1. PHYSICAL NEEDS

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

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

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

Always tired?

Fatigue is the most common symptom in people with advanced cancer.[1] This is not normal tiredness. The fatigue associated with advanced cancer can range from feeling tired to being absolutely exhausted.[83] As well, cancer related fatigue is less likely to be relieved by rest or sleep[2] and it can disrupt everyday life.[3]

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

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

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

Some specific signs of cancer-related fatigue include:

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

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

What may help

Talk to your Doctor

Write down what you want to tell you doctor:

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

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

Write down what you want to ask your doctor:

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

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

Naps

Small naps during the day will not take away the tiredness[2] but they may boost your energy and help you sleep better at night. Try not to nap in the late afternoon or evening if you aim to get a good night's sleep.[6]

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

The next section presents strategies to promote a restful sleep.

Planning and adapting activities

You will enjoy your activities more if you plan them for the times you know you will be least tired[7] – morning seems to be best for most people.

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

tip

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

Exercise

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

Control other symptoms

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

For more information

Try the information on the following websites:

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

Can't sleep?

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

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

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

What may help –

Talk to your Doctor

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

FACT

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

Write down what you want to tell you doctor:

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

Write down what you want to ask your doctor:

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

Talk to others

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

Relaxation

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

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

Exercise

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

tips

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

Worried about pain?

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

What may help –

Talk to your Doctor

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

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

Write down what you want to ask your doctor:

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

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

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

FACT

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

Pain relief[12]

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

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

FACT

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

Q&A

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

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

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

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

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

Know your doses

Take your medications on time. A key to keeping pain under control is to take the prescribed dose before the pain starts and regularly thereafter.
Your doctor, nurse or pharmacist should be able to help with any concerns.

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

tip

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

FACT

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

Control other problems

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

Alternative relief

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

FACT

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

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

For more information

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

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

Trouble breathing?

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

What may help –

Talk to your Doctor

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

Write down what you want to tell you doctor:

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

Write down what you want to ask your doctor:

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

Non-medical help

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

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

tip

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

Plan your activities

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

FACT

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

Experiencing bowel problems?

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

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

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

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

What may help –

Talk to your Doctor

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

Write down what you want to tell you doctor:

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

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

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

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

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

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

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

tips

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

Changes in diet

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

tips

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

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

½ cup margarine or butter
1 cup brown sugar
½ cup prune puree
1 egg
1 cup applesauce – any flavour
2 cups all bran cereal
1½ cups flour
½ teaspoon baking soda and
1 teaspoon of cinnamon or other spice to taste. Optional: ½ to 1 cup raisins, or chocolate chips, sunflower seeds, nuts.

Directions: In a large bowl, cream margarine with sugar. Add egg, then prune puree and apple sauce, mix well. Add dry ingredients. Mix well. Drop by spoonfuls onto 3 cookie sheets – 12 cookies per sheet. Bake in 180° oven for about 15 minutes. Cool on pans for a few minutes and then remove.

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

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

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

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

Exercise

Exercise can also help with constipation – be as active as you can be, but do not exceed your physical abilities. Walking 15-20 minutes once or twice a day or 30-60 minutes daily or 3 to 5 times per week is typically recommended.[84] If you are unable to walk or are restricted to bed, exercises such as pelvic tilt, trunk rotation and single leg lifts are recommended.[84]

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

Toileting and Privacy

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

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

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

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

For more information

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

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

Feeling sick?

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

What may help –

Talk to your Doctor

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

Write down what you want to tell your doctor:

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

Write down what you want to ask your doctor:

- What can be done to relieve nausea or vomiting?
- Ask your doctor what he or she will be prescribing to prevent or control nausea and vomiting.
- Find out if the chemotherapy drug you are receiving is likely to cause nausea and vomiting. If so, ask when these are most likely to occur and how long they typically last.

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

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

Meals

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

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

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

tips

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

FACT

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

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

Lost your appetite?

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

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

tips

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

What may help –

Talk to your Doctor

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

Changes to diet

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

Other suggestions include:

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

tips

Nourishing Drink Recipes[85]

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

Trouble getting around?

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

What may help –

Talk to your health care team

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

Support services

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

Commonwealth Carelink Centres

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

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

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

Assistance with personal care

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

Enhancing mobility

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

- **Occupational therapists**, who are trained to help you manage everyday activities. They can suggest mobility equipment and changes in the home. You should be able to find one through your local hospital, a specialist palliative care team or privately.
- Palliative care equipment is available for loan. Go to the **Palliative Care Australia** website **www.palliativecare.org.au** or phone **2 6232 4433** to find out about the contact details for the palliative care centre in your state.
- **The not-for-profit Independent Living Centres** in each state, which provide information and equipment for everyday living. Go to **www.ilcaustralia.org**, or call **1300 885 886**.
- **Other state-based programs for providing equipment for independent living**. In NSW for example, the Program of Appliances for Disabled People (PADP) provides aids for mobility, continence, communication, sleeping, nutrition and more.
- **Private organisations** that rent or sell equipment such as wheelchairs, walking frames, shower chairs, commodes, incontinence products and pressure-care mattresses. Look under "Disabled Persons Equipment &/or Services", "Home Health Care Aids" or "Hire – Medical Equipment" in the Yellow Pages.

Modifying your home

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

Seeking respite care

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

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

Needing help around the home

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

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

tip

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

Considering further treatment?

You may have undergone chemotherapy[27], radiotherapy or surgery in the earlier stages of your cancer. In progressive stages, the techniques are usually less about curing and more about improving the length and quality of your life.

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

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

These trials are usually run by teaching hospitals, universities, or drug companies and test techniques, vaccines or drugs that have shown promising results during development and are ready to be tested under controlled conditions in "real life". Some trials involve more risk than others, and some may have ethical concerns. A legitimate clinical trial will have complied with a number of strict conditions and passed an ethical review.

tip

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

FACT

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

What may help –

Ask questions

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

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

Research

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

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

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

For more information

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

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

Looking for other treatments?

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

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

FACT

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

- **Complementary therapies** are used alongside conventional treatments such as surgery, chemotherapy or radiotherapy, and include a range of methods: mind-body techniques such as meditation, counselling and hypnotherapy; body-based practices such as massage, acupuncture and yoga; and biological-based therapies such as naturopathic nutrition and Chinese herbal medicine. Complementary therapies don't claim to cure cancer, but aim to relieve side-effects of treatment, or reduce the emotional impact of a cancer diagnosis.
- **Alternative therapies** are used instead of conventional treatment. These therapies may be harmful if people with cancer delay or stop using conventional treatment in favour of them. Many of these therapies claim to stop cancer growth and to cure cancer. However, most alternative therapies have not been scientifically tested, so there is no proof that they work, or they have been found to be ineffective. Examples include microwave therapy, coffee enemas, high-dose vitamin supplementation or diets that replace conventional therapy.[89]

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

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

What may help –

Weigh it up

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

Talk to your Doctor

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

General questions to ask your doctor about complementary therapies:

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

FACT

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

Do your homework

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

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

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

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

General questions to ask any potential complementary therapist

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

For more information

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

Q&A

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

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

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

Sick of hospitals?

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

What may help –

Talk to your Doctor

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

Ask for help

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

tips

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

FACT

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

Personal Notes