

BEWARE DR GOOGLE: A GUIDE TO RELIABLE BREAST CANCER INFORMATION ON THE INTERNET

FACT SHEET

January 2017

This fact sheet was produced by Breast Cancer Network Australia

I have just learned about the My Journey Kit you send out to help us with our questions and information – it is so much better than Google.
– Liane

If you have recently been diagnosed with breast cancer, your mind is probably a whirl as you try to come to terms with what this means for you.

You might be feeling shocked, uncertain and anxious as you wait for test results and appointments, begin talking to your doctors about your treatment options, and share news of your diagnosis with family and friends. You may be starting to think about how breast cancer is going to affect your life, and you probably have many questions.

This is often a time when people turn to the internet, looking for information to help support them. While there is plenty of helpful information to be found, there is also information that may be unhelpful, inaccurate and scary. This fact sheet is designed to help you find websites that offer reliable, good quality, online information following your breast cancer diagnosis.

Not all of the information you read will be relevant to you and your specific diagnosis. So if what you read raises questions about your diagnosis or treatment, or if you are unsure what it means, please talk to a member of your treatment team.

Breast Cancer Network Australia's My Journey Kit

Before beginning to look online for information, you might like to make sure that you have received a copy of BCNA's *My Journey Kit*. *My Journey Kit* is considered the 'gold standard' information package for Australians diagnosed with breast cancer. More than 80 per cent of all women diagnosed receive a *My Journey Kit* free of charge from BCNA.

My Journey Kit has been developed with input from health professionals, as well as people who have been diagnosed with breast cancer. It provides information to help you understand more about your diagnosis and make decisions about your treatment and care. It also contains information about managing your physical and emotional health and practical matters such as financial and employment issues.

The kit includes many quotes from others affected by breast cancer about the impact of their diagnosis and what most helped them along their journeys.

The My Journey Kit has been a great benefit to me. Even at midnight when something was worrying me, the answer was usually there. – Sarah

More information about BCNA's *My Journey Kit* is available on the BCNA website at bcna.org.au. You can order a kit online or by phoning BCNA on 1800 500 258.





BCNA's online network – 24 hours a day, seven days a week

Learning about breast cancer, talking about it, being involved and listening to other women's stories made me realise that I wasn't alone on this journey. – Maxine

One of the online supports many women find useful is BCNA's online network. The online network connects you with others who have been diagnosed with breast cancer. You can ask questions, share how you are feeling, read comments on a wide range of topics, discuss any worries or concerns you may have and get advice and support from others in a similar situation.

You can access the online network day or night, and you can choose to remain anonymous or you can share information about yourself.

Keep in mind that the members of the online network are not medical experts. You should talk to a member of your treatment team for specific advice about your personal situation.

More information about the online network and how you can access it is available on BCNA's website at bcna.org.au.

Breast cancer and the internet

Listed below are a number of websites that BCNA recommends. Some are Australian-based and others are international.

The websites cover a range of topics including:

- the different types of breast cancer
- breast cancer treatments
- tips to help you get through the initial period following your diagnosis
- living with breast cancer
- talking to children about your diagnosis
- issues for young women
- complementary medicines and therapies
- myths about breast cancer
- advice and reflections from women affected by breast cancer
- information for men diagnosed with breast cancer
- breast cancer research and statistics.

A number of websites include links to booklets and fact sheets that you might find helpful, as well as webinars, newsletters and blogs.

It's important to remember that not all of the information will be relevant to you or your specific breast cancer diagnosis. If you have any questions about what you read, you can call BCNA or talk to a member of your treatment team.



Australia

Organisation	About	Information/resources
<p>Breast Cancer Network Australia (BCNA)</p>	<p>The peak national consumer organisation for Australians personally affected by breast cancer.</p> <p>BCNA works to ensure that all Australians affected by breast cancer receive the very best support, information, treatment and care appropriate to their individual needs.</p>	<p>BCNA's website has a range of information and resources for anyone newly diagnosed with breast cancer, including information about:</p> <ul style="list-style-type: none"> • the different types of breast cancer • treatment options • your medical team • getting through the first few weeks • talking to family and friends • myths about breast cancer • breast cancer in young women • breast cancer in the family • complementary therapies • physical and emotional wellbeing • personal reflections and videos from women about what helped them. <p>Online network</p> <p>The website also includes:</p> <ul style="list-style-type: none"> • an archive of past issues of BCNA's free quarterly magazine <i>The Beacon</i> • booklets and fact sheets that you can download or order, including information about breast cancer pathology, fertility, healthy eating, sexual wellbeing, exercise, financial and practical assistance, travel insurance and lymphoedema • a Local Services Directory, that helps you to find breast cancer related services and support groups in your local area. BCNA has hundreds of affiliated support groups across Australia. Joining a support group gives you the opportunity to connect with other women, ask questions and share experiences. <p>bcna.org.au</p>
<p>Cancer Australia</p>	<p>Cancer Australia is Australia's national cancer control agency.</p> <p>Cancer Australia works to reduce the impact of cancer and improve the wellbeing of those diagnosed by ensuring that evidence informs cancer prevention, screening, diagnosis, treatment and supportive care.</p> <p>Cancer Australia develops clinical guidelines for best practice cancer treatment.</p>	<p>Cancer Australia has developed the <i>Guide for women with early breast cancer</i>, which provides in-depth information for women newly diagnosed with breast cancer. This guide is included in BCNA's <i>My Journey Kit</i>, but can also be downloaded from Cancer Australia's website.</p> <p>Cancer Australia's website includes a breast cancer section, with information on:</p> <ul style="list-style-type: none"> • breast cancer statistics • the different types of breast cancer • treatment options • breast reconstruction • living with breast cancer • life after breast cancer. <p>canceraustralia.gov.au</p> <p>Young women</p> <p>Cancer Australia has a young women's website that provides information for women under the age of 40 diagnosed with breast cancer.</p> <p>breast-cancer-in-young-women.canceraustralia.gov.au</p>



		<p>Men</p> <p>Cancer Australia also has a website for men diagnosed with breast cancer. breastcancerinmen.canceraustralia.gov.au</p>
<p>Cancer Council Australia</p> <p>State and territory Cancer Councils</p>	<p>Cancer Council Australia provides advice to the Australian Government about the prevention, detection and treatment of cancer. It also provides support and information for those affected by cancer.</p> <p>Cancer Council Australia has a national office in Sydney and offices in each state and territory.</p>	<p>Cancer Council websites have booklets, podcasts, blogs and other resources that may help you cope with a diagnosis of breast cancer. Cancer Council resources can be downloaded or ordered as hard copy publications.</p> <p>Find a specialist</p> <p>Cancer Council Australia's website has a directory of professionals working in particular areas of medicine. It also has a list of other professional directories that may help you find specialists and services in your area.</p> <p>Myth busting</p> <p>The iheard website was developed to help combat myths and misinformation about cancer. If you have questions or have heard a rumour or claim about breast cancer, you can submit a question on the iheard website. Your question will be reviewed by staff and you will receive an answer based on the latest research. You can also view questions that have been submitted previously by others. iheard.com.au</p> <p>Cancer Council 13 11 20 information and support</p> <p>For information and support on cancer-related issues, call 13 11 20, 9.00 am to 5.00 pm, Monday to Friday, and you will be diverted to the Cancer Council in your state or territory. Trained staff, including oncology nurses and counsellors, are available to answer questions, provide information and discuss support that may be available in your area.</p> <p>Cancer Council Australia — cancer.org.au Australian Capital Territory — actcancer.org New South Wales — cancercouncil.com.au Northern Territory — nt.cancer.org.au Queensland — cancerqld.org.au South Australia — cancersa.org.au Tasmania — cancertas.org.au Victoria — cancervic.org.au Western Australia — cancerwa.asn.au</p>
Westmead Breast Cancer Institute (BCI)	The Westmead Breast Cancer Institute, located at the Westmead Hospital (NSW), is a service that provides screening and treatment for women diagnosed with breast cancer. The organisation also focuses on education and research.	The BCI website provides useful information about breast cancer, as well as a number of fact sheets that may assist women who have been diagnosed. Fact sheets can be downloaded, or you can request a printed copy be sent to you at no cost by using the online form or emailing your details to BCI-ResourceOrder@health.nsw.gov . bci.org.au
Breast Cancer Care WA	Breast Cancer Care WA is a not-for-profit organisation that provides support and information to people affected by breast cancer.	Breast Cancer Care WA provides useful information about breast cancer, suggestions about questions you may like to ask your health professionals and a range of fact sheets that are available online. breastcancer.org.au
CanTeen	CanTeen supports young people aged 12–25 years who have either been diagnosed with cancer themselves or who have a parent, caregiver or sibling who has been diagnosed with cancer.	CanTeen's booklet <i>Now What? Dealing with your parent's cancer</i> provides information on what might happen next when you have a parent diagnosed with cancer. It can be ordered or downloaded from the website. CanTeen also has an online community for young people who have a parent diagnosed with cancer. It provides information and support, and connections to other young people going through similar issues. Online counsellors are also available. canteen.org.au



Other helpful Australian websites

Organisation	About	Information/resources
Federal Department of Human Services	The Department of Human Services website is the entry point for information about Medicare and Centrelink.	<p>Centrelink provides information about Federal Government payments and services that you and your family may be eligible for following a breast cancer diagnosis. humanservices.gov.au/centrelink</p> <p>Medicare provides information about payments and services for health care and medicines that are available from the Federal Government humanservices.gov.au/medicare</p> <p>The Department of Human Services website also includes a 'Payment Finder' that will help you find the payments you may be eligible for based on your situation.</p>
Flinders University work and cancer website	This website is a guide for people diagnosed with cancer, health care providers and employers. It provides information on working during cancer treatment, returning to work when treatment is done and changing work.	<p>The work after cancer website provides advice to people diagnosed with cancer, their partners and family members, clinicians, and employers about their options, rights and responsibilities. workaftercancer.com.au</p>

International

Please note that not all of the information provided on overseas-based websites will be relevant to women in Australia, for example, information about health insurance entitlements. If you have any queries about the relevance of information, please speak to a member of your treatment team.

Organisation	About	Information/resources
BreastCancer.org (USA)	BreastCancer.org is a not-for-profit organisation that provides information about breast cancer and the latest research.	<p>BreastCancer.org provides a wide range of information and resources about breast cancer. The website also contains podcasts, a blog and updates about breast cancer research findings. breastcancer.org</p>
Breast Cancer Care (UK)	Breast Cancer Care UK is a not-for-profit organisation that provides information and support to those affected by breast cancer.	<p>Breast Cancer Care UK provides information about breast cancer, including for women who have been newly diagnosed. The website also contains the Breast Cancer Care blog and the online magazine <i>Vita</i>. breastcancercare.org.uk</p>
Memorial Sloan Kettering Cancer Centre (USA)	The Memorial Sloan Kettering Cancer Centre is one of the largest private cancer centres in the USA.	<p>For women interested in using complementary medicines, this website provides comprehensive and reliable information about the effects of particular herbs, botanicals, vitamins and supplements on breast cancer treatments. The website provides evidence-based information about possible side effects of these products and whether they reduce the effectiveness of breast cancer treatments. Links to scientific research are also provided. The Memorial Sloan Kettering Cancer Centre also provides this information on the free downloadable mobile app About Herbs. mskcc.org</p>
Macmillan Cancer Support (UK)	Macmillan Cancer Support is a not-for-profit organisation dedicated to providing support to those affected by cancer.	<p>While Macmillan Cancer Support is not solely focused on breast cancer, information about breast cancer is available on its website, along with more general information about cancer treatments and living with cancer. The website also contains a directory of cancer publications. While some have a cost, others can be downloaded free of charge. macmillan.org.uk</p>
Young Survival Coalition (USA)	The Young Survival Coalition provides information for young women who have been diagnosed with breast cancer.	<p>The Young Survival Coalition's website contains a range of fact sheets, booklets and navigation tools, which have been developed to address the specific needs of young women diagnosed with breast cancer. A range of talks relating to issues affecting young women are also available online, either as audio files or transcripts. youngsurvival.org</p>



<p>Susan G. Komen (USA)</p>	<p>Susan G. Komen is a not-for-profit organisation that provides breast cancer resources and programs, funds research and undertakes advocacy.</p>	<p>Susan G. Komen provides information for women diagnosed with breast cancer. The website also contains an interactive treatment navigation tool that provides information about the various treatments. komen.org</p>
<p>Facing Our Risk of Cancer Empowered (USA)</p>	<p>Facing Our Risk of Cancer Empowered (FORCE) is an organisation that provides information and resources for women affected by familial breast and ovarian cancers.</p>	<p>FORCE provides information for women who carry an inherited genetic mutation such as the BRCA1 or BRCA2 gene, including information for women newly diagnosed with breast cancer. The website discusses specific issues that women diagnosed with familial breast cancer may wish to take into account when making treatment decisions. The website also contains information about genetic testing, fertility and pregnancy, and talking to family members. An online newsletter is available, as are a range of videos and educational brochures, which may be downloaded. facingourrisk.org</p>
<p>Dr Susan Love Research Foundation (USA)</p>	<p>Dr Susan Love Research Foundation is a not-for-profit organisation that undertakes and funds breast cancer research and provides information about breast cancer.</p>	<p>Dr Susan Love Research Foundation provides information for women newly diagnosed with breast cancer. The website provides a list of answers to commonly asked questions, a blog, and a section that provides information about recent research. drsusanloveresearch.org</p>
<p>Malebreastcancer.ca (Canada)</p>	<p>Malebreastcancer.ca is a website that provides information for men diagnosed with breast cancer.</p>	<p>The Malebreastcancer.ca website includes information on treatment and care and personal stories from men diagnosed with breast cancer. malebreastcancer.ca</p>