Now what?
Understanding Grief

Find out more at: palliativecare.my
What is grief?

Grief is how we respond when we experience loss. Grief is a normal, natural and inevitable response to loss and it can affect every part of our lives.

Grief can seem like a roller-coaster ride with ups and downs, or it may feel like we are being battered about like a little boat in a storm. Sometimes it can seem overwhelming and frightening. Grief allows us to gradually adjust to our loss and find a way of going on with our life without the person who has died.

What does grief feel like?

Everyone experiences grief in their own way. There is no 'correct' way to grieve, and no way to 'fix it'.

*Feelings* – We may experience intense feelings such as shock, chaos, sadness, anger, anxiety, disbelief, panic, relief, or even numbness.

Some people are fearful as they are adjusting to a loss that they may forget or lose connection with the person who has died, or may even feel disloyal.

*Thoughts* – We may experience confusion and find it difficult to concentrate. It is not unusual for people to have 'extraordinary experiences' such as dreams of the person who has died or to have a sense of their presence. Mostly these are comforting and help us feel close to the person who has died.

We may think we will never get over this, or that we are going crazy. We may think that it is all too hard and wish we were with the person who has died. This is an expression of our pain and sadness.
**Physical reactions** – Sometimes we may have trouble sleeping. Grief can also lead to physical symptoms such as tiredness, loss of appetite, nausea or pain. If these symptoms persist, check with your doctor to exclude other causes.

**Relationships** – Relationships can be affected. Sometimes we will be preoccupied or tense, or feel disinterested in other people and things.

**Behaviours** – We may experience lethargy or over-activity, pay little attention to self-care, sleep a lot, desire to resort to alcohol or non-prescribed drugs and other potentially harmful behaviours.

**Beliefs** – Our beliefs about life may be challenged. Often grieving people wonder why this has happened to them.

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*When our son died, we got counselling for the girls. Counselling helped the girls deal with all the issues they had and move on with their lives. My older daughter took two and a half years to deal with her loss and my younger daughter went to about 10 counselling sessions and she was able to deal normally with her loss.*
How long will it take?

Grief has no timeline. It is not unusual for grief to be felt over an extended period of time, even for many years. At first, people tend to feel grief more strongly. As time passes, we learn to manage the grief.

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Sometimes, after a period of feeling good, we find ourselves experiencing sadness, despair or anger. This is often the nature of grief, up and down, and it may happen over and over.

Life will eventually have meaning again, although our loss will always be part of us.

How do we grieve?

Everyone grieves in their own way. There is no right or wrong way to grieve. Some people express their grief in private and do not show it in public. We do not always know how people are grieving simply by what we see.

Some people want to express their grief through crying and talking. Others may be reluctant to talk and prefer to keep busy. Members of the same family can grieve differently. People may behave differently at different times.

It is important to respect each other’s way of grieving.

Our motto became ‘Take one day at a time’. It was an old cliché, but boy it really helped us to get through a lot of dark days. Three years on, we feel we continue to heal and that our love for her keeps us on track.
Helping yourself

Grief is like a journey to an unknown destination that you cannot control or plan. Here are some suggestions for getting through the difficult times. Remember though, that you will grieve in your own way.

Privately and personally

You may sometimes prefer to keep your thoughts and feelings to yourself:

• try not to make big decisions too soon

• create a memorial - do or make something to honour the person who has died

• continue the relationship with the person who has died by talking to them, looking at photos, visiting special places

• develop your own rituals - light a candle, listen to special music, make a special place to think

• allow yourself to express your thoughts and feelings privately - keep a journal, draw, collect photos

• exercise - do something with your pent-up energy, walk, swim, garden

• draw on religious and spiritual beliefs if this is helpful

• read about other people’s experiences - find books and articles

• think about some self-care ideas such as meditation, massage or aromatherapy.
With other people

Sharing with other people can reduce the sense of isolation and feelings of loneliness that come with grief:

• allow people to help you—you will be able to help someone else at another time

• talk to family and friends—sharing memories

• consider joining a support group

• don’t feel you must grieve all the time — try somethings you enjoy as well, when you feel up to it

• talk with a counsellor to focus on your unique situation.

Being a carer for someone with a life-limiting condition can be quite isolating and exhausting. After the person has died, you may find it very difficult to reintegrate into work, groups, clubs or activities you previously enjoyed. Inviting a friend or volunteer to accompany you the first few times may make it a little easier.
Helping others

No one can take away the pain and sadness of grief, but knowing that people care is comforting and healing for grieving people. You cannot fix it, but you can help.

Here are some suggestions for things that might help:

• consider joining a support group

• don’t feel you must grieve all the time – try somethings you enjoy as well, when you feel up to it

• talk with a counsellor to focus on your unique situation.

• keep in touch and be prepared to just listen

• be open in showing your concern and care

• help in practical ways

• express your sorrow about their loss

• talk about the person who has died – use their name if culturally appropriate

• remember that many people may be grieving, including children, grandparents, friends

• make contact again, even if there was no response the first time – sometimes people will want to talk and sometimes they won’t

• share memories and stories

• remember and acknowledge birthdays, death days, anniversaries and other special days.
Sometimes, there are things that are not helpful, these might include:

- avoiding people who are grieving
- taking anger personally – often it is simply an expression of pain and grief
- saying ‘I know how you feel’, everyone feels differently
- telling them they ‘should’ be grieving in a certain way
- changing the subject or trying to cheer them up
- not using the name of the person who has died for fear of reminding them - they won’t have forgotten
- trying to find something positive in the death
- making suggestions to ‘replace’ the person who has died.
Use your judgement. If you are really worried about someone, ask them if they think they are doing okay.

If you make a mistake, it’s never too late to say sorry. If possible, don’t allow friendships and relationships to become strained.

Finally, don’t allow your inability to fix it stop you from reaching out to a grieving person and don’t underestimate the value of ordinary human kindness.

The palliative care service provided wonderful support for me when my husband was dying. After he died, I could continue talking to the palliative care service providers for support. With their help, I was able to face my grief and gradually start doing the things I had enjoyed doing before my husband became ill. But even with this help, it was a lot of hard work, some days good, some days bad.
Feeling overwhelmed?

Sometimes, we may need to seek help. Counselling is one option, or you might consider joining a support group.

Although the experience of grief is a normal and inevitable part of life, for some people it can be very distressing. If this happens, professional help is recommended.

Some signs that you may need to seek professional help include:

- a strong sense of meaninglessness that persists over time
- high levels of insomnia
- inability to carry on previous relationships
- deep yearning or searching for the person who has died
- deep depression or anxiety
- thoughts of self harm or harm to others.

Where can I find more information?

palliativecare.my
This website has a number of information resources available for download or in hard copy:

**What is palliative care?** – This brochure explains what palliative care and end of life care is about.

**What can I say – What can I do?** – When someone I know is living with a life-limiting condition – strategies for making a difference to help you help someone you know who is living with a life-limiting condition.

**Facts about morphine and other opioid medicines** – information on the facts and myths about medicines used in palliative care.

**Asking questions can help** – a booklet with a list of questions you may wish to ask when you are seeing a member of the palliative care team. This question list helps you get the information you want about palliative care and your illness.

**About the process of dying** – a brochure that guides you through what happens when someone is dying.

**Advance care planning** – A brochure to guide you as you complete an advance care plan so that your wishes for care at the end of life are known.
Several organisations provide information or telephone counselling:

Alzheimers Disease Foundation Malaysia
03-7956 2008/ 03-7958 3088

Befrienders
03-7956 8144/ 03-7956 8145

Breast Cancer Welfare Association
03-7954 0133

Cancerlink Foundation
03-7956 9499

Malaysian Mental Health Association
03-7782 5499

Majlis Kanser Nasional (MAKNA)
03-2162 9178

National Kidney Foundation of Malaysia
03-7954 9048/ 03-7954 9049

National Stroke Association of Malaysia (NASAM)
03-7956 4840

The Malaysian AIDS Council
03-4045 1033

Ti-Ratana Welfare Society
03-7988 1818
For more information on key palliative care contacts in Malaysia, refer to:
Website: palliativecare.my
Email: info@hospismalaysia.org
Tel: 603-9133 3936 (Hospis Malaysia General Line)

Acknowledgement:
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