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Introduction

It's something none of us would wish on anyone but receiving a diagnosis of a terminal illness is an unfortunate reality for some Australians.

Beyond the immediate impact this will have on you, many of us feel like we don't want to burden others with the reality of such a diagnosis, according to Judith Lillis, a Certified Bereavement Practitioner.

"We live in a death-denying society, where an openness to conversations about death does not exist in many spheres," Judith says. "Maybe there is the impression that we should be tough, or just keep busy, or pull up our boots, keep going and keep moving on.

In our previous eBook, <u>How to cope with the terminal illness</u> of a loved one, we shared information and tips on how

Australians can manage the distressing situation of caring for someone with a terminal illness.

In this eBook, we will discuss the challenges of helping loved ones cope with your terminal illness – from the initial discussion, to managing their various reactions, to getting your affairs in order following a terminal diagnosis.

The short-term may be a difficult time with lots of hard conversations and sombre moments, but we hope that this eBook can provide you with some useful resources to get the support you need – and to support your loved ones as you manage your treatment and quality of life.





How to tell loved ones you've been diagnosed with a terminal illness

The most important thing to remember is that you are under no obligation to tell every person you know about your terminal diagnosis immediately. When, where and how you break the news is entirely up to you, and you shouldn't feel forced or rushed into speaking about it.

It's also worth remembering that everyone will react differently. Your husband or wife, for example, will no doubt have a much stronger response to the news than your workmates. Because of this, it's best to be as mentally prepared as possible for each conversation.

Telling your partner, immediate family and close friends

This may be one of the hardest things you've ever done in your life. However, it will also be one of the hardest conversations for your loved one, so Judith says to remember that everyone copes with grief in different ways.

"Grief is a normal response to a loss, and while there are common reactions to recognise, it is helpful to know that ultimately everyone grieves in their own way," she says. "There are no right or wrong ways to grieve."

"Grief is not linear, and people do not move through a series of discreet stages. Grief can be like a storm that comes in waves. Grief can also be like arriving in a foreign or strange land where everything is unfamiliar. Learning more about grief can help to manage these feelings."



<u>Telling the truth is essential</u>. It may be difficult but being honest about the diagnosis and the amount of time the medical professionals have given you will make things easier down the track.

You'll also want to be as comfortable as possible. Consider having the conversation at home or somewhere else you feel safe. If you are worried about having to answer questions you simply can't respond to, you might also consider contacting your doctor so you can break the news to your loved ones with a professional in the same room.



Breaking the news to your children

Depending on the age of your child(ren), they may not understand at first what a 'terminal illness' is. In these cases, it's important to communicate as calmly and lovingly as possible.

<u>Using the right words</u> can make all the difference with children. Explaining what death means without the caveat of it being 'a long sleep' or that one day you could 'come back' is crucial here, as you don't want to confuse your child or give them false hope.

If they are very young, you might also want to explain the situation in a simple story. However you phrase it, be prepared for a range of emotions – from disbelief to fear and even anger. [Read more about managing reactions in Chapter 2]

Informing your colleagues

Telling your work about a terminal illness likely won't factor into your immediate thoughts, as knowing that you may have limited time left means preparing for your family's future first. It's recommended that you speak to your work as soon as you are comfortable.

Book a time to sit down with your manager and ideally someone from human resources. It's also advisable to bring a support person with you, such as your partner, parent or close friend. Outline the situation as clearly as possible and ask what your options may be for the future.

If you are able to, you may decide to continue working for the time being or you may choose to leave the company so you can

spend more time with loved ones. It depends on your particular needs and whether you are physically and mentally capable of working.

Sharing with acquaintances

This can be one of the most difficult conversations to have because a) you may not feel comfortable sharing the news with people you aren't very close with, and b) you may not feel they have the right to know about your terminal illness, particularly if you expect to be bombarded with messages (supportive or otherwise) after sharing the news.

It is entirely up to you about how you manage this conversation. Some people may feel they only want to share the news with close friends and family. Others may decide to take to social media to discuss the situation and ask for privacy in this difficult time. Or maybe you would prefer to let others share the news for you, so you don't have to deal with direct communication from dozens or even hundreds of acquaintances.

Different relationships, different reactions

In all these instances you'll likely receive a different reaction. Some of them will be challenging to manage, which is why it's important to be prepared for all types of responses. But also be open to the opposite – some of the responses you get may surprise you, with an outpouring of love and support a common by-product of sharing such news with your family and friends.



Tips for managing and understanding your family and friends' reactions

Once you share the news of a terminal illness, you may feel like a weight has been lifted from your shoulders – this is natural, especially if you've spent days or even weeks worrying about how and when to share the news.

What you may not expect is that the most difficult task is still to come: managing the range of emotions from the loved ones you tell.

What if they are angry?

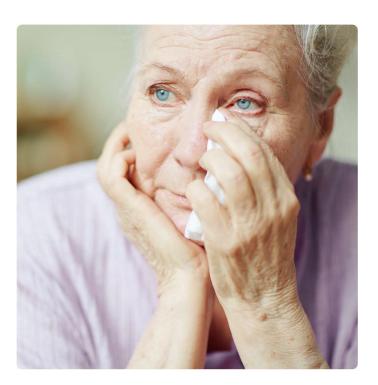
It may be the last thing you expect, but anger is a very common reaction to hearing the news that a loved one has a terminal illness, particularly if you are their partner, parent or child. Sometimes they will even direct their anger at you.

Recognise that this is simply their raw emotions speaking and they are not truly angry at you, but rather at the illness. Give them time to absorb what you've said and check in with them later once they have calmed down to ensure they have understood the news and what that means for everyone's future.

It might also be a good idea to look into counselling services. Professionals who work in the areas of grief and bereavement can be a supportive outside party during this extremely difficult time – for both you and your loved ones.

What if they are in shock?

"How could this happen to you?" "You're so healthy – that's impossible!"



Such responses are natural and are an expression of total disbelief at the situation. Particularly if you haven't been ill leading up to the diagnosis, your loved ones may not be able to process the news straight away.

At this time, you might want to support them and encourage them to continue speaking about the terminal illness. This may be painful, but it will help make the news more real. After all, you and they need to accept the awful news before you can move forward and make plans about what to do next.

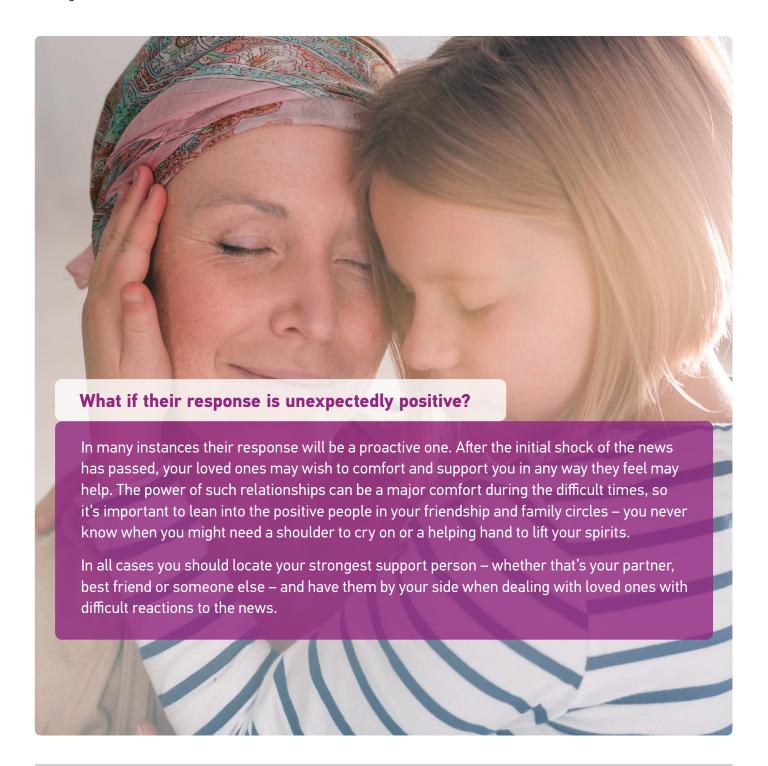
What if they become overly protective?

Partners and parents, in particular, have a tendency to become overprotective whenever you are sick, in danger or threatened. Being given the news that you may only have only years or even months to live is one of the worst things for a loved one to hear, and their inability to be able to heal your illness may trigger their protective mode into hyper-drive hear, and their inability to be able to heal your illness may trigger their protective mode into hyper-drive.

This is a normal reaction and one you should prepare for. That being said, it should not be encouraged or ignored, but rather addressed upfront so you can put boundaries in place for the coming weeks and months.

As Judith says, this may simply be a case of the loved one having a different "grieving style" to you. "Having a different grieving style to someone in your family might mean that you don't feel you can connect with those in your social sphere to have needed conversations or get support. You relate differently."

Take the time to educate them about the news, and you may wish to take them along to your doctor at your next visit so they can hear the news firsthand. If you find they are belligerent or won't respect your privacy, it may be worth investigating whether a grief and bereavement counsellor can help.





Let them know your needs: **Do you** want help or would you prefer space?

Telling your loved ones about your terminal illness and helping them cope is one of the first steps after diagnosis, however ultimately you need to put your own needs first and foremost.

It's easy to feel guilty that you aren't tending to everyone as you used to, but during this time it's important to outline what it is you need, so your loved ones know to respect your boundaries.

So after sharing the news, managing their reactions and then moving forward with a clear purpose, let them know about your needs. Do you want their help, or would you prefer space? Maybe you want to spend the next few days alone with just your partner or by yourself. Or perhaps you want to move back in with your parents to spend more time with them.

Don't be ashamed of telling people exactly what you need. It's likely that your loved ones haven't gone through this before, so it will be a learning experience for everyone.

Keep the lines of communication open

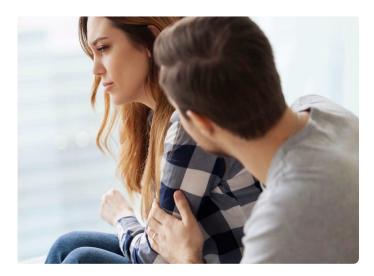
Whatever you decide you need in that moment, keep the lines of communication open. That doesn't mean always picking up the phone to stay in touch with everyone, nor does it mean you need to spend your every waking moment with other people even when you're feeling exhausted. It just means not shutting down.

Depression and anxiety are common symptoms following a terminal diagnosis. If you feel like you simply don't want to communicate with any loved ones or that you can't move forward, seek immediate support through a service like <u>Beyond Blue</u> by calling 1300 22 4636. You might also advise your loved ones that they can seek individual support through services like <u>GriefLine</u> (1300 845 745).

Be honest and transparent about the terminal illness

Honesty is always the best policy. Be <u>honest about the illness</u> <u>itself</u>, be honest about the time you have left so your loved ones are able to be with you, and most importantly be honest about your needs.

Only by communicating what it is you want will your loved ones be able to give it to you – and remember, they do want to support you through this very difficult time.





Getting your affairs in order **after a terminal diagnosis**

It may be small comfort but receiving a general timeline for a terminal illness is something most families don't get when a loved one passes away suddenly. This means you have an opportunity to get your affairs in order while you are still alive.

Letting loved ones know your wishes

First and foremost, what do you want to do in the short term? If you are physically able, you might want to check off a few items from your bucket list. Bringing your family into this conversation will make them feel appreciated and they may be able to provide a few suggestions you hadn't thought of.

Then there's the question of what – if any – end-of-life care you receive. It's worth knowing that while 70% of Australians with a terminal illness say they want to die at home, only about 15% actually get to do so according to research from the Australian Bureau of Statistics. Making a plan – and a backup plan – means you will know what to expect as your time approaches.

You might also want to think about what <u>sort of send-off you want.</u> It's never nice to think about, but a terminal illness means you now have the opportunity to tell your loved ones exactly what you want to happen after you pass away. Would you like a traditional funeral ceremony, an eco-burial, a celebration of your life, burial or cremation? You may also find a <u>death doula</u> is a supportive presence when preparing your end-of-life plan. There are lots of things to consider, so spend some time with your loved ones and write down your wishes to serve as your final instructions.

Organise your will

There are a number of <u>legal matters everyone should have</u> <u>sorted before they pass away</u>, the most important of which is writing your will. Even if you already have one, the news of a terminal diagnosis may cause you to reassess some of your inclusions – so review the will and ensure it's exactly what you want before your passing.

It's also important to share with your loved ones (and particularly the executor of your will) your documentation for <u>life insurance</u> or <u>funeral insurance you may have</u>. These can help cover expenses in the event of your passing, making a challenging time slightly easier with financial support.





Conclusion

There's no denying that receiving news of a terminal illness is an awful event that will drastically change your day-to-day life. It's important to take proactive steps to tell your loved ones about your diagnosis and try to manage their reactions as best as possible.

Most important of all is that you are honest and open about what you need. Sharing your wishes can lift a weight off your shoulders, but also help guide your loved ones as they navigate

their own emotions. During this difficult time your loved ones should be a source of constant support, and by keeping the lines of communication open you can help them help you, and they can help you.

It's not unusual to want help in the various stages encountered during such a difficult time – such as discussing your wishes about how you want things to be managed, preparing for end-of-life care, your final requests and will management.



Bio

Judith Lillis is a fully registered counsellor, based in Melbourne, Victoria, who has specialist grief counselling training and experience. She feels strongly that everyone grieves differently and is a counsellor who works from a person-centred style, putting her patients first, and using a range of approaches. Judith says that she does not counsel from a place of treating grief as a deficit or illness but instead views grief as a normal emotion. Judith works from a framework of health, capacity building and strength, and believes that all individuals have strengths which can be utilised to help when facing grief and loss, for hope in the present and future. Judith undertook specific training to specialise in bereavement counselling, completing the Vocational Graduate Certificate in Bereavement Counselling Intervention and then a supervised practice placement at the Australian Centre for Grief and Bereavement (ACGB). Since that time, she has been counselling vthe bereaved as a Practitioner Associate with the Australian Centre for Grief and Bereavement in Mulgrave.

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