



FOREWORD AND A(KNOWLEDGEMENTS

I am very proud of the role young women have played in the development of this National Breast Cancer Foundation (NBCF) report. To accompany our thorough review and analysis of the scientific literature around the world, we undertook qualitative research with young women themselves. I could not have been more touched by their avid response.

Young women are born activists despite how much they all have on their plates, and I am lost in admiration of their spirit. Despite having so much to deal with already, through surveys, in-depth phone interviews and focus group activity, the young women we reached out to keenly wanted to contribute, and volunteered their personal and professional skills.

These women ranged from someone diagnosed 12 years ago to someone diagnosed just 12 months ago, but their generosity did not differ and it is my privilege to thank each and every one of them for what they have co-created. I am confident you will enjoy hearing their voices and their stories, and seeing their images.

Prior to this report, there existed no comprehensive publication in Australia on the issues of young women and breast cancer – even though efforts in other countries precede us. Thanks to these young Australian women, we can now draw attention to the existence of breast cancer among them and to their needs. Together, we intend this to result in change, including NBCF's partnership with the Royal Australian College of General Practitioners to develop a relevant accredited online training module for GPs.

With the greatest gratitude and respect, I would like to thank:

- each of the young women who came forward to participate in our research
- my co-authors, Jennifer Henwood and Dr Sue Henshall
- Magalie Lameloise (magsblog.com) for the gift of her illustrations
- The Young Survival Coalition (US), Rethink Breast Cancer (Canada), the Sheba Medical Centre (Israel) and Dana Farber (US) for their inputs
- NBCF staff who have contributed in a variety of ways to the development of this report.

And a special thank you to Erica Packer for her gift to support production of this resource.

Carole Renouf

Chief Executive Officer

(álde Reso

DEDICATION

This report is dedicated to the memory of Frances Gill, who wanted to do all she could to help and honoured me with an interview (page 4) just 11 days before she died on 30th July 2014.



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EXE(UTIVE SUMMARY

Breast cancer in young women – defined in this report as women less than 40 years of age – is not a phenomenon that has received much attention to date in Australia. Yet almost 800 young women per year are diagnosed. While the incidence of breast cancer is not as high as in older generations, young women face an utterly disproportionate burden of impact on every aspect of their lives. This is poorly publicised, and even more poorly understood, thereby adding to that burden.

From the moment of concern when typically they may discover a worrying change in their breasts, young women face an uphill battle. Even being taken seriously with their request for diagnostic testing can be a challenge.

Young women tend to think they are 'bullet proof'. They are often fit, active and lean with no discernible risk factors. Because the incidence of breast cancer in the 20s and 30s is low, when it does occur it takes everyone by surprise. Mammographic screening is not offered to women under 40 in Australia, because it is not particularly effective in younger age groups. So, young women must rely on breast self-examination or clinical breast examination to find any changes.

For young women, having an accurate understanding of family history can be an important tool to aid early diagnosis. However, it's important that young women don't overestimate the role of family history in breast cancer. We know for women of all ages, only a maximum of 15% of breast cancers are related to family history.

Although breast cancer is not common in young women, those affected are typically diagnosed with more aggressive sub-types of the disease and larger tumours – which means a poorer prognosis. Because young women often manifest with 'triple negative' disease, there are few targeted therapies available for them – unlike older women who most often manifest with hormonally-driven breast cancers responsive to anti-hormone therapies. So, young women are often aggressively treated with chemotherapy, which can be effective but also a 'blunt instrument' in killing healthy cells as well as cancer cells, with effects for years to come. Treatments can have severe impacts on young women's abilities to remain employed and certainly to remain employed in the same job and with the same working conditions. This in turn can have very significant impacts on their financial situation and future career prospects.

More young women die of their disease, compared with older women, and they have a higher rate of recurrence and spread from the breast to other parts of the body, such as the bone, liver, lungs and brain. Once that metastasis has happened, the science today can keep them alive for some years, but ultimately cannot save them – yet. Young women in this situation are particularly challenged. The content in this report focuses on early detection and management of primary breast cancer. However, we are very conscious of the unmet needs of young women whose breast cancer has spread, and recognise the requirement for further support, greater awareness, better therapies and more research for these women.





NBCF SUPPORTS RESEARCH INTO BREAST CANCER IN YOUNG WOMEN

Since the National Breast Cancer Foundation was established in 1994, it has funded over \$11 million in research across 40 projects aimed at improving outcomes for young women with breast cancer.

These research projects continue to break new ground across the research spectrum – from support services for young women at high-risk of breast cancer, to understanding metastasis and improved therapies for young women with the disease.

NBCF is proud to continue its support of vital research into breast cancer in young women.

Young women's needs are very different to those of a woman in her 60s, 70s or 80s. Breast cancer typically visits them at a time when they are already extremely busy dealing with multiple major life events and choices, such as partnering, childbearing, parenting and careers, to name a few. Dealing with a life-threatening disease gets added to their 'must do' list.

Young women will not have had much prior experience negotiating with the health system. If diagnosed in their 20s, they will have only just 'flown the nest' and breast cancer will often set them back in terms of independence from their parents. If diagnosed in their 30s, parenting of young children plus ability to bear other children is often a major issue, as treatments can induce early menopause or decrease fertility. The impact on relationships, challenging at any age, can be huge. The impact on self-image, dating and sexuality can last for years. The psychosocial toll of breast cancer cannot be over-estimated, especially given that so many young women report being 'the only one' amidst a sea of older women. Living with fear of recurrence alone will last a lifetime.

It is not acceptable that when nearly 800 young women are stricken with breast cancer in Australia each year, we still do not have enough to offer them in the way of earlier diagnosis, targeted and personalised treatments, and age-appropriate psychosocial support – whether their cancer is confined to the breast or has spread. NBCF is committed to changing this, through awareness, training and research.



I've just managed to celebrate my 38th birthday with my family. It's accepted this is more than likely my last birthday. I was diagnosed two and a half years ago, and at that time I already had secondaries in my liver. I just thought, "How long have I got? I am going to die".

I'd had a fibrous mass in my breast since my early 20s. I'd had intermittent ultrasounds to get it checked, but I wasn't really scared. People just said, "Don't worry, you're too young". Gradually the mass got harder and more painful. Eventually, they did a biopsy, full body ultrasound and brain scan. My advanced breast cancer was oestrogen receptor-positive, but negative to HER2 and progesterone. I was treated with chemo, two different types to shrink the tumours before surgery. Initially the tumours shrank but then blew up again, so they tried a different chemo. Then I had a single mastectomy and they tried various drug combinations which didn't work. Now we're trying another chemo which is making me feel really sick and drowsy.

The hardest thing for me about having advanced breast cancer as a young woman is that nobody understands what this means. They all assume you'll get better. I have to deal every day with end of life decisions, while people say to me brightly, "When you're better, we can do x". I went to visit a friend and attended her mother's craft group. I was introduced as a special guest who's fighting the big fight and has come through the other side. Now that I don't look very well anymore, it's a bit easier – people are more sympathetic when you are hobbling along with a walking stick and no eyebrows and a face swollen by steroids.

My workplace was more than supportive, and I absolutely loved my job. In fact, having a job to do, and socialising with colleagues and clients helped me get through the first few rounds of chemo. Quitting work was a massive decision, and I only did it because I thought it was affecting my work quality (so much time off), more so than the implications it was having on my health. For a young single woman with a good career, losing this stuff is pretty tough!

I haven't been in a relationship since I had breast cancer. I was seeing someone before. But I have zero sex drive from the drugs, and what are the chances of a bloke walking up and me being interested? It's just not on the radar and that's really sad.

It's taken a huge toll on my family. My Mum and I are together 24/7. I'm always worrying about Mum and she's always worrying about me. My sister is having health issues. My parents have had to use their savings and redo their entire bathroom to make way for me when I get too sick. I accessed my super to help with finances and can tell you the super funds don't make it easy for you. They could show more compassion...

- FRANCES

ABOUT BREAST (AN(ER IN YOUNG WOMEN

WHO ARE WE CALLING 'YOUNG'?

Breast cancer research varies in the way it defines a 'young woman'.

Some research focuses on women younger than 35 years, other research draws the line at 45 years, still other projects define a young woman as any premenopausal woman.

For the purposes of this report, we have defined a young woman as any woman under the age of 40 years.



y 2020, a predicted 830 young women will be diagnosed with breast cancer in Australia each year. This year in Australia, just under 800 will be diagnosed. Where young women are concerned, the impact of the disease is out of all proportion to the incidence.

'THE STATS'

At the time of publishing this report, incidence and mortality statistics were available for breast cancer diagnosed in 2010.

During this year:

- 14,181 women were diagnosed with breast cancer, **767** of these were women under the age of 40 years.
- 2,837 women died from breast cancer, **67** of these were women under the age of 40 years. These were young women whose cancer spread from the breast to other parts of the body.

While breast cancer in women under 40 is relatively uncommon, the impact of the disease on a young woman's life is devastating.

Young women are typically diagnosed with more aggressive breast cancers than older women. As such, their long-term outcomes are generally poorer. In addition, young women face a unique set of practical, physical and emotional challenges, including:

- halted career progression and reduced earning potential
- impact of treatment on fertility and future childbearing
- effect of the disease on family life and relationships
- social isolation
- impact on self-image, self-esteem, anxiety, sexuality.

If they have breast cancer on their radar at all, young women typically do so only as a disease that can affect their mothers or grandmothers. They see it as an older woman's disease. They also think that because they may be thin, fit, eat well and drink little alcohol, they are not at risk.

NEED TO BRUSH UP ON YOUR BREAST CANCER KNOWLEDGE?

Throughout this report, you will read about different types and stages of breast cancer. Some people may benefit from an overview of breast cancer basics.

If this is you, head to **800youngwomen.org.au** for some Breast Cancer 101.

At the time of my diagnosis I was 27, married and a fairly new mother with an 18 month old boy. I had breastfed my son, practised yoga four times a week, didn't drink or smoke and am a size 8, so we didn't see it coming. I had detected some masses in my breasts three years earlier, but been told that I had very lumpy breasts and no importance was placed on the importance of regular checks.

We desperately wanted to conceive a second child before we got the diagnosis. Losing control over something major like family has been the biggest issue for us, all my girlfriends are having children and I am still on tamoxifen now, which definitely affects my sexuality and temperament. I need to take a six month break before we try to conceive, and there is very little research to show how much of a risk it is for me to have another child because my cancer is oestrogen positive. I didn't find the whole surgery and losing my breast thing difficult at all. In fact, I'm going back into surgery four days from now to have the other breast removed.

My husband was really good. He's a builder and not used to talking about feelings, so he didn't treat me like an invalid and that was helpful. The only time I saw him get really upset was when I asked him to shave my head. He took six months off work because while our son was in childcare, he kept coming back with all sorts of colds and making me sick – so he looked after both of us and we went backwards financially, all our savings went. We're just getting back on track now two years later – luckily I had life insurance with trauma cover and this gave us a payout. We could have gotten assistance from Centrelink for the time he took off work, but we didn't know. I'm a self-employed professional photographer, and now I'm back at work.

When I was sick, I didn't want to be treated like I was sick. They told me about support like *Look Good, Feel Better* but I didn't want to hang around other women with cancer or women who were much older than me. This was my individual battle.

- CARLIE



WHAT WE KNOW

Research tells us that there are a number of **characteristics of breast cancer in young women** that affect the treatment and survival of this group.

BREAST (ANCER IN YOUNG WOMEN IS TYPICALLY MORE AGGRESSIVE

• Young women are more likely than older women to be diagnosed with aggressive sub-types of breast cancer, such as triple negative and HER2-positive breast cancers.

YOUNGER WOMEN WITH BREAST (AN(ER HAVE POORER LONG-TERM OUT(OMES

- Young women diagnosed with breast cancer are at higher risk of their cancer returning (recurrence) compared with women diagnosed over the age of 40.
- Breast cancer in young women is more likely to spread to other parts of the body (metastasise) at an earlier stage than breast cancers in older women.
- Young women have a higher risk of dying from breast cancer compared with older women, regardless of the stage of their cancer.

YOUNGER WOMEN ARE AT HIGHER RISK OF DEVELOPING BREAST (AN(ER IN BOTH BREASTS

• If a young woman develops breast cancer in one breast, she has a higher risk of developing breast cancer in her other breast (contralateral breast cancer) compared with older women.

THE **NATURE OF A YOUNG WOMAN'S BREAST TISSUE** MAY PLAY A PART IN THE DEVELOPMENT OF BREAST (AN(ER

- Breast tissue in young women is typically denser than breast tissue in older women.
- Breast tissue in young women undergoes more hormonally-driven changes due to menstrual cycles, pregnancy, and breastfeeding.
- Some research suggests that these factors may influence the development of breast cancer in young women.

INSIDE THIS REPORT: KEY ISSUES FOR YOUNG WOMEN WITH BREAST CANCER

Our research and consultation process has identified six key issues for young women diagnosed with breast cancer:

- 1) Detection, diagnosis and treatment
- 2) Self-image and sexuality
- 3) Fertility and future child bearing
- 4) Relationships: family, parents, partners and the challenges of being single
- 5) Fear, stress and isolation
- 6) Employment, career and finances.

This report presents key research and findings about the main considerations for young women across these key issues.



DETECTION AND DIAGNOSIS OF BREAST (AN(ER IN YOUNG WOMEN

IN THIS SECTION

- RISK FACTORS FOR BREAST CANCER IN YOUNG WOMEN
- DETECTING BREAST CANCER
- INVESTIGATING A CHANGE IN YOUR BREASTS
- RECEIVING A DIAGNOSIS OF BREAST CANCER

At 27, I had just gotten married and was going on my honeymoon. One month later, I found a lump in my breast. I didn't go to see the doctor about the lump, but when I was there about other things – almost as an afterthought – I asked her to check it. "I wouldn't worry about it, you're far too young," was her response. After a mammogram, ultrasound and biopsy, my life became divided into life before breast cancer, and life after.

In your 20s you really think you are invincible, you're kind of naïve. I was fit, going to the gym, and although I'd had an Auntie die of cancer, I never thought it could happen to me. How did I deal with it? I wrote a lot, went to a café, ordered my coffee and wrote. That worked for me. Reading about the tsunami in Indonesia at the time also worked for me. It gave me a sense of perspective.

I was born in Cambodia and my heritage is Cambodian, Chinese and Australian. I couldn't tell Mum and Dad, it was huge. English is my first language and although I speak fluent Chinese, I gathered everybody in my family and asked my younger sister to interpret for me. Nobody spoke about cancer in my family, no one had ever spoken about my Auntie. Part of healing for me was to talk, especially after treatment. I was going to be interviewed on TV and my parents were horrified at me exposing my secret and embarrassing the family. My in-laws, who are Vietnamese, thought I got cancer because it was a punishment for my parents! To this day, they don't talk about it. At the time of diagnosis, my parents depended on me and all of a sudden, it felt like I was a child again.

At 27, I just didn't have the skills to deal with a life-threatening disease. I didn't know what to do. I couldn't go to my friends. I didn't know how to handle it at work. I told my manager, and she didn't tell anybody. After chemo I started wearing my wig to work and one day a colleague said to me "That's not your hair!" I fled and jumped into a cab and went home. The next day, I turned up at work wearing a head scarf and revealed the news I had breast cancer.

Like any new wife, my greatest hope was to be a mother. I was told by my oncologist that following chemotherapy, there was a high chance we wouldn't be able to have kids. After two years of treatment, the hardest decision was to let go of tamoxifen and leave it up to God. He must have been listening because not only did I get pregnant once, but a second time two years later. We now have two beautiful daughters and I have learned that you can breastfeed with just one breast.

As a young mother, recurrence is your greatest fear. It's always there. I used to only plan one year at a time. Now it's been nine years, I'm daring to plan two years at a time.

-VANESSA

ealthy young women in Australia face a range of mixed messages about breast cancer risk, self-examination and screening.

Many women under 40 believe they are just too young to get breast cancer. Some women do not know how to check for changes in their breasts.

Understanding the risk factors for breast cancer, and being breast aware is vital for the early detection of breast cancer in young women.

Earlier detection means more treatment options, a much higher chance of survival and an increased quality of life for women at all ages.

RISK FACTORS FOR BREAST CANCER IN YOUNG WOMEN

A risk factor is any characteristic or behaviour that may increase your chance of getting a certain disease.

For women of all ages, simply **being a woman** and **getting older** are the two strongest risk factors for developing breast cancer. Neither of these risks can be modified.

While breast cancer in young women is rare, there are some specific factors that can increase the risk of developing breast cancer at a younger age:

- having a family history of breast cancer
- carrying certain genetic mutations, such as BRCA1 or BRCA2 gene mutations
- being of Ashkenazi Jewish heritage
- having been treated with radiation therapy to the breast or chest during childhood/early adulthood
- previous diagnosis of breast health problems or breast cancer.

IF YOU FIND IT EARLY, IT'S SIMPLY A "TO DO" LIST TO GET THROUGH IT AND (OME OUT THE OTHER SIDE.

JENNIE

WHAT WE KNOW

FAMILY HISTORY IS A STRONG RISK FACTOR FOR BREAST (ANCER IN YOUNGER WOMEN

- A young woman's risk of breast cancer is increased if a close relative, like a mother or aunt, has had breast or ovarian cancer. There is a close relationship between breast and ovarian cancers.
- However, the role of family history in breast cancer in young women can be overestimated. Family history only explains a maximum of 15% of breast cancers in young women. For the vast majority, the causes are as yet unknown.
- For a young woman with a family history of breast cancer, her risk is further increased if her relatives were diagnosed with cancer at a young age, or she carries certain genetic mutations (see next page).

SOME GENETI(FACTORS ARE A STRONG RISK FACTOR FOR BREAST (AN(ER IN YOUNGER WOMEN

- A young woman's risk of developing breast cancer is increased if she carries a genetic mutation in certain genes, such as the BRCA1 or BRCA2 genes.
- In Australia, 5–10% of all women with a family history of breast cancer carry a mutation in the BRCA1 or BRCA2 genes.
- BRCA gene mutations can be more common among certain populations, such as Ashkenazi Jewish women.

Other factors that may increase risk of breast cancer or affect outcomes for young women with breast cancer include lifestyle factors such as weight, physical activity, diet and alcohol intake.

MAINTAINING A HEALTHY WEIGHT (AN IMPROVE OUT(OMES FOR YOUNG WOMEN WITH BREAST (AN(ER

- Recent research has also shown that younger women with oestrogen receptor-positive breast cancer are at increased risk of dying from the disease if they are obese.
- The Australian Government *Dietary Guidelines for Australians* recommends that all adults prevent weight gain by being physically active, eating a wide variety of nutritious food and limiting fat intake.

REGULAR EXERCISE (AN PLAY A ROLE IN REDUCING BREAST (ANCER RISK FOR WOMEN OF ALL AGES

- For women of all ages, regular exercise has been shown to play a role in reducing the risk of developing breast cancer, as well as helping improve outcomes for those diagnosed with the disease.
- The Australian Physical Activity and Sedentary Behaviour Guidelines recommend being active on most, if not all, days of the week.

REGULARLY DRINKING ALCOHOL (AN INCREASE THE RISK OF BREAST (ANCER

- Regularly drinking alcohol can increase the risk of breast cancer for women of all ages.
- The Australian Government *Dietary Guidelines for Australians* recommends that all adults limit their alcohol intake if they choose to drink.

UNDERSTANDING RISK

Having one or more risk factors for breast cancer does not mean that a woman will develop breast cancer. However, it is important for young women to be aware of the risk factors for developing breast cancer, and to have a realistic understanding of their individual risk.

To find out more about the different degrees of breast cancer risk, head to **800youngwomen.org.au**.

YOU KNOW YOUR BODY BEST,
AND DON'T LET ANYONE TELL
YOU OTHERWISE. I WAS TOLD THE
LUMP IN MY BREAST WAS NOTHING,
AND WENT BACK TWO MONTHS LATER
AND INSISTED ON GETTING IT SEEN
TO AGAIN. IF I DIDN'T DO THAT, I
MAY NOT BE HERE TODAY!

DETECTING BREAST CANCER IN YOUNG WOMEN

Finding breast cancer early – while it is still small and confined to the breast – improves a woman's chances of survival, gives her more treatment options and results in a better quality of life after treatment.

WHAT WE KNOW

For healthy young women at average risk of developing breast cancer, the best methods for the early detection of the disease are:

- breast awareness. Young women should be aware of the normal look and feel of their breasts so that they can spot any changes.
- clinical breast examination (i.e. breast check by a doctor). Young women can request regular breast checks with their doctor.

ROUTINE MAMMOGRAPHI(S(REENING IS **NOT RE(OMMENDED** FOR WOMEN UNDER 40

- In Australia, free routine mammographic screening is available through BreastScreen services in each state for women over the age of 40 years
- Routine screening is not offered to women under the age of 40 because:
 - research shows that women less than 40 with an average risk of breast cancer do not benefit from routine mammographic screening.
 - false-negative results occur more often in women under
 40 because younger women are more likely to have denser breast tissue.

YOUNG WOMEN AT HIGH RISK OF BREAST CANCER

Young women classified as being at high risk of developing breast cancer should discuss an individual routine screening program with their GP. This individualised program may include regular clinical breast examinations, and some screening with mammography or other more effective imaging technologies such as ultrasound or magnetic resonance imaging (MRI).

MRI for high-risk young women

Women under the age of 50 years who are at high risk of breast cancer are eligible for routine screening with MRI under Medicare. To access this screening service, young women must be referred by a GP or specialist.

BEING BREAST AWARE

It is important that young women know the changes in their breasts that could indicate the presence of breast cancer. Common changes that could be due to breast cancer include:

- a lump or thickening in the breast
- a change in the shape or size of the breast or nipple
- dimpling of the skin or the nipple
- discharge or blood from the nipple
- a rash or changes to the skin around the breast
- persistent pain in the breast or armpit
- swelling or a lump in the armpit.

These changes do not necessarily mean a young woman has breast cancer. However, if a young woman notices these, or any other, changes in the breast, she should see her doctor.

RAISING AWARENESS AMONG HEALTH PROFESSIONALS

As breast cancer in young women is rare, health professionals may be tempted to dismiss breast symptoms, such as a lump, in young women as cysts – adopting a 'wait and see' approach.

There may be a view by both the health professional and the young woman that she is 'too young' to develop breast cancer.

While breast cancer in young women is unlikely, health professionals must be aware that breast cancer can develop in women under 40 years of age. Likewise, health professionals must be aware that pregnant women can also be diagnosed with breast cancer.

DID YOU KNOW...

While very uncommon, pregnant women, and mothers who are breastfeeding can be diagnosed with breast cancer too.

During pregnancy and breast feeding, the breasts are undergoing a lot of changes. Young women need to be vigilant for any unusual changes to their breasts at this time. Young women may notice a change and think it is simply due to mastitis, but this may not always be true.

It is important for young women to discuss all breast changes with a doctor.

I AWOKE ONE MORNING WITH MY HAND ON MY (HEST. I FELT A HUGE LUMP UNDER MY RIGHT BREAST. I IMMEDIATELY SATUPRIGHT IN BED, AND YELLED OUT TO MY HUSBAND 'I'VE FOUND A LUMP'. HE REA(HED OVER AND FELT IT, AND WITHOUT SAYING ANOTHER WORD TO EA(H OTHER WE KNEW IT WAS (ANCER. IN MY PANIC, I IMMEDIATELY (ALLED VARIOUS BREASTS (REENING SERVICES TO ARRANGE A MAMMOGRAM OR ULTRASOUND, BUT IT SEEMED NO ONE WAS TAKING ME SERIOUSLY BE(AUSE OF MY AGE. I WENT TO MY GP STRESSING THAT I NEEDED A S(AN, SHE TOO WAS RELUCTANT AS SHETHOUGHT DUE TO MY AGE IT WAS PROBABLY A (YST, BUT AFTER MU(H DEBATE DECIDED TO LET ME GET THE S(AN. I HAD STAGE 3 (ANCER.

DEIRDRE

INVESTIGATING A BREAST SYMPTOM IN YOUNG WOMEN

When a young woman goes to her doctor to discuss a suspicious breast symptom, the doctor should be guided by the triple test, to investigate the symptom further. The young woman's history and circumstances should also be taken into account when carrying out these investigations, for example whether she has a strong family history of breast cancer, or has previously presented with unexplained breast symptoms or changes.

As the name suggests, the triple test has three components that must be completed in order to diagnose a breast symptom as breast cancer. The table below shows the process for investigating a new breast symptom.

MEDI(AL HISTORY AND (LINI(AL BREAST EXAMINATION

- The doctor should ask about a woman's medical history, including any previous breast problems, and her family history of cancer.
- The doctor should also ask about the breast symptom, including where it is and how long it has been there.
- The doctor should then perform a clinical breast examination to feel for palpable lumps or changes to the breast.

2 IMAGING

- If the doctor is suspicious or unsure about the breast symptom, the woman will be referred for some imaging to further investigate.
 - For women under 25: ultrasound will be used for imaging.
 Mammography will be used as a secondary imaging technique if the findings of the ultrasound are suspicious.
 - For women 25–35: ultrasound will be used for imaging.
 Mammography will be used as a secondary imaging technique if the findings of the ultrasound are suspicious or the young woman has a strong family history of breast cancer.
 - For women 35-40: ultrasound and mammography will be used together.

3 BIOPSY

- If the imaging confirms the presence of a suspicious lump, the woman will be referred for a biopsy.
- A biopsy is the removal of a small sample of tissue from the breast, for examination under a microscope, to help diagnose breast cancer.
- The tissue taken from the breast during the biopsy is then sent for testing to confirm if it contains breast cancer cells.

A CLINICIAN'S PERSPECTIVE

DR SHANI PALUCH SIMON, HEAD, BREAST CANCER SERVICE FOR YOUNG WOMEN, SHEBA MEDICAL CENTER, ISRAEL

We are a reference centre and 25% of women coming here are young – their needs are unique and different.

We aim to offer a clinically comprehensive service. We have on-site genetic testing and on-site fertility preservation as well as the services of a psychologist. There is so much demand for the services of the latter that she often has to run groups to fit everybody in. The big downer for young women typically comes after they finish having their treatment, so we don't limit when they enter or when they exit the psychological service.

We are definitely not able at present to offer sufficient support for partners of young women, or for parents. Many of these young women come in supported by their mothers, and this creates a very complicated dynamic especially for women in their 20s. The issue has come up repeatedly in our focus groups and requires attention. For example, one of my young patients complained because the surgeon called and gave her results to her mother.

Loneliness is another issue that comes up in our focus groups. Cancer is supposed to be a disease of older people. We need to create a time slot where young women can be treated at the same time as each other so they don't feel so isolated. A buddy system, with a woman who's been through breast cancer but is far enough out from it to have adjusted, would be ideal.

We don't have the funding to do a proper survivorship program. Young women often have a really hard time with lack of sex drive – we need a sexual therapy centre. They also have a really hard time going back to work. I push my patients to go back, even quarter time, because those who don't have a poorer outcome, e.g. depression and fibromyalgia.

There's a really misleading proportion of breast cancer ascribed to family history in this age group. Even with a concentrated population of Ashkenazi Jewish women (carrying the BRCA genes), it's only 30% of them that have family history. We don't have any explanation yet as to why the other 70% get breast cancer.

Breast cancer in young women is a lethal disease. Triple negative breast cancer is far more common, and the luminal B type that is far more aggressive. There is no prospective research in young women and not enough data to tailor therapies. They also experience recurrence sooner and more local recurrence – they are 9 times as likely to have local recurrence as an older woman. That is never discussed with them, typically. I'm also fairly sure that young women who opt for mastectomy are not clear what a mastectomy does or doesn't do for their future.

They often feel really lost when the whole process starts. It will be their first experience dealing with the health system, maybe they've only dealt with it in pregnancy before. The fertility issue is really loaded emotionally for them; they have a range of options but ideally we like to do egg harvest, egg freezing, embryo freezing (IVF – which has the best outcome) and also freeze some ovarian tissue. But this is difficult for women without a partner.

What can we tell them about managing risk? The only lifestyle issue with a clear correlation is alcohol – so decrease or stop drinking. Maintain a healthy weight and exercise. We recommend in Israel that from their 20s, they should go to a breast surgeon to have a clinical breast examination – in Australia, you would go to a GP or gynaecologist. If they have a family history, get genetic testing now. Familiarity with the normal look and feel of your breasts is important.

WHAT DIDN'T WORK WAS THE INFORMATION I FOUND ON THE INTERNET WHI(H SAID BREAST (AN(ER IS USUALLY PAINLESS — I HAD PAIN BUT (OULD NOT FEEL A LUMP AND FOR THIS REASON INITIALLY DE(IDED NOT TO SEE A DO(TOR. I ALSO LOOKED AT THE STATISTI(S (LESS THAN ONE PER(ENT OF AUSTRALIAN WOMEN DIAGNOSED ARE AGED UNDER 30) AND THE FA(TTHAT BREAST S(REENING IS ONLY OFFERED TO WOMEN OVER 40, AND (AME TO THE (ON(LUSION THAT I WAS BEING PARANOID.

ELISE

RECEIVING A DIAGNOSIS OF BREAST CANCER

Finding a breast symptom and being diagnosed with breast cancer can be an extremely challenging time for women at any age, but particularly for a young woman.



A NOTE ABOUT 'DR GOOGLE'

Anecdotal evidence suggests that almost 70% of Australians with regular access to the internet will go online to search for health information.

We are heading online to search for anything from information about medicines, to clues that will help us self-diagnose our ailments.

The internet can be a valuable source of information and support for young women who have been diagnosed with breast cancer. However, it is very important that young women are accessing reliable and accurate information. We've listed reliable sources in this Report.

Young women should always speak with their doctor about any questions or concerns that they have.

TREATMENT OF BREAST (AN(ER IN YOUNG WOMEN

N THIS SECTION

- TREATMENT OPTIONS FOR BREAST CANCER
 IN YOUNG WOMEN
- TREATMENT COMPLIANCE FOR YOUNG WOMEN

We live 95 kms out of Adelaide on a working farm. I was 32 and married with three kids aged between two and 15 when I found the lump. I checked my breasts a few times a year, but I knew straightaway it wasn't going to be good, even though breast cancer was seen to be an older woman's disease and I didn't have any of the risk factors. You've already got so much on at that age, you add breast cancer into the mix and it just topples your world.

I've had the works: axillary clearance of all the lymph nodes, chemo, radio, Zolodex, my ovaries removed, tamoxifen, and Arimidex for the foreseeable future. Making the choice to remove my ovaries was the hardest for me. When I found the lump, we were going for a fourth child.

Since then, the hardest thing has been the early menopause. I hate the night sweats, the hot flushes, the dryness. It's a pain, but I just deal with it and get on with it.

There was a support group locally but it was made up of older women so it wasn't very relevant to me, especially as I was a younger woman. I pretty much did it all on my own, with my husband for support and my mother-in-law next door. At that time we ran a dairy farm and the travel was hard, as I had to go to Adelaide for chemo and radio. We'd get up and milk in the morning before we left, get the kids ready for school and Grandma's, leave by 8 am, drive to Adelaide, finish chemo round 4.30 pm, drive back, milk the cows, get the kids to bed. This went on for three months. Then it was just me driving myself to Adelaide every day for 32 days for 15 minutes of radio, and back. I made this into 'me' time and used to stop off to have lunch and do a bit of shopping. Because we were 95 kms out of Adelaide and not 100, we didn't qualify for transportation assistance. We ended up going through the private system because of the kids, although it was expensive, but thankfully the Medicare Safety Net kicked in and made it less of a hardship financially. Going through the public system would probably have meant staying the week in Adelaide and I wanted to be home for the kids.

Life doesn't end with breast cancer. It never goes away, it's always in the back of my mind, especially every 12 months when I have my scans. And at the same time, the cows still need to be milked and fed, calves fed, paddocks watered. Life on a farm doesn't stop.

- REBECCA



he approach to treating breast cancer in young women typically depends on a number of factors, including:

- the type of breast cancer, and whether it is positive for any hormone receptors or HER2
- the location of the cancer, and whether it has spread to other parts of the body
- the young woman's general health.

Above all this, however, the most important factor influencing the treatment of breast cancer in a young woman is her personal preference.

Different treatments for breast cancer will have different physical and psychosocial side effects that impact on a woman's life after breast cancer – including her ability to have children, her ability to return to work, her self-image and sexuality. The practical, physical and emotional effects of breast cancer and its treatment are explored in subsequent sections of this report.



TREATMENT OPTIONS FOR BREAST CANCER IN YOUNG WOMEN

SURGERY

- Surgery is typically the first line of treatment for women with breast cancer.
- There are two types of surgery for breast cancer:
 - mastectomy involves removal of the whole breast, and often one or more lymph nodes in the armpit.
 - breast conserving surgery involves removal of the cancerous tissue in the breast, as well as some healthy tissue surrounding the cancer. Sometimes breast conserving surgery will also involve the removal of one or more lymph nodes in the armpit.
 Nowadays, the nipple is conserved wherever possible.

(HEMOTHERAPY

- Chemotherapy is a drug regimen that works by killing cells that are rapidly dividing, such as breast cancer cells.
- It can be given by a drip into a woman's arm, or in a tablet.
- As well as killing cancer cells, chemotherapy can also kill other cells in the body that are rapidly dividing, such as hair and skin cells. This is the reason why a woman's hair and nails can fall out during chemotherapy and why other side-effects can be severe.

RADIOTHERAPY

- Radiotherapy is the use of radiation (x-rays, gamma rays, electron beams or protons) to kill cancer cells.
- Radiotherapy targets the breast cancer, while limiting the exposure of healthy tissue surrounding the tumour to doses of radiation.

ANTI-HORMONE THERAPY

• Anti-hormone therapies, such as tamoxifen can be used to treat young women with hormone responsive (sometimes called oestrogen receptor-positive) breast cancers. Tamoxifen works by stopping the breast cancer from responding to oestrogen, slowing the growth of the tumour.

ANTIBODY THERAPY

- Antibody therapies are targeted treatments that stop certain breast cancer cell types from growing.
- Herceptin is a type of antibody therapy used to treat HER2-positive breast cancer.

RECONSTRUCTION AFTER BREAST SURGERY

Women may choose to have a breast reconstruction or use an external breast prosthesis to return the natural shape to their chest area after a mastectomy. It is important for young women to be aware of all the reconstructive options available to them.

Breast reconstruction may involve the insertion of an implant, or the transfer of tissue, skin and muscle from another part of the body into the chest area. The reconstruction can begin at the time of a woman's mastectomy, or can be delayed until after treatment.

An external breast prosthesis, sometimes called a 'breast form', is a piece of material that recreates the shape of the breast when worn in a bra or under clothing.

ANOTHER IMPACT HAS BEEN THAT I HAVE GAINED & KG SINCE STARTING TAMOXIFEN. IT IS NOT SUPPOSED TO BE A SIDE EFFECT BUT I HAVE NOT (HANGED MY EATING HABITS AND HAVE IN(REASED MY EXER(ISE. WHILE I KNOW THE "GOOD OUTWEIGHS THE BAD" IT (AN BE DEMORALISING AND ANNOYING TO TRY AND LOSE THE WEIGHT. AGAIN, KEEPING YOUR WEIGHT IN THE HEALTHY RANGE IS ESSENTIAL IN ENSURING THE (AN(ER DOES NOT RETURN SO IT IS SOMETHING ELSE TO WORRY ABOUT.

SALLY

WHAT WE KNOW

A lot of the evidence about the best ways to treat breast cancer has been developed based on research in women over 40 years of age. There are some questions about the limitations of current treatment guidelines for managing breast cancer in young women.

THE BENEFITS OF **Breast (onserving surgery** For young women are still being debated

- Due to the higher rates of recurrence in young women, there are questions regarding the effectiveness of breast conserving surgery.
- There is no evidence that breast conserving surgery results in the same long-term survival rates as mastectomy in younger women.

THE BENEFITS OF **AGGRESSIVE (HEMOTHERAPY** IN YOUNG WOMEN ARE DEBATED

- Because breast cancer in young women is generally more aggressive, there is support for the use of chemotherapy in all young women, regardless of the stage of their cancer.
- Chemotherapy in women under the age of 50 has been shown to reduce the relative risk of death from breast cancer by 38%.
- However, the benefits of aggressive chemotherapy should be weighed against the significant long-term physical and psychosocial effects of chemotherapy, including early menopause, sexual dysfunction and cognitive impairment (loss of concentration and memory).

YOUNG WOMEN MAY BENEFIT FROM AN EXTENSION OF ANTI-HORMONE THERAPY

- Current treatment guidelines recommend that women with hormone receptor-positive breast cancer take ongoing anti-hormone treatment, such as tamoxifen, for five years after their treatment for breast cancer.
- Research suggests that young women may benefit from an extension of this treatment.

STICKING WITH THE PROGRAM: A NOTE ON COMPLIANCE

Compliance to breast cancer treatment means taking a medicine or undergoing therapy exactly as it has been prescribed by a doctor. For young women, there are a number of practical challenges that can affect their compliance to different treatments or therapies.

ACCESSING RADIOTHERAPY

Receiving radiotherapy following breast conserving surgery may be an important part of a young woman's treatment plan.

Research has shown that young women, especially those with young children, are less likely to undergo radiotherapy. Research shows that access to childcare for her children may be an important consideration in a woman's decision to undergo radiotherapy. There may also be challenges accessing treatment for young women in regional and remote areas.

LONG-TERM ANTI-HORMONE THERAPY

It is recommended that young women with oestrogen receptor-positive breast cancer take an anti-hormone therapy, such as tamoxifen, for at least five years after their treatment.

Research has shown that one in five young women either do not start, or discontinue their use of anti-hormone therapy within months of starting treatment. In some studies, within two years, 42% of young women stopped treatment.

Anti-hormone therapy can have severe side effects by inducing menopause symptoms, such as night sweats, loss of libido, hot flashes, and also cannot be taken during pregnancy or breastfeeding. It is thought that these factors, together with a poor understanding of the importance of treatment and a waning fear of cancer recurrence, may contribute to poor compliance.









EMPLOYMENT, (AREER AND FINAN(ES FOR YOUNG WOMEN AFFECTED BY BREAST (ANCER

N THIS SECTION

- COMMUNICATING
 A DIAGNOSIS
 OF BREAST CANCEL
- RETURNING TO WORK
- FINANCIAL IMPACT OF BREAST CANCER

At the time of my diagnosis, my mum had already been diagnosed and I was a middle manager in a community health agency. I had been there about four years when I got sick. I informed my supervisor, who took it on board and wished me well. I was really conscious of the importance of telling my five direct reports one to one, to ensure succession planning and continuity of service. I visited each of them personally to give them the news. During my treatment the HR Manager checked in with me and one of my peers would text me every couple of days – I found that really helpful.

A car was part of my remuneration package. I had to use up my sick leave and then any other leave for my treatment initially, and I then went onto unpaid leave over a period of about four months. I lost the use of the car at that time as I no longer had that entitlement. That made it very hard to get back and forth to Melbourne for treatment. On the days I was well enough I would ride my daughter to school on the pushbike or roller skate to pick her up.

When it came time for me to go back to work I hoped to return parttime as I wasn't up to full-time, but the organisation felt you couldn't work in a middle management capacity on a part-time basis. I wish there could have been more flexibility, such as looking at a job share, but there wasn't. So I resigned, and that was the catalyst to me setting up my own business. I now provide training services, executive coaching and career development, mainly in the public sector.

The impact of a career disruption on your earning potential and superannuation – whether the break is due to illness or maternity leave – is significant. I went through the private system with no private health insurance. Things have been incredibly difficult financially. I had to go to Centrelink to apply for sickness benefits to sustain the house payments. This was on a day when I couldn't even stand up. My mum drove me there with her headscarf on and stood in line for me till I was called up, and then I had to justify asking for six weeks of benefits – it was horrible.

I saw a part-time job advertised coordinating a women's leadership group and applied for it. I got called to attend an interview just a couple of days after a chemo round – the worst possible time! I drove 60 kms to the venue, had a sleep in the car, and was then confronted with a massive flight of stairs to get up to the interview. I barely made it, but I got through the interview wearing my trendy headscarf, then had another sleep in the car and drove home. I was offered the job on a contract basis, and that was really the start of my business.

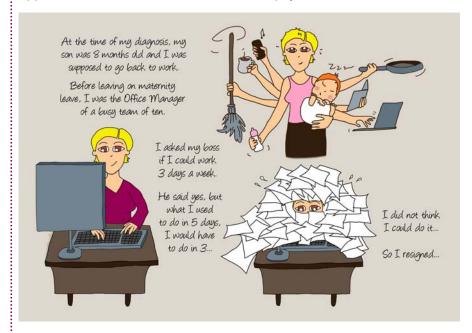
When you've been through breast cancer, the risk of financial ruin doesn't seem as bad as it did before! You have nothing to lose.

-GABBY

e live in a wonderful time when young women are encouraged to 'lean in' and have it all! Building a successful and satisfying career is a huge part of this.

For many young women, their burgeoning career is an integral part of their identity. A stable career signifies financial security, and independence from parents and partners.

A diagnosis of breast cancer is often difficult for a young woman to communicate in the workplace. It can have a detrimental effect on a young woman's career progression and future earning potential. Extended periods of time off work during the early stages of a career can negatively impact on professional development, resulting in lost opportunities for career advancement and pay rises.



TELLING PEOPLE AT WORK

While some young women are more comfortable concealing their diagnosis, this is not a sustainable solution. It's best for a young woman to be open with their manager, direct reports and peers, and discuss what to expect. Treatment will require some time off work, depending on its nature (surgery can have a shorter-term impact, chemotherapy or radiotherapy a longer-term one); and the impacts of treatment may also require this.

RETURNING TO WORK AFTER TREATMENT

While returning to work after breast cancer can be a daunting experience for many young women, research shows that it is beneficial. Getting back into a normal routine is an important factor for maintaining and improving quality of life.

Most young women who were working at the time of their diagnosis will return to work following treatment. However, we know that unemployment is higher in people who have had breast cancer compared to the general population. The physical and emotional effects of breast cancer and its treatment can have an impact on young women's employment. They may not be able to return to the same job, or even to the same working conditions.

WHAT WE KNOW

SIDE EFFECTS OF TREATMENT (AN AFFECT A YOUNG WOMAN'S ABILITY TO WORK

- Young women affected by breast cancer report more problems with their memory and concentration levels than older women.
- Treatment-related cognitive impairment can mean that some women are unable to perform to the same professional level that they did before their breast cancer treatment.
- Returning to a mentally-challenging job after chemotherapy is linked to poorer physical and mental health.
- Women who have had chemotherapy are more likely to be unemployed four years after treatment compared with women who have not had chemotherapy.

GOING THROUGH BREAST (AN(ER (AN PROMPT A JOB OR (AREER (HANGE

- The physical and emotional effects of cancer and its treatment are the two most common reasons why women change jobs after breast cancer:
 - -48% of women change jobs because they are physically unable to return to the same role.
 - 33% of women change jobs because they do not feel emotionally strong enough to return to the same role.







THE IMPORTANCE OF A SUPPORTIVE WORK ENVIRONMENT

A supportive work environment can reduce anxiety and provide confidence for a young woman as she re-starts her career after breast cancer.

Unfortunately, research shows that not all young women with breast cancer feel supported by their managers and workplaces. A Swedish study has found that 21% of women with breast cancer felt discriminated against at work, and 18% felt a lack of support from their co-workers.

Young women should feel confident that when they return to work after breast cancer, they will find a workplace that is willing to help them adapt to the challenges they may face. Employer sensitivity and flexibility will help to get valuable young workers back into the workplace.

A supportive work environment may:

- allow a young woman to work flexible hours to support medical appointments
- encourage a phased return to work to ensure a young woman is not overwhelmed
- communicate openly with a young woman's co-workers to ensure they understand the need for any special considerations.

WHAT WAS HARD WAS HAVING TO MANAGE THE (HILDREN WHILST HAVING NO ENERGY AND FEELING SI(K AND THE FINAN(IAL IMPACT TO OUR FAMILY. IF THERE WAS SOME SORT OF FUNDING AVAILABLE TO HELP WITH (HILDCARE, HOUSE (LEANING, WASHING ETC IT WOULD HAVE HELPED A BIT.

KATE

THE FINANCIAL IMPACT OF BREAST CANCER IN YOUNG WOMEN

International research tells us that the majority of cancer survivors are financially worse off as a result of their diagnosis.

Young women affected by breast cancer will experience a reduction in income and an increase in expenses – including costs related to transport, medicines, childcare and housekeeping.

A 2007 report into the true cost of a cancer diagnosis, commissioned by Cancer Council NSW, demonstrated that a young woman diagnosed at the age of 35 can expect to be over \$40,000 worse off over her lifetime due to lost income and out-of-pocket expenses. The majority of the out-of-pocket expenses will occur in the first year of diagnosis and treatment.



YSC MISSION STATEMENT

Young Survival Coalition (YSC) is the premier organisation dedicated to the critical issues unique to young women and breast cancer, located in the US. YSC works with survivors, caregivers and the medical, research, advocacy and legislative communities to increase the quality and length of life for women diagnosed with breast cancer aged 40 and younger.

ABOUT YSC

YSC was founded in 1998 by three young women who were under the age of 35 when diagnosed with breast cancer. They were discouraged by the lack of resources available and the underrepresentation of young women in breast cancer research. Today, YSC is the go-to organisation for young women facing a breast cancer diagnosis. Among other services, YSC:

- provides information, resources and support from diagnosis through long-term survivorship
- educates and empowers young women to be their own best health advocates
- works with healthcare providers, researchers and legislators to educate them about the unique issues young women face
- advocates for more studies on breast cancer in young women and access to quality care.

SPECIFIC YSC RESOURCES

YSC produces an outstanding Navigator series of resources to help along four stages of the breast cancer experience (www.youngsurvival.org):

- for the newly diagnosed
- post-treatment
- for the long-term survivor
- for young women with metastatic disease.

YSC CEO, Jennifer Merschdorf advises, "When a young woman is diagnosed with breast cancer, they may encounter doctors that have little experience with a woman of their age. YSC's newly diagnosed Navigator aid helps young women to be prepared for their appointments, know the questions to ask, and how to translate the answers. When treatment finishes, young women often feel left out in the cold and don't know how to tackle 'What's next?'. Our post-treatment guide helps there. YSC also produces a Navigator for those women who are confronting metastatic disease and helps both the woman and her family manage the challenges that come with such a diagnosis."

YSC's survivor SYNC program connects young women facing breast cancer face-to-face, online and one-on-one.

YSC is also proud of the Research Agenda they have published. This was a two-year process of consultation and brainstorming with young women affected, doctors, and researchers to identify the research priorities to improve outcomes for young women. Top of the line items are metastasis and targeted treatments. Jennifer says, "There is also a great need to understand more about the side effects or collateral damage of treatments."



THE PHYSI(AL EFFE(TS OF BREAST (AN(ER AND ITS TREATMENT

IN THIS SECTION

- THE PHYSICAL SIDE EFFECTS OF TREATMENT
- SELF-IMAGE AND SEXUALITY AFTER BRFAST CANCER
- FERTILITY AND FUTURE CHILD BEARING AFTER BREAST CANCER

I was initially diagnosed on my 24th birthday, and then again a year ago at 27 with cancer in the other breast. I saw a lump that first time and knew what it was, but it took going to quite a few GPs to finally find one that would send me for an ultrasound. I was told I was too young.

At the time of my first diagnosis, I made up my mind I wanted to have a bilateral mastectomy, but no one would do it. I spent four years trying to convince them all, I even did counselling and therapy to prove I was in my right mind with this decision. Then I had to fight Medicare, the hospital and the system to help me cost-wise, as initially I was informed it was going to cost me \$15,000 per breast!

I haven't had a reconstruction. My breasts were trying to kill me, and I wanted them off. I don't need breasts to feel beautiful. My flat chest does not bother me; it tells me that I am here for my husband and our three kids. I've never been self-conscious about my looks, and I'm happy with the way I look now. My sexuality hasn't changed, if anything I have become a bit more sexual. But my chest is still really tender and sore, and this makes it a bit hard for my husband – he doesn't want to hurt me.

I'm on a long term medication regime with three drugs, for at least 10 years. They've made me put on a lot of pudge around the middle, but it's not an issue for me. I was always quite little, and I was down to 40 kg with my second diagnosis. What I've found hardest is the hot flushes from the early menopause. I'd get that hot I'd feel ill, and my husband said I was unbearable! So I'm on anti-depressants to help with the flushes and mood swings.

What drove me mental was feeling suffocated by my extended family. I'm Italian and my husband is Aboriginal, so on both sides we have big, caring families. At 24, my husband and I had just got established in Melbourne and started our family. We'd just gotten out into the world, and suddenly breast cancer thrust me back into the position of a child again. My mother flew over within 48 hours of my diagnosis and lived with us for six months, and was in my face telling me what to do all the time. We fought constantly every day. I'm really happy to be alone with my husband and kids, and I love my family but it's better from afar. Mind you, I don't know how we would have managed without their support.

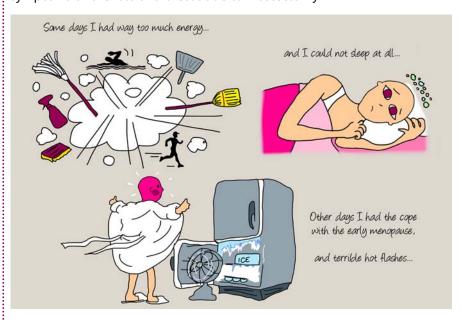
There are 75,000 people in the Latrobe Valley, and I am the only young person with breast cancer. It's affected my employment – I was a legal assistant but over the past four years, I've just been sick and we don't know if I'm going to get cancer again, my health is unpredictable. I can't have any more children now, but I did manage to squeeze two healthy pregnancies and births into 12 months right after my first diagnosis!

-CARA

reatments for breast cancer can result in physical changes to a young woman's body.

Some of these changes may be temporary side effects of treatment, such as nausea, vomiting or skin irritation. These will stop soon after treatment finishes.

Other changes will be more long-term, such as the onset of menopausal symptoms or the loss of a breast due to mastectomy.



PHYSICAL SIDE EFFECTS OF BREAST CANCER TREATMENT

Because all treatments for breast cancer work differently, they all have different side effects. Some of the common side effects of breast cancer treatments may include:

- nausea and vomiting
- pain in the area where surgery has occurred
- tiredness (fatigue)
- skin irritation in the area of radiotherapy
- menopausal symptoms, such as hot flushes, night sweats and heart palpitations
- weight gain
- swelling in the arm after the removal of lymph nodes (lymphoedema)
- problems with memory or concentration (cognitive impairment).

The physical side effects of breast cancer treatment can have a negative impact on a young woman's emotional wellbeing, leading to a decline in her quality of life. A young woman should always discuss the best ways to manage any side effects with her doctor.

SELF-IMAGE AND SEXUALITY

The physical changes to the body that occur as a result of breast cancer treatment and the psychological impact of these changes can have a significant effect on a young woman's self-image and sexuality.

WHAT WE KNOW

PHYSI(AL SIDE EFFECTS (AN AFFECT A WOMAN'S SEXUAL FUNCTIONING

- Treatment for breast cancer, such as chemotherapy and anti-hormone treatment, can result in vaginal dryness causing pain during sexual intercourse, low libido, and difficulty achieving orgasm.
- Women who undergo chemotherapy are at higher risk of sexual dysfunction after treatment than those who have not received chemotherapy.

PHYSICAL SIDE EFFECTS (AN ALSO AFFECT A WOMAN'S SEXUALITY

- Physical changes, such as hair loss and weight gain, can cause distress and negative feelings such as a loss of femininity and sexual unattractiveness.
- Some women who view themselves as infertile after treatment for breast cancer report to have lower levels of sexual and relationship satisfaction than women who believe they have normal fertility.
- Chemotherapy can also result in physical side effects such as nausea, vomiting, diarrhoea, hair loss and weight gain.

SINGLE WOMEN AND SEXUALITY

Not all young women diagnosed with breast cancer are in a personal relationship. Facing sexuality again after treatment for breast cancer can be particularly daunting for a single woman.

Young, single women face the challenge of recounting their breast cancer story to new partners. It can be difficult for these young women to feel comfortable in more intimate situations.

Some single women may feel that no one will ever be attracted to them after their breast cancer treatment. It is important to remember that this is a very common anxiety. A GP may consider referring a young woman for sexual counselling where appropriate.

Communicating openly about her breast cancer experience can help a single woman to feel comfortable and safe when entering a new intimate relationship.

I (OMMEN(ED A RELATIONSHIP 6 MONTHS AGO (WITH A MAN I HAVE KNOWN FOR 20 YEARS). IT IS THE FIRST RELATIONSHIP I HAVE HAD SIN(E MY DIAGNOSIS. IT WAS VERY DIFFI(ULT FOR ME TO LET HIM SEE MY MASTE(TOMY SITE AND TO BE PHYSICALLY INTIMATE WITH HIM DUE TO THE SCARS ETC... AND MY LACK OF (ONFIDEN(E/SENSE OF DESIRABILITY.

BROOKE

ITWAS DIFFICULT MAKING
DECISIONS AROUND FERTILITY
- WHETHER I SHOULD PUTEGGS
ON ICE WITHOUT THE PRESENCE OF
A PARTNER AND AT DETRIMENT
OF INCREASING THE SIZE OF MY
TUMOUR THROUGH OESTROGEN AND
AN EGG (OLLECTION.

MIMI

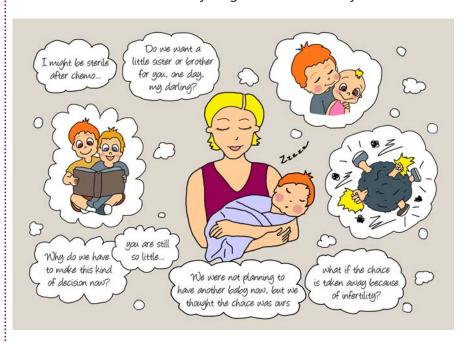
FERTILITY AND FUTURE CHILDBEARING

The impact of treatment on fertility can be one of the most challenging issues facing young women with breast cancer.

Treatment for breast cancer can affect a young woman's fertility either through:

- direct impact of chemotherapy on the way the ovaries work, leading to disrupted periods, which can progress to early menopause.
- delayed or decreased ability to get pregnant due to onset of early menopause caused by anti-hormone therapy following breast cancer treatment.

Research shows that concerns about fertility will influence the treatment decisions of about one-third of young women affected by breast cancer.



WHAT WE KNOW

TREATMENT WILL AFFECT A YOUNG WOMAN'S OVARIAN FUNCTION

- 10–20% of women under the age of 35 years, who undergo chemotherapy as part of their treatment, will lose their period. This percentage increases for women treated in their late thirties, with almost 90% of women over the age of 40 entering early menopause.
- Young women who continue or resume having their period after chemotherapy, will still have reduced ovarian function, and may experience menopause at a younger age than normal.
- Anti-hormone therapies, such as tamoxifen, may cause symptoms of menopause while a woman is taking them typically for five years.

PRESERVING FERTILITY

Some studies have shown that nearly three-quarters of young women concerned about fertility at diagnosis do not make use of strategies to preserve fertility.

This may be due to:

- concerns over the effectiveness of fertility preservation strategies available
- a lack of awareness about fertility preservation
- a lack of access to fertility preservation centres
- the perception that pregnancy after breast cancer can increase risk of the cancer coming back.

When considering fertility in the face of breast cancer treatment, young women are likely to be influenced by their doctors. It is important that doctors discuss fertility preservation options available to young women very early after diagnosis, so that young women feel well-equipped to make decisions about their treatment before it begins. Options include storing embryos, storing eggs, ovarian tissue freezing and hormone suppressing drugs.

FERTILITY PRESERVATION

Read more about fertility preservation strategies at www.800youngwomen.org.au.









THE SO(IAL AND EMOTIONAL IMPACTS OF BREAST (AN(ER IN YOUNG WOMEN

N THIS SECTION

- FEELING ISOLATED
- FEAR OF RECURRENCE
- IMPACT ON RELATIONSHIPS

I had just lost a baby for no apparent reason at five months. She had faded away through malnutrition, there was no heartbeat and I had to endure induced labour to say goodbye to her. I was then put into the care of a clinical physician, who conducted a thorough examination and found that my breasts were generally very lumpy. I don't think he was that surprised when I eventually found and queried a particular little lump in my right breast. This was treated with surgery, chemo and radiation – to be followed one year later with the same in my left breast.

Becoming a mother was a major issue for me. My husband is Catholic and as all our friends overtook us with multiple babies, I was so sure I could get back in the saddle and prove I was still fertile. We were fast-tracked through the IVF program between surgery and chemo until my clinical physician put the kybosh on the introduction of artificial oestrogen, given that my tumour was oestrogen-receptive. I just kept projecting myself forward in time to imagining myself having another baby, and eventually I was lucky enough to have our beautiful daughter Flora, who is now two – even though I lost another baby along the way.

I was the first person I knew who'd had breast cancer young and it felt pretty lonely. I knew of it, but it was really on the periphery as an older person's disease. Today, the image of breast cancer is still a 68-year-old woman with a curly perm.

I'd emigrated from the UK to Perth and left behind a career in TV production and friends I'd had for 20 years. Luckily, I had the most amazing in-laws and through breast cancer and motherhood, I quickly made friends equal to those I'd had in the UK. We didn't look closely enough at how my husband was coping, and he wasn't. He suffered from depression and our relationship still hasn't fully recovered – but we are moving forward and at least I am here to guide my daughter through her young life.

It certainly was expensive. We had private health insurance and just about everything was covered other than the gap. It still cost the equivalent of an overseas holiday but I really felt the doctors were doing their best and communicating well together.

During breast cancer, I 'downsized' several sizes and I was happy about it. I got streamlined down to a neat B cup and suddenly could easily go running and to the gym. The thing I struggle with is not my shape or my scars, but the side effects of overnight menopause. I haven't had depression but I do have sleep problems and low level anxiousness.

There is no time to be wasted. If you have any worries at all or family history, get checked immediately.

- ADRIANA

I WAS DIAGNOSED AT AGE
29, THE WEEK BEFORE MY
30TH BIRTHDAY, WITH A STAGE
2 PAPILLARY (AR(INOMA: MY
MOTHER WAS DIAGNOSED A FEW
WEEKS LATER WITH D(IS IN BOTH
BREASTS: I HAD A LUMPE(TOMY,
RADIOTHERAPY AND TAMOXIFEN,
SHE HAD A DOUBLE MASTE(TOMY.

JAMILLA

IT IS DEVASTATING NOT KNOWING IF I WILL EVER BE ABLE TO HAVE (HILDREN, AND WHAT THE RISKS WILL BE ASSOCIATED WITH THE GUILT OF THIS EVERY DAY AS I FEEL SOMETIMES I HAVE ROBBED MY HUSBAND OF THE (HANCE OF HAVING A FAMILY.

GAIL

t's important to remember that the emotional and psychological effects of breast cancer can be significant – for a young woman, her family and friends.

Young women with breast cancer have a high risk of emotional distress, and other psychological issues that require specialised management, including anxiety and depression. In addition, young women are known to experience a lower quality of life after breast cancer compared with older women. This may well be because they are dealing with so many other major life events at the same time as their breast cancer, and this can include having to cope with their own mother going through breast cancer at the same time.

Some research suggests that the poorer emotional wellbeing of young women with breast cancer may be due to:

- the aggressiveness of the breast cancer
- the fear of recurrence
- the physical impact of treatment
- feeling socially isolated
- being single or in the earlier stages of a relationship.

FEELING ISOLATED

Young women often report feeling socially isolated or alone during and after their breast cancer treatment – even if they are surrounded by a sea of supportive family and friends. Anecdotal evidence suggests this sense of isolation may occur because nearly all breast cancer support services are directed at much older women.

WHAT WE KNOW

A YOUNG WOMAN'S PERCEPTION OF SOCIAL SUPPORT IS LINKED WITH HER QUALITY OF LIFE

- The need to maintain a social network is important to young women affected by breast cancer.
- Young women may feel they do not have the experience or support to navigate the health system during their treatment.
- Once treatment is finished, the lack of follow-up support is keenly felt by young women who can find their re-entry into 'normal life' hard. This is a particularly tough time for young women.

FEAR OF RECURRENCE

Fear of recurrence is the fear that breast cancer could return in the breast, or in another part of the body. Obviously, this affects any woman diagnosed with breast cancer. However, young women must live much longer with this fear.

WHAT WE KNOW

YOUNG WOMEN ARE PARTICULARLY VULNERABLE TO FEAR OF RECURRENCE

- Fear of recurrence is acknowledged to be a distinct psychological problem. It does not appear to be linked with levels of social support, having children, or desire to have children in the future.
- Between 21–40% of people who have been through cancer will need help to manage their fear of recurrence.
- Women found to have general anxiety may have higher levels of fear of recurrence.

WHEN RECURRENCE HAPPENS

Breast cancer can return in the same breast or the other breast, or can return in other parts of the body, such as the bone, brain, liver and lungs. A recurrence of breast cancer may be found during a routine follow-up visit, or a young woman may notice a new symptom and visit her doctor.

Treatment for metastatic (also known as advanced or secondary) breast cancer aims to control the spread of the cancer and relieve the symptoms of the disease. These treatments can keep a woman alive for many years but cannot save her – yet.

Young women living with metastatic breast cancer are still a relatively new phenomenon. The physical, financial and perhaps above all psychological burdens of dealing with this situation are overwhelming and very poorly understood.

Neither the science, nor the support services, and not even our society, have yet really caught up with their needs and this is an important area for further research.

IMPACT ON RELATIONSHIPS

Receiving a diagnosis of breast cancer at a young age is not only a shock for the woman, but for any existing partner as well. Research shows that young women experience concerns or guilt over the strain of their diagnosis on these relationships.

Support from family can increase stress, as young women (particularly in their 20s) may have recently attained independence and a diagnosis of breast cancer can catapult relationships with their parents back in time. It can be hard for a 'sick' young woman to relate to all her healthy friends, and vice versa. If the young woman is also a young mother, the most challenging aspect of her disease will often be fear that her children will have to grow up without her.

THE HARDEST THING FOR ME WAS THE EFFECT IT HAD ON MY HUSBAND. HE WAS SO STRONG THROUGH THE WHOLE PROCESS, BUT YEARS LATER HE ENDED UP HAVING A NERVOUS BREAKDOWN FROM THE TRAUMA. IT'S HARD TO WATCH THE PERSON YOU LOVE MOST SUFFER. THE DIAGNOSIS WAS AT A TIME IN OUR LIFE WHEN WE SHOULD HAVE BEEN HAVING FUN AND ENJOYING OUR NEWLY MARRIED LIFE. ALL OUR FRIENDS WERE STARTING FAMILIES AND HAVING A GOOD TIME, AND WE WERE FIGHTING FOR MY LIFE.

WHAT WE KNOW

BREAST (AN(ER WILL IMPA(T ON A YOUNG WOMAN'S RELATIONSHIP WITH HER PARTNER

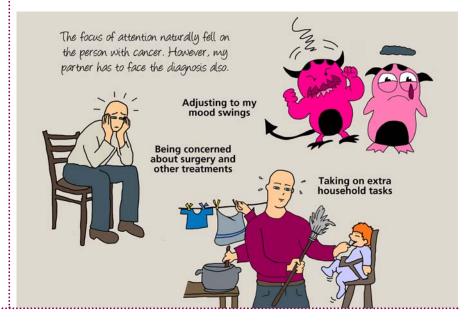
- Young women in a relationship at the time of their diagnosis are likely to feel guilty about the impact of the illness on their partner.
- The quality of a young woman's relationship prior to her breast cancer diagnosis is a good indicator of her sexual function and desire following treatment.
- Single women experience concerns about dating, future relationships and fear about talking to future partners about their illness.
- Women in lesbian relationships have reported feeling more supported by their partners, compared with heterosexual counterparts.

A YOUNG WOMAN'S RELATIONSHIP WITH HER PARENTS MAY INFLUENCE HER TREATMENT DECISION MAKING

- Anecdotal evidence suggests that young, single women living at home may not feel completely in control of their decision making.
- Becoming 'cared for' by parents again, due to breast cancer, can have negative psychological impacts.

MANAGING THE IMPACT OF BREAST (AN(ER ON YOUNG (HILDREN IN A MAJOR (ON(ERN

- As a mother of young children, managing the impact of breast cancer on your children is an additional major challenge during the breast cancer journey.
- Some women find it difficult to discuss their breast cancer with their children.
- Many young mothers express concerns about not seeing their children grow up.
- Some young women also hold concerns over their children's genetic risk of breast cancer.



INTERNATIONAL PERSPECTIVE ASSOCIATE PROFESSOR ANN PARTRIDGE, DANA FARBER CANCER INSTITUTE, UNITED STATES

I've spent over 15 years as an oncologist treating young women and as a researcher focused on the issues surrounding their care.

In 2004 we started the 'Young and Strong study', a program to help young women through their treatment which evolved into a web-based, virtual program. We're currently completing a randomised study to evaluate its impact in both educational terms and in supportive care. In 2006 we set up a multi-centre prospective cohort study, charting the path of over 1100 young women from diagnosis through to 10 years later. We've published analyses of their quality of life, fertility concerns, decision-making around surgery and more. One of the emerging fields is looking at young age and outcomes in large data sets. Our early findings are that not all young women necessarily do worse across all sub-types of breast cancer – for instance, HER2-positive young women appear to do as well as HER2-positive older women.

Young women face not only the threat of a cancer that potentially affects both their short-term and long-term survival and quality of life, but also unique concerns. The good news is that we are working hard to understand their needs and concerns and the biology of their disease. The inaugural BCY1 Conference was held in Dublin in 2012 and this released consensus guidelines about the treatment of young women.

While the incidence of breast cancer remains low in young women, when it happens it can be an absolute tragedy. The answer is likely going to lie in figuring out smarter ways to treat them. A big change in the US has been the acceptance that not all young women need chemo. We are getting better already at risk stratifying older and younger women regarding who is at greatest risk of recurrence and what are the best treatments for the sub-type of breast cancer a woman has. When I'm treating young women with advanced disease, I also try to get them onto clinical trials in the hopes that the next great drug will be coming along through the research pipeline.

I'm not satisfied with the current state of the art in terms of young women, and I'm not going to stop there. However, it's important to acknowledge that a young woman with breast cancer is going to live longer now than she would have 20 years ago. Young women have benefited from the research – survival rates remain lower than for older women but they have improved (and most young women will have long-term survival). For instance, it was only around 1995 that we figured out that hormone therapies could work for young women. I know they hate being catapulted into early menopause, but we're working on that too. We're all working to make it less crappy.

We're moving the needle both in terms of survival and quality of life in survivorship for young women with breast cancer. I am optimistic.



I went through the Defence Force Academy and had been in the Navy, and that's where I met my husband. At that time I was working as a drug and alcohol program advisor. I think my Navy training helped me get through breast cancer. I was deployed to the Gulf following September 11. When I was diagnosed at 35, I remember thinking I went to the Gulf, I got through it, I came home... and I'm going to do the same again here. My training taught me how to think logically, move forward step by step, deal with stress

At the time of diagnosis, my children were three and four, my husband had just returned from overseas and I had just started my own engineering consultancy. I exercised every day, didn't know anyone else who had had cancer, rarely drank and didn't smoke. I found it really hard to convince doctors that I should be tested for cancer, I had to be very persistent.

and debrief from crisis (with breast cancer, I used my journal!).

It was surreal trying to juggle the children and everything else during treatment. I kept working throughout – that really helped me. Sometimes I felt like I was really drugged. I didn't like telling people because they didn't believe me or instantly treated me differently. Most people didn't understand that I couldn't infect them. My mum and dad used to be at our house a lot, I didn't do any housework. I told my son (who at three was typically fascinated with his private parts) that I had found a ball in my breast and it made me sick. A four year old girl is quite knowledgeable, I told her and let her touch and feel the breast but I had to be careful because she would pick up on my emotions. She used to walk around with my wig on.

My husband is also very logical and we asked a lot of questions. Some things were not helpful, for example a breast care nurse gave my husband a CD to help him but she gave him the wrong one. This one was for palliative care and it really rocked him. After that, we tended to fear and avoid formal support. I really didn't want to join the groups. On the other hand, now I would love to help someone like me.

- CAROLINE

RESOUR(ES AND SUPPORT

GENERAL INFORMATION

Younger women with breast cancer, Cancer Australia

This section of the Cancer Australia website provides information for younger women about the effects of breast cancer treatment on fertility, contraception during and after breast cancer treatment, and pregnancy and breast cancer. There are also resources on breast cancer and early menopause and information on living with breast cancer.

www.canceraustralia.gov.au/affected-cancer/cancer-types/breast-cancer/about-breast-cancer/younger-women-breast-cancer

Curve Lurve, McGrath Foundation

A breast awareness initiative designed to share important information about breast awareness and help empower young Australians to take care of their bodies and embrace their curves.

www.curvelurve.com.au

Pink Hope

Pink Hope empowers women and their families to take control of their hereditary breast and ovarian health through education, prevention and support. Know your risk, change your future.

www.pinkhope.org.au

Unique Issues for Young Women with Breast Cancer, Susan G. Komen Cancer Centre (US)

Fact sheet and resources for young women with breast cancer.

www.komen.org/BreastCancer/YoungWomenandBreastCancer.html

Know: BRCA, Centre for Disease Control (US)

An online assessment tool for young women to assess their risk of having a BRCA mutation.

www.knowbrca.org

FERTILITY

Fertility-related choices: a decision aid for younger women with early breast cancer, Breast Cancer Network Australia

This booklet provides information about the possible effect of cancer treatment on fertility, and fertility options for young women who have recently been diagnosed with early breast cancer.

www.bcna.org.au/about-breast-cancer/young-women

Can I still have children?, Royal Women's Hospital Melbourne

The most recent edition of this booklet published in September 2013 discusses fertility options for young women having chemotherapy and radiotherapy.

www.mivf.com.au/sites/mivf.com.au/files/attachments/d13-096_canhavechild2013text_18_final.pdf

Fertility and Cancer – a guide for people with cancer, their family and friends, Cancer Council NSW

This booklet answers many common questions about fertility and suggests ways to discuss fertility with your medical team. There is general information about fertility preservation and fertility after treatment.

www.uws.edu.au/centreforhealthresearch/research/cancer_and_fertility/cancer_and_fertility_self-help_guide

BODY IMAGE

The SCAR Project

The SCAR Project is a series of large-scale portraits of young breast cancer survivors shot by fashion photographer David Jay. Primarily an awareness raising campaign, The SCAR Project puts a raw, unflinching face on early onset breast cancer while paying tribute to the courage and spirit of so many brave young women.

www.thescarproject.org

EMPLOYMENT, FINAN(ES AND LAW

Cancer, Work & You, Cancer Council NSW

Resources designed for anyone living with and/or surviving cancer, employers, colleagues, carers and professionals.

www. cancer council. com. au/get-support/information-support-for-employers-work places

Job Seeking Workbook, Cancer Council NSW

A booklet that provides practical guidance for people affected by cancer, including their carers, family and friends to return to work.

www.cancercouncil.com.au/wp-content/uploads/2014/04/Job-Seeking-Workbook-Final-2014.pdf

Making the law work better for people affected by cancer, McCabe Centre for Law And Cancer (AUS)

This report released in 2014 by Cancer Council Victoria and the McCabe Centre for law and cancer provides an overview of the major legal and policy issues around access to treatment, employment, insurance discrimination and end of life decision-making for people affected by cancer.

www.mccabecentre.org/downloads/focus_areas/treatment_support/Making_the_law_work_better.pdf

Work and cancer, MacMillian Cancer Support (UK)

Support and information about work and cancer designed for employees, carers, businesses and health professionals.

www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Workandcancer/Workandcancer.aspx

METASTATI(BREAST (AN(ER

Hope and Hurdles, Breast Cancer Network Australia

Hope and Hurdles is a resource for women of all ages with secondary breast cancer. It was developed in consultation with women living with secondary breast cancer and the health care professionals who treat and care for them.

www.bcna.org.au/hope-hurdles-pack

Understanding metastatic breast cancer, Young Survival Coalition (US)

Online resources and support providing information about metastatic breast cancer that is specific for young women.

www.young survival.org/breast-cancer-in-young-women/learn/metastatic-disease

Advanced breast cancer, Musa Mayer (US)

Online information and support specific to young women with metastatic breast cancer, their family and friends.

www.advancedbc.org

SUPPORT GROUPS AUSTRALIA

'Young Women' online support, Breast Cancer Network Australia

This group has been set up to provide a space for young women diagnosed with breast cancer to connect, share and support each other.

www.bcna.org.au/group/5157

SUPPORT GROUPS INTERNATIONAL

Young Survival Coalition (US)

The Young Survival Coalition (YSC) is an international, non-profit network dedicated to the concerns and issues unique to young women and breast cancer. Through action, advocacy and awareness, the YSC seeks to educate the medical, research, breast cancer and legislative communities and to persuade them to address breast cancer in women 40 and under. The YSC also serves as a point of contact for young women living with breast cancer and offers a range of educational resources and links to personal stories.

www.youngsurvival.org

Rethink Breast Cancer (Canada)

Based in Canada, the mission of Rethink Breast Cancer is to continuously pioneer cutting-edge breast cancer education, support and research that speaks fearlessly to the unique needs of young women.

Rethink is dedicated to putting 'sass and style into the cause'. As their name suggests, they seek to frame the issues and activities around young women and breast cancer differently. Rethink's commitment is to enabling young women to become part of a movement and connect.

www.rethinkbreastcancer.com

Dana Farber Cancer Institute (US):

The Program for Young Women with Breast Cancer

This program focuses on the unique needs of young women (in their early 40s and younger) who have been diagnosed with breast cancer. The Program brings together clinical researchers and scientists dedicated to improving understanding of breast cancer in young women, including the biology of the disease, response to therapy, and psychosocial and survivorship concerns. The Program also produces the Young & Strong newsletter for and about young women with breast cancer.

www.dana-faber.org

800 YOUNG WOMEN



FIND OUT MORE ABOUT THE KEY ISSUES FOR YOUNG WOMEN DIAGNOSED WITH BREAST CANCER IN THEIR 20S AND 30S

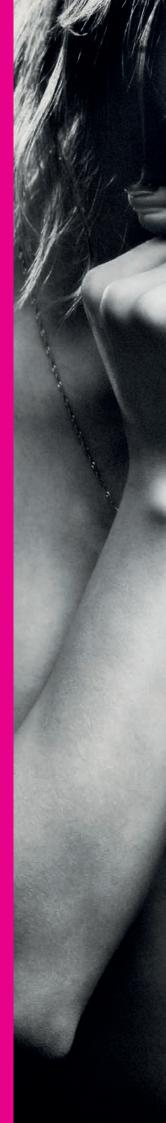
SHARE YOUR STORY TO SPREAD THE WORD!

NBCF believes in the power of personal stories. By sharing the story of your experience with breast cancer you can raise awareness about the disease among other young women.

We are collecting and sharing stories from young women, their family and friends, to highlight the diversity and generosity of the almost 800 young women who are diagnosed with breast cancer each year in Australia.

VISIT 800YOUNGWOMEN.ORG.AU TO UPLOAD YOUR STORY TODAY!





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