

Finding the words

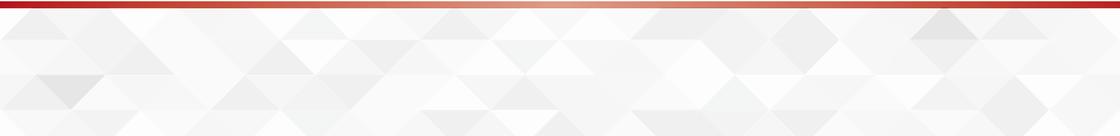
Starting a conversation
when your cancer has progressed



Australian Government
Cancer Australia

Finding the words

Starting a conversation
when your cancer has progressed



Finding the words - starting a conversation when your cancer has progressed

First edition published in 2010 by:

National Breast and Ovarian Cancer Centre

Finding the words. Starting a conversation when your cancer has progressed

Second edition published in 2016 by:

Cancer Australia

Locked Bag 3 Strawberry Hills NSW 2012 Australia

Tel: +61 2 9357 9400 Fax: +61 2 9357 9477

canceraustralia.gov.au

© Cancer Australia 2016

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

Recommended citation

Cancer Australia, 2016. *Finding the words. Starting a conversation when your cancer has progressed*, Cancer Australia, Surry Hills, NSW.

Finding the words. Starting a conversation when your cancer has progressed, can be downloaded from the Cancer Australia website: canceraustralia.gov.au or ordered by telephone: 1800 624 973.

Copyright statements

Paper-based publications

This work is copyright. You may reproduce the whole or part of this work in unaltered form for your own personal use or, if you are part of an organisation, for internal use within your organisation, but only if you or your organisation do not use the reproduction for any commercial purpose and retain this copyright notice and all disclaimer notices as part of that reproduction. Apart from rights to use as permitted by the Copyright Act 1968 or allowed by this copyright notice, all other rights are reserved and you are not allowed to reproduce the whole or any part of this work in any way (electronic or otherwise) without first being given the specific written permission from Cancer Australia to do so. Requests and inquiries concerning reproduction and rights are to be sent to the Publications and Copyright contact officer, Cancer Australia, Locked Bag 3, Strawberry Hills, NSW 2012.

Internet sites

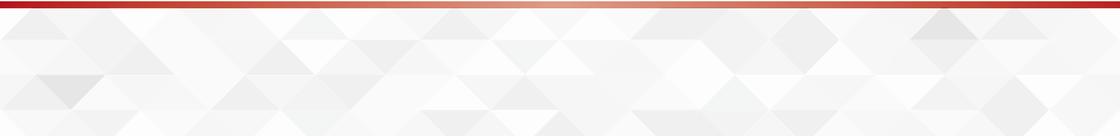
This work is copyright. You may download, display, print and reproduce the whole or part of this work in unaltered form for your own personal use or, if you are part of an organisation, for internal use within your organisation, but only if you or your organisation do not use the reproduction for any commercial purpose and retain this copyright notice and all disclaimer notices as part of that reproduction. Apart from rights to use as permitted by the Copyright Act 1968 or allowed by this copyright notice, all other rights are reserved and you are not allowed to reproduce the whole or any part of this work in any way (electronic or otherwise) without first being given the specific written permission from Cancer Australia to do so. Requests and inquiries concerning reproduction and rights are to be sent to the Publications and Copyright contact officer, Cancer Australia, Locked Bag 3, Strawberry Hills, NSW 2012.

Disclaimer

Cancer Australia does not accept any liability for any injury, loss or damage incurred by use of or reliance on the information. Cancer Australia develops material based on the best available evidence, however it cannot guarantee and assumes no legal liability or responsibility for the currency or completeness of the information. Cover image: ©iStock

Contents

Acknowledgements	2
Foreword.....	3
Introduction.....	4
Helping others to help you	4
Your family and friends	5
About palliative care	6
Asking the difficult questions	8
If I have palliative care, does it mean the aim of my treatment has changed	8
Do I still have choices?.....	8
Is palliative care only for end-of-life care?	9
Will my healthcare team change?	9
How do I plan for the future?	9
Starting the conversation	11
Useful resources.....	12



Acknowledgements

This guide has been published as an update of the resource '*Finding the words – starting a conversation when your cancer has progressed*'.

We particularly thank Professor Katherine Clark for her valued contribution to the update of this guide.

We also acknowledge the members of the multidisciplinary reference group who oversaw the development of the original guide:

Dr Julie Thompson (Chair)

Professor Katherine Clark

Dr Warren Hargreaves

Ms Susanne Melia

Dr Donna Milne

Professor Geoff Mitchell

Dr Deborah Neesham

Ms Marie Polla Mounter

Dr Catherine Shannon

Ms Dianne Shore

Professor Jane Turner

Cancer Australia acknowledges the contribution made by consumers and cancer organisations who participated in focus groups and interviews and provided comment on the original guide.

Foreword

Learning that your cancer has progressed 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 people with 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.

A handwritten signature in black ink, reading "Helen Zorbas". The signature is fluid and cursive, with a large loop at the end of the name.

Professor Helen Zorbas AO
Chief Executive Officer
Cancer Australia

Introduction

This guide has been developed to help people with cancer talk about how palliative care might help them to live as well as possible when cancer has spread. It aims to help you and your 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 metastatic cancer* that helps to relieve symptoms and improve day-to-day life can be considered palliative.

The confusion surrounding palliative care means that some people are reluctant to talk about this type of care with their healthcare team, or even, their family and friends. However, this might mean that people are missing out on important and valuable care, as well as support during their cancer journey.

* Metastatic cancer is also known as advanced or secondary cancer. Metastatic cancer refers to cancer that has spread to other parts of the body.

Helping others to help you

If you have metastatic cancer, your care and support needs will vary depending on how you are feeling physically and emotionally. Your partner, children and other 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. While it might seem strange to think about asking for help when you are still relatively well, accepting resources offered by palliative care can help you to save your energy for the things that are important to you.

Some people 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 are aware of what is available should you require it. 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

Finding ways to talk about your diagnosis and treatment for metastatic cancer 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.

"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.. "

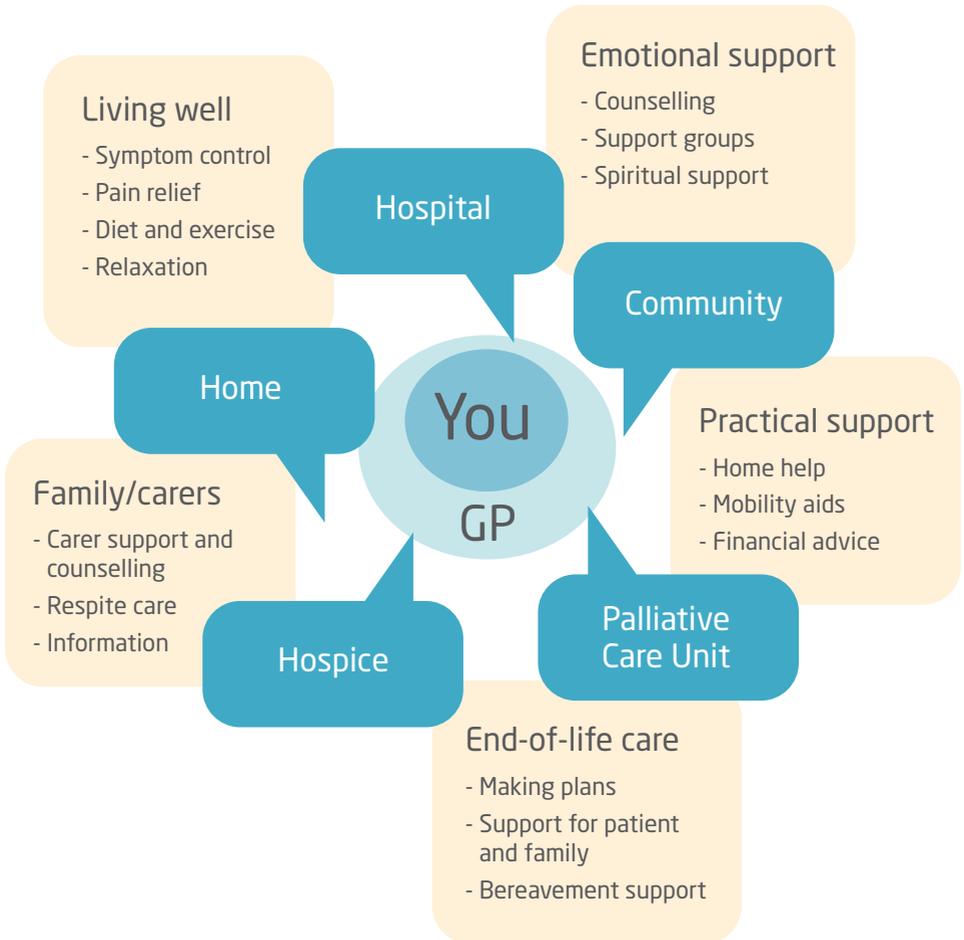
About palliative care

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 metastatic or advanced stage.
- ▶ Palliative care is not just for people who are dying.
- ▶ Palliative care provides **pain relief** and relief of other symptoms with approaches to managing these symptoms including active treatments such as radiotherapy, chemotherapy or surgery.
- ▶ Palliative care is also able to provide **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 metastatic cancer.
- ▶ You can continue to have treatment from the rest of your healthcare team while you are receiving palliative care.
- ▶ Many general practitioners (GPs) have extensive skills in palliative care and are able to work effectively with other members of the palliative care team. Your GP is still an important member of your healthcare team while you are receiving palliative care.

Figure 1 – 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 people who have been diagnosed with metastatic 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 metastatic cancer 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 (Figure 1), palliative care may include a range of services. You may not need all of these, and your needs are likely to change with time. You are entitled to share in the processes of making decisions about your own care as you will have the best understanding of your own needs, your own personal values and your experiences, including the choice of stopping treatment should you choose.

Is palliative care only for end-of-life care?

Palliative care has a role to play for people with metastatic cancer but you may not need to use the service continuously. It may come in and out of your life as your needs change. Palliative care can offer 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 GP or 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 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 means accessing a range of services to support you, not necessarily end-of-life care.

"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."

"I've been living with metastatic 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.

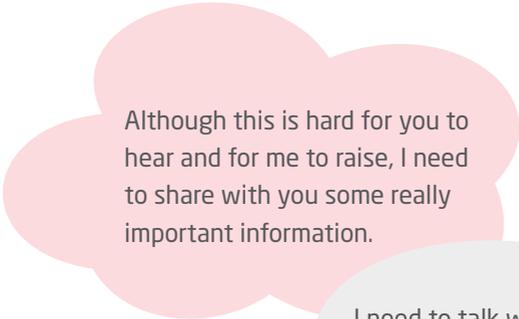
After that the palliative care nurse came and saw me every few weeks at home. It's comforting to know she's only a phone call away if I need her. And I can ask her questions I wouldn't want to ask the doctor.

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..."

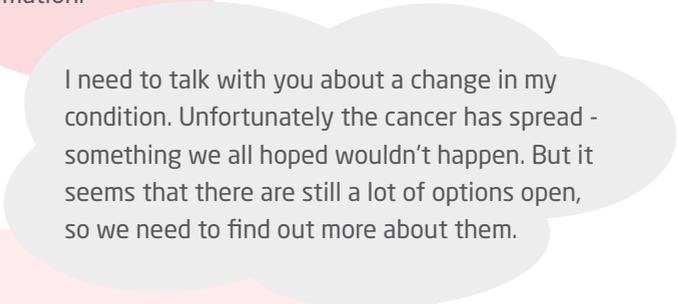
Starting the conversation

To find out more about palliative care and the services that might be available in your area, 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.

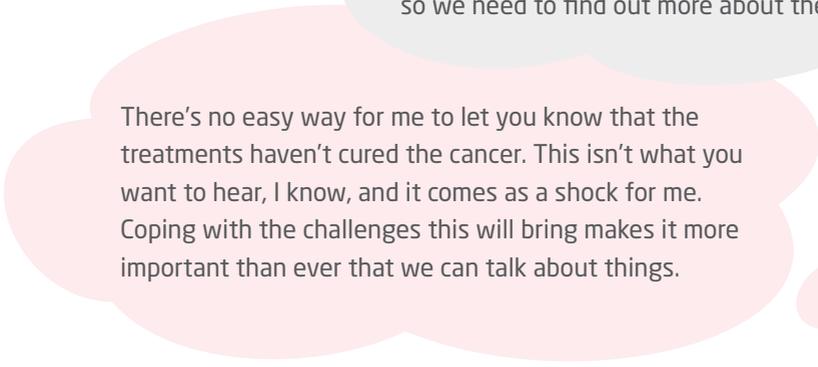
In starting a conversation with your family and friends, you may find it helpful to use phrases such as:



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 Australia has up-to-date evidence-based information about cancer. Information is available online and in print. Visit canceraustralia.gov.au or call **1800 624 973**

Cancer Council Helpline is a free confidential telephone and information support service. Specially trained staff are available to answer your questions about cancer and offer emotional and practical support. Call **13 11 20** from anywhere in Australia.

CareSearch is an online resource to help those needing information and resources about palliative care. Visit caresearch.com.au

Palliative Care Australia provides access to information for patients, carers and health professionals. Visit palliativecare.org.au

A list of support services for specific cancers is available at canceraustralia.gov.au

