

# Minds Matter

*The following article features in Issue One of the ST BREAST magazine.*



**Dr Lisa Beatty is a Senior Clinical Psychologist and Cancer Council South Australia Senior Research Fellow at the Flinders Centre for Innovation in Cancer. She has expertise in psycho-oncology - the scientific exploration of the psychological impact and treatment of cancer.**

BETWEEN 30 and 40%<sup>1</sup> of breast cancer patients will experience what psychologist Dr Lisa Beatty calls “clinically significant distress”.

This might present as anxiety, depression, adjustment difficulties and an overwhelming fear of cancer recurrence which can impact daily life and a woman’s ability to carry out her normal roles.

While rates of distress are similar for those women with early or metastatic disease, those with a documented mental health history, and those who have less support, are more likely to struggle.

Dr Beatty acknowledges that when it comes to managing breast cancer, some studies indicate that older women seem to have lower distress rates, “but that’s because they are at a very different life stage, and the worries they experience tend to be different than younger women who may have fertility challenges, younger/dependent children, and may be managing work and mortgage commitments. It’s not necessarily easier for them, just different.”

Distress screening is vital, because untreated distress in breast cancer patients has been shown to lead to an increase in the range and severity of symptoms and side effects experienced.<sup>2</sup> “Moreover, we see a three-fold reduction in a patient’s ability to adhere to cancer treatment if they are distressed,<sup>2</sup> and research shows us that untreated distress is associated with a 17% higher mortality rate.<sup>3</sup> Managing distress is critical.”

Dr Beatty says it is common for women to experience symptoms of grief, but it is the fear of recurrence that is predominant “and this is a universal fear”.

“When you have women who say they don’t fear recurrence, well I would really question whether they have processed what they have been through,” Dr Beatty says.

“A normal level of worry would be becoming anxious just before a scan or an anniversary.

“But some women are consumed by their fear and are unable to let it go. One woman I spoke to said it was like doing head miles, cycling through her head all the time. And it led to a lot of unhelpful behaviours like constant body checking, which can drive the anxiety further. It is when they are consumed by their thoughts and are really vulnerable that expert help is needed.”

That expert help may involve cognitive behavioural therapy, which involves re-training thought patterns.

## **Identity & Body Image**

A cancer diagnosis can also affect a woman’s whole sense of identity and role in

family life.

“Anecdotally, women will often say they tire of being the ones within a family who carry the mental load, and manage children and work, but that they then find it quite emotionally challenging when they are suddenly not able to do that,” Dr Beatty says. “In addition, their work roles might change, and they may find the very visible changes in their body, from hair loss to surgical changes, quite confronting.”

## **Breast Cancer and Relationships**

Relationships are also frequently impacted – and not just intimate relationships, because friendships can also change.

“Some women who are undergoing treatment for breast cancer report feeling socially isolated, and feel that they are getting less support from their friends when they really need more,” Dr Beatty says.

“We do see some friends really step up – and they might be unexpected supporters. It’s often the people who women predict will be their best supporters that might not be there.

“With intimate relationships, we find a cancer diagnosis will amplify existing dynamics.

“A lot of people make the assumption that cancer will bring them closer together and that can be the experience, but they are the people who have had stable foundations before cancer. Those that had a slightly rocky relationship before the cancer can find that this may be the thing that drives them apart.

“What we do know from research is that marital support has just as much of an impact on outcomes as chemotherapy. <sup>4</sup> Support has a huge impact on how someone will cope afterwards – it is a huge protective factor.”

## Career Path

Dr Beatty's interest in the psychological impact of cancer began when an aunt was diagnosed around the time she was determining her own career path.

"For me it was seeing the resources she did not have access to that really propelled me forward," she says.

"She had a lot of support, but at that stage psychology and cancer wasn't really an established area (either in research or clinically). This made me broadly interested and when I started my PhD it became a real passion. I wanted to make sure there were resources available for all women, and not just those who live in major urban areas."

So, for her PhD project, Dr Beatty developed and trialled a printbased workbook to support women through their diagnosis and treatment of breast cancer. This workbook then became the foundation of an online program called 'Finding My Way' that she developed with a team of collaborators, including medical oncologist Professor Bogda Koczwara and clinical psychologist Professor Tracey Wade.

This online resource helps patients navigate each stage of the cancer journey beginning with diagnosis, assisting with decision making, providing advice and directing them to relevant resources throughout the treatment pathway.

A national trial funded by the National Health and Medical Research Council demonstrated that the program helps people manage and live with distress, and reduced the need for people to access additional health services.

The program is now freely available, thanks to generous sponsorship by the Flinders Foundation, and in partnership with Cancer Council SA.

It is now being investigated with funding support from the Beat Cancer Project, in partnership with The Breast Cancer Network Australia (BCNA), for women with advanced breast cancer, and is the subject of new studies in the US, Romania and the United Kingdom.

# Finally

Dr Beatty says a good psychologist, social worker and/or mental health nurse can be great support, “and also don’t underestimate the importance of your family GP”.

“I would advise women to keep working in some capacity if you can (but this will vary from person to person), as this has been shown to help women emotionally. Exercise also has a huge beneficial impact.

“Breast cancer is never going to be easy, but we know if you have good supports around you, someone you can talk to, and solid internal coping strategies, then they are great steps forward.”

**Dr Lisa Beatty**

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## STRATEGIES *to assist your children*

It can be difficult to know how to help your child during your diagnosis and treatment. Below are some practical strategies that you can use for each age group and you can then add your own ideas for your children, including who may help support them.

## Infant-2 Years

<b>Affection</b>	Provide frequent hugs & cuddles.
<b>Consistency in caregiver</b>	Have a consistent and trusted caregiver (parent or relative).
<b>Maintain routine</b>	Have your relative or partner maintain your child's routine.
<b>Have regular contact with your child</b>	Even if you are sharing care, ensure that you see your child frequently.
<b>Special treats</b>	Read books together, record lullabies and leave voice-messages for them.
<b>Visits to the hospital</b>	Let your child see where you are receiving treatment.
<b>Provide reassurance</b>	That Mummy or Daddy will be home soon.

## 3-5 Years

<b>Information</b>	Let your child know you are sick and what that means (tired but not dying).
<b>Daily child care &amp; maintain routine</b>	Have a consistent substitute caregiver.
<b>Address guilt</b>	Tell them cancer is not their fault.
<b>Play &amp; artwork</b>	Use these opportunities with your children to express emotions & provide education.
<b>Question time</b>	Arrange a time each day (e.g. after dinner) when children can ask you questions and share feelings.
<b>Show your emotions</b>	Assure your child that expressing your emotions for brief periods is helpful.
<b>Mentor</b>	Have a relative or friend show a special interest in your child.

## 6-8 Years

<b>Education</b>	Tell your child you have cancer and explain treatment.
<b>Consistent caregiver &amp; routine</b>	Have a consistent substitute caregiver.
<b>Address guilt</b>	Tell them cancer is not their fault. Offer repeated reassurance.
<b>Inform school &amp; teachers</b>	This will help to ensure that your child will be supported at school.
<b>Question time</b>	Answer your child's questions honestly. Also let them know it's okay if they don't want to talk.
<b>Visits to the hospital</b>	Let your child see where you are receiving treatment and introduce them to your doctor.
<b>Mentor</b>	Have a relative or friend show a special interest in your child.

## 9-11 Years

<b>Education</b>	Give more detailed information about your cancer and explain treatment.
<b>Family approach</b>	Cancer is stressful for the whole family, but you will manage the uncertainty together.
<b>Address guilt</b>	Tell them cancer is not their fault and it is not contagious.
<b>Inform school &amp; teachers</b>	This will help to ensure that your child will be supported at school.
<b>Question time</b>	Answer your child's questions honestly. Also let them know it's okay if they don't want to talk.
<b>Maintain normality</b>	After-school activities, sports and time with friends are important to maintain.
<b>Reading &amp; Writing about your cancer</b>	Encourage your child to do this if they are interested.

## Teens

<b>Education</b>	Give more detailed information about your cancer and explain treatment.
<b>Maintain normality</b>	This is important at home and school. Remind teens it's okay to still have fun with friends.
<b>Encourage emotional expression</b>	Teens may do this by writing or talking (to you or others) about how they feel about your cancer.
<b>Inform school &amp; teachers</b>	This will help to ensure that your child will be supported at school.
<b>Support groups</b>	If your teenager is interested, contact CANteen for support, or investigate other online resources.
<b>Check out your expectations</b>	Don't expect your child to take on caregiving or challenging roles.
<b>Family Time</b>	Try and spend time together as a family.

For more information, go to: [www.findingmyway.org.au](http://www.findingmyway.org.au)

This is an open access/ free website for anyone with early stage breast cancer. [www.findingmywayadvanced.org.au](http://www.findingmywayadvanced.org.au) is a new adapted version of the website for women with metastatic breast cancer. It is currently only available as part of a clinical trial to evaluate efficacy. Women interested in being involved should contact: [info@findingmyway.org.au](mailto:info@findingmyway.org.au)

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