Rare Cancer Support Guide

DIAGNOSIS

USEFUL RESOURCES

Managing and navigating your cancer diagnosis

TITLE	ORGANISATION	HOW IT CAN HELP	LINK
Knowledge Base	Rare Cancers Australia	List of cancers and relevant information on them	https://knowledge.rarecancers.org.au/knowledgebase/cancer-types
Rare Cancers Information	Cancer Council	A guide to understanding some rare and less common cancers, including symptoms, diagnosis, and treatment	https://www.cancer.org.au/cancer-information/types-of-cancer/rare-cancers
What is a Rare Cancer?	Rare Cancers Australia	Rare and less common cancer definitions and statistics	https://www.rarecancers.org.au/page/131/what-is-a-rare-cancer
Glossary of Terms	Rare Cancers Australia	A glossary of terms you may hear during your diagnosis and treatment	https://www.rarecancers.org.au/page/72/glossary-of-terms
Cancer Words and Terms	Peter MacCallum Cancer Centre	Everyday cancer words and terms: A to Z	https://www.petermac.org/sites/default/files/page/downloads/Peter_Mac_cancer_words_terms-A_to_Z_WEB.pdf
Cancer Research	Walter and Eliza Hall Institute of Medical Research (WEHI)	Research in genomics to help improve the healthcare available for people with rare cancers	https://www.wehi.edu.au/research-diseases/cancer/rare-cancers
Understanding your Diagnosis	American Cancer Society	An online guide with information for people diagnosed with cancer, including treatment options and services	https://www.cancer.org/treatment/understanding-your-diagnosis.html
Questions to Ask	American Cancer Society	List of suggested questions to ask when first diagnosed with cancer	https://www.cancer.org/content/dam/cancer-org/cancer-control/en/worksheets/questions-to-ask-about-my-cancer.pdf
Language Resource	Cancer Australia	Cancer publications in 10 non-English languages	https://www.canceraustralia.gov.au/resources/culturally-and-linguistically-diverse-cald-services
Support for Mothers with Cancer	Mummy's Wish	Support for mothers diagnosed with cancer such as house cleaning and care packs	https://mummyswish.org.au/

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After a Diagnosis	Cancer Council	Guide to helping you and your loved ones to cope with a cancer diagnosis	https://www.cancer.org.au/cancer-information/after-a-diagnosis
Understanding Rare and Less Common Cancers	Cancer Council	A guide for people with cancer, their families and friends	https://www.cancer.org.au/assets/pdf/understanding-rare-and-less-common-cancers
Stages of Cancer	Cancer Institute NSW	Definition of cancer staging in different cancers	https://www.cancer.nsw.gov.au/about-cancer/cancer-basics/stages-of-cancer
Prognosis	National Cancer Institute	A guide to understanding your cancer prognosis	https://www.cancer.gov/about-cancer/diagnosis-staging/prognosis
Anxiety Self-Test	Black Dog Institute	Resources for stress, anxiety, and depression, including a short survey with printable results for you to discuss with your GP	https://www.blackdoginstitute.org.au/resources-support/digital-tools-apps/anxiety-self-test/
Support Service	Beyond Blue	One-on-one call with a trained mental health professional who can assist you in finding care	https://www.beyondblue.org.au/
Provider List	Cancer Australia	A list of healthcare professionals you can speak to depending on your needs	https://www.canceraustralia.gov.au/impacted-by-cancer/emotions/who-to-talk-to-about-cancer
Cancer Information	Cancer Australia	A range of resources about cancer, which have been translated into 10 languages other than English	https://www.canceraustralia.gov.au/
Emotional Impact Toolbox	Cancer Council	A toolbox for how to cope with the many stages of emotional impact from your cancer diagnosis	https://www.cancercouncil.com.au/cancer-information/when-you-are-first-diagnosed/emotions-and-cancer/
How to Cope with a Cancer Diagnosis	Cancer.Net	Recommendations on coping with stress, anxiety, and uncertainty after a cancer diagnosis	https://www.cancer.net/coping-with-cancer/managing-emotions/anxiety
Health Professional Definitions	American Cancer Society	Definitions of health professionals associated with cancer care	https://www.cancer.org/treatment/treatments-and-side-effects/choosing-your-treatment-team/health-professionals-associated-with-cancer-care.html#:~:text=Medical%20oncologist%3A%20A%20doctor%20who,mostly%20treats%20cancer%20with%20surgery
Interpreting Services	Translating and Interpreting Service (TIS National)	Provides access to phone and on-site interpreting services in over 150 languages 24/7 by phoning 131 450	https://www.tisnational.gov.au/

Managing and navigating a childhood cancer diagnosis

TITLE	ORGANISATION	HOW IT CAN HELP	LINK
Cancer Support	Canteen	Cancer support service for 12–25-year-olds	https://www.canteen.org.au/
Caring for Children with Cancer	American Cancer Society	Information on childhood cancers and planning	https://www.cancer.org/latest-news/caring-for-children-with-cancer.html
Life During and After Childhood Cancer	Cancer Council	Advice on managing life after a childhood cancer diagnosis	https://www.cancervic.org.au/cancer-information/children-teens-and-young-adults/life-during-and-after-childhood-cancer
Childhood cancer support hub	The Royal Children's Hospital Melbourne	Information about childhood cancer	https://www.rch.org.au/home/
Support Group	Canteen Connect	A community for young people dealing with their own or a close family member's cancer	https://canteenconnect.org/?gclid=EAIaIQobChMIpeyMuz9wIVSJNmAh3xNAmkEAAYASAAEgKAgvD_BwE&gclsrc=aw.ds
Support Group	Red Kite	Facilitated by RedKite social workers	https://www.redkite.org.au/service/connect-groups/
Support Service	Challenge	Supports children and families living with cancer	https://www.challenge.org.au
Support Service	Very Special Kids	Provides holistic care for Victorian families facing the potential death of a child	https://www.vsk.org.au/who-we-are/our-vision/
Children's Hospitals	Cancer Australia	A list of children's hospitals in Australia.	https://childrenscancer.canceraustralia.gov.au/glossary/childrens-hospitals-australia

Understanding your rights

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What Does it Mean to be an Empowered Patient?	Patient Empowerment Network	Understand what patient empowerment is and its importance	https://powerfulpatients.org/2018/05/22/what-does-it-mean-to-be-an-empowered-patient/
Partnering with Patients in Their Own Care	Australian Commission on Safety and Quality in Healthcare	Identifies the systems put in place to ensure clinicians are partnering with patients in the delivery of their care	https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard/partnering-patients-their-own-care
Research Tool	National Cancer Institute	A guide to finding cancer resources you can trust	https://www.cancer.gov/about-cancer/managing-care/using-trusted-resources
Research Tool	Cancer.Net	A guide to evaluating cancer information on the internet	https://www.cancer.net/research-and-advocacy/introduction-cancer-research/evaluating-cancer-information-internet
Rights and Roles of Australian Cancer Patients Report	Rare Cancers Australia	Explores how patients can be at the centre of their own care, well supported throughout their cancer journey, and have roles to inform healthcare decision making at the broader systems level	https://www.rarecancers.org.au/page/153/the-rights-and-roles-of-australian-cancer-patients