

Cancer how are you travelling?



Understanding the emotional and social impact of cancer



Australian Government
Cancer Australia

Cancer

how are you travelling?



Cancer — how are you travelling? Understanding the emotional and social impact of cancer
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** On 30 June 2011, National Breast and Ovarian Cancer Centre (NBOCC) amalgamated with Cancer Australia to form a single national agency, Cancer Australia, to provide leadership in cancer control and improve outcomes for Australians affected by cancer.*

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Note to reader

Every person's situation and needs are different.

Not all the information in this booklet will be relevant to you and your current situation.

You don't need to read this booklet from cover to cover.

Different chapters may be useful for you at different stages of your cancer journey.

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Introduction

This booklet provides information about the emotional and social impact of cancer. It has been written for people diagnosed with cancer, their family and friends.

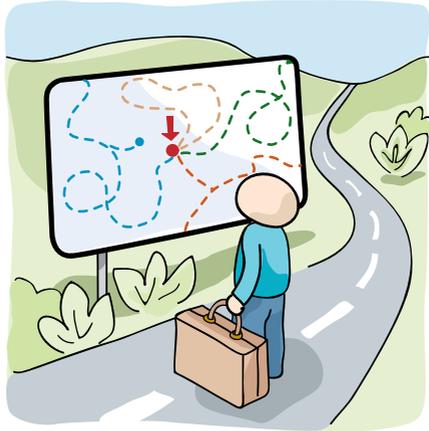
This booklet may be most useful for people recently diagnosed with cancer or currently undergoing treatment. However, there are some issues discussed that may be relevant at other times throughout your cancer journey.

It provides an introduction to some of the emotional, physical and practical challenges faced by people diagnosed with cancer. It is not intended to be a comprehensive guide but may help you to identify some of the issues you are facing and provide information about the types of support available.

This booklet is based on the *Clinical practice guidelines for the psychosocial care of adults with cancer* (2003). The guidelines were developed for health professionals by the National Breast and Ovarian Cancer Centre* and the National Cancer Control Initiative. The recommendations in both the guidelines and this booklet are based on research into the experiences of people with cancer and treatments that can help.

You will notice the term 'treatment team' used throughout this booklet. This refers to the group of health professionals involved in your care and may include people such as doctors, nurses, social workers, physiotherapists and your general practitioner (GP). The members of your treatment team with whom you have most contact will vary throughout different stages of your cancer journey.

Your cancer journey



A diagnosis of cancer marks the beginning of a journey full of **emotional, psychological, physical** and **practical** challenges. Some of these challenges are common to many people with cancer and others are faced by people diagnosed with particular types of cancer.

These challenges can relate to the shock of a cancer diagnosis and fears about the future. Or perhaps they are due to the physical side-effects of treatment such as nausea and fatigue. There are also the practical costs of treatment to deal with and the financial implications of having to take time off work. More specific emotional problems can range from concerns about body image after treatment to periods of anxiety or depression.

The emotional, physical and practical journey of some people can take a different direction altogether if the cancer comes back. Others must deal with the challenges of surviving cancer.

Emotional issues

When first diagnosed with cancer, many people feel anger, shock, distress, disbelief or fear about their future. Others experience feelings of grief, hopelessness or loss.

“The doctor said the word ‘cancer’ to me and I immediately switched off. He wasn’t talking to me. He was talking to somebody totally different.”

Other people say their emotions really hit them when their treatment was over and they had the time and space to reflect on what had happened.

Not everyone feels the same about the diagnosis and treatment of cancer. Many people find it difficult to talk about their feelings.

Everyone experiences a range of emotions at different times throughout life. But when these feelings are related to your cancer, they can last for longer periods of time and affect different areas of your life.

For many people, these feelings will reduce over time. However, your emotional care is just as important as your physical care throughout your cancer journey.

Psychological issues

As well as affecting your general emotional wellbeing, living with cancer can change how you feel about yourself and how you relate to other people in your life.

You might experience:

- ▶ Changes in the way you feel about your body after treatment for cancer. This could be because of scarring or body changes after surgery or side-effects of treatment like weight gain and hair loss.
- ▶ Changes in the way you feel about your sexuality and intimacy. This is closely connected to your body image, your self-esteem and mood, and how well you are feeling.
- ▶ Strain on relationships with people close to you, particularly your partner. A cancer diagnosis can be just as overwhelming and distressing for partners and other close family members as it is for the person diagnosed.
- ▶ Challenges in establishing a new relationship. Many people find it difficult to know how, when and how much to tell someone new about their cancer. Many people also feel conscious of the way their body has changed after treatment.

Many people with cancer will feel distressed at different times. Some people have more severe emotional reactions that can lead to high levels of anxiety and depression.

Anxiety

If you are constantly feeling agitated or angry, or you are having difficulty sleeping, concentrating or making decisions, you may be experiencing high levels of anxiety. Other symptoms of anxiety include avoiding distressing issues and situations, and feeling a constant need for reassurance. These feelings of anxiety can have a major impact on your quality of life and the lives of those around you.

“I had lots of support from people in the neighbourhood but I was really, really depressed. I was scared stiff.”

Depression

Depression is a very common problem in the community. Rates of depression are even higher in people with cancer. About one in three people with cancer may experience depression at some time.

Some of the key warning signs of depression include always feeling low or flat and losing interest in things that you used to enjoy. Having difficulty sleeping or a poor appetite can also be signs of depression. However, sometimes it can be difficult to tell if your poor appetite is a symptom of depression or a side-effect of treatment. Depression can make it harder to deal with physical symptoms and to cope with cancer.

Some people avoid talking about their emotional concerns or seeking help because they feel they should be coping or they don't want to be a burden to others. Other people are encouraged by those around them to be strong and positive, which can make it hard to ask for help.

It's important to know there are many effective treatments and services available to help you work through any challenges you may be facing.

Physical issues

People with cancer experience a range of physical symptoms and side-effects of treatment. These can include nausea and vomiting, pain, ongoing fatigue, fertility problems and lymphoedema (swelling in an area of the body). Some people also say they find it difficult to concentrate or think clearly during chemotherapy.

Symptoms don't have to be life-threatening to affect your quality of life. For example, a dry mouth, changes in taste and difficulties with hot food are experienced by some people after treatment and can have a major impact on your social activities and daily family life.

“If I start to feel tired I’ll think ‘right, just slow down a bit’. I’m learning to say ‘no, I’m not doing it today, I’ll do it later or I’ll get someone else to help me do it.’”

People will respond differently to different physical issues. But it's important to know that distress caused by physical issues can increase the likelihood of you experiencing anxiety and depression. Many of these symptoms will disappear after treatment is completed, but talk to your treatment team if your physical symptoms or treatment side-effects are affecting your quality of life.

You may also find that your diagnosis of cancer has a bigger impact on some parts or 'roles' in your life than others. For example, you might find you cannot do all the physical chores you used to do at home, but your cancer does not change your ability to do your job. Or vice versa, some people may experience little change at home but find they need long periods off work or may have to stop work completely. The impact of cancer on your different roles may change at different stages along your cancer journey.

Practical issues

After a diagnosis of cancer, there are many practical issues to think about. These can include the costs of treatment, support services, travel, accommodation, child care or specific items such as wigs or prostheses. There are also ongoing finances to think about if you find it difficult to work after treatment.

“I went through our patient assistance travel scheme. They found a place to stay not far from the hospital that came under the criteria, so they funded the bill.”

The practical challenges can also have an impact on your family. Sometimes people feel guilty that their cancer treatment means the rest of the family has to make changes to the way they are used to doing things. Maybe the children need to take on additional chores at home or the budget is a little tighter.

“I had to find babysitters while I had my treatment, or take my son to the hospital with me. I didn’t know that help might be available.”

Concern about these practical issues can affect how you are feeling, especially if it interrupts your daily activities.

Remember, your emotional care and social support is just as important as your physical care during your cancer journey. A range of health professionals and support services are available to help you through the challenging times. **You don’t have to go through this alone.**

Information about costs and different options for practical support, such as financial and travel assistance, is available from the Cancer Council Helpline on 13 11 20.

Travelling companions



Your cancer also affects the people around you — your family, friends and colleagues.

Your partner or children may find it difficult to cope and also need support.

Partners can experience higher levels of stress than the person with cancer and have different information needs. Children can become particularly stressed if they can't talk about their parent's cancer.

“I think it's really difficult for the people around you, it's frustrating, there is not really much that people can do, except be there.”

You may find some friends and colleagues don't know how to talk to you about your cancer and tend to stay away. Other people may pleasantly surprise you with their level of support and understanding.

“Some friends cope well, and others....they don't know what to say”

When the road gets bumpy



There are times in your cancer journey when you are more likely to experience higher levels of distress or anxiety, such as when you are first diagnosed or at the time of surgery. Some people also experience significant stress when they start hormonal therapies or chemotherapy or when they finish treatment.

It's very normal to feel fear and anxiety that the cancer may come back for years after your treatment has finished. Many people find this fear is particularly high around the time of regular medical check-ups.

“The stress level builds up as a check-up approaches. I tend to be more on edge and feel anxious coming up to my examination.”

If the cancer does come back, there may be a whole new range of challenges to deal with. Many people find the news of a cancer recurrence more devastating than the original diagnosis of cancer. It brings with it new levels of anxiety and uncertainty for both the person diagnosed and their family. While this booklet doesn't deal specifically with the challenges of advanced cancer, there are many people available who can help you, including your treatment team, support groups and spiritual advisors.

There are some people with cancer who may find the journey more difficult because of their age, family circumstances or other issues.

- ▶ **Younger people** may be particularly concerned about the impact of cancer on their partner and children, and may feel a sense of isolation.
- ▶ People with **marital or family difficulties** may feel like they don't have enough support.
- ▶ **People with children** often feel guilty about the impact their cancer has on their children and may face additional pressures about finances and childcare.
- ▶ **Single people** may feel isolated or have fears about starting a new relationship.
- ▶ People who have had to face **stressful life events in the past** may experience greater stress during their cancer journey.
- ▶ People with **financial concerns** may be confronted with the additional costs of treatment and taking time off work.
- ▶ People who have experienced **depression or anxiety in the past** may be at increased risk of experiencing periods of depression.
- ▶ People who have or have had **problems with alcohol or drugs** may experience more emotional distress.
- ▶ **Women** may be more likely than men to experience anxiety or depression, and issues about their sexuality or body image.

This is not an exhaustive list and there are many other people who find the road a little bumpier because of their individual circumstances. People from culturally and linguistically diverse backgrounds may feel isolated and find it difficult to talk about their cancer with friends and family because of their cultural beliefs.

How do you know if what you are feeling is normal?

Sometimes it can be difficult to put into words how you are feeling. Tools such as a *distress thermometer* can be very helpful in explaining what you are experiencing.

You may be familiar with a pain scale, where you are asked to describe your level of pain on a scale from zero to 10. A score above five indicates significant pain. Similar to the pain scale, a *distress thermometer* allows you to pinpoint exactly how you are feeling on a distress scale from zero to 10.

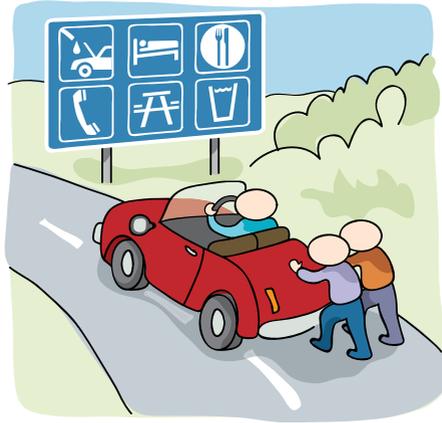
The thermometer can be filled out while you are waiting for treatment or an appointment. It asks you to rate how much distress you have been feeling over the past week including today. The scale ranges from 'no distress' (zero) to 'extreme distress' (10). People with a distress level above five on the thermometer will usually need some form of professional support.

The thermometer also comes with a list of specific problems different people face and asks you to circle any that have been an issue for you in the past week including today. This can open up the opportunity to work through specific issues.

An example of a *distress thermometer* tool is located on page 28.



Roadside assistance



Having support during your diagnosis and treatment is very important. Having good support from your family and friends, from health professionals or special support services will make it much easier to cope with having cancer.

You might find it helpful to talk with your partner, a friend or family member who makes you feel comfortable. You might prefer to seek help from a health professional or someone who has been through a similar experience. Or if your anxiety or fear feels overwhelming, there are different types of techniques and therapies that can help.

Your cancer journey doesn't always follow a straight path and you can't always anticipate the bumps and bends along the way. Talking about your feelings and concerns can make the journey much smoother. It can also help you to recognise any emotional issues you may be facing. The important thing to know is that help and different treatments are available and can make a big improvement to your quality of life.

Your pit crew



As well as your family and friends, there are several members of your treatment team who can support you through your cancer journey. You might hear members of the team refer to your emotional care and practical support as ‘psychosocial care’. Psychosocial care focuses on the emotional side of your cancer journey, taking into account your social situation, spiritual beliefs and individual concerns.

Who can help?

- ▶ **General practitioners (GPs)** provide a link to a range of health professionals who can assist with emotional care and practical support services. In many cases you will have an established relationship with your GP, who also knows your family, so they are in a good position to offer support and information.
- ▶ **Nurses** provide ongoing support throughout your cancer journey. They can provide advice about other health professionals who can help you with challenges along the way. Nurses are usually very experienced in helping people to cope with physical symptoms and are familiar with the emotional issues faced by people with cancer.

- ▶ **Social workers** provide advice about finances and practical support. They can also provide counselling, which can include other members of your family if needed.
- ▶ **Psychologists** provide counselling and can offer specific therapies to help you.
- ▶ **Psychiatrists** are doctors who specialise in mental health and the way the brain functions. In addition to counselling, they can treat conditions such as depression and anxiety and prescribe medication if necessary.
- ▶ **Counsellors** listen and help you to work out exactly what issues you are facing and what you would like to do next.
- ▶ **Occupational therapists** provide practical support to help you overcome physical problems or barriers at home or work. Some occupational therapists are qualified to provide specific treatments such as lymphoedema massage.
- ▶ **Physiotherapists** provide physical support, massage and manipulation to help with mobility, reduce your pain and assist with problems such as lymphoedema.
- ▶ **Speech therapists** help you with speech, eating and swallowing difficulties.
- ▶ **Dieticians or nutritionists** help you to overcome eating difficulties and maintain a healthy diet.
- ▶ **Spiritual advisors** can talk to you about matters of faith.

“I talked to a counsellor at the hospital. It would have been an hour and I just sat, and it all came out and it was great because he sat there and listened.”

In addition to your team of health professionals, a **support group** can also be a very valuable part of your pit crew. See the next section for more information about support groups.

Stopping for a service



What can help?

Specific therapies and treatments can help you to get through the emotional, practical and physical challenges of living with cancer.

Having the opportunity to talk about your cancer and how you are feeling can help you to feel less distressed. **Peer support groups** give you the chance to meet and talk with people who have been through or are going through similar experiences. Often people say they feel less anxious and alone and more optimistic about the future after meeting with a support group.

“In the support group I could tell them what a bloody awful week it’s been, because for other people I have to be so positive.”

But not everyone likes support groups, so don’t feel pressured to join one. If you don’t feel comfortable in a group situation, you may prefer some **one-on-one support** from someone who has been through a similar experience.

Peer groups and one-on-one support don’t always have to be face-to-face and can take place over the telephone or internet.

The Cancer Council Helpline can put you in touch with local support groups on 13 11 20.

Many hospitals or cancer centres also offer **programs** where you and your family can receive information about cancer in a group and discuss how you are coping.

You may find **family or couples therapy** helpful to improve communication about how different members of the family are feeling.

If you are experiencing high levels of distress, a psychologist or psychiatrist can help you with particular **therapies or treatments** to improve your quality of life, reduce anxiety and depression and help with physical symptoms. These include therapies to change unhelpful thoughts or behaviours, learn specific coping skills or relaxation techniques.

Here are some techniques that have been shown to help with specific issues. You may wish to talk to your treatment team about them or ask if there are other techniques which would be helpful for you:

- ▶ relaxation therapy can help to control **pain**
- ▶ muscle relaxation techniques and guided imagery can help with **anxiety**
- ▶ a range of techniques such as muscle relaxation, imagery, meditation, exercise and education can help to reduce **nausea and vomiting**
- ▶ exercises in breathing control and relaxation techniques can help with **breathing difficulties**.

Specialised care may be important for people experiencing depression or suicidal thoughts. This will usually involve a combination of therapies to change thoughts or behaviours and medication such as anti-depressants.

Useful tips for travellers



You may find some of these tips helpful in your cancer journey:

- ▶ Making sure you have all the information you need about your cancer may help your feelings of anxiety and helplessness. You might find it useful to tape your doctor's consultation, write a list of questions to take to the appointment or take a family member or friend along with you to help you remember information. See page 35 for a list of questions you may wish to ask your doctor.
- ▶ It's OK to ask for a second opinion if you feel you need more information or you don't feel like your concerns are being recognised.
- ▶ In general, acknowledging and tackling challenges as they arise can help. Avoiding talking about your emotions and other issues can lead to greater distress. Being flexible in your approach to your cancer journey can make things a little easier. People who feel the need to control things are often more likely to experience emotional distress.
- ▶ Exercise and a healthy, balanced diet, which includes plenty of fresh fruit and vegetables, are also very important for your wellbeing.

Refuel your tank with the good things in life!

Heading in the right direction



Who to talk to?

You can talk to any member of your treatment team about any emotional, physical or practical challenges you may be facing. Choose someone you trust and feel comfortable with — perhaps a nurse, a doctor or your social worker. They are all well placed to put you in touch with the best person to help you.

Your GP is part of your cancer journey from the beginning and can also provide a link to a range of emotional and practical support services.

“My GP was very supportive and after I started treatment I was given a number I could contact for the support service. It made a difference talking to someone who had been through similar things.”

How to ask for help?

It can be difficult for some people to talk about how they are coping. You may feel you don't have the words to describe how you are feeling. Perhaps you feel embarrassed or feel that you don't want to be a burden or the doctor is too busy. Here are some suggestions of ways you can bring up the issue of your emotional and practical care.

- ▶ "I've been having trouble sleeping/feeling really down/feeling like I'm not coping lately and I've heard there are treatments that can help. Can I talk to you about this?"
- ▶ "I haven't been coping as well as I want to, and I feel like I need some help managing. Do you know about services that can help me with this?"
- ▶ "I read something about emotional care for people with cancer. I've realised that I find it very hard to cope sometimes and I would like to talk to someone about it."

It can be difficult to ask for help but remember, many people will seek emotional support throughout their lives for lots of different reasons.

Talking to a health professional about how you are feeling doesn't mean you are 'crazy' or weak. It's normal — just like it's normal to seek professional help for an injury or pain.

You may also find that you are having some trouble coping but you don't necessarily want to seek professional help. Perhaps after talking with your doctor you feel you can manage on your own with some of the tips they give you. While it's good to seek help when you need it, it's also fine to manage on your own with the support of your family and friends. Or perhaps you would prefer to talk to someone who has been through a similar situation. This could be through peer support.

The main thing is to continue to be aware of your reactions to stressful events and any changes in your mood, feelings and energy levels. If things change, you may decide down the track that some professional support would be helpful.

What's around the corner



If you decide to ask for some help, your GP or a member of your treatment team will put you in contact with the best person or people to support you, depending on your individual situation. This could be any one of a number of health professionals such as a social worker, a counsellor or a psychologist, or perhaps peer support. If it is recommended that you see a health professional, you can then call their office to arrange an appointment.

Talking to someone who is interested in your concerns, is supportive and skilled in helping you to express yourself can be extremely helpful. It can also help you to become clearer about your concerns and fears and explore new ways of coping. Many people find this very comforting and leave the consultation feeling relieved and hopeful.

Many people find there are positive aspects to their cancer journey. Often it forces people to examine their lives and what is important to them. Some people say they have a new understanding of their priorities and a new appreciation of the things they value. Many people describe their cancer as a 'life changing experience'.

Moving forward



“Cancer has taught me to LIVE my life, not just exist.”

“I don’t look on having cancer as a gift nor as the best thing that ever happened to me. I learnt things about myself that make me feel good, that I can be strong and resilient but I also learned how fragile and imperfect life can be. I’m more accepting of the vulnerabilities in myself and others now.”

Remember, the feelings of anxiety, sadness, fear or worry that you may be experiencing won’t last forever. Most people find things improve with the available support and some feelings gradually disappear on their own over time.

If you find you are experiencing any of the emotional, physical or practical challenges of cancer described in this booklet and they are getting you down or making daily life difficult, there is help available.

It’s OK to ask for help when you need it.

Directory

The Cancer Council Helpline

Ph: 13 11 20

The Cancer Council Helpline provides general information as well as information on local resources. The service can be accessed from anywhere in Australia for the cost of a local call.

Cancer Australia

Ph: 1800 624 973

Email: enquiries@canceraustralia.gov.au

Website: canceraustralia.gov.au

State and Territory cancer organisations

State and Territory Cancer Councils provide information and educational resources on all types of cancer. To find out about cancer support groups and other local services, contact your local state or territory cancer organisation by calling the Cancer Council Helpline on 13 11 20.

Cancer Council Australia

www.cancer.org.au

Cancer Council ACT

Ph: (02) 6257 9999

Email: reception@actcancer.org

Website: www.actcancer.org

Cancer Council NSW

Ph: (02) 9334 1900

Email: feedback@nswcc.org.au

Website: www.cancercouncil.com.au

Cancer Council NT

Ph: (08) 8927 4888

Email: admin@cancernt.org.au

Website: www.cancercouncilnt.com.au

Cancer Council QLD

Ph: (07) 3634 5100

Email: info@qldcancer.com.au

Website: www.cancerqld.org.au

Cancer Council SA

Ph: (08) 8291 4111

Email: tcc@cancersa.org.au

Website: www.cancersa.org.au

Cancer Council TAS

Ph: (03) 6212 5700

Email: infotas@cancertas.org.au

Website: www.cancertas.org.au

Cancer Council VIC

Ph: (03) 9635 5000

Email: enquiries@cancervic.org.au

Website: www.cancervic.org.au

Cancer Council WA

Ph: (08) 9212 4333

Website: www.cancerwa.asn.au

Cancer Institute NSW

Ph: (02) 8374 5600

Email: information@cancerinstitute.org.au

Website: www.cancerinstitute.org.au

Action and support groups

Please note, this is not an exhaustive list. Please ask your treatment team for further details of organisations that are relevant to your cancer.

Breast Cancer Network Australia

Ph: 1800 500 258

Email: beacon@bcna.org.au

Website: www.bcna.org.au

Cancer Voices Australia

Ph: (02) 8063 4191

Website: www.cancervoicesaustralia.org.au

Leukaemia Foundation

Ph: 1800 620 420

Email: info@leukaemia.org.au

Website: www.leukaemia.org.au

OvCa Australia

Ph: 1300 660 334

Email: info@ovca.org.au

Website: www.ovca.org

Prostate Cancer Foundation of Australia

Ph: 1800 220 099

Website: www.prostate.org.au

Other organisations

Australian Council of Stoma Associations (ACSA)

Email: info@australianstoma.com.au

Website: www.australianstoma.com.au/

CanTeen (including programs for patients, siblings and offspring)

Ph: 1800 226 833

Email: admin@canteen.org.au

Website: www.canteen.org.au

Continence Foundation of Australia

Email: info@continence.org.au

Website: www.continence.org.au

Look good...feel better

Ph: 1800 650 960

Website: www.lgfb.org.au

National Continence Helpline

Ph: 1800 33 00 66

Palliative Care Australia

Ph: (02) 6232 4433

Email: pcainc@pallcare.org.au

Website: www.pallcare.org.au

The Lymphoedema Association of Australia

Website: www.lymphoedema.org.au

Translating and Interpreting Service

Ph: 13 14 50 (24 hours a day, 7 days a week, cost of a local call)

Self assessment

We have included three copies of the *distress thermometer* you may like to use at different times in your cancer journey such as diagnosis, during treatment and finishing treatment.

NCCN® Distress Thermometer

SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES NO Practical Problems

- Child care
- Housing
- Insurance/financial
- Transportation
- Work/school
- Treatment decisions

Family Problems

- Dealing with children
- Dealing with partner
- Ability to have children
- Family health issues

Emotional Problems

- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities

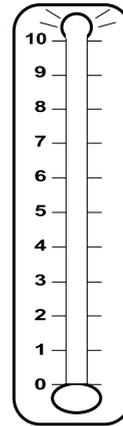
- Spiritual/religious concerns

YES NO Physical Problems

- | | |
|--|--|
| <input type="checkbox"/> <input type="checkbox"/> Appearance | <input type="checkbox"/> <input type="checkbox"/> Indigestion |
| <input type="checkbox"/> <input type="checkbox"/> Bathing/dressing | <input type="checkbox"/> <input type="checkbox"/> Memory/concentration |
| <input type="checkbox"/> <input type="checkbox"/> Breathing | <input type="checkbox"/> <input type="checkbox"/> Mouth sores |
| <input type="checkbox"/> <input type="checkbox"/> Changes in urination | <input type="checkbox"/> <input type="checkbox"/> Nausea |
| <input type="checkbox"/> <input type="checkbox"/> Constipation | <input type="checkbox"/> <input type="checkbox"/> Nose dry/congested |
| <input type="checkbox"/> <input type="checkbox"/> Diarrhea | <input type="checkbox"/> <input type="checkbox"/> Pain |
| <input type="checkbox"/> <input type="checkbox"/> Eating | <input type="checkbox"/> <input type="checkbox"/> Sexual |
| <input type="checkbox"/> <input type="checkbox"/> Fatigue | <input type="checkbox"/> <input type="checkbox"/> Skin dry/itchy |
| <input type="checkbox"/> <input type="checkbox"/> Feeling Swollen | <input type="checkbox"/> <input type="checkbox"/> Sleep |
| <input type="checkbox"/> <input type="checkbox"/> Fevers | <input type="checkbox"/> <input type="checkbox"/> Substance abuse |
| <input type="checkbox"/> <input type="checkbox"/> Getting around | <input type="checkbox"/> <input type="checkbox"/> Tingling in hands/feet |

Other Problems: _____

Extreme
distress



No distress

DIS-A

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NCCN® Distress Thermometer

SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES NO Practical Problems

- Child care
- Housing
- Insurance/financial
- Transportation
- Work/school
- Treatment decisions

Family Problems

- Dealing with children
- Dealing with partner
- Ability to have children
- Family health issues

Emotional Problems

- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities

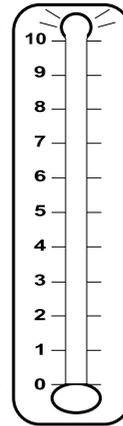
- Spiritual/religious concerns

YES NO Physical Problems

- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhea
- Eating
- Fatigue
- Feeling Swollen
- Fevers
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Substance abuse
- Tingling in hands/feet

Other Problems: _____

Extreme
distress



No distress

DIS-A

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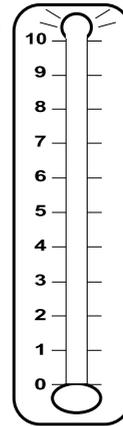
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- Sleep
- Substance abuse
- Tingling in hands/feet

Other Problems: _____

Extreme
distress



No distress

DIS-A

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To view the most recent and complete version of the guideline, go online to www.nccn.org. These Guidelines are a work in progress that will be refined as often as new significant data becomes available.

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What should I do about it?

Depending on your level of distress on the thermometer, and the number of problems you have ticked, you may like to consider taking up some of the ideas below. You may like to tick those you think are relevant to your situation. If you are uncertain how to access any of them, ask a member of your treatment team or phone the Cancer Council Helpline on 13 11 20.

People with a distress level above five on the thermometer usually need some professional support, such as from a psychologist, psychiatrist or social worker.

Finding out more information

- Use a question prompt list to help ask the doctor everything you want to know (see page 30).
- Ask your doctor to explain any words you don't understand.
- Tape your consultation.
- Make another appointment if you have any further questions.
- Ask for an information booklet on your cancer.
- Search on the Internet. Ask your treatment team to recommend a list of credible websites.
- Ask your doctor to clarify or confirm things you have found out on the Internet.

Discussing my diagnosis, prognosis or treatment

- Tell the doctor how much information you would like to know.
- Make sure you understand what the doctor has said by asking for things to be repeated, explained in a different way or written down.
- Ask about the benefits of each treatment and the side-effects.
- Ask the doctor to explain exactly what the treatment involves, including what will happen step-by-step and how it will feel.

Talking about my feelings

- Talk to your partner, other family members, or friends about how you are feeling.
- Talk to your doctor or nurses about your fears and worries regarding treatment.
- Go to a cancer support group to share your experiences.
- Go to a counsellor or social worker to talk about your emotions or anything that is worrying you.
- Get telephone counselling through your local state or territory Cancer Council.

Getting support for my family, friends and carers

- Ask a member of your treatment team to help explain your diagnosis or treatment to a family member or friend.
- Find out about support groups for family and friends.
- Organise couple counselling with your partner.

Coping with the extra challenge of cancer

- Speak to a member of the treatment team about how to deal with changes to your body.
- Speak to a counsellor about the impact of cancer on your sexuality.
- Discuss fertility issues with your doctor.
- Talk to your doctor if you have a physical problem.

Dealing with anxiety and depression

- See a health professional such as psychologist or a psychiatrist about feeling depressed or coping with anxiety.

Getting the practical support I need

- See a social worker to get help with finances.
- Ask a nurse to provide you with information about prostheses.
- Contact The Cancer Council in your state or territory for information about assistance with travel and accommodation expenses.
- Contact Centrelink for information on getting financial help while you cannot work.

Spiritual advice

- Speak to the hospital chaplain.
- Seek spiritual guidance.

Information adapted from Butow, P and Grivas, D, 2004 The psychosocial impact of cancer – a guide for adults with cancer, their family and friends, School of Psychology, University of Sydney.

Question prompt list

Most people seeing their doctor have questions and concerns, particularly the first time they see them. Often these questions are forgotten in the rush of the moment, only to be remembered later. To help you make the most of your time with the doctor we have compiled a list of questions people often ask.

You may like to tick the questions you would like to ask and then write down other questions in the space provided. You may also wish to ask the doctor the meaning of words you are not familiar with.

Diagnosis

- What kind of cancer do I have?
- What will the cancer do to my body?

Care

- Do you specialise in treating my type of cancer?
- How experienced are you in treating people like me?
- Do you work with other specialists in a multidisciplinary team?
- Are there other team members that I should meet?
- Who will be in charge of my care?
- How well established is the treatment you are recommending?
- Is there another specialist that you recommend for a second opinion who treats this type of cancer?

Treatment information and options

- Is treatment necessary?
- What are my options?
- What are the pros and cons of treatment?
- What exactly will be done during the treatment and how will it affect me in the short term?

- Are there any long-term side-effects from treatment?
- Are there any clinical trials that might be relevant for me?
- Will I be treated any differently if I enrol in a trial?
- What is your opinion about the best treatment for me?
- What is the treatment schedule, eg how many treatments and how often?
- How much time do I have to think about this?
- Do you need my decision today?
- What do I do if I get conflicting information?
- What is my long-term follow-up plan?

How can I help?

- Is there anything I can do before or after my treatment that might make it more effective?
- What are the 'dos' and 'don'ts'?
- Should I change my diet, work, exercise, etc?

The future

One of the issues that many patients want to discuss with their cancer specialist, but that can be difficult to raise, is what their future holds. Prognosis is a term used to describe what is likely to happen (in relation to the cancer) in the future. Many people think of prognosis as only meaning expected survival time, but it includes a broad range of issues, such as the effect of cancer and its treatment on lifestyle, or their ability to achieve certain goals. Some questions are listed here for you to consider asking your cancer specialist:

- Where is my cancer at the moment?
- Has it progressed/moved to other parts of the body?
- How possible is it that the cancer will develop in other parts of the body?
- What symptoms will the cancer cause?
- What is the chance that the treatment will improve symptoms?
- What are the common side-effects of treatment I should prepare myself for?
- Are there any uncommon side-effects that may affect me?
- Is there anything that can be done to treat these side-effects?
- What is the aim of my treatment? To cure the cancer or to control it and manage/relieve symptoms?
- Is there a period of time I will be likely to be without symptoms?
- If the treatment works, what are the chances of the cancer coming back?
- What can I expect if I decide not to have treatment?
- What is the expected survival for people with my type of cancer?
- Is it possible to give me a timeframe? How long will I live?
- Are there any factors which make my prognosis different to the average patient?
- How might my work be affected?
- How might my lifestyle be affected? (eg daily activities, sexual life)
- What is the best-case scenario? What is the worst-case scenario?
- Can you summarise what can be done for my cancer?

Support information

- What information is available about my cancer and treatment? (eg books, videos, websites)
- Are there any advantages/disadvantages of the private versus public health system for me?
- What costs will I incur through my treatment? (eg medication, chemotherapy)
- Am I eligible for any benefits if I cannot work?
- Can you give me any advice on how to cope better?
- Is there someone I can talk to who has been through this treatment?
- Are there services/support groups to help me and my family deal with this illness?
- Who do I contact if I experience any problems?

Other questions

Information adapted from Butow, P and Grivas, D, 2004 The psychosocial impact of cancer – a guide for adults with cancer, their family and friends, School of Psychology, University of Sydney.

