

Understanding Rare and Less Common Cancers

A guide for people affected by cancer

A cancer diagnosis is a life-changing event, and it is common to feel shocked or upset. Being told that the cancer is rare or less common may be particularly challenging.

A rare or less common (RLC) cancer may take longer and be more difficult to diagnose than other types of cancer. It may also be found at a late stage (advanced). See the next page for more about this.

About rare or less common cancer

An RLC cancer is a type of cancer that affects a small number of people.

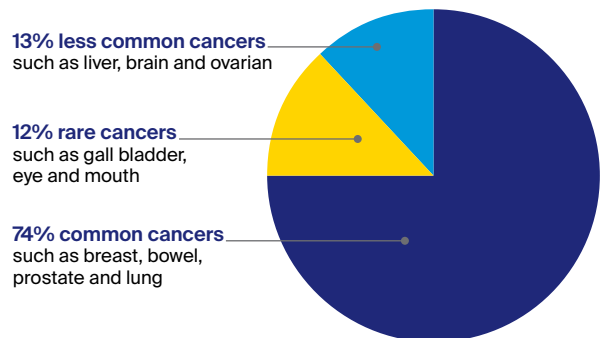
Common cancers – Breast, bowel, prostate and lung cancer are examples of common cancers. Many people are diagnosed with these types of cancers.

Rare or less common cancers – Small bowel and gall bladder cancer are examples of rare or less common cancers. Few people are diagnosed with these types of cancers.

A cancer may be considered an RLC cancer when it:

- is a subtype of a more common cancer (e.g. lymphoma is common; T-cell lymphoma is rare)
- is a common cancer in an unusual part of the body (e.g. melanoma is common, but melanoma found in the eye, called ocular melanoma, is rare)
- is in a part of the body where it is unusual to find cancer (e.g. the bones)
- started in a different type of cell than usual
- is more common to find this cancer type in the opposite sex (e.g. breast cancer in males)
- is found in a person younger than expected (e.g. prostate cancer in someone under 40).

How many Australians have a rare or less common cancer?



Note: Figures are rounded estimates

A rare cancer means fewer than 6 out of 100,000 people who are diagnosed with cancer have this type. A cancer is less common if 6 or more, but less than 12, out of 100,000 people are diagnosed with this type.

There are a large number of different types of rare or less common cancers. Although only a small number of people are diagnosed with each RLC cancer type (e.g. small bowel, gall bladder), together, they all add up to a large number.

Each year, it's estimated about 42,000 Australians are diagnosed with a cancer that is considered to be rare or less common. About 1 in 4 people diagnosed with cancer will have an RLC cancer.

The number of people diagnosed with an RLC cancer is increasing. While the incidence of certain RLC cancer types may be on the rise, this overall increase in numbers may also be partly due to: improvements in diagnosing different types of cancer; advances in testing (including genetic testing); and early detection thanks to more accurate cancer screening.

Diagnosis

The process of diagnosing a rare or less common cancer may be quite different to that of diagnosing a common cancer. It may take longer to get an exact diagnosis, and involve more doctors and tests.

An RLC cancer type may be more difficult to diagnose because:

- Some RLC cancers have symptoms that are less well known compared with the symptoms of more common cancers.
- Symptoms may be similar to some common conditions. And these conditions are usually ruled out first, before a rare cancer is investigated.
- Sometimes cancer develops in a person who is not expected to get cancer (e.g. due to their age or sex). This can lead to delays in looking for cancer.
- Several tests may be needed, or more than one specialist involved, before getting a diagnosis.
- Another diagnosis, or general cancer diagnosis may be made first, before the final diagnosis is confirmed (e.g. an initial finding of breast cancer, before a final diagnosis of metastatic triple negative breast cancer).
- The pathologist may need to do a number of specialised tests on your tissue or blood sample, or they may have to send the sample to a specialist laboratory for testing.

Challenges in diagnosing an RLC cancer may mean it is found at a later stage. See our *Living with Advanced Cancer* booklet for more information.

The length of time it takes to accurately diagnose an RLC cancer can be upsetting and frustrating. You may also have tests to see if the cancer is hereditary (see next page), which can be worrying and stressful for your family. For help with this, see *Coping with a rare or less common cancer diagnosis* on page 6.

Rare and less common cancer in children

Any cancer affecting children and teenagers is considered rare. This is because it is unusual for younger people to have cancer. The same type of cancer found in an adult may not be considered rare. For more information about children and cancer, see childrenscancer.canceraustralia.gov.au.

“Being diagnosed with a rare cancer can make you feel totally isolated. When I began my treatment, I started meeting people who had also been diagnosed with a rare or less common cancer. I soon began to realise that although my cancer was rare, I wasn’t alone.” NICOLE

Tests you may have

To find out what type of cancer you have, you may need several tests to look for the cause of your symptoms. Doctors will use the results of these tests to help work out the type of cancer you have and the best treatment for you.

Some specialised tests, including blood tests, may not be covered by Medicare or health insurance. Ask about the cost when booking or having these tests.

Physical examination – Your doctor may listen to your heart and lungs, look into your mouth or eyes, or feel your body to check for lumps, enlarged organs or other signs of cancer.

Scans and scopes – Tests might include an ultrasound and scans such as a CT (computerised tomography), a PET (positron emission tomography) or an MRI (magnetic resonance imaging). Tests could also include an endoscopic examination, which allows doctors to see inside your body using a small camera.

Blood tests – You will usually have blood tests to measure your white blood cells, red blood cells and platelets, and check how well your kidneys and liver are working. Blood tests can also look for infection and tumour markers (proteins produced by cancer cells). Urine tests may also check organ function or other markers.

Biopsy – To diagnose many cancers, a doctor may need to remove a sample of tissue from the affected area. The cells are then examined under a microscope by a specialist doctor called a pathologist. This is called a biopsy. The type of biopsy you have will depend on your symptoms and which part of the body is being checked.

Molecular and genetic testing

Every cell found in the human body has about 20,000 genes, which tell the cell what to do and when to grow and divide. Cancer starts because of changes to the genes (known as mutations).

Some people are born with a gene change that increases their risk of cancer (called an inherited faulty gene), but most gene changes that cause cancer happen during a person's lifetime (called acquired gene changes).

For some people with an RLC cancer, doctors may recommend extra tests to look for acquired gene changes (molecular tests) or inherited gene changes (genetic tests). Ask your doctors whether you need to have molecular or genetic testing.

For some cancers, molecular or genetic tests may help make a diagnosis, or guide your doctor to the most effective treatment. For other cancers, these tests may not offer any benefit, or will not change what treatment is likely to be offered.

Molecular testing

You may be offered extra tests on a biopsy sample known as molecular or genomic testing. This looks for gene changes and other features in the cancer cells that may help your doctor decide which treatments to recommend.

Medicare may or may not cover molecular testing, depending on the cancer type. These tests can be expensive, so check the cost and how helpful they would be. If you are having molecular testing as part of a clinical trial, the costs may be covered.

Genetic testing

If your doctor suspects the RLC cancer is linked to an inherited or faulty gene (e.g. because other members of your family have had cancer), they may refer you to a family cancer clinic for more tests and genetic counselling.

These tests, known as genetic or germline tests, may help your doctor work out what treatment to recommend. The tests can also provide important information for your blood relatives, who may also have inherited a faulty gene.

Genetic counselling can help you understand what tests are available, and what results mean for you and your family. You may also want to be included on a hereditary or familial cancer registry in your state. If you feel worried or stressed, see *Coping with a rare or less common cancer diagnosis* on page 6.

Medicare covers some genetic tests, but others have a cost. Ask your treatment team what you will pay.

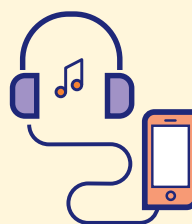
Waiting for test results

Be prepared for results to take time



It may take days, a couple of weeks, or even longer to get your test results. This can be an anxious time. You may feel like the future feels very uncertain, that something serious might be found, or that you have no control over what is happening to you. You may feel like you keep having tests and not getting any answers.

Try to focus on other things



There is no right or wrong way to deal with the anxiety of waiting. Some people find it helpful to keep doing their usual activities, such as going to work, as this is a good distraction from worrying about the test results. But others may find it hard to concentrate on anything else.

Let others know how you are feeling



While you are waiting, it might help to talk to a close friend or relative about how you feel. You can also call Cancer Connect on 13 11 20, where qualified professionals can listen to your concerns, answer questions about cancer, and provide you with helpful resources and links to support services.

Making treatment decisions

It can be overwhelming to decide on a treatment path. If the cancer was difficult to diagnose, it may have been diagnosed at a later stage. Your options may feel very limited compared with a common cancer. While some people want detailed information, others prefer to leave decisions to their doctors.

► Listen to our *Making Treatment Decisions* podcast.

Talking with doctors

Understanding the cancer, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check with your specialist how soon treatment should begin, as it may not affect the success of the treatment to wait a while. Ask them to explain your options and take as much time as you can before making a decision. It is also okay to ask what will happen if you do not have treatment.

Know your options

You may have a range of treatment options or they may be very limited. Common cancer treatments are based on established guidelines for the best care for that type of cancer. An RLC cancer may not have any guidelines. Treatment for RLC cancers can be quite different from treatment approaches for more common cancers – even when the RLC cancer is a subtype of a common cancer.

In general, your treatment options will depend on:

- the type of cancer you have
- the stage and grade of the cancer
- extra tests that give more information about the cancer (e.g. genetic or molecular tests)
- your overall health
- any other medical problems you might have
- your personal preferences.

See a specialist treatment team

Your treatment is usually planned and managed by a multidisciplinary team (MDT). This is a group of health professionals who work together to discuss your physical and emotional needs and decide on a treatment to recommend. Some RLC cancers are subtypes of common cancers, so are managed by the MDT for that cancer. In other cases, treatment will be very different, and you may have an MDT with more experience in your specific cancer type.

You may need to travel to a specialist centre to see the right team for you. Or you may have some telehealth appointments. Treatment may be planned by an MDT at the specialist centre but then given in a hospital closer to home. Or the treatment may need to be given in a specialist centre.

Record the details

When your doctor first says you have cancer, you may not remember everything you are told. You will probably have many medical appointments. Taking notes can help or you can ask if you can record these discussions. It can help to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

Ask questions

You are likely to have a lot of questions. If you are confused or want to check anything, it is important to ask your doctor. Try to prepare a list before each appointment (see pages 5 and 7 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

Consider a second opinion

You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or know you have explored all your options. Specialists are used to this. Your doctor or specialist can refer you to another specialist and send them your initial results.

You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide to be treated by the second specialist. You may also be able to have a video consultation with overseas specialists with experience in your RLC cancer.

It is your decision

Adults have the right to accept or refuse any treatment offered. Some people with advanced cancer choose treatment that has many side effects even if it gives only a small benefit for a short time. Others focus their treatment on quality of life. You may want to discuss your decision with your treatment team, GP, family and friends.

► See our *Cancer Care and Your Rights* fact sheet.

Treatment

Depending on the RLC cancer type or how advanced it is, treatment may include surgery, radiation therapy, chemotherapy, immunotherapy and targeted therapy. You may also be offered newer treatments, such as cell and gene therapies or personalised cancer vaccines. Treatment is sometimes part of a clinical trial (see next column).

Some people with cancer will have one treatment, but often people need a combination of treatments (e.g. surgery and targeted therapy). Treatments may sometimes be given at the same time. An example of this is chemoradiation – when radiation therapy and chemotherapy are given together. Your specialist will work with the multidisciplinary team (see page 4) to recommend the best treatment options for you.

For information about treatments and their side effects, Cancer Council has resources available online and in print. See page 7 for your local website, call Cancer Connect on 13 11 20 for a free copy, or ask at your treatment centre. There are booklets about surgery, chemotherapy and radiation therapy, as well as facts sheets about immunotherapy, targeted therapy and some rare cancers.

Where will I have treatment?

To see specialist doctors or have specific treatment, people with an RLC cancer who live outside a major city may need to travel. Your doctor will let you know where the best place to have treatment is for you.

Rare Cancers Australia has a list of doctors and a list of Australian hospitals and treatment centres with cancer care services (for public and private treatment centres). Call 1800 257 600 or visit rarecancers.org.au. Depending on the RLC cancer type, there may also be a support organisation that you can contact for a directory of specialists and treatment centres.

If you need to travel far from home for treatment, some costs may be covered. For example, some people may be able to get help paying for travel and accommodation through a government service or insurance. For more information, ask your treatment centre, doctor or call Cancer Connect on 13 11 20.

What to ask about your treatment

Information may not always be easily available for an RLC cancer, so ask your treatment team about:

- what treatment options are available and if they are different to treatments for the more common cancer
 - the aim of treatment – whether it is trying to cure the cancer or control symptoms
 - how long treatment may take and where you will have it
 - any risks, short-term and long-term side effects, and how they can be managed
 - how treatment will impact your ability to work, do everyday activities or your quality of life
 - how you will know if treatment is working
 - what will likely happen if you do not have treatment
 - what costs may be involved, such as out-of-pocket expenses not covered by Medicare or private health cover, and any options if you cannot afford to pay
 - what impact treatment may have on your sex life and fertility. Ask about any short-term or long-term side effects and ways to manage any changes.
- See our *Sex, Intimacy and Cancer* and *Fertility and Cancer* booklets and listen to our “Sex and Cancer” podcast.

Can I join a clinical trial?

Clinical trials of new treatments for RLC cancers are difficult to conduct due to the low number of patients. This is because clinical trials usually rely on large groups of people who have a similar condition. However, if there is a suitable clinical trial available, your doctor or nurse may suggest you take part.

Clinical trials test new or modified treatments to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit australiancancertrials.gov.au.

- See our *Understanding Clinical Trials and Research* booklet.

“As my cancer was so rare, there were no specific protocols to treat it.” WAYNE

Coping with a rare or less common cancer diagnosis

A cancer diagnosis usually brings uncertainty, but for people with an RLC cancer, that uncertainty and feeling of isolation may be harder. You may also feel distress and a range of strong emotions, such as shock, disbelief, fear, anger, sadness and anxiety. Below are some ways that may help you manage how you are feeling.

Find out more information



Not knowing what to expect can be tough. There's a lot you can't predict or control – when you will get a confirmed diagnosis, what treatment you will have and how long it will take. It may help to find out as much information as you can. Ask your doctor questions as well as where you can find more reliable information. Make a list of things to ask at your appointments (see pages 5 and 7 for suggestions). You may be able to email follow-up questions or talk to a cancer care coordinator or nurse.

Join a support group



Talking to people who have the same type of cancer can make you feel less alone. You can join the Cancer Council Online Community to connect with others in a similar situation. See the online resources listed on page 7, or you can call Cancer Connect on 13 11 20 to find a support group that suits you.

Rare Cancers Australia runs support programs and a community for people diagnosed with a rare or less common cancer. Call 1800 257 600 or visit rarecancers.org.au.

Stay connected



If you have to travel away from home for treatment, you may feel lonely without the usual support of your family, friends or community. Or people may not be able to visit you because you need to avoid infections. You may stop work, and miss your co-workers and usual routine. Use email, social media or a blog to stay in touch with family and friends.

Try complementary therapies



Complementary therapies, such as massage and meditation, are therapies used alongside conventional medical treatments. They may help people cope with symptoms or side effects and lower stress and anxiety. Talk to your doctor about any therapies you may want to use, to ensure they are safe.

► See our *Understanding Complementary Therapies* booklet.

Get help with work and money



Cancer can be expensive and may mean that you cannot do your usual work. This can make you feel more stressed. If you need legal or financial advice, Cancer Council may be able to connect you with professionals who can help.

► See our *Cancer and Your Finances* and *Cancer, Work and You* booklets.

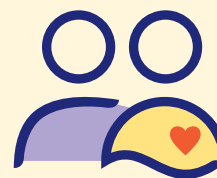
Talk about how you are feeling



It is natural to feel overwhelmed by the diagnosis. Your cancer team can be an important source of support. The social worker at the treatment centre or hospital can also help. It is important to let your doctors know how you are feeling. They can refer you to a counsellor, psychologist, psychiatrist or another health professional trained to help. They may also be able to put you in touch with other people who are going through similar treatment.

► See our *Emotions and Cancer* booklet.

Watch for feelings of sadness



If you regularly feel sad, have trouble getting up in the morning or lose motivation to do what used to make you happy, you may be depressed. This is common for people who have cancer. Talk to your GP, as counselling or medication – even for a short time – may help. Some people can get a Medicare rebate for sessions with a psychologist. For information on depression and anxiety, call Beyond Blue on 1300 22 4636 or visit beyondblue.org.au. For 24-hour crisis support, call Lifeline on 13 11 14 or visit lifeline.org.au.



It is common to worry about cancer returning, even if you've been told it is cured. You can listen to our *Managing Fear* podcast episode.

When the cancer is advanced

RLC cancer may be advanced when found, it may spread, or it may come back after treatment. There may still be treatments to remove the cancer or help control its growth. Advanced cancer usually cannot be cured, but may be controlled with palliative treatment. Treatment will depend on the cancer, how far it has spread, your general health, treatment goals or preferences, and quality of life.

► See our *Living with Advanced Cancer* booklet and *The Thing About Advanced Cancer* podcast series.

Question checklist

It is important to ask your doctors questions, especially if you feel confused or uncertain. You may want to make a list of questions before appointments and include some of these questions:

- What type of cancer do I have? Why is it considered a rare or less common cancer?
- Where is the cancer and has it spread? If so, where to? How fast is it growing?
- Can you explain the test results to me?
- What are my treatment options? (See page 5 for more questions to ask about treatment.)
- Is there a patient organisation or support group for the type of cancer I have?
- How many patients with this type of cancer have you treated before?
- Can you give me an idea of my prognosis?
- How often will I need check-ups?
- If the cancer returns, how will I know? What further treatment could I have?

Where to get help and information

Call Cancer Connect on 13 11 20 or visit the website for more information about cancer and health care. Qualified professionals can listen to your concerns, put you in touch with local services and send you free copies of our booklets. You can also visit your local Cancer Council website.

Cancer Connect	cancerconnect.org.au
ACT	actcancer.org
NSW	cancercouncil.com.au
NT	cancer.org.au/nt
QLD	cancerqld.org.au
SA	cancersa.org.au
TAS	cancer.org.au/tas
VIC	cancervic.org.au
WA	cancerwa.asn.au
Australia	cancer.org.au

Other useful websites

Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Council podcasts	cancercouncil.com.au/podcasts
ANZUP Cancer Trials	anzup.org.au
Australian Cancer Trials	australiancancertrials.gov.au
Australian Rare Cancer Portal	arcportal.org.au
Cancer Australia	canceraustralia.gov.au
CART-WHEEL Center for Analysis of Rare Tumours	cart-wheel.org
eviQ	eviq.org.au
Rare Cancers Australia	rarecancers.org.au

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Note to reader

Always consult your doctor about matters that affect your health. This fact sheet is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities.

While all care is taken to ensure accuracy at the time of publication, Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this fact sheet.

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Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past and present.

