



Diagnosis

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This guide has been developed to give you and your loved ones clear information, practical tools and useful advice to help you manage and navigate your cancer experience from diagnosis.

診斷

1

本指南旨在為您和您的摯愛提供清晰的資訊、實用的工具和有用的建議，以協助您從確診開始，管理並應對癌症歷程。

If you have a rare and less common cancer, you may have fewer treatment options and less access to experts and support. At Rare Cancers Australia (RCA), we understand that it can be hard to know what happens next or where to go for help, especially if English is not your first language.

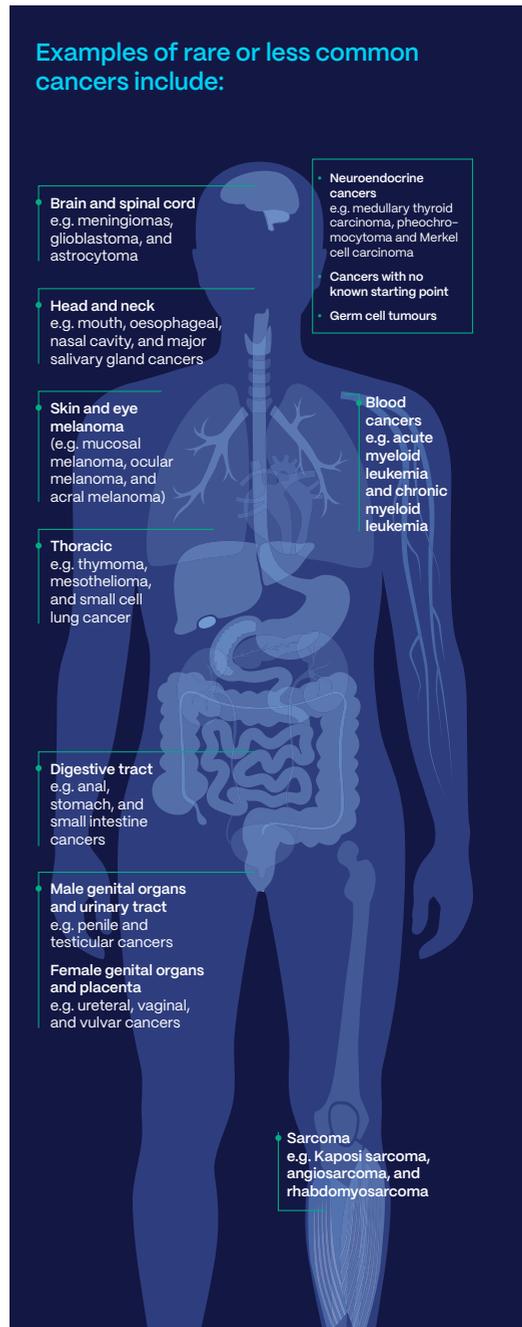
What is a rare or less common cancer?

A cancer is considered rare if fewer than 6 in 100,000 people are diagnosed with the cancer type, and less common if 6–12 in 100,000 people are diagnosed with the cancer type.

As our understanding of cancer and genomic sequencing continues to evolve, it is becoming harder to say how many rare and less common cancers there are, as more rare subtypes of common cancers are discovered.

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).



如果您患有罕見或不常見的癌症，治療選擇可能比較少，並且較難獲得專家醫治和支援服務。澳洲罕見癌症協會 (Rare Cancers Australia, 簡稱 RCA) 理解您可能難以獲知接下來會發生什麼，或該向何處尋求協助，特別是如果您的母語不是英語。

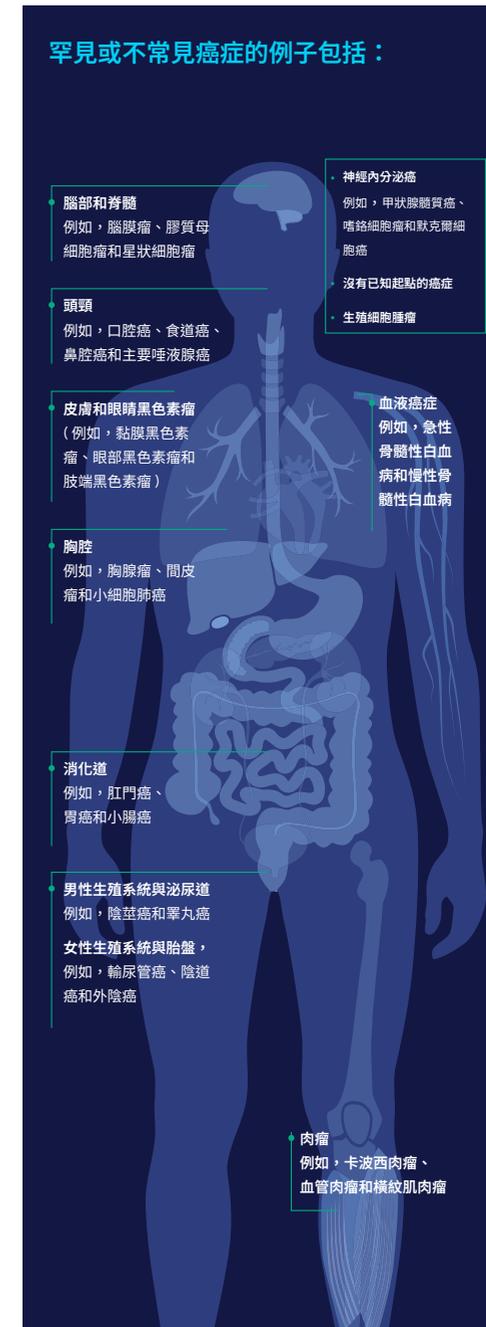
什麼是罕見或不常見的癌症？

如果每 10 萬人中少於 6 人被診斷出患有某種癌症，則該癌症被視為罕見癌症；如果每 10 萬人中有 6 至 12 人被診斷出患有某種癌症，則該癌症被視為不常見癌症。

隨著我們對癌症和基因組測序的理解不斷演進，發現了越來越多屬於常見癌症的罕見亞型，因此越來越難以確定罕見和不常見癌症的數量。

如果符合以下情況，癌症可被視為罕見或不常見：

- » 它非常罕見，僅見於極少數人。
- » 它影響的患者年齡遠低於或高於該癌症的典型診斷年齡範圍（例如，40 歲以下男性的前列腺癌）。
- » 它影響兒童。
- » 它是一種常見癌症，但發生在意想不到的部位（例如，始於眼睛的黑色素瘤）。
- » 常見癌症的罕見亞型（例如，三陰性乳癌）。
- » 這種癌症類型在異性身上更常見（例如男性乳癌）。



Just diagnosed

Hearing that you have a type of cancer you've never heard of before can feel overwhelming or confusing. It is normal to feel many different emotions, or even nothing at all. Talking about it can help.

Informing yourself

When you are told you have cancer, it can feel overwhelming. You might hear new words like "staging," "CT scan," or "adjunct therapy," which can be confusing at first. Understanding these terms and your treatment options can help you and your family feel more informed and involved in decisions about your care.

If you are searching online for information, keep these tips in mind:

- › Look for trusted, evidence-based information from government websites, major charities, universities, or medical organisations.
- › Check that claims are supported by research, not just opinions or online forums.
- › Make sure treatment advice is based on clinical trials.
- › Be cautious of people or businesses trying to sell you products or asking for your personal details. These could be scams.
- › Remember that healthcare systems vary between countries. Some treatments, medicines, or clinical trials you read about overseas may not be approved or available in Australia.

Here are some services that can help support you and your family:

- › **Rare Cancers Australia**
1800 257 600
- › **Cancer Council**
13 11 20
- › **Lifeline**
13 11 14
- › **Beyond Blue**
1300 22 4636
- › **Black Dog Institute**
blackdoginstitute.org.au
- › **Headspace**
headspace.org.au
- › **Cancer Australia**
canceraustralia.gov.au
- › **Cancer.Net**
cancer.net

A good place to start is the [RCA KnowledgeBase](#), which has information on over 200 cancer types.



Note: Information on the KnowledgeBase is only available in English.

剛確診

聽到自己患上從未聽過的癌症，可能會感到不知所措或困惑。出現各種不同的情緒，甚至毫無感覺，都是正常的。談論它會有所幫助。

自行了解資訊

當您被告知患有癌症時，可能會感到不知所措。您可能會聽到一些新詞彙，例如「分期」、電腦斷層掃描 (CT scan) 或「輔助治療」，這些詞彙一開始可能會令人困惑。了解這些術語和您的治療方案，可以幫助您和您的家人感覺更了解情況，更能參與與您照護相關的決策。

如果您在網上搜尋資訊，請記住以下提示：

- › 尋找來自政府網站、主要慈善機構、大學或醫療機構的可靠、有實證的資訊。
- › 檢查這些說法是否有研究證據支持，而不僅僅是基於意見或網路論壇。
- › 確保治療建議是基於臨床試驗的。
- › 警惕那些試圖向您推銷產品或索取您個人資料的人或企業。這些可能是詐騙。
- › 請記住，各國的醫療保健系統各不相同。您讀到的一些國外的治療、藥物或臨床試驗，可能未在澳洲獲批或提供。

以下是一些可以幫助支援您和您家人的服務：

- › **澳洲罕見癌症協會**
(Rare Cancers Australia)
1800 257 600
- › **澳洲防癌協會**
(Cancer Council)
13 11 20
- › **Lifeline**
13 11 14
- › **Beyond Blue**
1300 22 4636
- › **Black Dog Institute**
blackdoginstitute.org.au
- › **Headspace**
headspace.org.au
- › **Cancer Australia**
canceraustralia.gov.au
- › **Cancer.Net**
cancer.net

建議您優先瀏覽 [RCA 知識庫](#)，其中包含超過 200 種癌症的相關資訊。



注意：知識庫中的資訊僅提供英文版本。



“At the beginning, we didn’t know what questions to ask or what signs to look for – but learning gave me confidence. The more I understood, the better I could support my husband and make sure he got the care he needed.”

– Geli (Cantonese-speaking Carer for her husband Wai)



「一開始，我們不知道該問什麼問題，也不知道該注意什麼跡象—但學習讓我有了信心。我了解得越多，就越能更好地支援我的丈夫，並確保他獲得所需的照護。」

— Geli (為丈夫 Wai 提供照護的照護者，說粵語)



Preparing for appointments

It can be hard to remember everything during your appointments. Preparing ahead can help you feel more confident and ensure you get the most out of your time with your healthcare team.

Rare Cancer Australia's Specialist Cancer Navigators are experts in supporting people through complex cancer journeys. They can help you and your loved ones prepare by giving you information, guidance, and support before and after your appointments.

Here are some tips to help:



Write down your questions



Ask for some time to think and process information



Take a support person



Record your appointment



Ask for an interpreter, if you need one

Questions to ask your doctor



Here are some questions you might like to ask:

- » What type of cancer do I have?
- » Have you treated this type of cancer before?
- » Are there specialists who focus on my cancer?
- » Where is it located and has it spread?
- » What are my treatment options?
- » Are there any clinical trials available?
- » Are there combination treatments that could work?
- » Can we do a genetic or tumour test to see if there are any options signs that might point to another treatment option?
- » Can I get a second opinion? Who would you recommend?
- » Does this cancer have any implications for my family's health?
- » Where can I find more information?
- » How can I contact you later if I have follow-up questions?

準備就診

在就診時很難記住所有事情。提前準備可以幫助您感到更有信心，並確保您更有效運用與醫療團隊的時間。

澳洲罕見癌症協會的專科癌症導引員是協助人們度過複雜癌症歷程的專家。他們可以在您就診前後提供資訊、指導和支援，幫助您和您的摯愛做好準備。

以下是一些有用的提示：



寫下您的問題



請求一些時間來思考並處理資訊



帶支援人士陪同



記錄您的預約



如有需要，請要求安排口譯員

要問醫生的問題



以下是一些您可能想問的問題：

- » 我患有什麼類型的癌症？
- » 您以前治療過這種癌症嗎？
- » 有專門治療我這種癌症的專家嗎？
- » 它的位置在哪裡？是否已經擴散？
- » 我的治療方案有哪些？
- » 有沒有可用的臨床試驗？
- » 是否有組合療法可能奏效？
- » 我們是否可以做基因或腫瘤檢測，看看有沒有任何指標顯示可考慮其他治療方案？
- » 我可以尋求第二意見嗎？您會推薦誰？
- » 這種癌症對我家人的健康有任何影響嗎？
- » 我可以在哪裡找到更多資訊？
- » 如果我有後續問題，之後我該如何聯絡您？



Understanding a prognosis

A prognosis is your doctor's best estimate of how the cancer might affect you. It helps doctors recommend the best care for you. A cancer prognosis is based on what usually happens for people with the same type and stage of cancer. This includes statistics that describe how many people are alive after a certain time — for example, 2 or 5 years after

diagnosis. These figures are based on large groups of patients and are general in nature, so they may not reflect your individual situation.

A prognosis can help give an idea of:

- » whether the cancer can be cured
- » how well treatments might work
- » how long you might live

Cancer staging

Staging describes how much the cancer has grown and whether it has spread. This helps your healthcare team decide on the best treatment. Doctors can assess the severity of cancer in a few ways, including:

TNM staging

T (Tumour)

Describes the size of the cancer and whether it has grown into nearby tissue (rated from 1 to 4)

N (Nodes)

Shows whether the cancer has spread to nearby lymph nodes (rated from 0 to 3)

M (Metastasis)

Shows whether the cancer has spread to other parts of the body:

- **M0** = No spread
- **M1** = Cancer has spread

Numbered staging

Stage 0

Cancer hasn't spread

Stage 1

Small, localised cancer

Stage 2 & 3

Cancer has spread to nearby areas (may include lymph nodes)

Stage 4

Cancer has spread to other parts of the body



了解預後

預後是您的醫生對癌症可能發展狀況的專業判斷。這有助於醫生為您推薦最佳的照護方案。癌症預後是根據患有相同類型和分期癌症的常見情況來判斷的。這包括描述在某個特定時間點後有多少人存活的統計數據，例如，確診後 2 年或 5 年。這些數據基於大量病患的整體統計結果，屬於一般情況，未必能完全反映您的個人狀況。

預後可以幫助了解：

- » 癌症是否能被治癒
- » 治療方法可能的有效性
- » 您可能的存活時間

癌症分期

分期描述的是癌症生長了多少，以及是否已經擴散。這有助於您的醫療團隊決定最佳治療方案。醫生可以透過幾種方式評估癌症的嚴重程度，包括：

TNM 分期

T (腫瘤)

描述癌症的大小以及它是否已生長到附近的組織（分為 1 至 4 期）

N (淋巴結)

顯示癌症是否已擴散到附近的淋巴結（分為 0 至 3 期）

M (轉移)

顯示癌症是否已擴散到身體其他部位：

- **M0** = 無擴散
- **M1** = 癌症已擴散

分期編號

第 0 期

癌細胞尚未擴散

第 1 期

體積小、局部性癌症

第 2 期、第 3 期

癌細胞已擴散至鄰近區域（可能包括淋巴結）

第 4 期

癌症已擴散到身體其他部位

Cancer grading

Grading describes how abnormal the cancer cells look under a microscope and how quickly they are likely to grow.



Grade 1

(Low grade / well differentiated)

Cells look close to normal and grow slowly.



Grade 2

(Intermediate / moderately differentiated)

Cells look somewhat abnormal and grow faster than normal cells.



Grade 3

(High grade / poorly differentiated)

Cells look the most abnormal and grow quickly.



Grade 4

(High grade / undifferentiated)

Cells look most abnormal and grow very aggressively.



For example, a patient with a small, localised pancreatic tumour would be told they have Stage 1 pancreatic cancer according to this scale.



癌症分級

分級描述的是癌細胞在顯微鏡下顯示的異常程度，以及可能生長的速度。



1級

(低惡性度 / 分化良好)

細胞看起來接近正常，且生長緩慢。



2級

(中度分化)

細胞看起來有些異常，且生長速度比正常細胞快。



3級

(高度惡性 / 低度分化)

細胞看起來的異常程度最高，且生長快速。



4級

(高度惡性 / 未分化)

細胞看起來的異常程度最高，且生長非常快。



例如，一名患有小型局部胰臟腫瘤的病人，根據此分期方式，會被診斷為第1期胰臟癌。



Understanding your rights

As a patient, you have rights. You have the right to receive quality healthcare, be treated with respect, ask questions, and understand what is happening with your care. These rights apply to everyone — no matter where you live, your background, age, type of cancer or when you were diagnosed.

The **Australian Charter of Healthcare Rights** describes what you can expect when receiving healthcare in Australia.



AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

For more information, ask a member of staff or visit safetyandquality.gov.au/your-rights

Note: The information on this website is only available in English.

了解您的權利

作為病人，您享有權利。您有權獲得優質醫療照護、受到尊重對待、提出問題，並了解您的照護情況。這些權利適用於每一位病人 — 無論您的居住地、背景、年齡、癌症類型或何時確診。

《澳洲醫療照護權利憲章》

(**Australian Charter of Healthcare Rights**) 闡述了您在澳洲接受醫療照護時享有的權利。



澳洲醫療安全與品質委員會
(**AUSTRALIAN COMMISSION**
ON SAFETY AND QUALITY IN HEALTH CARE)

如需更多資訊，請詢問工作人員或瀏覽 safetyandquality.gov.au/your-rights

注意：本網站資訊僅提供英文版本。

Get support and information in your language

If English is not your first language, it can be harder to understand cancer information and ask for support.

You can request an interpreter to join your appointments.

Contact RCA



RCA's Specialist Cancer Navigators are experts in rare and less common cancers. They can support you and your loved ones with information, guidance, and care planning. You can get in touch by phone, request a call back or by email.

By phone

The Translating and Interpreting Service (TIS National) provides free phone interpreters in more than 150 languages.

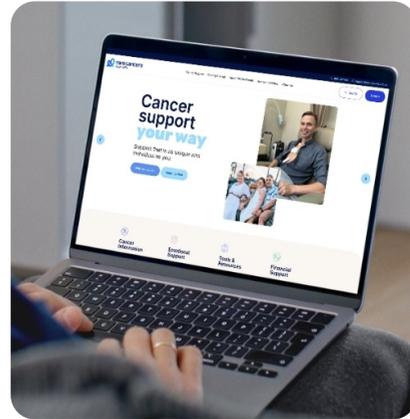
To speak with RCA's Specialist Cancer Navigators through an interpreter, call TIS on 131 450 (Monday to Friday, 9am–5pm, excluding public holidays) and ask to be connected with Rare Cancers Australia.

Request a call back

You can ask for a call from a RCA Specialist Cancer Navigator — with an interpreter — through the RCA website. Simply visit www.rarecancer.org.au/languages and complete the form.

By email

You can contact the RCA team in your language by sending an email to support@rarecancers.org.au



How RCA can help



RCA offers personalised support based on what matters most to you and your family. This may include:

Emotional support to help you cope with uncertainty.

Peer support to connect you with others who understand your experience.

Practical and social support to help you live as well as possible.

Financial support to help you find services and options that reduce costs.

Clinical support to help you work with your healthcare team and understand the system.

Find more information in your language

www.rarecancers.org.au/languages



獲取以您慣用語言提供的支援與資訊

如果英語不是您的母語，理解癌症資訊及尋求支援可能會更加困難。

您可以要求口譯員加入您的預約。

聯絡 RCA



RCA 的專科癌症導引員是罕見和不常見癌症的專家。他們可以透過提供資訊、指導和照護規劃，支援您和您的摯愛。您可以透過電話、要求回電或電子郵件與他們聯絡。

電話

全國口筆譯服務處 (TIS National) 提供超過 150 種語言的免費電話傳譯。

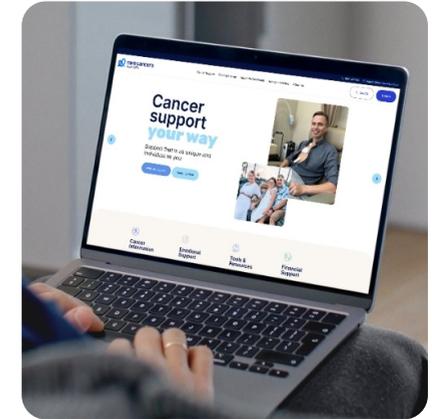
如需透過傳譯員與 RCA 的專科癌症導引員通話，請致電 131 450，聯絡 TIS (週一至週五，上午 9 點至下午 5 點，公眾假期除外)，並要求轉接至澳洲罕見癌症協會 (Rare Cancers Australia)。

要求回電

您可以透過 RCA 網站，要求 RCA 專科癌症導引員在口譯員協助下致電與您聯絡。只需訪問 www.rarecancer.org.au/languages 並填寫表格。

電郵

您可以透過發送電子郵件至 support@rarecancers.org.au，以您慣用語言聯絡 RCA 團隊



RCA 如何提供協助



RCA 根據對您和您的家人最重視的需求，提供個人化支援。這可能包括：

情感支援，幫助您應對不確定性。

同儕支援，讓您與理解您經歷的人建立聯繫。

實務與社交支援，幫助您維持良好生活品質。

財務支援，幫助您找到可降低成本的服務和選項。

臨床支援，幫助您與醫療團隊合作並了解醫療體系的運作。

尋找以您慣用語言提供的更多資訊

www.rarecancers.org.au/languages



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-  @RareCancers

www.rarecancers.org.au

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Scan the QR to
access more
information in your
language

掃描 QR 碼以獲取更
多以您慣用語言提供
的資訊

