

Life, Hope and Reality



For people living
with advanced cancer



**Information for people with
advanced cancer, their families,
caregivers and friends.**

CONTENTS

INTRODUCTION

Purpose of <i>Life, Hope and Reality</i>	6
About cancer	9

1. PHYSICAL NEEDS

Always tired?	16
Can't sleep?	18
Worried about pain?	20
Trouble breathing?	24
Experiencing bowel problems?	25
Feeling sick?	30
Lost your appetite?	32
Trouble getting around?	34
Considering further treatment?	36
Looking for other treatments?	38
Sick of hospitals?	41

2. EMOTIONAL NEEDS

Feeling anxious?	46
Feeling depressed?	47
Lost hope?	48
What about intimacy and sex?	49
What about dignity?	50
Not thinking clearly?	52

3. SOCIAL NEEDS

Social support	56
Relationships	57
Talking to family and friends	58
Talking to health professionals	60
Cultural differences	62
Language barriers	62
Spirituality	64

4. LIFESTYLE

Diet	68
Exercise	71
Work and leisure	72

5. FINANCES

Costs and expenses	78
Paying the bills	79
Caregiver benefits	80

6. END OF LIFE

Advanced care planning	84
Other decisions	85
Making a will	86
Organ donation	87
A desire to die	89

7. THE PEOPLE WHO CARE

Physical health	94
Mental health	95
Social effects	97
Financial effects	97
Access to information	98
Effect on families	100
Practical matters	100

8. PALLIATIVE CARE

What is it?	106
Where is it provided?	106
Who provides it?	106
When and why should I use it?	109
How much will it cost?	109
Is it right for me?	110
How do I get access to care?	110

USEFUL SELF ASSESSMENT TOOLS

Needs Assessment Tool – P & F	116
Symptom Distress Scale	124
Fatigue Scale	126
Pain Assessment Tool	130
Emotion Thermometers	133
Helpless/Hopeless and Fighting Spirit Scales	135

REFERENCES	137
------------	-----

GLOSSARY	140
----------	-----



INTRODUCTION

Purpose of *Life, Hope and Reality*

Progress in cancer screening and treatment have resulted in an increase in the number of people diagnosed with cancer and the number of people who live with it for longer periods of time. For some, following intense treatment, the cancer may be cured, whereas for others it can spread or come back. This means that some individuals live with the disease for many years.

The purpose of this booklet is to provide information about the needs that people with advanced cancer may be experiencing and key strategies to help in managing these. It also provides information about other resources and services for further support, if needed.

This booklet draws on the many information resources that already exist for people with advanced cancer, including those available from state based Cancer Councils. It aims to bring this information together into one resource and presents key take-home messages. This booklet integrates the most recent research evidence, as well as experiences of people with advanced cancer, their family, friends and health professionals. This may help you, and your family and friends, manage some of the challenges imposed by an advanced cancer. We hope that this information will assist you to live as well as possible.

Cancer comes in many different forms, with many different treatments and the same cancer can affect people differently. You will find responses to some common questions and concerns throughout this booklet and although no single answer will cover every need you may be experiencing, this booklet may help you identify your needs and provide some information about where you can go to obtain additional care and assistance.

This booklet is not meant to replace the information given to you by your health care providers; rather it is designed to complement their advice and suggestions.

How to use *Life, Hope and Reality*

Depending on your needs, you may decide to read this booklet from start to finish or refer only to the sections that are most relevant to you. Certain sections provide information that your family and friends may find useful as well.

In reading this booklet, you may uncover issues you may not have discussed with your health care team. **The Needs Assessment Tool – Patients & Families (NAT-P&F)** is a short guide included on pg 116 to help you and your family and friends identify some of these issues. It will guide you to where to find information in this booklet which may help, or allow you to flag the issues of concern to be raised with members of your health care team.

Feel at ease to complete **The Needs Assessment Tool – Patients & Families (NAT-P&F)** and take it to your health professionals. Together you will be able to discuss areas where you and your family may need help, and where to find that help.

Complete this Needs Assessment as often as you think is necessary. The health professionals you discuss these issues with may vary along your cancer journey; it may be a doctor (doctor or specialist), a nurse, a naturopath, a dietician, a social worker, a psychologist or others and these tools may help them identify what you need. Your symptoms and needs may also change over time, so it is important for you and your team of health professionals to reassess your needs regularly and adjust your care plan to ensure you are as well and as happy as you can be.

We have also included at the end of this booklet other assessment guides which are sometimes used by health care providers to better understand your needs and symptoms.

Many are available and we have only included the following few:

Page 124: Symptom Distress Scale may help you identify some of the physical symptoms you are experiencing.

Page 126: Fatigue Scale may help you to identify the level of fatigue you are experiencing.

Page 130: Pain Assessment Tool may help you better identify any pain you are experiencing.

Page 133: Emotion Thermometers may help you identify some of your emotional needs, including distress, anxiety, depression and anger.

Page 135:

Helpless/Hopeless and Fighting Spirit Scales may help you further identify some of your specific emotional needs, particularly if you feel like giving up or think nothing else can be done.

This booklet, including the assessment tools provided, recognise that your needs may not be limited to the disease itself and can include a broad range of issues such as emotional support or financial guidance.

This booklet also includes suggestions about where you or your health professional may find more information about available local services to meet your needs.

Throughout this booklet key points are emphasised in boxes labelled **Facts, Question and Answer (Q&A) and Tips**. These are meant to further explain important issues and provide strategies to help you manage.

As you read this booklet, if there is a word you do not understand, please consult the glossary on pg 140.

Where to go for help

Your doctor or relevant members of your multidisciplinary health care team (your oncologist, surgeon, specialist, nurses, social workers or other health professionals) should be the first ones you call on for any concerns.

In general, specialists should be able to help with matters related to your cancer. You may find that the health professional you are closest to, such as the nurse or social worker, may be the best person to speak to about other personal and social concerns. If you are not sure, ask your doctor about where you might find the support you need.

If you are looking for further information on local support services, your community health centre may be able to help with suggestions and contacts.

Another helpful resource is the **Cancer Council Helpline** (phone 13 11 20 anywhere in Australia at the cost of a local call), where experienced professionals provide free confidential information and counselling and can put you in touch with other services.



The **Commonwealth Carelink Centres (Freecall 1800 052 222)** provide information for older people, people with disabilities and ill health as well as those who undertake a caregiver role. Further information on these services and others, is provided throughout this booklet.

Your doctor and community health centre should have information on local palliative care services (for definition of “palliative care” see Glossary on pg 140). In Chapter 8 of this booklet, you will find details about palliative care and how palliative care services can support you and your family.



FACT

It is a common misconception that palliative care is the “last stop” for people with advanced cancer. In fact, palliative care staff and specialists can help you and your family at any stage of your illness after curative treatment, especially given their training and experience in helping people with a wide range of needs and concerns.

About cancer

What is cancer?

Cancer is the abnormal growth of the body’s cells, caused by damage to the genes that control the cells’ growth and regeneration. This damage may be environmental, inherited or both.

Abnormal cells may grow into a lump called a tumour which may be benign (localised and non-cancerous) or malignant (cancerous and capable of spreading to other parts of the body).

Cancer usually starts as a tumour at a “primary” site (main tumour site). It may be contained there, or it may spread to surrounding tissue via the lymphatic system or blood stream. Cells that move to other parts of body and grow into new tumours are said to have metastasised, creating “secondary” cancers.

In some cases, a new cancer may appear after a primary cancer is cured.

Cancer is said to be “advanced” when it reaches the point where treatment is unlikely to eradicate the abnormal cells. At this stage, the disease may progress, or it may be controlled but chronic. People can live for many years with advanced cancer.

Types of cancer

Cancers are named after the part of the body where they start. A secondary cancer is still labelled as the original cancer, even though it has moved to a different spot.

- Bone
- Breast
- Central nervous system (brain, meninges, spinal cord)
- Gynaecological (ovaries, cervix, uterus, vulva, vagina, endometrium)
- Head and neck (tongue, mouth, salivary glands, oropharynx, nasopharynx, nasal cavity and larynx)
- Leukaemia (bone marrow)
- Lower gastro-intestinal (colorectal or bowel)
- Lung
- Lymphoma (lymphatic system)
- Prostate
- Renal and urinary tract (kidney, bladder, urethra, renal pelvis)
- Skin
- Testicular
- Unknown primary site
- Upper gastro-intestinal (oesophagus, stomach, small intestine, liver, gallbladder and pancreas)

The five most common cancer sites in Australia are: prostate, colorectal, breast, melanoma and lung cancer.

Tests for cancer

Cancer can be detected and monitored using a combination of tests, including:

- **Visual monitoring** – changes to the body, such as lumps, irregular discharges or bleeding, pain or soreness, skin changes, unexplained weight changes.
- **Blood and/or urine tests** – looking for indicators that something abnormal is happening in the body. For instance, a Prostate Specific Antigen (PSA) blood test can be used to screen for and monitor the progression of prostate cancer.
- **X-rays or ultrasound** – may reveal tumours in certain parts of the body.

- **Biopsy** – tissue samples taken from “suspicious” lumps (using surgery, fine needles or scopes) and tested for cancer.
- **MRI (Magnetic Resonance Imaging)** – a magnetic field and radio waves used to get images of inside the body that x-rays cannot capture (eg. soft tissue).
- **CT (Computerised Tomography) scan** – medical imaging using x-rays and computer technology to create multi-dimensional “photographs” of structures inside the body.
- **PET (Positron Emission Tomography) scan** – medical imaging involving the injection of small amounts of radioactive material, which shows areas of fast cell growth.

Treatments

Cancer can be treated using several conventional therapies. Non-mainstream or complementary therapies are also available, depending on the progression of the disease, these treatments may focus on curing or relieving symptoms.

Conventional medical therapies include:

- **Surgery** – to remove or reduce tumours.
- **Radiotherapy** – using x-rays to destroy cancer cells.
- **Chemotherapy** – using drugs (taken orally or intravenously) to destroy cancer cells.
- **Hormone therapy** – decreasing or increasing hormones that affect cell growth.
- **Immunotherapy** – using substances to encourage the immune system to fight cancer cells.

Complementary therapies, such as massage or herbal medicine, may also be used to treat cancer. Often these are used in tandem with conventional treatments. Some people also choose to try alternative methods (eg. microwave therapy), which tend to be less orthodox.



FACT

It is very important that you discuss any complementary or alternative therapies you are using with your health professional, as some of these are known to negatively interact with conventional therapies.

Sources: Cancer Australia, NSW Cancer Council, Better Health Channel (Victorian Government)

Personal Notes

A blank, lined page for personal notes. The page is white with light blue horizontal ruling lines. The top of the page is rounded. The page is part of a notebook with a blue cover, visible at the edges.



1. PHYSICAL NEEDS

You may be wondering: What will happen to my body? How well or unwell, will I feel? These are obvious concerns for people with advanced cancer. Nobody can say for sure how your body will respond to the physical challenges imposed by an advanced cancer and its treatment. Some people experience many symptoms, whereas others experience few, if any.

At the end of this booklet a needs assessment tool is included to help you identify and communicate with your health professionals about your physical and other needs.

Here are some of the symptoms often reported by people with advanced cancer and, where possible, some suggestions for coping with them.

Always tired?

Fatigue is the most common symptom in people with advanced cancer.¹ This is not normal tiredness. The fatigue associated with advanced cancer can range from feeling tired to being absolutely exhausted.⁸³ As well, cancer related fatigue is less likely to be relieved by rest or sleep² and it can disrupt everyday life.³

Cancer related fatigue may result from the sheer duration of your illness, stress and anxiety, treatment or its side-effects, lack of appetite and therefore nourishment or additional medical conditions (eg. cardiac disease). Other symptoms such as ongoing pain, vomiting, diarrhoea and breathing difficulties can also lead to fatigue.

When fatigue is related to treatment, it will often vary according to when you receive chemotherapy or radiotherapy. It is normal to feel most fatigue a few days after chemotherapy, whereas fatigue may peak several weeks after radiotherapy. Typically, fatigue will decrease after that, but it may persist for some time after treatment.⁸³

Regardless of its cause, fatigue may make you emotional and impatient, which can test your relationship with family and friends. You may also find that you no longer enjoy what you do, that you want to isolate yourself from friends and family and that you have trouble thinking, speaking or making decisions.

Some specific signs of cancer-related fatigue include:

1. Feeling much more fatigued than usual, feeling like you have less energy or needing to rest often.
2. Feeling weak or feeling like your limbs are just too heavy.
3. Not being able to concentrate or pay attention as much as you used too.
4. Not finding pleasure or not being interested in your usual activities.
5. Having difficulty sleeping (insomnia), or sleeping too much (hypersomnia).
6. Not feeling as rested as you would expect after a good night's sleep.
7. Finding it really difficult to overcome inactivity.
8. Feeling upset because you are always fatigued.
9. Having difficulty completing your daily tasks.
10. Perceived problems with short-term memory.
11. Feeling unwell for several hours after activity.

Fatigue is a very subjective experience, which means that only you really know how it feels and you may find it difficult to describe your fatigue to others. You can complete the fatigue assessment guide included at the end of this booklet to help you communicate with your family, friends and health care providers about fatigue.

What may help

Talk to your Doctor

Write down what you want to tell you doctor:

- When did the tiredness begin?
- How long have you been experiencing tiredness?
- What have you done to try to manage tiredness? Was this helpful?
- What seems to make you more fatigued?
- Are there particular periods in the day where you feel more fatigue?

Tell your doctor how the fatigue is affecting your daily life and how it is making you feel

Write down what you want to ask your doctor:

- What may be causing your fatigue?
- When is fatigue expected to peak after treatment?
- Will it get better after that?
- What might relieve it?
- Who can help?

Many people think nothing can treat tiredness so they don't mention it.⁴ In fact, your doctor may have some suggestions or medicines that may help you.⁵ He or she may look at how other things – such as medications, eating or sleeping, other symptoms or separate medical conditions – could be affecting you.

Naps

Small naps during the day will not take away the tiredness² but they may boost your energy and help you sleep better at night. Try not to nap in the late afternoon or evening if you aim to get a good night's sleep.⁶

Also try to make the most of your rest at night by going to bed and waking up at a similar time each day and avoid stimulants such as caffeine before bed.⁶

The next section presents strategies to promote a restful sleep.

Planning and adapting activities

You will enjoy your activities more if you plan them for the times you know you will be least tired⁷ – morning seems to be best for most people.

Vary your activities and alternate your rest and “play”. Try to do things just before meals, for instance, and rest after them. It is normal if it takes you longer to do some activities or if you ask for help to complete them (eg. housework).



- Use your energy for the things you enjoy the most and find rewarding. Avoid using a lot of energy on unnecessary activities. It is OK to leave some things out.

Exercise

Regular light exercise, such as walking, can help with fatigue during cancer therapy or following treatment.^{6, 8-10} Do not forget to rest though. There is no “best” type of exercise,⁶ but your physiotherapist, occupational therapist or doctor may help you decide what, and how much exercise will suit you.

Control other symptoms

Other symptoms sometimes contribute to feeling fatigue (eg. pain); it is important that these are properly managed. For more information on some of these other symptoms, please refer to chapters later in the book.

For more information

Try the information on the following websites:

- Cancer Council Victoria: Fatigue & Cancer Treatment: www.cancervic.org.au
- Cancer Council NSW: Living with Advanced Cancer: www.cancercouncil.com.au
- CancerBackup (UK source), Symptoms & Side-effects – Fatigue www.cancerbackup.org.uk

Can't sleep?

You would hope that if you are constantly fatigued sleep would come easily. Many people with advanced cancer say it does not always work that way. They have trouble falling asleep and staying asleep (also called insomnia) and do not feel rested if they do manage to sleep.²⁵

It is normal to have problems sleeping during this challenging time in your life. Difficulty sleeping may be caused by fear and worry about cancer and treatment, side-effects from treatment, and being less active during the day.

Sleep is an important part of the healing process and not being able to do so can be distressing. If you can't sleep within 30 minutes of going to bed, get up and do something not too stimulating (eg. quiet reading, listen to music) until you feel sleepy again. “Clock watching” may cause more distress and contribute to not sleeping.

What may help –

Talk to your Doctor

The underlying reason for your poor sleep may be treatable, or your doctor or nurse may be able to offer you appropriate prescription medicines.



FACT

It is very important that you let your health care team know about all the medicines you take including over-the-counter medicines, as these may interact with medicines he or she may have suggested to help you sleep.

Write down what you want to tell your doctor:

Keep a record of your sleep pattern, including what you are eating, drinking and doing during the day and just before bed. When did you start not sleeping well? When do you go to bed? Do you fall asleep immediately? When do you wake up? What wakes you up? Share this record with your doctor and health care team so you can come up with a plan to help you sleep.

Write down what you want to ask your doctor:

What can be done to help you sleep? Ask your doctor about medicinal and non-medicinal strategies to help you sleep. If you are prescribed a sleeping medication, ask your doctor: How long will it take to work? How often should I take it? Should I take more medication if I can't sleep? Are there other options if the medication doesn't work? What are the possible side-effects of the medication? How can the side-effects be managed? Who will I continue seeing about my sleep problems (eg. doctor or palliative care nurse)?

Talk to others

If anxiety, stress or worry about yourself or those close to you are disrupting your sleep, talking to your family, friends or a trained professional (such as a counsellor or a psychologist) may make a difference.

Relaxation

Some people who have trouble sleeping find relaxation techniques, such as meditation, deep breathing exercises, muscle relaxation, yoga or self-hypnosis, useful. Your doctor or nurse may know where you can learn these techniques and where to find self-hypnosis tapes. Also, your community health centre may have a list of relevant services.

Try to deal with things that may be worrying you earlier in the day and plan more relaxing activities for the late afternoon.

Exercise

Regular exercise is also a good way to reduce anxiety and improve sleep quality. However, vigorous exercise right before bed should be avoided as it promotes wakefulness.

tips

- Try to go to bed and get up at a similar time every day
- Establish a regular, relaxing bedtime routine.
- Avoid caffeine-rich beverages (eg. coffee, cola) and alcohol before bed.
- Avoid eating a heavy meal before bed.
- If you have to take a nap, make it no longer than 30 to 40 minutes.
- Some people find that drinking warm milk with honey or decaffeinated teas before going to sleep helps.

Worried about pain?

Depending on your cancer, you may or may not experience pain. But if you do experience pain, don't hesitate to seek relief because uncontrolled pain can lead to anxiety and depression, decreased mobility and potentially more hospital admissions.¹¹ You should not have to tolerate any pain and many things can be done to help you to manage your pain.

What may help –

Talk to your Doctor

Do not suffer in silence. Tell your doctor about any pain even if you do not think it can be relieved. Most pain can be reduced to a bearable level, even if it's not completely controlled.

A Pain Assessment Guide is included at the end of this booklet (p130) to help you discuss any pain you may have with your health professional. You may find it useful to complete this guide at different periods of time to keep a record of how your pain varies. It is also important to complete this assessment after you have taken a medicine to decrease the pain, as it will help your health professional identify if you are taking the right medication and the right amount of that medication.

Write down what you want to ask your doctor:

- What is causing my pain? When is it likely to get better or worse?
- What can be done for pain relief? Ask your doctor about pharmacological (or medicine) and non-pharmacological (alternate) options to alleviate pain

If you are prescribed pain relieving medication ask the person prescribing it:

- How long will it take to work?
- How often should I take it?
- What should I do if I still have pain?
- What are possible medication side-effects?
How can the side-effects be managed?
- What are the other options if the medication doesn't work?
- Who should I call if I have more questions about pain relief?
- Who will I continue to see about my pain relief?



FACT

Effective pain relief is dependent upon an in-depth pain assessment; therefore it is important that you discuss your pain with your health care provider.

Pain relief¹²

For minor pain: Drugs such as aspirin, paracetamol and codeine may be taken as tablets, oral mixtures, suppositories, patches or injections.

For moderate to severe pain: Morphine can be taken as a tablet, oral mixture, suppository, patch or injection and is commonly used because it is quick acting and long lasting. Its reputation as only a drug for addicts or people who are dying is undeserved.



FACT

- You do not become addicted to morphine if you are taking it to relieve pain.¹³ Actually, research shows that addiction to morphine among cancer patients is rare.
- Morphine can cause sedation and constipation. Laxatives can relieve or prevent constipation. Drowsiness will decrease after the initial doses.¹⁴ Your health care team can help you manage this.



Q&A

Q: If I start vomiting after taking morphine, does that mean I have taken too much?

A: Not necessarily, since morphine often causes nausea, especially the first few times it is taken. A medication to suppress nausea or vomiting such as maxolon or cyclizine, can be prescribed with morphine to alleviate this problem. Ask your health care provider about other options for pain relief if vomiting continues.

(Source: Helen Moore, Service Manager, Palliative Care, Calvary Health Care Sydney.)

Nerve block: If the cancer affects nerves, or if nothing else is working, a drug such as a local anaesthetic may be injected into the nerve to stop pain signals from reaching the brain.

Chemotherapy, radiotherapy and surgery: These treatments are used against primary cancers but they can also control the symptoms of some advanced cancers (see 'Considering further treatment?' in this chapter). Chemotherapy may shrink a cancer that is causing pain in a particular spot. Also, short courses of radiotherapy may relieve symptoms such as headaches and bone pain caused by metastases (secondary cancers). In some cases, surgery may improve the results from chemotherapy and radiotherapy.

Know your doses

Take your medications on time. A key to keeping pain under control is to take the prescribed dose before the pain starts and regularly thereafter.

Your doctor, nurse or pharmacist should be able to help with any concerns.

Remember to find out if you should avoid taking other substances with your medications. It pays to carefully read the information that comes with each medication so you and those around you can be alert to its strength and potential side-effects, such as extreme drowsiness.



- Check the strength of your medication before you take it, especially if you are likely to be home alone. Some people find their prescribed doses have a significant sedative effect.



FACT

- Pain relief can be taken for a long time in increasing doses, if needed, and does not have to be kept for when the pain gets "really bad".
- It is easier to control low or mild pain intensity than it is to relieve a high intensity of pain.
- Pain relief is more effective if you use it consistently to keep the pain away, rather than waiting till it comes back.
- Living with a high level of pain does not increase your tolerance to pain and may actually contribute to other symptoms and health problems.

Control other problems

Pain and other symptoms can often seem worse when other things are worrying you.^{15,16} For instance, if you are feeling depressed, anxious, lonely or afraid, call on your health care team to help you deal with these feelings, as they may be contributing to your pain.

Alternative relief

Being relaxed reduces muscle spasms, encourages sleep and can help other pain treatments work. A psychologist or other health professional can help you with relaxation techniques or point out places you may learn them, such as community meditation classes.



FACT

Using a combination of pain relief medication and alternative pain relief methods can be quite successful in helping reduce pain intensity.

Massage may help you relax, and hot or cold packs can relieve pain, as can techniques such as acupuncture and TENS (Transcutaneous Electric Nerve Stimulation). You should ask your doctor, physiotherapist or nurse about which of these methods is most appropriate for you.

For more information

Patients and caregivers often report not having enough information about pain management and do not feel competent enough to administer medications.¹¹ Here is what you can do:

- Talk to your Doctor or nurse
- Call the **Cancer Helpline on 13 11 20** and talk to trained nurses
- Read the Cancer Council booklet *Overcoming Cancer Pain*, which you can access by ordering free from the **Helpline (13 11 20)** or via the Cancer Council website <http://www.cancercouncil.com.au/editorial.asp?pgid=1159>
- Download the Palliative Care Australia brochure *Facts about Morphine and Other Opioid Medicines in Palliative Care* from www.pallcare.org.au

Trouble breathing?

Some people report difficulty breathing, an inability to get enough oxygen or a feeling of suffocation (also called shortness of breath or dyspnoea).¹⁸ Whatever it feels like, trouble breathing can be a frightening and debilitating symptom for people with advanced cancer and those around them.

What may help –

Talk to your Doctor

Finding out why you are having breathing problems is the first step towards treatment. For instance, a fluid build-up around the lungs may be drained, while oxygen or certain medicines may work against other causes.^{19,20}

Write down what you want to tell you doctor:

- What brings on your shortness of breath?
- What are the particular activities that trigger your shortness of breath?
- What helps you manage shortness of breath?
- Have you experienced shortness of breath before?

Write down what you want to ask your doctor:

- What can be done for shortness of breath?
- When is shortness of breath an emergency?

Non-medical help

Depending on what is causing your breathlessness, you may find some relief in:

- Increasing the air circulation and, where possible, lowering the temperature and humidity.
- Finding a position that is comfortable for you. Some people find it useful to sit in a chair and lean forward with their arms and upper body supported on a table.
- Focusing on your breathing pattern: Take slow even breaths. When you breathe out, put your lips together, like slowly blowing out a candle (also called pursed lip breathing).
- Attempting to relax – using music, deep breathing, guided imagery or meditation, for example.
- Seeking emotional support and reassurance from those around you and health professionals.²¹



• If you are experiencing breathlessness, turning on a fan or opening windows may help you feel as though you are taking in more air.

Plan your activities

- If you are doing an activity and become short of breath, you should stop the activity and rest.
- Rest before and between doing activities that take extra energy.



FACT

If your shortness of breath is accompanied by any chest pain, you should seek immediate medical attention.

Experiencing bowel problems?

Dysfunctional bowel movements, whether diarrhoea or constipation, can be inconvenient at best and painful at worst. It is common for people with advanced cancer to suffer from one of these, or both at different times.

Constipation is defined as the passage of small, hard stools infrequently and with difficulty.⁸⁶ It can be a result of the cancer itself and is not helped by inactivity, dehydration, poor nutrition or medications such as morphine.²² The discomfort of constipation can be distressing not only for the person who has it, but for caregivers, who often feel powerless to help.²³

Diarrhoea is defined as the passage of frequent loose stools with urgency (ie. more than three loose stools within a 24-hour period).⁸⁶ Medications, chemotherapy, a lack of fibre (especially if you are having trouble digesting food), conditions such as radiation enteritis (swelling of the small intestine from ongoing radiation therapy) and anxiety can all contribute to this problem.

Urinary incontinence, or a loss of bladder control, may also be a problem, particularly for people who have had major surgery for prostate and colorectal cancers. Many people with incontinence find it is necessary to use continence products such as pads, pants, catheters, or bedding protection to manage their condition.

What may help –

Talk to your Doctor

Your doctors and nurses should be able to suggest appropriate medications. If you are making an appointment with your doctor, ask for a long consultation so you can explain the problem without feeling rushed. Movicol, for instance, may be prescribed for constipation if you are taking opioid pain medications (eg. codeine or morphine).

Write down what you want to tell your doctor:

- What is your usual bowel movement pattern?
- What is your current bowel problem? How often does it occur?
Have you experienced any bowel problems before? You may find it useful to note down the date and time you have had bowel problems.
- When did constipation, diarrhoea, or urinary incontinence start?
Did you identify a provoking factor (eg. types of food or drinks)?
- What have you tried to relieve constipation, diarrhoea, or urinary incontinence?
- The amount and type of fluid consumed and the type of diet generally consumed.

You may also like to write down a few questions to ask your health professionals such as:

- What is causing these bowel problems?
- When is it likely to get better or worse?
- What can be done for bowel problems?

If you are prescribed medicine to help you with your bowel problems ask:

- How long will it take to work?
- How often should I take it?
- What should I do if I continue to experience bowel problems?
- Are there other options if the medication doesn't work?
- What are the possible side-effects of the medication?
- How can the side-effects be managed?
- Who will I keep seeing about my bowel problems?

If diarrhoea is the problem, your doctor may be able to prescribe anti-spasmodic medications.

Some medications can also help to tighten, or in some cases relax, muscles around the bladder to help counter incontinence. In worse cases, a temporary catheter may be preferable to living with the unease of an unreliable bladder.⁸⁷

tips

- Mix Movicol in fruit juice to improve taste. Apple juice is best. Sip it over an hour if you have difficulty swallowing fluids
- When anti-nausea drugs cause constipation after chemotherapy try 20 drops of Duralax with a cup of tea on the morning of treatment and the day after.

Changes in diet

Simple things included in your daily routine can help prevent constipation. Try drinking at least six glasses of water a day. A warm drink first thing in the morning may help. Eat plenty of fibre-rich foods such as wholemeal bread and high-fibre cereals, fruit and vegetables. Adding some boiled prunes into your diet may help. Snack on high-fibre food, such as fruit and nut mixes, sesame and nut bars and wholemeal biscuits.

tips

- Vegetables high in fibre include asparagus (raw), bean sprouts (raw), broccoli (raw), brussels sprouts (cooked), carrots (raw), cauliflower (raw), mushrooms (canned or raw), onions (raw), peapods (cooked), spinach (canned), chinese cabbage (raw) and zucchini (raw).
- Fruits high in fibre include apple (unpeeled), apple sauce, blackberries (raw), blueberries (raw), nectarines, pears (canned), raspberries (raw), strawberries, tangerines, apricots (dried), figs (dried), prunes and raisins.⁸⁴



If your dietary restrictions allow it, this Get Up and Go Cookies recipe may help with constipation:⁸⁴

½ cup margarine or butter

1 cup brown sugar

½ cup prune puree

1 egg

1 cup applesauce – any flavour

2 cups all bran cereal

1½ cups flour

½ teaspoon baking soda and

1 teaspoon of cinnamon or other spice to taste. Optional: ½ to 1 cup raisins, or chocolate chips, sunflower seeds, nuts.

Directions: In a large bowl, cream margarine with sugar. Add egg, then prune puree and apple sauce, mix well. Add dry ingredients. Mix well.

Drop by spoonfuls onto 3 cookie sheets – 12 cookies per sheet.

Bake in 180° oven for about 15 minutes. Cool on pans for a few minutes and then remove.

If diarrhoea is the problem, the following suggestions may help:

- Eating smaller meals more frequently (if your appetite allows) may take some of the pressure off your bowel. Try to eat three small meals and three snacks each day.⁸⁵
- Beware of dairy products, alcohol, and spicy or fatty foods.
- Avoid skins, pips and seeds from fruit and vegetables, whole grain bread, bran-based and muesli breakfast cereals, nuts and legumes such as lentils, dried beans, dried peas and baked beans.⁸⁵
- If you have gas or cramping, avoid foods that can increase gas production, such as dried peas and beans, broccoli, cabbage, cauliflower, onions, brussel sprouts, carbonated beverages, beer and chewing gum.

For mild diarrhoea, clear fluids and the BRAT (banana, rice, apples and toast) diet are often recommended. Other foods to choose from include soft, well-cooked peeled vegetables and fruits or canned fruits, white bread and pasta, cornflakes, rice-based breakfast cereals, well-cooked rolled oats and semolina, and lean meat, fish, chicken, eggs and dairy products.⁸⁵

Caffeine, alcohol and other diuretic substances are not great if you have urinary incontinence, because they increase the amount of fluid there is to leak and the rate at which these are eliminated. However, you should still continue to drink water, as reducing your fluid intake can make bladder problems worse as it concentrates the urine and irritates the bladder.⁸⁷

Exercise

Exercise can also help with constipation – be as active as you can be, but do not exceed your physical abilities. Walking 15-20 minutes once or twice a day or 30-60 minutes daily or 3 to 5 times per week is typically recommended.⁸⁴

If you are unable to walk or are restricted to bed, exercises such as pelvic tilt, trunk rotation and single leg lifts are recommended.⁸⁴

For incontinence, some people find Kegel exercises, designed to strengthen your pelvic muscles, and bladder training, which encourages people to extend the time between urination, helpful in controlling urinary incontinence. However, these are specific exercises and programs and you should ask your doctor, oncologist, physiotherapist or nurse if these are right for you.⁸⁷

Toileting and Privacy

If there is a time you usually feel like going to the toilet, try to be in a place where you can relax at that time each day. For people restricted to using bed pans or needing help to go to the toilet, embarrassment may cause constipation. It helps to create an environment that is as private and relaxed as possible.²⁴

A squat position can facilitate the defecation process. If you are unable to use the toilet (eg. bed-bound), the squat position can be stimulated by lying on the side and bending the knees and moving the legs toward the abdomen.⁸⁴



- The Commonwealth Department of Health and Ageing provides a National Public Toilet Map as part of its National Continence Management Strategy. This may be useful when planning excursions. Go to www.toiletmap.gov.au.

Diarrhoea also comes with its share of embarrassment, of course, and it can make it easier if those around you understand that you may have urgent needs and can be discreet about helping you. This could mean identifying the nearest toilets and helping you get to them quickly. Try to make sure that some sort of toilet facility is always in reach. Carry damp wipes and a change of clothes if you are out.

For more information

- More information about Kegel Exercises and other strategies to maintain bladder and bowel health can be found on the Continence Foundation of Australia website at <http://www.continence.org.au>

- You can also call the National Continence **Helpline 1800 33 00 66 (free call)** for information and advice from continence nurse advisors.
- Talk to your Doctor or nurse regarding a referral to a continence clinic or call the National Continence Helpline **1800 33 00 66 (free call)** or visit <http://www.continence.org.au/site/index.cfm?display=112843> to know which continence services are closest to you.
- The Continence Foundation of Australia also offers information about funding schemes to help you pay for continence products (eg. pads) call the National Continence **Helpline 1800 33 00 66 (free call)** or visit <http://www.continence.org.au/site/index.cfm?display=112775> for more information.

Feeling sick?

Chemotherapy, radiotherapy, morphine, stress and bowel obstructions, not to mention the cancer itself, can all cause nausea and vomiting. You should not, and do not, have to put up with these symptoms; these are uncomfortable and distressing and can cause rapid weight loss and other health problems.

What may help –

Talk to your Doctor

Your doctor or nurse should be able to work out what is causing the nausea and vomiting and suggest treatments (eg. adjusting your diet or medications).

Write down what you want to tell your doctor:

- When does the nausea or vomiting occur? How long does it last for? It might be useful to keep a diary to record this information.
- What are some of the things that seem to bring on nausea or vomiting?
- What seems to make the nausea or vomiting worse?
- What have you tried to relieve nausea or vomiting?
- Have you experienced nausea or vomiting before?

Write down what you want to ask your doctor:

- What can be done to relieve nausea or vomiting?
- Ask your doctor what he or she will be prescribing to prevent or control nausea and vomiting.

- Find out if the chemotherapy drug you are receiving is likely to cause nausea and vomiting. If so, ask when these are most likely to occur and how long they typically last.

If you are prescribed medicine to help you with nausea or vomiting ask:

- How long will it take to work?
- How often should I take it?
- What should I do if I continue to experience nausea or vomiting?
- Are there other options if the medication doesn't work?
- What are the possible side-effects of the medication? How can these be managed?
- Who will I keep seeing about my bowel problems?

Meals

The following may be helpful to manage nausea or vomiting:⁸⁵

- Sip small amounts of liquid as often as possible if you have persistent vomiting, don't try to force food down.
- You may also find it helpful to suck hard, sweet flavoured ice chips or an ice block.
- Eat small meals frequently rather than one big meal. Eat slowly and chew well to help you digest your food better.
- If appropriate, try to take anti-nausea medications before meals.
- Avoid fried or fatty foods, which are difficult to digest.
- Avoid stomach irritants (eg. tobacco, aspirin).
- Some people report that cold foods are better than hot foods.
- Rest after eating, but do not lie completely flat, to aid with digestion.
- Avoid strong scents or odours.
- Avoid eating in a room that is hot or filled with cooking odours.
- Avoid your favourite foods when experiencing nausea. You do not want your body to learn to associate them with nausea.
- Eat before you get too hungry. Hunger can aggravate nausea.
- Eat more during periods with less nausea. For instance, if you feel hungrier at breakfast time, have your main meal then and eat a light meal at a time when you feel more nauseous.

- Do not eat or drink at the same time. It is usually recommended to drink liquids an hour before eating.
- Cook and freeze several meals that you can reheat during times when you are nauseated.
- Eat dry foods such as dry cereal, toast or bread with honey, jam, Vegemite or Marmite, or crackers, without liquids especially first thing in the morning.
- Try eating foods and drinking beverages that have made you feel better when you had the flu such as bland foods, sour candy, pickles, dry crackers, salty foods such as pretzels, dry ginger ale, cold flat lemonade, soda water, Lucozade or chilled tomato juice.

tips

- Some people find that keeping crackers at their bedside is useful in case they wake up in the middle of the night with nausea.
- Recent research has found that half a teaspoon of ground ginger a day can reduce nausea associated with chemotherapy when used along with anti-nausea medications (<http://www.medpgtoday.com/HematologyOncology/Chemotherapy/14221>).



FACT

Even when ill, it is important that you continue drinking clear liquids to avoid dehydration.

As nausea and vomiting decrease, foods can be slowly reintroduced, beginning with simple, bland foods that do not irritate the stomach and intestines. The BRAT diet previously suggested for diarrhoea is also recommended here.

Lost your appetite?

You may not want to eat because you feel sick, or you may simply have lost interest in food. Various treatments and medications can dull or physically change your taste buds, which may take the enjoyment out of eating.

Some people report that chemotherapy, for instance, changes the taste of food. Meanwhile, mouth ulcers, a sore throat or other symptoms and side-effects can make eating uncomfortable.

tips

- Some people find it easier to drink liquids with a straw when they have mouth sores.
- Rinsing or gargling with a solution of saltwater and baking soda (½ teaspoon of salt plus ½ teaspoon of baking soda in a glass of water) is found to help with mouth sores.
- If a dry mouth is a problem, try sucking on cubes of frozen pineapple juice (prepared in ice-cube trays).
- Patients who experience taste change often find it helpful to:
 - Use plastic utensils instead of metal.
 - Eat with friends or family to provide a distraction from tastes.
 - Add taste by using strong flavours in foods or marinating foods.
 - Serve food cool or chilled which often feels better on the tongue than hot foods.

What may help –

Talk to your Doctor

First, your doctor can check out what may be turning you off food and suggest possible treatments. Even if conditions such as mouth ulcers and sore throats cannot be prevented, they may be eased.

Changes to diet

A dietician may suggest foods that are easier to chew and swallow. Ask your doctor for a referral.

Other suggestions include:

- Try not to miss meals.
- Eat small meals often or even just a few mouthfuls of food.
- Make sure what you eat and drink is nourishing. Fruit juice, milkshakes or liquid supplements can be suitable meal substitutes.
- Keep snacks handy to eat whenever you can (eg. nuts and dried fruit).

tips

Nourishing Drink Recipes⁸⁵

- Strawberry smoothie – ½ cup strawberries (or other fruit), ½ cup high-protein milk, few drops vanilla essence, pinch cinnamon. Blend fruit thoroughly. Add all other ingredients to fruit and blend again. Serve chilled. Add sugar if you like a sweeter drink.
- High-energy milkshake – 1 cup high-protein milk, 1 scoop ice-cream, milkshake flavouring, Milo, Ovaltine, coffee, malt, ice-cream toppings. Whisk together and serve chilled.

Trouble getting around?

For many people who may be physically limited, a loss of functional independence has more than just practical implications. An inability to shower and dress yourself, or just to get on with your daily activities, can also be a psychological and social blow.²⁶ Most of the help available aims to increase your independence as much as possible.

What may help –

Talk to your health care team

It is important that you communicate to your health care team if you have any difficulties doing strenuous activities (eg. carrying a heavy shopping bag), have any trouble taking a walk outside of the house, need to stay in bed or a chair during the day, need help with eating, dressing, washing yourself or using the toilet, are limited in doing either your work or other daily activities or are limited in pursuing your hobbies or other leisure time activities.

Support services

Many community support services offer practical assistance, but it is not always easy to find them. Below are the details of some organisations that can help you with various mobility related needs.

Commonwealth Carelink Centres

These centres are a useful first stop, providing free information on support services covering personal care, nursing, linen, domestic help and accommodation in nursing homes and hostels. Your local centre will also have information on other services in your area.

The information is available in 16 languages other than English and also caters for indigenous and vision-impaired people.

To contact the centres, you can phone **Freecall 1800 052 222**, log on to www.commcarelink.health.gov.au or visit your local Carelink Centre (phone the Freecall number for locations).

Assistance with personal care

Community nurses may be able to assist with showering, dressing and medical care. Your health care team can put you in touch with the services you need. Alternatively, you can contact your local community health centre (under “Community Health” in the telephone directory), or Carelink (details above) may be able to help.



Enhancing mobility

Some of the groups and organisations that can assist with your physical independence include:

- **Occupational therapists**, who are trained to help you manage everyday activities. They can suggest mobility equipment and changes in the home. You should be able to find one through your local hospital, a specialist palliative care team or privately.

- Palliative care equipment is available for loan. Go to the **Palliative Care Australia** website www.palliativecare.org.au or phone **2 6232 4433** to find out about the contact details for the palliative care centre in your state.
- **The not-for-profit Independent Living Centres** in each state, which provide information and equipment for everyday living. Go to www.ilcaustralia.org, or call **1300 885 886**.
- **Other state-based programs for providing equipment for independent living**. In NSW for example, the Program of Appliances for Disabled People (PADP) provides aids for mobility, continence, communication, sleeping, nutrition and more.
- **Private organisations** that rent or sell equipment such as wheelchairs, walking frames, shower chairs, commodes, incontinence products and pressure-care mattresses. Look under “Disabled Persons Equipment &/or Services”, “Home Health Care Aids” or “Hire – Medical Equipment” in the Yellow Pages.

Modifying your home

The Commonwealth Carelink Centres (see previous pg) have directories of people qualified to modify your home. They can also put you in touch with Home and Community Care (HACC), which helps with the modifications needed to keep you at home. The Independent Living Centres (see above) in each state also have information about home modifications.

Seeking respite care

The states have **Commonwealth Carer Respite Centres (Freecall 1800 059 059)**, which provide in-home, day, emergency and holiday respite for relatives and friends caring at home.

The Commonwealth Carelink Centres (see above) will also have a list of state-based respite services in your area.

Needing help around the home

Services available to help you around the house and garden include:

- **Home and Community Care (HACC)**, which offers home nursing and relief care, and help with personal hygiene, household tasks and home maintenance. Contact HACC in your area through your Commonwealth Carelink Centre (see pg 34).
- **Meals on Wheels services**, will deliver hot, chilled or frozen meals, for a small cost. Check with your local Commonwealth Carelink Centre for details on services in your area.
- **The Department of Ageing, Disability and Home Care**, which can provide domestic and maintenance services for people at home. Also, Commonwealth Carelink Centres (see pg 34) can put you in touch with people in your area who can help out.



If you live alone, consider having an alarm installed in case of an emergency.

Considering further treatment?

You may have undergone chemotherapy²⁷, radiotherapy or surgery in the earlier stages of your cancer. In progressive stages, the techniques are usually less about curing and more about improving the length and quality of your life.

The treatments may be used, alone or together, to shrink the cancer or slow its growth, particularly if it is causing pain. Not everyone will benefit from palliative chemotherapy, radiotherapy or surgery, but it is worth discussing with your doctor or oncologist.

The treatment of all types of cancer is always being researched and breakthroughs occur regularly. If you have given up on the tried and tested, you may find hope in clinical trials relevant to your illness.

These trials are usually run by teaching hospitals, universities, or drug companies and test techniques, vaccines or drugs that have shown promising results during development and are ready to be tested under controlled conditions in “real life”.



Traces of some chemotherapy drugs can be passed to others through bodily fluids, so it may be necessary to take precautions (eg. latex gloves, condoms). Ask your oncologist.

Some trials involve more risk than others, and some may have ethical concerns. A legitimate clinical trial will have complied with a number of strict conditions and passed an ethical review.



FACT

Most clinical trials especially for drugs, are conducted under “double blind” conditions, which means neither you nor your doctor know whether you are taking the drug or a placebo.

What may help –

Ask questions

It may be helpful to ask your doctor or oncologist questions such as:²⁸

- How will chemotherapy, radiotherapy or surgery affect the size of the cancer?
- Will palliative chemotherapy, radiotherapy or surgery give me more time? If so, how much?
- What are the potential benefits for me?
- What are the main side-effects and will I feel better or worse?
- Are there other options, such as hospice or palliative care?

Research

The internet can be a helpful tool when it comes to researching other treatments, vaccines and clinical trials. But, always be wary of the credibility and accuracy of the information. Ask your doctor or specialist for their thoughts on any information you gather.

The results of clinical trials are often published in medical journals – such as the Medical Journal of Australia – many of which are available online.

Some research organisations advertise for trial participants, so keep an eye on the notice boards at the hospital you attend. It is also worth checking if your doctor, oncologist or other specialists have been approached by researchers looking for trial participants.

For more information

Up-to-date information on clinical trials can be found at:

- The Australian New Zealand Clinical Trials Registry – www.anzctr.org.au
- The Commonwealth Government's Cancer Australia website – www.canceraustralia.gov.au/consumer-support-and-information/clinical-trials.aspx
- The National Health and Medical Research Council's Clinical Trials Centre, affiliated with the University of Sydney's Faculty of Medicine. See www.ctc.usyd.edu.au
- The Cancer Council's booklet on Understanding Clinical Trials. Phone 13 11 20 or go to www.cancercouncil.com.au

Looking for other treatments?

If you and your doctor have not already considered complementary treatments or alternative therapies in the earlier stages of your cancer, there is a good chance you may look at them as your disease progresses.

It is easy to confuse the terms complementary and alternative, or even to use them interchangeably. The fact is they are distinct from each other.



FACT

Here is how the Cancer Council NSW defines the differences between complementary and alternative therapies:

- **Complementary therapies** are used alongside conventional treatments such as surgery, chemotherapy or radiotherapy, and include a range of methods: mind-body techniques such as meditation, counselling and hypnotherapy; body-based practices such as massage, acupuncture and yoga; and biological-based therapies such as naturopathic nutrition and Chinese herbal medicine. Complementary therapies don't claim to cure cancer, but aim to relieve side-effects of treatment, or reduce the emotional impact of a cancer diagnosis.
- **Alternative therapies** are used instead of conventional treatment. These therapies may be harmful if people with cancer delay or stop using conventional treatment in favour of them. Many of these therapies claim to stop cancer growth and to cure cancer. However, most alternative therapies have not been scientifically tested, so there is no proof that they work, or they have been found to be ineffective. Examples include microwave therapy, coffee enemas, high-dose vitamin supplementation or diets that replace conventional therapy.⁶⁹

You may find some complementary therapies help you control certain symptoms and side-effects, help you relax, help your body fight infection or generally seem to be a “healthier” way of managing your cancer. Whatever your reasons, you would be one of the 65% of people with cancer who use complementary therapies.⁸⁹

Your doctor is probably less likely to recommend or endorse alternative therapies. Nevertheless, some people with advanced cancer turn to less orthodox treatments, especially if they feel they have run out of options. It is important to weigh up the potential harms and benefits of any treatment option or therapy.

What may help –

Weigh it up

The Cancer Council NSW advises you consider the likely benefits and side-effects, possible negative interactions with conventional medicine, the credentials of the practitioner and the cumulative costs of treatment.

Talk to your Doctor

You may think your doctor would resist the idea of non-conventional therapies. In fact, many see value in complementary medicines and advise their patients to use them.

General questions to ask your doctor about complementary therapies:

- Are you familiar with complementary therapies or medicines?
- Are you qualified in complementary therapies yourself?
- Are there any complementary therapies that you think might benefit me?
- Would you be happy for me to use complementary therapies?
- Would you be willing to guide me in my research or choice of complementary therapies?
- Would you be willing to talk to my complementary therapists about my case?
- Can you recommend any complementary therapists to me?
- Do you know whether the complementary medicines I am taking or wish to take will interfere with my chemotherapy or other conventional treatments?



FACT

Whether you are acting on your doctor's advice or not, it is important for them to know what medicines or therapies you are using, in case of a potentially dangerous interaction with your regular medicine.

Do your homework

Many complementary therapies are accepted practices carried out by qualified practitioners, as are some alternative therapies. If you are worried about the legitimacy of a therapy, a good place to start is the **Australian Competition and Consumer Commission** (www.scamwatch.gov.au or www.accc.gov.au), which keeps a record of known medical scams. **Quackwatch** (www.quackwatch.com) a not-for-profit website from the US, which claims to be an independently run guide to “quackery” and health fraud, may also be worth a look.

Some questions you might consider when deciding what complementary therapies to use or whether to use them at all are:

- How does the therapy work?
- Will the therapy directly harm me because of:
 - its side effects?
 - possible interaction with other medication?
 - needing to stop conventional treatment?
 - being told by the therapist to stop or delay all conventional treatment?
- Is the cost of the therapies or medicines beyond my means?

To help you answer these questions, you need to talk to complementary therapists and doctors. Depending on their area of specialty, they may not know the answers to some of these questions and you may need to work together to find out more information.

General questions to ask any potential complementary therapist

- What are your qualifications? Are you a member of a professional association?
- What training or experience do you have in treating people with cancer?
Have you treated anyone with my type of cancer?
- Are you willing to work with my doctors or other health professionals I may need to see?
- How can the therapies you practise help me? Are there any specific precautions you would take for me?
- Are there side effects or risks associated with these therapies?
- Has the therapy been tested in clinical trials?
- Have the findings been published and are they available for me to read?
- Can these therapies be combined with conventional treatment?
- How long should I use this therapy and how will I know if it's working?
- Are you able to do home visits if I am not well enough to attend your clinic?

- How long are your consultations?
- What do you charge for a consultation?
- What can I expect from a consultation?
- Do you dispense your own medicine and supplements?
- How much can I expect to pay for medicines?
- Have the products or medicines you dispense been approved by the Therapeutic Goods Administration?

For more information

Call the **Cancer Council Helpline on 13 11 20** or go to www.cancercouncil.com.au, for a copy of Understanding Complementary Therapies, which covers more than 20 therapies and the issues around choosing a therapy.



Q&A

Q: How do I know if a practitioner of complementary or alternative therapy is legitimate?

A: The main thing is to be wary of vague or incredible claims. If a “therapy” claims to cure all cancers, uses “secret” ingredients with “amazing” results, or is backed by clinical studies that are never specified, then alarm bells should ring. Also, watch for practitioners who do not display any credible qualifications, who demand a lot of money (especially in advance), or who say you should stop your conventional treatment.

(Source: Cancer Council NSW, Understanding Complementary Therapies, 2008)

Sick of hospitals?

Your treatment and state of health will dictate how long you spend in hospitals. The time spent travelling to and from the hospital and waiting around for appointments and treatment and even stays in hospital, can be a major physical (not to mention mental) drain.

What may help –

Talk to your Doctor

If hospital visits are particularly difficult for you, ask the doctor managing that specific treatment if there are alternative ways to receive it. If there are not, the doctor may be able to suggest ways to make it more bearable. There will not always be a better way, but your doctor or nurse needs to know how you are coping.

Ask for help

There may be ways of easing your discomfort, so it is worth asking. For instance, a social worker may be able to arrange assistance with transport, if travelling to hospital treatments is proving difficult. Or it may be something as simple as asking a nurse at the hospital for a cushion to make the wait more comfortable.

tips

- If having an intravenous (IV) inserted each time you receive treatment is causing distress, ask your doctor about suitable alternatives such as a port – a cath (an access device surgically implanted in your vein).
- Take a book to read while waiting for treatments and try to avoid scheduling scans for Mondays, when the hospital is more likely to be crowded with the weekend’s spill-over.



FACT

Did you know that your old x-rays – and you may accrue plenty of them – can be recycled to produce new silver? Go to Planet Ark’s recycling website, recyclingnearyou.com.au, and select “x-ray films” from the product list.

Personal Notes

Handwriting practice area with 20 horizontal dotted lines.



2. EMOTIONAL NEEDS

A long and serious illness takes its toll as much on the mind as it does on the body. Distress or emotional upset can arise at any time and can last for days, weeks, or even months. Most people with advanced cancer, and their family and friends, will already have travelled an emotional roller-coaster and are looking for the strength to continue.

The way you think about cancer and its consequences may have changed. Depending on your condition, you may be thinking more seriously about living with a chronic or disabling disease, or, at times, even about death and dying.

You, your family and friends will probably cope with feelings and psychological stresses in different ways, but it helps to know what kind of assistance is available, and what has worked for others when it comes to living a fulfilling life.

An emotional assessment guide is included at the end of this booklet to help you, your family and friends identify feelings of distress, anxiety, depression and anger. After you have completed this questionnaire, share your answers with your doctor to help her or him identify the best way to help you.

Feeling anxious?

Anyone who has had cancer will be familiar with the fear and uncertainty that comes with diagnosis. Knowing the disease has progressed may increase the concerns about what the future holds for you and your family.

You may be worried about how an ongoing illness will affect your relationships with the people around you, how your family will cope, how you will deal with treatment side-effects or, ultimately, how you will face death.

These are normal thoughts and feelings. It is important to keep tabs on these emotions, and if the anxiety is leading to panic or paralysing your everyday life, it is time to seek help. After all, the last thing you want is for anxiety to dilute the quality of life you and those around you deserve. ^{32,33, 34}

What may help

Talk to your Doctor

Anxiety often stems from the unknown. Perhaps your doctor or nurse can put your mind at ease with answers to some of your questions. Failing that, they may be able to refer you to a mental health specialist to further explore with you what is making you anxious. Use the emotional assessment guide included at the end of this booklet to further discuss anxiety with your doctor.

Talk with others

Some people with advanced cancer find understanding and support from others in the same situation.³⁵ They can “vent” to each other, share ideas, or even talk about anything other than cancer.

The Cancer Council can tell you about support groups in your area or, through **Cancer Connect (phone 13 11 20)** and can put you in touch with individuals you may relate to. If you are in a rural or remote area, meetings over the internet or telephone can sometimes be organised.

Feeling depressed?

Feelings of grief and sadness may follow the news that your cancer has returned or progressed, and it is important to be wary of signs of depression. Depression can make your life miserable, amplify your symptoms¹⁵ or even lead to a desire to die.³⁶

Possible signs of depression include ongoing despair and feelings of sadness or hopelessness that dramatically affect your ability to get on with things. In this case, you may need a health professional to help you get back on track.

What may help

Listen to those around you

The people who care about you can sometimes see things you cannot. If they are worried about your state of mind and can see you are struggling with everyday life, it may be the cue for you to seek professional advice.

Talk to your Doctor

Depression is often under-diagnosed in people with advanced cancer³⁷⁻³⁹, so if you feel you are sliding down that slope, talk to your doctor as soon as possible. They are able to assess how you are feeling and suggest appropriate medications or counselling. Use the emotional assessment guide included at the end of this booklet to further discuss depression with your doctor.



Q&A

Q: If I think I am suffering from depression, should I ask my doctor for Prozac?

A: You should certainly talk to your doctor if you think you are depressed. But he or she will need to assess the real root of your symptoms first. A large trial in Australia in recent years raised questions about the benefits of doctor-prescribed antidepressants for people with advanced cancer.⁴⁰

Get counselling

Psychotherapy (group or individual counselling) works well on depression in some people with advanced cancer,^{40 41} and can increase self-esteem and satisfaction with life.⁴² Your doctor, nurse or social worker may be able to recommend programs or groups in your area.

For more information



- Call the **Cancer Council Helpline on 13 11 20** to speak to a trained cancer nurse, who may also refer you to a counsellor if you need to speak to one.
- Go to **Beyond Blue**, www.beyondblue.org.au for information on depression and how to deal with it.

Lost hope?

Hope means different things to different people. For many, it is about being optimistic and positive in the face of reality. It is not unusual for someone with an incurable illness to lose hope (also called helplessness), let their illness take over and even say they want to die. Unrelenting symptoms and loss of independence can all become too much.

Even if there is no hope of a cure, you can still have other hopes and dreams – for the relief of your symptoms, for comfort and peace, for your relationships, for your family and friends. Any or all of these hopes can help you sustain a good quality of life.

Losing hope because you do not think you or those around you can cope any longer is not necessarily the same as the often serene acceptance at the end of life that the battle is no longer worth fighting. It may take a professional – either physical, psychological or both – to pick the difference.

It is important for you, and particularly your family and friends, to recognise that a sense of hopelessness is often not a permanent state of mind, but an emotional symptom they need to recognise and help you deal with.



- Reading inspiring biographies and other accounts from people who have battled serious illness and adversity may help if you feel you have lost hope.

What may help

Talk to your Doctor

Your doctor or specialist may be able to assure you that there are still things you can do to cope with your illness physically. They may refer you to a mental health worker who can help you find hope emotionally.

You may find it difficult to communicate with your doctor about loss of hope. You can complete the hope assessment guide included at the end of this booklet to help you talk about loss of hope.

Set goals

Setting small goals and making plans for the near future can help build a sense of optimism and give you something to work towards each day.

Be inspired

Talking to someone who has experienced similar feelings may help you work through the despair. The **Cancer Council's Cancer Connect network (13 11 20)** can put you in touch with groups and individuals you may seek inspiration from. People in these groups may also have suggestions about books or articles that have helped them.

Rethink your expectations

Hope does not have to be an all-encompassing emotion. Relatively small things – such as days when you feel good, looking forward to activities you enjoy and watching those around you thrive – can provide hope in smaller, but effective, doses. Some people find comfort and hope in their faith or religious beliefs.⁹¹

What about intimacy and sex?

Just as physical symptoms, such as loss of weight, pain and fatigue, can affect your sexual responses, so too can emotions, such as embarrassment over changes in your body and worry about whether your partner finds you attractive.

If you are finding sex uncomfortable, for any reason, some techniques, therapies, medications or counselling may help. It is also important to remind yourself that intimacy is not just about intercourse. Touching, cuddling, kissing, caressing and spending time together are also important in expressing love and affection.

What may help

Talk to your Doctor

Some people feel that their doctor is reluctant to discuss sexuality.⁴⁶ Don't let that stop you. Your sexuality is likely to be crucial to how you feel about yourself and your life, so seek all the advice you need. Your doctor may be able to help with physical matters

and, if they do not have the answers to emotional concerns, they will refer you to someone who may, such as a social worker, psychologist or counsellor.

Talk to your partner

Talking about your feelings, concerns and anxieties helps your partner both understand and, hopefully, help. Even if sex itself is off the agenda, warmth, closeness and intimacy are just as important.



Q&A

Q: Do I still need to use contraceptives and other precautions if I have had, or am having, extensive cancer treatments?

A: Infertility may be temporary or permanent after treatments such as radiotherapy, especially in the pelvic area, or chemotherapy. Although, fertility problems can be a side-effect of cancer treatment, this is not always the case. You need to consider the risks of becoming pregnant or your partner becoming pregnant. Remember that it can be dangerous for a baby to be conceived during and immediately after chemotherapy. Chemotherapy drugs can stay in your system for about 48 hours. So it may be wise to avoid intercourse during this time or use a barrier contraceptive, such as a condom.

(Source: Cancer Council Victoria, Sexuality and Cancer, October 2007)

For more information

- Call the **Cancer Council (13 11 20)** to talk to trained counsellors.
- The Cancer Council has booklets on Sexuality for Men With Cancer, Sexuality for People Who Have Stoma (Ostomy) and Sexuality for Women With Cancer. Go to www.cancercouncil.com.au or call **13 11 20** to have them sent to you.

What about dignity?

Dignity means different things to different people but, in general, it is related to feelings of self-worth.

Your feelings of dignity, regardless of how far your cancer has progressed, may depend on controlling pain and symptoms, remaining independent, receiving honest but tactfully delivered news from your doctor, looking good and maintaining the highest quality of life possible.

What may help

Spell it all out

Your dignity is a team effort. You will do what you can, but you also need your health professionals, carers, family and friends to respect your wishes. It will help you and them if you think about what decisions and choices may lie ahead and spell out your preferences.

This may begin with talking frankly to those around you about the help you need and how you would like to interact with them. Ultimately, you may need to think about what you want to happen towards the end of life. Do you want to continue treatment after a certain point? Do you want to end up at home or stay in hospital?

You may like to prepare an Advance Care Directive, or living will, which outlines the medical care you wish to have, in case you can't speak for yourself. (See more about advance care planning in Chapter 6)

Talk to your Doctor

Talk to your Doctor, nurses and other health professionals about the things that are important to you so they can help you make plans that reflect your values. Tell them about your concerns regarding future care so they can help you live the way you would like.

Talk to your family

Your dignity will also be important to those closest to you. Talking to them about your wishes and values will help them make the right decisions now and in the future.

If your condition deteriorates, family members are usually the ones who talk with health professionals about your care. Therefore, open, honest and clear communication is critical.



- If a family member or friend is in denial or too distressed to listen to your wishes, write them a letter they can refer to later.

Not thinking clearly?

Impaired thinking and changes in awareness can affect people with advanced cancer in varying degrees. These symptoms known as confusion and delirium, may range from occasional forgetfulness to, in extreme cases, dramatic changes in personality and a loss of any sense of reality.

Confusion can come on suddenly or gradually, it can come and go or be more permanent, and it can have an impact on your activity level and alertness.⁴⁷

The type of cancer itself (eg. a brain tumour) may cause the confusion. It can be caused by medications, dehydration, changes in the body's chemical balance, infection or reduced amounts of oxygen getting to the brain.⁴⁸

While confusion and delirium is common in the final days of life, it is particularly distressing when your faculties are otherwise in order and you are aware of your feeling of confusion.

What may help

Talk to your Doctor

Whatever is causing the confusion, it may be treatable. Some medications may be available to help you.

Get organised

If you are worried that forgetfulness or other lapses in awareness may affect your everyday duties, you may need to swallow your pride and consider delegating the more important responsibilities, keeping thorough diary entries for example about what you normally do in a day or what needs to be done, writing notes to yourself (that others may take a cue from if need be) or asking trusted friends to follow up with you.



- If you are worried you may be caught out by confusion in public, wear a medical bracelet that carries your details and the nature of your condition.

For more information

- Palliative Care Victoria has a brochure about confusion and terminal restlessness. Go to <http://www.pallcarevic.asn.au/resources-links/uploadedFiles/1219726068671-0667.pdf> or phone (03) 9662 9644.

Personal Notes



3. SOCIAL NEEDS

A person soldiering on with advanced cancer may tell you they depend on good doctors, latest treatments and a positive frame of mind. But it is more likely they will dwell on the support they have received from family, friends, their community, their church, their beliefs – or the lot.

A life-changing illness can add new weight to social, cultural and spiritual connections. Strong networks, effective communication and spiritual fulfilment can all help to make life that little bit easier.

Social support

A good social support network usually includes family, friends, community members and others who provide physical, practical and emotional help.

Just as individuals need different levels of social support, people around them are likely to react to those needs in different ways. Some people have family and friends who rally around and cannot do enough for them. Others find the people they most depend on withdraw because it is all too distressing for them, or they do not know how to help.



FACT

People with advanced cancer and their caregivers, who feel that they have a good support network tend to cope better with their diagnosis and generally have a better quality of life than those who do not have such back-up.^{50 51}

What may help

Make contact

A variety of groups and services offer support for people with advanced cancer, their caregivers, family and friends. These include face-to-face groups, or email and telephone contact, especially for people who live in rural areas or are less mobile.



You may start with the Cancer Council's services (phone 13 11 20), enquire about the Cancer Connect program, state-based and cancer-specific support groups and its Helpline.

Contact your hospital or talk to your cancer nurse or a social worker to get more information about other local support groups.

Carers Australia, has information on carer support groups around Australia. Contact **Freecall 1800 242 636** for information, or for over-the-phone counselling and support.

Accept help

Try not to let your pride or reluctance to “impose” stop you from accepting help. Most offers of assistance, especially from those close to you, are genuine. In many cases, this is their way of letting you know you are not alone.

Family or friends may be able to pick up medications, cook or simply sit with you. Hopefully they will appreciate your honesty when you really want to be alone or want to do something for yourself. But, for the most part, their help may in fact be helpful to all of you, including them.



• If you want to help someone who may be reluctant to accept it, specific offers (“Tell me what I need to pick up from the chemist”) are often more effective than “open” offers (“What can I do to help?”)

Relationships

Advanced cancer takes its toll on all of those concerned and relationships are often affected. As your physical abilities change, the role you play in the household and within your family may change. Also, you and those you love may experience emotional ups and downs that are not likely to be synchronised with each other.

While the strain may widen existing cracks in relationships, times such as this often bring out the best in people and strengthen the bonds between them. This usually takes work, though.



FACT

“Studies of couples where one partner has a life-threatening disease show that good relationships generally stay good and the less strong ones continue to be less strong.”

(Source: Cancer Council Victoria, Advanced Cancer – Emotional Impact, www.cancervic.org.au)

What may help

Talk to each other

Openness and honesty about how you are feeling and what you need from each other often works best. For instance it might be difficult to tell your partner that they are stifling you with too much attention is likely to be far less damaging than the frustration and resentment that may build up otherwise.

Talk to others

Talking about relationship matters with others in a similar situation may help you see things more clearly or give you a few hints. [Cancer Connect \(13 11 20\)](#) can put you in touch with support groups in your area.

See a counsellor

Ask your doctor to refer you to a counsellor who may help you – and, where appropriate, the people you love – work through your feelings.

Talking to family and friends

As hard as it may be to deal with your diagnosis, it is important to talk to others about what is happening and the uncertainty the future now brings. Your family and friends may worry about you and want to know how you are feeling and how they can help.

Discussing the progression of your illness and even end of life decisions may be draining, but avoiding the subject only makes it harder to cope. Indeed, talking about your feelings, hopes and dreams can be healing and comforting.

From a practical perspective, the people around you need to understand your needs, plans and wishes, especially if you are likely to get to a point where you cannot make decisions for yourself.

Regardless of their reaction, talking openly and honestly in an age-appropriate way will assist them to understand your illness.

What may help

Plan your chat

Think about what you want to say and how you will respond to questions. You may find it useful to write this down and refer to it during your interactions. Find a quiet time when you are least likely to be interrupted and ensure that is also a good time for the person you want to speak to. The last thing you want is to have this conversation with someone who is tired and stressed.



tips

When discussing your diagnosis and illness with those around you:

- Speak from the heart – use direct language that describes how you are feeling.
- Allow time for the other person to talk, in case they want to

ask questions or discuss their own feelings.

- Don't try to cover everything – there is probably much to discuss, but you may need to allow time for bits of information to digest.

Telling the children

As for “telling the kids”, that is never going to be easy for either you or them, but do not be tempted to shield them from upsetting news. Children often know when there is something wrong and may immediately think the worst.

Children and teenagers may react to the news in different ways, whether it be anger, confusion, sadness⁵² or denial. . Plan what you want to tell them and deliver the news in a language they can understand. Young children can be confused by too much information, whereas emotionally mature teenagers may feel they are left hanging with too little information.

tips

When discussing your diagnosis and illness with children and teenagers:

- Always be honest – in times of uncertainty, honesty is often the one thing children can depend on.
- Encourage them to ask questions and answer them as fully as you can.
- Explain the impact on them – children and most teenagers are

fairly ego-centric and need to know how their everyday lives will be affected.

- Be as positive as possible but avoid making promises.⁹²
- Listen to their thoughts and feelings without judgement.

Talk to a professional

If you need assistance talking to your family and friends, counselling from a mental health professional may help. If you do not want or need professional help, your carer, family or friends can always make appointments for themselves.

Take the lead

Some of your family, friends or colleagues may be unsure of how to talk with you. They may be worried about saying the wrong thing or about whether they should mention your illness.

It may pay for you to take the lead. Acknowledge your illness with them and give them some tips on how you wish to be treated, and what you are happy to talk about with them and when. Many people with advanced cancer say this openness often relieves the awkwardness.

For more information

- The Cancer Council has a booklet, *When a Parent Has Cancer: How to Talk to Your Kids*, which is not specific to advanced cancer but contains useful information. Go to www.cancercouncil.com.au to download a copy, or **call 13 11 20** to have it sent to you.
- The **US National Cancer Institute** has helpful information about talking with partners and children. Go to www.cancer.gov/cancertopics/advancedcancer
- A US website, **Cancer Care**, also has information about communicating with family. Go to www.cancercare.org

Talking to health professionals

It may not always be easy to open up to your health professionals. You may feel you are taking up too much of their time or that you have bent their ear once too often. Regardless of how busy they are, doctors, oncologists, and other health professionals would rather have too much information from you than not enough.

Research consistently shows that good communication between patients and their health care teams not only improves patient satisfaction with care, but also improves their quality of care.⁸²

What may help

Ask questions

It is important that you understand the information given to you by your health care team. It may help to write down your questions so you do not forget to ask them. Don't be afraid to ask what you might think are "dumb" questions – they

are often the best ones. You do not want your health care team to make incorrect assumptions about what you know because you are not communicating openly with them.

Take notes of the answers to your questions, especially if it is detailed information. If you are feeling emotional, shell-shocked or overwhelmed or if you did not understand what your doctor said, ask them to repeat or write down for you some key words that will help you to remember what was discussed in case you need it. Your doctor may also be happy for you to tape your discussions. Patients often report finding such tapes very helpful to listen to again after the consultation and also help their family to better understand what is going on.⁹⁴

Know who to contact

People with advanced cancer and their carers often say they don't feel comfortable calling their doctor with questions between visits, or that they are not sure their doctor is the person they should be asking.

During a consultation, ask your doctor who you should contact regarding specific matters, such as mobility aids, respite care or emotional support. They may also be able to tell you who to call for after hours help.

tips

- For effective communication with your health care team:
 - Be prepared with a list of questions, or write them down as you think of them during the visit. Some people say they often do not know which questions to ask – use this booklet as a guide to help you identify areas that you may want to know more about.
 - Book a longer consultation if you know you have a lot to talk about. That will help you and your doctor to feel less rushed.
 - Take along a friend or family member to help you absorb the information and ask the necessary questions.
 - Take notes and ask for clarifications, in plain English, of anything you don't understand.

For more information

- Palliative Care Australia's free booklet *Asking Questions Can Help: An Aid for People Seeing the Palliative Care Team* lists questions you may like to ask your doctor. Phone **Palliative Care Australia** on **(02) 6232 4433** or go to www.palliativecare.org.au

- The Cancer Institute NSW has brochures about asking questions of your haematologist, medical oncologist and surgeon.
Go to www.cancerinstitute.org.au/cancer_inst/patients/questions.html

Cultural differences

Australia is a multicultural country filled with diverse groups of people whose collective beliefs and values guide different types of thinking and behaviour.⁵³

As such, cultural requirements and sensitivities are important considerations in the care of people with advanced cancer.

What do you want to know about your illness? What does your family need to know? What level of treatment is acceptable? How do you talk about death? These are some points of cultural difference that, with the right communication, can be integrated into your care.

What may help

Talk to your Doctor

Talk to your Doctor and other health care providers about customs or family traditions that they may need to consider. This may be as simple as working around prayer times, or as detailed as instructing them on how to handle a body after death.

Call on your community

You may like to enlist the help of family members, friends or others from your cultural community in ensuring your beliefs and customs are respected. If you are unwilling or unable to assert your wishes, they can step in on your behalf.

Language barriers

Comprehending a diagnosis of advanced cancer and a raft of treatment options can be daunting for the most proficient of English speakers. So if you have difficulties with written or spoken English you may not only misunderstand what you have been told about your illness, but also miss out on additional useful information and services.

It is very important, if English or literacy is not your strength, to seek help in finding and interpreting information related to your illness.

What may help

Talk to your Doctor

If English is your second language, ask your doctor or health care provider to speak more slowly, repeat information, explain colloquialisms or even write down crucial points for you.

Use an interpreter

With notice, hospitals or doctors can sometimes provide an interpreter to translate at a consultation or over the phone. If not, you may need to organise one or find a family member who can do it.

Language resources

A variety of cancer and palliative care resources are available in languages other than English:



- The Cancer Council SA has publications printed in a number of different languages.
Go to www.cancersa.org.au to download a copy or call the **Cancer Council on 13 11 20** and ask for one to be mailed to you.

- The Cancer Council Helpline offers information and support for people with cancer in Cantonese and Mandarin (1300 300 935), Greek (1300 301 449), Italian (1300 301 431) and Arabic (1300 301 625).

Interpreting services

The **Translating and Interpreting Service (13 14 50)** offers assistance with communicating in a language other than English. You can ask for a male or a female interpreter, if need be. There is a fee for some services, but communication with medical practitioners is usually free. Go to www.immi.gov.au/living-in-australia/help-with-english/help_with_translating/index.htm

Private interpreting services in your area may be found in the Yellow Pages under “Translations” and “Interpreters”.

Spirituality

A diagnosis of advanced cancer is often the cue for people to search for meaning in life. For some, this may be the first time they are confronted with the thought of death or dying.⁹⁸

People may want to understand their purpose and legacy, to celebrate their life, and look for strength, peace, harmony and comfort. They, and those around them, may change their priorities and think about what they want from life.⁵⁴

This is when spirituality, religion, faith or belief in a greater power comes into play. For some, it is an unstructured approach – spending time with others, basking in memories and reflecting on their experiences. For others, prayer, religious rites and spiritual guidance not only provide comfort and support⁵⁵, but increase their ability to cope with their illness.⁵⁶ If this applies to you:

What may help

Social and pastoral care

Social and pastoral care workers can offer support, guidance and prayer, and discuss spiritual concerns. Previous involvement, or not, in formal worship is usually unnecessary. Your local hospital or palliative care team, or your local church or religious organisation, should be able to help you find the appropriate people.

Finding meaning

Searching for meaning or finding that one's life has order and purpose has been shown to influence satisfaction with life and well-being.⁹⁸ Every person is different, but some people have found that going through old photos, writing down memories, or leaving a lasting legacy such as a taped or written message for a child, have helped them find peace and comfort. Others may find it useful to re-evaluate their priorities and goals and determine specific strategies to help achieve them.

For more information

- **Growth House Inc**, an international resource for end-of-life care, has the Handbook for Mortals, which contains a chapter on finding meaning in life. Go to www.growthhouse.org
- The US National Cancer Institute has information on looking for meaning and celebrating your life. Go to www.cancer.gov

Personal Notes



4. LIFESTYLE

This booklet is about living with advanced cancer, including how you choose to eat, exercise, work and relax within the limitations of your illness. To try to get the most out of life, some people with advanced cancer make major changes to their lifestyle, whereas others prefer to continue on as normally as possible.

Diet

Eating can become a vicious cycle for someone with advanced cancer. You know you need a balanced diet to stay well and strong enough to control symptoms, but those symptoms may have stolen your appetite and made eating unpleasant.

Depending on your treatment, the right kinds of food can improve your strength, fight infection and help you recover more quickly.⁹⁴ You may also need to adapt your diet to cope with symptoms such as pain, constipation or diarrhoea⁹⁵ (see Chapter 1 [pgs 25-30] for dietary tips for coping with various symptoms).

If you are losing weight due to treatment, or because you are struggling to eat, you may need to increase your protein and calories. If you are overweight, or if treatment⁹⁵ or a lack of mobility is causing you to put on weight, you may need a diet that is rich in nutrients but lower in energy.

The guidelines for a balanced diet when you have advanced cancer resemble those for healthy eating in general: eat fruit and vegetables, whole grains, legumes/beans, small amounts of meat or fish and a smattering of good fats. All this should be done, as far as your illness will allow and in consultation with your health care team.

When appropriate, the Cancer Council Australia recommends the following for people with advanced cancer:

- Eat plenty of vegetables, legumes and fruit – five or more servings of vegetables and two or more servings of fruit per day.
- Have cereals (preferably wholegrain) – between three and twelve servings each day, depending on age, gender and energy needs.
- Eat meat in moderation – no more than three to four servings of lean red meat each week and avoid processed meats.
- Select lower fat foods like lean meat and reduced-fat dairy products, and try using low-fat cooking methods like grilling instead of frying.
- Choose low-salt products – flavour foods instead with herbs and spices.

tips

- 1 serving of vegetables: ½ cup cooked vegetable or cooked legumes, 1 medium potato, 1 cup salad vegetables.
- 1 serving of fruits: 1 medium piece (eg. apple), 2 small pieces (eg. apricots), 1 cup chopped or canned fruit.
- 1 serving of cereals: slice of bread (35g), ½ pita bread (35g) or 125ml (½ cup) of cooked pasta, rice or couscous.

The ideal, for an optimum quality of life, is to get the nutrients you need in food that you can both stomach and enjoy, and to be able to dine with your family and friends.

What may help

Talk to your Doctor

Your doctor may be able to treat some of the symptoms – such as nausea or mouth ulcers – that hinder eating. They can also advise you on weight management and eating or refer you to a dietician.

Talk to a dietician

A dietician can provide you with a dietary plan that meets your nutritional needs while taking into account the factors affecting your eating.

Talk to your friends

Your friends and family may be happy to accommodate your dietary needs so you can enjoy eating with them. You may prefer to go out for breakfast or lunch, for instance, rather than go to dinner when you may be tired and the food may be too heavy and the portions too big. If friends or family want to cook for you, brief them on what you can eat.



Q&A

Q: I love to have a drink with my friends, but should I be avoiding alcohol?

A: Despite convincing evidence that alcohol is a risk factor for some types of cancer, there is no evidence to say that drinking if you have cancer is a concern. The Cancer Council recommends cancer survivors limit (no more than two standard drinks a day for men and one for women) or avoid alcohol, and this is probably a good guideline for someone with advanced cancer too – if only to help your body remain as strong as possible to fight symptoms. Talk to your Doctor about it and ask about how alcohol may mix with your treatment and medications.

- If you have no appetite but need to maintain or increase your weight, try:
- Eating small meals more often
 - Eating as soon as you feel hungry, rather than waiting for meal times
 - Using supplements, such as Sustagen or Fortisip (ask your doctor, nurse or dietician for advice)
 - Adding cream or butter to meals
 - Snacking on yoghurt, cheese and crackers, or milkshakes
 - Adding lentils or split peas to soups and casseroles
- If you need to control your weight but maintain your nutrients, try:
- Eating regularly – don't skip meals, but keep them small
 - Replacing energy-dense foods with vegetables and salad (soft or pureed, if necessary)
 - Filling up on soup
 - Making your carbohydrates wholegrain, where possible (eg. brown rice, wholemeal bread)
 - Using reduced-fat dairy products
 - Using high-density foods such as lollies, chocolate, pastries and biscuits as occasional treats only
 - Watching out for “sneaky” calories in soft drinks and alcohol⁹⁶

For more information

- The **Cancer Council Helpline (13 11 20)** can provide you with dietary advice.
- The Cancer Council NSW has a booklet on Living with Advanced Cancer, which has some dietary tips. Call **13 11 20** to have one sent to you or go to www.cancercouncil.com.au to download a copy.
- You may find some useful links to dietitians and other dietary information through the **Dietitians Association of Australia (www.daa.asn.au)** and **Nutrition Australia (www.nutritionaustralia.org)** websites.



Exercise

The consensus seems to be that the more you can keep your body moving, the better it will be for many (though not necessarily all) of your symptoms, your overall strength and stamina, and your state of mind.

Exercise may help to fight infection (primarily by increasing oxygen in the blood), reduce pain (by releasing opiate-like endorphins), strengthen joints, relieve constipation or nausea, encourage sleep, relieve stress⁹⁷ and expose you to fresh air and sunlight.

Some people with advanced cancer will struggle to exercise, while others may overdo it. The type and amount of exercise you can manage depends on your cancer, treatment, symptoms and other factors which your doctor or relevant health professionals will need to take into account.

What may help

Talk to your Doctor

Even if you feel well enough to run a half-marathon, check with your doctor, physiotherapist or occupational therapist first. They will want to encourage your enthusiasm, but they will also know more about potential complications. Alternatively, they may be able to help you with symptoms that are preventing you from exercising, or with some advice on getting moving.

Work out with others

If you are capable of exercising but can't get motivated try walking or cycling with a friend. Make sure they understand your limitations. You may find an exercise partner in a cancer support group.

Work out alone

Going at it alone may work if you are concerned about holding others back, or even a little awkward about your physical restrictions. You may simply enjoy the time alone.

Look for alternatives

If your choice of exercise is ruled out, there may be other things you can do. Swimming or cycling may replace weight-bearing activities such as jogging, walking, yoga or tai chi may be options. If you are not into exercise as such, maybe dancing or gardening will interest you.

- Some general guidelines for exercising when you have advanced cancer:
- Listen to your body – if it is screaming for you to stop, then perhaps you should.
- Give yourself a day's rest after chemotherapy and other taxing treatments.
- Try working out in short daily bouts, as opposed to one gruelling session a week.
- If you are too exhausted to work out, some stretching or taking a stroll outdoors may suffice.
- If you are bedridden, speak to a physiotherapist about any exercises you can do.⁹⁷

For more information

- Seek advice through the **Cancer Council Helpline (13 11 20)**.



- The Victorian Government's **Better Health Channel (www.betterhealth.vic.gov.au)** has a useful fact sheet on Cancer – Exercise to Help You Cope.

Work and leisure

A diagnosis of advanced cancer does not necessarily mean the end of your work life. Depending on your physical and mental health, you may prefer to continue working because you enjoy what you do, want the social engagement, want to fulfil commitments, need the money, or want a “normal” routine.

Whatever your reasons, you will need to consider how work fits in with your changing physical abilities and your treatment. Your boss and workplace may give you the flexibility you need. If not, something else may suit you.

If your reason for working is more than financial you may find some satisfaction in volunteering or community work.

If you cannot work but want to be involved you may consider studying or learning a skill for the fun of it (eg. pottery or art class) or joining or starting a book club or Scrabble group.

Your leisure time may become even more important to you. Holidaying, eating out and going to shows, movies and sports events may boost your emotional and social wellbeing.

What may help

Talk to your boss

All workplaces are different and not all will be flexible and understanding, but you can never be sure until you ask. Many bosses will do anything for a valued worker, so if you are open about how your illness may affect you and your work, they may well fit around you.



Q&A

Q: Am I legally entitled to keep my job, even if my cancer is affecting how I do it?

A: This depends on your individual situation, but there are laws to protect workers from unfair dismissal, unlawful termination and disability discrimination. So, if you think you have been unjustly treated, you may want to seek specific legal advice. Most states have a workplace rights advocate, or you can try the Federal Workplace Ombudsman (www.w.o.gov.au)

Talk to an occupational therapist

Your doctor or local hospital should be able to refer you to an occupational therapist who can advise you on what work and activities may suit you.

Check your finances

Try to let your health and state of mind and not your bank account, influence your work decisions but stopping or reducing your work may have a financial impact. See Chapter 5 (pg 78) for information on what financial assistance may be available.

Read the fine print

Before you book any holidays, check with a good travel agent for travel insurance that will cover your needs. Also, pay close attention to itineraries to ensure you are not too far from reliable medical facilities.

It is also worth checking the cancellation policies on tickets for travel and events, just in case you are not well enough to attend.

Plan your play

Your friends and family may not always remember or recognise your limitations, make sure they are aware of what you can manage when planning holidays and outings. Beware of over-committing yourself for fear of upsetting other people's plans, because that may only cause more disruption in the end.

Remember that this may well be a time when your family and friends simply want to spend time with you, so any activities you suggest are likely to suit them too.

For more information

- If you are worried about your rights at work, try the website of the **Australian Government's Workplace Ombudsman, www.wo.gov.au**
This gives an overview of your rights and also provides links to other useful sites related to the workplace
- If you are looking to do unpaid community work, go to the **Volunteering Australia website, www.volunteeringaustralia.org** for details of your nearest volunteer resource centre, which can point you to appropriate organisations

Personal Notes



MORTGAGE

5. FINANCES

At a time when you may prefer to be concentrating on coping with advanced cancer and spending time with your family and friends, you are confronted by harsh practicalities such as money matters.

Organising your finances is important. Your income, outgoings and general financial and legal status, are likely to be affected by your state of health.

Costs and expenses

If your work is affected, loss of income is likely to be a major financial stress – doubly so if a partner stops or reduces work to care for you.

You may have already confronted other expenses related to cancer, including medications and treatments, the out-of-pocket costs of some services and travel. The progress of your illness may now mean buying or hiring special equipment, paying for household services, modifying your home⁵⁷ or running two households if you relocate for palliative care.⁵⁸

What may help

Travel assistance

A few organisations or schemes can help you with the cost of travelling to see health professionals, including palliative care specialists.

- In NSW for example, the **Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)** helps people who live more than 100 kilometres from the nearest specialist. Other states have similar schemes. Your doctor or other health care providers should have more information. Also the **Cancer Council Helpline (13 11 20)** will have information about the support in your state.



Equipment assistance

Equipment needed for your care at home can be expensive. There are a number of programs in each state that may help with this cost. See the earlier section on “Trouble getting around?” in Chapter 1 (pg 34) for more information.

Financial assistance

Check with Centrelink whether you qualify for any benefits or pensions such as a sickness allowance, disability support pension, family allowance or a carer’s allowance. You may also be eligible for a health care card, which can reduce the cost of your medications or a pension travel card, which can reduce the cost of public transport. Call **13 27 17** or go to www.centrelink.gov.au



Q&A

Q: Given the progression of my cancer, can I use my superannuation now?

A: Under recent changes to Federal legislation, you may be allowed to draw on your superannuation if your illness is considered terminal. To be eligible, you must provide statements from two medical practitioners (at least one being a specialist) certifying that you have a life expectancy of 12 months or less. Contact your superannuation fund to discuss this with them.

For more information



- The **Cancer Council Helpline (13 11 20)** can provide you with general information and perhaps put you in touch with some financial assistance services.
- The Cancer Council has a Welfare Grants Program that, in cases of extreme hardship, can provide financial help to people with cancer. Contact the Cancer Council in your state.
- Financial counselling is also available from some charity organisations, such as the Salvation Army or St Vincent de Paul Society.

Paying the bills

Unfortunately bills do not have any respect for your state of health. They keep rolling in and the last thing you want is essential services being cut off because you have not been able to pay them.

What may help

Organise back-up

If you are normally responsible for paying the household bills, brief your partner, a family member or a trusted friend on how to take over from you. Don’t just assume these duties will be picked up by someone else in the household and if you live alone, it’s very important that you organise the back-up support.

Check your accounts

Set up your accounts so that whoever is going to be paying your bills has access to them. Someone you have briefed and trust will need to be able to make or authorise payments on your behalf.

Talk to service providers

Some utilities will deal only with the person who set up the account when it comes to connecting, disconnecting or querying services so inform those service providers that authority has been passed on to someone else.

Also some organisations such as electricity and phone companies are prepared to discuss difficulties in paying bills (a number is usually listed on mailed accounts) and it is better to contact them sooner rather than later.



• Keep non-PBS (Pharmaceutical Benefits Scheme) medicine receipts for tax purposes. Ask the Tax Office or your accountant about the safety-net level over which you can claim out-of-pocket medical expenses as deductions. You can also go to www.pbs.gov.au/html/consumer/home for more information about the PBS.

Caregiver benefits

Finances are also likely to be an issue for those who care for you. Travel, loss of income and various out-of-pocket expenses can add up. Any financial assistance they receive will not only take some pressure off them, but will also ease some of the concerns you may have about the sacrifices those around you are making.

What may help

Government benefits

Government payments available through Centrelink include:

- A non-means-tested allowance for anyone caring for an adult with a condition who needs care and attention.
- A means-tested payment for people who provide constant care in the home of a person with a severe disability or medical condition.
- The Carer Adjustment Payment for families in which a child aged up to six is diagnosed with a severe illness, medical condition or a major disability.
- The Employment Preparation Service to help caregivers who have been out of the workforce for two years or more return to work.

For information on any of these payments, go to www.centrelink.gov.au or phone 13 27 17.

Personal Notes

A bright sun with a starburst effect is positioned in the upper left quadrant of the image, shining through a clear blue sky. Large, fluffy white clouds are visible on the left side and bottom of the frame, partially obscuring the sun's rays. The overall scene is bright and airy.

6. END OF LIFE

Many people may have thought about their dying wishes when preparing wills or chatting with others about funeral preferences and organ donation. These discussions take on greater significance, however when confronted with advanced cancer. At some time after your diagnosis, it may be necessary to clearly outline your wishes for future medical care and death.

Advance care planning

An advance care directive, sometimes referred to as a living will, is a written legal document that outlines your specific wishes for future medical care. It is implemented only if you are unable to make your own decisions.

It may cover issues such as assisted nutrition, life-sustaining treatments and resuscitation, as well as nominate someone to make decisions for you when you are no longer able if you wish. This person is often referred to as your enduring guardian or durable power of attorney.

The more guidance you can provide them on your preferences, the more likely your family and health care providers will make decisions that respect your wishes.⁶⁰



FACT

Research shows that people who prepare advance care directives are more satisfied and more comfortable about making end-of-life decisions.⁵⁹

What may help

Update your plans

You can review your advance care directive whenever you wish. Make sure that the people who are caring for you are always up to date with any changes and keep these papers in a safe place. Give a copy to your own doctor, your enduring guardian (if you have appointed one), a family member or friend and also your solicitor if you wish.

Do the paperwork

Legislation regarding advance care directives varies from state to state.

NSW, Tasmania and Western Australia do not have specific laws, but directives may still be valid under common law. Information can be obtained from the Department of Health in your state or you can go to **Care Search** website at www.caresearch.com.au

For more information

- Contact the **Advance Care Directives Association** at www.advancedirectives.org.au
- **Palliative Care Australia** <http://www.palliativecare.org.au/>

- Palliative Care Victoria has A Guide to Decision Making in Health Care, available at www.pallcarevic.asn.au
- The Australian Government has a website for people over 50, which has a section on living wills. Go to www.seniors.gov.au/internet/seniors/publishing.nsf/Content/Making+a+living+will

Other decisions

At some stage during your illness decisions not related to your health care may need to be made on your behalf. These decisions may have to do with finances, legal matters or lifestyle (eg. where you will live).

Again you can consider appointing the equivalent of a general power of attorney to oversee your legal and financial matters or separate powers of attorney to look after different matters. The roles and terminology can differ from state to state.



Q&A

Q: Is it strange to want to plan your own funeral?

A: For many people whose illness is considered terminal, this is a comforting part of preparing to die. You can be as general or as detailed as you like – even down to the music, readings and epitaph. You can put your instructions in your will, write notes for your family or lodge a formal plan with a funeral company (often with advanced payment).

What may help

Get expert advice

The Justice Department websites for each state often have good information on the different types of guardianship and powers of attorney. You can also try looking up the Public Trustee in each state or territory which can also help you make a will (see the following section).

You may feel more comfortable letting a solicitor handle it all for you. They should be able to talk you through the planning decisions and draw up the papers.

Clear the obstacles

You will want your family and those looking after your affairs to strike as little red tape as possible. It may be wise, to transfer a joint bank account into your partner's name to stop the account being frozen if you die. Your accountant or solicitor, or even a palliative care social worker may talk this through with you.

Making a will

A will is a legally binding document that details how you want your assets and belongings to be distributed after you die.

You don't have to make a will since the law provides guidelines for distributing the assets of people who die without a will, but it is highly recommended that you do to give yourself the peace of mind that comes with control over one's own life; especially if you are married, in a de facto relationship, have dependents or have significant assets.

What may help

Talk to an expert

While you are entitled to draft your own will, you may prefer to ask a solicitor to do it especially if your affairs are complex or if you have specific matters to be addressed. Shared assets, broken marriages and blended families can all complicate things and a will can be declared invalid for any number of reasons.

A solicitor will enable you to ensure everything is in order as well as act as the will executor, help you appoint a power of attorney and even store the will in a safe place.

Go public

Another option is to use the Public Trustee in your state. This is the government body responsible for making wills, managing deceased estates and overseeing powers of attorney.

Most Public Trustees will help you draw up a will for a nominal fee, store and execute the will, and then claim a small percentage of the estate in the end. Search online for "public trustee" in your state or go to the local phone book.



Do it yourself

If you decide to draft a will on your own make sure the document is clearly marked and dated as the latest version of your "last will and testament".

Will kits which provide a template, are available in various forms and price ranges. You can usually pick up a basic and reliable kit from a post office or newsagency.

tips

When drafting a will:

- Set out your wishes in plain English (don't try for legalese).
- Sign and date all pgs.
- Have two witnesses (not beneficiaries of the will) sign and date the document.

Talk to a social worker

If you are concerned about making a will a social worker may help. Ask your health care team about how to find such support.

For more information



- The Cancer Council publishes a free booklet called *You Never Know Who it Might Help: Your Guide to Wills and Bequests*. Phone the Helpline on **13 11 20**

Organ donation



FACT

One organ and tissue donor can make a difference to the lives of up to 10 people.

The heart, pancreas, liver, kidneys and lungs can all be transplanted, as can heart valves and tissue from the bone, skin and eyes.

A serious illness does not necessarily stop you from donating. Even if dying is not on your horizon, it is still worth documenting your wishes regarding organ donation and what you want to happen with your body.

What may help

Register your organs

Many people incorrectly assume that the “organ donor” note on their driver’s licence means their intentions have been formally registered.

In fact, to record your formal consent (or objection) to donating organs, you will need to sign on to the [Australian Organ Donor Register](#), through Medicare. You need to be over 18 and you can stipulate which organs or tissue you would be prepared to donate. Authorised medical staff can use this database to verify your wishes regarding donations.

Go to www.medicareaustralia.gov.au/public/services/aodr/register.jsp to register online. Otherwise, phone **1800 777 203** or visit a Medicare office.

Talk to your family

Even if you have formally registered your consent to donating organs you should discuss your decision with your family since they may have an option to override your decision in the end.



- Grieving family members may well be more sensitive than you expect about how your body is treated after death, so make sure they understand your feelings about organ donation.

For more information

- Medicare oversees the [Australian Organ Donor Registry](#). Go to www.medicareaustralia.gov.au/public/services/aodr
- The [Australian Red Cross Blood Service’s LifeGift Program](#) helps hospitals coordinate organ donations. Go to www.organdonor.com.au
- You can see some of the research the [National Health and Medical Research Council](#) is looking at regarding the ethics of organ donation at www.nhmrc.gov.au/health_ethics/health/index.htm

A desire to die

You may have heard about or even know people with advanced cancer who decide it would be best – for themselves and those close to them – if they sped up their death. Some people give up on living because they feel they are a burden on their family or that they have little support.^{43, 44, 45}

This is not necessarily the same as refusing treatment because you, and possibly your doctor feel it is futile and painfully prolonging the inevitable.

A desire to actively hasten death can be a sign that some sort of help or support is needed. This may include relief of physical symptoms, counselling for depression or more emotional support. It is common for someone who says they want to die to change their mind later.⁴⁴

The wish to die is a difficult matter for all concerned and needs to be handled sensitively by all those involved – including health professionals – and with your dignity in mind.



FACT

It is illegal in every state of Australia to help in speeding up a person’s death (otherwise known as euthanasia or assisted suicide)

What may help

Talk to your Doctor

Many issues such as depression or simply the feeling that you can’t cope may lie behind a desire to die. Start by talking to your doctor, nurse or social worker who may then refer you to a more appropriate person for you to talk to.

Talk to others

Talking to someone who is in a similar situation may help. The [Cancer Council \(13 11 20\)](#) can help you get in touch with appropriate support groups or individuals.

Seek professional advice

While the desire to die is a highly personal matter, you need to consider the implications – legal and otherwise – for those around you. Find a friend with legal knowledge, or even a trusted lawyer, you can talk to.

For more information

The [Cancer Council Victoria](#) has information on treatment decisions and voluntary euthanasia. Go to www.cancervic.org.au/about-cancer/advanced-cancer/treatment.html

Personal Notes

A blank sheet of lined paper with horizontal ruling lines, intended for taking notes.



7. THE PEOPLE WHO CARE FOR YOU

Caregivers come in all shapes and sizes and for people with advanced cancer they are often the secret to an optimum quality of life.

Caregivers can be spouses, partners, grown children, other family members, friends or neighbours. They may care for you full-time or they may call in now and then to cook meals, do housework, pay some bills, sit with you or provide emotional support.

Adjusting to being a caregiver can take time and can be fraught with strong and often conflicting emotions. For some, caring for someone close to them makes them feel good about themselves. It allows them to appreciate life and makes them feel useful and needed.^{61, 62} Care giving can also strengthen relationships.

On the other hand providing care can be time consuming and emotionally draining. Long-term carers may also find that their employment, social activities and overall physical and emotional wellbeing suffer.^{58, 63, 64, 65}

Identifying carers' needs is the first step in helping them overcome issues that may be causing much distress and anxiety. The Needs Assessment Tool (Patients & Families) included on pg 116 may help a caregiver identify the areas they may require additional help with. Please pass it on to anybody you think may benefit from it.

Physical health

Shopping, housework, cooking, personal care, medicating, lifting, transporting, calling health care workers, making medical appointments, offering a shoulder to cry on^{63, 66, 67} and more, could be in the job description of someone caring for a person with advanced cancer.

It is little wonder then that many caregivers say they have too much on their plate⁶⁷ and their own health suffers as a result. They may be tired and exhausted, have back, neck and shoulder problems, struggle with weight and fitness or be sick from stress.⁶³ To top it off, they may not be getting enough sleep.⁵⁸

What may help

Looking after themselves

This is easier said than done when someone else is depending on them. Eating regular, balanced meals – even if you do not have the appetite to eat with them – is the key to keeping up their energy and strength.



- You may be able to draw on services such as Meals on Wheels, to free up time for a carer whose duties include cooking.

Both you and your caregiver may be able to look at the list of things to be done and see where time may be freed up for the carer to perhaps get some exercise or sleep. Again, family or friends may be able to take over for a short period of time while your caregiver takes a mini-break.

Safety first

To maintain physical and emotional well being, your carer needs to be aware of safety and hygiene for their sake as well as for yours. Your doctor or hospital may be able to suggest an occupational therapist who can advise on suitable equipment, lifting techniques and other physical matters. A nurse will also be able to advise on hygiene practices.

Help with coping

The Commonwealth Carer Resource Centre can put caregivers in touch with services in their area that may be able to provide some assistance. Go to the [Carers Australia website, www.carersaustralia.com.au](http://www.carersaustralia.com.au) or phone **Freecall 1800 242 636** for state and territory carers associations.

Respite care

Respite care – provided by family, friends, neighbours or a formal service – allows caregivers to take a break.

A formal service may arrange for you to access a day care centre or admit you to a hospital or aged-care facility for a short time. Alternatively, a trained person may take over in your home. The relief care may be for a few hours or a few days, depending on your needs and those of your caregiver.

If your caregiver needs help organising respite care, talk to your doctor or health care team or call the **Commonwealth Carer Respite Centre** on **Freecall 1800 059 059** or the **Commonwealth Carelink Centres** on **1800 052 222**, or go to the **Department of Health and Ageing website, www.health.gov.au**

Mental health

Looking after someone close to them can bring a carer much pride and satisfaction.⁵⁸ It may mean they get to spend more quality time with you at home and this can strengthen your relationship.^{61 68}

The caring role can take a mental toll. They may feel anxious, sad, depressed or even resentful about your illness and the care you need. These feelings in caregivers may also increase as the health of the person they are caring for worsens.^{69 70}

Carers may also experience degrees of grief and the demands on their time may leave them feeling isolated and lonely. Left untreated, these states of mind can affect their long-term health and it can take years for them to recover.

What may help

Take breaks

Carers can try to schedule time each week to do things they enjoy – walking, gardening, having coffee with a friend or spending time with their family.

Family or friends may be able to take over some duties while your carer takes a break. If not, formal respite care (see under “Physical health” in this chapter) may be an option.



Q&A

Q: How can I get my carer to take a much-needed break?

A: They may feel guilty about taking a break, so maybe you need to step in and arrange it (or get a social worker to help you). How about pointing out to them that the break, even a short one, will probably be as good for you as it is for them?

(Source: Australian Government Department of Health and Ageing)

Talk your Doctor

If your carer seems anxious or sad, suggest that their doctor may be able to prescribe some medications that can help them feel better, or refer them to a psychologist or counsellor.

Emotional support

A carer may find it helpful to talk to someone else about how they are feeling, perhaps someone who is going through the same thing. Even if they don't feel comfortable talking with you about things (for fear of worrying you, for instance), they may be willing to talk to trusted friends or family members. At the very least, it may help those close to them understand their situation.



If they don't have that sort of support, or need more than family and friends can provide, there are trained counsellors through the [Cancer Council Helpline \(13 11 20\)](#).

These counsellors, or even the carer's own doctor, may also direct them towards local support groups. [Carers Australia \(Freecall 1800 242 636\)](#) has officers who, among other services can provide emotional support, information and referrals to counsellors for people who are caring for someone with advanced cancer.



• A sense of humour is always a good thing for a caregiver. Even though your illness is serious, sometimes the best way to deal with embarrassment and other awkward moments is to have a laugh.

Social effects

Taking on a caring role can mean hobbies, social outings, work, travel, holidays, shopping and time with family and friends fall by the wayside.

These are sacrifices many caregivers are prepared to make for someone they love, but they may also feel a sense of loss, loneliness or isolation because of these social limitations.

It is important that your carer somehow finds time for social activities, since doing things they enjoy will help sustain a positive approach to their caring role and relieve the stress on their other relationships.

What may help

Talk about it

If your caregiver is generally positive about their role, those around them may not realise how much they are missing in their life. Being open and honest with family and friends may draw out some helpful ideas and offers of help.

Respite care

Family, friends or community members may be able to offer a caregiver some informal respite so they can take part in occasional, or preferably regular, social activities. Formal relief care from agencies may also be available (see "Physical Health" in this chapter pg 94).

Financial effects

A caregiver may well need to reduce work hours, or even give up work. On top of that they may have extra expenses. They may have to travel to be with you and perhaps pay for help (such as child care) to cover their other responsibilities. They may also be reluctant to reclaim the cost of medications, products and other household items that they may pick up for you.

What may help

Government benefits

While they will not cover the full cost of caring for a person with advanced cancer, the payments and allowances available through Centrelink for caregivers are worth investigating. See "Caregiver benefits" in Chapter 5 for the details.

Access to superannuation

With the right documentation (written certification from a specialist and one other doctor) a person who is expected to live for less than a year may apply to their superannuation fund for a lump-sum payout. You may choose to use some of this money to cover your caregiver's costs.

Other assistance

The Cancer Services Directory on your state's Cancer Council website will have information about the financial assistance programs run by charities in your area. Some of these programs may help with the cost of care giving.

For more information

- **The Federal Department of Health and Ageing** has a fact sheet for caregivers on managing money. Go to www.health.gov.au/internet/main/publishing.nsf/Content/ageing-carers-carerkit.htm
- The Cancer Council has a Welfare Grants Program that can, in cases of extreme hardship, provide financial help to people with cancer. Contact the Cancer Council in your state.

Access to information

A major concern for carers of people with advanced cancer is just how much they don't know. Many become stressed and frustrated by what they see as a lack of adequate information. The more they can find out about your illness, the better they will be able to cope.

What may help

Talk your Doctor

Carers should not hesitate to ask any questions of their doctor, your doctor or other members of your health care team. It may help for them to write down their questions before a consultation or phone call. They can book a longer appointment to give them ample time to talk. The Needs Assessment Tool (Patients & Families) on pg 116 may help identify any questions they may have.

Talk to you

You may not have told your caregiver everything about your illness, possibly for fear of worrying or overwhelming them. Tell them they should not be afraid to ask you anything, and that you will be as honest as you can in reply.

For more information

A wide variety of information is available for caregivers, much of it accessible online:

- Care Search provides reliable information about advanced cancer, palliative care and the types of services in the different states. There are also links to other reliable websites. Go to www.caresearch.com.au
- Carers Australia provides caregivers with information and education resources. Go to www.carersaustralia.com.au or phone **Freecall 1800 242 636**
- The Cancer Council has a range of brochures for people with advanced cancer, their caregivers and families. Call the **Helpline** on **13 11 20**, or go to www.cancercouncil.com.au
- **The Department of Health and Ageing** has fact sheets in a caregiver information pack. They cover topics such as managing money, taking a break and loss and grief. Go to www.health.gov.au/internet/main/publishing.nsf/Content/ageing-carers-carerkit.htm
- The **US Caring Connections** website has detailed information for patients and caregivers. Go to www.caringinfo.org
- The **US National Cancer Institute** has a booklet on support for caregivers. Go to www.cancer.gov



Effect on families

Caregiving often changes the roles and responsibilities of every member of a family, and this can take some getting used to.

The most noticeable impact is usually on young children, particularly if the carer is their mother or father. As a rule, children like routine, and a parent's focus on someone else's needs can throw them. If they are not coping with these changes, they may not sleep well, may wet the bed, or they may play up as a way of reclaiming attention.

Care giving may also put strain on other relationships within the family. Some family members may feel they are carrying the burden of responsibility, while others may feel left out. Some may resent the changes in routine and loss of normality.

What may help

Reassure children

Children need to know they are loved and will be cared for. Communication is the key. Let them know what is happening and who will be taking care of them. If a caregiver can't give their children the time they need they may like to ask another trusted adult to give them some extra attention.

Family talks

It may pay to schedule in regular family meetings (perhaps a weekly meal) where everyone can air their thoughts and feelings without being judged. This may also be a good time to go over routine matters in order to maintain a sense of normality in day-to-day life.

Practical matters

Caring for someone with advanced cancer is a big undertaking and depending on your needs, many of the jobs involved may be new to your caregiver.

What may help

Community nurse

Community nurses can often come to your home and teach carers how to carry out many of the tasks. They may for example help organise medications,

demonstrate how to change dressings or give advice on aids. Your doctor or local hospital should have details about services available in your area, or ask at your nearest community health centre.

For more information

- **The Palliative Care Council of SA** has a resource called Palliative Caring at Home, which provides information for caregivers about the practical aspects of caring for someone at home. Go to the council's website www.pallcare.asn.au or phone **Freecall 1800 660 055**



- The Cancer Council NSW booklet on Caring For Someone with Cancer. Call the **Helpline on 13 11 20** to get a copy sent to you, or go to www.cancercouncil.com.au to download it.
- **Carers Australia** has fact sheets on managing health care and medications and emergency care plans. Go to www.carersaustralia.com.au/index.php?option=com_content&task=view&id=27&Itemid=105 or phone **Freecall 1800 242 636**
- **Care Search** also has information on practical care giving and has contact details for national and state support. Go to www.caresearch.com.au

Personal Notes

A blank sheet of lined paper for notes, featuring horizontal ruling lines across the page.



8. PALLIATIVE CARE

People with advanced cancer may need to use palliative care services for any number of reasons at any stage after curative treatment stops. The term palliative care covers a lot of ground and you may have many questions about what it means for you.

What is it?

Palliative care is the support of people with serious illnesses considered to be chronic if not incurable. It is a holistic approach that aims to achieve the best possible quality of life for you and for those close to you.

Palliative care is not just for people who are “waiting to die” and is not limited to physical health or pain control. Rather, it encompasses the full range of needs you or those around you may have including psychological or social support or a broad range of services.

Where is it provided?

Where you receive palliative care will depend on your circumstances. At any given time, it may be provided in your home, a hospice, a hospital or a nursing home.

Palliative care teams are particularly useful in assisting people who are being cared for at home. If it is difficult, or not advisable for you to remain at home you may need to be admitted to a hospital with palliative care beds or to a specialist palliative care unit or hospice.

Who provides it?

Palliative care may be provided by your specialist, doctor, community nurse and other members of your health care team. However, if you develop problems that are complex or difficult to manage, then your doctor may refer you to health care workers who have training and experience in palliative care services, or to a specialist palliative care team.

Given your experience with cancer, the list of health workers providing palliative care may well be familiar. In this case, all of them will have been trained to meet your needs at this stage of your illness, and be more focused on your quality of life than on a cure.



• Seek palliative care as soon as you think you may need it, because that is when it is most effective. People often say they wish they had known about the services earlier.

Professional health workers

Doctors

Your doctor or treating specialist (if you are using one) is likely to be co-ordinating your care in the first instance. This doctor will oversee your care at home, liaise with the community nurse and refer you to other support people if needed.

If and when your care becomes difficult for your own doctor to manage they may refer you to specialist palliative care doctor or team and if necessary, arrange your admission to a hospital, palliative care unit or hospice.

Palliative care specialists are doctors who can prescribe treatment for your symptoms, liaise with your oncologist and doctor and refer you to other services. These doctors may or may not be part of a specialist palliative care team or service.

Nurses

Palliative care nurses may either work for the community nursing service or in a specialist palliative care team. They may monitor your symptoms and help you with your medications, dressings, personal hygiene and day-to-day care.

To access community nurses who do palliative care, ask your doctor to refer you or contact them through your local community health centre.

Social workers

Social workers can provide social and emotional support to you, your carers and your family. They can help you find services such as in-home respite care, meal deliveries, personal alarms, laundry services and financial assistance.

Counsellors and psychologists

These mental health workers can help you with relationship or family issues, adjusting to and coping with new situations, show you ways of dealing with anxiety and depression, and provide grief counselling to your family and caregivers.

Occupational therapists

Occupational therapists can suggest modifications to your home to aid your independence and ensure your safety. They can also provide special equipment and show you how to use it, as well as advise your caregivers on lifting, transport and hygiene.

Physiotherapists

Palliative physiotherapy can help you manage pain, incontinence, lymphoedema (swelling caused by lymphatic problems) and other symptoms. A physiotherapist can also help you recover from operations and work on your mobility.

Dieticians

Dietary advice may become more important as your illness progresses, especially if your appetite and digestive system are not co-operating with your will to remain as healthy as you can. A dietician can help with eating plans and nutritional supplements, among other things.

Volunteers

Also available are the many people who donate time and can take you to your medical appointments or shopping, help you with housework and gardening and can provide respite for your caregivers.

Specialist teams or services

Although many health care workers offer palliative care as part of a wider range of services, some health professionals specialise in such care. They are usually part of a specialist palliative care team or service, and can include doctors, nurses and any of the health professionals listed above.

Members of these teams are highly experienced in helping people with difficult and complex problems and are very good at talking with people about their condition.⁷¹

You can talk to your doctor or nurse if you would like access to a specialist palliative care service, or you can contact a service directly. Palliative Care

Australia has a National Palliative Care Service Directory (see contact details at the end of this chapter). Receiving care from a specialist palliative care service does not mean you need to stop seeing your other doctors. Palliative care can complement other forms of treatment at any time during your illness.



When and why should I use it?

Some people avoid palliative care services because they think they are “not at that stage yet”. Referral to a palliative care service is not governed by the stage of your disease or how long you are expected to live. Such care is appropriate if and when you, your carer or family identify needs that are complex or simply not being met. Your needs may be medical, emotional, social or spiritual.

The benefits of palliative care include:

- Practical help that may allow you to be cared for at home or in another place of your choice.
- Co-ordination of your care between the many different people involved.
- Information about all aspects of your care.
- Physical, emotional and social support for you, your caregivers and family.
- Help to make practical changes around the house to reduce stress and frustration.
- Help to identify your priorities and to live as well as possible for as long as possible.
- Information and support on bereavement, loss and grief.



Q&A

Q: How long is it feasible for me to remain at home alone?

A: You can stay at home for as long as you wish, provided you have adequate support from community nurses and carers, and your symptoms are manageable. If you live alone, a community nurse will discuss with you how much help you need with daily living. Your carers need to be able to cope with any decline in your health and you need to be aware that the risk of distressing symptoms, such as a catastrophic bleed, may make hospitalisation necessary in some cases.

(Source: Helen Moore, Service Manager, Palliative Care, Calvary Health Care Sydney)

How much will it cost?

The cost of palliative care depends on the services you use. Some core services are free in the public health system but you may have to contribute to the cost of care in other instances.

Private health insurance does not always cover your expenses. You may find yourself paying out of pocket for services such as specialised equipment, 24-hour nursing staff, private hospital stays, some respite care or complementary or alternative treatments.

Some service and programs may be able to help you with some of the out-of-pocket expenses. It may help to call the **Cancer Council Helpline** on **13 11 20** for information about this.

Is it right for me?

Your doctor or your most trusted health professional, can help you decide if palliative care is right for you. You and your caregiver can prepare for this decision by filling out the Needs Assessment Tool-Patients & Families included at the end of this booklet. This tool will document your needs and those of your family member(s) or caregiver(s) so you can discuss them with your doctor. They will also direct you to the sections in this booklet that can give you more information if you want to read more to help yourself.

If you or your caregiver has identified needs on the Needs Assessment Tool-Patients & Families that, for whatever reason, are not being met under your existing circumstances, palliative care may be a solution.



Q&A

Q: What should I do when all treatment has stopped and my oncologist has told me there is nothing more to be done?

A: Palliative treatment can come into play when all curative treatment has stopped and can continue until the very end. Palliative chemotherapy and radiotherapy are commonly used to reduce symptoms, for instance. Your oncologist may still be involved but the palliative care specialist will probably be looking after your overall care.

(Source: Helen Moore, Service Manager, Palliative Care, Calvary Health Care Sydney)

How do I get access to care?

Some palliative care services need to have a referral from your doctor, while others can accept a referral from you, a family member or friend, community health centres and local hospitals. Your doctor, or the individual services, will be able to tell you when formal referrals are needed.

Talking with your Doctor

It is sometimes hard to tell your health professional that you need more help. Research has shown that it helps to take a list of questions to consultations with

your cancer doctors.⁸² That way, you are both focused on what is important and relevant to you at that time.

The Needs Assessment Tool-Patients & Families (pg 116) can help you identify your concerns and may be a way of raising palliative care as an option for you.


For more information


The following organisations can provide information on palliative care and what services are available in your area:

- **Commonwealth Carelink Centre** – phone **Freecall 1800 052 222**, go to www.commcarelink.health.gov.au or visit your local Carelink Centre (phone the Freecall number for locations).
- **Palliative Care Australia** – phone **(02) 6232 4433** to use the National Palliative Care Service Directory to find details of services in your area or go to www.pallcare.org.au

Alternatively, you can contact the palliative care body in your state:

- **Palliative Care Association of NSW** – phone **(02) 9334 1891**, or go to www.palliativecarensw.org.au for a directory of services listed by area.
- **Palliative Care Association of Victoria** – phone **(03) 9662 9644**, or go to www.pallcarevic.asn.au and select the “Resources and Links” option to search by postcode for services in your area.
- **Palliative Care Association of Queensland** – go to www.pallcareqld.com and select the “Resource Centre” link, then search by services.
- **Palliative Care Council of SA** – go to www.pallcare.asn.au and select “Location of Services” for a list of hospice, palliative care, nursing and domiciliary services in each area.
- **Palliative Care WA** – go to www.palliativecarewa.asn.au and select “Location of Services”.
- **NT Department of Health and Community Services** – go to www.nt.gov.au/health/index.shtml and select “A-Z Topics and Services”.
- **ACT Health** – go to www.health.act.gov.au/c/health and select “Health Services”.

- **Tasmanian Department of Health and Human Services** – go to www.dhhs.tas.gov.au and select “Service Directory”.
- Other information resources include:**
- 
 - The Cancer Council booklet Understanding Palliative Care is available by calling the **Cancer Council Helpline on 13 11 20**.
- Cancer Council Victoria’s booklet When Cancer Won’t Go Away, available by calling the **Cancer Council Helpline on 13 11 20**.



FACTS

There are many myths and misconceptions about palliative care:

Myth: Palliative care is only for people who are dying.

Fact: Palliative care is not about dying; it is about living as well as you can for as long as you can. It can be used at any stage during your illness after curative treatment has stopped.

Myth: Palliative care is the same as euthanasia.

Fact: Palliative care may not be focused on prolonging life, but it is certainly not there to shorten it⁷². Euthanasia is assisted suicide, whereas palliative care is assisted living.

Myth: Palliative care gives pain relief in increasing doses, which eventually causes respiratory depression and death.

Fact: Palliative care services help manage your pain, often using drugs such as morphine. Some people think the use of pain-killing drugs causes early death.⁷³ Research does not support this. Minor respiratory depression may occur when strong pain killers are introduced but this settles down quickly. Opioid pain killers should be carefully managed so as to relieve pain without causing excessive sleepiness. Palliative care doctors and nurses are trained and experienced in administering such medications to ensure maximum benefit with minimum harm.⁷⁴

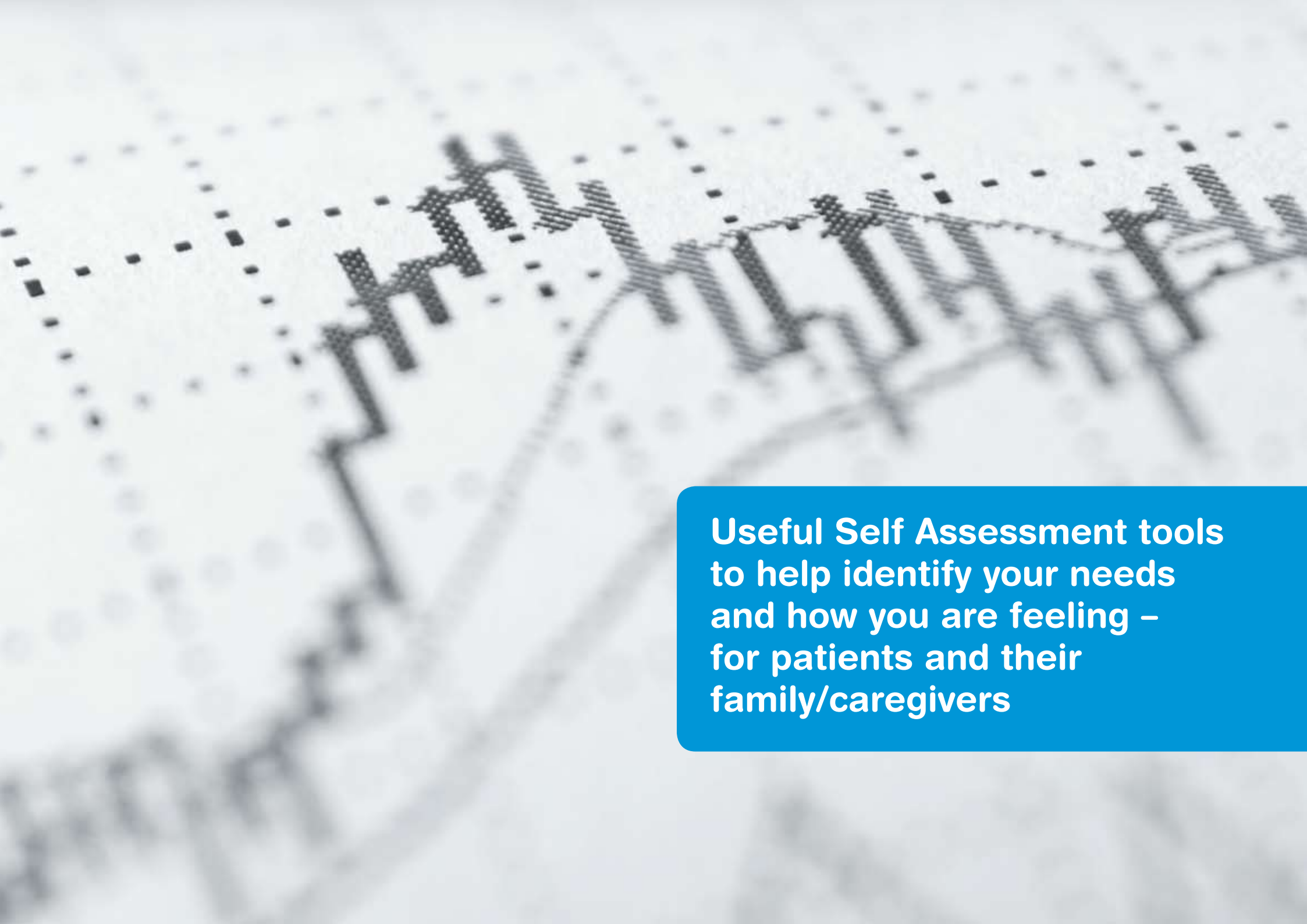
Myth: Palliative care achieves nothing.

Fact: Palliative care is an active approach to symptom management and emotional and social support. The sophisticated medical technology it uses can control symptoms and improve your quality of life.

Myth: People who are referred to palliative care give up and die.

Fact: People who use palliative care may live longer⁷⁵. They also report a better quality of life and more satisfaction with their care.^{76 77} There are also benefits for caregivers and families.⁷⁸⁻⁸¹

Personal Notes



**Useful Self Assessment tools
to help identify your needs
and how you are feeling –
for patients and their
family/caregivers**

Needs Assessment Tool – Patients & Families [NAT-P&F]

The topics below are often a concern for people with cancer and those close to them. Section 1 is for patients to assess their levels of concern about a range of issues. It can be completed on their own or with the help of a family member or friend. Section 2 is for caregivers, friends or family to assess their own levels of concern.

Please indicate how concerned you are now about each issue, by placing a tick in the appropriate column (Level of Concern).

Indicate with a second tick whether you need to discuss the issue with your doctor or other health professional (eg. cancer care coordinator) or whether you would like to address this concern yourself (Actions).

The last column indicates where in Life, Hope and Reality you may find resources to help you address the specific issue.

Take the completed Needs Assessment Tool (NAT-P & F) with you to your next doctor's appointment. You can use it as a prompt to raise and discuss your concerns.

DATE COMPLETED: _ _ - _ - _						
Section 1: For the person with cancer	Level of Concern			Actions		Read more in <i>Life, Hope & Reality</i>
	None/ minor	Some	A lot	Discuss with doctor	Address concern myself	
How concerned are you NOW about:						
Finding general information about cancer						Introduction
Physical Symptoms						
Managing physical symptoms (eg. pain, fatigue)						Chapter 1 and Symptom Distress Scale (p124) Fatigue Scale (p126) Pain Assessment Tool (p130)

DATE COMPLETED: _ _ - _ - _						
Section 1: For the person with cancer	Level of Concern			Actions		Read more in <i>Life, Hope & Reality</i>
	None/ minor	Some	A lot	Discuss with doctor	Address concern myself	
Physical Symptoms Cont.						
Knowing more about which physical symptoms should I expect						Chapter 1
Carrying out normal daily living activities (eg. walking, getting out of a chair)						Chapter 1
Determining availability of other treatments						Chapter 1
My time spent travelling to hospitals and waiting around for appointments						Chapter 1
Getting more information about my physical needs and where to go to obtain the care I need						Chapter 1
Emotional Needs						
Identifying and managing feelings of anxiety, depression sadness, regret or anger						Chapter 2 and Emotion Thermometers (p133)
Trying to maintain hope or finding meaning in my life						Chapter 2 and Helpless/ Hopeless and Fighting Spirit Scales (p135)
Dealing with changes in sexual feelings or intimate relationships						Chapter 2
Dealing with feelings of being unworthy						Chapter 2
Thinking unclearly or changes in my level of awareness						Chapter 2

DATE COMPLETED: _ _ _

Section 1:**For the person with cancer****Level of Concern**None/
minor

Some

A lot

ActionsDiscuss
with
doctorAddress
concern
myselfRead more
in *Life, Hope
& Reality***Emotional Needs Cont**

Accessing health professionals that can help me with my emotional needs

Chapter 2

Social Needs

My current social support network

Chapter 3

My relationship with my partner and family

Chapter 3

Communicating well about important issues between me and members of my family

Chapter 3

Communicating well with my health professionals

Chapter 3

Conflicting beliefs between my current health care and my way of life or customs

Chapter 3

Overcoming language barriers

Chapter 3

My spirituality and finding meaning in my life

Chapter 3

Lifestyle

Losing or gaining weight

Chapter 4

Increasing my level of exercise

Chapter 4

Balancing work and my current health

Chapter 4

DATE COMPLETED: _ _ _

Section 1:**For the person with cancer****Level of Concern**None/
minor

Some

A lot

ActionsDiscuss
with
doctorAddress
concern
myselfRead more
in *Life, Hope
& Reality***Finances**

My financial situation or legal issues

Chapter 5

End of Life

Developing an advance care directive or "living will"

Chapter 6

My feelings about death and dying

Chapter 6

Making plans for the future or making other decisions

Chapter 6

The person who cares for you

Being a burden to loved ones

Chapter 7

Accessing support for those in my family or friends caring for me

Chapter 7

Palliative care

Knowing when palliative care is appropriate for me

Chapter 8

Knowing which cancer specialist to see to obtain palliative care

Chapter 8

Other topics of concern? Please list here and discuss with health professionals:

.....

.....

.....

.....

.....

DATE COMPLETED: _ _ - _ - _

**Section 2:
For Caregivers,
family members
or friends**
Level of Concern
None/
minor

Some

A lot

Actions
Discuss
with
doctorAddress
concern
myselfRead more
in *Life, Hope
& Reality*
How concerned are you NOW about
Finding general
information about cancer

Introduction

Patient's Physical Symptoms
Knowing the physical
symptoms that the
person with cancer may
experience
**Chapter 1 and
Symptom
Distress Scale
(p124)
Fatigue Scale
(p126)
Pain Assessment
Tool (p130)**
Knowing the extent to which
I can help the person with
cancer with managing
physical symptoms.

Chapter 1

Knowing the extent to
which I can help the person
with cancer in performing
daily living activities
**Chapter 1
Chapter 7**
Providing physical care
the person with cancer
requires
**Chapter 1
Chapter 7**
The difficulty the person
with cancer is having
looking after him/herself
**Chapter 1
Chapter 7**
Determining availability
of other treatments

Chapter 1

My time spent travelling
to hospitals and waiting
around for appointments

Chapter 1

Getting more information
about the physical needs
of the person with cancer
and where to go to obtain
the care needed

Chapter 1

DATE COMPLETED: _ _ - _ - _

**Section 2:
For Caregivers,
family members or
friends**
Level of Concern
None/
minor

Some

A lot

Actions
Discuss
with
doctorAddress
concern
myselfRead more
in *Life, Hope
& Reality*
Patient's Emotional Needs
Identifying and managing
the feelings and emotional
issues
the person with cancer may
be experiencing
(eg. anxiety, depression)
**Chapter 2
Emotion
Thermometers
(p133)
Helpless/
Hopeless and
Fighting Spirit
Scales (p135)**
Identifying and
managing the feelings and
emotional issues
I am experiencing
(eg. anxiety, depression)
**Chapter 2
Emotion
Thermometers
(p133)
Helpless/
Hopeless and
Fighting Spirit
Scales (p135)**
Maintaining or instilling
hope in the person with
cancer and myself
**Chapter 2
Helpless/
Hopeless and
Fighting Spirit
Scales (p135)**
Dealing with changes in
the person with cancer's
sexual feelings

Chapter 2

Dealing with changes in my
intimate relationship with
the person with cancer

Chapter 2

Maintaining the person
with cancer's sense
of worthiness

Chapter 2

Managing impaired
thinking and changes in
awareness the person with
cancer may be experiencing

Chapter 2

Accessing health
professionals that can help
the person with cancer and
me with emotional needs

Chapter 2

DATE COMPLETED: _ - -

Section 2:
For Caregivers,
family members
or friends

Level of Concern

Actions

None/
minor

Some

A lot

Discuss
with
doctorAddress
concern
myselfRead more
in *Life, Hope
& Reality*
Social Needs
My current social
support network

Chapter 3

My relationship with the
person with cancer

Chapter 3

Communicating well with
the person with cancer

Chapter 3

Communicating well with
health professionals

Chapter 3

Conflicting beliefs between
my current health care and
my way of life or customs

Chapter 3

Overcoming language barriers

Chapter 3

My spirituality and finding
meaning in my life

Chapter 3

Lifestyle
Helping the person
with cancer maintain
a healthy lifestyle

Chapter 4

Obtaining resources so I can
maintain a healthy life myselfChapter 4
Chapter 7Maintaining the person with
cancer's work

Chapter 4

Obtaining resources so I can
continue to workChapter 4
Chapter 7
Finances
My financial situation or
legal issues that are upsetting
me or that require assistance.

Chapter 5

End of Life
Helping the person with
cancer to develop an advance
care directive or "living will"

Chapter 6

DATE COMPLETED: _ - -

Section 2:
For Caregivers,
family members
or friends

Level of Concern

Actions

None/
minor

Some

A lot

Discuss
with
doctorAddress
concern
myselfRead more
in *Life, Hope
& Reality*
End of Life Cont
My feelings about
death and dying

Chapter 6

Making plans for the future or
making other decisions

Chapter 6

Implications of caring for a person diagnosed with cancer
Providing the help and
support that the person
with cancer requires

Chapter 7

Accessing information
relevant to your own needs
as a caregiver from relevant
support services

Chapter 7

Taking the break I need

Chapter 7

My illnesses or injuries that
make it difficult for me to care
for the person with cancer

Chapter 7

Feeling burnt out by my care
giving role

Chapter 7

Support for my family or
friends caring for me

Chapter 7

Palliative Care
Knowing when palliative care
is appropriate for me care for
the person with cancer

Chapter 8

Knowing which cancer
specialist the person with
cancer should see to obtain
palliative care

Chapter 8

Other topics of concern? Please list here and discuss with health professionals:

.....

.....

.....

Symptom Distress Scale

Date completed: ____/____/____

Instructions to complete assessment: Below are 5 different numbered statements. Think about what each statement says, then place a circle the statement that most closely indicates how you have been feeling lately. The statements are ranked from 1 to 5, where number 1 indicates no problems and number 5 indicates the maximum amount of problems. Numbers 2 through 4 indicate you feel somewhere in between these two extremes.

Nausea (1)

1	2	3	4	5
I seldom if ever have nausea	I have nausea once in a while	I have nausea fairly often	I have nausea half the time at least	I have nausea continually

Nausea (2)

1	2	3	4	5
When I do have nausea, it is very mild	When I do have nausea, it is mildly distressing	When I have nausea, I feel pretty sick	When I have nausea, I usually feel very sick	When I have nausea, I am as sick as I could possibly be

Appetite

1	2	3	4	5
I have my normal appetite and enjoy good food	My appetite is usually, but not always, pretty good	I don't really enjoy my food	I have to force myself to eat my food	I cannot stand the thought of food

Insomnia

1	2	3	4	5
I sleep as well as I always have	I occasionally have trouble getting to sleep and staying asleep	I frequently have trouble getting to sleep	I have difficulty getting to sleep and staying asleep almost every night	It is almost impossible for me to get a decent night's sleep

Pain (1)

1	2	3	4	5
I almost never have pain	I have pain once in a while	I have pain several times a week	I am usually in some degree of pain	I am in some degree of pain almost constantly

Pain (2)

1	2	3	4	5
When I do have pain, it is very mild	When I do have pain, it is mildly distressing	When I do have pain, it is usually fairly intense	The pain I have is very intense	The pain I have is almost unbearable

Fatigue

1	2	3	4	5
I seldom feel tired or fatigued	There are periods when I am rather tired or fatigued	There are periods when I am quite tired and fatigued	I am usually very tired and fatigued	Most of the time, I feel exhausted

Bowel

1	2	3	4	5
I have my normal bowel pattern	My bowel pattern occasionally causes me some discomfort	My present bowel pattern occasionally causes me considerable discomfort	I am usually in considerable discomfort because of my present bowel pattern	I am in almost constant discomfort because of my bowel pattern

Concentration

1	2	3	4	5
I have my normal ability to concentrate	I occasionally have trouble concentrating	I occasionally have considerable trouble concentrating	I usually have considerable difficulty concentrating	I just can't seem to concentrate at all

From McCorkle R, Cooley ME, She JA. A user's manual for the Symptom Distress Scale. Philadelphia: University of Pennsylvania

Instructions to interpret assessment: The presence of any symptom should be discussed with your health professional (2 or above). The more intense these are (3 and above), the more it may become urgent for you to discuss these with your health professionals.

Fatigue Scale

Date completed: ____/____/____

Instructions to complete assessment: Many individuals can experience a sense of unusual or excessive tiredness whenever they become ill, receive treatment or recover from their illness/treatment. This unusual sense of tiredness is not usually relieved by either a good night's sleep or by rest. Some call this symptom "fatigue" to distinguish it from the usual sense of tiredness.

For each of the following questions, please fill in the space provided for that response that best describes the fatigue you are experiencing now or for today. Please make every effort to answer each question to the best of your ability.

1. How long have you been feeling fatigue? (Check one response only).

- ☐ 1. Not feeling fatigue
- ☐ 2. Minutes
- ☐ 3. Hours
- ☐ 4. Days
- ☐ 5. Weeks
- ☐ 6. Months
- ☐ 7. Other (Please describe)_____

2. To what degree is the fatigue you are feeling now causing you distress?

No Distress									A Great Deal
1	2	3	4	5	6	7	8	9	10

3. To what degree is the fatigue you are feeling now interfering with your ability to complete your work or school activities?

None									A Great Deal
1	2	3	4	5	6	7	8	9	10

4. To what degree is the fatigue you are feeling now interfering with your ability to socialise with your friends?

None									A Great Deal
1	2	3	4	5	6	7	8	9	10

5. To what degree is the fatigue you are feeling now interfering with your ability to engage in sexual activity?

None									A Great Deal
1	2	3	4	5	6	7	8	9	10

6. Overall, how much is the fatigue which you are now experiencing interfering with your ability to engage in the kind of activities you enjoy doing?

None									A Great Deal
1	2	3	4	5	6	7	8	9	10

7. How would you describe the degree of intensity or severity of the fatigue which you are experiencing now?

Mild									Severe
1	2	3	4	5	6	7	8	9	10

8. To what degree would you describe the fatigue which you are experiencing now as being?

Pleasant									Unpleasant
1	2	3	4	5	6	7	8	9	10

9. To what degree would you describe the fatigue which you are experiencing now as being?

Agreeable									Disagreeable
1	2	3	4	5	6	7	8	9	10

10. To what degree would you describe the fatigue which you are experiencing now as being?

Protective									Destructive
1	2	3	4	5	6	7	8	9	10

11. To what degree would you describe the fatigue which you are experiencing now as being?

Positive									Negative
1	2	3	4	5	6	7	8	9	10

12. To what degree would you describe the fatigue which you are experiencing now as being?

Normal									Abnormal
1	2	3	4	5	6	7	8	9	10

13. To what degree are you now feeling:

Strong					Weak				
1	2	3	4	5	6	7	8	9	10

14. To what degree are you now feeling:

Awake					Sleepy				
1	2	3	4	5	6	7	8	9	10

15. To what degree are you now feeling:

Lively					Listless ("washed out")				
1	2	3	4	5	6	7	8	9	10

16. To what degree are you now feeling:

Refreshed					Tired				
1	2	3	4	5	6	7	8	9	10

17. To what degree are you now feeling:

Energetic					Unenergetic				
1	2	3	4	5	6	7	8	9	10

18. To what degree are you now feeling:

Patient					Impatient				
1	2	3	4	5	6	7	8	9	10

19. To what degree are you now feeling:

Relaxed					A Great Deal				
1	2	3	4	5	6	7	8	9	10

20. To what degree are you now feeling:

Exhilarated					Depressed				
1	2	3	4	5	6	7	8	9	10

21. To what degree are you now feeling:

Able to Concentrate					Unable to Concentrate				
1	2	3	4	5	6	7	8	9	10

22. To what degree are you now feeling:

Able to Remember					Unable to Remember				
1	2	3	4	5	6	7	8	9	10

23. To what degree are you now feeling:

Able to Think Clearly					Unable to Think Clearly				
1	2	3	4	5	6	7	8	9	10

24. Overall, what do you believe is *most* directly contributing to or causing your fatigue?

25. Overall, the *best* thing you have found to relieve your fatigue is:

26. Is there anything else you would like to add that would describe your fatigue better to us?

27. Are you experiencing any other symptoms right now?

From Piper BF, Dibble SL, Dodd MJ, Weiss MC, Slaughter RE, Paul SM. The revised Piper Fatigue Scale: Psychometric evaluation in women with breast cancer. *Oncology Nursing Forum*. 1998 May; 25(4): 677-684

Instructions to interpret assessment: If you have scored 4 and above on questions 1-23, detach this sheet and use it to discuss your fatigue with your health professionals. Also, complete questions 24-27, as this will help your health professional better understand you experience with fatigue

Pain Assessment Tool

Date completed: ____/____/____

Instructions to complete assessment: The following assessment is to help you evaluate any pain experienced.

1. Please mark the area of pain on the drawing. If you have more than one pain, label them A, B, C, etc. and describe your pain in the box:

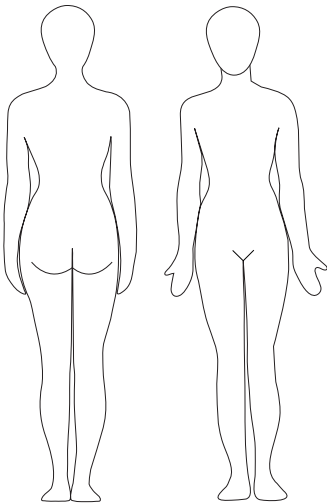
Identification of areas of pain:

A.

B.

C.

D.



2. How would you rate your overall pain?

Use the scale below where 0 = no pain and 10 = severe pain.

No pain									Severe
1	2	3	4	5	6	7	8	9	10

3. How and when did your pain begin?

4. Check the words that best describe the kind of pain you have:

- ☐ Dull ache
- ☐ Stabbing
- ☐ External
- ☐ Pins & needles
- ☐ Internal
- ☐ Sharp
- ☐ Burning
- ☐ Cramping
- ☐ Throbbing
- ☐ Other (describe): _____

5. How long does the pain usually last?

- ☐ Seconds
- ☐ Hours
- ☐ Minutes
- ☐ Constant

6. What makes the pain worse?

- ☐ Walking
- ☐ Moving
- ☐ Eating
- ☐ Other (describe): _____

7. Is your pain worse at a particular time of day? When?

8. What makes the pain better?

- ☐ Heat/cold
- ☐ Distraction
- ☐ Medication
- ☐ Massage
- ☐ Lying still
- ☐ Relaxation
- ☐ Changing position
- ☐ Other (describe): _____

9. What pain medications are you presently taking?

1. _____

2. _____

3. _____

4. _____

5. _____

10. What medications have helped to control your pain?

1. _____

2. _____

3. _____

4. _____

5. _____

11. What medications have not helped?

1. _____

2. _____

3. _____

4. _____

5. _____

12. Has the pain or treatment produced any other effects?

- ☐ Nausea ☐ Drowsiness ☐ Anxiety ☐ Unclear thinking
☐ Constipation ☐ Disturbed sleep ☐ Dizziness ☐ Diarrhea
☐ Changes in mood ☐ Loss of appetite
☐ Other (describe): _____

13. How has the pain affected your daily activities (eg. bathing, sleeping, eating)?

14. How has the pain affected you life (eg. finances, job, family relationships)?

From Registered Nurses Association of Ontario.

Nursing Best Practice Guideline: Assessment and Management of Pain. 2007.

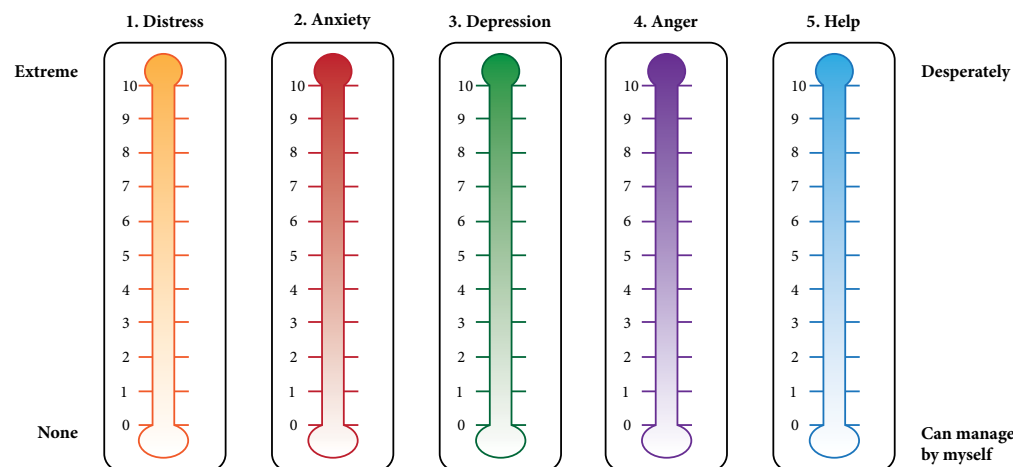
Instructions on how to interpret assessment: Please detach this assessment sheet and bring it to your doctor, so they will be able to find the best way to help alleviate your pain

Emotion Thermometers

Date completed: ____/____/____

Instructions to complete assessment: The following assessment is to help you or your family members or friends evaluate the extent to which you or they are emotionally upset.

1. In the first four columns or thermometers, please circle the number that best describes how much emotional upset you have been experiencing in the past week, including today. In the last column please indicate how much you need help for these concern:



Instructions to interpret assessment: If you scored a 4 and above on any of these thermometers, please detach this sheet and communicate your assessment with your health professional.

2. Please indicate whether the following is contributing to being emotionally upset:

NO	YES		NO	YES	
		Practical Problems			Physical Problems
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Insurance	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Work/School	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
<input type="checkbox"/>	<input type="checkbox"/>	Childcare	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
			<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
		Family Problems	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Mouth Sores
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Eating
			<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
		Emotional Problems	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
			<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet
		Spiritual/Religious Concerns	<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
<input type="checkbox"/>	<input type="checkbox"/>	Relating to God	<input type="checkbox"/>	<input type="checkbox"/>	Sexual
<input type="checkbox"/>	<input type="checkbox"/>	Loss of Faith			

Other Problems:

Helpless/Hopeless and Fighting Spirit Scales

Instructions to complete assessment: A number of statements are given below which describe people’s feeling of hope. Please mark with a ‘√’ or an ‘x’ your answer to each statement that indicates how far it applies to you at the present. For example, if the statement definitely does not apply to you then you should answer ‘1’.

DATE COMPLETED: __ - __ - __				
	1	2	3	4
	Definitely does not apply to me	Does not apply to me	Applies to me	Definitely applies to me
I see my illness as a challenge				
I feel like giving up				
I feel completely at a loss about what to do				
I try to fight the illness				
I can’t handle it				
I am not hopeful about the future				
I feel there is nothing I can do to help myself				
I think it is the end of the world				
I am very optimistic				
I feel that life is hopeless				
I can’t cope				
I am determined to fight this disease				

From Watson M, Law, M, dos Santos M, Greer S, Baruch J, Bliss J. The mini-mac: Further development of the mental adjustment to cancer scale. Journal of Psychosocial Oncology 1994; 12(3): 33-46.

Instructions to interpret assessment: Add up all of your answers. If your score is less than 25, you should discuss your answers with your health professional.

A number of references to websites and other sources of information are suggested throughout this booklet. They were accurate at the time of publication. If you are unable to get access to a particular reference, you are welcome to contact our research centre, the **Centre for Health Research and Psycho-oncology (CHeRP)**, at CHeRP@newcastle.edu.au or on (02) 4913 8604.

Some other useful websites include:

- American Cancer Society – www.cancer.org
- Cancer Answers (Cancer Council NSW)
– www.cancercouncil.com.au/canceranswers
- Cancer Australia – www.canceraustralia.gov.au
- Cancerbackup (Macmillan Cancer Support – UK site)
– www.cancerbackup.org.uk
- CancerWeb (UK) – cancerweb.ncl.ac.uk
- Health InSite – www.healthinsite.gov.au
- myDr – www.mydr.com.au/cancer-care
- Private health – www.privatehealth.gov.au
- The National Prescribing Services – www.nps.org.au
- US National Cancer Institute – www.cancer.gov
- Virtual Cancer Centre – www.virtualcancercentre.com

Useful websites for some types of cancer include:

- Bladder and bowel – Federal Department of Health and Ageing's Bladder and Bowel Website (www.bladderbowel.gov.au)
- Bowel – Bowel Cancer Australia (www.bowelcanceraustralia.com)
- Brain – Brain Foundation (www.brainaustralia.org.au)
- Breast – National Breast and Ovarian Cancer Centre (www.nbocc.org.au), National Breast Cancer Foundation (www.nbcf.org.au), Breast Cancer Network Australia (www.bcna.org.au)
- Head and neck – Sydney Head and Neck Cancer Institute (www.shnci.org), UK Mouth Cancer Foundation (www.mouthcancerfoundation.org)

- Leukaemia – Leukaemia Foundation (www.leukaemia.org.au)
- Liver – American Liver Foundation (www.liverfoundation.org)
- Lung – Lungevity (www.lungevity.com.au), Australian Lung Foundation (www.lungfoundation.com.au), MesotheliomaWise (www.mesotheliomawise.org)
- Lymphoma – Lymphoma Australia (www.lymphoma.org.au)
- Ovarian – National Breast and Ovarian Cancer Centre (www.nbocc.org.au)
- Prostate – Prostate Foundation of Australia (www.prostate.org.au), Lions Australian Prostate Cancer Website (www.prostatehealth.org.au)
- Skin – Skin & Cancer Foundation Australia (www.scfa.edu.au)

REFERENCES

1. Lidstone V, Butters E, Seed P, Sinnott C, Beynon T, Richards M. Symptoms and concerns amongst cancer outpatients: Identifying the need for specialist palliative care. *Palliative Medicine* 2003;17(7):588.
2. Bower J. Fatigue in cancer patients and survivors: Mechanisms and treatment. *Primary Psychiatry* 2005;12:53-57.
3. Reddy A, Bruera E, Pace E, Zhang K, Reyes-Gibby C. Clinically important improvement in the intensity of fatigue in patients with advanced cancer. *Journal of Palliative Medicine* 2007;10 1068-1075.
4. Curt G, Breitbart W, Cella D, Groopman J, Horning S, Itri L. Impact of cancer related fatigue on the lives of patients: New findings from the Fatigue Coalition. *Oncologist* 2000;5:353-360.
5. Minton O, Stone P, Richardson A, Shape M, Hotopf M. Drug therapy for the management of cancer related fatigue. *Cochrane Database of Systematic Reviews* 2008;2.
6. Portenoy RK, M. IL. Cancer-related fatigue; Guidelines for evaluation and management. In: (Eds.) IMMSR, editor. *Scientific Updates 5*: Elsevier, 2001.
7. Ahlberg K, Ekman T, Gaston-Johansson F, Mock V. Assessment and management of cancer-related fatigue. *Lancet* 2003;362:640-650.
8. Cramp F, Daniel J. Exercise for the management of cancer-related fatigue in adults. *Cochrane Database of Systematic Reviews* 2008;2.
9. Mock V, Frangakis C, Davidson NE, Ropka ME, Pickett M, Poniatowski B, et al. Exercise Manages Fatigue During Breast Cancer Treatment: A Randomized Control Trial *Psycho-Oncology*, 2005;14: 464-477.
10. Mock V, Pickett M, Ropka ME, Muscarel E, Stewart KJ, Rhodes VA, et al. Fatigue and quality of life outcomes of exercise during cancer treatment *Cancer Practice* 2001;9:119-127.
11. Oldham L, Kristjanson LJ. Development of a pain management programme for family carers of advanced cancer patients. *International Journal of Palliative Nursing* 2004;10:91-99.
12. Regaard A. The principles of pain management in advanced cancer. *British Journal of Community Nursing* 2000;5:382-386.
13. Bender J, Hohenadel J, Wong J, Katz JN, Ferris L, Shobbrook C, et al. What patients with cancer want to know about pain: a qualitative study. *Journal of Pain & Palliative Care* 2008;35:177-187.
14. Walker VA, Hoskin PJ, Hanks GW. Evaluation of WHO analgesic guidelines for cancer pain in a hospital based palliative care unit. *Journal of Pain and Symptom Management* 1988;3:145-149.
15. Lloyd-Williams M, Dennis M, Taylor F. A prospective study to determine the association between physical symptoms and depression in patients with advanced cancer. *Palliative Medicine* 2004;18(6):558-563.
16. Morasso G, Capelli M, Viterbori P, Di Leo S, Alberisio A, Costantini M, et al. Psychological and symptom distress in terminal cancer patients with met and unmet needs. *Journal of Pain and Symptom Management* 1999;17(6):402-409.
17. Dumitrescu L, van den Heuvel-Olaroiu M, van den Heuvel-Olaroiu W. Changes in symptoms and pain intensity of cancer patients after enrolment in palliative care at home. *Journal of Pain and Symptom Management* 2007;34:488-496.
18. Del Fabbro E, Dalal S, Bruera E, Arnold R, Liao S. Symptom control in palliative care-Part III: Dyspnoea and Delirium. *Journal of Palliative Medicine* 2006;9:422-436.

19. Jennings A, Davies A, Higgins J, Broadley K. Opioids for the palliation of breathlessness in terminal illness. *Cochrane Database of Systematic Reviews* 2008;2.
20. Uronis H, Currow D, McCrory D, Samsa G, Abernethy A. Oxygen for relief of dyspnoea in mildly – or non-hypoxaemic patients with cancer: a systematic review and meta-analysis. *British Journal of Cancer* 2008;98(2):294-9.
21. Ripamonti C, Fusco F. Respiratory problems in advanced cancer. . *Supportive care in cancer*. 2002;10(3):204-16
22. Kyle G. Constipation and palliative care – where are we now? *International Journal of Palliative Nursing* 2007;13:6-16.
23. Murray B. Preventing Constipation *Journal of Community Nursing* 1997;11:18-20.
24. Campbell T, Draper S, Reid J, Robinson L. The management of constipation in people with advanced cancer. *International Journal of Palliative Nursing* 2001;7:110-119.
25. Sela RA, Wantanabe S, Nikolaichuk CL. Sleep disturbances in palliative cancer patients attending a pain and symptom control clinic. *Palliative and Supportive Care* 2005;3:23-31.
26. Chevillat A. Rehabilitation of patients with advanced cancer. *Cancer Rehabilitation and the New Millennium* 2001;92:1039-1047.
27. Zeller JL. Cancer Chemotherapy *JAMA* 2008;299:2706.
28. Harrington S, Smoth T. The role of chemotherapy at the end of life: “When is enough, enough?” *JAMA* 2008;299:2997-2678.
29. Lawenda BD, Kelly KM, Ladas EJ, Sagar SM, Vickers A, Blumberg JB. Should Supplemental Antioxidant Administration Be Avoided During Chemotherapy and Radiation Therapy? *J Natl Cancer Inst* 2008;100:773 – 783.
30. Sparreboom A, Cox MC, Acharya MR, Figg WD. Herbal Remedies in the United States: Potential Adverse Interactions With Anticancer Agents. *J Clin Oncol* 2004;22(12):2489-2503.
31. Bjelakovic G, Nikolova D, Gluud LL, Simonetti RG, Gluud C. Mortality in Randomized Trials of Antioxidant Supplements for Primary and Secondary Prevention. *Systematic Review and Meta-analysis*. *JAMA* 2007;297(8):842-857.
32. Smith EM, Gomm SA. Assessing the independent contribution to quality of life from anxiety and depression in patients with advanced cancer. *Palliative Medicine* 2003;7:509-513.
33. Aranda SK, Hayman-White K. Home caregivers of the person with advanced cancer. *Cancer Nursing* 2001;24(11):300-306.
34. Valdimarsdottir U, Helgason AR, Furst CJ, Adolffson J, Steineck G. The unrecognised cost of cancer patients' unrelieved symptoms: a nationwide follow-up of their surviving partners. *British Journal of Cancer* 2002;86(10):1540-1545.
35. Pascoe S, Edelman S, Kidman A. Prevalence of psychological distress and use of support services by cancer patients at Sydney hospitals. *Australian and New Zealand Journal of Psychiatry* 2000;34(5):785-791.
36. Kelly BJ, Pelusi D, Burnett PC, Varghese FT. The prevalence of psychiatric disorder and the wish to hasten death among terminally ill cancer patients. *Palliative and Supportive Care* 2004;2(2):163-169.
37. Fallowfield L, Ratcliffe D, Jenkins V, Saul J. Psychiatric morbidity and its recognition by doctors in patients with cancer. *British Journal of Cancer* 2001;84(8):1011-5.
38. Kadan-Lottick NS, Vanderwerker LC, Block SD, Zhang B, Prigerson HG. Psychiatric disorders and mental health service use in patients with advanced cancer. *Cancer* 2005;104(12):2872-81.
39. Newell S, Sanson Fisher RW, Girgis A, Bonaventura A. How well do medical oncologists' perceptions reflect their patients' reported physical and psychosocial problems? *Cancer* 1998;83(8):1640-1651.
40. Akechi T, Okuyama T, Onishi J, Morita T, Furukawa T. Psychotherapy for depression among incurable cancer patients. *Cochrane Database of Systematic Reviews* 2008;2.
41. Savard J, Simard S, Giguere I, Ivers H, Morin CM, Maunsell E, et al. Randomized clinical trial on cognitive therapy for depression in women with metastatic breast cancer: psychological and immunological effects. . *Palliative & Supportive Care* 2006;4:219-37.
42. Ramsay K, Ramsay J, Main D. Both group peer counselling and individual counselling reduce anxiety and depression, and increase self-esteem and overall life satisfaction in palliative cancer care. *Counselling. Psychology Quarterly* 2007;20:157-167.
43. Coyle N, Sculco L. Expressed desire to hasten death in seven patients living with advanced cancer: a phenomenological inquiry. *Oncology Nursing Forum* 2004;31:699-709.
44. Rodin G, Zimmermann C, Rydall A, Jones J, Shepherd FA, Moore M, Fruh, M., et al. The desire for hastened death in patients with metastatic cancer. *Journal of Pain and Symptom Management* 2007;33:661-675.
45. Hudson P, Kristjansson L, Ashby M, Kelly BJ, Schofield PE, Hudson R, et al. Desire for hastened death in patients with advanced disease and the evidence base of clinical guidelines: a systematic review. *Palliative Medicine* 2006;20:693-701.
46. Bruner D, Boyd C. Assessing women's sexuality after cancer therapy: checking assumptions with the focus group technique. *Cancer Nursing* 1999;22:438-447.
47. Oneschuk D, Tarumi Y. *Palliative Care Tips*, 2008.
48. Shuster JL. Delirium, confusion and agitation at the end of life. *Journal of Palliative Medicine* 1998;2:177-186
49. Breitbart W, Gibson C, Tremblay A. The delirium experience: delirium recall and delirium-related distress in hospitalised patients with cancer, their spouses/caregivers, and their nurses. *Psychosomatics* 2002;43(3):183-194.
50. Ell K, Mantell J, Hamovitch M, Nishimoto R. Social support, sense of control and coping among patients with breast, lung, or colorectal cancer. *Journal of Psychosocial Oncology* 1989;7(3):63-89.
51. Haley WE, LaMonde LA, Han B, Narramore S, Schonwetter R. Family caregiving in hospice: effects on psychological and health functioning among spousal caregivers of hospice patients with lung cancer and dementia. *Hospice Journal* 2001;15(4):1-18.
52. Christ GH, Siegel K, Freund B, Langosch D, Henderson S, Sperber D, et al. Impact of parental terminal cancer on latency-age children. *American Journal of Orthopsychiatry* 1993;63(3):417-425.
53. Hall P, Stone G, Fiset VJ. *Palliative Care: how can we meet the needs of our multicultural communities?* *Journal of Palliative Care* 1998;14(2):46-4946.
54. Grant E, Murray S, Kendall M, Boyd K, Tilley S, Ryan D. Spiritual issues and needs: Perspectives from patients with advanced cancer and non-malignant disease: a qualitative study. *Palliative and Supportive Care* 2004;2(371-378).
55. McClain-Jacobsen C, Rosenfeld B, Kosinski A, Pessin H, Cimino JE, Breitbart W. Belief in an afterlife, spiritual wellbeing and end of life despair in patients with advanced cancer. *General Hospital Psychiatry* 2004;26:484-486.
56. Breitbart W. Spirituality and meaning in supportive care: spirituality – and meaning-centered group psychotherapy interventions in advanced cancer. *Supportive Care in Cancer* 2002;10(4):272-280.
57. Fisher D. Caring Costs. A survey of tax issues and health and disability related costs for carer families. Canberra: Carers Association of Australia, 1998.
58. Grbich CF, Maddocks I, Parker D. Family caregivers, their needs, and home-based palliative care services. *Journal of Family Health* 2001;7(2):171-188.
59. Tierney WM, Dexter PR, Gramelspacher doctor, et al. The effect of discussions about advance directives on patients' satisfaction with primary care. *Journal of General Internal Medicine* 2001;16:32-40.
60. Waddell C, Clarnette RM, Smith M, Oldham L, Kellehear A. Treatment decision-making at the end of life: a survey of Australian doctors' attitudes towards patients' wishes and euthanasia. *Medical Journal of Australia* 1996;165:540-544.
61. Grbich C, Parker D, Maddocks I. The emotions and coping strategies of caregivers of family members with a terminal cancer. *Journal of Palliative Care*. 2001;17(1):30-6.
62. Hudson P. Positive aspects and challenges associated with caring for a dying relative at home. *International Journal of Palliative Nursing* 2004;10(2):58-65.
63. Briggs H, Fisher D. Warning – caring is a health hazard. Canberra: Carers Association of Australia, 2000.
64. Goldstein NE, Concato J, Fried TR, Kasl SV, Johnson-Hurzeler R, Bradley EH. Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *Journal of Palliative Care* 2004;20(1):38-
65. Aoun S. The hardest thing we have ever done: The social impact of caring for terminally ill people In Australia 2004. Deakin West: Palliative Care Australia, 2004.
66. Australian Bureau of Statistics. Disability, ageing and carers, Australia: summary of findings, 1998: Australian Bureau of Statistics, 1999.
67. Schofield HL, Herrman HE, Bloch S. A profile of Australian family caregivers: diversity of roles and circumstances. *Australian and New Zealand Journal of Public Health* 1997;21(1):59-66.
68. Stajduhar KI. Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care* 2003;19(1):27-35.
69. Grov EK, Dahl AA, Moum T, Fossa SD. Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Ann Oncol* 2005;16(7):1185-1191.
70. Grunfeld E, Coyle D, Whelan T, Clinch J, Reyno L, Earle CC, et al. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal* 2004;170(12):1795-1801.
71. Palliative Care Australia. A guide to palliative care service development: A population based approach. Deakin West: Palliative Care Australia, 2005:1-48.
72. World Health Organization. National Cancer Control Programmes: Policies and managerial guidelines. 2nd ed. Geneva: World Health Organization, 2002.
73. James N, Field D. The routinization of hospice: charisma and bureaucratization. *Social Science & Medicine* 1992;34(12):1363-1375.
74. Fohr SA. The double effect of pain medication: Separating myth from reality. *Journal of Palliative Medicine* 1998;1(4):315-328.
75. Pyenson B, Connor SR, Fitch K, Kinzbrunner B. Medicare cost in matched hospice and non-hospice cohorts. *Journal of Pain and Symptom Management* 2004;28(3):200-210.
76. Higginson I, Finlay I, Goodwin D, Hood K, Edwards A, Cook A, et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *Journal of Pain and Symptom Management* 2003;25(2):150-68.
77. Higginson I, Goodwin I, Edwards A, Norman C. Do hospital-based palliative teams improve care for patients or families at the end of life? *Journal of Pain and Symptom Management* 2002;23(2):96-106.
78. Christakis NA, Iwashyna TJ. The health impact of health care on families: A matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Social Science and Medicine* 2003;57:465-475.
79. Harding R, Higginson I. What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine* 2003;17(1):63-74.
80. Ransford H, Smith M. Grief resolution among the bereaved in hospice and hospital wards. *Social Science and Medicine* 1991;32(3):295-304.
81. Ringdal G, Ringdal K, Jordhøy MS, Ahlner-Elmqvist M, Jannert M, Kaasa S. Health-related quality of life (HRQOL) in family members of cancer victims: results from a longitudinal intervention study in Norway and Sweden. *Palliative Medicine* 2004;18(2):108-120.
82. Clayton JM, Butow PN, Tattersall MHN, Devine RJ, Simpson JM, Aggarwal G, et al. Randomized Controlled Trial of a Prompt List to Help Advanced Cancer Patients and Their Caregivers to Ask Questions About Prognosis and End-of-Life Care. *Journal of Clinical Oncology* 2007;25(6):715-723.
83. Mock V. *Fatigue Management: Evidence and Guidelines for Practice*. Cancer; 2001:1699-1707.
84. Registered Nurses' Association of Ontario (RNAO). *Nursing Best Practice Guidelines: Prevention of Constipation in the Older Adult Population*. Ontario: RNAO publications.
85. Cancer Council NSW. Food and Cancer. Accessed online May 2009 at <http://www.cancercouncil.com.au/html/patientsfamiliesfriends/livingwithcancer/foodandcancer/downloads/foodandcancer.pdf>
86. Doyle D, Hanks G, Cherny N, Calman K. *Oxford Textbook of Palliative Medicine*. 3rd ed. Oxford: Oxford University Press, 2005.
87. Continence Foundation of Australia. Living with Incontinence. Accessed online May 2009 at <http://www.continence.org.au/site/index.cfm?display=112741>
88. Hume Regional Integrated Cancer Services, Clinical Practice Guideline: Diarrhoea Associated With Chemotherapy, 2007
89. NSW Cancer Council, Understanding Complementary Therapies, 2008

90. Stockler, M.R., O'Connell, R., Nowak, A.K., Goldstein, D., Turner, J., Wilcken, N.R.C., Wyld, D., Abdi, E., Glasgow, A., Beale, P.J., Jefford, M., Dhillon, H., Heritier, S., Carter, C., Hickie, I.B. and Simes, R.J. (2007) Effect of sertraline on symptoms and survival in patients with advanced cancer, but without major depression: a placebo-controlled double-blind randomised trial. *The Lancet Oncology*, 8 7: 603-612.
91. NSW Cancer Council, *Living with Advanced Cancer*, 2007
92. Cancer Council of Victoria. *Advanced Cancer – Emotional Impact*. Accessed online May 2009 at www.cancervic.org.au/about-cancer/advanced-cancer/the_emotional_impact.html
93. Tattersall MHN, Butow PN. Consultation audio tapes: an underused cancer patient information aid and clinical research tool. *Lancet Oncology* 2002; 3: 431–37
94. God's Love We Deliver Nutrition Department, *Nutrition Fact Sheet – Cancer*, www.glwd.org
95. Doyle C, Kushi LH, Byers, T, Courneya KS, Demark-Wahnefried W, Grant B, McTiernan A, Rock CL, Thompson C, Gansler T, Andrews KS. *Nutrition and Physical Activity During and After Cancer Treatment: An American Cancer Society Guide to Informed Choices*. CA: A Cancer Journal for Clinicians. 2006; 56: 323-353.
96. Doyle C, Kushi L H, Byers T, Courneya KS, Demark-Wahnefried W, Grant B, McTiernan A, Rock CL, Thompson C, Gansler T, Andrews KS for the 2006 Nutrition, Physical Activity and Cancer Survivorship Advisory Committee. *Nutrition and Physical Activity During and After Cancer Treatment: An American Cancer Society Guide for Informed Choices* updated 19/11/2008.
97. Victorian Government www.betterhealth.vic.gov.au, *Cancer – Exercise to Help You Cope*. 2007
98. Lee Virginia, *The existential plight of cancer: meaning making as a concrete approach to the intangible search for meaning*. *Supportive Care in Cancer*. 2008;16:779-785.

GLOSSARY

Acupressure: Treatment of symptoms by applying pressure with the fingers to specific pressure points on the body.

Acupuncture: A procedure used in which specific body areas are pierced with fine needles for therapeutic purposes or to relieve pain or produce regional anesthesia.

Addiction: Emotional need for pain medication because of the feeling that is received from the medicine.

Advanced cancer: Cancer is said to be “advanced” when it is unlikely to be eradicated by treatment.

Advanced care directive: Legal documents in which you give written instructions about your health care if, in the future, you cannot speak for yourself.

Alternative therapies: Are used instead of conventional treatment. These therapies may be harmful if people with cancer delay or stop using conventional treatment in favour of them.

Anaesthetic: A drug that stops a person from feeling pain during a medical procedure.

Analgesic: A drug used to relieve pain.

Anaemia: Lower-than-normal number of red cells in the blood.

Antibiotic: Medication used to fight germs or bacteria that cause infection.

Antiemetic: Medication used to stop or help prevent nausea and vomiting, common side-effects of some chemotherapy.

Anxiety: Uneasy feeling, or a feeling of apprehension.

Benign: Not cancerous, not malignant.

Biofeedback: Learning to control muscles to help control pain with the help of a licensed technician.

Biopsy: The removal of a small amount of tissue from the body, for examination under a microscope, to help diagnose a disease.

Brachytherapy: A type of radiotherapy treatment that implants radioactive material sealed in needles or seeds into or near the tumour.

Bone scan: Bone scans use nuclear medicine imaging to spot cancer in the bone. A radioactive substance is injected into a vein and is attracted to areas of cancer. The radioactivity is recorded by a special camera as a picture. There is a phenomenon called “normal physiological uptake,” which may vary from individual to individual. Also previous trauma or fractures can elicit a positive signal as well.

BRAT diet: Acronym for Banana, Rice, Apples and Toast.

Cancer: Disease of the body’s cells that starts in the genes. Damaged genes cause cells to behave abnormally and they may grow into a lump called a tumour.

Cancer-related fatigue: Feeling of debilitating tiredness or total lack of energy that can last for days, weeks or months.

Cannula: Plastic tube inserted into a narrow opening so that fluids can be introduced or removed.

Catheter: Flexible tube inserted into a narrow opening so that fluids can be introduced or removed.

Cells: Building block of the body. A human is made of million of cells, which are adapted for different functions.

Chemotherapy: Use of drugs, which kills or slow cell growth.

Clinical trial: A research study that tests new and better ways of improving health in people.

Complementary therapies: Supportive treatments that are used in conjunction with conventional treatment. They improve general health, well-being, quality of life and help people cope with side effects of cancer. Complementary therapies may include meditation, counselling, hypnotherapy, massage, acupuncture and yoga. Not all therapies have been scientifically validated, but there is growing evidence in favour of them.

Computerised Axial Tomography (CT/CAT): Uses x-rays to see the body in a three-dimensional way. CT scanning is used to diagnose end stage cancer. Sometimes it is necessary to use a contrast medium for the images to show up on the computer.

Counsellors: Mental health workers who can help you with relationship or family issues, show you ways of dealing with anxiety and depression and provide grief counselling to your family and caregivers.

Constipation: Difficulty passing stools, incomplete or infrequent passing of hard stools.

Dehydration: Excessive loss of body water.

Diagnosis: The identification and naming of a person's disease.

Dietician: Health professional who specialises in human nutrition.

Distraction: Learning to direct pain at something other than pain.

Diuretic: Any drug that increases the excretion of water from the body and consequently elevates the rate of urination.

Dose: Amount of medication to be taken.

Dose titration: Adjustment of medication dose either up or down.

Double blind: Trial in which neither the patient nor their doctor knows what treatment the patient is receiving, to reduce bias.

Dyspnea: Difficult or laboured breathing.

Ethics committee: Hospital committee that reviews the plan for a clinical trial to ensure it is safe and ethical.

Grade: Score that describes how quickly the tumour is likely to grow.

Holistic care: Care that incorporates different types of therapies and services to ensure that your physical, emotional, spiritual and practical needs are met.

Hormone: Substance that affects how your body works. Some hormones control growth, others control reproduction. They are distributed around the body through the bloodstream.

Hormone replacement therapy: Use of hormones to treat the symptoms of menopause.

Hormone therapy: Treatment to block the body's natural hormones that help cancer grow.

Hospice: A place which provides comprehensive care for people with a life-threatening illness. This includes inpatient medical care, respite care and care of dying person if he or she is not able/or wish to to die at home.

Immunotherapy: A treatment that attempts to use the body's own defences to fight cancer by trying to strengthen the immune system so it will destroy the cancer cells.

Incontinence: Inability to hold or control the loss of urine or faeces.

Informed consent form: Form a person signs to show that they understand the information they have been given about a trial and they agree to take part.

Infusion: Refers to a number of sleep complaints including difficulties falling asleep, difficulties staying asleep, poor sleep quality and daytime tiredness.

Insomnia: A long period of time when you are unable to fall sleep.

Interferon: Substance that occurs naturally within your body and which enhances your immune system's fight against viruses. Interferon is manufactured for use as a medication and has shown anti-tumour activity against some uncommon cancers.

Intolerance: Unable to digest properly.

Intravenous: Into a vein. An intravenous drip gives drugs directly into a vein.

Investigator: Researcher in a treatment trial.

Laxative: Something to relieve constipation.

Lymph: Clear fluid that circulates around the body through the lymphatic system, carrying cells that fight infection.

Lymph nodes: Also called lymph glands. Small bean-shaped structures scattered along the lymphatic vessels, particularly in the neck, armpit and groin. They filter the lymph to remove bacteria and other harmful agents to prevent them from entering the bloodstream. Lymph nodes also produce lymphocytes, a type of white blood cell.

Lymph vessels: Network of thin tubes that transport lymph into tissues all over the body.

Lymphatic system: Network of vessels that carry a clear fluid called lymph from the body's tissues to the bloodstream. The lymphatic system is part of the body's immune system and helps the body fight infection.

Lymphoedema: Swelling caused by a build-up of lymph fluid. This happens when lymph nodes do not drain properly, usually after lymph glands are removed.

Magnetic Resonance Imaging (MRI): A diagnostic test that uses a combination of magnetism and radio waves to create three-dimensional sectional images of part of a person's body. MRIs are particularly good for soft tissue, brain and spinal cord, joints and abdomen and may be used for detecting some cancers or for following their progress.

Malignant: Cancerous. Malignant cells can spread (metastasise) and can eventually cause death if they cannot be treated.

Mammogram: An x-ray of the breast which can pick up cancers when they are still too small to be felt.

Mastectomy: Surgical removal of the whole breast.

Metastasis: Also known as a secondary cancer. A cancer that has spread from another part of the body.

Morphine: Strong and effective painkiller, which is commonly used to treat people with cancer who have pain.

Multidisciplinary team: A health care team consisting of a group of experts, which may include doctors, nurses, a general practitioner, a surgeon, a medical oncologist, a radiation oncologist, a palliative care specialist, a nurse consultant, nurses, a dietician, a physiotherapist, an occupational therapist, a social worker, a psychologist, a counsellor and/or a pastoral care worker who specialise in the

treatment of specific types of cancer. Most doctors who treat the common types of cancer work with experts in a multidisciplinary team.

Nerve block: Pain medication that is injected directly into or around a nerve or into the spine to block pain.

Nutrition: Process of eating and digesting the necessary food the body needs.

Nutrition supplement: Food or drink that provides extra energy, protein and/or vitamins.

Nutritious/nourishing: Food that is a good source of energy (calories) and/or protein as well as vitamins and minerals.

Occupational therapist: Rehabilitation professional who assists individuals to compensate for functional limitations as a result of an injury, illness or disability by learning skills and techniques needed to perform activities of daily living and optimise independence.

Oncologist: doctor who specialises in the study and treatment of cancer.

Oncology: Study of tumours or cancer.

Opioids: Strongest pain relievers available. Include morphine, fentanyl, codeine, oxycodone, hydromorphone and methadone.

Over-the-counter medicines: Medicines you can buy without a doctor's prescription.

Palliative care: Holistic care of people who have a life-limiting illness, their families and carer. It aims to improve quality of life by addressing physical, emotional, spiritual, social and physical needs. It is NOT just for people who are about to die although end-of-life care is a part of palliative care.

Palliative care nurse: Nurse with special training in easing of cancer-related symptoms. Palliative care nurses work with a team in the hospital and can also visit the patient at home.

Palliative treatment: Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms of cancer. Treatment may include radiotherapy, chemotherapy or other medication.

PET scan: Positron Emission Tomography. Technique used to build up clear and detailed cross-sectional pictures of the body involving the injection of small amounts of radioactive material, which show up areas of fast cell growth.

Physiotherapist: Health care professional who specialises in physical therapy and who can help you manage pain, incontinence, lymphoedema and other symptoms. A physiotherapist can also help you recover from operations and work on your physical mobility.

Placebo: A dummy pill or injection, which looks like the new treatment being tested but contains no active ingredient.

Port-a-cath: Small medical appliance that is installed beneath the skin. A catheter connects the port to a vein. Through the port-a-cath drugs can be injected and blood samples can be drawn many times, usually with less discomfort for the patient than a more typical “needle stick”.

Primary cancer: Original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancer forms.

Prognosis: Likely outcome of a person’s disease.

Prostate specific antigen (PSA): Protein produced by prostate cells. It can be used to test for prostate cancer or to monitor its recurrence.

Psychologists: Mental health workers who can help you with any emotional issues including relationship or family issues, ways of dealing with anxiety and depression, for you, your family and caregivers.

Quality of life: Measure of your comfort and satisfaction, based on how well your individual physical, emotional, spiritual, sexual, social and financial needs are being met within limitation of your illness. How cancer and its treatment affects a person’s day-to-day functioning.

Radiation enteritis: Swelling (inflammation) of the lining of the small intestine due to radiation therapy.

Radiation oncologist: doctor who specialises in treating cancer with radiotherapy.

Radiation therapist: Health professional who administers radiotherapy.

Radiotherapy: Use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow or multiply.

Randomised controlled trial: Trial in which participants are randomly allocated to receive the new treatment or the standard treatment (the control).

Recurrent cancer: Cancer that grows from cells of a primary cancer that have evaded treatment.

Relapse: The return of a disease after a period of improvement.

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

Screening: Organised program to identify disease, such as cancer, before symptoms appear.

Secondary cancer: Also called a metastasis. A tumour that has spread from the original site to another part of the body.

Shortness of breath: Difficulty in drawing sufficient breath or laboured breathing.

Specialist palliative care team: Holistic team of health professionals who offer a range of services to improve your quality of life and help with any problems you have. A community nurse or palliative care nurse usually coordinates the team.

Stomatitis: Inflammation of the mouth.

Suppository: Drug delivery system that is inserted either into the rectum (rectal suppository), vagina (vaginal suppository) or urethra (urethral suppository) where it dissolves.

Tumour: New or abnormal growth of tissue on or in the body.

Ultrasound: Use of soundwaves to build up a picture of the internal parts of the body.

Vaccine: Biological preparation that establishes or improves immunity to a particular disease.

Voluntary euthanasia: Choosing a painless, medically assisted death in accordance with person’s expressed wishes and directions when that person is suffering severe pain or distress, with no reasonable prospect of recovery.

Will: Legally binding document that details how you want your assets and belongings to be distributed after you die.

X-ray: X-rays or ultrasound – may reveal tumours in certain parts of the body.

