



what to ask, when

questions for **younger
women** with breast cancer

feelings
body image
relationships
contraception
fertility
menopause

acknowledgements

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- ◆ The members of the Western Breast Services Alliance Breast Services Enhancement Program Young Women's Consumer Working Party
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The quotes included in this booklet were collected in the course of consultations for the younger women's breast cancer project. We selected these quotes because they might offer inspiration, comfort or information to other women. We recognise that they are only a small fraction of the hugely varied experiences of women who have breast cancer.

We appreciate the contributions of all the women who shared their stories and thoughts with us during the consultation period.

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An electronic version of this booklet is available to health professionals on intranet sites of The Royal Women's Hospital, The Melbourne Hospital and Western Health

resources

General Practitioner (GP)

Your local doctor can be a good source of information and advice

Jean Hailes Foundation

Provides services on women's health and menopause, including alternative/complementary therapies.
Tel 9562 6771
www.jeanhailes.org.au

Menopause Clinics

Mercy Hospital for Women
Tel 9270 2855

The Royal Women's Hospital

Tel 9344 2183

Monash Medical Centre

Tel 9594 2445

National Breast Cancer Centre

www.nbcc.org.au or

www.breasthealth.com.au/

Psychologists

Aust Psychological Society

Tel 1800 333 497

referral@psychsociety.com.au

The Royal Women's Hospital Information Line

Tel 9344 2007

Sexuality Counselling Clinic – The Royal Women's Hospital

Tel 9344 2717

Translation and Interpreting

If you need an interpreter, this service will connect you and an interpreter to the service you wish to speak with
Tel 131 450

Well Women's Website

Provides a range of information about women's health and services at The Royal Women's Hospital's
Tel 9344 2007
Freecall: 1800 442 007
www.rwh.org.au/wellwomens

WIRE

A free information, support and referral service available to all Victorian women
Tel 1300 134 130
www.wire.org.au

Women's Health Services

These services are located across Victoria. Most have libraries and information on breast cancer. Some also have Women's Health Nurses and other services. To find the service closest to you, contact: Women's Health Victoria
Tel 9662 3742
www.whv.org.au
or ring WIRE (see above)

resources

Breast Care Nurse

Can provide information and support and link you with other hospital resources such as social workers. Contact via your hospital's switchboard

BreaCan

Victorian breast cancer information and peer support service and referral
Tel 9664 9333
www.whv.org.au/breacan.htm

Breast Cancer Network Australia

Has a section on website specifically for young women with breast cancer
Tel 1800 500 258
www.bcna.org.au

The Cancer Council Victoria

Offers advice about treatments, management, support services and research. Services include a Look Good, Feel Better program, Cancer Connect and other support groups, helpline, financial assistance, Living With Cancer education program, multilingual cancer information line and educational resources
Tel 131 120
www.cancervic.org.au

Choices Clinic – The Royal Women's Hospital

Offers advice, consultation and treatment for all contraceptive and sexual health needs. Female doctors and nurse practitioners are available
Tel 9344 2183

Community Health Centres

Your local centre might have a Women's Health Nurse, counsellor or social worker. Refer to the White Pages for your local centre

Fertility Clinics/Reproductive Services

These have counsellors, a fertility specialist and a specialist gynaecologist. All women are welcome to see a counsellor to discuss the impact of cancer treatment on their reproductive health
Royal Women's Hospital
Tel 9344 2057 or 9344 2372
Sunshine Clinic
Tel 9356 9133
Epping Clinic
Tel 9408 2236
Ringwood Clinic
Tel 9871 4766
Dandenong Clinic
Tel 9706 9995

'I like the idea of having a checklist of questions to ask because you're taking in so much information and you tend to only remember stuff that you need to know at the time.' (Tina)



everyone has questions

The experience of living with breast cancer is different for every woman. 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.

Yet some things are the same for all women when they have breast cancer: worry, stress, change and lots of questions.

In 2003 we undertook a project to learn more about the experiences of women who were still in their fertile years when they learned they had breast cancer. These women developed cancer at a younger than average age. Their questions and issues were different to those of older women.

Having breast cancer and treatment was affecting many aspects of these women's lives, but in particular they were concerned about:

- ◆ The way it affected their relationships, sexual feelings and experiences
- ◆ The way they looked and felt about themselves
- ◆ Contraception during and after treatment
- ◆ Fertility (their ability to conceive, have a full term pregnancy, give birth and breastfeed)
- ◆ Early menopause

Most women had worries and questions about these issues. Often they wanted help and encouragement to ask questions and talk about their feelings. Above all, they wanted to know they could take their time to read, think and understand their choices.

relationships & sexuality

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. No-one can tell you what you should be feeling, thinking or doing. You should do and say what feels right for you.



BEFORE

Around the time of diagnosis, or before surgery or adjuvant therapy, women often ask:

1. How can I tell my partner /children/parents/others? What might help them cope?
2. I'm having relationship difficulties even before I start treatment. Who can my partner and I see about this?

3. How might treatment impact on my sexual feelings and sexual relationship(s)?



AFTER

At completion of treatment or in the longer term, common questions that women have are:

4. If my partner and I are having relationship difficulties, how can we get information/support?
5. What vaginal lubricants are best to use?

There are many internet resources that might help you and the significant people in your life to manage the effects of breast cancer. They include:

A general site:
www.breasthealth.com.au/

A site for men:
www.breasthealth.com.au/boysdocry/

A site for children:
www.myparentscancer.com.au



my questions & notes

'We are much closer together ... he's always had a weak stomach and during chemotherapy I had to have injections in my stomach and he gave them to me ... and before he couldn't even stay with me when I had my children - so a complete turnabout.' (Maria)

'I have a female partner and she was really good, really supportive.' (Susan)

'... After my treatment, my perspective had changed ... there was a lot of stress in the marriage before my breast cancer and so I just decided to walk away from it.' (Linda)

relationships & sexuality

about this booklet

This booklet was put together by the Western Breast Services Alliance, with younger women who have experienced breast cancer. It was written because younger women with breast cancer have specific information needs.

The booklet complements existing breast cancer information for women. We hope it will help you to:

1. Keep track of questions for your doctor or other people in your health care team
2. Get more specific information for yourself at various stages of your treatment
3. Explore treatment options with your health care team and then together choose the best treatment for you

The booklet is structured around five key issues that might be relevant to you around the time of diagnosis, before surgery or adjuvant therapy (either hormonal or

chemotherapy), or at the completion of treatment or in the longer term.

Each section has questions that women often find helpful to ask. Of course you will probably want to ask your own questions as well.

At the back are details of services and resources about breast cancer and related issues. We hope these will be useful sources of support and information.

Many women have found it helpful to speak to another young woman who has been through a similar experience. If you want to make contact with other women, you could call:

Cancer Connect
Tel 131 120

BreaCan
Tel 9664 9333

The Young Ones Breast Cancer Support Group
Tel 0411 235 964



asking questions

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

If you want to get information that addresses your own needs and worries, you will have to ask questions. What's more, asking questions can help you to feel more in control of the process and of what happens in your body.

Yet knowing this might not make asking questions any easier. You will need to find a way to get information that works for you.

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
- ◆ Practise asking difficult questions or putting your point of view
- ◆ Take this booklet with you and refer to it at your doctor's appointments
- ◆ 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)
- ◆ 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 all right
- ◆ Ring your doctor or make another appointment if you have more questions

feelings & body image

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.



BEFORE

Around the time of diagnosis, or before surgery or adjuvant therapy, women often ask:

1. What are the likely physical and emotional impacts of treatment?
2. What might help me to feel better about myself during treatment?
3. If I'm feeling depressed or upset, who might be able to help me?
4. I'm having difficulties with the way I look and how I feel even before I start treatment. Who can I talk with or where can I get information?
5. What will my breast look like after the surgery?

6. Is breast reconstruction a suitable option for me? When could it be done?
7. What are the pros and cons of having a breast reconstruction?
8. Can I see a prosthesis?
9. Can my partner and I touch my operated breast when it has healed?
10. Will I have the same sensations in my operated breast once it has healed?
11. When will I feel better?



AFTER

At completion of treatment or in the longer term, common questions that women have are:

12. What might help me to increase my energy or feel stronger or less depressed?
13. If I'm having difficulties with the way I look or how I feel, who can help? Where can I get information?

my questions & notes

'My middle son said to me, 'Mum, if you're worried about having no hair, I'll just take mine off'. So the three of them (sons) did ... it was wonderful. We had a big unveiling ... and in the end I thought, I can't stand the wig - it's so hot. I took it off and we were all dancing around the room. It was just the best day.' (Anna-Marie)

'... what I saw in the mirror (with no hair or with a blonde wig) was not me. Then as soon as I had on a wig that was my own style and everything, then I thought "'Right! I am going to get one of them'... It helped me to remember who I was.' (Jenny)

body image
& feelings

getting quality care

Often women find that their time with a health professional is limited. These tips might help you to get the most out of your appointments.

'The person' referred to below might be your specialist doctor, your GP or any other health professional.

- ◆ If there are answers you don't understand, ask the person to explain them again
- ◆ If you would like a second opinion, ask for a referral (it's okay to get more than two opinions)
- ◆ If you would like to tape-record a consultation, ask the person at the start of the consultation
- ◆ If you don't feel comfortable with the person on your first visit, consider giving it a second try. If you still don't feel comfortable after a second visit, you might wish to try someone else

- ◆ Take a notepad or use this booklet to take notes (maybe your support person could take notes for you)
- ◆ 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.

The State Ombudsman's office might also be able to help you work out the best course of action (Tel 03 9613 6222).

my questions & notes

'I was 42 when I was diagnosed so I've stopped menstruating now. I must say you would think that I would be relieved ... but somehow I just feel it's a loss of another bit of me. I wasn't ready really ... not that I was thinking of having any more children, but it was a loss.' (Alex)

'I went to see the reproductive technology unit and I ended up having ovarian tissue frozen. It may not work, I may never use it but it gave me this peace of mind.' (Judith)

fertility

signs of menopause

Treatment for breast cancer can cause early menopause. For many women this is permanent, but some women do find that 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, dry vagina, greatly reduced interest in sex, and sleeplessness.



BEFORE

Around the time of diagnosis, or before surgery or adjuvant therapy, women often ask:

1. Which forms of treatment are likely to bring on early menopause?
2. What can I do to protect my body from the effects of treatment?
3. What effect might menopause have on my body?
4. How long can signs of menopause last? What can I do to relieve them?

5. If I have signs of menopause, how will I know whether they are permanent?
6. How can I get more information about early menopause?



AFTER

At completion of treatment or in the longer term, common questions that women have are:

7. If I've experienced menopause, what health problems am I at risk of and what should I do to keep my health?
8. Can I use Hormone Replacement Therapy (HRT)? What are the potential risks and benefits of HRT for me?
9. Do I still need to have Pap smears?

Many women have had children after breast cancer. However, treatment for breast cancer might affect your ability to have children.



BEFORE

Around the time of diagnosis, or before surgery or adjuvant therapy, women often ask:

1. How would each of the treatment options affect my fertility?
2. Will I be able to have children in the future?
3. Is there anything I can do to protect my fertility (e.g. embryo/egg/ovarian tissue freezing)?
4. Is there any medication I can take that might reduce the effects of chemotherapy on my ovaries? What side effects might that medication have?
5. Can you refer me to a reproductive specialist to discuss my options?



AFTER

At completion of treatment or in the longer term, common questions that women have are:

6. After treatment, how long should I wait before trying to become pregnant?
7. What are my chances of becoming pregnant in the future?
8. How can I find out now whether I can become pregnant in the future?
9. What might be the impact of pregnancy on my health?
10. If I became pregnant, would it affect the risk of the cancer returning?
11. Who can I see or where can I go to help me to cope with my continued feelings of grief/sadness associated with the potential loss of fertility?
12. Can I still breastfeed if I have had breast cancer?

'I just felt that I had been ripped off and I'd become middle-aged post-menopausal woman.' (Michelle)

'I gradually increased my dose of Tamoxifen ... I still get hot flushes but I am able to cope with them.' (Susie)

my questions & notes

'I actually fell pregnant (and) the doctor said "How come you're pregnant?" At the time I felt wanted by the act [sex] but wasn't allowed any type of hormonal contraceptive and we didn't think about alternatives. Maybe women need a bit more help in dealing with the intimate side of things.' (Sarah)

contraception

contraception

Doctors strongly advise that you do not become pregnant at any time during your treatment. You might wish to discuss this further with your doctor.



BEFORE

Around the time of diagnosis, or before surgery or adjuvant therapy, women often ask:

1. What should I be doing about contraception?
2. Why should I avoid the Pill or other types of hormonal contraception?
3. What methods of contraception are safe and effective? What are their side effects?
4. How can I get more advice or information about contraception?
5. Even if my periods stop, do I still need to use contraception?
6. Do I still need to have regular Pap smears?



AFTER

Women often find that they need to ask the same questions again after surgery.

At completion of treatment or in the longer term, other common questions that women have are:

7. If/when my periods return, do I still need to use contraception?
8. Now that my treatment is complete, what contraception can I use?
9. Who could my male partner talk with about having a vasectomy?
10. If I'm still having problems with my periods (e.g. heavy periods), who can help? In particular, who best understands this issue in the context of my breast cancer?
11. Are there tests that I can have to find out if I'm fertile?