

This brochure suggests some strategies for making a difference, to prepare you to help someone you know who is living with a terminal illness.

A terminal illness is one that can't be cured.

When Sally 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 Sally 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'.

Finding out that someone you know - a relative, an acquaintance, workmate, or friend is terminally ill - 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 may be receiving palliative care. This involves looking after all their needs with physical, emotional, social, cultural and spiritual support. It aims to allow the person to stay in control and also to care for the person's family and associates.

That's where you come in...



1. Understanding emotions and feelings

The pain of loss needs time to be worked through. 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.

2. Understanding the experience of living with a terminal illness

Everyone's experience is different.

Generally though, people with a terminal illness make gradual adjustments to the way they live with 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 terminally ill person can be draining. Carers are trying hard to keep things normal in an abnormal situation. Roles change. Relationships

can come under strain as people adjust to their new lives. Yet most carers and families say how rewarding it is. 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 terminally ill people 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.

We couldn't have survived without our closest, dearest friends, who closed in around us and put their lives on hold to help support us.

3. 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.

4. 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, for example.

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 lawn needs mowing? 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.



5. After death - what can you say to the carer and family?

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

A hug can be just as good as words.

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. Try these contacts to start:

National Palliative Care Information Line no. 1800 660 055

Palliative Care Australia

T (02) 6232 4433

E pcainc@pallcare.org.au

W www.pallcare.org.au

Palliative Care Council of New South Wales

T 0403 699 491

E info@palliativecare NSW.org.au

W www.palliativecare NSW.org.au

Palliative Care Queensland

T (07) 3633 0096

E info@pallcareqld.com

W www.pallcareqld.com

Palliative Care Victoria

T (03) 9662 9644

E info@pallcarevic.asn.au

W www.pallcarevic.asn.au

Palliative Care WA

T (08) 9212 4330

E pcwainc@palliativecarewa.asn.au

W www.palliativecarewa.asn.au

Palliative Care Council of South Australia

T (08) 8291 4137

E pallcare@pallcare.asn.au

W www.pallcare@asn.au

Tasmanian Association for Hospice and Palliative Care

T (03) 6234 7577

E tahpc@associationoffices.com.au

ACT Palliative Care Society

T (02) 6273 9606

E acthpc@bigpond.com

Palliative Care NT

T (08) 8922 8824

E moq13026@hcinternet.com.au

Commonwealth Carer Resource Centres: 1800 242 636 (freecall*)

The PCA National Community Education Initiative is supported by the Australian Government Department of Health and Ageing