



Treatment

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This guide has been developed to give you and your loved ones clear information, practical tools, and useful advice to support you as you manage and navigate your cancer treatment.

治療

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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，以支持您管理和應對癌症治療。

Planning treatment for a rare or less common cancer can feel overwhelming. Treatment might involve surgery, radiation, medication or other therapies. The aim is to cure the cancer, shrink it, or slow its growth so you can live as well as possible, for as long as possible. At Rare Cancers Australia (RCA), we understand that it can be hard to know what to expect or where to find support.

Your treatment plan

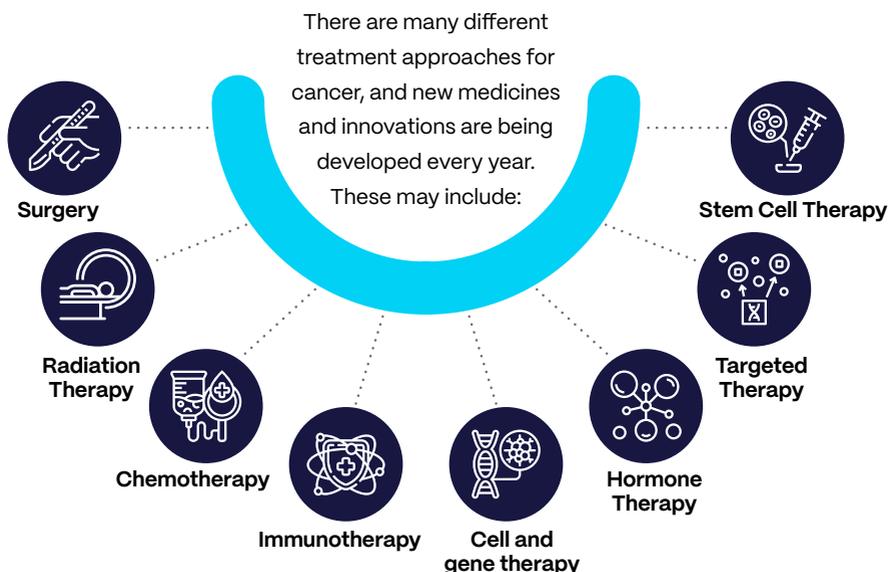
If treatment is needed, planning usually begins soon after diagnosis.

Every plan is personal. It depends on the type and stage of your cancer, your preferences, and how you respond to treatment. Your plan can also change over time as your needs change.

A treatment plan might cover:

- » tests and treatment options
- » treatment cycles (active treatment + recovery time)
- » managing side effects
- » what happens after treatment
- » ongoing monitoring

Treatment types



There may be times when standard treatments are not available or suitable for your cancer. In these situations, you might consider other options such as clinical trials, compassionate access programs or off-label treatments.

規劃罕見或不常見癌症的治療可能會讓人感到不知所措。治療可能包括手術、放射治療、藥物或其他療法。目標是治癒癌症、縮小腫瘤，或減緩其生長，以便您盡可能地維持良好生活品質並延長壽命。澳洲罕見癌症組織 (RCA) 理解你難以預料將會發生甚麼事和如何尋求幫助。

您的治療計劃

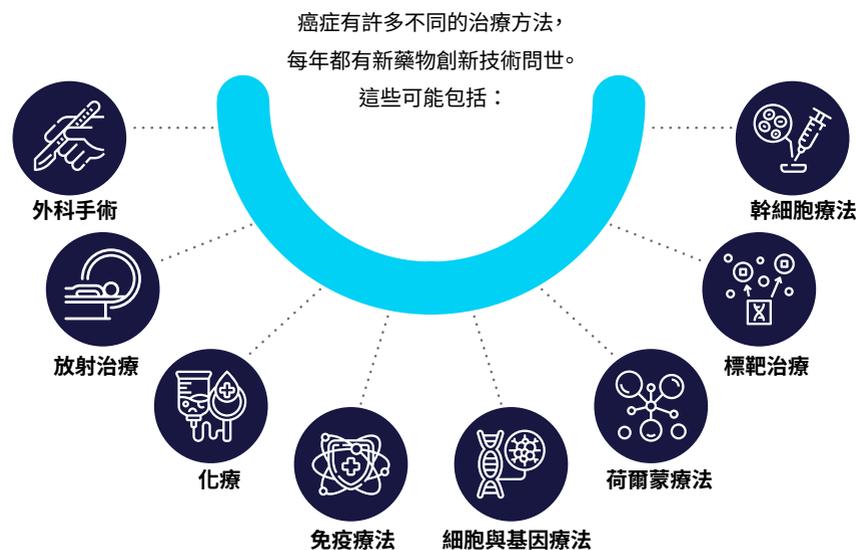
若需要治療，規劃通常會在確診後立即開始。

每個計劃都是個人化的。取決於癌症的類型與分期、您的偏好，以及您對治療的反應。您的計劃也會隨著時間的推移，以及您的需求變化而改變。

治療計劃可能涵蓋：

- » 檢查與治療選項
- » 治療週期（活躍治療 + 恢復時間）
- » 管理副作用
- » 治療後會發生什麼
- » 持續追蹤

治療類型



有時，標準治療可能不適用或不適合您的癌症。這些情況下，您可以考慮其他選擇，例如臨床試驗、恩慈用藥計劃或仿單標示外使用治療。

Off-label treatment: Off-label use means a medicine is prescribed in a different way from how it was originally approved by the authorities. If your doctor recommends an off-label medicine, you may need to sign a consent form to show you understand the possible benefits and risks. For example, a chemotherapy drug approved for one cancer type might be used to treat a different type of cancer.



Compassionate access schemes:

Compassionate access allows a pharmaceutical company to provide a medicine for free or at a reduced cost when no approved or funded treatment is available. Each request is assessed individually and access is decided by the company.



For more information in your language, scan the QR code



仿單標示外使用治療：仿單標示外使用是指藥物處方方式與當局最初批准的方式不同。如果您的醫生建議使用仿單標示外藥物，您可能需要簽署一份同意書，以表明您了解其可能的益處和風險。例如，一種獲批用於治療某種癌症的化療藥物，可能會用於治療其他類型的癌症。



恩恤用藥計劃：恩恤用藥允許製藥公司在沒有獲批或資助的治療方案時，免費或以優惠價格提供藥物。每項申請都會單獨評估，並由公司決定是否提供。



掃描 QR 碼以獲取更多以您慣用語言提供的資訊



Questions to ask your doctor

You might like to ask your doctor:

What is my treatment plan and why was it chosen?

Are there any clinical trials available to me?

What support services can I access?

What tests will be used to check how well the treatment is working?



What are my options if this treatment doesn't work?

Can I get a second opinion?

Will my treatment be in the public or private system, and what costs should I expect?

Has my tissue sample been tested for genes or mutations?

可詢問醫生的問題

您可能想問您的醫生：

我的治療計劃是什麼，以及為什麼選擇此方案？

我可以參加哪些臨床試驗？

我可以使用哪些支援服務？

將使用哪些檢測來檢查治療效果如何？



如果這種治療無效，我有哪些選擇？

我可以尋求第二意見嗎？

我的治療將在公立還是私立系統進行？我預計需要支付哪些費用？

我的組織樣本是否已進行基因或突變檢測？

Your healthcare team

During your cancer treatment, you may see many different health professionals. They usually work together as a team. For rare or less common cancers, they might also speak with specialists in other states or even overseas.

Who might be in your healthcare team?

Surgeon

Removes tumours or takes tissue samples for testing.

Surgical Oncologist

Specialises in cancer surgery.

Pathologist

Examines tissue samples to help diagnose cancer.

Medical Oncologist

Treats cancer and works with your team to plan treatment and manage side effects.

Radiation Oncologist

Uses radiation to kill cancer cells.

Integrative Oncologist

Combines standard cancer treatments with evidence-based complementary therapies.

Haematologist

Treats blood cancers and diseases.

General Practitioner

Supports your overall health, refers you to specialists, and helps manage your care long term.

Palliative Care Doctor

Focuses on comfort, pain relief and quality of life, especially when cancer is advanced.

Radiation Therapist

Plans and delivers your radiotherapy and monitors and supports you during treatment.

Nurse

Provides care, information and support, and often acts as your main point of contact.

Psychologist

Helps you manage your mental health and cope with the emotional impact of cancer.

Radiographer

Takes medical images, such as x-rays or scans, to help diagnose and monitor your cancer.

Speech Pathologist

Helps you if you have trouble speaking or swallowing due to cancer treatment.

Occupational Therapist

Helps you manage everyday tasks at home or work by finding practical solutions.

Exercise Physiologist

Creates safe, personalised exercise plans to improve your strength, fitness and overall wellbeing during and after treatment.

您的醫療團隊

在您的癌症治療期間，您可能會見到許多不同的醫護專業人員。他們通常以團隊形式合作。對於罕見或不常見的癌症，他們可能還會與其他州甚至海外的專科醫生進行交流。

您的醫療團隊可能包括哪些成員？

外科醫生

切除腫瘤或採集組織樣本進行檢測。

外科腫瘤科醫生

專門從事癌症手術。

病理科醫生

檢查組織樣本以協助診斷癌症。

內科腫瘤科醫生

治療癌症，並與您的團隊合作規劃治療和管理副作用。

放射腫瘤科醫生

利用放射線殺死癌細胞。

整合腫瘤科醫生

將標準癌症治療與循證輔助療法結合。

血液科醫生

治療血液癌症和疾病。

家庭醫生

支援您的整體健康，將您轉介給專科醫生，並協助長期管理您的護理需求。

舒緩治療醫生

專注於舒適、止痛和生活品質，尤其是在癌症晚期。

放射治療師

規劃並執行您的放射治療，並在治療期間進行監測、提供支援。

護士

提供護理、資訊和支援，通常是您的主要聯絡人。

心理醫生

協助您管理心理健康，並應對癌症帶來的情緒影響。

放射技師

拍攝醫學影像，例如 X 光或掃描，以協助診斷和監測您的癌症。

言語治療師

如果您因癌症治療而出現說話或吞嚥困難，他們會提供協助。

職業治療師

透過尋找實用解決方案，協助您在家或工作中管理日常事務。

運動生理學家

制定安全、個人化的運動計劃，以改善您在治療期間及之後的力量、體能與整體健康。

If you live rurally

Living in a rural or remote area can make it harder to access cancer care. Some treatments or services might not be available where you live. But there is support available, and you don't have to manage this on your own.

Ask your healthcare team or RCA Specialist Cancer Navigators about:

Telehealth

Many appointments can now be done by phone or video, which can save you time and reduce travel costs. Some providers offer bulk-billed telehealth appointments.

Tele trials

Some clinical trials can be partly completed through telehealth, working with your local doctor. Ask whether this could be an option for you.

Online support groups

RCA and other organisations offer online groups where you can connect with others, no matter where you live.

Travel support schemes

Every state and territory has programs to help cover the cost of travel and accommodation when you need to travel for treatment.



Your doctor can also use the Australian Rare Cancer (ARC) Portal to connect with cancer specialists across Australia.



For more details about travel support where you live, visit the web page for your state or territory:

New South Wales

iptaas.health.nsw.gov.au/For-patients

Queensland

qld.gov.au/health/services/travel/subsidies

Victoria

health.vic.gov.au/rural-health/victorian-patient-transport-assistance-scheme-vptas

Northern Territory

nt.gov.au/wellbeing/health-subsidies-support-and-home-visits/patient-assistance-travel-scheme

Australian Capital Territory

canberrahealthservices.act.gov.au/before-during-and-after-your-care/staying-at-canberra-hospital/before-you-arrive/getting-here-and-getting-around/travelling-from-outside-canberra

Western Australia

wacountry.health.wa.gov.au/Our-patients/Patient-Assisted-Travel-Scheme-PATS/

Tasmania

health.tas.gov.au/patients/support-services-your-visit-hospital/travel-support-ptas

Note: Information on these portals is only available in English.

如果您居住於鄉村地區

居住在鄉村或偏遠地區，可能會更難以獲得癌症照護。您居住的地區可能無法提供某些治療或服務，但仍有支援可用，而且您不需要獨自面對一切。

詢問您的醫療團隊或 RCA 專科癌症導引員以下事項：

遠距醫療

許多預約現在可以透過電話或視訊進行，這可以為您節省時間並減少交通費用。部分服務提供者提供直接結算的遠距醫療預約。

遠距試驗

某些臨床試驗可以透過遠距醫療，並在當地醫生配合下部分完成。他們亦會諮詢療程是否適合你？

線上互助群組

RCA 及其他組織提供線上群組，無論您住在哪裡都可以與他們聯繫。

出行支援方案

各州和領地均設有支援計劃，協助支付就醫所需的交通與住宿費用。



您的醫生也可以使用澳洲罕見癌症 (ARC) 入口網站，聯繫全澳洲的癌症專科醫生。



如需了解更多關於您所在地的出行支援方案詳情，請瀏覽您所在州或領地的網頁：

新南威爾斯

iptaas.health.nsw.gov.au/For-patients

昆士蘭

qld.gov.au/health/services/travel/subsidies

Victoria

health.vic.gov.au/rural-health/victorian-patient-transport-assistance-scheme-vptas

北領地

nt.gov.au/wellbeing/health-subsidies-support-and-home-visits/patient-assistance-travel-scheme

澳洲首都領地

canberrahealthservices.act.gov.au/before-during-and-after-your-care/staying-at-canberra-hospital/before-you-arrive/getting-here-and-getting-around/travelling-from-outside-canberra

西澳大利亞

wacountry.health.wa.gov.au/Our-patients/Patient-Assisted-Travel-Scheme-PATS/

塔斯曼尼亞

health.tas.gov.au/patients/support-services-your-visit-hospital/travel-support-ptas

請注意：這些網站上的資訊僅提供英文版本。

Managing costs

Cancer treatment can be expensive, with costs including hospital stays, medicines, appointments, tests and travel. It's a good idea to ask about costs before agreeing to any treatment. Cancer Council Australia has a Standard for Informed Financial Consent to help guide these conversations.

There are also other forms of financial support, including:



- » **RCA Patient Treatment Fund**
An online fundraising platform that helps raise donations for costs related to your cancer — such as treatment, travel, bills or lost income.
- » **Other organisations**
You can search for financial support services on the RCA KnowledgeBase: knowledge.rarecancers.org.au/knowledgebase/support-services
- » **Special access programs**
Some drug companies offer programs to help people with rare cancers get treatments, sometimes with flexible payment options. Doctors can find these through the Medicines Access Portal via medicinesap.com

Managing work

Deciding what to do about work during cancer treatment is personal and there's no right or wrong choice. You might not know how you will feel, how much energy you'll have, or if you can afford time off. What you want or need may also change as treatment goes on.

If you are working when diagnosed, you might choose to:

- » keep working
- » change your hours or days
- » work from home
- » take short breaks or use leave
- » take extended leave
- » job share
- » resign

The right option for you will depend on things like your finances, how you're feeling, and your job situation.

Talking to your boss about cancer — or about caring for someone with cancer — can feel difficult. Try to speak with someone you feel comfortable with, such as your manager, a senior leader, or someone in Human Resources.



承擔費用

癌症治療費用可能很高，涵蓋住院、藥物、預約、檢查及交通等。在同意任何治療之前，建議先詢問相關費用。澳洲癌症協會制定了《知情財務同意標準》(Standard for Informed Financial Consent)，以協助規範相關討論。

另有其他形式的財務支援，包括：



- » **RCA 患者治療基金**
線上募款平台，協助為您的癌症相關費用籌集捐款，例如治療、交通、帳單或收入損失。
- » **其他組織**
您可以在 RCA 知識庫中搜尋財務支援服務：knowledge.rarecancers.org.au/knowledgebase/support-services
- » **特殊取用計劃**
一些藥廠提供計劃，幫助罕見癌症患者獲得治療，有時還提供彈性付款選項。醫生可以透過 Medicines Access Portal 找到這些計劃：medicinesap.com

工作安排

在癌症治療期間如何處理工作屬於個人決定，沒有對錯之分。您可能無法預計自己感覺如何、精力狀態，或者是否能負擔得起休假。隨著治療的進行，您的需求或期望也可能會改變。

如果您在確診時正在工作，您可以選擇：

- » 繼續工作
- » 調整工作時間或天數
- » 在家工作
- » 短暫休息或休假
- » 休長假
- » 職務分擔
- » 辭職

最適合您的選擇將取決於您的財務狀況、身體感受以及工作情況等因素。

與老闆談論癌症或談論照顧癌症患者，可能會讓人感到困難。請嘗試與您感到自在的人交談，例如經理、高級主管或人力資源部門的同事。



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.

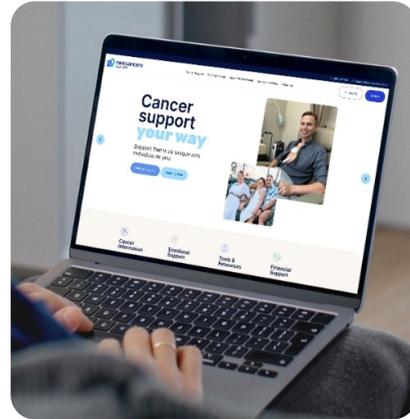
To speak with RCA's Specialist Cancer Navigators through an interpreter, call TIS on 131 450 (Monday to Friday, 9am–5pm, excluding public holidays) and ask to be connected with Rare Cancers Australia.

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。

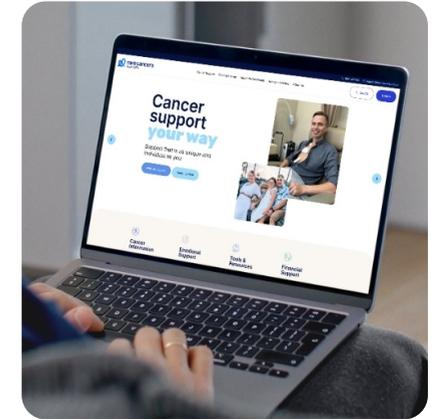
如需透過傳譯員與 RCA 的專科癌症導引員通話，請致電 131 450，聯絡 TIS（週一至週五，上午 9 點至下午 5 點，公眾假期除外），並要求轉接至澳洲罕見癌症協會（Rare Cancers Australia）。

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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