Finding the words

starting a conversation when your cancer has progressed

NATIONAL BREAST AND OVARIAN CANCER CENTRE

Acknowledgements

National Breast and Ovarian Cancer Centre (NBOCC) gratefully acknowledges the support and input of all the individuals and groups who contributed to the development of this guide.

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We very much appreciate the contributions made by women from the following organisations who participated in focus groups and interviews:

- Breast Cancer Network Australia
- Breast Cancer Action Group, NSW
- Gynaecological Cancer Support Group, Cancer Support Centre, Sydney Adventist Hospital, NSW
- The Oncology Unit, The Royal Women's Hospital, Vic

We also very much appreciate comments received from the following organisations:

- Cancer Voices
- Cancer Council Australia
- Breast Cancer Network Australia
- Breast Cancer Action Group, NSW
- Ovarian Cancer Australia

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Developed by National Breast and Ovarian Cancer Centre

Funded by the Australian Government Department of Health and Ageing

Finding the words
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ISBN Print: 978-1-74127-154-6 Online: 978-1-74127-155-3 CIP: 616.99449

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This resource can be downloaded from the National Breast and Ovarian Cancer Centre website: www.nbocc.org.au or ordered by telephone: 1800 624 973.

Recommended citation

National Breast and Ovarian Cancer Centre. Finding the words - starting a conversation when your cancer has progressed. National Breast and Ovarian Cancer Centre, Surry Hills, NSW, 2010.

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National Breast and Ovarian Cancer Centre is funded by the Australian Government Department of Health and Ageing.

Foreword

Learning that you have secondary cancer can present a whole new set of challenges. Acknowledging the enormity of this transition can feel overwhelming. This guide is designed to assist you in this transition, to empower you to take control. By assisting you to talk with the people who can support you, your family, friends and members of your healthcare team can be there with you during this transition.

The most difficult first step is finding the words to start a conversation. This guide is designed to help you with those difficult first conversations and contains quotes and stories from women with breast or ovarian cancer describing their experiences. We hope you find their words reassuring and that the guide provides a source of both factual information and inspiration to assist you in receiving the care and support you need.

Dr Helen Zorbas
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Introduction

This guide has been developed to help women with breast or ovarian cancer talk about how palliative care might help them to live as well as possible when cancer has spread. It aims to help women and their carers and healthcare team discuss an often misunderstood area of cancer care. Many people think that palliative care is only for people who are dying or nearing the end of their life. In fact, any treatment for secondary cancer* that helps to relieve symptoms and improve day-to-day life can be called palliative care.

The confusion surrounding palliative care means that some people are reluctant to talk about it with their healthcare team or with their family and friends. This can result in them missing out on important and valuable care and support during their cancer journey.

* Secondary cancer is also known as advanced or metastatic cancer

Helping others to help you

If you have secondary breast or ovarian cancer, your need for care and support is likely to vary depending on how you are feeling physically and emotionally. Your partner, children and carers are also likely to need support at different times. A palliative care service can help to ensure you get the support you need when you need it. It may seem strange to think about asking for help when you are still relatively well. However, accepting help and support can help you to save your energy for the things that are important to you.

Some women say they had no idea what palliative care could offer until they experienced it, and then wished they had asked for help earlier.

Finding out about palliative care means that you know what help is available if you need extra support. You may also find there are some services that would be helpful for you now.

"I was terribly proud. I'm learning to accept help a bit. And I think part of that is learning to know that you deserve help."

Your family and friends

Talking about your diagnosis and treatment for secondary cancer and how you do this is very personal. For many people this can be quite challenging. Open communication with your partner and those close to you is important. If you have children, you may want to talk to them so they can make sense of what is happening around them. Answer their questions as honestly as possible in words they can understand. What they imagine to be happening is possibly more upsetting to them than the reality, once it is explained.

The information in this guide is designed to help you with some of these conversations. Use it as a starting point and remember that you can ask your healthcare team for help and support if needed.

Anne's story

"I was diagnosed with advanced ovarian cancer 4 years ago. I feel OK but I find I get more tired than I used to and that slows me down. My doctor put me in touch with palliative care. They've organised so many things for me. They came and did an assessment of the house and put up some railings in the bathroom. I didn't think I needed them but actually being able to sit down to have a shower is really helpful – especially if I'm having a slow day.

I also have a physiotherapist who visits me at home. And there's a home help who comes every 2 weeks. I still do the dusting and wipe down surfaces but it's good to have someone to do the heavy stuff. It's also a relief for my daughters – they live close by but it means the burden is lifted a bit for them, knowing there's someone else available who can help out..."

About palliative care

When you talk with your healthcare team about palliative care, you will probably want to know what that means for you and those close to you.

These key facts about palliative care may help answer some of your initial questions.

- Palliative care improves **quality of life** for people who have cancer in a secondary or advanced stage.
- Palliative care is not just for people who are dying.
- Palliative care provides **pain relief** and may include active treatments such as radiotherapy, chemotherapy or surgery to relieve symptoms.
- Palliative care also provides **emotional, spiritual and social support** to patients and their families.
- In later stages of the illness, palliative care can help people prepare for death.
- Palliative care can be delivered at home, in the community, in hospital or an outpatient clinic or in a hospice or specialist palliative care unit.
- You can be referred to a specialist palliative care service at any point after a diagnosis of cancer.
- You can continue to have treatment from the rest of your healthcare team while you are receiving palliative care.
- Many GPs have extensive skills in palliative care and experience in working effectively with other members of the palliative care team. Receiving palliative care does not mean that you are no longer able to be treated by your GP.

An overview of palliative care services

Asking the difficult questions

Your healthcare team can give you information about palliative care and can answer your questions. However, there may be some questions you may be worried about asking. Or there may be questions you have not yet thought about.

This section is based on discussions about palliative care with women who have been diagnosed with secondary breast or ovarian cancer. The information may help you when you are talking to your healthcare team or to your family and friends about your diagnosis and care. Remember that no question is too 'silly' to ask – if you have a question, the chances are you are not alone.

"I didn't like the idea about being referred to palliative care when I had only just been diagnosed with secondary disease but I found it really helped. They told me how to apply for financial assistance and they gave me helpful suggestions about how to control the pain under my shoulder."

If I have palliative care, does it mean the aim of my treatment has changed?

Palliative care can include active treatments such as chemotherapy, radiotherapy or surgery. By controlling the cancer, these treatments can help to keep symptoms and pain under control to allow you to live well and with as few symptoms as possible.

Do I still have choices?

Your treatment options will depend on a number of things, including your cancer, your symptoms and your general health. As you can see from the overview of palliative care services on page 5, palliative care offers a range of services. You may not need all of these, and your needs may change over time. You are entitled to make decisions about your own care, based on your own needs, your own personal values and your experiences, including the choice of stopping treatment if that is your preference.

Is palliative care only for end of life care?

Palliative care has a role to play for women with secondary cancer. You may not need to use the service continuously. It may come in and out of your life as your needs change. Palliative care offers a range of services to look after your whole wellbeing. These may include talking about your feelings, discussing spiritual and practical support, as well as management of your symptoms. Talk to your palliative care team about any issue that might be causing you distress.

Will my healthcare team change?

Some people worry that if they have palliative care, the people managing their care will change. However, the specialist palliative care team is just another part of the treatment team. Your care can still be managed by your existing GP, who may remain one of the most important team members, but there may be some additional health professionals involved.

How do I plan for the future?

Everyone responds differently to treatment for breast or ovarian cancer. Everyone has different support and information needs, and everyone is different in how much they want to think about the future. Having a conversation with those close to you can be the first step in planning for the future. Raising the topic of accessing palliative care services can be very challenging when your friends and family may not be aware that your disease has progressed. You can reassure them that palliative care does not mean end of life care, it means accessing a range of services to support you.

"I thought that once you had palliative care you were going to die. I didn't realise that they could come in when you were in a crisis situation and then as you got better they went out."

Mary's story

"I've been living with secondary breast cancer for 12 years and have been receiving support from the palliative care team on and off for the past 3 years. I have nothing but positive feelings about my involvement with them. It's not all the time but I know they're there if I need them.

When you say palliative care people jump because they think it means end of life. The social worker at the hospital explained it to me. She said, this isn't about end of life, this is just to help you to get back into your normal way of life.

Last year I went through a bad patch. I was in quite a lot of pain and it was making me sick so I wasn't eating properly. I called the palliative care nurse and she visited me at home and gave me an injection and set me up with another one which I could give myself.

She called me back after a few hours and came to see me again the next day to check I was OK. She said if the pain continued I might need to go into hospital for a while – but it settled down and I didn't need to go. She also arranged an appointment with a dietician for me.

After that the palliative care nurse came and saw me every few weeks at home. It's comforting to know she's only a phone call away if I need her. And I can ask her questions I wouldn't want to ask the doctor.

They have also put me in touch with lots of other services I wouldn't have thought of – music therapy and meditation. They told me what was available and it was up to me to decide whether to take it up – but I'm really glad that I did..."

Starting the conversation

To find out more about palliative care and the services available, talk to your GP or another member of your healthcare team. Having this conversation does not mean that your current treatment needs to change. Nor does it mean that you have to access palliative care services straight away or that you will lose your independence. However, finding out what services are available will give you and those close to you access to valuable care and support when you need it.

In starting a conversation with your family and friends, you may find it helpful to use phrases such as:

> *Although this is hard for you to hear and for me to raise, I need to share with you some really important information.*
>
> *I need to talk with you about a change in my condition. Unfortunately the cancer has spread – something we all hoped wouldn't happen. But it seems that there are still a lot of options open, so we need to find out more about them.*
>
> *There's no easy way for me to let you know that the treatments haven't cured the cancer. This isn't what you want to hear, I know, and it comes as a shock for me. Coping with the challenges this will bring makes it more important than ever that we can talk about things.*

Useful resources

In addition to the information you receive from your healthcare team, you might find it helpful to get information from different sources. The organisations below are a good starting point.

Cancer Council Helpline can provide up-to-date, local information about services available in your area. Call 13 11 20 from anywhere in Australia.

National Breast and Ovarian Cancer Centre (NBOCC) has up-to-date evidence-based information about breast and ovarian cancer. Information is available as printed booklets and online.

Resource order line: 1800 624 973 Website: **www.nbocc.org.au**

Breast Cancer Network Australia (BCNA) is the national voice of Australians personally affected by breast cancer. BCNA provides breast cancer information and resources developed by women with breast cancer, including a free *Hope and Hurdles Pack* for women with secondary breast cancer.

Information line: 1800 500 258 Website: **www.bcna.org.au**

Ovarian Cancer Australia provides information and resources for women with ovarian cancer, including a free *Resilience* kit, as well as support groups.

Information line: 1300 660 334 Website: **www.ovariancancer.net.au**

CareSearch is an online resource of palliative care information and evidence.

Information line: (08) 7221 8233 Website: **www.caresearch.com.au**

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Funded by the Australian Government Department of Health and Ageing

FTWC 05/10