and dad and their other significant others. They may become very clingy and demanding. Not wanting parents and family out of their sight for even a minute. Younger children (anything from ten and under) may revert to very babyish behaviour such as thumb sucking and wanting to be carried. While this will all be very tiring and taxing on their already stressed parents this is a cry for help and reassurance.

Less common reactions they may have**Intrusive vivid memories:**

Constant and unwanted flash backs about particularly distressing incidents as defined by them.

Regressive behaviours:

Finding it difficult to be their normal developmental age or self at any time of the day or night in anyone's company.

Social isolation:

Becoming completely withdrawn and isolated from family, friends and school.

Fantasies:

Constantly living in a fantasy world that does not and will never exist. This is different from children fantasising every now and then about outcomes. This is when children use fantasy as a way of totally denying what the reality is for them and their family.

Personality changes:

When your child becomes completely different to their normal selves and maintains these changes consistently and constantly in everyone's company.

Pessimism about the future:

When your child feels there is no hope for anything in the future and the loss event has destroyed all chances of happiness.

■ WHAT DIFFERENCE DOES AGE MAKE WHEN TALKING WITH CHILDREN?

While chronological age can be used as a general guide as to what children will understand and how they will respond to a loss event it is more important to be aware of your child's developmental age or maturity level when talking to them. As a child's parent or carer you will be the best person to judge where your child is at.

The cognitive developmental level (the thinking or maturity level) of children has a significant bearing on their capacity to understand the concepts of grief. Here are a few of the broad themes and ideas around children's cognitive development:

What might a baby understand?

Babies do not understand the concepts of time or death. The main guiding factors for a baby is their attachment and bonding to their primary care giver (usually mum). If the baby's primary care giver is stressed, absent or finding it hard to respond to their needs may become fussier, they may cry more and/ or have difficulty feeding. If the primary care giver is still able to respond to the baby normally despite what is happening in the household you may see absolutely no change in the baby what so ever.

What do toddlers understand?

Most toddlers will respond similarly to baby. As long as their primary care giver/s are present and their routines can continue as normal they usually are fine. If your toddler sees you crying or upset do let them know what is happening and why you are upset. This knowledge will usually be enough for them to continue to feel comfortable and safe. Young children, especially under the age of 3 years, exempt themselves from the possibility of death. However if someone close to them dies, they may believe that someone else they know may also die which will cause them fear.

What do children under the age of six years understand?

Children in this age group are very egocentric (think about the world only in relation to themselves). This can be difficult for families as they struggle to find the balance between having a child with a life-limiting condition and having a child or children who demand that their world stays the same. One danger for this age group is because the world is 'all about them', they may feel responsible for anything that happens in the house.

This age group has little understanding of the permanency of situations such as disability, ill health or even death. In relation to death they often believe that death is reversible and that the dead live on somewhere else such as in the cemetery. Children in this age range may believe that those who have died actually see, talk, eat and walk around. Death is often associated with sleep, which needs to be dismissed in the incident of death, or young children may develop a real fear of sleep and subsequent sleep disorders.

Children of this age are usually very curious and may want to ask lots of questions which adults may find distressing. They do not deliberately seek to distress adults; they are too young to understand the implications of their questions that they simply want answered. Speak to them openly and honestly at all times.

The biggest fear for these young children is the fear of being separated from their parents, especially their mother. This anxiety may be intense and surface when children believe they will be left alone. Magic and fantasy are often intertwined with children's thinking at this stage. This has been strongly reinforced by movies such as "Harry Potter" and the "Lord of the Rings". Given that children of this age may genuinely fear going down the drain when you pull the plug out of the bath they can make all sorts of assumptions and stories about a loss event.

Children are never too young to participate in significant events that are happening in the household.

What do children of early school age understand (aged 6-9 years)?

This age group usually understand that 'bad' things such as illness and death can happen but they usually think that it only happens to others and that their own world could not be affected by such things.

This age group is starting to really understand the issues and require very concrete and real explanations from their families. They will be very aware of everything that is happening for them and their family whether they are included in family discussions or not. Once children start school they will inevitably hear rumours and half stories from their school friends and peers as these children have overheard their own parents whispered conversations.

Socialisation is very important for this age group and returning to school life after the initial crisis needs to be discussed openly with the child involved and their parents. The main fear of children in this age range has shifted from fear of separation from their parents, to fear of bodily injury or mutilation to themselves. They will need lots of reassurance that whatever is happening to their sibling can not be caught or suddenly acquired.

Should death become an issue then this age group will usually view this as scary and frightening. Uncertainty still exists whether all children see death as inevitable by the end of this phase. It is suggested that in this age range children move toward understanding that death is irreversible. Death can mean the end of life, as they know it. However the work of Speece and Brent (1984) raises the possibility that advances in the medical technology may interfere with this perception. Children and adults believe that medical intervention can “cure all”.

What do children aged 9-12 years understand?

This is an important developmental stage as it is the bridge between childhood and adolescence. This is usually a time of great change where children learn problem solving, the ability to reason and think abstractly. This is a time when the harsh realities of life and the world can sink in for the child. It is usually the time when the quest for independence begins.

These children can usually develop a more mature understanding of life-limiting illness including the fear of death. These children may feel caught between adolescence and adulthood in managing loss and normal adolescent crises. There may be times when they may want to be held and comforted like a child and times when they want to be treated a lot older. They may also try to suppress feelings that are too intense to deal with.

Children in this age range realise that death occurs as a result of the deterioration of the body as well as a full range of internal and external causes. They will become concerned about the relationship between illness and death. If they are continually asking questions about the child with the life-limiting condition (especially if it is themselves) and death this will need to be addressed. They primarily believe that old age is the cause of most deaths. As they develop they will gradually understand that death can occur to children and young people but believe death is still far away in the future. The acknowledgement that everyone dies, including themselves begins to be understood.

At this age children often express interest and concern in the rituals of burial, what happens at funerals etc. Children at this age may have various anxious feelings in relation to what will happen when and after they die. It may be a time when they question their own or the family spirituality or religious practices.

What do young people and adolescents understand?

There are three distinct stages of being a young person or adolescent, again it is difficult to say what age your child will reach these stages, as each child is different. Just to use as a guide we may assume that:

Early adolescence can occur somewhere between 10 years and 14 years. During this stage children become more aware that their actions effect the family unit. How the

family unit functions and what are the implications for the family when there is a crisis. They may become more aware of things like the family finances and the cause and effect of having a child with a life-limiting condition in the family.

Middle adolescence can occur somewhere between 14 years and 17 years. Between the ages of 14 and 16 years you usually see the peak of rebellion and turmoil. These young people often exhibit a 'fight or flight' response to crisis and conflict. Typically young girls in this age group will do lots of shouting and slamming of doors. They tend to be quite dramatic and state they are misunderstood and unloved. Boys tend to isolate themselves in their rooms and listen to lots of music. This is the age when young people feel and believe they "know it all". It is typically an age when parents may become the 'worst enemies' and 'dags'. For this age group their peers or friends become the major priority over the family unit.

This may be an age where it is useful to introduce a counsellor or significant adult in the family (be it an uncle or aunt or whoever) for the young person to talk too if they are not speaking openly to their parents. They may still need to talk to an adult or have someone to confide their concerns and worries too.

Late adolescence can occur somewhere between 16 years and 20 years. This is frequently the age when young people attempt to impart meaning to death as well as to life. They explore their own spirituality and try to find meaning to life.

Most young people frequently daydream and reflect upon both past and present concerns. Some daydreams may harbour anxieties that accentuate their concerns and fears of death. Anxiety may surface when they feel compromised or overwhelmed. Such anxieties may be associated with failure at school, loss of social support, injury or serious illness. The illness or death of a close relative or friend may threaten their personal integrity and well being as well as generate fears associated with existential concerns about life and death. (What is really out there? What is the meaning of life?).

■ SUMMARY ON TALKING TO CHILDREN

- As long as the child has a good relationship with their parents and the parents have the capability to support their child or children then PARENTS are the best person to work out what their child needs and how to provide it.
- Counsellors and health care professional should build parental confidence with skills and knowledge. It is the job of professionals to empower parents to assist their own children.
- Try to normalise behaviour for children and parents. Knowledge is power and allowing kids and their parents to know that ‘weird’ things can be ‘normal’ when it comes to loss and grief will allow families to survive better.
- Do not make a big deal if there isn’t one. Children do not have to react to a loss event. Small children may not show any signs of loss and grief and that can be ok, and not seen as a sign of deep-rooted psychopathology. Some small children do not react when a new baby presents in the house and may not react with illness or death either as long as their own world remains stable.
- Children primarily get their cues from their parents. Encourage parents to share their loss and grief with their kids. Displaying emotion, and working through loss and grief issues with children will hopefully create a generation of better-adjusted adults. If children perceive that it is not ok to cry and express feelings because of their parent’s behaviour they will hide and repress their own feelings.
- Use appropriate language. Tell the child exactly what the diagnosis is and what part/s of the body will be impacted as a result. If we simply use the word “sick” you can create a fear of illness. Children can accept and learn medical technology and it avoids confusion with other childhood ailments and fantasies down the track.
- Small children have a limited range of expressing themselves. They do not have the vocabulary, rationale or reasoning to express what is happening for them. They can not express that they are having a bad or sad day, that they are anxious or insecure. They can only react to these feelings. They can usually only express it through:
 - Fear and anxiety: clinging to parents, fear of the dark, loneliness. Expressing new fears in common situations.
 - Behaviour – be it showing off for attention; acting like a baby; anger and tantrums.
 - Physically: mouth ulcers, bed-wetting or soiling pants after toilet training. Believing they are sick or actually feeling sick without physical cause.
 - Parents need to be made aware of the above so they can respond appropriately.

Remember there are no clear reactions, steps or guides when it comes to individuals being effected by a loss event. Whether we are a child or an adult, even if we all belong to the same family we will all cope in very different ways.

■ USEFUL ORGANISATIONS IN QUEENSLAND

1. Organisations that offer counselling (and can be found regionally)

Queensland Health organisations do offer free counselling services with a Social Worker or Psychologist though there may be a waiting list

- Community Health – usually found under ‘Queensland Health’;
- Your local hospital

The below services offer counselling usually on a sliding pay scale (e.g. what is affordable)

- Lifeline: includes a 24 hour crisis line (Phone 13 11 14);
- Centacare: (Ph: 07 3250 4305; cfcs@centacarebrisbane.net.au);
- Kinnections: (Freecall: 1800 600 636 or 07 3435 4300).

2. Support Groups

Cystic Fibrosis Queensland

Rainbow House
31 Kate Street, Kedron 4031
Ph: 07 3359 8000
Fax: 07 3359 3380 Freecall: 1800 670 990
Email: admin@cysticfibrosisqld.org.au

Muscular Dystrophy Association Queensland

Level 1, 147 Wharf Street, Spring Hill
Ph: 07 3016 1800
Fax: 07 3831 2666 Freecall: 1800 676 364

Queensland Clinical Genetics Service

Royal Children’s Hospital, Herston. 4029
Ph: 07 3636 1686

MPS: Mucopolysaccharidoses and Related Diseases Society Australia

30 Paringa Place, Bangor, New South Wales 2234
Ph: 02 9543 9003

SIDS : Sudden Infant Death Syndrome

68 Creek Road, Mt Gravatt
Ph: 3849 7122
Fax: 3849 7121
Email: Brisbane@sidsaustralia.org.au

SANDS Inc : Sudden and Neonatal Death Syndrome

PO BOX 49, Royal Brisbane Hospital, Brisbane 4009
Ph: 3252 286

Compassionate Friends (support for bereaved parents)

PO Box 218, Springwood Queensland 4127
Ph: 0732542657
Email: tcfqld@powerup.com.au; Website: <http://www.uq.net.au/tcfbrisbane>

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