



What Can I Say, What Can I Do?

When someone
I know is living with
a life-limiting illness

Find out more at: palliativecare.my

Prepared by:



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This brochure suggests some strategies for helping someone you know who is living with a life-limiting condition.

*When Tina got sick, it really frightened me. I didn't know what to say, so I thought it was best to leave her alone. I wanted to help but didn't know how. When I finally got the courage to ask Tina what she needed, She thanked me and agreed to ask me for help if she needed it. She said it was important that she was treated as 'normal'.
- A friend*

Finding out that someone you know - a relative, an acquaintance, workmate, or friend has a life-limiting illness comes as a shock. Their world has suddenly changed. Anxiety, sadness and even anger at the news are all quite common reactions.

Many people, though, choose to see themselves as living with a disease rather than dying from it.

The person will be receiving care that aims to help them live as well as possible and to stay in control. This involves looking after all their needs with physical, emotional, social, cultural and spiritual support. Importantly, it also involves caring for the person's family and carers.

That's where you come in, you can play an important role.

Understanding emotions and feelings

People need time to work through the pain that comes from loss. Grief is a process, rather like going on a journey without a map. There's no formula for what should happen.

It will be helpful to your friend and their family to know you'll be there to support them, whatever comes along.

This person will be learning to live with and express their feelings, such as sadness and other emotions. Be prepared to listen and recognise their feelings. This gives the person dignity: they feel that you accept them as they are.

It is sad to see changes in someone you know well. Value your relationship and treat the person who is ill as you always have, with warmth and concern. That helps you as well as them. Just be yourself. This is a sad time but it can also be fulfilling.

Understanding the experience of living with a life-limiting illness.

Everyone's experience is different. Generally though, people with a life-limiting illness make gradual adjustments to the way they live, often with a great deal of uncertainty. They keep hope alive and continue to set goals. They may want to explore what it means to be dying and test ideas on you.

Be prepared to listen. Every person's journey is one they have to make as individuals. You can help them not to feel alone.

Caring for a person with a life-limiting illness can be demanding. Carers try hard to keep things normal in an abnormal situation. Roles change. Relationships can come under strain as people adjust to their new lives. Yet, more families and carers talk about how rewarding it can be. You can support them by letting them know what a good job they're doing.

Your friend's life might have changed but that doesn't mean they have. Listen to them and learn to accept their understanding of the new situation. The most valuable thing you can give is your continued support.

Managing health

Palliative care helps to manage the person's health and the symptoms and side effects, such as exhaustion, nausea and weight loss, as well as their emotional wellbeing. The aim is for the person to live each day as well as they can to fulfil their wishes.

Social activities

Your friend will want to remain in touch and feel part of the world. Help them to avoid isolation by adapting social activities to suit. Find out their best time of day, and plan to visit, or take them out, when they're feeling most like company.

Working

Many people with a life-limiting illness want to keep working, making the most of their time. Others may work part-time or from home. Support their decision and then if they have to leave work, keep up your friendship by phone or use email to stay in touch.

What can you say?

The person you know will want you to continue to speak with them as an equal. Don't worry that you'll say the wrong thing or that you'll both get emotional - just be there to talk.

Encourage memories and value the explorations of friendship they bring. These may be ways for the person to say goodbye. You'll always be glad of those conversations.

What can you say to the family?

Let the family know how much you value their loved one and how you support what they're doing. Offer to help in whatever way you can. Let them know that you feel for them.

What can you do?

Just your willingness to be there is half the battle. Your friendship prevents isolation. Emotional support comes from remembering the person hasn't changed and letting them know that your friendship hasn't changed, either.

Know that you can make a difference by:

- Offering your support
- Showing your respect
- Following their lead
- Asking how you can help

Accepting practical help can be hard at first. Allow the person and their family to make the decisions, and fall in with them. You can give help in many ways - by cooking or gardening, providing books or DVDs, picking up the kids from school or assisting with the visits for treatment.

Your role is to try to alleviate the family's stress. You can help by being a good listener and making practical suggestions:

- How about I drive you to your next hospital visit?
- Why don't I do the shopping for you?

Being observant also helps: the washing-up needs doing?

The plants need watering? Just do it!

Remember to give yourself some 'downtime', ensuring that you too have some way of expressing your feelings and relaxing. It's not an easy time.

A good friend stepping in to give us a rest is like a shot of adrenaline. It allows you to regain your energy so that you can get through all this. I just felt that we could not leave him – But the break gave us the strength to be better for him.

- a family member

After death - what can you say to the family and carers?

Even when a death is expected it comes as a shock. It is even harder if people stay away or don't do anything. Just be yourself — "I'm so sorry this has happened. I'm really sad for you".

What can you do to show you care?

There's no timeline for grief and no solution to fix it. The process of grief is actually part of the healing. Hang in there with the family and accommodate your help to their needs.

How will you care for yourself?

Value the relationship you've had. Take the time to grieve. Remain close to your friends and family for support. Your kindness and compassion have helped others and enriched your life as well. A good friend is one of the greatest benefits of being human. You have done all you could.

Who can help and where to go for help?

You're not alone. You can benefit from the collective wisdom of many who've shared your journey. Here's a list of support groups that can help you through troubled times:

- **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:

This document was prepared by Hospis Malaysia with information extracted from the "What Can I Say, What Can I Do?" guide prepared by Palliative Care Australia, with its kind permission.

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