

Rare Cancer Support Guide

LOOKING AHEAD

USEFUL RESOURCES

Adjusting to life after cancer treatment

TITLE	ORGANISATION	HOW IT CAN HELP	LINK
Life After Treatment	Cancer Council	Emotions after treatment and finding a new normal	https://www.cancercouncil.com.au/cancer-information/when-you-are-first-diagnosed/emotions-and-cancer/life-after-cancer/
Common Survivorship Issues	Peter MacCallum Cancer Centre	A directory about common survivorship issues	https://www.petermac.org/survdirect
Improving Life with Cancer and Beyond	Flinders University	Life beyond cancer	https://www.flinders.edu.au/content/dam/documents/research/flinders-cancer-research/flinders-cancer-research.pdf
When Someone You Love Has Completed Cancer Treatment	National Cancer Institute	A booklet for carers and family who have a loved one who has completed treatment	https://www.cancer.gov/publications/patient-education/someone-you-love-completed-cancer-treatment
Coping with Cancer	National Cancer Institute	Cancer survivorship topics including follow-up medical care, family issues and caring for childhood cancer survivors	https://www.cancer.gov/about-cancer/coping/survivorship
Australian Cancer Survivorship Centre	Peter MacCallum Cancer Centre	Resources and events to help people move from initial treatment to post treatment and beyond	https://www.petermac.org/cancersurvivorship

Patient advocacy

TITLE	ORGANISATION	HOW IT CAN HELP	LINK
We Can Do Better. We Will Do Better	Rare Cancers Australia	The importance of advocacy and research in Australia to promote a better healthcare system for patients	https://www.rarecancers.org.au/page/96/advocacy-research
How Can You Make a Difference	Patient Voice Initiative	A collaboration between health consumers, researchers and industry working towards improving the patient voice in the Australian health system	https://www.patientvoiceinitiative.org/patients/how-to-make-a-difference-pvi/
From Molecule to Medicine to Australian Patients	Bristol-Myers Squibb	An infographic outlining the Health Technology Assessment process of a medication	https://www.patientvoiceinitiative.org/wp-content/uploads/2019/08/BMSA0551_HTA-Process_Infographic_AW06.pdf
Action in Advocacy: a 3 Minute Guide	Rare Diseases 360	A resource hub for multiple rare diseases to help health care professionals make a big impact on the small patient populations	https://rd-360.com/alagille-syndrome/action-in-advocacy-a-3-minute-guide/

Palliative care, end-of-life-care, and advance care planning

TITLE	ORGANISATION	HOW IT CAN HELP	LINK
The Thing About Advanced Cancer	Cancer Council	Podcast episodes on advanced cancer, including end of life	https://www.cancercouncil.com.au/advanced-cancer-podcasts/
Palliative Care Services	Palliative Care Australia	Palliative care services in your area as well as other resources	https://palliativecare.org.au/
Palliative Care Support	Health Direct	What palliative care is, resources and support	https://www.healthdirect.gov.au/palliative-carez
Advance Care Package	NSW Health	Making an Advanced Care Directive	https://www.health.nsw.gov.au/patients/acp/Pages/acd-form-info-book.aspx