

A guide for talking about advanced cancer

Advice for people living with advanced cancer, their friends and family.

Written on behalf of the Advanced Cancers Coalition (ACC). Co-authored with Dr Mary Burgess, lead consultant clinical psychologist.

The ACC is a coalition of UK cancer patient groups with a shared interest in delivering improvements in care and treatments for people with advanced cancer.

The ACC is dedicated to improving the quality of life for advanced cancer patients and raising awareness of the unique needs that people living with advanced cancers face.

WHY GOOD COMMUNICATION MATTERS

We all hear information differently and our understanding depends on many factors: **when** it is given; **who** is giving it; **what** we (wish to) hear and **how** it is given. How often do we check what has been said and mutually understood? Misinterpretation can leave us feeling isolated, misunderstood and out of step with one another.

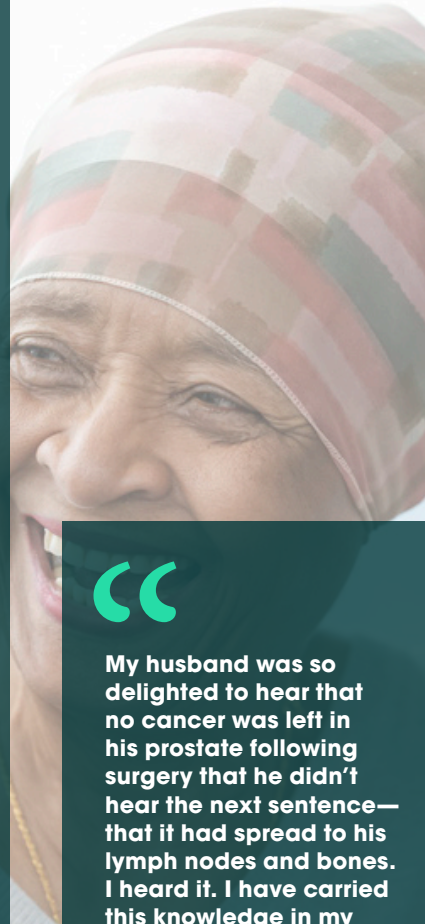
There is no right or wrong way to communicate but studies show that families of patients who talk things out feel better about the care their loved ones get and the decisions they make.

DR MARY BURGESS
Lead Consultant
Clinical Psychologist

No matter what your role is, in any conversation about a life-limiting illness, you will need to respond to emotion, make decisions that might be at odds with other people's choices, deal with the stress of meeting expectations (or not) and nurture hope when the future looks bleak. This sets a high bar for any conversation.

The complexity of the interaction can so easily create miscommunication, which in turn thwarts the understanding of treatment expectations or the involvement of others in the decision-making process. Being able to create the moment where the conversation can take place can be a real gift. It can be transformative for everyone and crystallise values, wishes and stories, delivering outcomes you could never imagine. This is why effective communication when living with advanced cancer is so key to our well-being.

DR HELEN BULBECK
Director at Brainstrust
and ACC member



My husband was so delighted to hear that no cancer was left in his prostate following surgery that he didn't hear the next sentence—that it had spread to his lymph nodes and bones. I heard it. I have carried this knowledge in my heart, not knowing if I should burst his bubble and be truthful. I watch him enjoying life; what is the point in telling him?

DR HELEN BULBECK



INTRODUCTION

This short guide has been developed with Dr Mary Burgess, lead consultant clinical psychologist, to encourage more productive conversations about advanced cancer.

The emotional and psychological experiences of living with an advanced cancer can impact how we communicate with our loved ones and how others communicate with the person living with advanced cancer. Some people may wish to talk openly about their experiences and others hardly at all. Either way, talking about advanced cancer can be difficult, both for people living with it and those around them.

It can be difficult to know what to say, how to say it and when to say it. As a consequence, people living with advanced cancer can be left feeling isolated and unsupported. This short guide has been developed in collaboration with Dr Mary Burgess, lead consultant clinical psychologist, and has been designed to support conversations in advanced cancer, encouraging more positive and productive outcomes.

This booklet can be used on an ongoing basis to support you in either living with or knowing someone with advanced cancer.



THE IMPACT OF CANCER

A lot of the distress experienced after a diagnosis can be resolved with time as people better understand their condition and make any necessary lifestyle changes.

Cancer not only affects the person diagnosed but also those around them. It affects social and sexual well-being; it changes family roles and responsibilities.

Distress is unavoidable and normal over the course of a cancer diagnosis. Because everyone is unique, different ways of coping may be developed. Our personality, social and cultural environments, understanding and previous experience of cancer, and the level of support available all impact how we cope with a cancer diagnosis.

Most distress resolves with time as people adjust and adapt to their changed situation.

An advanced cancer diagnosis may mean that new decisions need to be made. These decisions often come with many emotions such as fear of the unknown, sadness and anger. These emotions can impact how we talk to each other and how productive conversations are.

COMMON FEARS IN ADVANCED CANCER CAN INCLUDE:

- starting treatment
- talking about diagnosis and/or changes in treatment
- pain management
- financial worries
- impact of cancer on family roles and responsibilities
- end of life and death

The level of anxiety or fear experienced by one person may differ from the anxiety experienced by another person. In most cases, anxiety or fear can be reduced by learning more about cancer, being clear about the options available to move forward and talking openly with one another.

THE IMPACT OF CANCER ON COMMUNICATION

Avoidance or denial is a normal response in advanced cancer. In fact, denial is an important coping mechanism for some as it allows the person time to process distressing information. However, *continued* avoidance usually increases our fear and can leave us feeling stuck and increasingly isolated. Fear is also a common barrier preventing us from speaking openly. There can be a fear of accepting change; of upsetting the ones we love; of the unknown and fear of feeling vulnerable.

As a patient, the way in which you talk about how you're feeling may change as you go through diagnosis and treatment.

PRACTICAL TIPS TO SUPPORT GOOD COMMUNICATION:



Pace conversations at a level your partner/family members/friends can understand



Make time for the conversation so it is not rushed



Choose a good time that works for everyone



Take a few deep breaths before a conversation to help you keep calm

TIPS TO SUPPORT PRODUCTIVE CONVERSATIONS

Having open conversations will help you to feel understood, to look at your options clearly and figure out how best to manage any concerns or worries you have. So how can we open up conversations in advanced cancer?



- Seeing situations as challenges to respond to, rather than threats to avoid, can be a more constructive approach to help open up conversations in advanced cancer



- Identify what your concerns or worries are; writing them down before a conversation can be helpful. Be specific about what is concerning you and how it makes you feel; give an example



- Communicating your concerns is an important first step to identify solutions – different concerns will need different solutions. Not talking about your concerns can prevent you from focusing on what is important to live well



- Prioritise concerns or worries; you cannot sort out everything at once. By prioritising them in order of importance, you can agree on a plan of action



- Honest, clear, sensitive communication can help everyone to successfully respond and adjust to changing circumstances, in a supportive and collaborative way



- Be curious and non-judgmental. Try not to take what is said personally



- Check that you have heard correctly and how an issue or particular problem it is making the person feel

Above all, let each other know you are there for one another, whatever happens.

Read the Advanced Cancer's Coalition: Your Right, Your Choices – a guide to get the most from interactions with health and care professionals.

IN SUMMARY

Conversations about advanced cancer are emotionally charged. It is hard for patients and families to take on / make decisions without first processing some of the accompanying emotions.

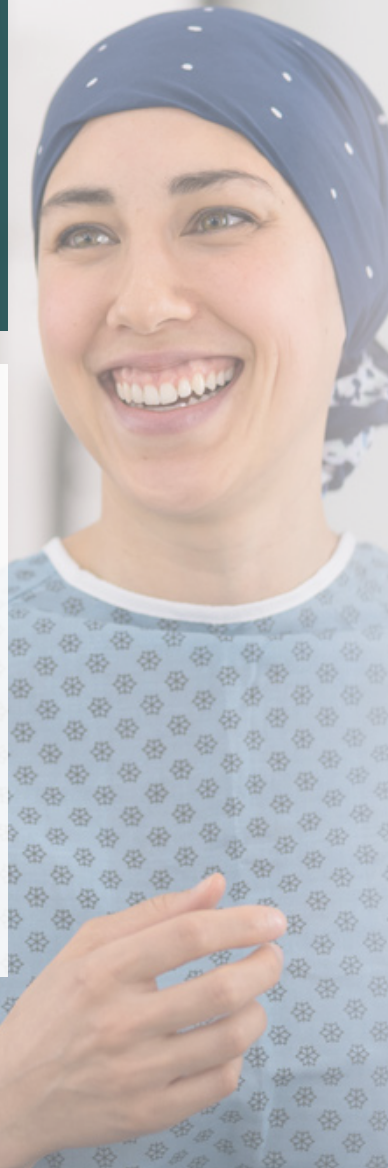
A good starting point is simply to make time to listen. You don't have to sort everything out all at once. Good communication is ongoing.

Finally, getting the balance right between a life-limiting condition and living can be a challenge. However, the reward can be living a meaningful life, focusing on what and who is important to you and your family.

HELP AND INFORMATION

To help start or continue those all-important conversations with the ones you love and care for, there are a number of sources of support which are available online, via telephone and in person:

- If you or someone you know has been diagnosed with cancer, Macmillan Cancer Support provides information on what to expect, practical advice and support. You can call their team on 0808 808 00 00
- Personal advice and support from professional staff and an online community can also be found via Maggie's Centres which is a network of regional centres. You can call their team on 0300 123 1801





The activity of the ACC is funded by Roche Products Limited. Roche participates in ACC discussions in calls and meetings. Roche is involved in the development of content related to ACC activity requested by, and in conjunction with, members of the ACC who approve all materials published. The Secretariat for the ACC is provided by MHP Communications, and Virgo Health supports the ACC with their external communications, both of whose services are also paid for by Roche Products Limited. Members of the ACC receive no payment from Roche for attending meetings or conference calls, except to cover appropriate travel costs.