

# Rare Cancer Support Guide

## LOOKING AHEAD

### USEFUL RESOURCES

## Adjusting to life after cancer treatment

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

## Patient advocacy

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

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

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