



**Cancer  
Council**  
SA

# **Making decisions when you're diagnosed with cancer.**

Information.  
Treatment.  
Support.

Information and support

**13 11 20**

[cancersa.org.au](http://cancersa.org.au)



## What is cancer?

Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and to heal injuries. Normally cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause the tissue to form a lump called a tumour, or blood or lymph fluid in the body to become abnormal. A tumour can be benign or malignant.

A **benign tumour** means cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

A **malignant tumour** is made up of cancerous cells which have the ability to spread. They can then travel through the bloodstream or lymphatic system (lymph fluid) to other parts of the body.

The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ where it first started or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels (angiogenesis).

If cancerous cells grow and form another tumour at a new site then it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, breast cancer that has spread to the lungs is called metastatic breast cancer even though the person may be experiencing symptoms caused by problems in the lungs.

## When cancer is diagnosed

Many people feel understandably upset when told they have cancer. You may have feelings of shock, disbelief, anger, sadness and grief. It can be confusing or overwhelming, and you might not know how you feel. Some people also feel a sense of relief that they have a diagnosis for their symptoms and that they can now begin treatment.

Having these thoughts and feelings is a natural reaction to a difficult and stressful situation. You may have trouble thinking clearly, eating or sleeping and may feel unable to make decisions. It's common to feel that you are on an emotional rollercoaster.

### Cancer care and your rights

When cancer is diagnosed, you enter into a partnership with your doctor/s and other health professionals in the decisions related to your health. As a patient, you have the right to:

- ask questions about your treatment
- be informed about the specific details of your care (including costs)
- be given details about all treatment options in order to make an informed choice
- seek a second medical opinion and/or information from other sources about your diagnosis and treatment.

Each person with cancer is different, therefore the health professionals involved in your care are the best people to give you the information specific to you.



Being diagnosed  
is a shock and  
you'll need time  
to adjust.

## Questions about your diagnosis

- What type of cancer do I have?
- Where is the cancer located?
- What stage is my cancer? What does that mean for me?
- How far has the cancer spread?
- Is it slow or fast growing?
- Can I continue to work?
- What are my chances of surviving this cancer?

## Questions about tests

- What will this test involve? What will this tell you?
- Are there any benefits or risks to me in having this test?
- Will the results of this test make any difference to the decision on what type of treatment I have?

## Treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast. Check with your doctor when your treatment should start, and take as much time as you need before making a decision.

Understanding details about the disease, the available treatments and their possible side effects will help you make a well-informed decision. This decision will also take into account your personal values and the things that are important to you and your family.

To help you make decisions:

- ask for printed information, books or pamphlets, so that you have time to absorb and think about the information your doctor discussed with you
- weigh up the advantages and disadvantages of different treatments including the impact of any side effects
- find a quiet, private place where you can discuss the information openly with your partner and family
- if only one type of treatment is recommended, ask your doctor why other choices have not been offered
- if you need more information think about getting a second opinion.

You have the right to accept or refuse any treatment offered by your doctors and other health care professionals. Some people with advanced cancer choose treatment even if it only offers a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life. Some people choose options that focus on reducing symptoms and make them feel as well as possible.

## Questions about treatment decisions

- What treatment is best for me? Do I have a choice of treatments?
- What is the aim of this treatment? Is it to cure my cancer, prevent it coming back, prevent it spreading or to relieve symptoms?
- Is it necessary to have treatment right now? When do you need my decision?
- How is the treatment given?
- How does the treatment work?
- What difference will this treatment make to my quality of life; will I feel unwell? Can I work, drive, have sex, etc?
- What are the possible side effects of treatment? Will I lose my hair?
- Can these side effects be prevented or controlled? Are the effects temporary or permanent?
- Will this treatment affect my ability to have children? Should I see a fertility specialist before I start treatment?
- How will we know if the treatment is working?
- Are there any clinical trials suitable for me?
- Will there be any out-of-pocket expenses? Will there be extra expenses not covered by Medicare or my private health fund?
- How do I apply for benefits or access my insurance if I cannot work? Who can I talk to about this?
- What if I choose not to have treatment?

## Questions about treatment planning

- Do you specialise in treating my type of cancer?
- Has this treatment been used for a long time or is it new?
- I'm thinking of getting a second opinion before I make my decision. Is there someone you would recommend?
- Will a multidisciplinary team be involved in my care? How will you all communicate with each other and me?
- Who will be in charge of my care?
- Who do I contact if I have questions or if a problem arises?
- Can I work while I have treatment?
- Is there anything I can do that will help me cope with treatment?
- Are there things I shouldn't do while having treatment?
- Should I exercise? How much? What type would you recommend?
- Do I need to follow a special diet?
- Are there any complementary therapies that you believe may be helpful?

*N.B. It is important to let the health care professionals know if you are taking any alternative or complementary therapies when undergoing treatment. Some therapies can interfere with treatment.*



**Take the time  
to get the answers  
you need.**

## People who have been diagnosed with cancer often begin a search for information using the internet

This information can assist you to make decisions about your illness and treatment.

As the internet is open to anyone who wishes to publish information, there is no regulation of the information or its accuracy. It can be difficult to know if all the information that you find there is reliable. You may like to start by looking at the Cancer Council SA website.

## How can the Cancer Council SA website [cancersa.org.au](http://cancersa.org.au) help me?

The Cancer Council SA website provides a wide range of cancer-related information for people affected by cancer. Topics include 'What is cancer?', 'Coping with cancer', 'Support services', 'After treatment—what now?' and 'A guide to cancer services'.

Cancer Council SA also provides links to cancer organisations around the world that publish accurate and up-to-date information about specific cancers and treatment, clinical trials and complementary medicine. You might also like to conduct your own further research.

## How do I know if a website has good information?

- Look at the URL (web address). Web addresses containing **.gov** are government-funded sites, **.org** are often not-for-profit websites, **.com** sites are usually commercial and **.edu** are educational institutions.
- Good websites tell you about their organisation—who funds them, why they exist, where they are located and what their purpose is.
- Think about possible conflicts of interest—are they trying to sell you something or promote a particular viewpoint?
- Can you find the information you are looking for? Is it up to date and helpful? Who reviewed it?
- Does this website link to other reputable sites?

## Finding the right information

- Think about what sort of information you're looking for before you start searching. For example, you may want to read about other people's experiences but not be faced with details on statistics.
- Remember that you are an individual and that your diagnosis is unique. This means that not all information you obtain will apply to your situation.
- Some of the information you find on the internet may be upsetting. Make sure there are people you can talk to about this, or have a friend or relative research with you.
- Don't expect to find all the answers you need on the internet. Have a pen and paper ready to note any questions or concerns as you search.
- Bookmark good sites to go back to for reliable information.
- Print out information to read and think about later and to discuss with your doctor and health care team.
- Call **Cancer Council 13 11 20** and speak to a registered nurse about any questions or concerns you may have.



**It's okay to reach out  
for help and support.**

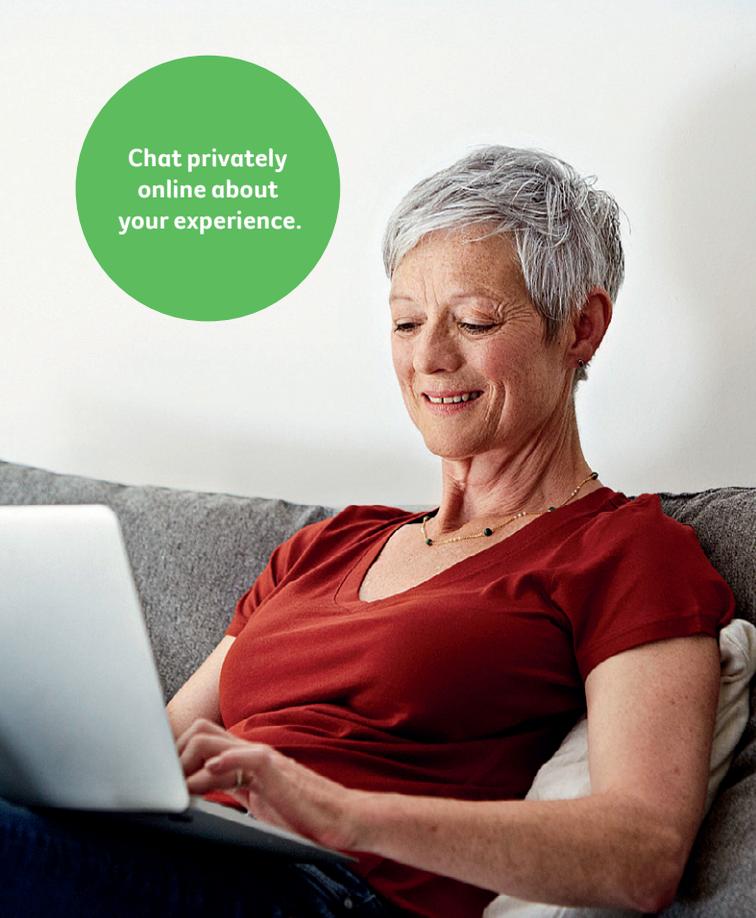
**13 11 20**

## Online forums and chat rooms

Online forums and chat rooms are a great way to connect to other people affected by cancer. For many, 'chatting' online can be a new experience and it may be difficult to work out where to start.

Cancer Council Online Community, managed nationally by Cancer Council staff, is an online community that links people with cancer, their carers and families. On this site you can ask questions, discuss issues, or just be a visitor and learn from other people's experiences. To use this site you must first register as a user; this will give access to more information. It's free and open to anyone affected by cancer.

See [cancercouncil.com.au/onlinecommunity](http://cancercouncil.com.au/onlinecommunity) for more information.



Chat privately  
online about  
your experience.

## Some useful websites

This list is not comprehensive—there are many other reputable sites that are not listed here. Call **Cancer Council 13 11 20** if you want to discuss the information you find.

|                           |  |
|---------------------------|--|
| Bowel                     | <a href="http://bowelcanceraustralia.org">bowelcanceraustralia.org</a> |
| Breast                    | <a href="http://bcna.org.au">bcna.org.au</a>                           |
| Leukaemia Foundation      | <a href="http://leukaemia.org.au">leukaemia.org.au</a>                 |
| Lung                      | <a href="http://lungfoundation.com.au">lungfoundation.com.au</a>       |
| Melanoma                  | <a href="http://melanoma.org.au">melanoma.org.au</a>                   |
| Prostate                  | <a href="http://prostate.org.au">prostate.org.au</a>                   |
| Cancer Australia          | <a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>     |
| Carers SA                 | <a href="http://carers-sa.asn.au">carers-sa.asn.au</a>                 |
| SA Health                 | <a href="http://sahealth.sa.gov.au">sahealth.sa.gov.au</a>             |
| Palliative care           | <a href="http://palliativecare.org.au">palliativecare.org.au</a>       |
| MacMillan                 | <a href="http://macmillan.org.uk">macmillan.org.uk</a>                 |
| National Cancer Institute | <a href="http://cancer.gov">cancer.gov</a>                             |
| American Cancer Society   | <a href="http://cancer.org">cancer.org</a>                             |

You don't have to rely solely on the internet for cancer information and support. Cancer Council SA produces a range of printed booklets and brochures. Most of our publications are on our website and are available in downloadable formats or can be posted to you by contacting **13 11 20**.

*Cancer Council SA does not necessarily endorse the opinions or recommendations of the websites listed.*

## Cancer Council SA support services

Cancer Council SA offers information, support, practical assistance and understanding to anyone affected by cancer.

### Cancer Council 13 11 20

Experienced cancer nurses can assist you with information and support you may find helpful for your needs. Call **13 11 20** Monday to Friday, 8.30 am to 5.30 pm.

### Accommodation

People from rural and remote areas may need to travel to the city for cancer treatment. We offer supportive, subsidised accommodation at Council Council Lodge—Flinders and Greenhill and assistance with transport to some treatment centres.

### Information and printed resources

You may seek clear, up-to-date and evidence-based information, or you may want practical resources that can help you with things like talking to kids about cancer. Resources are available for people with cancer, partners, carers, friends and colleagues. Visit [cancersa.org.au](http://cancersa.org.au) or call **13 11 20**.



## Cancer Counselling Service

Professional counsellors can help you talk through and better manage the challenges of living with cancer.

### Connect to someone

Join our confidential online chat groups, telephone and internet support groups and Cancer Connect telephone service. They can assist in linking you to someone with a similar cancer experience and can understand your concerns.

### Legal and financial assistance

We can help you find relevant community and government resources that may be able to assist you with legal or financial issues.



## Asking questions

To help you get the information you want from your doctor, it may help to:

- ask for a longer appointment if you have a lot of questions
- ask a friend or relative to go with you
- write your questions down and take the list with you.

If you have difficulty speaking or understanding English, then ask for an interpreter or contact the free\* Interpreting Service **13 14 50**.

\*Cost of a local call.





# Cancer Council SA

For free\* and confidential information and support about cancer, Monday to Friday 8.30 am – 5.30 pm:

- call Cancer Council **13 11 20**
- chat online at **[cancersa.org.au](https://cancersa.org.au)**
- email **[askanurse@cancersa.org.au](mailto:askanurse@cancersa.org.au)**

Free\* interpreting service is available on **13 14 50**

\*Cost of a local call