Traditional Chinese | 繁體中文

rare cancers Australia

Looking Ahead 4

This guide has been developed to help you look ahead. It offers clear information, practical tools and advice to support you and your loved ones as you adjust after cancer treatment.

展望未來 4

本指南旨在幫助您展望未來。它提供清晰的資訊、實用的工具和建議，以支援您和您的摯愛在癌症治療後進行調整。

Looking ahead after cancer treatment

A rare or less common cancer diagnosis can affect not just your health, but also your relationships, work, and daily life. As treatment ends, you may be adjusting to a new way of living. People around you might not always know how to support you, and balancing their needs with your own can feel difficult. At Rare Cancers Australia (RCA), understand that this can be a challenging time.

What to expect after treatment

Many people hope life will go back to normal once treatment ends. Sometimes it does, but often it takes time to adjust. Everyone's "new normal" looks different. Your doctor will create a follow-up plan to monitor your health. This usually includes regular check-ups, tests, or scans to look for changes or side effects from treatment.

You may hear terms like:

- **Partial remission** – this means the cancer has become smaller, and treatment may pause.
- **Complete remission or NED (no evidence of disease)** – this means there are no signs of cancer on tests or scans.
- **Stable disease** – this means the cancer is not growing or spreading. Some people live with stable disease for years, with or without active treatment.

When treatment ends, you might expect to feel relieved, but it is also common to have unexpected emotions.

The regular check-ups and familiar support you had during You may miss the routine of regular appointments or the support you felt during treatment. Some people return to their pre-cancer routines, while others make changes in their life. Both experiences are completely normal. Everyone's experience is different.

癌症治療後的展望

確診罕見或不常見的癌症不僅會影響您的健康，還會影響您的人際關係、工作和日常生活。隨著治療結束，您可能正在適應一種新的生活方式。您周圍的人可能不總是知道如何支援您，也可能難以平衡他們的需求和您的需求。澳洲罕見癌症組織 (Rare Cancers Australia，簡稱 RCA) 理解這個時期可能充滿挑戰。

治療後可以期待什麼

許多人希望治療結束後生活能恢復正常。有時確實如此，但通常需要時間來適應。每個人的「新常態」都不同。您的醫生會制定後續追蹤計劃來監測您的健康狀況。這通常包括定期檢查、檢測或掃描，以發現治療帶來的變化或副作用。

您可能會聽到以下術語：

- **部分緩解** – 這表示癌症已縮小，治療可能會暫停。
- **完全緩解或 NED（無疾病證據）** – 這表示在檢測或掃描中沒有癌症跡象。
- **疾病穩定** – 這表示癌症沒有生長或擴散。無論是否接受積極治療，有些人可與病情穩定的癌症共存多年。

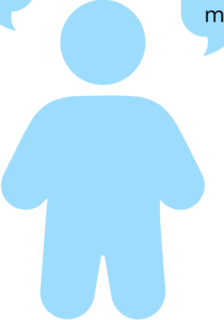
治療結束時，您可能會預期感到鬆一口氣，但出現意想不到的情緒也很常見。

您可能會懷念定期預約的規律感或治療期間感受到的支持。有些人會回到患癌前的生活習慣，而另一些人則會改變他們的生活。這兩種經歷都完全正常。每個人的經歷都不同。

Questions for your care team

Life after treatment can be confusing and may not feel as simple as you expected. Knowing the right questions to ask your doctor can help you feel more prepared for what comes next.

You might like to ask your doctor:



- What follow-up care do I need?
- What signs or symptoms should I watch for?
- What can I do if I feel unwell?
- What can I do to feel more like myself again?
- What is the chance that my cancer could return?
- What support services are available?
- Can you recommend any support groups?

If cancer comes back or progresses

It can be frightening to know that cancer may return or get worse after treatment. This is called a recurrence or relapse. Some cancers are more likely to come back than others. Some recurrences can be treated and even cured, while others cannot. Even when cancer cannot be cured, treatment can often help control it, allowing many people to live with cancer for years.

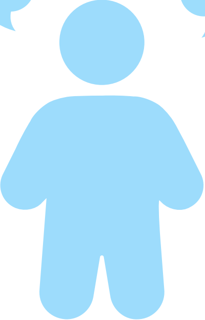
With rare and less common cancers, it is often harder for doctors to predict how well treatment will work. Feeling scared, worried, or overwhelmed is completely normal.

If your cancer comes back or or continues to grow despite treatment, you may need explore other options, such as clinical trials or off-label treatments. A RCA Specialist Cancer Navigator can support you with this.

向您的護理團隊提問

治療後的生活可能會令人困惑，並且可能不像您預期的那麼簡單。知道該向醫生詢問哪些重點問題，可以幫助您為接下來做好更充分的準備。

您可能想問您的醫生：



- 我需要哪些後續護理？
- 我應該注意哪些徵兆或症狀？
- 如果我感覺不適，我可以怎麼辦？
- 我能做些什麼來找回自我？
- 我的癌症復發的機會有多大？
- 有哪些支援服務可用？
- 你們可以推薦支援團體嗎？

如果癌症復發或惡化

知道癌症在治療後可能復發或惡化，會令人感到恐懼。這稱為復發。有些癌症比其他癌症更容易復發。有些復發可以治療甚至治癒，而有些則不能。即使癌症無法治癒，治療通常也能幫助控制病情，讓許多人與癌症共存多年。

對於罕見和不常見的癌症，醫生通常更難預測治療效果。感到害怕、擔憂或不知所措是完全正常的。

如果您的癌症復發，或儘管接受了治療但仍持續生長，您可能需要探索其他選擇，例如臨床試驗或仿單標示外治療。RCA 專科癌症導引員可以為您提供支援。

Taking care of yourself

If your cancer returns, your emotions may feel stronger or different from before. Support from others might change, and people may not always know what to say or how to help.

It's important to take care of your emotional wellbeing. Talking with a counsellor who understands cancer or joining a support group can make a big difference. If you feel alone, remember that many others have been through similar experiences — you are not alone.

Palliative care

Palliative care helps people live as well as possible with a serious illness like cancer. It is not just for end of life – it can be part of your care at any stage to manage symptoms, improve comfort, and support you and your family.

Palliative care can include:

- managing pain and other symptoms
- social, emotional, spiritual, and psychological support
- help at home (such as respite care or specialist therapies)
- planning for future care

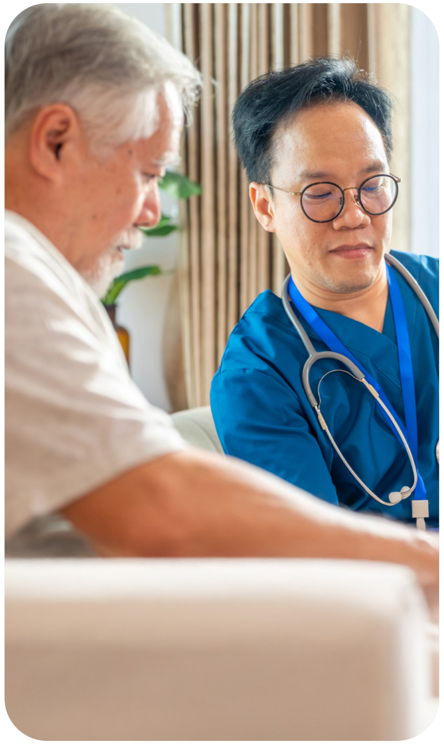
A palliative care team may include doctors, nurses, social workers, psychologists, therapists, and trained volunteers. Services depend on where you live, what you need and can often be provided at home.

Advance care planning

Advance care planning means making decisions about the healthcare you would want in the future, especially if there comes a time when you cannot speak for yourself. These decisions are based on your values, beliefs, and what matters most to you.

It can include treatments you want — or do not want — if your condition changes. You have the legal right to refuse treatment if that is your choice.

You can start by talking with your doctor, who can guide you through the process. You can also look for online resources and official forms from your local health service.



照顧自己

如果您的癌症復發，您的情緒可能會比以前更強烈或有所不同。他人的支持可能會改變，人們可能不總是知道該說什麼或如何提供幫助。

照顧您的情緒健康很重要。與了解癌症的諮詢師交談或加入支援團體可以帶來顯著改變。如果您感到孤單，請記住許多其他人也有過類似的經歷 — 您並不孤單。

紓緩治療

紓緩治療幫助患有癌症等嚴重疾病的人盡可能過上舒適的生活。它不僅適用於生命末期，而是可以在任何階段成為您護理的一部分，從而管理症狀、提高舒適度並支援您和您的家人。

紓緩治療可以包括：

- 疼痛及其他症狀管理
- 社交、情感、精神和心理支援
- 居家協助（例如暫息照護或專科治療）
- 未來照護規劃

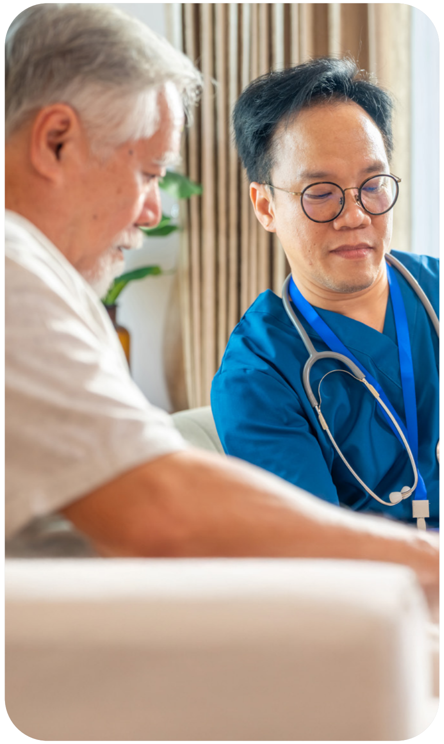
紓緩治療團隊可能包括醫生、護士、社工、心理醫生、治療師和受過訓練的志工。服務取決於您的居住地和您的需求，並且通常可以在家中提供。

預立醫療照護計畫

預立醫療照護計畫是指對您未來希望獲得的醫療照護做出決定，特別是在您無法表達自己意願的時候。這些決定基於您的價值觀、信仰以及對您而言最重要的事情。

它可能包括在您的病情變化時，您想要或不想要的治療。如果這是您的選擇，您有法定權利拒絕治療。

您可以先與您的醫生交談，他們可以引導您完成整個過程。您也可以從當地衛生服務機構尋找線上資源和官方表格。



Your voice matters

Sharing your cancer story can be powerful. It can help highlight where the system needs to improve and help you and others feel less alone. Your experience may encourage others to speak up, seek support, or share their own stories.

您的心聲很重要

分享您的癌症故事可以帶來強大的力量。它可以幫助突顯系統需要改進的地方，並讓您和他人感到不那麼孤單。您的經歷可能會鼓勵其他人發聲、尋求支持或分享他們自己的故事。

"An unexpected but wonderful benefit of my advocacy was meeting other patients, hearing their stories and sharing our experiences."

– Sarah (diagnosed with gastrointestinal stromal tumours)

「我倡議的一個意想不到的好處是，我遇到了其他病患，傾聽他們的故事並分享我們的經歷。」

– *Sarah*（被診斷出患有胃腸道基質瘤）

Ways to share your voice

- **Share your story publicly**
  Share you story via media, social media, reports, conferences, or community events.
- **Talk to decision-makers**
  Write to or meet with your local member of parliament and other government leaders to share your experience.
- **Support awareness and education**
  Take part in fundraising, educational activities, or awareness campaigns.
- **Contribute to submissions or inquiries**
  Share your views in written statements to help shape policy and healthcare decisions.
- **Work with organisations**
  Join advocacy groups like RCA, Consumers Health Forum, Patient Voice Initiative, or Cancer Voices to strengthen the impact of the patient's voices.

Sharing your story is a personal choice. It can be meaningful, but also emotionally demanding.

If you are thinking about advocacy, you can talk with an RCA Specialist Cancer Navigator about what's involved and what might feel right for you.

分享心聲的方式

- **公開分享您的故事**
  透過媒體、社交媒體、報告、會議或社區活動分享您的故事。
- **與決策者對話**
  致函或會見您當地的國會議員及其他政府領導人，分享您的經歷。
- **支持提高意識和教育**
  參與籌款、教育活動或宣傳活動。
- **參與提交意見或調查**
  以書面陳述方式分享您的觀點，以協助制定政策和醫療保健決策。
- **與組織合作**
  加入倡議團體，例如 RCA、消費者健康論壇（Consumers Health Forum）、病患心聲倡議（Patient Voice Initiative）或癌症心聲（Cancer Voices），以增強病患心聲的影響力。

是否要分享您的故事是個人的選擇。這很有意義，但也可能有很高的心理負擔。

如果您正在考慮參與倡導，您可以與 RCA 專科癌症導引員討論相關事宜，以及什麼可能適合您。

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.

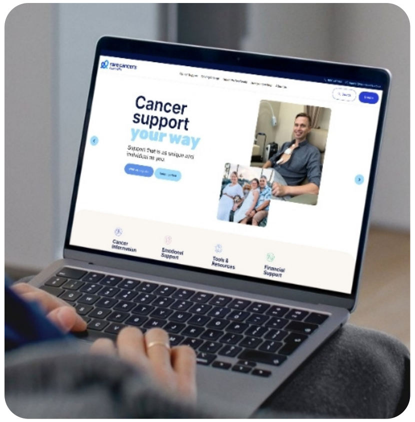
To speak with RCA's Specialist Cancer Navigators through an interpreter, call TIS on 131 450 (Monday to Friday, 9am–5pm, excluding public holidays) and ask to be connected with Rare Cancers Australia.

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。

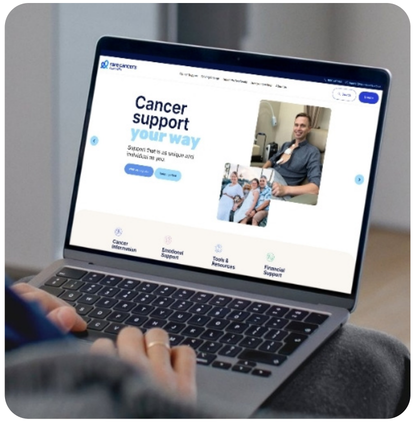
如需透過傳譯員與 RCA 的專科癌症導引員通話，請致電 131 450，聯絡 TIS (週一至週五，上午 9 點至下午 5 點，公眾假期除外)，並要求轉接至澳洲罕見癌症協會（Rare Cancers Australia)。

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

rare cancers
Australia

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

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