

# Kowhai Programme

Support for families, whānau & carers

## Learning about loss

Grief is a normal process of responding to a loss

### Loss and grief

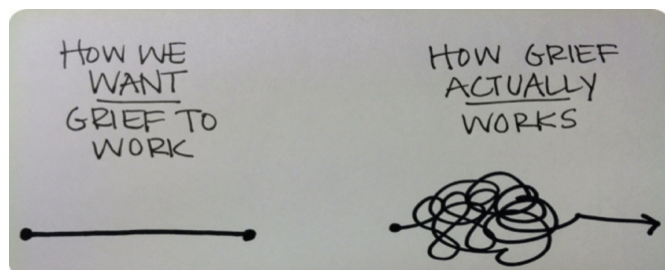
Grief, in all its forms, is about learning to live with loss and the changes that the loss brings about in life. We think about grief in terms of the death of someone we love, but it is more than that. Sometimes, grieving can begin as we anticipate the loss of something important to us or of someone we love. Losses and a process of grieving will take place from the time the person we care about has been diagnosed. Some of these losses might be experienced by both patient and their carer; others will be experienced by the carer alone. Even when the loss being experienced is the same, each person's grief response will be different. There is no right or wrong way of grieving.

When we are faced with the loss of something that doesn't change life much, or that we didn't place much value on, we might be able to manage this more easily. When we are faced with big losses, or even an accumulation of lots of seemingly little losses, our resources can become depleted.

We can also have different ways of managing loss and stressful situations. Some people want to know more and talk about it. Some don't want to think about it or talk about it, and others can become angry or try to find other options or ways around. All these can help us to manage a difficult situation. Different members of the family/whānau may have different ways of managing stressful situations. Seeing loss differently or having different ways of managing can lead to challenges in our relationships with family and friends.

Losses through illness of a family member begin to alter aspects of our lives and relationships that are familiar and cherished. Roles change, our ways of relating change, and things we took for granted are no longer in reach. The impact of this will be felt in many ways, including physically, spiritually, mentally and emotionally, and in family/whānau relationships.

**While grief is normal, it is also ok to ask for support.**



### Potential losses for carers

Serious illness creates loss and change across all aspects of life for carers leading to grieving. Losses could be:

#### Physical

- Changes in the person's body as you knew it before the illness.
- Less physical intimacy/sleeping apart.
- Less sleep (can effect energy and mood).
- Exhaustion due to complex demands.
- Increased responsibility for household affairs.
- Responsibility for counting and dispensing medicines and managing symptoms.

#### Spiritual / Purpose and meaning

- Less able to attend church/hui or other meetings of significance.
- Potential questioning of matters of faith (Why us? Why is God allowing this?).
- Less possibility to go into nature or visit places of peace and nourishment.
- Having to give up hobbies or clubs that have offered meaning and structure.

#### Mental and emotional

- Experiencing a rollercoaster of emotion.
- Fear of not coping (especially as the illness progresses), fear of the unknown.
- Anxiety about the future after the person has died.
- Feeling anger and frustration with people and/or the situation.
- Feeling trapped, wanting to escape.
- Feeling unable to express one's own needs.
- Worry about finances.
- Ruminating and regretting things done or not done in the past.
- Complicated new daily routines and appointments to keep track of.

#### Family/whānau relationships

- Role changes from partner to care-giver.
- Other people's anger or frustration.
- Less time with other family members.
- Complexity of differing responses of family members to the illness.
- Feeling overwhelmed / let down by supports.
- Managing visits to match capacity of the patient (and being able to say "No" at times).
- Updating family members living at a distance.
- Taking care of other's needs and feelings at the expense of being honest about your own.
- Dealing with other's opinions of "you should..."

## The experience and expression of grief

While we all recognise sadness and tears, this is not always the way in which grief is experienced or expressed. It is useful to know this as grief can sometimes be mistaken for something else. Grief that is unrecognised or ignored can lead to further distress. Grief can be experienced in many different ways.

### Physical

- Headaches.
- Aches, pains or weakness in the muscles.
- Changes to sleep patterns, vivid dreams.
- Changes to appetite.
- Fatigue or lack of energy.
- Hypersensitivity to noise.
- Restlessness.
- Dry mouth.
- Nausea.

### Spiritual

- Loss of hope.
- Inability to draw on sources of strength.
- Questioning – “why me?” “Why now?”.
- Questioning what you have done to deserve this.
- Feeling unsure of what was once thought of as “right” and “wrong” or “good” and “bad”.
- Feeling lost or disconnected.

### Emotional

- Sadness.
- Feelings of guilt.
- Concern about being a burden.
- Overwhelming anxiety/panic
- “I’m going mad”.
- Feeling hurt or numb.
- Irritability.
- Feeling easily overwhelmed.

### Family/Whānau

- Withdrawing or increased dependence.
- Lashing out.
- Challenging expectations on others/self.
- Feelings of loneliness even when with others.
- Feeling vulnerable or exposed.
- Feeling abandoned.
- Withdrawing from relationships.

## When experiencing the impact of loss, what can help?

- Acknowledge the losses and the impact they have had on your life. Allow the time it takes for you to adjust.
- Acknowledge also what has not been lost – enjoy those things that you can still do.
- Be aware of the losses that other members of the family might be experiencing, and that they might be adjusting or coping in ways that are different to yours.
- Adjust expectations of yourself and others if needed.
- Be open and honest with your healthcare team and family about any problems, what you want and what you need. If they don’t know, they can’t support you.
- Set achievable goals.

- Some structure in the day can be useful.
- Pace yourself with each task.
- Allow the way tasks are prioritised to change – question whether this can be left to another day or time.
- Give yourself permission to say no or set limits to phone calls and visits.
- Ask for help. Allow others to help you.
- Have things to look forward to, no matter how small.
- Find ways of connecting:
  - With your faith
  - With your family, friends and others
  - With things you enjoy (hobbies, sports, music...
  - With yourself (journaling, meditating, time for self).
- Self-care is not a luxury. Find ways of caring for yourself physically, emotionally, spiritually and in your social connections.

## When to seek help

Human beings need each other and it is okay to ask for help. You do not have to do this on your own. If you experience any of the following, seek support.

- If you can no longer carry out the ordinary tasks of everyday life.
- If you are reliant on alcohol or other drugs to get you through the day, or are using ways of coping that might be harmful in the long term (such as compulsive gambling or shopping).
- If you find yourself withdrawing from the people you love.
- If you are worried about yourself and concerned about how you are doing.
- If you experience suicidal thoughts or thoughts of harming yourself, seek immediate help.

## Where to go to find support

- The other sessions in the Kowhai programme can help with ideas to address the whole picture of what you are facing.
- Talk to friends and family who can listen.
- Hospice offers counselling support including for up to a year post bereavement.
- Hospice also offers spiritual care and social work support if needed.
- Your GP is also someone who can help.

### Each person grieves in their own way; your way is the right way for you

If you would like to have further assistance to help manage your stress and be referred to one of our counsellors, please contact the Otago Community Hospice ph 0800 473 6005.



Support for families, whānau & carers