



When Cancer Won't Go Away

For people whose cancer has advanced



When cancer won't go away

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Introduction

This booklet is for adults who have a cancer that is not likely to be cured and are looking for information and support.

Health professionals use several different names to describe cancer that has advanced beyond early stages, including advanced, secondary, metastatic and progressive cancer. Sometimes, health professionals don't use a special name. In this booklet, we use the term '**advanced cancer**'.

Whatever words you use, it can be devastating to hear that cancer has advanced.

This booklet offers general information about advanced cancer, telling you what might happen and where help can be found. For carers, there is a separate booklet called *When cancer won't go away: for carers of people whose cancer has advanced*.

Most of the quotes in this booklet are from people with advanced cancer. They tell us how they faced the situation and what has helped them. Above all, they offer hope to others. But reading the booklet may stir up difficult feelings. Try reading the parts that seem useful now and leave the rest until you are ready. The words in **bold** are explained in the glossary and the services and information sections.

We hope that you find the information presented in this booklet helpful: it was produced with the assistance and advice of health professionals and people with advanced cancer.

*** Are you reading this for someone who does not understand English? Tell them about the Multilingual Cancer Information Line. See the inside back cover for details.**

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Cancer that has advanced

Each type of cancer has its own pattern of development. Some grow very slowly, others tend to advance rapidly, and some are unpredictable. Some types are known to respond well to treatment in most people, while other types are generally more difficult to treat successfully. Although many early cancers can be cured, there are many people now living with cancer who at some time in the future will die of their disease.

Knowing more about a particular cancer can help make sense of symptoms and the treatments that may be offered.

Advanced cancer is a term commonly used to describe:

- metastatic or **secondary cancer** that is unlikely to be cured
- **primary cancer** that is unlikely to be cured.

These terms are explained below.

Cancer is the name for abnormal **cells** that divide and multiply uncontrollably. When cancer begins, these cells usually develop into a mass (or **tumour**). This mass of cells is known as the primary cancer.

If the primary cancer is not treated, or cannot be treated, a few cancer cells can break away and move through the bloodstream or **lymphatic system** to other parts of the body. There, they multiply uncontrollably and form other masses of abnormal cells (**metastases**). When cancer spreads from the place it started, to grow in other parts of the body, it is known as **secondary** or metastatic cancer.

Advanced cancer usually cannot be cured; however, it usually can be treated to slow the growth and spread of the cancer, sometimes for months or years, and reduce its symptoms. Treatment can keep some cancers under control for long periods and is especially helpful in controlling pain.

First reactions

You have been told, or you have come to realise, that you have advanced cancer – cancer that won't go away and is unlikely to be cured.

Most people say it is devastating to realise this, even worse than when their **primary cancer** was diagnosed. For people who didn't even know that they had primary cancer, a diagnosis of **advanced cancer** can be a double blow. Sometimes there is also relief: you may have suspected that something was wrong and now you know.

There are big decisions to make about treatment, what to tell family and friends and what to do at home and work. The news touches every aspect of your life. At first, it may be hard to accept that things will improve – but they can. In time, you're likely to feel more normal again. So don't rush into decisions at this point.

Will I die?

Death is one of the first things people think of when they learn that their cancer is advanced.

'It was like facing a firing squad.'

This is often mixed with other feelings, like dread at the thought of the journey ahead – perhaps pain, dependence and loneliness.

These emotions can be overwhelming at first, but with time and some help, your feelings are likely to change. Some people begin to live 'day to day'. Others find that preparing for death helps them to feel more in control of their life.

'There is still a life to be lived and pleasures to be found and disappointments to be had. Living with advanced cancer is a different life, not just a journey towards death.'

What do I do now?

Take some time and allow the news to sink in.

You will need to discuss your cancer and your outlook (**prognosis**) with your doctor – although no one will be able to tell you exactly what course your cancer will take.

Remember that for some people, treatment for the cancer can keep the disease in check for months or years. Symptoms of **advanced cancer**, such as pain, are usually very manageable. Even though the cancer cannot be stopped, treatment will continue. Treatment decisions are very important at all stages of your illness.

Most people find they want information and support. You might find encouragement through talking with other patients or by joining a support group for people with cancer. See the services and information section on page 53–55 of this booklet.

Hope

There may be times when hope seems absent.

But everyone needs something to hope for. Sometimes, you may hope for recovery or survival. Other times, you may hope for good days with understanding company or the love of family and friends. You may find yourself hoping you will keep your dignity and be free of pain. Some people explore paths they've never tried before and find hope in this new dimension of their lives. Others find hope in small projects, such as planning a swim in the sea next summer. Some people find hope in their religious beliefs and some describe feelings of hope that are hard to explain to others.

‘It seemed to help me when I put my feelings on paper. The file was called “hope” at first. Now I call it “healing”. What shall I call it next?’

The emotional impact

When you realise your cancer is unlikely to be cured, you face big changes. Your body, mood, beliefs, relationships and other major aspects of your life are likely to be affected.

The effect on you

Many people experience a ‘roller coaster’ of emotions when they realise what they are facing. These emotions include numbness, fear, anguish, sadness and anger.

There is no need to turn away from painful thoughts and feelings. It is better simply to feel them, and know that they will change over time, just as feelings always do.

Trying to ‘think positively’ won’t always be possible. Whatever you feel, you feel. There is no evidence that thinking either positively or negatively will influence your disease.

‘When I’m low, I often think I will scream if one more well-meaning person says “Be positive!”. However, even when I’m low, I can decide to take positive action ... Miraculously, taking positive action will often turn you around and you find yourself laughing and celebrating life all over again.’

After a while, as you work your way through the challenges, a sense of achievement can emerge.

‘I got rid of all the garbage I’d been living with for years and I became the person I was meant to be.’

You might feel concerned about the financial impact of **advanced cancer**. Money problems will make it harder to cope with other fears.

You may need advice about negotiating leave from work or obtaining an early superannuation payment. Whether or not you are employed, you may be eligible for a sickness or disability payment. Speak to a social worker or see the services and information section on pages 53–55 of this booklet.

The effect on people close to you

It is likely to be very hard when you tell people close to you about what is happening.

‘Telling people was difficult before. This time it was absolutely terrible. They’re hearing it fresh; they haven’t had time to come to terms with it.’

And while you get on with your life, the people around you may move more slowly – or not at all. Families tend to want to protect you, wrap you up in cotton wool and keep you from further harm. There may be an atmosphere of things unspoken, because the pain could be too great for all of you. This is a sure way to prolong the pain. Sharing fears can be a great relief.

‘She worried about us and we worried about her, each side certain it would be too much for the other to bear ... none of us would talk about it when we were all together. We kept up the charade until the end.’

Sometimes family or friends withdraw. They might not be able to cope with the idea that things have changed for you. It is also a reminder that all life is fragile. They may not be able to think about things that are too painful to contemplate.

‘Workmates couldn’t cope in the beginning – they were embarrassed, formal, evasive. “Stuff this,” she said. “I’m only missing a few mammary glands, I haven’t had a lobotomy. Bloody cancer’s not catching, you know.”’

You may find that someone who you thought was a good friend stops contacting you. This can be very hurtful, but it is quite a common experience for people with **advanced cancer**. Other friends may respond with understanding and openness, and become even closer.

Some people will not know how to respond. You can speak frankly to them, or just treat people as you always have. Your friends or family may begin to take their lead from you.

If you know you can rely on family support, you are fortunate, but it’s likely that friends will also be invaluable. If your family is not nearby or helpful, you’ll be even more thankful for friends.

‘We were his support network, his confidantes, his family. His real family was thousands of miles away and not really in touch with him. He wasn’t in a relationship and lived alone. We had a roster and supported Frank totally throughout his illness. We weren’t experts but we enabled him to die at home, which is what he wanted.’

Some friends are able to listen to whatever you want to say – complaints, hopes, fears, wishes – without judging you and without that extra involvement that a partner or relative will feel. They will also be a practical help.

‘Noni assigned us tasks. We were companions, soup makers, drivers, information providers, superannuation sorter-outers. She didn’t want washers. Most of us didn’t know each other. We meant to meet, but it wasn’t until her memorial service that we actually saw each other.’

The news of your advanced cancer may come when your relationship is shaky and your friends are all you've got. You'll probably find that, even though they can't all manage it, there will be a few who will be able to give you the support you need.

Being alone

If you are alone or your friends are caught up with their work or families, or they live at a distance, you could call on community services that arrange for volunteer visitors to visit people's homes (see 'Services and information' on pages 53–55). Or think about joining a support group: these are often good places to form friendships which can quickly become close.

Getting help

'People have shown concern in so many ways: by holding my hand after surgery, letting me cuddle their babies and play with their kids, leaving messages on my answering machine, emailing their best wishes, and by not being too afraid to ask how I am.'

People might be eager to offer help when they first hear what has happened. But it can be a problem if your friends want to protect you rather than help you preserve your independence. Even when your friends are genuinely willing, it can be hard to ask for help. Few of us like to appear needy.

Some people find it easy to directly ask for help. Others say how nice it would be if they didn't have to ask – if others would 'just do it'. Most people, however, just don't know how to respond in a situation like this, and need some guidance.

'It was hard for me to ask my friends to drive me. If I ever have the opportunity to help someone, I am going to be the transportation chairman and line up drivers for chemo.'

Some people will prefer doing active things for you, such as cooking a meal or visiting the library; others may be good at keeping you company. People you know from your current or past workplace may be able to help by keeping you in touch with what is going on at work. But sometimes you might need friends and family to help by staying away for a while.

'We badly needed quiet times to gather our thoughts and strength ... To give us the respite we needed, we photocopied and sent out updated messages to concerned friends as required.'

Home based palliative care services are available in most areas and can provide care and support to enable you to live life as fully and comfortably as possible. To find out what home help is available in your local community, see the services and information section on pages 53–55.

Young children

It is common for everyone to want to spare children pain. You may think it is better to delay telling them what is going on, or even to let them expect that things could return to normal. But it is best to be honest with young children, even when you find this difficult.

Children always know that something is wrong. So they will need explanations they can understand. If you have explained cancer treatment to them before, it might be easier now.

Children will want to know in advance if you will be staying in hospital at times or needing spells of bed rest at home. They will want to be reassured that even when you are no longer there, there will always be someone to care for them.

‘When she explained to five-year-old Katie that she would not be there much longer, Katie asked, “But who’ll pick me up from school?”. “Someone very special. Someone I think you’ll like very much,” her mother answered.’

If you are a sole parent, it will be especially hard to plan. Discuss your situation with someone who can offer expert advice, for example, the hospital or community social worker.

Children of any age can feel responsible for your illness. They may think they did something wrong and caused you harm. If your child is acting strangely, look for any suggestion of guilt and reassure them that the disease is no one’s fault. They might also fear the same thing happening to them or to someone else close to them.

Your child is likely to understand the situation gradually. When you tell them at first, and as questions arise in the future, remember to:

- listen to what children have to say – this will give you a feel for what they can handle
- communicate feelings as well as facts
- give simple, honest answers, and clarify any misunderstandings
- try to explain what will happen next
- reassure them that even if things are not good at the moment there will be better times
- only make promises if you are sure you will be able to keep them
- try to keep their routines as normal as possible.

If your child begins to act differently – for example, if they become ‘clingy’, don’t eat properly, sleep poorly, don’t want to go to school or become aggressive – this means that they are distressed. If you can’t work out how to help your child, seek advice from a general practitioner or nurse. They may refer you to some support services.

★ **The Cancer Council Helpline has information on how to talk to children about cancer. Visit www.cancervic.org.au or telephone 13 11 20 for a copy. The social worker at your hospital may also be able to help.**

Teenage children

Like younger children, teenagers can feel abandoned as the family focuses on the sick member. If their behaviour seems hard to fathom, they may be reacting to feelings that they are not really aware of or cannot acknowledge, like anger, guilt or grief.

Instead of focusing on themselves and learning how to be independent of parents, teenagers are now confronted with the needs of other family members. Because of these pressures, there may be outbursts over trivial things.

‘There is always a flickering flame of anger springing from the perceived unfairness of having to cope with a sick mother. I also experience the further pain of watching my husband becoming the scapegoat.’

Teenage children react in different ways, ranging from withdrawal to offers of help and assurances of love.

‘My son is fourteen now, but he still gives me a big hug whenever he goes past. And he says “I love you, Mum” morning, noon and night.’

As with younger children, teenagers need to keep as much of their normal routine as possible – school, outings, holiday activities and homework. This may be difficult to manage when you are feeling unwell and is particularly hard for a single parent. If you have a partner at home, they may need to keep on with paid work as well as caring for you, and this can leave little energy for children’s needs.

- When neighbours, friends or relatives ask what they can do to help, you could ask for a specific task to be done for your child, for example, regularly taking them to sports practice.
- Teenagers may need a break from the situation at home, for example, a family holiday, a trip with peers or a regular night out.

Adult children

Adult children will struggle, too. You may feel you have to, or want to, carry on as the head of the family, reassuring everyone that things are the same as always. Adult children can become aware of their own childish need to have their parent forever available.

‘That night, while looking at my small daughter as she slept, I cried. I thought, “No! Don’t you dare die, Mum. I’m not ready for you to die yet. I still need you.” Selfish thoughts? Maybe. But they were real ones.’

It may take a long time for them to get used to the situation – you will probably find that they switch their concern on and off.

Parents

It is one of life’s most painful experiences to be the parent of someone with **advanced cancer**. It seems to go against nature to outlive your children. Your parents are likely to feel overwhelmed with sorrow and helplessness at first. You will have to trust that their life experience and their maturity will support them through this. It may take them a long time to adjust.

‘I tried to tell Mum but she blocked it and I thought, “So be it. She’ll feel the pain all in good time. Why force it on her now?”’

- Information about your condition will help your parents or your grown-up children cope with their own feelings.

- Learning about up-to-date approaches may lessen any fears arising from their past experiences with cancer.
- Attending a course such as the Living with Cancer Education Program could help. See page 19 for more details.

Partners

We use the word ‘partner’ to mean husband, wife, girlfriend or boyfriend. If you have been with your partner for a long time, you will remember other life crises that you have experienced together. This one may be more intense, but you have probably weathered storms before. Studies of couples where one partner has a life-threatening disease show that good relationships generally stay good and less strong relationships continue to be less strong.

‘We have faced many trials and traumas together, always managing somehow to get round, get over or get under them. There had always been a way out, that is until ... The diagnosis was ovarian cancer, giving a one-in-three chance of survival.’

Often, your feelings and attitudes are not ‘in synch’. This can cause frustration and misery, or it can help you to cope: as each new event presents itself, you may find that one of you expresses hope while the other is more pessimistic. Sometimes it can be hard for partners to help you to make decisions about treatment.

Your partner may overwhelm you by trying to protect you. Equally difficult and painful is the partner who doesn’t want to face what is happening.

‘My husband thinks if you talk a lot about it you worry more. He thinks we have to leave this problem and forget.’

Changing roles

Many people who have experienced cancer, particularly when it has occurred over significant periods of time, say that their relationships and roles with partners often undergo a radical transformation. Many conversations may focus on trips to the doctor or treatment options you may be considering. You may even feel that your previous roles as parent, lover, friend or partner have altered with the cancer experience. It is natural to feel that, despite physical and emotional changes, you would like to be valued for who you are and the qualities you bring to the relationship.

Feeling frustrated with not being able to do what you used to is common among people as their cancer advances. But you will risk feeling helpless and then hopeless if you can't take any part in the work of your household.

It may help if you work out what you most need from your partner when things are tough and ask for this. Women often say that their biggest need is for a sympathetic listener; many male partners acknowledge their difficulty providing this.

'I have often lacked the ability to encourage and to say the right thing at the right time ... On the plus side, I have become quite adept at using the washing machine and the clothes drier.'

Action, even bold action, may be tempting.

'Ian promptly bought a property miles from anywhere in the outback. My mother hid her own fears and left her job to look after him. In the beginning he was embarrassed by the sad faces and so he found a place where he and Mum could come to terms with his illness in private.'

Sometimes partners find it all too much.

'My husband finished the marriage three weeks ago. There's just the three of us now. It was pretty rough, and it still is, but look what I've got – the two girls.'

Sex and closeness

Sex may have been a big part of your life or you may value close contact, like hugging, as much as sexual intimacy.

'Every morning we hug and hold one another, gently breathing in unison and feeling close. It helps keep our connection going through the day, when things can get a bit out of control.'

Either way, when you have **advanced cancer** there will be times when it is difficult to get the kind of closeness you would like.

Your body will probably change. Loss of weight is very common. You might find it hard to accept how you look and think that others will also struggle to accept your body.

'I hate looking in the mirror now: my once-athletic body withered and shrunken.'

If you have a partner, you may avoid physical contact for fear of rejection. Most people find it is easier to re-establish contact by starting with simple things: just lying close together in bed or hugging gently. If these first steps are difficult, you could ask for expert help. An experienced doctor or nurse counsellor may be able to suggest ways to break the silence and perhaps make sexual intercourse easier. If this is no longer possible or desired, you may be able to satisfy your need for physical closeness in other ways – cuddling, stroking or massage.

‘Apart from discomfort, there was the stinging uneasiness of the radiation burns to her groin area. Consequently there was a waning of interest in sex. Sensuous massage became a tool of communication, gently restoring and relaxing, and increasing our physical contact. Yet we couldn’t help feeling that we were missing out.’

‘Your libido does go down and you prefer memories and cuddling to what was previously an active sex life. I am fortunate that Charles, my partner, is so understanding and supportive.’

If the cancer spreads to the bones, you can feel sore all over and not able to tolerate even a gentle hug. Some couples find that simple hand holding becomes an expression of closeness.

Even if you haven’t known your partner long, you might find that love and desire help you get around some problems.

Physical and emotional intimacy can keep us all going through difficult times. Whether or not you have a regular partner, you will find that a sense of closeness can come unexpectedly. A timely kiss from a child, a hug from a friend, or a touch from a caring nurse or doctor as they talk to you, can make all the difference to your day. It takes time to adapt to the physical and emotional changes you have been experiencing. Even though you may feel different as a person, if you come to accept the changes in your life, you may find new ways to be content in your relationships.

Cancer Support Groups

Many people are greatly helped by joining a Cancer Support Group. Here, you and other people with cancer can talk about your deepest wishes and fears.

‘It’s good to be able to get together and just talk ... like the support group which Joanne was going to, where they were all living with breast cancer with secondaries so that they could share their experiences, their different treatments and the effect it was having on them.’

When you are still coming to terms with your situation, you may feel reluctant to share your story or listen to other people’s. And not all groups will suit you. But if you find one that’s right for you, you’ll benefit from the close bonds with the other group members.

People talk of the strength they have found in sharing feelings and facing reality. They also talk about the laughter that’s a big part of any group. Your hospital may run Cancer Support Groups: check with your doctor, nurse or social worker, or contact the Cancer Council Helpline on 13 11 20.

Living with Cancer Education Program

The Cancer Council’s Living with Cancer Education Program provides information on cancer and ways of coping with it. The program runs over one day or several weeks. Groups are small, with plenty of time for talking. Courses are held at hospitals and community organisations throughout Victoria. Contact your hospital social worker or the Cancer Council Helpline. The program is also conducted in languages other than English in some areas.

These groups are free. They usually meet for several sessions, each of which focuses on a particular topic. Speakers with expertise in many areas are invited. The course is led by trained health professionals, including nurses and social workers. It provides information and support for people with cancer and their friends and families.

‘Attending the Living with Cancer group has been invaluable. All members of the group have similar cancers and have had similar treatments. But I remember an earlier stage when I didn’t want information and I didn’t want to hear about the experiences of other patients.’

★ For help finding your nearest program, call the Cancer Council Helpline on 13 11 20.

Talking about it

Research has shown that people cope better with the experience of cancer when they are open about their feelings, for example, when they talk about their anger or fear.

But you are not a statistic and you must do it your own way. Perhaps you are the sort of person who has always kept your troubles to yourself.

‘And amidst this began Dad’s cancer battle.
About which very little was said.
In public, he held his head up high
And fought his battle in his shed.’

Even if you are not in the habit of talking about your personal concerns, you may at some stage want to tell someone – a nurse, your general practitioner or someone else – how it feels. Most people find they need help in learning to live with **advanced cancer**. It can be hard to share your feelings, and it can also be hard to know what words to use about your condition. Finding the words that feel right for you can help you to talk about your situation. Keep trying until you find the sort of help that you need.

Treatment

Advanced cancer means a new phase of treatment. Just as with early cancer, it is important to find out what a suggested treatment means for you.

Some people with advanced cancer thoroughly research proposed treatments, question doctors and read everything available on the subject. The Internet is used for this purpose by many families. It is a good idea to check with your doctor. Much information on the Internet is unreliable, so if you uncover something that disturbs you, contact the Cancer Council Helpline and ask them about it.

Can advanced cancer ever be cured?

‘I hang on to my favourite daydream in which I receive a call from the oncologist who apologises profusely for misdiagnosing my condition. In this dream she tells me that basically all I have is a form of internal dandruff.’

Although **primary cancer** can sometimes be cured, most advanced cancers can’t. This doesn’t mean you may as well give up.

‘At age forty-nine, Ian had an operation to remove a tumour from his bowel, and soon after was diagnosed with cancer of the liver. While the rest of us struggled to come to terms with this news, he was planning his future. These plans didn’t merely stretch into the six months that the doctors had allotted for him.’

Treatment can keep some advanced cancers under control for months or years. In other cases, treatment can help to control symptoms, including pain.

Having advanced cancer means living with a lot of uncertainty – from the big questions, like how long you will live, to the smaller but very stressful questions, such as what the next test will show. You might find you feel contradictory things – you hope for a cure, but accept whatever the future brings.

‘I’m not worried about dying. I know that when the time comes, it will be my time, this body will be worn out ... I just bought a new car and my last car I drove for sixteen years so I fully expect to get sixteen years out of this one. I’m very confident of the future.’

Not all people with advanced cancer die of it – other factors can intervene. We have all heard of unlikely cures. As one woman with uterine cancer puts it, ‘It is no one’s business to take away hope.’

Rehabilitation

It is frustrating to find that cancer limits your activities. Rehabilitation is a way of restoring your independence to the level you can manage.

Rehabilitation includes assistance with anything that will help you to be more independent or more comfortable. Rehabilitation can include exercise programs, pain management, assistance with bowel and bladder problems, helping you return to your work or home, and assistance for your family and carers. An occupational therapist is a good person to ask about dealing with any symptoms you have.

‘I did a lot of surfing and hiking, and I am used to being very, very physical. It was a big loss. But I find that even now, when I take my walker outside and walk around the yard, I can feel the same physical challenge. The doctor is really amazed that I am able to keep up with my weight training.’

Returning to work is one form of rehabilitation. When you can’t work any longer, or work full-time, you need something to help you feel involved in life and connected with people. It may be writing your family history, meeting regularly with friends or joining a support group. Your hospital should have an occupational therapist who can help you think through the possibilities.

Palliative care

Palliative care emphasises comfort, providing care and support, so that people can live full and comfortable lives even if their disease cannot be cured. Many people think that palliative care is just for the end of life, but it is appropriate at any stage of **advanced cancer**. Palliative care workers are skilled in helping with common physical discomforts, including pain and nausea, but also with other issues, such as the emotional and family problems, which are so common. The emphasis is on family care.

Palliative care services work with the local doctor and with doctors and nurses from the hospital or clinic – they do not take over all the care and treatment decisions. Palliative care involves coordinating the care given by doctors, specialists, nurses, volunteers, social workers and pastoral care workers.

Palliative care regards dying as a natural event and does not prolong treatment when there is no longer any benefit. It does not include the deliberate ending of life.

All Victorians have access to a palliative care service. Your local service can assist you on request. Palliative care can be provided in the home, a hospital or a **hospice** setting. After asking for help from or being referred to your local service by your doctor or nurse, a care worker will visit you and your family and together decide what help you need and want.

Home-based care

Palliative care can be based at home. Services often can include visits from a trained volunteer support worker. If you wish, the palliative care service can be responsible for coordinating all your needs, including medical, practical, social, emotional and spiritual needs.

In general, palliative care services are free. There may be a charge for hire of some equipment for home care.

Hospices and palliative care units

A hospice or palliative care unit is a place that provides day care and longer-term residential palliative care services. It is a place that has hospital facilities but a home-like atmosphere, where specially-trained staff care for people with life-threatening illnesses. A person may go into a hospice to have pain or other worrying symptoms brought under control, to give the person caring for them a break, or to spend their last days or weeks in a suitable environment. Many people go into a hospice for a short time and then return to their home. On average, most people would return to their home after a week or so, or until symptoms are well managed and your family or carers feel confident to resume your care.

When treatment seems too much

Sometimes you will ask yourself if the treatment is worth it.

‘She hadn’t any further wish to be jabbed and scanned or struggle to keep appointments. She simply preferred to enjoy her time with me and inspired her visitors with her carefree determination and religious belief.’

What does quality of life mean to you? Perhaps you would choose **chemotherapy** if it meant you could have two good weeks in each month. Or you might value keeping mobile, being able to spend as

much time as possible with family and friends, without the disruption of treatment.

‘If I were told I had six months, but with a certain treatment I could extend it to one year, first off I would say, “What kind of side effects?” If they say my quality of life would be compromised greatly, I would say, “Forget it.” I have had enough side effects to last me two lifetimes, I wouldn’t want any more. Now that doesn’t mean I would be giving up, far from it. I would be fighting with every ounce of life left in my body.’

- Before you stop treatment, give yourself time to think about it.
- Are you feeling bad from the side effects of the treatment, from advancing disease or from emotional overload? Some or all of these can be treated.
- Talk with others, particularly your doctor and those close to you.
- If you feel uncertain, you can speak to someone less closely involved – a counsellor, social worker or the Cancer Council Helpline – who can help you to weigh up what is best for you.

Responsibility for medical decisions

In the same way that treatment can prolong life, medical intervention can delay death. There can be choices and decisions to be made about continuing treatment. It is difficult to know what you may want ahead of time. Some people have strong wishes and may want to know that these will be respected.

You may also appoint an enduring power of attorney (medical treatment): someone who you trust to make medical decisions for you should you become unable to make competent medical decisions because of illness. You can get information about this from the Office of the Public Advocate, Victoria Legal Aid (see services and information on pages 53–55), your solicitor or social worker.

Refusal of medical treatment

Under Victorian law, you can refuse medical treatment if you wish. Palliative care, including pain relief and the reasonable provision of food and drink, will always be available for you.

For your refusal to be valid, you must fully understand the nature of the treatment proposed and the consequences of not having the treatment. You can refuse each treatment separately – you do not have to accept treatment on an all-or-nothing basis. You can complete a refusal of medical treatment certificate, outlining your wishes, which your treating doctors must comply with.

Voluntary euthanasia

You may think about **voluntary euthanasia** (choosing to die rather than suffer the possible effects of treatment or disease). If an illness is prolonged or is very debilitating, voluntary euthanasia can become an issue for some people.

Sometimes people feel that life is not worth living because of poor control of pain or other symptoms, and some people become depressed because of their illness. Pain and depression can almost always be treated, and help is generally available for other symptoms. It is most important that you talk to your doctor or nurse about any physical or emotional symptoms that are causing you pain or grief, and find out what treatment is available.

A person with cancer may decide that they want their death hastened, but later decide that they don't. At this stage of life, as at other times, pains, fears and concerns can pass, and more accepting or positive feelings take their place.

Voluntary euthanasia is illegal in every state in Australia. Nevertheless, it is something that many people consider when they are seriously ill. Discuss your feelings with your doctor, family, friends, a counsellor or social worker.

Treatment for advanced cancer

This section explains the treatments which can ease the symptoms of advanced cancer or keep it in check.

Chemotherapy

Chemotherapy is the most widely-used treatment when cancer has spread. It is the use of particular drugs to kill cancer **cells** or slow their growth.

Chemotherapy is usually given over a few days, followed by a rest period of two to three weeks. Several courses of treatment are usually given. You should discuss with your doctor which combination of drugs you are having and how long your treatment will last.

Chemotherapy is usually given by injecting the drugs into a vein. This is called intravenous treatment. Other drugs may be given to you as tablets.

Chemotherapy can have side effects, including nausea, vomiting, depression, feeling off-colour, tiredness and loss of hair from your body and head. These side effects are temporary and steps can be taken to prevent or reduce them.

★ **The Cancer Council's booklet *Coping with chemotherapy* discusses ways of managing side effects. Visit www.cancervic.org.au or telephone 13 11 20.**

Surgery

Surgery can remove affected organs and relieve discomfort caused by **tumours** which obstruct organs or cause bleeding. You might be offered surgery on certain organs that haven't been affected by tumours, for example, if they produce a hormone that encourages tumour growth.

Radiotherapy

Radiotherapy treats cancer by using x-rays to destroy cancer **cells**, or injure them so that they cannot multiply. These x-rays can be

precisely targeted onto cancer sites in your body. Treatment is carefully planned to do as little harm as possible to your normal body **tissues**. Radiotherapy can shrink **tumours** or stop them from spreading further. It can also relieve symptoms such as pain from **secondary cancers** in the bones. Since treatment can only be given at a specialised centre, you may have to arrange to stay away from home for this period. External beam radiation or internal radiation (brachytherapy) may be offered.

Radiotherapy can cause fatigue, skin problems, loss of appetite and other side effects. Some are temporary and others may be longer term.

★ **The Cancer Council's booklet *Coping with radiotherapy* discusses ways of managing side effects. Telephone 13 11 20 or visit www.cancervic.org.au**

Hormone therapy

Cancers that grow in response to hormones can often be slowed by taking drugs to suppress the body's production of the hormone. Other hormone treatments interfere with the effect of hormones on tumour **cells**.

If you have prostate, breast or uterine cancer, at some stage you will hear about hormone therapy. These are among the kinder cancer treatments that your body will experience. But they do have side effects.

For women, certain hormonal drugs will promote menopausal symptoms, whatever your age. A class of drugs called the aromatase inhibitors may be used if you are past menopause and these can make you feel slow or sleepy. For men, hormone treatments can produce hot flushes.

Making decisions about treatment

'What you can do, and I believe must do, is learn a lot about the specifics of the case at hand so that you are in a position to make the decisions that need to be made. Doctors may have more information, but they don't necessarily make better decisions.'

To cure a **primary cancer**, it can seem worth undergoing harsh or disfiguring treatments. But when you know cure is not possible, it can seem less reasonable to choose treatments that leave you feeling exhausted or sick.

Some people feel they want to fight on with whatever is available. They visit their **oncologist** with printouts from Internet sites detailing the latest experimental treatments from overseas. Other people want to give it all they have, but prefer to pick and choose among treatments. Perhaps you are not clear about what is best for you, and you want your doctor to advise and help you to decide.

Rarely do decisions have to be made on the spot. Talk it over and take your time.

Talking to your doctor

It can be hard to talk openly with the different doctors you see. You might be concerned about taking up too much time, or your doctor might give the impression of being rushed. But it is essential that you have good, clear, open communication with the doctor treating you. It usually takes time for information to sink in and even more time to think over choices being offered.

'My advice to everybody I have known in a similar situation is to question, question, question and to have the courage to change doctors until the responses begin to feel right.'

One vital point to talk over with your doctor is how, and in what situations, you should contact him or her. When an unexpected problem arises, it can add to your stress to be confused about who you should telephone, and how to do this.

In fact, you should be clear at all times about who's coordinating your care. As you go from one type of doctor to another, you might wonder who is responsible for what. It saves time and trouble when there's one person who keeps track of your situation. This may be your general practitioner, the palliative care doctor, the **oncologist** or any other member of your treatment team that you feel you trust and get on well with.

If you feel that your doctor is difficult to talk to, even after several visits, it is important to tell them. Most doctors want to be able to communicate well with their patients: it helps them, too. However, it can take time to get a good working relationship going. You can help, for example, by preparing a list of the questions you want to ask before your appointments.

'After Colleen had been through five different treatment regimes at three different hospitals, we were referred back to the original oncologist. We knew him now, and felt that he knew us too. What a difference it made. He said more; we said more. He communicated with more feeling, and we felt more like we had a caring friend rather than an unknown, detached medico.'

All patients have the right to seek a second opinion from another doctor. Your specialist or general practitioner can refer you to another specialist and you can ask for a medical history to be sent to the second-opinion doctor. Ask for your x-rays and scans and take them to new appointments.

Taking part in a clinical trial

You may consider taking part in a clinical trial.

Clinical trials are a vital part of the search to find better treatments for cancer. Doctors conduct clinical trials to test new or modified treatments and see if they are better than existing treatments. Your doctor will only discuss a clinical trial with you if the treatments are considered to be as good as or better than the standard treatments.

Many people all over the world have taken part in clinical trials that have resulted in improvements to cancer treatment. However, the decision to take part in a clinical trial is always yours.

If you are considering taking part in a clinical trial, make sure that you fully understand the reasons for the trial and what it means for you. Before deciding whether or not to join the trial, you may wish to ask your doctor:

- What treatments are being tested and why?
- What tests are involved?
- What are the possible risks or side effects?
- How long will the trial last?
- Will I need to go into hospital for treatment?
- What will I do if any problems occur while I am in the trial?
- What can I hope to achieve from taking part in the trial?

If you decide to join a randomised clinical trial, you will be given either the best existing treatment or a promising new treatment. You will be chosen at random to receive one treatment or the other, but it will always be at least the best treatment available.

If you do join a clinical trial, you have the right to withdraw at any time. Doing so will not jeopardise your treatment.

It is always your decision to take part in a trial. If you do not want to take part, discuss the best current treatment with your doctor.

★ The Cancer Council has more information about clinical trials. Visit www.cancervic.org.au or telephone 13 11 20.

Common symptoms

You will be aware of many different symptoms at different times.

Some symptoms are a side effect of treatment, while others are caused by the cancer itself.

Remember that not all symptoms will be related to cancer. Of those that are, it's impossible to cover many in a booklet this size, so here we discuss some common symptoms: nausea, pain, tiredness, breathlessness and lack of appetite. There may be times when you will need immediate advice about any of these that you may be experiencing. For this reason, it is essential that you know which doctor or nurse you can contact at any hour of the day or night for the help you might need.

Nausea

As with any symptom, it is necessary to find out what is causing the nausea before deciding on the best way to deal with it.

Nausea is an unpleasant symptom that can be caused by:

- treatment with **chemotherapy** or **radiotherapy**
- the location of the cancer
- stress or anxiety
- an imbalance in the minerals in the blood, for example, calcium
- drugs that control other symptoms, for example, **morphine** for pain
- a bowel obstruction or blockage
- increased pressure around the brain as a result of cancer in the brain or cancer affecting the fluid around the spinal cord.

Many people talk about anticipatory nausea, the response your body learns and then recalls when you know it is chemotherapy time again. Even much later, there can be a surge of nausea when you're just driving past or walking around the place where you once had chemotherapy.

You do not have to put up with nausea. Tell your doctor or nurse: they will identify the cause of the nausea so the right treatment can be given. Treatments for nausea include:

- adjustment to the diet
- anti-nausea medication taken regularly and before pain medication or in higher doses
- stress reduction techniques
- a drug which lowers calcium levels in the blood
- dry ginger ale or ginger tea. Some people say this helps.

Pain

The great majority of people with **advanced cancer** experience pain, but it is always possible to reduce it or alleviate it completely.

People with cancer do not necessarily experience increasing pain as the cancer progresses. Pain depends on the location of the cancer and its size. If you do experience pain, in most cases it can be controlled. It may take a little time to find the correct pain-control measure.

*** The Cancer Council has an information sheet called *Cancer pain – common questions*. Visit www.cancervic.org.au or telephone 13 11 20.**

Pain management is a specialised field for doctors and nurses. Palliative care services specialise in pain management.

Pain may come and go. It may be worse on some occasions than others or it may be always present. Keeping a record of your pain can help your doctor work out the best way to relieve your pain. Is the pain worse at certain times? Does the pain relief work at all? How bad is the pain? Try scoring your pain on a scale of one to ten, with one being no pain and ten being the worst pain you can imagine. Generally, pain can be controlled.

There are many ways to manage pain, including:

- medications such as **morphine**, codeine and paracetamol
- treating the cause of the pain with **chemotherapy**, surgery and **radiotherapy**, alone or together
- rarely, 'nerve block' procedure is used when targeted medication is not effective.

A combination of these methods may achieve the best results. How and where the pain is felt, and how it affects one's life, can change. Regular reviews by pain-management experts will ensure the best results are achieved.

Each of the main methods of pain management is briefly described below.

Pain-relieving drugs

Pain-relieving drugs (**analgesics**) may be mild, like aspirin or paracetamol; moderate, like codeine; or relatively strong, like **morphine**. Pain-relieving drugs may be taken as tablets, other oral mixtures, suppositories, patches and injections.

Other drugs may also be prescribed, like non-steroidal anti-inflammatory drugs (NSAIDs) and antidepressants.

The doctor will aim to find the right drug, dose, frequency for taking the drug and delivery means (for example, tablet or injection), and aim to control any side effects. This may involve trying one drug at different doses and then trying another drug at different doses.

'There does come a time when common analgesics are no longer sufficient and I found the decision to begin taking morphine on a regular basis very difficult to make. Having made it, I have been taking the slow release morphine tablets for eighteen months with no appreciable side effects. Without the morphine the pain would now be too debilitating for me to continue doing all the things I do now.'

Morphine

Morphine is one of the most common drugs used to control moderate to severe cancer pain. It comes in quick-acting and long-acting forms.

Morphine has been used for centuries as a pain reliever. Unfortunately, morphine has an undeserved reputation, because some people associate it with drug addiction and people often think that morphine is only used for people who are dying.

- A person does not become addicted to morphine if they are taking it to relieve pain.
- Morphine is a very effective pain reliever. It can be taken for a long time, in increasing doses if needed. It doesn't have to be kept for 'when the pain gets really bad'.
- The 'drowsiness' effect of morphine decreases after a couple of days and people can continue their normal activities and be pain free.
- Morphine causes constipation. Regular laxatives can relieve or prevent this.
- Morphine is most effective when taken regularly, even if the pain is not present. It is better to stay pain free rather than wait to treat the pain when it returns.
- Some people cannot tolerate morphine because of side effects such as nausea. Other drugs can be as effective.

A small number of people taking morphine have hallucinations. This means thinking that you see (or sometimes hear) something that isn't real. Hallucinations can be strange and frightening. Tell your doctor if this happens. They will be able to prescribe other methods of pain control.

'I finally came to terms with the concept of being morphine dependent when the oncologist pointed out that nobody thinks that diabetics are drug addicts because they need insulin.'

Chemotherapy, radiotherapy and surgery

Chemotherapy, radiotherapy and surgery are used to cure **primary cancers**. They are also used in **advanced cancer** to reduce symptoms such as pain.

Chemotherapy can sometimes shrink cancer that is causing pain because of the cancer's size and location. Radiotherapy can relieve some symptoms, such as headaches caused by increased pressure in the brain due to brain metastases. When used for symptom control, courses of radiotherapy are usually much simpler and shorter than when treating early cancer. Surgery may be done to improve outcomes from chemotherapy and radiotherapy by reducing the size of the cancer. It may also be used to treat a serious condition, such as a bowel obstruction, that is causing pain.

Tiredness

For many people, extreme and constant tiredness ('fatigue') can be a significant problem. It can be very distressing for the person experiencing it and for those around them. Some people say their tiredness is worse than any pain or nausea they experience.

Tiredness can be caused by a range of things such as:

- spread of the cancer
- cancer treatment such as **chemotherapy** and **radiotherapy**
- poor nutrition causing loss of weight and muscle tone
- anxiety
- not enough sleep
- drugs such as **analgesics**, antidepressants and sedatives
- anaemia
- infection.

Unfortunately, treating tiredness successfully is not as straightforward as treating some of the other symptoms. It can be very difficult

to describe: what one person experiences as extreme fatigue may be simple tiredness for another person.

'It was a strange tiredness ... It was a feeling of being totally drained of energy: as if someone had pulled out the plug connecting me to my power source ... Words cannot describe this tiredness.'

Good things to do when you experience tiredness are:

- Talk about the tiredness to your friends, relatives and supporters: it helps them to understand how you feel.
- Plan to do things at the time of day when tiredness is least severe. Morning is best for many people.
- Plan your activities so that you conserve your energy for the things you really want or need to do.
- Take short naps during the day. Naps allow you to feel better, yet still sleep at night.
- Take gentle exercise, like walking to the letterbox or sitting out of bed for meals. This preserves muscle tone and a sense of normality.
- Have high-calorie, high-protein drinks. This may slow weight loss and help maintain muscle strength.

Tell the doctor or nurse if you become weaker or more fatigued. The cause may be something treatable, like anaemia or a mineral imbalance.

★ **The Cancer Council has an information sheet called *Coping with fatigue caused by cancer treatments*. Visit www.cancervic.org.au or telephone 13 11 20.**

Breathlessness

Some people with **advanced cancer** experience breathlessness. It is likely to be frightening for you if you find yourself feeling breathless at some time. Your breathing rate goes up or you feel you can't catch your breath. Your doctor or nurse should be called and told what is going on.

Treatment will depend on the reason for the breathlessness. You can be short of breath if there is fluid around your lungs. This may need to be drained or medication may be prescribed if there is an infection. Or it could be caused by the cancer itself, scarring from **radiotherapy** or pressure from a swollen abdomen. Asthma or emphysema might be present. Whatever the cause, feeling anxious can make it worse.

While you wait for treatment to take effect, you could make a few simple changes. First, try to relax. Have a fan in the room or open a window and get a draught of air moving near your face. Sit up to ease your breathing or lean forward resting on a table. If you don't own a reclining chair, see if you can borrow one so you can sleep in a more upright position. You may want to practise breathing techniques, alone or with someone else. Try breathing with someone else, especially slowing your breathing. This can be done during a breathless episode and at other times, to practise.

Some breathing problems respond to oxygen, and this is usually available if needed. A wheelchair can help if you want to move around more freely. As well as being useful for pain, **morphine** in small doses is very effective in relieving breathlessness and coughing. It is important to discuss any fears you have about your breathing with your doctor or another member of your treatment team.

★ **The Cancer Council has an information sheet called *Coping with breathlessness caused by cancer or cancer treatments*. Visit www.cancervic.org.au or telephone 13 11 20.**

Lack of appetite

Lack of appetite is a common problem faced by people with **advanced cancer**. It can result from illness, treatment, tiredness, an altered sense of taste, pain, lack of activity, depression, nausea and vomiting.

You may go through phases of not wanting to eat. These phases may last a few days or weeks or it could become the 'norm' for you: you may just be unable to eat the way you used to.

Some ideas that may be useful to promote your appetite are:

- Eat small meals and snacks frequently.
- Use a small plate so a small amount doesn't look lost. Dessert in a wineglass is another idea.
- Eat moist food, for example scrambled eggs, which is usually easier to eat and is less irritating to a sore mouth.
- Add ice cream or fruit to a drink to increase calories and nutrients.
- Drink from a 'half-full' glass. It is more satisfying to empty a half-full glass than only half finish a full one.
- If solid food does not always appeal to you, ask your dietitian if it is okay to have commercially prepared nutritional supplements. These can supplement solid food.
- Lemon juice and salt may give flavour to food when it tastes bland.
- Salads or cold food will help with the nausea that some food smells can bring on.
- You may prefer to sip clear liquids and then follow these with biscuits or something light.
- Avoid fatty foods or heavy, sugary food.
- Try to eat a small amount, regularly, so that your stomach is never quite empty.
- Cold foods are easier to tolerate than hot.
- Eat more of your favourite foods – follow your impulse.
- If you are not eating properly because you have a sore mouth, tell your doctor or nurse. The soreness could be treatable.

* The Cancer Council's booklet *Nutrition and exercise* has more suggestions. Visit www.cancervic.org.au or telephone 13 11 20.

Tell your doctor or nurse if you are constipated. Constipation is a common cause for lack of appetite and nausea, and is often made worse by strong pain killers.

Speak to a dietitian with a special interest in cancer – ask your doctor, your hospital or the Cancer Council Helpline.

'After being introduced to some exciting new tastes, we were determined to continue healthier eating when we returned to Sydney. But on our drive home it proved nearly impossible to get a lentil burger in Goulburn on a Sunday!'

Alternative treatments

Complementary therapies

Complementary therapies can be useful in increasing your sense of control over what is happening to you, reducing your feelings of helplessness, decreasing stress and anxiety and improving your mood. Some complementary therapies may reduce the amount of medication needed for pain control.

'Prayer and meditation have become part of my coping strategies. I have tuned in to my need to explore my sense of the spiritual. This was blocked out before I had cancer because it was something I thought I might get around to but was always too busy.'

Some people find that meditation and other relaxation techniques can be calming and sometimes helpful in easing pain. Yoga, t'ai chi and guided imagery could also take you out of the stresses of the moment. Massage, too, can be a great release, but find out from medical staff if there are areas of your body that shouldn't be touched. Hypnotherapy is another technique that can help to relieve anxiety and deal with pain.

Complementary therapies can be part of a coordinated pattern of treatment. For example, **palliative care treatment** can be arranged to include complementary therapies.

'I had a series of tapes made for me by a hypnotherapist which I use regularly on a daily basis. I have also supplemented her treatment with that of another hypnotherapist. Both of them have slightly different approaches. I enjoy this kind of therapy because I feel that I am the one who is in charge.'

Most complementary methods will cost money. You could enquire at your nearest community health centre to see what they offer free of charge or for a small fee per session. If you use a private practitioner and have private health insurance, check with your health fund to see if there is a rebate for the service.

Let your doctor know if you plan to use complementary therapies. It will help them to understand your needs and advise you how to avoid any adverse interactions.

Unproven remedies

Some people, on hearing that their cancer has spread and cure is unlikely, turn away from regular medical treatment, feeling that it has failed them. You may think about trying an unproven remedy, especially if it seems to offer a 'cure'.

Unproven remedies are treatments that have not been tested in clinical trials or scientifically proven to be effective. Many are promoted in books or through the Internet to people with cancer. They include magnets, diets from which a whole food group is removed or a supplement or supplements added, coffee enemas, fresh cell therapy, microwave therapy, oxygen therapy and laetrile and other plant products.

Some unproven remedies are harmful, for example taking high dose vitamins while having some **chemotherapy** or eating a diet that takes out foods that are important for your health and wellbeing. Unproven remedies:

- can be very expensive
- sometimes require you to travel to other countries or interstate
- generally waste time, money and energy
- can be physically stressful
- often require major changes in lifestyle.

Some people spend a lot of time and money pursuing unproven remedies which turn out not to work. Afterwards, they often regret the time they lost.

Sometimes practitioners of unproven remedies make people feel guilty when their treatment doesn't work. This is unjustified and unhelpful, and a clear sign that you should not continue with that practitioner.

Question all information you read or are given about cancer 'cures'. Whether it comes from a medical practitioner or a practitioner of unproven remedies, ask questions, verify claims, seek supporting information and be sure that the practitioner is qualified and trustworthy. One or two books by people who deliver a certain treatment is not strong evidence. Look for articles in recognised medical or scientific journals. Recognised medical journals are listed in PubMed, an international database of biomedical journals.

★ **The Cancer Council has a booklet *Complementary and alternative cancer therapies*. Visit www.cancervic.org.au or telephone 13 11 20.**

Let your doctor know if you plan to use unproven remedies. It will help them to understand your needs and to advise you how to avoid any adverse interactions.

Death and dying

This section is written for people who know that their time is limited by cancer and want some ideas or strategies to reflect on and turn to for their own use.

It is quite common, and very human, to avoid talk of death and dying. If that is how you feel, leave this section until you feel ready.

Talking about death

There will be times when your morale slumps, you feel terrible – physically and emotionally – and you wonder what it is all about. At other times, you may feel optimistic about your situation. Talking about these feelings may be hard, for you and for the people you are talking to. It will be especially hard for the people who love and know you best. They will need time to adjust.

People with **advanced cancer** mention two different positions that friends can cling to – regarding them as already dead, or refusing to contemplate the possibility.

‘People saying, “You’ll get well” makes me really cross. I know I won’t be well. I want to say to them, “I am going to die and don’t you dare deny me this business of dying”’

You may come to terms with your situation faster than those who love you. While your family and friends adjust, it might help to share your feelings with the doctors, nurses or others who are looking after you. You may find comfort in discussing death and dying with a minister or spiritual figure. They are generally experienced and accepting of being with people at this stage of their lives.

How long have I got?

‘It was like appearing in court expecting a death sentence and discovering the judge didn’t want to commit himself.’

You might find your doctor is not precise about how long you have to live. They can only estimate, based on the life expectancies of people with a similar cancer at a similar stage to yours. But if it is important for you to have an estimate, say so.

It is likely to be tough if you are told that time is short. Even if it is only a matter of weeks, though, there can be a real change in how you feel. Your mind and feelings may become focused and you may find yourself making decisions about things that are important to you. Getting over that point when you first realise that death could come soon is likely to be one of your biggest challenges.

‘The doctors said, “You haven’t got much time. Do what you have to do, do what you want to do”. Suddenly they were talking weeks not months. That was a very difficult time. At night I wouldn’t know if I was going to wake up. I didn’t know when somebody left if that was the last time I’d see them. I made very certain everybody knew how important they were to me. I wanted people to feel free and released from any unfinished business between us.’

You can feel uneasy or unsettled if you live past the expected time, not quite knowing what you should do now.

‘Last year I was living thinking I was dying, making the most of it, not planning anything for the future. In a funny sort of way it was quite easy. You can plan to die. This year is different. When I kept on living it was a problem. What on earth is this for?’

'I'd made a will and left money for my cat to be looked after. I'd given away all my Led Zeppelin records. Now the cat's dead and I'd really like to play one or two of those pieces.'

Facing death

Many of us have no fixed ideas about death until we are faced with the reality of it – our own or that of someone close to us. Even people who believe in an afterlife can find that they have not thought much about dying itself.

'When I was told, "You're going to die," it made me ask myself what dying means. I decided nobody really knows, nobody sends you a postcard from Heaven to tell you what it's like.'

Where do you go for help in sorting out your feelings about this new stage of your life? Facing death means leaving people, places and things you hold dear. It is natural to grieve for their loss. And it is natural to want to share your hopes and fears with an understanding listener.

When talking things over, you may find there is more to dying than grief and loss. There can be a positive side to preparing for your death, getting yourself ready in both your inner and outer lives. People living with **advanced cancer** say how important it is to say farewell to people – work colleagues as well as family and friends.

The good death

You may wonder about the big questions now: What are life and death all about? Where am I going? How much of me will stay behind with the people I love – the ones who have loved me? If you have children, particularly if they are young, this last question is something you will struggle with.

'I remember Fred saying he hoped he lived long enough so the twins would remember him.'

People who work with the dying say that pain in mind and body can be lessened when these fears and hopes are talked about: to hospital staff, family or friends. However hard it can be to find the words, these concerns are central to the human experience. Conversations about them can be a precious memory for those involved. If you wish, hospital or hospice staff will be able to arrange for someone of your faith to visit you.

Trust yourself to do it your way when the time comes, but make sure that you have the help you need. This means talking to your doctor or nurse about what will happen and what your wishes are.

Perhaps you want your doctors to know your wishes about **resuscitation**.

If you have precious last messages for people, you can make a point of passing them on now. That way, there is a chance for dialogue – time for people to listen and respond.

If you have children and feel that you haven't passed on all you know, you can consider making a 'moral will' – a letter or tape telling them what you think it is important for them to know. If your children are very young, they will understand your words when they are older. Some people like to make keepsakes for their children. Your social worker will be able to help you with this.

Remember, there is no 'right' way or place to die. You and your family will go through it in your own way when the time comes.

'Mrs Keith, twenty-five kilos, propped up, cheaply wigged, knitting a jumper for her daughter and planning a trip to England at four in the afternoon of the night she died, talking of her family too, glowing tales of their achievements.'

When people know their death is not far off, one of the things they often say is, 'I don't mind dying but I don't want to suffer.' Some people feel this so strongly that they want things sped up – they don't want to wait around feeling helpless and in pain. If they can talk this over with a doctor or a spiritual adviser, they will often change their minds and come to see every day as precious. So if this is how you feel, tell your doctor or nurse. They will talk to you about what is likely to happen and what can be done to ease your final days.

Sometimes people approaching death fear going to sleep, in case they don't wake up again. This is usually unwarranted and is something to discuss with your doctor or nurse.

Pastoral care workers are part of palliative care teams. They are trained to discuss spiritual issues, whatever your religion, or if you are atheist or agnostic and wish to discuss life's meaning.

What is it going to be like?

As you approach death, you may become unconscious. Some people lapse into and out of consciousness and are able to talk at times to people around them. Some people stay alert almost until the end.

If you are unconscious, the people around you will see and take notice of things that you may not be aware of. Your breathing will sound different and your appearance will change. It may seem to the people watching that it is an effort for you to breathe, but we do not know whether dying people experience it as an effort.

Death is as much a process as an event, so your body will 'shut down' bit by bit. It seems that hearing is the last sense to go (although we cannot be sure about this). With this in mind, the people caring for you will tell you what they're doing – for example, turning you on your side to make you more comfortable, and moistening your lips.

'When patients ask about the dying process, I describe it as the physical and emotional experience of gradually becoming weaker and letting go of their attachment to living.'

No one really knows how a dying person experiences the moment of death. We each imagine it differently. Some people see it as a moment of release from suffering and care; others imagine falling into a blissful sleep. People with religious faith look forward to the time after death, when they will reach Heaven or Paradise. Some people believe that their 'life force' will leave their body and become a part of a greater life force. Perhaps death is the last and greatest experience of them all.

**'You lay there
Not so much sleeping as leaving
Many of those who loved you
Stood or sat around you ...
That fearful tearful moment was not far away
Yet
The room was alive with love
Pain had succumbed to peace
Ending surrendered to beginning.'**

Hospital, home or hospice

'When the inevitable comes, I'd rather be home with the kids.'

Lots of people prefer the idea of dying at home. With the help of a palliative care team and family or friends, this may be possible. Even if you live alone, you can plan to stay as long as possible in your own home.

Still, there may be reasons why you can't. You may have medical needs that only a hospital can meet or live in an area too remote for

home visits. Housing can be unsuitable, perhaps with stairs or small bathrooms. Or as your cancer advances you may need to be in the more secure environment that a hospital or **hospice** can provide.

When you die in your own home, those close to you can say their farewells in their own time. This is often the case in hospitals, too, where you may rest in a private area where people can stay as long as they wish.

‘I felt very privileged and pleased to be able to fulfil her last wish of looking after her at home and letting her die peacefully in our bed.’

Making a will

A will states what is to happen to a person’s belongings when they die. For those left behind, a will simplifies matters, especially if a person leaves assets such as property or money. A will also helps to ensure that ‘special things’ are given to the right people after death. If you made a will before your cancer diagnosis, you may wish to review it to make sure it reflects your current wishes.

‘The oncologist told us that there was no more treatment for Bill. He said we should go home, write a will and then do whatever we wanted – enjoy ourselves. We already had a will, but we rewrote it to say who should be guardians for our children if something should happen to me as well.’

For a person with young children, the will states who is to become guardian of the children and how the children will be provided for. You may also want to say in your will who is to look after your pet or pets and how their care will be paid for.

Alternatively, you may like to try a do-it-yourself will, especially if the division of assets is straightforward. Will kits are available from legal stationers and at some newsagents. If you live in a city there may be a community legal service that can assist. Other alternatives include a personal solicitor or a trustee firm. If your assets are substantial, or the division of them will be complex (for example, if any important relationships are not fully recognised by the law), it is advised that you seek the assistance of a solicitor or trustee firm. Ask about the cost involved first.

Planning the funeral

‘I’m planning my funeral to have the music I want. It is the music that has been a special part of my life. I also intend to leave a tape to be played at the service – they haven’t heard the last of me. My two closest friends are going to have something to say about my life – warts and all. I hope my funeral will be a celebration of life.’

You can plan your own funeral if you wish. This means it will be conducted as you want it to be conducted. Also, your family will not have to try to guess what you would have wanted.

You can lodge a plan with the funeral company of your choice well before it is needed.

If you feel you need to make preparations but you can’t do the work, or prefer not to, consult a social worker or pastoral care worker who will help you work out what you can do.

It is probably not easy for most of us to hear or think about the reality of what is involved in funerals. However, there can be a satisfaction in leaving your mark on the occasion, and also involving your family beforehand.

'I didn't know Penny very well. She was dying when I joined the support group and I didn't realise. I missed the meeting when she came to say goodbye. I was awed when I heard that her kids decorated her coffin in their garage while she was still alive.'

Living well, dying well

Whatever your belief is about what happens after death, you can make the most of the time you have now. A palliative care doctor suggests: 'Maintain purpose for living and express feelings. Don't aim to stay alive, but to live.'

'Keep planning and setting goals, however small or big. Keep your mind active. I'm always planning for the next thing: someone to love, something to do, something to look forward to.'

There are positive things you can do, for yourself and for those close to you. If you have strategies to get you through the more difficult situations, you'll have a sense of being in control of your life. For example, if you live alone, you could call on home help and palliative care services sooner rather than later.

The aim is to feel free to do whatever you can. That might be something big like travelling. Or perhaps it is just enjoying small things in your daily life, even if this is no longer an active one. Being able to live in the moment is a gift, but it can also be learnt. Whether the moment is especially good, utterly ordinary, or even painful, you can live it to the full.

Services and information

A brief listing of some of the major services available in Victoria.

Information & support for people with cancer and carers

Cancer Council Helpline

The Cancer Council Helpline is a service for people with cancer and their carers, friends and relatives. Telephone 13 11 20.

Cancer Support Groups

The Cancer Council Helpline can refer you to a Cancer Support Group in your area. Telephone 13 11 20.

Carers Advice Line

The Carers Advice Line provides information and support for people caring for people with illness and disability. Telephone 1800 242 636.

Care Ring

Care Ring can provide information, counselling and referral for people with health- and family-related problems. Telephone 13 61 69, 24 hours, Monday to Friday.

Grief Line

Grief Line offers support to people who are experiencing grief as a consequence of a significant loss in their lives. Telephone 9596 7799.

Home visitors

DoCare (see the White Pages for the service in your region) and the Australian Red Cross (8327 7700) can organise home visitors. Other charitable organisations may be able to help, as may a cancer support group. For information, telephone 13 11 20.

Lifeline

Lifeline provides information, counselling and referral for people with personal problems. Telephone 13 11 14, 24 hours, seven days.

Living with Cancer Education Program

A course for people with cancer and their families and friends, held at hospitals and community organisations throughout Victoria. Ask your hospital's social worker for details or contact the Cancer Council Helpline on 13 11 20.

Social and pastoral care workers

For information, support and advice, contact your hospital and ask for the social worker or patient services unit. Your local community health centre may also have a social worker on staff, or be able to refer you to a social work service. Pastoral care workers are able to discuss practical and spiritual concerns (from all religious and atheistic viewpoints). Contact your hospital, hospice or palliative care service.

When Cancer Won't Go Away Forums

A free forum for people with **advanced cancer** held at community organisations throughout Victoria. Covers topics such as finance and legal issues, treatment options, clinical trials, support services and family issues. Call the Cancer Council Helpline on 13 11 20 for more details.

Financial, legal & practical services

Australian Funeral Directors Association

The Australian Funeral Directors Association can provide a listing of funeral directors and estimates of funeral costs. Telephone 9859 9571.

Cancer Council

The Cancer Council's Welfare Grants Program can provide financial assistance for people with cancer. Telephone 13 11 20.

Centrelink

Can provide information on Commonwealth Government disability, sickness and carers payments. Telephone 13 27 17.

Legal advice and information

If you have one, see your solicitor. If you do not, contact the Law Institute of Victoria's Legal Referral Service, telephone 9607 9550. You can also contact Victoria Legal Aid on 9269 0234 or 1800 677 402 (country callers) or visit www.legalaid.vic.gov.au

Local councils

Local councils provide a range of community and in-home services, including foster care for children, meals on wheels, housekeepers and **respite care**. Telephone your council (the White Pages).

Office of the Public Advocate

The Office of the Public Advocate can help with information about enduring power of attorney. Telephone 1800 136 829 or visit www.publicadvocate.vic.gov.au

Palliative, hospice and respite care

Palliative Care Victoria

Palliative Care Victoria provides information about palliative care and hospice facilities and services. Telephone 9662 9644.

Royal District Nursing Service

The Royal District Nursing Service provides care to people with terminal illness in their own home and advice and support for family and carers. Telephone 9536 5222.

Respite care

Your local council can tell you about services available in your area. Telephone your council (listed by council name in the White Pages). Your local palliative care group or hospital social worker will also be able to advise you.

Glossary

Most of the words listed here are used in this booklet, others are words you are likely to hear used by doctors and other health professionals who will be working with you.

advanced cancer Secondary/metastatic and primary cancer that is unlikely to be cured.

anaesthetic A drug given to stop a person feeling pain. A 'local' anaesthetic numbs part of the body; a 'general' anaesthetic causes temporary loss of consciousness.

analgesics Drugs that relieve pain.

carer A person who provides physical and emotional support to someone who is ill or disabled.

cells The 'building blocks' of the body. A human is made of millions of cells, which are adapted for different functions. Cells are able to reproduce themselves exactly, unless they are abnormal or damaged, as are cancer cells.

chemotherapy Treatment of cancer with drugs that destroy cancer cells or prevent or slow further growth.

hospice A place which provides comprehensive care for people with incurable disease. This includes inpatient medical care, respite care and care of the dying person if they are not able to die at home. Hospices also offer day care facilities and home visiting teams.

lymphatic system The lymphatic system is part of the immune system, which protects the body against 'invaders', like bacteria and parasites. The lymphatic system is a network of small lymph nodes connected by very thin lymph vessels, which branch into every part of the body.

metastases Also known as 'secondaries'. Tumours or masses of cells that develop when cancer cells break away from the original (primary) tumour and are carried by the lymphatic and blood systems to other parts of the body.

morphine A strong and effective pain reliever which is used commonly to treat people with cancer who have pain.

oncologist A doctor who specialises in the study and treatment of cancer.

palliative care treatment Treatment which aims to promote comfort, relieve symptoms and maximise quality of life, when cure is no longer possible.

primary cancer The original cancer. At some stage, cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

prognosis An assessment of the course and likely outcome of a person's disease.

radiotherapy The use of radiation, usually x-rays or gamma rays, to destroy cancer cells, or injure them so that they cannot multiply. Radiation can be directed at a tumour from outside the body, or a radioactive source may be implanted into the tumour and its surroundings.

respite care Alternative care arrangements which allow the carer and person with cancer a short break from their usual care arrangements.

resuscitation The process of reviving someone who appears to be dead, for example by heart massage or artificial respiration.

secondary cancer Cancer metastases.

tissue A collection of cells.

tumour A new or abnormal growth of tissue on or in the body.

voluntary euthanasia Choosing to die rather than suffer from the possible effects of treatment or disease.

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Cancer information in other languages

خط معلومات السرطان باللغة العربية
 إتصلوا بالخط
 للتحدث الى ممرضة عن مرض السرطان
 باللغة العربية على لرقم **9209 0160**

Polskojęzyczna Infolinia na Temat Raka
 Aby móc porozmawiać z pielęgniarką na temat raka w języku polskim należy dzwonić pod numer **9209 0165**

廣東話癌症信息專線

Информационная линия по раковым заболеваниям на русском языкеЕсли вы хотите поговорить по-русски с медсестрой о раковых заболеваниях, то позвоните по номеру **9209 0166**

用廣東話與護士談論癌症
 請致電 **9209 0161**

Ελληνική Γραμμή Πληροφοριών για τον Καρκίνο
 Για να μιλήσετε σε μια νοσοκόμα σχετικά με τον καρκίνο στα Ελληνικά, τηλεφωνήστε στο **9209 0162**

Línea telefónica de Información sobre el Cáncer en el Idioma Español
 Para hablar con un(una) enfermero(a) en español llame al **9209 0167**

Linea Informazioni sul cancro in italiano

Đường dây Chỉ dẫn về bệnh Ung thư bằng tiếng Việt

Per parlare del cancro con un infermiere in italiano chiama il **9209 0163**

Nói chuyện với y tá về bệnh ung thư bằng tiếng Việt, gọi số **9209 0168**

普通话癌症信息专线

若要用普通话与护士讨论癌症
 请电 **9209 0164**

For other languages please call 9209 0169. Tell us which language you speak and an interpreter will help you talk to a nurse. To speak to a nurse in English, call 13 11 20.

INTERNET: For information in a range of languages please visit our multilingual website at: www.cancervic.org.au/other_languages



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