

# I'm aware of rare



Rare Cancer Awareness Day  
Information Kit



# Why should I be aware of rare?

## Rare cancer is **more common** than you think

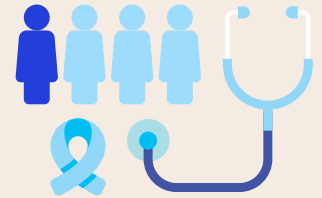
The term 'rare cancer' encompasses hundreds of different cancers. Although each type affects a small number of people – which is why it's called 'rare' – collectively they add up.

In Australia a **rare** cancer has fewer than **6 diagnoses** per 100 000 people in the population.

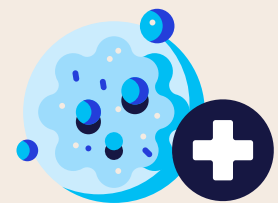


A less common cancer has fewer than **6–12 diagnoses** per 100 000.

**One in four** cancers diagnosed in Australia are **rare** or less common. That's one person diagnosed **every 12 minutes**.



**Over one third** of all deaths from cancer in Australia are from **rare** or less common cancers. That's **43 people every day**.



Source: 1. [Cancer data in Australia, Overview of cancer in Australia, 2025 – Australian Institute of Health and Welfare](#)

## What is rare cancer?

A cancer can be considered rare or less common if:

- It is very unusual and seen in very few people
- It affects people who are much younger or older than the typical age range for people diagnosed with it (e.g. prostate cancer in someone under 40)
- It affects children
- It is a common cancer in an unexpected location (e.g. a melanoma that started in the eye)
- Small subtypes of common cancers (e.g. triple negative breast cancer)
- It is more common to find this cancer type in the opposite sex (e.g. breast cancer in males)

**Examples of RLC cancers, which can be found anywhere in the body include:**

**Brain and spinal cord**  
e.g. meningiomas, glioblastoma, and astrocytoma

**Head and neck**  
e.g. mouth, oesophageal, nasal cavity, and major salivary gland cancers

**Skin and eye melanoma**  
(e.g. mucosal melanoma, ocular melanoma, and acral melanoma)

**Thoracic**  
e.g. thymoma, mesothelioma, and small cell lung cancer

**Digestive tract**  
e.g. anal, stomach, and small intestine cancers

**Male genital organs and urinary tract**  
e.g. penile and testicular cancers

**Female genital organs and placenta**  
e.g. ureteral, vaginal, and vulvar cancers

**Neuroendocrine cancers**  
e.g. medullary thyroid carcinoma, pheochromocytoma and Merkel cell carcinoma

**Cancers of the unknown primary**

**Germ cell tumours**

**Blood cancers**  
e.g. acute myeloid leukemia and chronic myeloid leukemia

**Sarcoma**  
e.g. Kaposi sarcoma, angiosarcoma, and rhabdomyosarcoma

To learn more about rare cancers, visit [Rare Cancers Australia](#).

# There is **no early detection test** for rare cancer

Unlike the screening tests available for breast, bowel, and cervical cancer in Australia, there is no single test that can detect rare cancer early. That's because 'rare cancer' isn't one disease – it's hundreds.

Each person's cancer is as unique as their fingerprint, which means there is no straightforward path through a rare experience. Having a rare cancer can be like navigating a maze; not knowing where to go and facing barriers at every turn.

Being aware of what rare cancer are, and knowing where to find support, is the best way to access information and options as early as possible.

Following up on any unusual or persistent health problems is critical when it comes to diagnosing any type of cancer from the very beginning.

## People with rare cancer often **face additional challenges**

People with rare and less common cancers often face a deeply unequal system. Access to specialised expertise and treatment can be limited, especially for people in rural and remote areas, and essential treatments often come with a heavy price tag – one that many families simply can't afford.

We all need to be aware of this, so we can pull together to bring about positive change. These are men, women and children in our families, workplaces and communities whose wellbeing and survival affects us all.

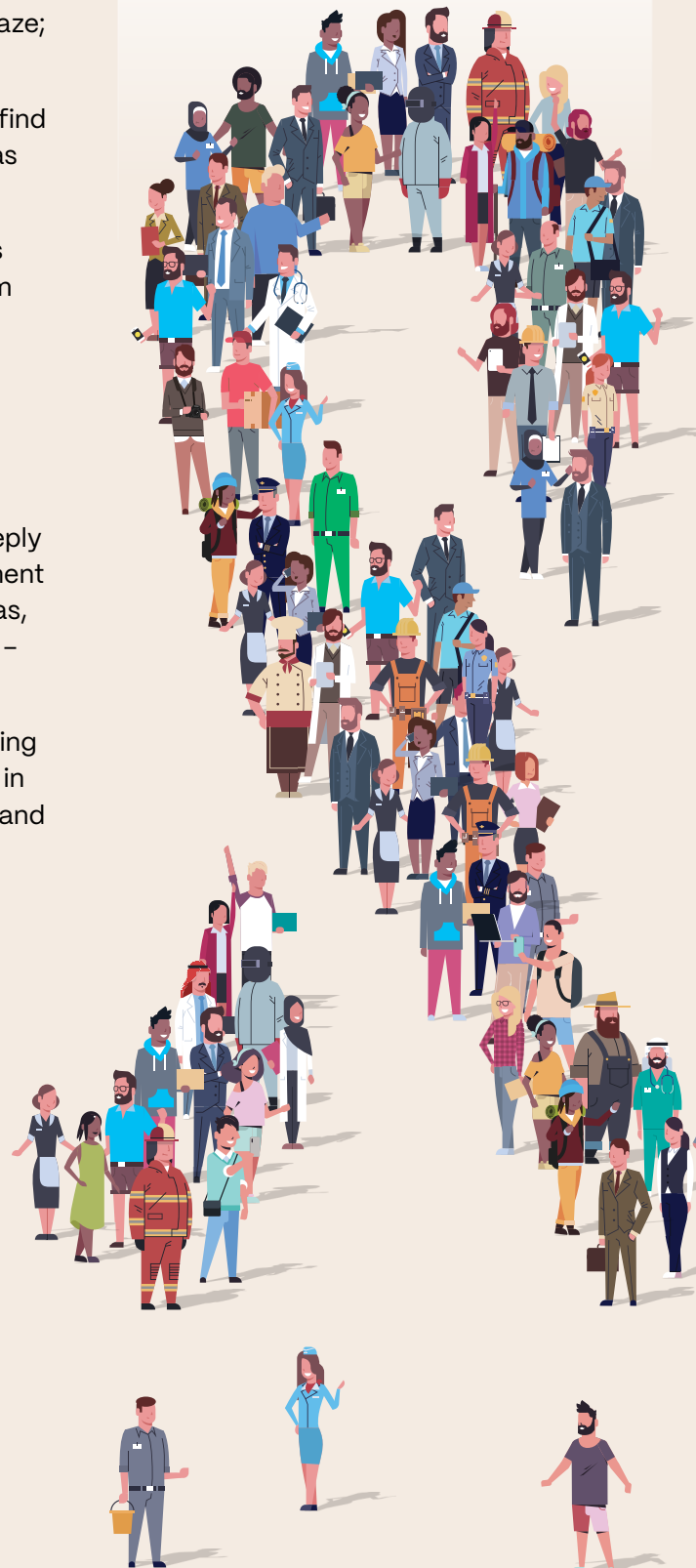
A rare cancer diagnosis can mean:

- High treatment costs for medications that aren't listed on the Pharmaceutical Benefits Scheme (PBS)
- Less treatment options
- Limited information
- Lack of support options

This is due to the limited awareness, knowledge, expertise, and research in rare cancers.

➔ To learn more about the reality of rare, visit [Why rare cancer patients need our support.](#)

As a collective group, rare cancers are the third most diagnosed cancer behind Breast and Prostate, making up about one quarter of all diagnoses in Australia<sup>1</sup>.



# If you're concerned about changes in your health keep an eye on **symptoms**

Sometimes, the symptoms of a rare cancer can be very vague and subtle. Being aware of changes is key, especially if you're at higher risk (from your family history, lifestyle or exposure history).

General signs might include:

- ✓ Unexplained weight loss
- ✓ Persistent fatigue
- ✓ New or changing lumps
- ✓ Unusual bleeding
- ✓ Long-lasting pain

**Of course, these symptoms don't necessarily mean cancer. But it's a good idea to get checked out by your GP.**

## NOEL'S STORY

### Thymic Cancer

In February 2023, 35-year-old Noel was busy building his life – raising his son, planning a wedding, and working toward his goals – when a persistent cough led to a shocking diagnosis: a rare type of cancer called Thymic Carcinoma.

"Hearing 'you have cancer' was gut-wrenching," Noel recalls. "My future shattered in seconds."

Within a week, he underwent urgent surgery, followed by chemotherapy and immunotherapy. With 12 rounds costing around \$60,000 – and not covered by the Government's Pharmaceutical Benefits Scheme – Noel turned to fundraising for support and reluctantly accessing his wife's superannuation.

"It's hard to believe this treatment isn't covered for rare cancers. I had no idea of the challenges that rare cancer patients had to face," he says.

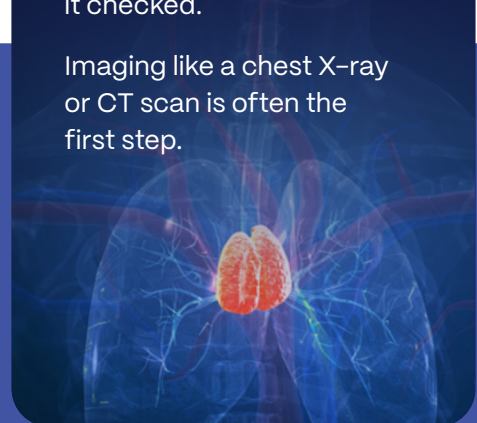
"I wish I was more aware of rare and had not ignored that cough for so long."

### About Thymic Cancer

Thymic cancer is a type of thoracic tumour. Thoracic tumours occur in the chest (thoracic) cavity. This area includes your lungs, heart, thymus gland, and part of the spine.

If you have symptoms that don't go away or get worse over weeks (such as a cough or ongoing shortness of breath), unexplained weight loss, persistent fatigue, or new, unusual pain in the chest or back – it's a good idea to get it checked.

Imaging like a chest X-ray or CT scan is often the first step.



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**I wish I was more aware of rare and had not ignored that cough for so long.**

# Questions to ask when something doesn't feel right



If you're worried about symptoms or changes in your health, these questions may help guide the conversation with your doctor:

## 1 Symptoms

- ✓ Could these symptoms be a sign of cancer?
- ✓ Are there other conditions that might explain what I'm experiencing?

## 2 Testing

- ✓ Do I need any tests to rule out something serious, like cancer?
- ✓ If you don't think I need tests now, what should I watch for?

## 3 Timing and next steps

- ✓ If symptoms get worse, what should I do?
- ✓ Can I have a follow-up appointment to review my symptoms again?

## 4 Risk and history

- ✓ Based on my family history or lifestyle, am I at higher risk for cancer?
- ✓ Should I have any routine cancer screenings?



There's no such thing as the wrong question! If you feel like something isn't right, go to your GP, let them know how you're feeling and bring questions along with you.

# About Vulvar Cancers

Vulvar cancers are most commonly found in women who have gone through menopause or over 60 years old, however, it can affect anyone with female genitalia – including women, teenagers, transgender men, non-binary individuals, and intersex people – at any age.

If you have ongoing symptoms such as itching or burning of the vulva, a painless lump, sore, swelling, wart-like growth, thickened or raised skin, tenderness, an ulcer that doesn't heal, or hard or swollen lymph nodes in the groin, it's important to get checked.

Don't be afraid to use a mirror to look and become familiar with what's normal for you.

## JANE'S STORY

### Vulvar Cancer

After losing her mother at a young age to breast cancer, and even going through her own experience with it, Jane had always been vigilant in screening and checking her own breasts for abnormalities but never thought to check anywhere else.

It wasn't until one day in July 2022, when Jane started to experience discomfort and soreness "down there". Initially she ignored it, but the pain intensified to the sensation of broken glass being smashed in between her legs and she knew she had to do something about it.

"I experienced fevers and pain while urinating, during intercourse and sometimes randomly for no reason at all," Jane recalls.

"While feeling somewhat embarrassed, I decided I had to see my doctor about it, so I booked an appointment. She listened to my symptoms and determined that I was perimenopausal, she didn't even look down there.

"I knew it wasn't just perimenopause, so I bit the bullet, took out the mirror and looked down there myself. I remember looking and thinking "Oh my God".

"It took six months for me to get a diagnosis; it was just before Christmas in December of 2022. They took a biopsy and the results came back with a diagnosis of Stage 3 Vulvar cancer.

“

I wish I was more aware of rare and wasn't afraid to look.



"What's a vulva? Was my first thought. I had never heard of it before. My thoughts then went to the other word "cancer" which I knew about all too well."

The next few months saw Jane undergo two surgeries to remove the lesions and surrounding tissue. Unfortunately, further testing showed the cancer had also spread to her lymph nodes, so she also had to go through six weeks of radiation and chemotherapy.

"Thankfully I have recovered well, I started seeing a psychologist who has been wonderful, and now nearly 18 months later I am happy to say I am still doing well.

"My experience was awful, I really had to fight to be taken seriously and advocate for myself. I want people, especially women, to know my story and learn from my experience. We have a vulva and it can get cancer, cancer that spreads!

"If I had one message to leave with people, it would be to get to know your own body and to listen to it. If you feel like something's wrong, go get it checked, because it could save your life."

# How can I share awareness of rareness?

With **friends, family** and **colleagues**


You can help raise awareness of rare cancer by [sharing](#) one or more of these tiles across social media using **#AwareofRare** in the lead up to, and during, Rare Cancers Awareness Day on Friday, 26 June 2026.

Every 12 minutes,  
a person in Australia is  
diagnosed with a rare or  
less common cancer.

**That's 120 people a day.**



Rare Cancers Awareness Day  
26 June



**One in four** cancer  
diagnoses are rare or  
less common.

rare cancers are more common  
than you think.



Rare Cancers Awareness Day  
26 June



Without awareness,  
people with rare cancers  
face **isolation** and **inequity**.

Awareness changes lives.  
You can help change the next 12 minutes.



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## Wear it Rare

Purchasing official 'rare' gear from Rare Cancers Australia is another great way to raise awareness and support people impacted by rare cancer at the same time. Our extensive range includes limited edition hats and beanies, as well as tees, tanks and hoodies – all available in a wide range of sizes and colours.

Visit the [Rare Shop](#) to browse the standard and limited edition 'rare' range.

We love acknowledging rare supporters, so remember to take a snap of yourself in your new gear and tag [@RareCancersAustralia](#) on Facebook or [@RareCancers](#) on Instagram with [#AwareofRare](#).

## With **someone you know** who has cancer

Sometimes, people can have great trouble navigating the health system and finding the options they need because they don't realise their cancer is considered rare or complex.

Does this sound like someone you know with cancer?

- Their cancer is not responding to treatment as expected.
- Their cancer is considered treatable (that is, it can be kept stable) but is not curable.
- Their cancer is a small, rare subtype of a common cancer.
- Their cancer is usually diagnosed and treated early but has been found at an advanced stage, such as stage 4 cervical cancer
- They have been told there are no further standard treatment options available.

**If you or someone you know is facing a rare, less common or complex cancer, Rare Cancers Australia is here to help. We support all patients—because no one should face cancer alone.**



## Supporting someone with rare cancer

When someone you care about is diagnosed with a rare cancer, it's natural to feel uncertain about what to expect – or how to help. You may not have all the answers, but your support, presence, and care can make a real difference.

While every experience is different, here are some simple, meaningful ways to be there for them.

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My experience as a carer was one of the most rewarding and at the same time challenging experiences of my life.”

– Nicholas



### Medical support

- Learn about their specific cancer and treatment options from reliable sources like the [RCA Knowledgebase](#).
- Offer to attend appointments, take notes, and help track symptoms and side effects.
- Speak up early to the treating team if something doesn't feel right, acting as their advocate when needed.
- Get to know the medical team, including key contacts such as the clinical nurse coordinator, how to reach them, and when they are available.



### Emotional support

- Expect mixed emotions. Fear, frustration, confusion, or grief are all normal.
- Encourage connection with others who understand rare (such as RCA [Support Groups](#)).
- Offer to find professional support, like a psychologist, to help process what's happening.



### Practical support

- Assist with transport, meal preparation, chores, and personal care if needed.
- Help manage administrative tasks like paperwork, prescriptions, and appointments.
- Share updates with family and friends as needed.



### Financial support

- Manage the payment of bills, insurances and medical costs.
- Investigate flexible working arrangements if needed during this period.
- Explore financial support or fundraising options if expenses are feeling overwhelming.

## Remember that **you matter**, too

Your wellbeing matters, not only because it supports the care you give, but because you matter. Caring can be demanding and emotionally exhausting, and you are not expected to do it alone. Make time for yourself where you can, and ask for help early and often. Prioritising your own needs helps you stay present, resilient, and better supported. Connecting with others, such as through the [RCA Carers Support Group](#), can also provide understanding, shared experience, and practical support when you need it most.

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**He had no indications of being unwell, just a cough he couldn't shake. After a while I insisted that he go to the doctor."**

**"They found a large tumour in his chest and within a week he was having surgery. They told us he had a rare cancer.**

**"We are a young family, it has been a lot to go through.**

**"You have no choice but to sit back and watch it happen to the person you love. You have no control.**

**"But hearing from his doctor that there's nothing more they can do because his cancer is so rare. I won't accept that. I won't hear it, we must keep digging, keep looking, keep fighting. You can't take no for an answer."**

**- Cheyanne, carer to husband Noel who was diagnosed with a rare cancer**



## Support **without limits**

Whether you have questions no one else can answer, need help understanding treatment options, or simply want someone to stand in your corner, we can help. Our Specialist Cancer Navigators do whatever it takes to be there for all you need.

## Contact Rare Cancers Australia

Connect with our team to find the right support options for your unique situation.

 **1800 257 600**

 **support@rarecancers.org.au**

 @RareCancersAustralia

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[www.rarecancers.org.au](http://www.rarecancers.org.au)

