



A PRACTICAL GUIDE FOR COUPLES FACING CANCER

# GETTING ON TOP OF SYMPTOMS

## **The challenges addressed in this booklet...**

- Tracking your fatigue
- Identifying pain and getting on top of it quickly
  - Anticipating and preventing nausea
- Dealing with loss of appetite and changes in taste
  - Dealing with constipation and diarrhoea
- Putting in place a continence management plan
  - Prevention and management of mouth sores
- Discussing sexual problems with your partner and doctor
  - Recognising and monitoring other symptoms
- Solving problems to minimise the impact of symptoms on everyday life

### **Note to reader**

This booklet is not intended as a substitute for consultation with your health care professionals. Patients or partners with health care questions should call or see their health care professional promptly and should not disregard professional medical advice, or delay seeking it, because of information encountered in this booklet. Before commencing any health treatment, always consult your doctor.

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# GETTING ON TOP OF SYMPTOMS

Cancer and its treatment may cause physical problems, even after treatment ends. Different treatments cause different symptoms or side effects, and people may experience them differently.

This booklet offers strategies to better manage symptoms of cancer and its treatment.



# Meet the experts

Every ***Coping-Together*** booklet has sections where health care professionals have been invited to discuss the information and strategies that are presented. Each expert is easy to identify – their picture is included next to their input, and you will recognise some of their faces from the ***Coping-Together*** DVD.

In this booklet, ***Getting on Top of Symptoms***, our experts are Karen Dahdah, Professor Geoff Delany and Professor Dorothy Keefe.



**Karen Dahdah** is a Rural Cancer Care Coordinator at the Manning Hospital, Taree and has been working in nursing for 20 years. She is passionate about providing best practise care for patients and their families. Her role includes facilitating continuity of care, particularly where the treatment regime involves multiple service providers.

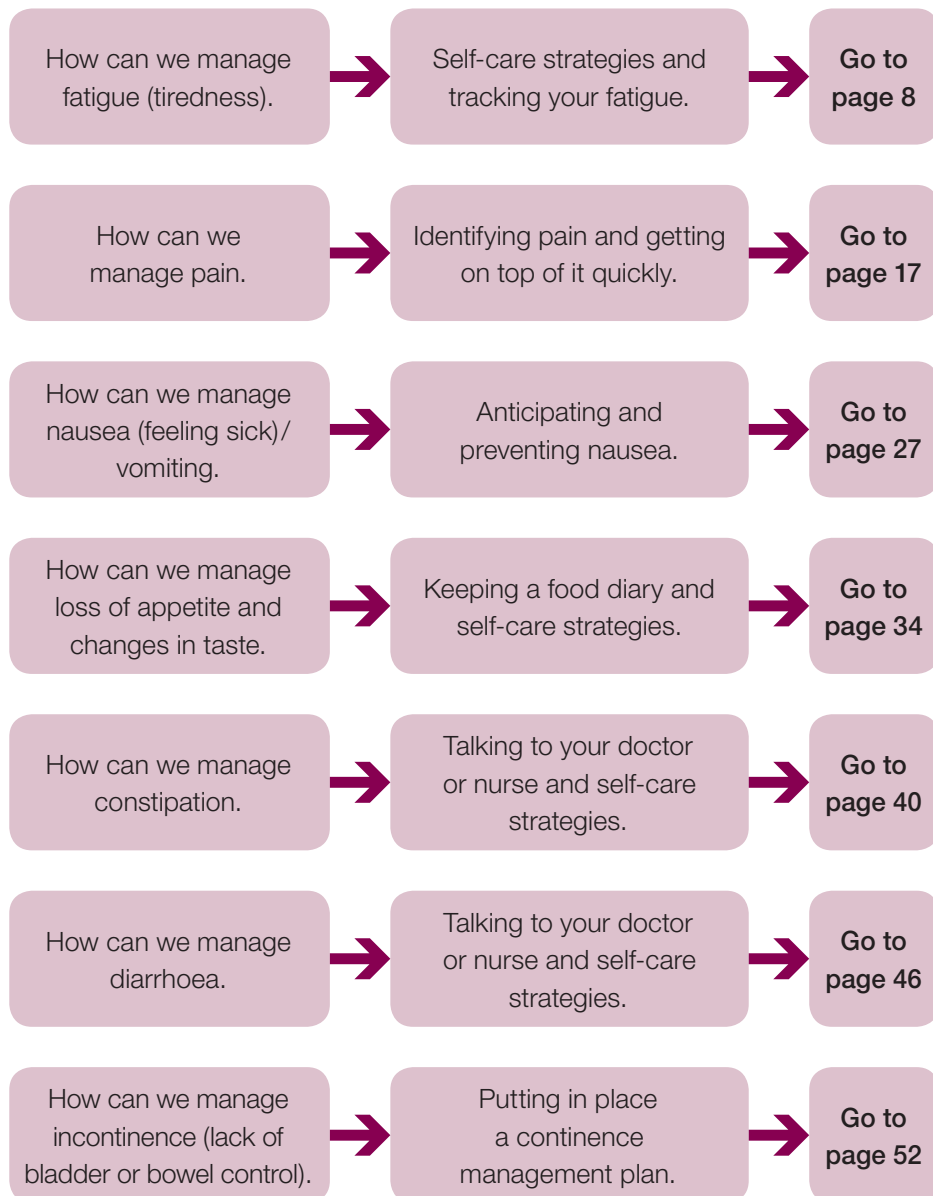


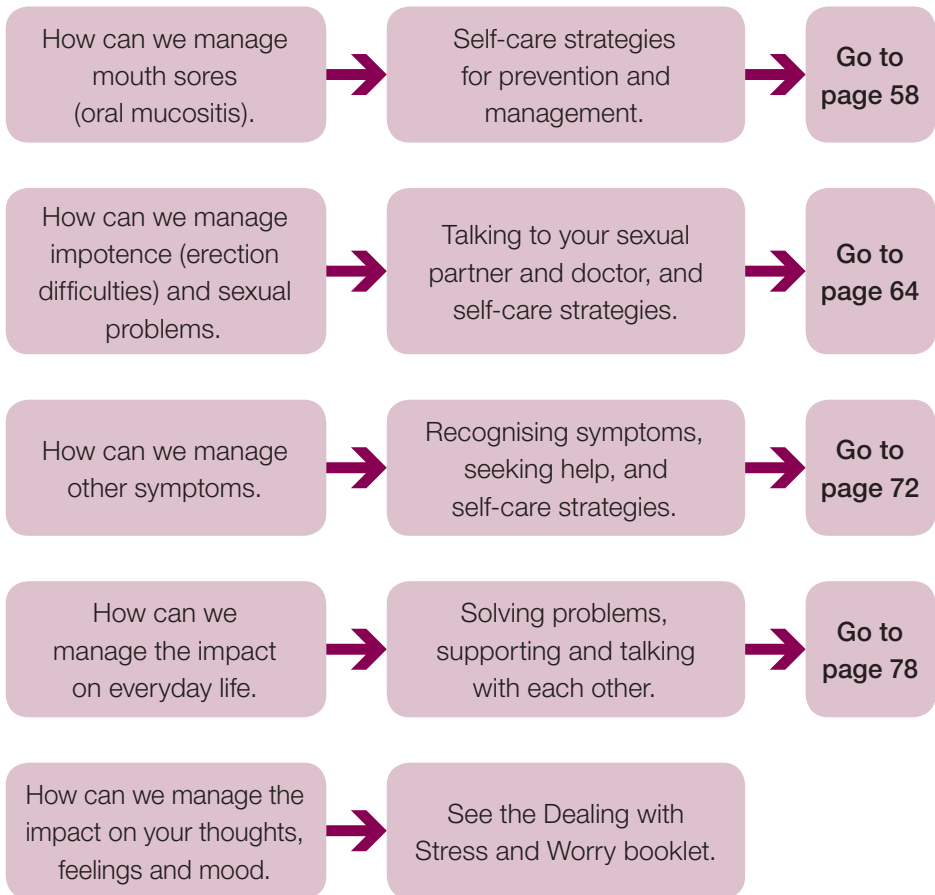
**Professor Geoff Delany** is the Director of Cancer Services in South West Sydney Local Hospital District and the Liverpool Hospital Cancer Therapy Centre. He began his career as a radiation oncologist, and continues to see breast cancer patients. Geoff has a strong research background, and his interests include improving health service delivery to survivors.



**Professor Dorothy Keefe** is the Director of the South Australian Cancer Service, Professor of Cancer Medicine at the University of Adelaide, and a Senior Medical Oncologist at Royal Adelaide Hospital Cancer Centre. Professor Keefe's research interest is in toxicity of cancer treatment and mucositis.

The following flowchart shows common symptoms and side effects of cancer and treatments. Navigate your way through the chart until you recognise your own symptoms and choose the strategies recommended on the right. Go to the relevant pages for more detailed information.





# How can we manage fatigue (tiredness)?

👏👏 It was more than just tiredness. My whole body felt so heavy it was an effort just to move around sometimes. I would go to bed and sleep for hours and wake up feeling like I hadn't slept a wink! 🤖🤖

*Rochelle, diagnosed with breast cancer.*

## Suggestions for managing fatigue

1. **Monitor fatigue using a symptom diary** – Keeping a diary will allow you to keep track of your fatigue.
2. **Talk to your doctor, nurse or cancer care coordinator.**
3. **Try self-care strategies** – Self-care strategies take trial and error but a good starting point is to find out what has worked for other people.



## What causes cancer-related fatigue?

The exact causes of cancer-related fatigue can be hard to determine. Some factors that contribute to fatigue include the changes to your body caused by the cancer and treatment, pain, lack of sleep, medications, poor nutrition or low exercise due to treatment, your emotions, or anaemia.





## *Suggestion 1: Use a symptom diary*

Tracking your fatigue in a symptom diary, such as the one included at the end of this booklet, is a good habit to develop because it helps you identify what causes or makes your fatigue worse.

### **Note in your diary the answers to the following questions:**

1. When did the fatigue start or how long have you been feeling unusually tired (e.g. a week)?
2. How often do you feel fatigued (e.g. daily, weekly)?
3. How long does the fatigue last (e.g. all day, a few hours)?
4. When are you most likely to feel fatigued (e.g. a certain time every day)?
5. What does it feel like?
6. How does the fatigue affect you?
7. At its worst, how severe is the fatigue on a scale of one to 10?
8. What are you/have you been doing when it happens?
9. What do you do to try to relieve your fatigue?
10. What seems to work best?

### **Top Tip: Avoid fighting fatigue**

Listen to your body and watch for signs that you are becoming tired.



## *Suggestion 2: Talk to your doctor, nurse or cancer care coordinator*

Talking to your doctor, nurse or cancer care coordinator is vital to ensure you get appropriate help in a timely fashion. Show your health care professional your symptom diary (example included at the end of this booklet), this will help them determine the most appropriate and helpful support.

### **Below are some questions you could ask your doctor or nurse to help you manage fatigue:**

1. Is this a 'normal' or expected symptom?
2. What is the likely cause (e.g. treatment, the cancer itself)?
3. How long is it likely to last?
4. Will it change (e.g. get worse or get better)?
5. Is there an effective treatment for it?
6. What can I do to manage it (e.g. diet, exercise, rest)?
7. How might it affect my treatment and recovery?
8. If and when it goes away, is it likely to return?
9. When should I contact you (e.g. if it gets worse or changes)?
10. Are there other health care professionals who can help me manage it?

For more information about talking to your health care professional, see the question checklists in the **'we don't know what to ask'** section of the ***Getting What You Need From Your Health Care Team*** booklet.

# Suggestion 3: Try self-care strategies

Below are some common strategies to help you cope with fatigue.

## 1. Pace yourself

Conserve your energy by maintaining a fairly even level of activity throughout the day, rather than wearing yourself out trying to do too much in one go. Here are three steps to help you conserve energy:



**Step 1: Prioritise your activities** – Decide what is most important for that day and what can wait. Make a to-do list (see table below for an example) and be ruthless about keeping it to a manageable size.

Example of a to-do list

Date	Job	When?	Priority – Low Medium High	Help needed?	Helper
26/7	School pick-up	3pm	High	Yes	Jennifer R.
	Laundry	2–3 days	Medium	Yes	Olivia
	Cake for fete	Friday	Low	No	

**Step 2: Balance your day** – Plan your activities around the times when you usually have more energy and plan regular breaks. Do things at a steady pace and try little changes, such as sitting when you would normally stand (e.g. taking a seat while you clean your teeth).

**Step 3: Delegate** – Ask for help with everyday jobs that wear you down.

– *Karen Dahdah*

**Top Tip:** Assistance is also available from community services (e.g. Meals on Wheels, Australian Home Care). Contact the Cancer Council on 13 11 20 or visit [www.cancer.org.au](http://www.cancer.org.au) to find out what services you can access to help you with your to-do list, or look through the **Getting the Support You Need** booklet.



## 2. Restore your energy

Making time for things you enjoy doing and that are not physically taxing can help you re-energise (e.g. gardening, reading, visiting a park or museum, seeing a movie). It is a good idea to plan for half an hour of 'restorative time' at least three or four times a week.

## 3. Get enough sleep

Research suggests that **'catch-up' naps during the day** can help some people. Limit naps to **20 or 30 minutes** and try not to nap late in the day so it doesn't interfere with the quality of your night-time sleep. It also helps to do some light activity, such as walking, after a nap.

### Top Tip: Getting a better night's sleep

- ✓ Develop a strict sleep routine that encourages clear sleep patterns. For instance, go to bed and wake up at the same time each day, limit naps to 20-30 minutes, avoid naps within four hours of bedtime, and use bed only for sleep and sexual activity (e.g. no TV in the bedroom).
- ✓ Avoid caffeine, sugary food and drinks and exercise in the few hours before going to bed.
- ✓ Banish thoughts and worries that keep you awake (e.g. keep a notepad by your bed so you can write down thoughts and 'file them away'; get out of bed and do something else).
- ✓ Try relaxation techniques. See the section **'I feel tense, angry and/or stressed'** in the ***Dealing with Stress and Worry*** booklet for examples of relaxation techniques and/or listen to the **'Learning to Relax'** CD included in your package.
- ✓ See the **'I feel tired'** section of the ***Dealing with Stress and Worry*** booklet.



## 4. Eat well

Poor nutrition can worsen your fatigue, so it's worth speaking to an oncology dietitian about your diet. You can find an oncology dietitian by asking one of your health care professionals, by visiting [www.daa.asn.au](http://www.daa.asn.au) or by phoning 1800 812 942.

Here are some suggestions for cooking and eating even if you have lost interest in food:

- ✓ Save your favourite foods for non-treatment days so they aren't linked to unfavourable events.
- ✓ If you can't eat full-sized meals, eat small meals more often. Eat larger meals when you feel better.
- ✓ If you can't stomach food, try high-calorie or protein drinks, such as milk, juice, smoothies, milkshakes or nutritional supplements (such as Sustagen).
- ✓ Fill your pantry with groceries on days you are less fatigued.
- ✓ Do some cooking in advance and freeze meal-sized portions.
- ✓ Keep foods handy that need little to no preparation (e.g. bread, tinned soup, tuna, eggs, cheese, dried fruits, nuts).

## 5. Exercise regularly

Walking, even for just 10 to 15 minutes each day, can reduce fatigue.

- ✓ Devise a walking program – start with a short, slow stroll and gradually increase the time and distance you walk.
- ✓ Walk with your partner or a friend – you can motivate each other and catch up at the same time.
- ✓ Avoid overdoing it – if your body is telling you to stop, listen to it (and check with your doctor).

If weather is against you, try other walking plans (e.g. stride through a shopping centre or find a treadmill) or a different light exercise (e.g. a gentle swim in a heated indoor pool).



– **Professor Geoff Delany**

**FACT:** When you are fatigued, exercise is probably the last thing you want to do! However, physical exercise decreases fatigue, improves other symptoms (e.g. nausea) and helps your mood. Ask your doctor or nurse for a referral to a physiotherapist to find out what exercise might be right for you. You can also find an accredited exercise physiologist (AEP) through Exercise and Sports Science Australia (ESSA). See [www.essa.org.au/](http://www.essa.org.au/) for more details.



## 6. Focus on other things

Being distracted – even if it's just for 15 minutes at a time – helps take your mind off your fatigue and increases your concentration and sense of wellbeing. Here are some suggestions: phone a family member or friend; arrange to meet a friend for a 'cuppa'; read the newspaper or browse the Internet; watch a movie and/or put on your favourite songs and sing along. For more ideas see the ***Dealing with Stress and Worry*** booklet.

## 7. Try relaxation techniques

Relaxation techniques can reduce stress and relax your body, aiding fatigue management. Different relaxation techniques work for different people, but some common ones are warm baths, soothing music, meditation, yoga, prayer, guided imagery, visualisation and physical therapies (such as float tanks and relaxation massages). See the section '***I feel tense, angry and/or stressed***' in the ***Dealing with Stress and Worry*** booklet for examples of relaxation techniques and/or listen to the '***Learning to Relax***' CD included in your package.

## 8. Manage other side effects

Fatigue may be related to other symptoms. See the '***how do we manage other symptoms***' section in this booklet and talk to your health care team.

## 9. Look at other causes



Your fatigue may provide clues to other things that are going on with you and your body, so it's important you discuss them with your health care team.

### Contact a doctor or cancer care coordinator if you have:



- ✓ A temperature over 38°C.
- ✓ Barely eaten for more than five days.
- ✓ Struggled to drink fluids for more than 24 hours.
- ✓ Difficulties chewing or swallowing.
- ✓ Not been able to maintain weight.
- ✓ Been too tired to get out of bed for more than 24 hours.
- ✓ Become confused.
- ✓ Trouble sleeping at night.
- ✓ Instances of breathlessness, dizziness or a racing heart after only mild activity.
- ✓ Want to see a dietitian about nutrition concerns.

If you or your partner are receiving chemotherapy and are experiencing these symptoms, you should seek medical attention immediately (through your regular doctor, or the local emergency department).

### What others say about using these strategies

 I was constantly tired during treatment that I could barely get out of my office chair some days. I thought I was just going to have to live with it. But by using a diary, I worked out that, although it happened at about the same time every day, it seemed to be worse when I hadn't managed to get out for a quick walk at lunchtime. 

*Rob, diagnosed with prostate cancer.*

 I was told I would probably feel tired during treatment, but I didn't realise it would knock me about so much. All I wanted to do was sleep, but then I couldn't seem to get a restful sleep. My doctor and I talked through a typical day and came up with a plan of attack – tweaking my routine, talking to a social worker about getting some help and trying a gentle sleep medication, for a start. 

*David, diagnosed with colorectal cancer.*

### Key Points: Managing fatigue

1. Fatigue is a common symptom. It can be a direct result of the cancer or treatment, but can also be caused by other side effects or conditions.
2. People with cancer can often manage fatigue through self-care measures and/or professional treatment.
3. Tracking fatigue can enhance discussions about possible treatments with your health care professionals.





# How can we manage pain?

Pain is a very personal sensation and is described by people in many different ways (e.g. tingling, numbing, gnawing, burning, aching, throbbing and sharp or stabbing).

**FACT:** You don't have to put up with pain. Most pain can be controlled and is easier to manage in its early stages. Pain may also be an early-warning sign for other conditions and side effects, so it's worth speaking up about it.



## Suggestions for managing pain

1. **Monitor pain using a symptom diary** – Use the symptom diary at the end of this booklet to keep track of your pain.
2. **Talk to your doctor, nurse or cancer care coordinator.**
3. **Control your pain with medication and non-medicinal pain relief** – On the advice of your health care professionals, you can control pain with medicinal and non-medicinal pain relief.



## Suggestion 1: Use a symptom diary

Tracking your pain in a symptom diary, such as the one included at the end of this booklet, is a good habit to develop because it helps you identify what causes or makes your pain worse. On the next page is an example of how to complete your diary to keep track of pain.

# Example: Symptom diary

Date	What I did	What I ate/drank	What	Description
16/8/11	<b>Treatment/ medication</b> e.g. IV hydrocortisone pre-chemo.  e.g. Head and neck massage (Chinese therapist).  <b>Other activities</b> e.g. Worked on computer for 5 hours; went for an hour's walk; 2 hours of housework (washing, vacuuming).	<ul style="list-style-type: none"> <li>• <b>Breakfast</b> e.g. 2 x toast/ vegemite, 1 cup black tea</li> <li>• <b>Lunch</b> e.g. 1 cup chicken noodle soup, 1 apple</li> <li>• <b>Dinner</b> e.g. Small bowl of pasta/vegetables; 1 scoop vanilla ice-cream</li> <li>• <b>Snacks</b> e.g. Handful rice crackers and hummus; 3 cups water with lemon; 1 low-fat latte</li> </ul>	• side effect or symptom  1. e.g. Pain	• where • what it felt or looked like  e.g. Ache in shoulders and neck, with occasional shooting pain into head
			2.	
			3.	
			4.	

SYMPTOMS OR SIDE EFFECTS					
	<b>Duration</b> <ul style="list-style-type: none"> <li>when did it start</li> <li>when/how often it occurred</li> <li>how long it lasted</li> </ul>	<b>Severity</b> <ul style="list-style-type: none"> <li>how bad was it</li> <li>on a scale of 1 to 10 1=Mild 10=Severe</li> </ul>	<b>Effect</b> <ul style="list-style-type: none"> <li>how it affected you</li> </ul>	<b>Management</b> <ul style="list-style-type: none"> <li>what you did to relieve it</li> <li>how well it worked</li> </ul>	<b>Other comments</b>
	e.g. Woke with pain – all day	e.g. 4	e.g. Stiff movements – too sore to hang out washing.	e.g. Stretching, massage, Panadol – massage eased it for an hour but returned	e.g. slept restlessly, woke early, busy all day but felt tired.

## Suggestion 2: Talk to your doctor, nurse or cancer care coordinator

Talking to your doctor, nurse or cancer care coordinator is vital to ensure you get appropriate help in a timely fashion. Show your health care professional your symptom diary and allow them to provide the most appropriate and helpful support.

We all feel pain differently. How you describe pain can give your health care professional some very important clues and information about which treatments to use. If you are experiencing pain, the diagram below outlines how you can go about describing it:

### The OPQRST of describing pain

#### Region/Radiation

"It hurts here ..."  
"It moves this way ..."

#### Scale

"It hurts this much ..."  
"From 1 to 10, I'd rate it ..."

#### Quality

"It feels like ..."  
"I'd describe it as ..."

#### Timing

"It started when ..."  
"It hurts this often ..."

#### Provoking factors

"It happens when ..."  
"This makes it worse ..."

#### Other

"This helps ..."  
"This happens ..."



### Example: Describing pain using the OPQRST formula

Doctor, I have just started getting this burning [quality] pain in the upper-left side [region] of my stomach. It started a couple of days ago [timing] after I ate pizza [provoking factor]. I took some antacid and it felt a bit better [other – relieving factor]. But I'm getting worried because yesterday I threw up and there was some blood [other – associated symptom]. The pain gets quite bad at times – so much so that I almost double over in agony [scale]. It sometimes shoots across my stomach [radiation].

### At your next appointment, you could also ask your health care professional the following questions to help you better manage pain:

1. Is this a 'normal' or expected level of pain?
2. What is the likely cause (e.g. treatment, the cancer itself)?
3. How long is it likely to last?
4. Will it change (e.g. get worse or get better)?
5. Is there an effective treatment for it?
6. What can I do to manage it (e.g. exercise, rest, medication)?
7. How might it affect my treatment and recovery?
8. If and when it goes away, is it likely to return?
9. When should I contact you (e.g. if it gets worse or changes)?
10. Are there other health care professionals who can help me manage it?

For more information about talking to your health care professional, see the question checklists in the ***'we don't know what to ask'*** section of the ***Getting What You Need From Your Health Care Team*** booklet.

**FACT:** It is easier to control lower levels of pain. Living with high levels of pain does not increase your tolerance and can contribute to other symptoms and health problems.



## Suggestion 3: Control pain with medication and non-medicinal pain relief

### Medicinal pain relief

Pain-relieving medications, or analgesics, control the pain itself, rather than the cause. The World Health Organisation (WHO) advocates that people “*receive medications appropriate to their clinical needs, in doses that meet their own individual requirements, for an adequate period of time*”. WHO has set out three steps for using appropriate pain medications.

#### Step 1

Usually for minor pain (e.g. head and body aches). Over-the-counter (OTC) drugs (e.g. aspirin, paracetamol).



#### Step 2

Minor to moderate pain (e.g. stronger headache). If Step 1 is not enough, combining OTC relief with a mild opioid (e.g. codeine). A prescription may be required.



#### Step 3

Moderate to severe pain (e.g. post-surgical pain). If Step 2 does not work, your doctor may prescribe stronger, quick-acting and long-lasting drugs (e.g. morphine).



# Combining medications

In some cases, the best results in pain relief come from combining medications. Your doctor may prescribe medications that work in conjunction with your main medication (also known as ‘adjunct’ or ‘adjuvant’ medications). Some medications for more persistent pain (e.g. codeine) can cause constipation or nausea, so you may need additional medications to combat these side effects.

Here are some medications that might be used in combination with your pain medicines:

Types of medication	What they treat	Examples
Antidepressants	Tingling and burning from nerve damage, phantom pain, sleep problems	Amitriptyline
Anticonvulsants	Nerve pain, stabbing pain, jerky muscles	Gabapentin, carbamazepine, phenytoin
Corticosteroids	Nausea, bone pain, pain from brain and spinal-cord tumours, lack of appetite	Dexamethasone, methylprednisolone, prednisone
Local anaesthetics	Nerve pain (e.g. from shingles)	Lidocaine

Adapted from Cancer Care (2009).

## Top Tips: For managing pain medication

- Ensure you know how they work, how much to take, how to take them (e.g. with food), when to take them, what not to do while taking them (e.g. avoid drinking alcohol), and any of their possible side effects.
- Even if a certain pain medication has worked for you in the past, or has worked for others, things might be different in the context of your illness and other treatments. Seek advice from your doctor, nurse or pharmacist.
- Tell your doctor or nurse about any reactions you have to medication, even if mild, as they might be able to help you bring any side effects under control.

– *Professor Dorothy Keefe*



## Misconceptions about pain medication

Misconception	Fact
<b>If I use pain medicines too often, I will become addicted.</b>	People who have never abused drugs do not become addicted to opioid pain relievers. Your dosage may need to be increased over time, but this is not a sign of addiction.
<b>I should wait until the pain returns before taking more medication.</b>	Pain is much easier to control if you strike preemptively.
<b>Dosage instructions on the pack are often just guides.</b>	Taking more than the prescribed or recommended dose of any medication, even a 'mild' one, can be harmful.
<b>It can't hurt to take vitamins or herbal supplements with pain medications.</b>	Some herbal supplements can be harmful in combination with other substances. Always tell your doctor or nurse about any supplements you plan to take while using your pain medication.
<b>I don't need to check over-the-counter pain relief with a health professional.</b>	While you might not need a prescription for over-the-counter medicines, it is wise to check with your doctor or nurse before you start taking them. Even some milder pain medicines can be harmful if combined with other medications.
<b>If I vomit after taking morphine, I have taken too much or am allergic to it.</b>	Vomiting is a common reaction to morphine, especially the first few times it is taken, and does not necessarily mean that you've taken it the wrong way or will always have a bad reaction to it. Check with your doctor or nurse, who can prescribe an anti-nausea medicine (or anti-emetic) such as Maxalon or Cyclizine.
<b>Putting up with pain will increase my ability to tolerate it.</b>	You might get used to feeling pain, but this does not mean that your body is tolerating it better. Putting up with pain actually decreases your pain tolerance.
<b>It is not a problem to crush or break pain relief tablets.</b>	Some tablets are in 'timed-release form' and can be harmful if broken. Always check with your doctor, nurse or pharmacist.



## Non-medicinal pain relief

These approaches might not provide pain relief when used alone, but they can be used in combination with pain relieving medication.

### Heat and cold packs

Before using heat and cold packs it is crucial that you seek advice from a health care professional, especially if you are undergoing, or have undergone, radiotherapy. There is a risk of injury if these packs are used inappropriately on a radiation site.

**Heat packs** (e.g. moist hot towels, hot water bottles, commercial heat packs) help to relax muscles and ease pain in joints and bones. Make sure the pack does not feel too hot. Use for a maximum of 20 minutes at a time and take care not to fall asleep with a heat pack.

**Lukewarm baths or heated pools** can help to relieve head and body aches by warming up and relaxing muscles. The water should not be too warm – some people may become less sensitive to heat and risk scalding or over-heating.

**Cold compress** (e.g. ice in a bag, frozen vegetable packets) can numb pain (particularly swelling and bruising) and ease spasms. Wrap the ice pack in a towel or some sort of material to prevent ‘iceburns’. Limit to 10-15 minutes at a time.

### Relaxation techniques

This includes controlled diaphragm breathing, progressive muscle relaxation, and guided visualisation. For a description of these techniques and others, see the ***Dealing with Stress and Worry*** booklet and/or listen to the ***‘Learning to Relax’*** CD included in your package.

### Physical techniques

**Exercise** – gentle stretching or walking can help warm up the body to relieve pain and release endorphins (the mind’s ‘feel-good’ chemicals). Other good options can include swimming and aqua exercise in heated pools. Talk to your doctor about what exercise would be good for you.

**Yoga** – gentle exercises, stretches and ‘poses’ can relieve pain by relaxing the mind and body.

### Other forms of pain relief

**Physical therapy** – Massage and physiotherapy can help you deal with the physical causes of pain. Talk to your health care team about appropriate services for you such as physiotherapy or exercise physiology.

**Acupuncture** – This form of Chinese medicine, using thin needles, has been shown to help ease or treat the cause of pain in people with cancer. Check with your doctor whether it could be appropriate for you and ask about qualified practitioners. To find a practitioner in your area visit the Acupuncture Association of Australia website [www.acupaa.com.au](http://www.acupaa.com.au) or call 07 4159 2020.

### Contact a doctor or cancer care coordinator if you:

- ✓ Have new or more severe pain.
- ✓ Develop new symptoms (such as trouble walking, eating or urinating).
- ✓ Cannot swallow or keep anything down, including your pain medicine.
- ✓ Have trouble waking up or staying awake.
- ✓ Become constipated, nauseated or confused.

### What others say about using these strategies

👍👍 At first, I thought I should try to be brave and put up with a bit of pain. But after it got worse, I realised I should have been open about it from the start because I caused myself a lot of needless suffering. 🗨️

*Derek, diagnosed with prostate cancer.*

👍👍 I was prescribed a painkiller that worked really well, so I'd take it, and then forgot about it until I was in agony again. Then I'd take some more, but there was half an hour where I could hardly bear it. My nurse told me I should take it every four hours, even if I wasn't in pain. That made all the difference. 🗨️

*Joshua, diagnosed with melanoma.*

### Key Points: Managing pain

1. Most pain can be managed, but it's much easier to control if it's dealt with early.
2. Monitoring pain and discussing it with your health care professional is the best way to manage your pain.
3. Self-care strategies can be a useful tool when combined with pain medication.



# How can we manage nausea (feeling sick)/vomiting?

👂👂 Sometimes I'll be feeling fine, and then suddenly I'll be hit by a wave of heat that also leaves my skin feeling cold. I'm never quite sure if I'm going to throw up or not. 🤢🤢

*Judy, diagnosed with breast cancer.*



It's not easy being green, but think of the good you're doing for the environment, honey!

## Suggestions for managing nausea/vomiting

1. **Monitor nausea and vomiting using a symptom diary** – The most effective way to manage nausea/vomiting is to track when it happens and what seems to set it off. Use the symptom diary at the end of this booklet to help you keep track of these changes.
2. **Talk to your doctor, nurse or cancer care coordinator.**
3. **Try self-care strategies** – It might take some trial and error to work out how best to manage nausea and vomiting, but a good starting point is to see what has worked for other people.



## Suggestion 1: Use a symptom diary

Tracking your nausea/vomiting in a symptom diary, such as the one included at the end of this booklet, is a good habit to develop, as it can help identify what is causing or exaggerating symptoms.

### Note down in your diary the answers to the following questions:

1. When did/does the nausea start (e.g. a week ago)?
2. How often do you feel nauseous (e.g. daily, weekly)?
3. How long does it usually last (e.g. five minutes, five days)?
4. When are you most likely to feel nauseous (e.g. after certain activities or treatments)?
5. What does it feel like (e.g. queasy, cramps, violently ill)?
6. At its worst, how severe is the nausea?
7. Is it usually accompanied by vomiting?
8. How does nausea or vomiting affect you?
9. What are you/have you been doing when it happens (e.g. eating, travelling to treatment)?
10. What do you do to control the nausea/vomiting?
11. What seems to work best?

**FACT:** A number of anti-nausea medications are available, so if you find one doesn't work for you, ask your doctor or nurse about an alternative.



## *Suggestion 2: Talk to your doctor, nurse or cancer care coordinator*

Talking to your doctor, nurse or cancer care coordinator is vital to ensure you get appropriate help in a timely fashion. Show your health care professional your symptom diary (example included at the end of this booklet), this will help them determine the most appropriate and helpful support.

You may need an anti-nausea drug (or anti-emetic) during treatment and, if your doctor knows you have anticipatory nausea or vomiting, they can also prescribe other medications, such as Ativan, to take prior to treatment.

**At your next appointment, you might also ask your health care professional the following questions to help you better manage nausea or vomiting:**

1. Is nausea a 'normal' or expected symptom?
2. What is the likely cause (e.g. treatment, the cancer itself)?
3. How long is it likely to last?
4. Will it change (e.g. get worse or get better)?
5. Is there an effective treatment for it?
6. What can I do to manage it (e.g. diet, exercise, rest)?
7. How might it affect my treatment and recovery?
8. If and when it goes away, is it likely to return?
9. When should I contact you (e.g. if it gets worse or changes)?
10. Are there other health care professionals who can help me manage it?

For more information about talking to your health care professional, see the question checklists in the **'we don't know what to ask'** section of the ***Getting What You Need From Your Health Care Team*** booklet.

## Suggestion 3: Try self-care strategies

Here are some suggested self-care strategies  
I recommend for managing nausea and vomiting.

– **Karen Dahdah**



Problem	Self-Care Strategies
<b>Food</b> Some foods (e.g. strong smelling foods such as cabbage or cauliflower, or rich or sweet foods) can trigger nausea or vomiting, as can a lack of food or appetite.	<p>Many people say food tends to have a metallic taste, which makes it unappetising. You might try:</p> <ul style="list-style-type: none"><li>• Using plastic utensils instead of metal ones.</li><li>• Rinsing your mouth with a teaspoon of sodium bicarbonate (baking soda) dissolved in a glass of water to clean your mouth before eating.</li><li>• Adapting your meals and eating times to fit in with how well you tend to feel at certain times of day.</li><li>• Eating smaller meals more often.</li><li>• Eating lighter meals, such as soup or salad.</li><li>• Avoiding very sweet, salty, rich or strong-smelling foods.</li><li>• Eating food cold or at room temperature to reduce the smell.</li><li>• Eating high-protein and high-energy snacks, such as milkshakes and wholegrain crackers with cheese.</li><li>• Eating more when you are feeling well.</li><li>• Sucking on mints, barley sugar or lemon lozenges.</li></ul>
<b>Lack of fluids</b> Dehydration can lead to a feeling of sickness, though some people find it difficult to swallow even liquids or to keep anything down.	<ul style="list-style-type: none"><li>• Drink plenty of water – always keep a water bottle close by.</li><li>• Carbonated (even slightly ‘flat’) drinks, such as soda water, lemonade or ginger ale, may help an upset stomach.</li><li>• Ice cubes, icy poles, or sucking on fruit can help, however lots of sugar may make your stomach feel worse.</li></ul>

Problem	Self-Care Strategies
<p><b>Strong smells</b></p> <p>(e.g. coffee or perfume) can exacerbate nausea.</p>	<ul style="list-style-type: none"> <li>• Avoid enclosed spaces where you might be overwhelmed by perfume and avoid scented candles and ‘musky’ air fresheners.</li> <li>• Open windows to let fresh air flush out lingering odours.</li> </ul>
<p><b>Fatigue</b></p> <p>Fatigue can make you feel sick.</p>	<ul style="list-style-type: none"> <li>• Rest after treatments and meals to help prevent nausea.</li> <li>• Resting on a slight incline (e.g. a reclining chair or against pillows) works better than lying flat. See <b>‘how can we manage fatigue?’</b> in this booklet.</li> </ul>
<p><b>Medicines</b></p> <p>Some pain relievers and anti-inflammatory medications can irritate the stomach.</p>	<ul style="list-style-type: none"> <li>• There are many highly effective anti-nausea (or anti-emetic) medications.</li> <li>• Check with your pharmacist, doctor or nurse if you think you’re having a reaction to any medication, and ask for an alternative.</li> </ul>
<p><b>Movement</b></p> <p>Sudden movements or exercise that is too strenuous may cause you to feel sick or vomit.</p>	<ul style="list-style-type: none"> <li>• Keep movements smooth and gentle.</li> <li>• If you have been sitting, avoid standing suddenly.</li> <li>• Try ginger as a way of reducing the nausea when travelling.</li> <li>• Ask your doctor or nurse about motion-sickness tablets. Discuss appropriate exercise options with your healthcare team.</li> </ul>
<p><b>Anticipation / Mood</b></p> <p>Sights, smells and thoughts associated with your treatments or anxiety can make you feel sick or trigger vomiting.</p>	<ul style="list-style-type: none"> <li>• Talk to a psychologist, your doctor or nurse about relaxation or distraction that you might use before treatments or before other things you know are likely to worry you.</li> <li>• See the <b>‘I feel tense, angry and/or stressed’</b> section in the <b><i>Dealing with Stress and Worry</i></b> booklet, or use the <b>‘Learning to Relax’</b> CD to learn some relaxation techniques.</li> </ul>

### Contact a doctor or cancer care coordinator if you:

- ✓ Vomit more than three times an hour for three hours or more.
- ✓ Vomit regularly for more than a day.
- ✓ Cannot keep fluids down for more than 12 hours or are showing signs of dehydration (e.g. severe headache, dizziness, dark urine, weakness, dry mouth or severe thirst).
- ✓ Vomit blood or bile (green liquid).
- ✓ Cannot take your medicines.
- ✓ Vomiting is accompanied by severe stomach cramps, headaches and/or a stiff neck.
- ✓ Become dizzy, weak or confused.





## What others say about using these strategies

👤👤 I was worried about vomiting after chemotherapy, but my doctor said the anti-emetic medications he would give me would bring that under control. I also found that a couple of dry Cruskits, a weak tea and a quiet sit in the hospital gardens before we drove home after treatments helped a bit. 🙌🙌

*Ginny, diagnosed with colorectal cancer.*

👤👤 When I went in for my chemotherapy treatment at the hospital, I had an education session with the cancer nurse – she was very good and explained how I might feel while I'm going through treatment. She was the one who told me about sucking on lemon sherbet lollies to ease the nausea. 🙌🙌

*Joan, diagnosed with bladder cancer.*

👤👤 I survived on strawberry milkshakes. I'd have to hold the vomit for long enough to get this big milkshake down to settle everything, but it was worth the struggle, every time. 🙌🙌

*Helena, diagnosed with breast cancer.*

### Key Points: Managing nausea/vomiting

1. Talk to your doctor, nurse or cancer care coordinator about medications that might help control nausea/vomiting.
2. Take anti-nausea medicine at the first sign so that you can try to stave off any vomiting.
3. Avoid environmental cues (e.g. strong smells, bright lights, stuffy rooms) to reduce the feeling of nausea.



# How can we manage loss of appetite and changes in taste?

## Suggestions for managing loss of appetite and changes in taste

1. **Monitor changes in appetite and taste using a symptom diary** – Use the symptom diary at the end of this booklet to help you keep track of changes in appetite and taste.
2. **Talk to your doctor, nurse or cancer care coordinator.**
3. **Try self-care strategies** to manage problems with appetite and taste.



## Suggestion 1: Use a symptom diary

Tracking changes in appetite and change in taste in a symptom diary, such as the one included at the end of this booklet, is a good habit to develop, as it can identify what is causing or exaggerating symptoms.

### Note the answers to the following questions in your diary:

1. When did the appetite/taste changes start (e.g. a week ago)?
2. How often do the appetite/taste changes occur (e.g. daily, weekly)?
3. How long does it usually last (e.g. five minutes, five days)?
4. When are you most likely to experience the changes?
5. What does it feel/taste like?
6. At its worst, how severe is the change?
7. What are you/have you been doing when it happens?
8. What have you done to increase your appetite/deal with changes in taste?
9. What seems to work best?

## Suggestion 2: Talk to your doctor, nurse or cancer care coordinator

Talking to your doctor, nurse or cancer care coordinator is vital to ensure you get appropriate help in a timely fashion. Show your health care professional your symptom diary (see example at the end of this booklet), as it will clearly communicate what you are experiencing, and allow them to provide the most appropriate and helpful support. You may also wish to ask for a referral to a dietitian.

**At your next appointment, you could also ask your doctor, nurse or cancer care coordinator the following questions to help manage appetite/taste changes:**

1. Are appetite/taste changes 'normal' symptoms?
2. What is the likely cause (e.g. treatment, the cancer itself)?
3. How long are these changes likely to last?
4. Will it change (e.g. get worse or get better)?
5. Is there an effective treatment?
6. What can I do to manage these changes (e.g. diet, exercise, rest)?
7. How might it affect my treatment and recovery?
8. If and when it goes away, is it likely to return?
9. When should I contact you (e.g. if it gets worse or changes)?
10. Are there other health care professionals who can help me manage it?

For more information about talking to your health care professional, see the question checklists in the **'we don't know what to ask'** section of the **Getting What You Need From Your Health Care Team** booklet.

## Suggestion 3: Try self-care strategies

Here are some self-care strategies I recommend for managing taste and appetite changes.

– Professor Geoff Delany



Strategy	Examples
<b>‘Set the scene’ for food</b>	<ul style="list-style-type: none"><li>• Eat when you are pleasantly distracted (e.g. in front of the TV).</li><li>• Eat with friends – go out for lunch or dinner and order something you usually enjoy.</li><li>• Have a friend or family member do the cooking.</li><li>• Try meals that don’t take a lot of effort to prepare (e.g. omelettes or quick stir-fries).</li></ul>
<b>Play with taste</b>	<ul style="list-style-type: none"><li>• If food tastes bitter or acidic, try adding fruit juice or a sprinkle of sugar. Citrus and acidic flavours can ‘cut through’ the taste barrier (except if you have mouth sores).</li><li>• If food tastes metallic, try using plastic cutlery.</li><li>• Marinate meats and seafood to improve the flavour.</li><li>• Suck on mints, barley sugar or lemon drops to get rid of unpleasant tastes in your mouth.</li></ul>
<b>Play with textures</b>	<ul style="list-style-type: none"><li>• Use sauces and gravies to make foods softer.</li><li>• Where you might have made a casserole, turn it into soup.</li><li>• Puree, grate or mash food that is harder to chew, swallow or digest.</li></ul>
<b>Reduce odours</b>	<ul style="list-style-type: none"><li>• Eat food cold or at room temperature.</li><li>• Avoid strong-smelling or ‘sulphurous’ foods such as cabbage, onion and cauliflower.</li><li>• Cook outdoors or in the microwave.</li><li>• Drink through a straw or put lids on cups.</li></ul>
<b>Avoid ‘spoilors’</b>	<ul style="list-style-type: none"><li>• Carbonated drinks can make you feel full while providing few nutrients.</li><li>• Avoid foods that tend to ‘repeat’ on you (e.g. onions).</li><li>• Heavy, stodgy, deep-fried foods can sit heavily in your stomach.</li></ul>

Strategy	Examples
<b>Make portions manageable</b>	<ul style="list-style-type: none"> <li>• If you can't face a full meal, try small snacks throughout the day.</li> <li>• Eat when you are hungry, rather than waiting for set mealtimes.</li> <li>• Eat a good breakfast, especially if your appetite tends to wane during the day.</li> </ul>
<b>Drink liquids</b>	<ul style="list-style-type: none"> <li>• Milkshakes and protein shakes can provide easily swallowed nutrients. For example, slice up a ripe banana and blend with a few drops of vanilla essence and a cup of milk.</li> <li>• Sip water (perhaps with a splash of lemon or lime juice) during the day.</li> <li>• Drink fruit or vegetable juice, or suck on fruits, such as oranges.</li> </ul>
<b>Make every bite count</b>	<ul style="list-style-type: none"> <li>• Eat high (but not empty) calorie foods that are easy to eat (e.g. cheese and peanut butter).</li> <li>• Choose wholemeal and wholegrain options (e.g. multigrain bread, brown rice).</li> <li>• If you only feel like sweet things, try fruit and sweet vegetables.</li> </ul>
<b>Try other options</b>	<ul style="list-style-type: none"> <li>• Ask your doctor or dietitian about vitamin supplements and protein drinks.</li> <li>• Ask your doctor about appetite stimulants (e.g. hormones that can increase your appetite).</li> </ul>
<b>Take physical measures</b>	<ul style="list-style-type: none"> <li>• Arrange a dental check-up. Clean your teeth regularly and use a non-alcohol mouthwash.</li> <li>• Exercise lightly before meals to try to improve your appetite.</li> <li>• Take anti-nausea medication an hour or so before eating.</li> <li>• Avoid smoking, which can affect taste.</li> </ul>

**Contact a doctor or cancer care coordinator if you:**

- ✓ Have a temperature over 38°C.
- ✓ Feel too sick to eat for more than a day.
- ✓ Vomit whenever you eat and drink.
- ✓ Can't swallow your medication or keep it down.
- ✓ Are losing weight quickly without trying.
- ✓ Find that it hurts to eat.
- ✓ Are not urinating, or your urine is minimal, dark yellow and strong smelling.
- ✓ Feel too weak to get out of bed.
- ✓ Are dizzy or confused.

How is it, hon?



Ummm...maybe  
there's too much  
iron in this meal?

## What others say about using these strategies

👤👤 The metallic taste in my mouth reminded me of when I was pregnant. Then, I was aware of the importance of maintaining nutrition for my baby. I tried to get myself into the same frame of mind this time – for my own sake. This gave me the incentive to make an effort to eat. 🗨️🗨️

*Laura, diagnosed with ovarian cancer.*

👤👤 It doesn't help when people bug me about eating. I know how important it is to keep up my strength. But that thought doesn't help my food to settle any better. It does help, though, when they turn up with something nice to put in the cupboard or the freezer for the brief windows of time when I feel like I might enjoy a snack. 🗨️🗨️

*Aaron, diagnosed with colon cancer.*

👤👤 You can hear so many people in the hospital with you saying 'Oh, that taste'. I told them to stop using the metal cutlery and to use plastic instead. It helps. 🗨️🗨️

*Helena, diagnosed with breast cancer.*

### Key Points: Managing loss of appetite and taste changes

1. People often say they have lost interest in eating and don't enjoy food, because it tastes strange.
2. Forcing food down is not advisable, but 'tweaking' food and changing the way it is eaten can help to make it more palatable.



# How can we manage constipation?

## Suggestions for managing constipation

1. **Monitor constipation using a symptom diary** – Use the symptom diary at the end of this booklet to help you keep track of constipation.
2. **Talk to your doctor, nurse or cancer care coordinator** – Read on for some suggestions on discussing constipation with your health care professional.
3. **Try self-care strategies** – There are self-care measures that people with cancer say have worked for them.



Thanks for  
your help, Doc.



Uh...this is isn't quite what I had in  
mind when you said you needed  
help to get things moving!



## Suggestion 1: Use a symptom diary

Tracking constipation in a symptom diary, such as the one included at the end of this booklet, is a good habit to develop as it can identify what causes the symptoms and makes it worse.

### **Note down in your diary the answers to the following questions:**

1. When did you first notice changes to your bowel movements (e.g. two weeks ago, two days ago)?
2. What changes have you noticed (e.g. small, hard stools)?
3. What do you consider to be a normal bowel pattern for you (e.g. well-formed stools every day)?
4. How would you describe your stools now (e.g. small and hard)?
5. How are you managing to pass stools?
6. How is the problem affecting you (e.g. feeling bloated or tired, having stomach aches)?
7. What have you done to manage the constipation?
8. What seems to work best?
9. Do you have any history of constipation or other bowel-related problems? If so, how have you treated them?

Constipation is a 'relative' condition, in that it's judged against what is considered normal for you. Someone who is constipated might experience: small, hard bowel movements, leakage stools, a lack of bowel movements for three days or more, stomach cramps, passing wind, a distended stomach and/or headaches.

**– Professor Dorothy Keefe**



## Suggestion 2: Talk to your doctor, nurse or cancer care coordinator

Talking to your doctor, nurse or cancer care coordinator is vital to ensure you get appropriate help in a timely fashion. Show your symptom diary (see example at the end of this booklet) to your health care professional, as it will clearly communicate what you are experiencing, and allow them to provide the most appropriate and helpful support.

**At your next appointment, you could also ask your doctor, nurse, cancer care coordinator, or dietitian the following questions to help you manage your constipation:**

1. Is constipation a 'normal' or expected symptom?
2. What is the likely cause (e.g. treatment, the cancer itself)?
3. How long is it likely to last?
4. Will it change (e.g. get worse or get better)?
5. Is there an effective treatment for it?
6. What can I do to manage it (e.g. diet, exercise, rest)?
7. How might it affect my treatment and recovery?
8. If and when it goes away, is it likely to return?
9. When should I contact you (e.g. if it gets worse or changes)?
10. Are there other health care professionals who can help me manage it?

For more information about talking to your health care professional, see the question checklists in the **'we don't know what to ask'** section of the **Getting What You Need From Your Health Care Team** booklet.

## Suggestion 3: Try self-care strategies

Here are some self-care strategies other people have used to manage constipation.

Strategy	Examples
<b>Increase fibre in your diet</b>	<p>Before you make any changes, speak to a dietitian about what you should include in your diet. If you're given the go-ahead to increase your fibre, here are some tips:</p> <ul style="list-style-type: none"><li>• Eat fruit and vegetables as much as you can, especially apples, broccoli, peas, sweet potato, cabbage, corn spinach and bananas. Eat the skin where possible.</li><li>• Prioritise eating fruit over drinking fruit juice, as solid fruit contains more fibre.</li><li>• Replace refined carbohydrates with wholemeal and wholegrain versions (e.g. brown bread).</li><li>• Eat nuts (preferably avoiding those with added oil and salt) and dried fruit, but only a handful at a time, as large quantities can 'block' you up more.</li><li>• Consider snacks such as bran muffins, popcorn, baked beans, lentil soup, dahl, nuts, peanut butter, whole grain cereals and breads, trail mix and muesli bars.</li></ul>
<b>Increase fluids</b>	<ul style="list-style-type: none"><li>• Sip water during the day (avoid drinking too much at once, as this can make you feel bloated).</li><li>• Drink fruit juice or lemon in warm water – this is especially effective in the morning.</li><li>• Try vegetable juices or juice incorporating prunes or apricots.</li><li>• If you are having trouble drinking, sip on ice chips or suck on an icy pole.</li></ul>
<b>Avoid some foods and drinks</b>	<ul style="list-style-type: none"><li>• 'Gassy' foods such as grapes, cabbage and beans, can make you feel more bloated.</li><li>• Avoid fizzy or carbonated drinks and take care with milk (especially if you don't tolerate lactose well).</li></ul>
<b>Pace your intake</b>	<ul style="list-style-type: none"><li>• Try to eat in small amounts at regular intervals, rather than eating a big meal when you feel hungry.</li><li>• Avoid eating just before you go to bed.</li></ul>

Strategy	Examples
Try to get moving	<ul style="list-style-type: none"> <li>• Talk to your doctor about what level of exercise is advisable for you.</li> <li>• Try light walks or gentle swimming, if possible.</li> </ul>
Go with the urge to 'go'	<ul style="list-style-type: none"> <li>• Try not to ignore the urge to move your bowels – get to the toilet as soon as you can.</li> <li>• Holding bowel movements back can teach your body bad habits.</li> </ul>
Think about toilet posture	<ul style="list-style-type: none"> <li>• Adjusting the way you sit on the toilet can assist your bowel movements – sitting with your feet propped up on stool and either lean back or lean forward.</li> <li>• Try to relax and breathe deeply, rather than 'forcing' the movement with your muscles.</li> </ul>
Use laxatives	<ul style="list-style-type: none"> <li>• If you're having difficulty managing constipation with self-care measures alone, your health care professional may suggest or prescribe a natural or drug-based stool softener or laxative, such as Duralax.</li> <li>• Your doctor or nurse might automatically prescribe a laxative medication along with your pain medication. If not, ask if such medicines could work for you.</li> <li>• Avoid using suppositories or enemas – natural or drug-based laxatives or stool softeners, which can be taken orally, can help. <b>It is important that you only ever use laxatives on the advice of your health care professional.</b></li> </ul>
Try not to worry	<ul style="list-style-type: none"> <li>• Anxiety can make constipation worse – relaxation techniques, such as yoga, meditation or deep breathing, might help.</li> <li>• See the <i>Dealing with Stress and Worry</i> booklet for more information on such techniques, or use the <i>'Learning to Relax'</i> CD.</li> </ul>

### Contact a doctor or cancer care coordinator if you have:

- ✓ Noticed a change in your usual bowel habits.
- ✓ Blood in your stools or around your anal area.
- ✓ Not moved your bowels within a day or two of taking a laxative.
- ✓ Constant cramps or vomiting.
- ✓ Diarrhoea that won't stop after taking a laxative.

### What others say about using these strategies

👤 I had to laugh when I was talking to my doctor about being constipated – all I could think about were the days when discussing the finer details of my babies' 'Number Twos' with the GP. Now here I was, having the same discussion with my GP, only about myself. She said she was really glad I brought it up though, because apparently a lot of people don't and it can make them quite sick. 🙌

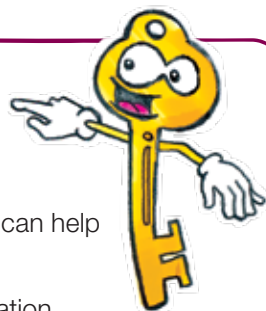
*Hayley, diagnosed with breast cancer.*

👤 When I started feeling blocked up and sluggish after my chemo, I thought all I needed to do was drink some Metamucil or something like that. I hated the way it cramped me around the stomach like a vice, so my GP put me on to a dietitian. One of things she suggested was to drink lemon in water when I wake up, which seems to help. 🙌

*Anthony, diagnosed with colorectal cancer.*

### Key Points: Managing constipation

1. Constipation is a common, but often under-reported, side effect.
2. Changes in treatment and lifestyle adjustments can help to manage constipation.
3. Laxatives are an option for dealing with constipation, but should be used only on advice from a doctor or nurse.



# How can we manage diarrhoea?

It is estimated one in 10 people with cancer experience diarrhoea while they are ill. If you pass loose or watery stools more than twice a day, you might have diarrhoea, but a diagnosis will depend on what your bowel movements were like before.



## In general terms, the symptoms of diarrhoea are:

- ✓ Increased number of bowel movements in a day.
- ✓ A change in the consistency of stools (usually from solid to watery).
- ✓ A notable increase in the volume of stools passed.
- ✓ A reduced ability to control, or hold back, the urge to pass stools.

– **Professor Geoff Delany**

**FACT:** Diarrhoea is more than just an inconvenience. If it persists, you can become dehydrated. It can also be a sign of other infections or conditions that need to be treated. It is important to seek medical advice if you think you have diarrhoea.



## Suggestions for managing diarrhoea

1. **Monitor diarrhoea using a symptom diary** – Use the symptom diary at the end of this booklet to help you keep track of diarrhoea.
2. **Talk to your doctor, nurse or cancer care coordinator.**
3. **Try self-care strategies** – Once you have seen your doctor, there are a number of measures you can take to help alleviate your diarrhoea.



## *Suggestion 1: Use a symptom diary*

Tracking diarrhoea in a symptom diary, such as the one included at the end of this booklet, is a good habit to develop, as it can help identify what causes or exaggerates symptoms.

### **Note in your diary the answers to the following questions:**

1. When did you first notice changes to your bowel movements (e.g. two weeks ago, two days ago)?
2. What changes have you noticed – be as specific as possible (e.g. thin, runny stools)?
3. What do you consider to be a normal bowel pattern for you (e.g. well-formed stools every day)?
4. How would you describe your stools now (e.g. runny, large amounts of watery stools)?
5. How are you managing to pass stools (e.g. an 'explosive' expulsion of stools)?
6. How is the problem affecting you (e.g. feeling dizzy, weak or drowsy)?
7. What have you done to manage the diarrhoea?
8. What seems to work best?
9. Do you have any history of diarrhoea or other bowel-related problems? If so, how have you treated them?

## ***Suggestion 2: Talk to your doctor, nurse or cancer care coordinator***

Talking to your doctor, nurse or cancer care coordinator is vital to ensure you get appropriate help in a timely fashion. Show your health care professional your symptom diary (example included at the end of this booklet) and allow them to provide appropriate and helpful support.

**At your next appointment, you could also ask your health care professional the following questions to help manage diarrhoea:**

1. Is this diarrhoea 'normal' or expected symptom?
2. What is the likely cause (e.g. treatment, the cancer itself)?
3. How long is it likely to last?
4. Will it change (e.g. get worse or get better)?
5. Is there an effective treatment for it?
6. What can I do to manage it (e.g. diet, exercise, rest)?
7. How might it affect my treatment and recovery?
8. If and when it goes away, is it likely to return?
9. When should I contact you (e.g. if it gets worse or changes)?
10. Are there other health care professionals who can help me manage it?

For more information about talking to your health care professional, see the question checklists in the **'we don't know what to ask'** section of the ***Getting What You Need From Your Health Care Team*** booklet.



## Suggestion 3: Try self-care strategies

Here are some self-care measures I recommend that might help you to manage your diarrhoea.

– Karen Dahdah



Strategy	Examples
Drink clear liquids	<ul style="list-style-type: none"><li>• Such as water, weak tea or clear broth. <b>Make sure you see a doctor, nurse or cancer care coordinator, if this is all you can manage for more than a day or two.</b></li><li>• If you are having trouble keeping up your fluids, try sucking on ice chips or on icy poles that contain electrolytes and glucose (available from chemists).</li></ul>
Replace salts and minerals	<ul style="list-style-type: none"><li>• When you can manage it, try to eat small amounts of banana or potato for potassium.</li><li>• Sip sports drinks (but not too much, as sugar can make your diarrhoea worse) or try icy poles from the chemist that are designed to replace electrolytes.</li></ul>
Eat small meals	<ul style="list-style-type: none"><li>• When the worst of your diarrhoea has passed, go easy on your stomach – eat small, easily digestible snacks or meals.</li><li>• Many dietitians recommend the BRAT diet – bananas, rice, apple sauce and toast, because it is relatively easy on the stomach.</li></ul>
Avoid some foods and drinks	<ul style="list-style-type: none"><li>• Acidic foods such as tomatoes can further upset your stomach, as can fizzy drinks.</li><li>• Milk and full-fat dairy products can also be too heavy in your stomach.</li><li>• Avoid alcohol and caffeine (except for weak black tea).</li><li>• Steer clear of greasy or salty food and sweet, rich snacks such as biscuits and cakes.</li></ul>

Strategy	Examples
<b>Look after the sore parts</b>	<p>Diarrhoea can irritate your anal area, so try:</p> <ul style="list-style-type: none"> <li>• Cleaning with mild soap and warm water after a bowel movement, or using baby wipes.</li> <li>• Using a water-repellent ointment, such as petroleum jelly (e.g. Vaseline) or pawpaw cream.</li> <li>• Sitting in a warm bath, or what is known as a ‘sitz bath’ (soaking for a short while in warm water which may contain baking soda or a gentle cleansing substance, up to the pelvis).</li> <li>• Patting the anal area with toilet paper, instead of wiping, to limit chafing.</li> </ul>
<b>Be prepared</b>	<ul style="list-style-type: none"> <li>• When you are going out, check that you know where the nearest toilets will be. The Commonwealth Department of Health and Ageing’s National Public Toilet Map is a useful guide – <a href="http://www.toiletmap.gov.au">www.toiletmap.gov.au</a></li> <li>• Carry toilet paper or wipes, absorption pads and spare underwear as an added precaution.</li> </ul>

### Contact a doctor or cancer care coordinator if you:

- ✓ Have more than six loose bowel movements a day for more than two days.
- ✓ Notice blood in your stools or around the anal area.
- ✓ Have stomach cramps or pain for more than two days.
- ✓ Have a temperature of more than 38°C.
- ✓ Do not urinate for more than approximately 12 hours.
- ✓ Cannot keep liquids down after two days.
- ✓ Are losing weight and feeling weak or fatigued.
- ✓ Are showing signs of dehydration, such as dizziness, weakness, dry mouth or rapid heartbeat.
- ✓ Vomit more than three times an hour for three hours or more.

## What others say about using these strategies

👤 At first, I was too embarrassed to talk to my doctor about my diarrhoea, especially since I didn't think it was such a big deal. But then I realised how much it was disrupting my life and that I wasn't eating properly because I was too worried about having to run to the toilet. So I spoke to my GP, who said I needed to drink more and suggested it might be related to another medication I was taking. I felt more in control then. 🗨️

*Louis, diagnosed with prostate cancer.*

👤 I was warned that the chemo might cause some diarrhoea, but I wasn't quite ready for how tired and wiped out I felt with it. My nurse helped me with Imodium to bring it under control, which was a big relief. 🗨️

*Michelle, diagnosed with breast cancer.*

### Key Points: Managing diarrhoea

1. Diarrhoea is a common side effect in people who are being treated for cancer and, depending upon the cause, can be an acute or ongoing problem.
2. Severe or continued diarrhoea can lead to dehydration and further health problems, and should be treated and managed as soon as possible.
3. Severe diarrhoea should be treated by medical experts, but there are many self-care measures for people managing a less severe problem.



# How can we manage incontinence (lack of bladder or bowel control)?

👏👏 It's frustrating to feel like you can't control something that has come naturally since I was about three. I'll be happily going about my business then suddenly I'll feel like I've wet myself – it can be quite demoralising. 🙏🙏  
*Shane, diagnosed with prostate cancer.*

Incontinence is the accidental or involuntary release of urine, faeces or wind. Incontinence usually occurs in one of four forms:

1. **Stress incontinence** – sudden leakages caused by activity such as jumping, or actions (e.g. sneezing).
2. **Urge incontinence** – sudden and strong need to urinate even if your bladder is not full.
3. **Overflow incontinence** – when the bladder does not empty properly.
4. **Functional incontinence** – inability to recognise the need to go to the toilet, or even to find the toilet.

## Suggestions for managing incontinence

1. **Monitor incontinence using a symptom diary**  
– Use the symptom diary at the end of this booklet to help you keep track of incontinence.
2. **Talk to your doctor, nurse or cancer care coordinator** – Read on for some suggestions on discussing incontinence with your health care professionals.
3. **Try self-care strategies** – Once you have seen your doctor, consider developing a continence management plan.



## Suggestion 1: Use a symptom diary

Tracking incontinence in a symptom diary, such as the one included at the end of this booklet, is a good habit to develop, as it can identify what causes and makes symptoms worse.

### **Note down in your diary the answers to the following questions:**

1. When did you first experience incontinence?
2. When are the leaks or accidents most likely to happen (e.g. sudden movements, after drinking)?
3. What changes have you noticed – be as specific as possible?
4. How long have you been experiencing incontinence?
5. How severe is the lack of control (e.g. small leaks, total loss of control)?
6. How is the problem affecting you (e.g. embarrassed, worried, exhausted)?
7. Does anything seem to help (e.g. specific foods, exercises)?
8. What other treatments are you receiving (e.g. radiotherapy, medicines)?
9. What other symptoms are you experiencing (e.g. nausea, diarrhoea, constipation)?

### **Top Tip: Planning for travel**

Planning for travel and times when you may find yourself in unfamiliar surrounds is an important part of managing incontinence. Think about things like timing and accessibility to public toilets and other facilities. The Commonwealth Department of Health and Ageing has a National Public Toilet Map that may help with planning travel, see [www.toiletmap.gov.au](http://www.toiletmap.gov.au)



## Suggestion 2: Talk to your health care team

Talking to your doctor, nurse, cancer care coordinator, continence nurse, or a continence physiotherapist is a vital part of ensuring that you get appropriate help in a timely fashion. Show your health care professional your symptom diary (example included at the end of this booklet), this will help them determine the most appropriate and helpful support.

**At your next appointment, you could also ask your health care professional the following questions to help manage incontinence:**

1. Is this incontinence a 'normal' or an unexpected symptom?
2. What is the likely cause (e.g. treatment, the cancer itself)?
3. How long is it likely to last?
4. Will it change (e.g. get worse or get better)?
5. Is there an effective treatment for it?
6. What can I do to manage it (e.g. diet, exercise, rest)?
7. How might it affect my treatment and recovery?
8. If and when it goes away, is it likely to return?
9. When should I contact you (e.g. if it gets worse or changes)?
10. Are there other health care professionals who can help me manage it?

For more information about talking to your health care professional, see the question checklists in the **'we don't know what to ask'** section of the **Getting What You Need From Your Health Care Team** booklet.

# Suggestion 3: Try self-care strategies and develop an incontinence plan

Continence experts, usually nurses or physiotherapists, can be found in hospitals around the country. Ask your doctor to recommend an expert or contact the Continence Foundation of Australia's Helpline (1800 33 00 66, or visit [www.continence.org.au](http://www.continence.org.au)) for a directory of experts. You could also contact Australian Nurses for Continence ([www.anfc.org.au](http://www.anfc.org.au)). Below are some strategies your continence expert might include in your plan.



– Karen Dahdah



Strategy	Explanation
Dietary adjustments	What you eat and drink may affect how well your bladder or bowel copes. Dietary adjustments may include decreasing fluid and fibre intake or avoiding caffeine.
Pelvic floor muscles	Strengthening muscles that support the bowel and bladder may help with flow control. The pelvic floor tilt is the main exercise continence experts encourage to strengthen the pelvic floor muscles supporting the bladder. The Continence Foundation website ( <a href="http://www.continence.org.au">www.continence.org.au</a> ) has a guide to exercising pelvic floor muscles. The site also has a list of free resources, including the brochures <b>Pelvic Floor Muscle Training for Men</b> and <b>Pelvic Floor Muscle Training for Women</b> .
Toilet techniques	A continence expert can advise you on ways to control urinary flow when using the toilet, which in turn can help control your bladder.
Bladder training program	A continence expert can help you train your bladder so you have more control. This might take several appointments and involve keeping a bladder diary.
Medication	Some medications help ease bowel incontinence. Your continence expert can help you with this or refer you to a doctor.

Strategy	Explanation
<b>Medical treatment</b>	Sometimes more invasive treatments such as catheter drainage or surgery are needed to control incontinence. Your continence expert will advise.
<b>Additional products</b>	A continence expert, or even your GP, oncologist, nurse or pharmacist, might also be able to suggest aids, such as pads and odour control products, to help you manage any leakage.



### Contact a doctor or cancer care coordinator if you:

- ✓ Suddenly experience total loss of bladder or bowel control when you have had no previous problems with incontinence.
- ✓ Are having major 'accidents' more than once a day.
- ✓ Experience pain when you urinate or move your bowels.
- ✓ Find that your urine or stools contain blood.
- ✓ Feel a constant need to urinate but can't.

### What others say about using these strategies

 I was initially a bit embarrassed to tell my doctor about the 'accidents' I was having. But when I finally did, she took it very seriously. She asked me lots of questions and recommended someone to help with bladder training. 

*Ron, diagnosed with prostate cancer.*

 I've been doing the exercise program developed for me by the continence nurse to strengthen my pelvic floor muscles. Now that's been very handy. 

*Steve, diagnosed with prostate cancer.*



## Key Points: Managing incontinence

1. A continence expert can help you manage incontinence.
2. A continence management plan can include exercises to strengthen the pelvic floor muscles, techniques to train the bladder, medications, and tips for being prepared.
3. In more serious cases, surgery may rectify the cause of incontinence and a continence nurse can help with a longer-term management plan.



Right, there are  
two toilets a little  
to the west.



# How can we manage mouth sores (oral mucositis)?

👄 It was painful to eat and talk because every time I opened my mouth, I felt like my teeth were catching on these little blisters on the insides of my cheeks. 🦷

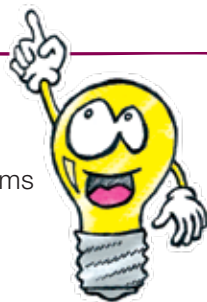
*Penny, diagnosed with bowel cancer.*

Mouth sores are little ulcers in the mouth, they can form on the lips, gums, tongue, inside cheeks or on the roof or floor of the mouth. The discomfort caused by these sores can be enough to make swallowing, eating, talking and breathing difficult.

Some problems people report about mouth sores are: swelling or redness in the gums and inside of the mouth, painful 'pits' or open sores on the gum or inside the cheeks, a whitish film in the mouth or on the tongue, blood, or sometimes pus, in the mouth, stinging from food and drink (especially acidic foods or citrus), irritation from teeth, sore throat, 'pimples' or rough patches on the tongue, increased saliva or mucous in the mouth.

## Suggestions for managing mouth sores

1. **Monitor mouth sores using a symptom diary** – keeping a diary helps to keep track of when symptoms are worst, and what has helped you manage them.
2. **Talk to your doctor, nurse or cancer care coordinator.**
3. **Try self-care strategies** to prevent or manage the problem.



## *Suggestion 1: Use a symptom diary*

Tracking mouth sores in a symptom diary, such as the one included at the end of this booklet, is a good habit to develop because it helps you identify what causes or exaggerates your symptoms.

### **Note the answers to the following questions in your diary:**

1. When did the sores start appearing (e.g. a week ago, a month ago)?
2. How do they look and feel (e.g. painful blisters, stinging sores)?
3. How long do they last (e.g. five days, three weeks)?
4. How painful are they (e.g. on a scale of 1–10)?
5. What seems to make them better or worse (e.g. food, ice chips)?
6. Do they seem to be related to anything (e.g. food, treatment)?
7. Have you had any other illness or infections (e.g. cold, gastro)?
8. How is the problem affecting you (e.g. unable to eat, irritable)?
9. What have you done to manage the mouth sores?
10. What seems to work best?

## ***Suggestion 2: Talk to your doctor, nurse or cancer care coordinator***

Talking to your doctor, nurse or cancer care coordinator is vital to ensure you get appropriate help in a timely fashion. Show your health care professional your symptom diary (see example at the end of this booklet) as it will clearly communicate what you are experiencing, and allow them to provide the most appropriate and helpful support.

### **At your next appointment you could also ask your health care professional the following questions to help manage mouth sores:**

1. Are mouth sores a 'normal' or an unexpected symptom?
2. What is the likely cause (e.g. treatment, the cancer itself)?
3. How long are they likely to last?
4. Will they change (e.g. get worse or get better)?
5. Is there an effective treatment for them?
6. What can I do to manage it (e.g. diet, exercise, rest)?
7. If and when it goes away, is it likely to return?
8. When should I contact you (e.g. if it gets worse or changes)?
9. Are there other health care professionals who can help me manage it?

For more information about talking to your health care professional, see the question checklists in the **'we don't know what to ask'** section of the ***Getting What You Need From Your Health Care Team*** booklet.

## Suggestion 3: Try self-care strategies

Here are some self-care strategies for preventing and coping with cancer-related mouth sores.

– **Professor Dorothy Keefe**



Strategy	Examples
<b>Go to the dentist</b>	<ul style="list-style-type: none"><li>• Problems with your teeth and gums (e.g. cavities, gum disease) can make you more susceptible to mouth sores.</li><li>• Before your treatment, a dental hygienist can give your teeth a good, professional clean and offer advice on oral hygiene.</li><li>• If you use dentures, check that they are fitting correctly, or take them out during treatment if they are irritating your mouth.</li></ul>
<b>Keep your mouth clean</b>	<ul style="list-style-type: none"><li>• Brushing your teeth and tongue gently and rinsing a few times a day (particularly after meals) will help to keep your mouth clean and free of infection.</li><li>• Avoid abrasive toothpastes and alcohol-based mouthwashes, which can irritate sores.</li><li>• Use a soft toothbrush and avoid flossing to prevent bleeding.</li><li>• Rinse your toothbrush in hot water and let it dry thoroughly.</li><li>• If a toothbrush hurts too much, try wrapping gauze around an icy pole stick, or use a cotton swab to rub your teeth.</li><li>• If you have dentures, take them out regularly and soak them in antibacterial solution.</li></ul>
<b>Try a soothing mouth wash</b>	<ul style="list-style-type: none"><li>• Mix a teaspoon of baking soda in two cups of water and, before and after eating, swish this around your mouth – including gargling – before spitting it out.</li><li>• Adding a teaspoon of salt can be a great help in cleaning sores.</li></ul>

Strategy	Examples
<b>Keep up your fluids</b>	<ul style="list-style-type: none"> <li>• Sip plenty of water, weak tea or milk to keep you hydrated (which can stop your mouth drying up and irritating sores).</li> <li>• Avoid alcohol, fizzy drink and juices (such as orange and pineapple) that can sting sores.</li> <li>• Use a straw to try to bypass sores.</li> </ul>
<b>Eat the right food</b>	<ul style="list-style-type: none"> <li>• Have small, regular meals to minimise the amount of chewing you do during each meal.</li> <li>• Puree, or grate food, or cut it into small pieces.</li> <li>• Avoid tough, chewy or hard food.</li> <li>• Avoid spicy or salty food.</li> </ul>
<b>Keep your lips moist</b>	<ul style="list-style-type: none"> <li>• Using a water-repellent balm, such as lanolin, aloe vera or pawpaw cream, can help prevent and soothe sores on the lips.</li> </ul>
<b>Use ice</b>	<ul style="list-style-type: none"> <li>• Drinking cold water or sucking on ice chips can temporarily numb pain from sores.</li> </ul>
<b>Use medications</b>	<p>Ask your doctor, nurse or pharmacist about:</p> <ul style="list-style-type: none"> <li>• Medicines that ‘coat’ the lining of your mouth with a protective film. Be aware that this can numb your mouth to heat and cold.</li> <li>• Medications to promote cell growth in the mouth.</li> <li>• General pain relievers, such as paracetamol.</li> </ul>
<b>Give up smoking</b>	<ul style="list-style-type: none"> <li>• Smoking can increase your susceptibility to sores and can also increase healing time.</li> <li>• Contact the Australian Government Quitline on 13 18 48 or 13 78 48, or talk to your GP about quitting.</li> </ul>
<b>Monitor your mouth</b>	<ul style="list-style-type: none"> <li>• Use a small mirror or torch to help you check sores and tell your doctor if you’re concerned about them not healing, or if there is excessive pus or blood.</li> <li>• Tell your doctor or nurse if you notice changes in taste that may be associated with mouth sores.</li> </ul>

### Contact a doctor or cancer care coordinator if you:

- ✓ Have redness or swelling that continues for more than two days.
- ✓ Have a distinctive lump that has formed under or around a sore.
- ✓ Have individual sores that do not stop bleeding or oozing pus.
- ✓ Have individual sores that take more than four weeks to clear up.
- ✓ Can't eat or drink properly or take your medicines.
- ✓ Have bleeding gums.
- ✓ Have white patches on your tongue or on the inside of your cheeks.

### What others say about using these strategies

👍 I had a sore inside my bottom lip for weeks, which would 'pop' and ooze pus every now and then. I finally mentioned it to my GP, who said it was a bacterial infection that needed to be treated before it caused more problems. It hadn't even occurred to me that it could make me sicker. ⚡

*Charles, diagnosed with melanoma.*

👍 I was skipping meals because it wasn't pleasant to eat with the ulcers in my mouth. A nurse suggested I try swishing milk in my mouth before eating. It seemed to help – it kind of coated my mouth and stopped the sting. ⚡



*Bernadette, diagnosed with breast cancer.*

### Key Points: Managing mouth sores

1. Mouth sores are often more than just an inconvenient side effect of cancer treatment.
2. Mouth sores are most serious when they disrupt eating and drinking, or allow infection into the body.
3. The most effective way of managing mouth sores is to try to prevent them. However, if they do occur, keep the mouth clean and minimise the chance of infection.



# How can we manage impotence (erection difficulties) and sexual problems?

 Impotence is the inability to achieve or maintain penile erection sufficient to complete satisfactory intercourse or any other chosen sexual activity; ejaculation (coming) may or may not be affected. Impotence is also known as erectile dysfunction. 

*Impotence Australia, [www.impotenceaustralia.com.au](http://www.impotenceaustralia.com.au)*

Apart from the lack of erection, some men experience 'dry orgasms', where little semen is released, while others report feeling pain during orgasm. Other sexual problems include reduced libido, vaginal discomfort (dryness or tenderness) or body image and self-esteem issues.

## Suggestions for managing impotence and sexual difficulties

- 1. Talk to your partner** – Some people find this embarrassing and difficult, but avoiding talking about impotence and sexual difficulties may lead to a build-up of unnecessary stress.
- 2. Monitor impotence and sexual difficulties using a symptom diary** – Keeping a diary helps keep track of when impotence or other sexual problems occur, and what might help you manage it.
- 3. Talk to your doctor, nurse or cancer care coordinator** – Many hospitals have nurses who are experts at helping people cope with sexual problems.
- 4. Try self-care strategies** to manage the problem.





## Suggestion 1: Talk to your partner

If you feel embarrassed or awkward talking to your partner, try writing down your thoughts and concerns before you discuss them. Here are some general strategies to help you guide your discussion:

Strategy	Explanation/Examples
<b>Make sure the timing is right</b>	<ul style="list-style-type: none"><li>• Try to talk when you are both relatively relaxed and free of distractions.</li><li>• Make sure you have enough time to talk the issue through.</li></ul>
<b>Use 'I' rather than 'you'</b>	<ul style="list-style-type: none"><li>• Describing your concerns in terms of how you feel can reduce the chances of your partner feeling like they are the problem.</li><li>• For instance you might say: "I've been a bit anxious about having sex lately because I'm finding it quite uncomfortable. I feel too dry and tender."</li></ul>
<b>Suggest ways your partner can help</b>	<ul style="list-style-type: none"><li>• Are there things your partner can do or say, other ways you can be intimate, or different techniques you can try to work around the problems you are experiencing?</li></ul>
<b>Use humour</b>	<ul style="list-style-type: none"><li>• Laughter, as long as it isn't at the expense of the other person, can be a way of relieving awkwardness and embarrassment.</li></ul>

**Top Tip:** For more tips on communicating with your partner about sensitive issues see the ***'I don't know how to talk about the hard stuff'*** section in the ***Supporting Each Other*** booklet.



## Suggestion 2: Use a symptom diary

Tracking sexual difficulties in a symptom diary, such as the one included at the end of this booklet, is a good habit to develop because it helps you identify what causes or makes your sexual problems worse.

### Note down in your diary the answers to the following questions:

1. What is the nature of the problem – physical (e.g. impotence, dryness), emotional (e.g. body image, stress), or both?
2. How is the problem affecting you (e.g. anxious, depressed)?
3. How long have you been experiencing this problem?
4. What is going on in your life at the moment (e.g. stress, treatment)?
5. What have you done to manage the problem (e.g. counselling, different techniques)?
6. What seems to work best?
7. Have you discussed this with your partner? Has that helped?

**FACT:** Research suggests that the earlier you seek help for impotence, the more successful the treatment is likely to be.



## What treatment options are available to manage sexual problems?

Here are some options you might discuss with members of your health care team:

### Physical treatment

- ✓ Some people require surgery; penile implants are sometimes recommended.
- ✓ Physical therapies such as massage or physiotherapy might help others.
- ✓ Other physical aids can help (see the 'self-care' section below).

### Psychological treatment

- ✓ You might ask for a referral to a psychologist, counsellor or sex therapist.

### Medication

- ✓ For impotence, a doctor can prescribe tablets, known as PDE5 inhibitors, which increase the flow of blood to the penis.
- ✓ Men can also be taught to inject themselves with a drug that opens up the blood vessels in the penis and creates an erection.
- ✓ A testosterone supplement, or in some cases, hormone replacement therapy, may be prescribed to those who are battling a severely reduced sex drive.

**Top Tip:** Be informed about how the cancer treatment may impact on you/your partner's sexuality. Knowing what to expect can help you plan how to address the issues if they occur.



## Suggestion 3: Talk to your health care team

If you're worried about how to talk about impotence and sexual problems, try writing down some questions that you can use either as a prompt or to show your health care professional.



– **Professor Geoff Delany**

### Here are examples of question you might want to ask:

1. Are sexual changes 'normal' or an unexpected symptom?
2. What is the likely cause (e.g. treatment, psychological factors)?
3. How long are they likely to last?
4. Will it change (e.g. get worse or get better)?
5. Is there an effective treatment?
6. What can I do to manage it (e.g. talking with partner, medications, physical aids)?
7. If and when it goes away, is it likely to return?
8. When should I contact you (e.g. if it gets worse or changes)?
9. Are there other health care professionals who can help me manage it?

**FACT:** Counsellors, psychologists and sex therapists can help you manage the issues in your sexual relationship. For more information on sexual counselling, or to find a counsellor, psychologist or sex therapist, talk to your doctor, nurse or cancer care coordinator (ask if your hospital has a nurse who specialises in this area), or contact the Australian Society of Sex Educators, Researchers and Therapists (ASSERT) at [www.assertnational.org.au](http://www.assertnational.org.au) (click on 'Professional Accredited Members'), or call 02 9280 0151.



# Suggestion 4: Try self-care strategies

Strategy	Examples
Physical aids	<ul style="list-style-type: none"><li>• Physical aids for erectile dysfunction include penile rings and vacuum pumps.</li><li>• Women struggling with vaginal dryness or tenderness may benefit from using unscented, chemical-free and colour-free lubricants (such as commercial gels like KY Jelly).</li><li>• If you are having vaginal surgery, talk to your doctor or nurse about vaginal dilators (or enlargers) to use after surgery. These (or even your fingers, your partner’s penis or a sexual aid) may be used three or four times a week to stop the vagina tightening during radiation treatment to the pelvic area.</li></ul>
Physical techniques	<ul style="list-style-type: none"><li>• If having intercourse is uncomfortable, try other sexual activities, such as manual stimulation, oral-genital stimulation, caressing or kissing.</li><li>• Changing sexual positions might help to control movement or ease pressure on tender areas (e.g. lying on your sides, ‘spooning’ or reversing positions).</li><li>• When the vaginal area is tender, women can control the depth of penetration by circling a thumb and finger around the penis at the mouth of the vagina.</li><li>• If some parts of you are too tender, suggest other erogenous zones (e.g. breasts) that your partner can stimulate.</li></ul>
Lifestyle factors	<ul style="list-style-type: none"><li>• Regular exercise, where possible, can help to boost hormone levels and improve body image, which can promote sexual interest and/or function.</li><li>• Too much alcohol can hinder erections.</li><li>• Tiredness and anxiety can cause sexual problems.</li></ul>
Medication	<ul style="list-style-type: none"><li>• Talk to your health care team about self-administered medications to help your sexual performance (e.g. drugs to stimulate erections).</li></ul>

Strategy	Examples
<b>Emotional support</b>	<ul style="list-style-type: none"> <li>• Openly discussing problems with your partner can help reduce the stress of sexual problems. It will help both of you understand how the other is feeling and allow you to discuss alternative ways of being intimate.</li> <li>• Talk to your doctor or cancer care coordinator about seeing a psychologist, counsellor or sex therapist.</li> <li>• Understand you cannot give your partner cancer via sexual contact.</li> </ul>
<b>If you have a stoma (or ostomy)</b>	<ul style="list-style-type: none"> <li>• Empty the bag before sexual activity.</li> <li>• Push the bag to the side or wear a comfortable belt or sash that you can tuck it into.</li> <li>• Try different sexual positions to work around the stoma.</li> <li>• Wear crotchless underwear (that covers the stoma but not your genitals) or wear a top.</li> <li>• If there is a leak, wash or shower with your partner – and don't forget that mutually enjoyed humour can be a big help.</li> </ul>

### Contact a doctor or cancer care coordinator if you:

- ✓ Have pain during sexual activity that changes or worsens.
- ✓ Experience bleeding after sexual activity.
- ✓ Feel, or your partner notices, that you are becoming depressed.

**Top Tip:** You may prefer to talk to an 'anonymous' expert about sexual problems. The Cancer Council helpline (13 11 20) staff can connect you to a counsellor you can talk to on the phone.



## What others say about using these strategies

👤 When I was still having trouble ‘keeping it up’, so to speak, a few months after prostate surgery, I began to fret about it. I tried to laugh about it with my wife but I think it was really affecting how I felt about myself as a man. One night, I decided to just come out with it, and once we had talked about it I felt so much better. 🗨️

*Tom, diagnosed with prostate cancer.*

👤 I had always had what I thought was a healthy libido, but suddenly I found sex really uncomfortable. I managed to grit my teeth through it most of the time, but I just happened to mention it to my doctor one day when we were talking about some personal stuff. I was strangely relieved when she told me it was fairly common – so it wasn’t just all in my head! 🗨️

*Libby, diagnosed with breast cancer.*

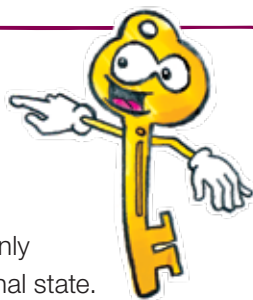
👤 It’s about adjusting around the fact that [partner Rodney] doesn’t have a huge sex drive now ‘cos he always did have. But in actual fact it’s reassuring myself that he’s still attracted to me and he is; there’s a bit of adjustment happening around that but it’s not a problem. 🗨️

*Carla, partner of Rodney, diagnosed with prostate cancer.*

*(Street et al., 2009:239)*

### Key Points: Managing sexual problems

1. Impotence, lack of libido and other sexual problems are legitimate medical complications that can be successfully treated.
2. Impotence and other sexual problems are not only caused by, but can be affected by, your emotional state.
3. Open and honest communication with sexual partners and health care professionals is the key to resolving and working around sexual problems.



# How do we manage other symptoms?

While some symptoms are more common than others, different people have different physical and psychological responses to cancer and its treatment. Below are three general suggestions for managing the other symptoms you may experience.



– **Professor Geoff Delany**

## Suggestions for managing other symptoms

### 1. Monitor symptoms using a symptom diary –

Keeping a diary helps to keep track of when symptoms are worst, and what has helped you manage them. Even if you are unsure what the symptom is, use the diary to describe it as best you can.

### 2. Talk to your doctor, nurse or cancer care coordinator

– If you notice a new symptom, talk to your doctor or nurse. Even if it seems like a minor thing, it may tell them something important about your cancer, treatment, general health and wellbeing.

### 3. Seek further help –

In many cases, you might need to seek help from a health care professional with specialist skills or expertise. Ask your doctor or nurse for a referral or recommendation.





## Suggestion 1: Use a symptom diary

Tracking symptoms in a symptom diary, such as the one included at the end of this booklet, is a good habit to develop because it helps you identify what causes or makes your symptoms worse.

### Note the answers to the following questions in your diary:

1. Do they seem to be related to your treatment or other symptoms? What else has been happening to you at the same time?
2. What changes have you noticed? Be as specific as you can in describing these changes.
3. Where is it, if applicable, or what does it feel or look like.
4. When did you first notice the changes (e.g. "I noticed a couple of pale spots two weeks ago")?
5. How bad was it, on a scale of 1 (mild/minor) to 10 (severe)?
6. How are the changes affecting you?
7. Have you done anything to relieve the problem? Discuss any strategies you might have tried and whether they have worked.

### Can I prevent my hair from falling out?

Hair loss is common due to temporary damage to the hair follicle. Look after your hair and scalp by using gentle hair care products (e.g. baby shampoo, soft brush), cover your head when you're in the sun and avoid harsh chemicals (e.g. hair colour) and high heat (e.g. hair dryers and straighteners).



## ***Suggestion 2: Talk to your doctor, nurse or cancer care coordinator***

Talking to your doctor, nurse or cancer care coordinator is vital to ensure you get appropriate help in a timely fashion. Show your health care professional your symptom diary (see example at the end of this booklet) as it will clearly communicate what you are experiencing, and allow them to provide the most appropriate and helpful support.

**At your next appointment, you could also ask your health care professional the following questions to help manage your symptoms and side effects:**

1. Is this a 'normal' or an unexpected symptom?
2. What is the likely cause (e.g. treatment, the cancer itself)?
3. How long is it likely to last?
4. Will it change (e.g. get worse or get better)?
5. Is there an effective treatment for it?
6. What can I do to manage it (e.g. diet, exercise, rest)?
7. How might it affect my treatment and recovery?
8. If and when it goes away, is it likely to return?
9. When should I contact you (e.g. if it gets worse or changes)?
10. Are there other health care professionals who can help me manage it?

For more information about talking to your health care professional, see the question checklists in the ***'we don't know what to ask'*** section of the ***Getting What You Need From Your Health Care Team*** booklet.

## Suggestion 3: Seek further help

Your doctor, nurse or cancer care coordinator may refer you to other health care professionals who can help with a specific symptom. You can also identify who in your health care team might be useful and do some research of your own using any of the following resources.

Health care professionals	
Some of the health care professionals who might be able to help you with specific symptoms or side effects are:	
<b>General Practitioner</b>	For general guidance and tips.
<b>Oncologist</b>	Can help with identifying a possible cause and how it relates to your cancer and treatment.
<b>Radiation Oncologist</b>	If the side effect is caused by, or related to, radiation therapy.
<b>Cancer Care Coordinator or Oncology/Cancer Support Nurse</b>	Can help with tips for coping and medication.
<b>Community Nurse</b>	Can help with identifying changes and administering medication.
<b>Palliative Care Specialist</b>	Especially for managing pain associated with side effects.
<b>Dietitian</b>	If the side effect is related to nutrition or diet.
<b>Occupational Therapist</b>	Can help with managing daily activities if affected by side effects.
<b>Counsellor/Psychologist/Psychiatrist</b>	Can help to deal with side effects related to emotional or psychological issues.
<b>Physiotherapist or an Accredited Exercise Physiologist</b>	Can prescribe an exercise programme, including for the pelvic floor. You can find an accredited exercise physiologist through Exercise and Sports Science Australia, see <a href="http://www.essa.org.au">www.essa.org.au</a> or call 07 3856 5622 for more details.

## Cancer organisations

Cancer Council Australia ([www.cancer.org.au](http://www.cancer.org.au)) is the peak body for all of the State-based cancer councils, through which you can access hotlines, fact sheets, brochures and other information. Call the Cancer Council Helpline on 13 11 20. Most cancer organisations have websites that include information on side effects and coping with cancer. Here are a few:

Cancer Australia	<a href="http://www.canceraustralia.gov.au">www.canceraustralia.gov.au</a>
Cancer Council Australia	<a href="http://www.cancer.org.au">www.cancer.org.au</a>
National Cancer Institute (US) CancerNet	<a href="http://www.cancer.gov/cancertopics">www.cancer.gov/cancertopics</a>
Macmillan Cancer Support (UK)	<a href="http://www.macmillan.org.uk">www.macmillan.org.uk</a>

For information related to a particular cancer, try community-funded organisations such as:

Breast Cancer Network Australia	<a href="http://www.bcna.org.au">www.bcna.org.au</a>
National Breast Council Foundation	<a href="http://www.nbcf.org.au">www.nbcf.org.au</a>
Prostate Cancer Foundation Australia	<a href="http://www.prostate.org.au">www.prostate.org.au</a>
Bowel Cancer Australia	<a href="http://www.bowelcanceraustralia.org">www.bowelcanceraustralia.org</a>
Melanoma Patients Australia	<a href="http://www.melanomapatients.org.au">www.melanomapatients.org.au</a>

## Other people with cancer

Some of the best tips for effectively managing side effects come from cancer patients and their partners. You can ask your doctor or cancer care coordinator if they know people you can talk to, or you can try to contact others through the Cancer Council Connect service (13 11 20). You might also try web-based forums, blogs, podcasts or social networks (such as Facebook), many of which you can find through reputable cancer sites. See the ***Getting the Support You Need*** booklet for further information.

## Support groups

You can tap into others' experiences with side effects through cancer support groups, which can be found through cancer agencies, hospitals and doctors' surgeries.

## Book shops and libraries

For specific, research-based texts on cancer side effects, try the state and national libraries (indexes for most of which you can find online), university libraries, or ask your health care professionals about useful books. Some cancer support groups gather books and information resources and lend them to their members. As well as producing their own free booklets, the State Cancer Councils usually have recommended reading lists and often have other publications for sale.

For more information about the roles of your health care team members, see the **‘we don’t know who to ask’** section of the **Getting What You Need From Your Health Care Team** booklet.

### What others say about using these strategies

👤 After I started chemo, I began to notice all these little things – like tingling in my fingers, itchy skin, hot feet and cold sores – which didn’t seem like much, and I began to wonder if I was becoming a bit of a hypochondriac. But I made a list anyway and showed it to my doctor. I was pleasantly surprised when, far from rolling his eyes, he went through the list and took it all very seriously. 🙌

*Lucas, diagnosed with melanoma.*

### Key Points: Managing other symptoms

1. Symptoms and side effects may vary between patients.
2. Your health care team want to know about ‘small’ problems so they can help prevent them growing into bigger ones.
3. Keeping a symptom diary will help you discuss the symptoms with your health care professionals.



# How can we manage the impact on everyday life?

👏👏 I thought I'd gotten a shock when I was first diagnosed, but my family and friends didn't know what hit them either. Not only were they worried about me, but our usual routine went straight out the window; we didn't know if we were coming or going. You know, I wouldn't wish this on anyone, but it gave me a chance to see how the people around me could band together – it was so tough, but I think we ended up closer to each other. 🙌🙌

*Susan, diagnosed with melanoma.*

A cancer diagnosis can change the routines, finances, social lives, relationships and health of everyone involved – patients, their immediate family, wider family and friends.

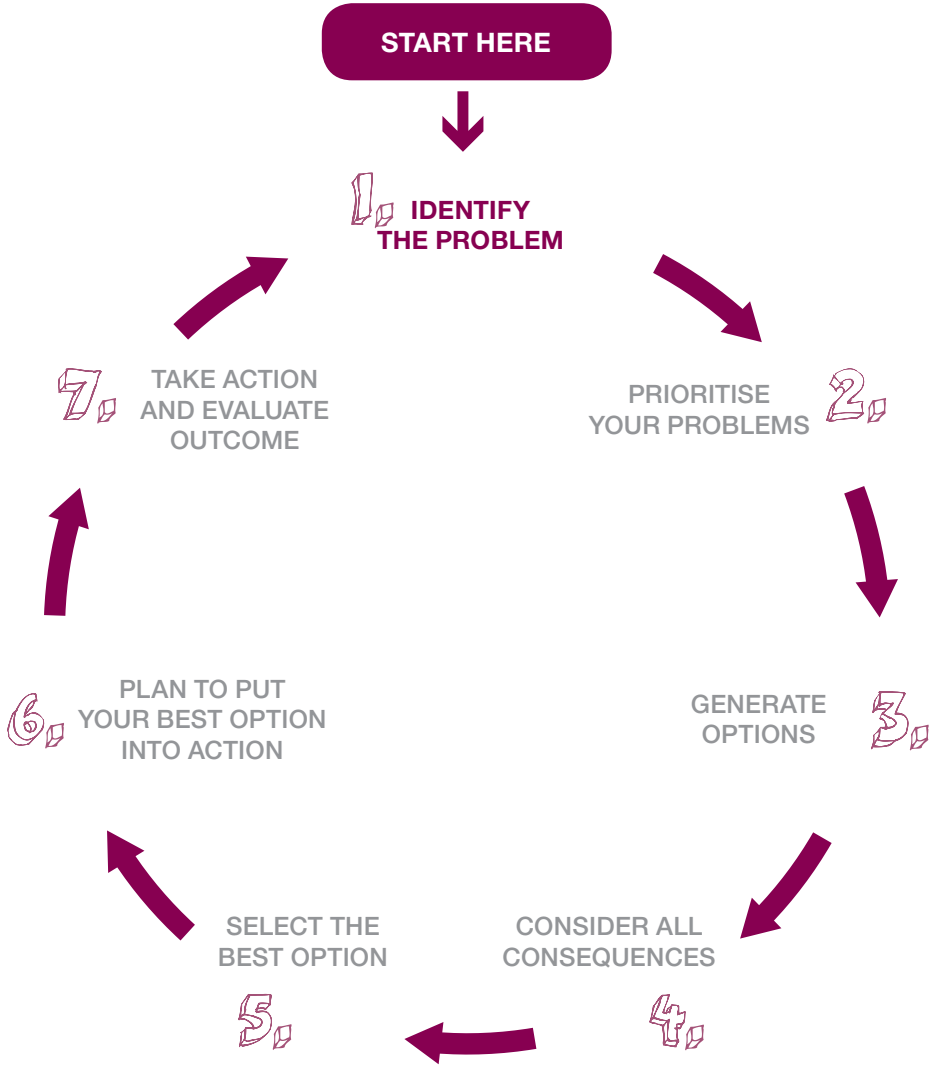
## Suggestions for managing the impact on everyday life

1. **Problem solving** – The first step is to identify problems and work out solutions.
2. **Asking for or giving help** – Emotional and practical support.



# Suggestion 1: Problem solving

It's often hard to know what to do when you are faced with a new challenge or problem. The following problem solving steps may help.



See the *Dealing with Stress and Worry* booklet for worksheets, and an example of working through each step.

## Suggestion 2: Asking for or giving help and support

Patients, partners, family members and friends can help and support each other **emotionally** or with **practical** and **day-to-day** assistance.

### Emotional support

Emotional support involves listening to what the other person wants to say, showing you understand what they're saying and helping them to open up about a problem. This might not feel like the most practical type of support you can give, but when people feel stressed, they often don't want or need a solution to the problem. Instead, they just want someone to listen to them.

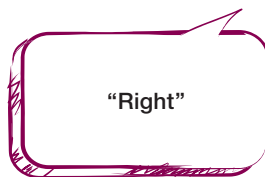
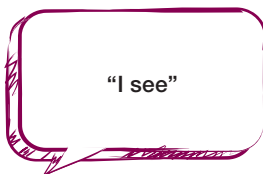
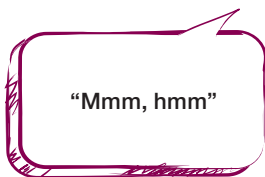


– Karen Dahdah

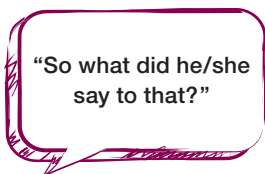
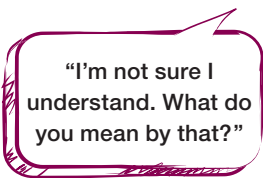
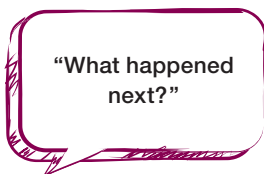
### How you do it

Really listen to the person while they're talking. There are several ways you can show them that you're listening:

- ✓ Use your body language; look at your loved one and maintain eye contact, adopt and maintain a relaxed and open body posture, face your body towards them and nod your head from time to time
- ✓ Use short phrases of acknowledgement to show your interest, such as:



- ✓ Ask questions to better understand what the person is saying, or to help them open up, such as:



For more information on listening and other communication skills, see the **Supporting Each Other** booklet.



## Practical and day-to-day support

Partners, family and friends are usually keen to help, but are not always sure what they can do or how much they can commit to. The following list offers suggestions on how you can help, including tips for helping with specific symptoms and side effects.

Examples of what partners, family members and others can do	
<b>General</b>	<ul style="list-style-type: none"><li>• Be an exercise partner, where needed (and on a health care professional's advice).</li><li>• Manage visitors and activity around the house (e.g. quiet when needed).</li><li>• When possible, attend appointments and treatments.</li><li>• Talk to doctors and other health care professionals on their behalf.</li><li>• Visit when they are up to it, and be a pleasant distraction.</li><li>• Invite them on social outings that they can manage.</li><li>• Provide food (check their dietary needs).</li></ul>
<b>Fatigue</b>	<ul style="list-style-type: none"><li>• Help prioritise chores and share them among others – perhaps set up a roster.</li><li>• Offer fluids and snacks.</li><li>• Create a relaxing environment (e.g. make up a fresh bed, keep the house quiet, run a bath).</li><li>• Be company on short walks or other forms of physical activity such as cycling, swimming, weight training.</li><li>• Check if they are up to visits before dropping in.</li><li>• Offer to help with small tasks (e.g. water the garden, clean the bathroom) when visiting.</li><li>• Bring food that can be easily prepared or reheated.</li></ul>
<b>Pain</b>	<ul style="list-style-type: none"><li>• Assist with managing medication times and dosages.</li><li>• Look for signs of pain (e.g. grimaces or trouble moving).</li><li>• Help with other pain relief (e.g. preparing heat packs, gentle massage).</li><li>• Sign up to a yoga or meditation session with them.</li></ul>



## Examples of what partners, family members and others can do

<b>Nausea (feeling sick) or vomiting</b>	<ul style="list-style-type: none"> <li>• Minimise cooking smells and other 'trigger' odours.</li> <li>• Provide any food and drink they can manage and check whether it stays down.</li> <li>• Monitor medication and whether they keep it down.</li> <li>• Ventilate rooms and let fresh air in.</li> <li>• Create social opportunities away from food and smells that might make them nauseous.</li> <li>• Bring food they can manage.</li> <li>• Try not to wear strong-smelling perfumes.</li> </ul>
<b>Loss of appetite and changes in taste</b>	<ul style="list-style-type: none"> <li>• Prepare meals and snacks to suit their taste.</li> <li>• Try to minimise cooking smells (e.g. cook outdoors).</li> <li>• Create a pleasant setting for meals (e.g. set the table, music) so the food is not the focus.</li> <li>• Be flexible with meals (e.g. they might feel like breakfast cereal at dinner time) and mealtimes.</li> <li>• Encourage them to sip fluids, especially if they are not eating.</li> <li>• Try to avoid badgering them about eating.</li> <li>• Ask what foods they can eat before bringing meals or snacks.</li> <li>• Meet in places where food is not the focus (e.g. a park instead of a café).</li> </ul>
<b>Bowel and bladder problems</b>	<ul style="list-style-type: none"> <li>• Make sure fluids are readily available.</li> <li>• Help them manage and administer medications and other substances to treat the problem.</li> <li>• Ensure sanitary products are available, when needed.</li> <li>• Check for amenities on outings. Be aware of their needs (e.g. access to public toilets) when out.</li> </ul>



## Examples of what partners, family members and others can do

<b>Mouth sores</b>	<ul style="list-style-type: none"> <li>• Help to check and monitor sores (especially in spots they can't see).</li> <li>• Provide ice chips and drinks to sip on.</li> <li>• Ask what food they can manage before bringing meals or snacks.</li> <li>• Avoid food-centred social outings (e.g. go for a walk instead of meeting at a café).</li> </ul>
<b>Impotence and sexual problems</b>	<ul style="list-style-type: none"> <li>• Discuss concerns openly and honestly. Ask them how you can help.</li> <li>• Try to avoid making comments (other than positive ones) about physical changes.</li> <li>• Be open to trying, and suggest, different sexual activities and techniques.</li> <li>• Show affection and intimacy in other ways (e.g. lots of hugs or touching).</li> <li>• See a counsellor, psychologist or sex therapist with your partner (or by yourself, if necessary).</li> <li>• Depending on your relationship, be available for them to talk, if they feel they need to.</li> </ul>

### How have others managed the impact on partners, families and everyday life?

 I put together a list of things my friends and family could do to help. They felt better, because they knew exactly what to do. I felt better because I was getting exactly what I needed. It was win-win. 

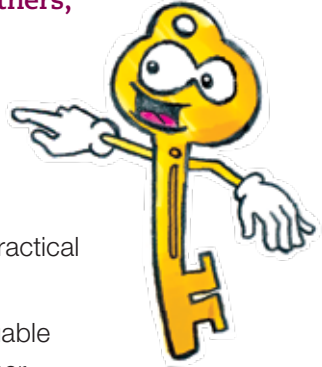
*Olivia, diagnosed with breast cancer.*

 Probably the biggest shock for the kids was that we weren't spending our weekends riding bikes as a family anymore. But they made sure we still had fun. They insisted that we pull down all the old board games and play them for hours on end. I think it made our family feel like we could still laugh a lot. 

*Tim, partner of Beth, diagnosed with melanoma.*

### **Key Points: Managing the impact on partners, families and everyday life**

1. A cancer diagnosis can change the routines, finances, social lives, relationships and health of everyone involved.
2. Offering problem solving, emotional and practical support will help your partner cope.
3. Family members and friends can be a valuable source of support for a couple facing cancer.



# Support organisations and other resources

Throughout this booklet we have provided you with lots of information and contacts for support organisations. The following list summarises some of the sources mentioned in this booklet, so that you can find them if you want further information or resources.

Australian organisations	
Acupuncture Association of Australia	07 4159 2020 <a href="http://www.acupaa.com.au">www.acupaa.com.au</a>
Australian Government Quitline	13 18 48 or 13 78 48 <a href="http://www.quitnow.gov.au">www.quitnow.gov.au</a>
Australian Home Care	1300 303 770 <a href="http://www.ahcs.org.au">www.ahcs.org.au</a>
Australian Nurses for Continence	ACT 02 6205 5113 NSW 02 9739 2367 NT 08 8922 7163 QLD 07 3343 6288 SA 08 8282 1617 TAS 03 6222 7321 VIC 03 9265 1402 WA 0405 746 927 <a href="http://www.anfc.org.au">www.anfc.org.au</a>
Australian Society of Sex Educators, Researchers and Therapists (ASSERT)	02 9280 0151 <a href="http://www.assertnational.org.au">www.assertnational.org.au</a>
Bowel Cancer Australia	02 9923 8269 <a href="http://www.bowelcanceraustralia.org">www.bowelcanceraustralia.org</a>
Breast Cancer Network Australia	1800 500 258 <a href="http://www.bcna.org.au">www.bcna.org.au</a>

Cancer Australia	1800 624 973 <a href="http://www.canceraustralia.gov.au">www.canceraustralia.gov.au</a>
Cancer Council Australia	02 8063 4100 Helpline (all States) 13 11 20 <a href="http://www.cancer.org.au">www.cancer.org.au</a>
Continence Foundation of Australia	1800 330 066 <a href="http://www.continence.org.au">www.continence.org.au</a>
Dietitians Association of Australia	1800 812 942 <a href="http://www.daa.asn.au">www.daa.asn.au</a>
Exercise and Sports Science Australia	07 3856 5622 <a href="http://www.essa.org.au">www.essa.org.au</a>
Impotence Australia	1800 800 614 <a href="http://www.impotenceaustralia.com.au">www.impotenceaustralia.com.au</a>
Meals on Wheels	ACT      02 6234 7600 (through Red Cross) NSW      02 8219 4200 NT      08 8924 3900 (through Red Cross) QLD      07 3205 5588 SA      1800 854 453 TAS      03 6228 4546 VIC      0459 406 433 WA      08 9244 8233 (through Aged and Community Services) <a href="http://www.mealsonwheels.org.au">www.mealsonwheels.org.au</a>
Melanoma Institute Australia	02 9911 7200 <a href="http://www.melanoma.org.au">www.melanoma.org.au</a>
Melanoma Patients Australia	1300 884 450 <a href="http://www.melanomapatients.org.au">www.melanomapatients.org.au</a>
National Breast Cancer Foundation	1300 708 763 <a href="http://www.nbcf.org.au">www.nbcf.org.au</a>
Prostate Cancer Foundation Australia	1800 220 099 <a href="http://www.prostate.org.au">www.prostate.org.au</a>

## International organisations

MacMillan Cancer  
Support (UK)

[www.macmillan.org.uk](http://www.macmillan.org.uk)

National Cancer Institute  
CancerNet (US)

[www.cancer.gov/cancerinformation](http://www.cancer.gov/cancerinformation)

## Booklets, publications and websites

“A guide for women with metastatic breast cancer”, National Breast Cancer Centre. Available through Cancer Australia, or Google search using the title.

“Controlling cancer pain: What you need to know to get relief”, Cancer Care, [http://media.cancercare.org/publications/original/9-ccc\\_pain\\_control.pdf?1302555870](http://media.cancercare.org/publications/original/9-ccc_pain_control.pdf?1302555870)

“Coping with side effects of treatment for prostate cancer”, Cancer Council Victoria, [www.cancervic.org.au/about-cancer/cancer\\_types/prostate\\_cancer/coping\\_with\\_prostate\\_cancer.html](http://www.cancervic.org.au/about-cancer/cancer_types/prostate_cancer/coping_with_prostate_cancer.html)

“How can we manage constipation?”, National Cancer Institute, [www.cancer.gov/cancertopics/coping/chemo-side-effects/constipation](http://www.cancer.gov/cancertopics/coping/chemo-side-effects/constipation)

“How can we manage diarrhoea?”, National Cancer Institute, [www.cancer.gov/cancertopics/coping/chemo-side-effects/diarrhea](http://www.cancer.gov/cancertopics/coping/chemo-side-effects/diarrhea)

“How can we manage impotence (erection difficulties) and sexual problems?”, Impotence Australia, [www.impotenceaustralia.com.au](http://www.impotenceaustralia.com.au)

“How can we manage impotence (erection difficulties) and sexual problems?”, MacMillan Cancer Support, [www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Relationshipscommunication/Sexuality](http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Relationshipscommunication/Sexuality)

“How can we manage impotence (erection difficulties) and sexual problems?”, Prostate Cancer Treatment Guide, [www.prostate-cancer.com/coping-with-prostate-cancer/coping-with-impotence.html](http://www.prostate-cancer.com/coping-with-prostate-cancer/coping-with-impotence.html)

“How can we manage loss of appetite and changes in taste?”, National Cancer Institute, [www.cancer.gov/cancertopics/pdq/supportivecare/nutrition/Patient](http://www.cancer.gov/cancertopics/pdq/supportivecare/nutrition/Patient)

“How can we manage mouth sores (oral mucositis)?”, National Cancer Institute, [www.cancer.gov/cancertopics/pdq/supportivecare/oralcomplications/patient/page5#Section\\_32](http://www.cancer.gov/cancertopics/pdq/supportivecare/oralcomplications/patient/page5#Section_32)

“How do we manage other symptoms?”, Breast Cancer Network Australia, [www.bcna.org.au/new-diagnosis/treatment/chemotherapy/nail-changes](http://www.bcna.org.au/new-diagnosis/treatment/chemotherapy/nail-changes)

“How do we manage other symptoms?”, Cancer Council,  
[www.cancercouncil.com.au](http://www.cancercouncil.com.au)

“How do we manage other symptoms?”, Jonsson Comprehensive Cancer,  
[www.canceralternatives.mednet.ucla.edu](http://www.canceralternatives.mednet.ucla.edu)

“Nursing best practice guideline: Assessment and management of pain”,  
Registered Nurses Association of Ontario 2007,  
[www.rnao.org/Storage/29/2351\\_BPG\\_Pain\\_and\\_Supp.pdf](http://www.rnao.org/Storage/29/2351_BPG_Pain_and_Supp.pdf)

“Pelvic floor muscle training for men”, Continence Foundation of Australia,  
[www.bladderbowel.gov.au/assets/doc/brochures/05PelvicFloorMen.pdf](http://www.bladderbowel.gov.au/assets/doc/brochures/05PelvicFloorMen.pdf)

“Pelvic floor muscle training for women”, Continence Foundation of Australia,  
[www.bladderbowel.gov.au/assets/doc/Factsheets/English/06PelvicFloorWomenEnglish.pdf](http://www.bladderbowel.gov.au/assets/doc/Factsheets/English/06PelvicFloorWomenEnglish.pdf)

Public toilet map, Department of Health and Ageing, [www.toiletmap.gov.au](http://www.toiletmap.gov.au)

“Teamwork: The cancer patient’s guide to talking with your doctor”,  
National Coalition for Cancer Survivorship 2011  
[www.canceradvocacy.org/assets/documents/teamwork-resource.pdf](http://www.canceradvocacy.org/assets/documents/teamwork-resource.pdf)

“Solving life’s problems: A 5-step guide to enhanced well-being”, Nezu, A.M.,  
Nezu, C.M. and D’Zurilla, T.J., 2007.

“Step-by-step problem solving: A practical guide to ensure problems get  
(and stay) solved”, R.Y. Chang and P.K. Kelly.

“WHO’s pain ladder”, World Health Organisation,  
[www.who.int/cancer/palliative/painladder/en/](http://www.who.int/cancer/palliative/painladder/en/)



## NOTES

# Symptom Diary

Date	What I did	What I ate/drank	<b>What</b> <ul style="list-style-type: none"><li>side effect or symptom</li></ul>	<b>Description</b> <ul style="list-style-type: none"><li>where</li><li>what it felt or looked like</li></ul>
			1.	
			2.	
			3.	
			4.	

SYMPTOMS OR SIDE EFFECTS					
	<b>Duration</b> <ul style="list-style-type: none"> <li>• when did it start</li> <li>• when/how often it occurred</li> <li>• how long it lasted</li> </ul>	<b>Severity</b> <ul style="list-style-type: none"> <li>• how bad was it</li> <li>• on a scale of 1 to 10 1=Mild 10=Severe</li> </ul>	<b>Effect</b> <ul style="list-style-type: none"> <li>• how it affected you</li> </ul>	<b>Management</b> <ul style="list-style-type: none"> <li>• what you did to relieve it</li> <li>• how well it worked</li> </ul>	<b>Other comments</b>

The best cancer care starts with getting the cancer information you need. Well-informed patients and partners are their own best advocates and invaluable partners for health care providers. **coping together** puts the focus on the patients and their partners, providing the practical information they need to learn new coping skills and build confidence in using them. **coping together** has been put together by a team of researchers and clinicians, including psychologists and nurses, with expertise in helping people cope with cancer.

👤👤 Incontinence has just crept into our world this last week. So I just saw that in the **Coping-Together** book and I thought I will go back to that section and look at that. Loss of appetite is creeping into it as well so there are things that I will now have to look at. 🦋🦋  
*Valarie, wife of Quinton, diagnosed with prostate cancer.*

👤👤 They talk about that metallic taste that you get in your mouth, a nurse told me about lemon sherbets, I've gone and bought dozens of packets. Another woman that had just finished her breast cancer chemo as I started – she said to me, 'mandarins...when you feel a bit funny, eat a mandarin' and I found mandarins terrific. 🦋🦋  
*Joan, diagnosed with bladder cancer.*

👤👤 I love my t-bone steaks and I don't think I've had one since chemotherapy. It's just that I was sick, just the smell of it. I found the suggestions in the **Coping-Together** booklet very good when it came to 'how to get away from the smells' and things like that. 🦋🦋  
*Perry, diagnosed with bowel cancer.*

