

Young Women Talking



...about living with breast cancer

'If other young women can take comfort in knowing there are women – like us – who have been through it (breast cancer), and are living well...it makes sharing our stories and experiences worthwhile'.

Joanne, Mary M, Mary N and Rita

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Young Women Talking



Women's Health Victoria



BreaCan is a statewide information and support service for people affected by a gynaecological or breast cancer. BreaCan offers a range of services and programs including a resource centre, fortnightly information sessions, and services specific to the needs of women with advanced cancer.

Call 1300 781 500 for information or support.

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The script for the DVD was developed by Joanne Smith, Mary Macheras-Magias, Mary Neofitou and Rita Marigliani in collaboration with Generations Productions.

Some of the material in this booklet has been drawn from *'What To Ask, When – Questions For Younger Women With Breast Cancer'*, a booklet which was produced by the Western Breast Services Alliance in 2004. We would like to acknowledge all the people who contributed to that project.

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Young Women Talking



Introduction

Young Women Talking explores the issues affecting young women with breast cancer, as told by a group of young women, in their own words.

Being diagnosed with breast cancer is confronting for any woman. Some things are the same for all women when they have breast cancer - worry, stress, change and lots of questions. However, young women face some unique problems due to their earlier life stage. For women diagnosed when they are pre-menopausal, some of the issues they have to confront include early menopause, contraception and concerns about fertility.

The experience of living with breast cancer is different for every woman – younger or older. Each woman's body is different and will respond to cancer and cancer treatment differently. Each woman has her own set of values and beliefs. Each woman has a different self-image, sexuality and relationship with her own body.

This DVD and booklet have been developed by BreaCan, a gynaecological and breast cancer support service, together with four young women – Joanne Smith, Mary Macheras-Magias, Mary Neofitou and Rita Marigliani. They reflect on their own experiences and provide insight into how they have learnt to live with breast cancer. From BreaCan's perspective it was essential these four remarkable women be involved in all stages of the process – from the initial concept through to developing 'the script', the issues covered and editing the final content. They have been willing to share their own stories to help other young women.

There are very few resources for young women with breast cancer. This DVD attempts to highlight some of the specific issues young women face. It is a Victorian based production but the themes covered are relevant to all young women and complement existing breast cancer information available throughout Australia.

The DVD does not involve health professionals as the young women decided they wanted you to hear their voices and not the voices of others. However, there is a brief guide in the back of this booklet for how health professionals may use the DVD as a resource with young women.

The four women profiled in the DVD have been living with breast cancer for up to seven years since being diagnosed; and they are all living well. One of the women was diagnosed only a year before participating in this project. There is no 'set time' for how a woman will adjust or make sense of her breast cancer experience. Women say that as a consequence of being diagnosed they have to come to terms with 'living with breast cancer' but what that means for each woman is different. The term 'living with breast cancer' is used throughout the booklet in recognition that the four women who share their stories describe it in this way.

Women who are newly diagnosed and undergoing treatment may gain different benefits from this DVD than a young woman who has been living with breast cancer for a year or more. Women who are recently diagnosed may find some of the content challenging so it may be best to watch it with another person or at least be aware of the issues that it covers.

The information in this booklet is supplementary to the DVD. It is not an exhaustive resource but touches on some of the perspectives and themes discussed by the women. The booklet contains information on treatment and its long term effects, body image, relationships, personal feelings and the future. It also contains insights from other young women living with breast cancer and lists some useful resources and contacts for more information.



Joanne

I was diagnosed with breast cancer in 2005, aged 32. Everything was in slow motion when the surgeon told me. I sat there with my husband in a state of shock. I would need surgery, chemotherapy and radiotherapy. I was numb. As we left his room he handed me the name of a fertility specialist. A fertility specialist? What? It was too much to take in. My mind had shut down to protect me.

I had been married for only 14 months and we planned to try and start a family. We had to make decisions, quickly. Fertility. It was strange to talk about fertility when I was facing my own mortality. My husband and I decided to freeze embryos before my chemotherapy, and to have IVF.

I had chemo and radiotherapy. Friends and family who were pregnant or had babies were always tired. My fatigue was from the side effects of treatment.

I began to feel teary around babies and pregnant women in the street. When my friends had christenings and children's birthdays, I was genuinely happy for them, yet I felt emptiness, isolation. How could they really understand? How could I express my mixed feelings? I needed to come to a place of acceptance.

After treatment, I went on holiday to the beach. At sunset, looking out at the ocean, I shredded the cards from my radiotherapy appointments, one by one, and threw them in the sea. I cried then.

Joanne

It is now a year since I was diagnosed. I have my down days and that's part of it. I go to BreaCan and to support groups. I speak to other young women with breast cancer.

For the last year, I have been climbing a mountain! It has been an adventure. I feel more alive. Some days the clouds hang over my mountain. Other days I can see and feel the sunshine.

one

1. Diagnosis & Treatment

- You have just been told you have cancer. Your world has just come to a sudden halt and may never return to life as you knew it.
- Along with being diagnosed comes fear, shock, denial and anxiety but everyone is different in how they feel and make sense of their emotions.
- Sometimes when a woman is first diagnosed, she can't take in all the detail or information – this is normal.
- Readiness to talk to others about being diagnosed and sharing it will vary with each woman.

'I found it good to sort of plan your diary around treatment, so I knew that the first week was going to be awful I would have something nice planned for that second or third week, so something out with my friends, or picnics or movies or whatever...

It was just good to have something to look forward to...

So you were making the most of the good days and allowing yourself to just curl up in front of a DVD when you couldn't'.

Rita

Things to Consider

Asking Questions

Asking questions is one of the many difficult things about having breast cancer – especially at the time of diagnosis and treatment. Some women feel they might seem ignorant or stupid when they ask a question or they fear they won't understand the answer. At some point, most women also feel scared they will receive an answer they don't want to hear.

Asking questions helps you gain information that addresses your own needs and worries and can help you feel more in control of the treatment process and of what happens in your body.

Here are some tips:

- Be honest with yourself about your worries and concerns.
- Write down questions or ideas as you think of them.
- Talk about your questions and concerns with people you feel close to and practise asking difficult questions or explaining your point of view.
- Ask a family member and/or a close friend to go to appointments with you (you can also ask them to ask questions on your behalf if you don't feel able to).
- If you would like to tape-record a consultation, ask the person at the start of the consultation. Alternatively, take a notepad.
- Think beforehand about how you would like to handle the answers to your questions.
- Tell your doctor what you have understood and ask if you've got it right, and if there are answers you don't understand, ask for them to be explained again.
- If you don't feel comfortable with the doctor on your first visit, consider giving it a second try. If you still don't feel comfortable after a second visit, you might want to try someone else. If you want a second opinion, ask for a referral (it's okay to get more than one opinion).

- Everyone has the right to professional and non-judgemental care. If you have a complaint about your care, it's usually best to begin by talking with the person concerned. If you don't feel you can do this, or if the situation cannot be resolved, you could discuss it with your GP or (if a hospital is involved) the Patient Representative.

About Fertility and Contraception

Many women have children after breast cancer. However breast cancer may affect your ability to have children.

- Ask your doctor to what extent the treatment options may affect your fertility and capacity to have children in the future. There may be different fertility related side effects for each of the treatment options.
- There may be ways to protect your fertility so ask what your options are and who you can talk to about them (e.g. a reproductive specialist/fertility specialist).
- Check with your doctor about what you should do about contraception while having treatment, such as what is safe and effective, and if there are likely to be any side effects. Check again about contraception after your treatment.
- If you and your partner planned to have children in the future it's important to talk through the various implications of treatment.

Other things to consider

- Treatment can take up a lot of time and energy. Remember to be flexible; you may have to change your plans if your energy levels are low.
- Set some realistic goals that take into account your needs; some days will be good, and some days not so good.
- It may help to talk to someone who is living with breast cancer.
- Talk to your doctor or Breast Care Nurse about what the likely physical and emotional impacts of treatment are. Although everyone reacts differently, sometimes it can help to know what to expect.
- If you're feeling depressed or upset, or having difficulty with the way you look, seek help from your Breast Care Nurse, a support service or counsellor.
- During treatment plan something special to look forward to such as having lunch with a friend. You may find exercise, meditation and or massage helpful.
- Think about how you have dealt with a crisis or challenge in the past and reflect on how this may help you now.
- If you are feeling isolated, perhaps consider logging onto an online discussion site for young women with breast cancer such as the **Young Survival Coalition** (refer to section **7: Resources** for website details). For young women living in a rural area this may be particularly useful.

*'How does life go off the track with just
one word – cancer?'*

Mary N



Mary N

I was only 32 when I was diagnosed with breast cancer. I was married with four children, aged four, six, seven and nine. So I was flat out with kinder drop offs, school activities, raising a young family. But life was fun, carefree and innocent.

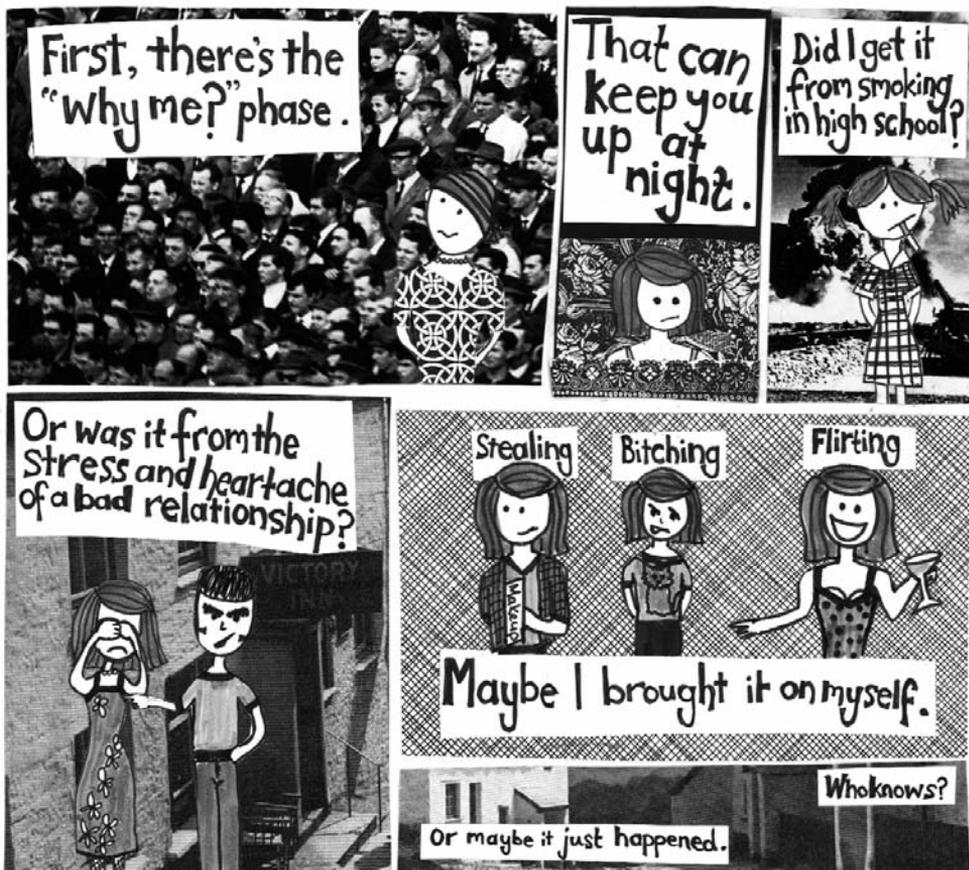
My diagnosis was a shock. When I went to my doctors with a lump, they kept saying, 'Don't worry, you're too young to have breast cancer.' I had a grade three tumour, an aggressive breast cancer. I had a lumpectomy, then chemo and radiotherapy. Two years later I had a prophylactic (preventative) bi-lateral mastectomy and a full hysterectomy. I didn't want a recurrence. My biggest fear was that my children would grow up without a mother. And that I would miss out on so much of their lives, and of mine.

I have been volunteering for the last three years at BreaCan, which is a gynaecological and breast cancer information and support service in Victoria.

Breast cancer made me stop and think about life. I am now four years on since diagnosis, and I enjoy my precious life as I always have.

Holly Shorland

Holly Shorland is a writer, a comic artist and in her words 'a maker of things crafty'. She is also a cancer survivor. Holly has contributed the comics throughout this booklet, which reflect her experience of breast cancer.



two

2. Body Image

Hair Loss

'I shaved my hair so that I could take control because it was all going to fall out. I cut it short a little bit first so I wouldn't be in shock when all the clumps began to fall out and then I shaved it. So that was gaining a bit of control over the situation'.

Mary N

Things to Consider

Having breast cancer and treatment can have a huge effect on how you feel about yourself. It can especially affect your emotions, body image, energy, strength and sexuality.

- Hair loss can be a side effect of chemotherapy that many women find very confronting.
- Consider having your hair cut short before your treatment starts. Some people find it helpful to cut their hair in stages so they have time to adjust to losing their hair. Long hair can be heavy and may pull on your scalp, which may feel sensitive at this time.
- Visit a wig shop prior to your treatment so that they can see what your hair looks like before you begin treatment, so its easier to get a similar style.
- You may wish to wear a turban, bandana or headband.
- If your hair loss is partial, talk to your hairdresser about different styles to disguise thinning hair.

Breast Forms (Prostheses) and Breasts

Oh sweetie, you're too young for this...

'I had a really cute fitter when I went to get fitted for a breast form (prosthesis); she was terrific and a bit older. She pulled out a few mastectomy bras and they weren't right.

She said to me 'oh sweetie, you're too young for this come on lets go and have a look at the other ones'. She was the first person to say to me you really don't need a mastectomy bra, you'll have your prosthesis and you can wear it in a normal bra.

So that kind of made me feel a lot better, that I had choices again, because that's one thing you sort of feel you lose when you're diagnosed, all those choices'.

Mary M

Things to Consider

Having all or part of your breast(s) removed due to breast cancer can be very confronting. It raises complex issues about loss, notions of femininity, your identity as a woman and about body image.

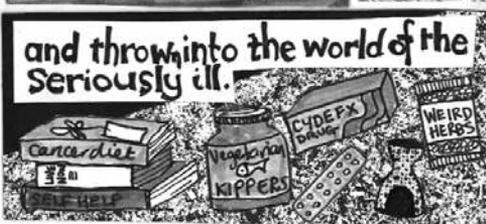
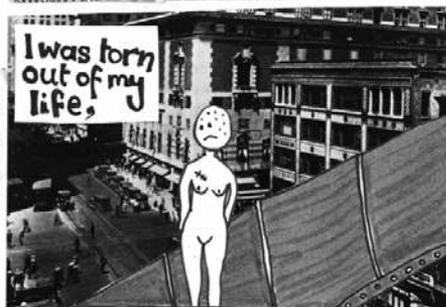
Some common questions you may want to ask are:

- What will my breasts look like after surgery?
- Will I have the same sensations in my operated breast once it has healed?
- Should I consider breast reconstruction and when could it be done?
- Are there different types of breast reconstruction?
- What are the pros and cons of breast reconstruction?
- Can I see a breast form (prosthesis)?

Whether or not a woman chooses to use a breast form (prosthesis), considers breast reconstruction or decides not to do anything at all is a very individual choice.

There are different opinions about when is the best time for a woman to have a breast reconstruction. The timing can depend on many things so it's important to talk to your breast surgeon about the various options available. You should also consider talking to a plastic surgeon.

- Be creative – some bathers can be adapted. Don't feel you have to wear something more suitable to an older woman. Sew in a pocket for your breast form, or find someone who can.
- Check with your Breast Care Nurse, social worker or hospital if you are eligible for financial assistance to help purchase a breast form.



Holly Shortland ©

three

3. Long term Effects of Treatment

Menopause

'The fear for me was not just the hot flushes and things that might be a bit uncomfortable, but again its old people symptoms, I didn't want to turn into an old woman'.

Mary N

Many women talk about the difficulty they experience soon after treatment is over of feeling very isolated. The time it takes to adjust to living with breast cancer is different for everyone. For young women this can be compounded by the onset of early menopause. For some women menopause is permanent, but some women find it is temporary and their fertility returns.

The signs of menopause vary for each woman. Some women have no signs other than their periods stopping. Other common signs are hot flushes, mood swings, a dry vagina, greatly reduced interest in sex, and sleeplessness.

Things to Consider

- You may want to ask your doctor how long the signs of menopause last and what can be done to relieve them?
- If you have signs of menopause you may need advice about how to know whether they are permanent and if they are how to manage them.
- If you've experienced menopause, you may like to find out more about health problems you may be at risk of and what you should do to stay healthy.
- If you want to become pregnant, ask your doctor how long you should wait before trying and discuss any concerns you may have about the impact of pregnancy on your health.
- There is no simple answer to whether or not you can become pregnant after breast cancer treatment, other than actually trying and seeing what happens.
- Discuss with your doctor whether there is a need for you to use contraception after treatment and if/when your periods may return.
- Fatigue can be a problem for many women as a result of treatment. You may need to accept that you are not able to do what you did prior to treatment – energy wise, pace yourself, be gentle on yourself. Your mind and body have been through a lot and need to heal.
- You may feel a real sense of loss and sadness about not being able to have children. If so, you may want to talk to a counsellor or someone you trust about it.





Rita

I was 33. I had just moved in with my partner and I found out that I had breast cancer. I couldn't believe it – I was too young for breast cancer, and certainly not ready to die.

Telling my partner, family and friends, was hard – trying to show strength and optimism you don't feel.

I still wasn't sure if I wanted children. Even if I wasn't going to, I wasn't ready for menopausal symptoms from chemo, making me old, before my time. And I was still establishing a relationship with my partner. I felt as if I was forced to make decisions I wasn't ready for.

I had chemo and radiotherapy. I worked right through my treatment, wanting my life to continue as normal and not wanting to affect my career.

I discovered a support group for young women with breast cancer. It was great to be able to share my story and fears. They could understand, in a way my family and friends couldn't, despite their love and concern.

Breast cancer has certainly changed my life. I'm afraid of a recurrence, but I focus on the future and try to live and love life. I feel stronger and more self-assured than I ever have. I'm single now too. Sometimes I wonder, how would I introduce these issues into a new relationship?



f

four

4. Impact on Relationships & Feelings

'My husband was watching me go through it and he was my rock and he tried to do everything to make it okay but he couldn't fix everything...

It was easier for me to cope than it was for my husband and my children because you have to find a way to cope...

Four years down the track it's taken my husband a long time to be able to get over the anxiety of 'is it going to come back?' He just thought, you know, we'll deal with this and as time goes on it will get easier. But it didn't, it made him really, really anxious if I had an ache or a pain...

And so now he's gone to get some help in working through some strategies to help him deal with the anxiety he has about 'am I going to be around, are we going to grow old together?'

Mary N

Things to Consider

Managing the affects of breast cancer and adjusting to living with the disease can be a difficult time. Everyone is different and will respond to the impact of breast cancer differently. No-one can tell you what you should be feeling, thinking or doing. You should do and say what feels right for you.

- The physical and emotional stresses of breast cancer don't only affect you. Your experience also affects partners, children, friends and family. These people have their own feelings of grief and worry. Your relationships with them might change as a result.

If you are seeking support or information about these issues, keep in mind that everyone is different.

- Talking honestly with your partner/parents and friends is important. Don't just assume they know how you're feeling or what they might be able to do to support you.
- Deciding what to tell children can be difficult. It is important to provide them with information that is 'age appropriate'.
- You may find it helpful to involve your children in some way – to demystify your cancer experience for them. For example, you may want to take them along to your chemotherapy treatments or meet someone who is living well with cancer – depending on what is comfortable for you and them.
- Treatment might impact on your sexual feelings and your sexual relationships so talking to your partner about it is important, as is trying to create special time for the two of you to spend together.
- Telling your employer:
 - Women may make quite different decisions about what they tell their employer and work colleagues about their diagnosis and treatment.
 - It's important to feel comfortable. You may choose to tell some people more about your situation than others. Often people are unsure of what to say in response so be aware of this.

'When going for a job after treatment I wasn't sure how I would explain my absence from the workforce for almost a year. I thought if it came up I would be honest, and it did so I shared my experience and luckily the employer saw it as a positive and that I was a resilient individual. It was the first job I went for and was successful. I thought that if they discriminated against me I didn't want to work for them anyway'.

Joanne



Mary M

My breast cancer story begins in 1998 just before Christmas.

I had found a peculiar swelling under my left armpit. I knew that I needed to have it checked out. Three years before, I was diagnosed with thyroid cancer and I was very aware of any changes to my body.

My GP examined me and concluded that I had an ingrown hair! I got a second opinion.

By the time I had a mammogram and ultrasound, there was a small lump just above my nipple. Without the ultrasound it would have been difficult to diagnose my 33 year-old breast.

As a young woman you don't expect to develop breast cancer. And I'd already paid my cancer dues. Besides, there were only a few weeks to do Christmas shopping!

My house was being renovated too. My husband, my son and I were living out of a suitcase at different relatives, spread around town. We needed extra room. I wanted more children, not more cancer.

The day I was diagnosed my husband, Paul, was with me. We wanted to grieve over this news together yet we had nowhere to go. Our house was gutted like our hearts. The two of us sat in our tiny car and comforted each other.

Mary M

In the New Year I went in for a lumpectomy and lymph nodes removed. The good news – the lymph nodes were clear. The bad news, I had three large tumours, not just one, and two were the aggressive type.

I had a mastectomy, then chemotherapy. Hairless and boobless.

One good thing was that our builders, who had been so slow, finally finished the job. The house was ready the weekend before chemo began. We were a family again.

A couple of years after diagnosis, I decided to have reconstructive surgery. Now I have a nice pair of very young perky breasts. I might be 38 but my breasts are only four years old.

I sit on a number of committees representing other women. My passion, however, lies in the needs of young women. In many ways our needs are unique. Breast cancer has a big impact on our lives.

I have been very active in breast cancer awareness and advocacy for young women. Recently I travelled to Sri Lanka with other breast cancer survivors and helped build houses. We were helping a poor community living in a shanty town next to the city tip.

five

5. The Future

'I'm only 33, I expect to live at least for another 30 or 40 years thanks very much'.

Rita

Women living with breast cancer often talk about how it has profoundly changed their lives. Being diagnosed often takes away some of the choices young women imagined they would have. For each young woman, coming to terms with the uncertainty of living with breast cancer – and ways of coping – will be different.

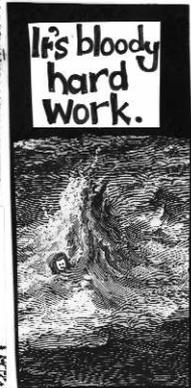
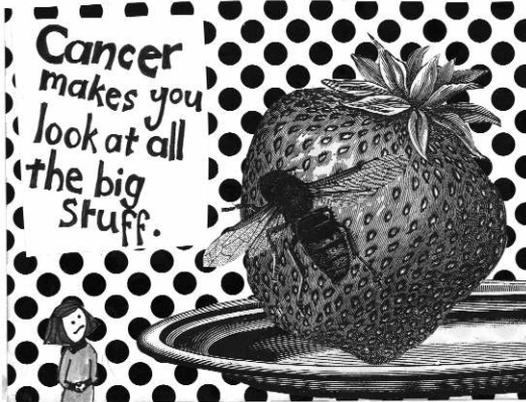
It takes time to find what some women say is the 'new normal' of their lives. Women may experience difficulties after treatment is completed. Their safety net has been removed as they no longer have a medical team caring for them. Loved ones expect life to go back to how it was before. Also, women talk about the difficulty of living with uncertainty and the fear of a recurrence.

Over time women talk about regaining a sense of hope and meaning in their lives. Women often say they come to realise much more acutely what really matters.

Things to Consider

- Once treatment is over it is very normal to feel lost, apprehensive and uncertain.
- After treatment you may feel like your support network no longer exists.
- Many women feel anxious and 'low' after treatment. It's okay to still need support. Perhaps consider seeing a counsellor.
- Many women reassess their priorities and start setting some goals, such as things they wanted to do but have put off in the past.

- It is important to acknowledge it will take time to re-focus, rebuild and create a 'new normal'.
- You will have ongoing appointments and follow ups. It is important to feel comfortable with your doctor – someone who understands your history and treats you with respect.
- It is not unusual to feel anxious on the anniversary of appointments.
- After treatment you can keep yourself well by doing things like exercise and eating a healthy, balanced diet.
- You may find it worthwhile to join a young women's support group but it's an individual thing – it's not for everyone.
- Some women may find value in supporting other women diagnosed with breast cancer. You may consider being a consumer advocate, providing peer support with a support service or volunteering in some other way.
- Perhaps consider doing a survivorship course at a hospital.
- You may be more aware of aches and pains in your body. Learning to deal with each concern as it arises and choosing an appropriate time to act on them is a balancing act. If you are still concerned after a period of time, make an appointment with your doctor and have your concern checked.
- Women often say that part of living with breast cancer is having a sharper sense of living in the present – but they also look forward to the future.



Single With a Difference

Silvana Cavalli

Silvana wrote this in 2004. These are ten lessons she learnt along the way. Two years on, many things have changed, but the lessons are as important now as they were then. Silvana is now 34.

LESSON ONE Sometimes a holiday is the start of something else.

My story starts in Italy on the Amalfi coast, in August 1999. I was 27 years old. I was sunbathing on the black sands of Positano when I discovered a lump in my breast.

LESSON TWO Listen to your instincts.

My instincts told me to get a biopsy, this came back abnormal and a few weeks later I was in day surgery having the lump removed – it was breast cancer. It was November I had just turned 28. My life plans had been put on hold, my outlook on the future changed forever.

LESSON THREE Anything can happen and probably will.

On the day of diagnosis I took my sister with me. When the Doctor gave me the news, my sister turned white and looked like she was going to faint. I found myself looking out for her instead of thinking about what the diagnosis meant for me. Later that day alone in a dark x-ray room, I cried.

LESSON FOUR Getting mad doesn't mean you get even, but it sure feels good.

After the diagnosis, I was angry, upset and grieving. I was living with my parents who wanted to put me in a bubble. It was frustrating, my independence was slipping away. I didn't want them to stress so I never showed them how exhausted, upset or scared I really was. My fear settled in at night.

During chemo I decided to get counselling, not because I wasn't coping but because I needed a neutral place to talk about my feelings, without the fear of scaring or hurting anyone. Life was on hold and I began to realize, I would never return to what used to be 'normal'.

Single With a Difference

Silvana Cavalli

LESSON FIVE Ask as many questions as you need to.

I wanted to make the most informed choices about my treatment so I read up on things, looked at statistics and asked doctors lots of questions. Before chemo I went to see a fertility specialist to learn about my options, I weighed up all the information and made a choice.

LESSON SIX Talk about it with anyone that wants to listen.

Being single I didn't have one particular person I could share my concerns or worries with. I talked to close friends, work mates and family members about my experience. The more I talked about it, the more it felt surreal, like I was talking about someone else. At the same time talking about it helped me process the experience. This was part of my healing.

LESSON SEVEN Sometimes you can surprise yourself.

During the months of investigation, diagnosis and treatment I really trusted myself. My survival instincts kicked in, I was facing my own mortality. People would say how brave or calm I was and I too surprised myself. I felt I was touching life more intensely and I was more in tune with myself and my abilities. I had more courage and less self doubt, I didn't show my fear to anyone.

LESSON EIGHT Clocks can tick double time.

The first time I heard my biological clock ticking was in January 1999. I was standing in a kids store and I immediately got teary. Now, so many clocks tick at once. Some of them have a direct link with my cancer experience and compound the issues that single women my age face. Some days the ticking is loud but other days I feel positive and courageous and have faith in the universe.

Single With a Difference

Silvana Cavalli

LESSON NINE *Fat or skinny I'm still a beautiful person.*

During chemo I put on about 15 kilos and I felt like my body aged, some days I didn't even recognize myself. I haven't managed to lose the weight and I feel some anger and resentment over this because I lost control over my body image. It took me about a year to get to know my body again, to understand its different rhythm and cycle. Having had cancer has not prevented me from falling in love, feeling beautiful and having intimate moments. I am always open about my cancer experience which is part of my life and now makes up part of who I am.

LESSON TEN *Explore your life slowly.*

I reassessed my life during the cancer experience and I am still adjusting. Now four years on I've achieved all the plans I thought were lost to me. I still get concerned about the unknown, I'm scared about a recurrence and I have unanswered questions about my possible fertility. I put a lot of pressure on myself to make everyday count. I find it difficult to make long term plans and I'm always looking for meaning in everything I do.

I've also learnt that going back to 'normal' is not possible because life has moved forward. There are no quick answers so I'm trying to stop rushing, explore my life slowly and try to be in the moment.

SIX

6. For Health Professionals

Messages from the Young Women

'When a woman with a young family is diagnosed remember it is not just her that is affected but her whole family. The timing of a cancer diagnosis is crucial. If a woman sees you on a Friday night and she has three days to wait for further tests/surgery, don't leave her in the dark and the unknown without support. Put her in contact with a Breast Care Nurse or someone she can talk to in those few days'.

Mary N

'No woman expects a breast cancer diagnosis, but when it comes at a young age she may not have had any experience or knowledge of the disease. Respect and listen to the unique needs, hopes, wishes and concerns of young women and provide them with the information they will need to make the decisions which are right for them. Listen to a woman's concerns, don't assume that young women don't want children and even if they don't, it does not mean they will be prepared to be told they can't'.

Rita

This section has been written as a brief guide for health professionals to explain how they might like to use this resource.

- The enclosed DVD is a unique resource. It is highly accessible and easy to use, and is in a portable format. It will help inform health professionals about the long term implications of being diagnosed with breast cancer at a young age.
- Please remember that the DVD focuses on the experiences of young women who have been diagnosed at least a year prior to participating in this project. Some young women who are newly diagnosed may find some of the discussion confronting so it is important to explain the issues covered in the DVD. It is suggested that health professionals watch the DVD for their own information, prior to providing it to a young woman
- The DVD and booklet can be used to complement a woman's treatment and care. For example, it could be used as part of a support group or by Breast Care Nurses as a basis for discussion.
- This resource is not an exhaustive guide on all the issues women need to consider but should be seen as the experiences of a small group of women, from their personal perspective.

seven

7. Resources

This section lists some resources which are available for young women living with breast cancer.

Books / Booklets

All listed books are available for loan from BreaCan.

A Guide for Partners of Women with Breast Cancer – How to Help
Cancer Council Queensland website: www.qldcancer.com.au

A Woman's Decision: Breast Care, Treatment and Reconstruction
Berger, Karen; Bostwick, John. St Louis, MO: Quality Medical Publishing, 1999

Clinical Practice Guidelines for the Management and Support of Younger Women with Breast Cancer (2004) (Australian)
National Breast and Ovarian Cancer Centre 2004. This book is written for clinicians.

Dr. Susan Love's Breast Book
Love, Susan M. 4th edition. US: Da Capo Press. 2005

Fighting for our Future: How Young Women Find Strength, Hope and Courage While Taking Control of Breast Cancer
Murphy, Beth. Sydney: McGraw-Hill. 2003

Breast Cancer Husband: How to Help Your Wife (and Yourself) During Diagnosis, Treatment and Beyond
Silver, Marc. USA: Holtzbrinck. 2004
This book was written by a husband who supported his wife through breast cancer. It contains practical information for partners.

Just Get Me Through This: The Practical Guide to Breast Cancer

Cohen, Deborah; Geldfand, Robert. Kensington Publishing Corporation. 2000

No Less a Women: Femininity, Sexuality and Breast Cancer

Kahane, Deborah Hobler. Alameda, CA: Hunter House. 1995

Sexuality and Fertility After Cancer

Schover, Leslie R. Brisbane: John Wiley and Sons. 1997

When a Parent Has Cancer: How to Talk to Your Kids – A Guide for Parents With Cancer, Their Families and Friends

Website: www.cancercouncil.com.au

When a Parent Has Cancer: A Guide to Caring For Your Children

Harpham, Wendy Schlessel. New York: Harper Collins. 1997

Victorian Resources

BreaCan – Gynaecological and Breast Cancer Support

BreaCan is a unique service providing free and confidential information, support and referral for people with a gynaecological or breast cancer, their families and friends.

Location: Queen Victoria Women's Centre, Ground Floor, 210 Lonsdale Street.

Opening times: 10am-2pm every Monday, Wednesday and Thursday

Telephone: 1300 781 500 (cost of a local call for callers in Victoria)

Website: www.breacan.org.au

Carers Victoria

Carers Victoria is a state-wide organisation that has carers as its primary focus, including partners and family members.

Website: www.carersvic.org.au

Familial Cancer Centres

Familial Cancer Centres can provide genetic counselling, medical advice and support for people who are concerned about their family history.

Website: www.cancervic.org.au/familycancer

So, I Have Breast Cancer, What Now? A Guide for Women and Their Families

This is a DVD produced by the Women's Health Program of Monash University.

Website: <http://womenshealth.med.monash.edu.au/dvd.html>

The Cancer Council Victoria (TCCV)

TCCV provides information and support through the Cancer Helpline, Multilingual Cancer Information Line, 'Living with Cancer' Program, Cancer Connect and other support programs.

Telephone: Cancer Helpline 13 11 20 (For all states of Australia)

Website: www.cancervic.org.au

The Young Ones

The Young Ones is a social support group for Victorian women under 45 who have experienced breast cancer.

Telephone: 0411 235 964

Website: www.theyoungones.asn.au

To find a support group in your state contact **The Cancer Council on 13 11 20.**

Upfront About Breast Forms (protheses)

Information for women who have had all or part of a breast removed because of breast cancer. It includes information on Victorian retailers and fitters of breast forms and bras and information on eligibility for government assistance to purchase breast forms.

Website: www.cancervic.org.au/breastforms

Young Action on Breast Cancer (YABC)

YABC is a committee focused on the needs of young women affected by breast cancer. It is open to women who have experienced breast cancer at a young age.

Email: ya-bc@hotmail.com

The Otis Foundation

The Otis Foundation provides retreat accommodation, free of charge, to those with breast cancer at a time in their journey when they need some time to rest and rejuvenate.

Telephone: 03 5439 3220

Website: www.otisfoundation.org.au

National Resources

Breast Cancer Network Australia

This organisation has a section on their website specifically for young women with breast cancer. BCNA produces *The Beacon*, a free national magazine for women with breast cancer, the *My Journey Kit*, a comprehensive information resource for women newly diagnosed with breast cancer and *Hopes & Hurdles*, an information pack for women affected by advanced breast cancer.

Telephone: (03) 9805 2500 / Free call: 1800 500 258

My Journey kit: 1300 785 562 Website: www.bcna.org.au

Empowering Young Women with Early Breast Cancer DVD

Partnership between the Northern Rivers Division of General Practice (NSW) and the National Breast and Ovarian Cancer Centre. Contact National Breast and Ovarian Cancer Centre.

National Breast and Ovarian Cancer Centre

The centre's website contains information on breast cancer, including a section called Breast Health, a consumer website.

Telephone: (02) 9357 9400/Free call: 1800 624 973

Website: www.nbocc.org.au or www.breasthealth.com.au

For Men: www.breasthealth.com.au/boysdocry

Look Good Feel Better workshops teach women beauty techniques to help restore appearance and self image during cancer treatment.

Contact the National Programme Centre on 1800 650 960.

YWCA Encore Encore is an 8 week exercise program for women after breast cancer surgery and/or treatment. participation is free, and is by enrolment only and medical approval is required..

Free Call: 1800 305 150 Website: www.ywcaencore.org.au

Some Websites

Australian

Breast Cancer Knowledge Online

Website: www.bckonline.monash.edu.au

New South Wales Breast Cancer Institute

Website: www.bci.org.au

My Parents Cancer – When Your Mum or Someone You Love Has Breast Cancer, a website for children.

Website: www.myparentscancer.com.au

Aussie Breast Cancer Forum Cancer, a forum for people affected by breast cancer.

Website: www.bcaus.org.au <<http://www.bcaus.org.au>>

International

The Alexander Foundation for Women's Health is a recognised expert in women's health and gynaecological psychiatry.

Website: www.afwh.org

Cancer Backup, Europe's leading cancer information charity.

Website: www.cancerbackup.org.uk

The American Cancer Society

Website: www.cancer.org

The Young Survival Coalition, an international, non-profit network dedicated to the concerns and issues unique to young women and breast cancer.

Website: www.youngsurvival.org

ORDER

To order your free copy of this resource contact
BreaCan, gynaecological and breast cancer information and support on
1300 781 500
or email breacan@breacan.org.au

Young Women Talking

DVD instructions

- 1. Put DVD into player**
- 2. Press PLAY**

The DVD running time is approximately 22 minutes.