

Discussing palliative care with ABC patients

A resource to help structure conversations

Starting conversations about palliative care

Many Advance Breast Cancer (ABC) patients can live for many years with good quality palliative care if offered early. Before talking to your patient about palliative care, you should consider the following to ensure that both you and your patient are both ready to discuss the option of palliative care:

- **Is palliative care the right pathway for my patient?**
 - Do I understand what my patient's goals are and can palliative care offer this?
 - Have I explained clearly and precisely what palliative care is, what it can offer my patient and am I completely sure that my patient is fully aware of what is in store?
 - Has the patient expressed that this is the route they would like to choose?
 - Is my patient aware that palliative care can be given in conjunction with active therapy?
 - Are my patient and their caregivers aware of the implications of palliative care on support and wellbeing?
 - Does my patient fully understand the pros and cons of continuing curative treatment versus opting for palliative care?
- **Is it the right time?**
 - Is my patient ready to consider this option?
 - Are my patient's family/loved ones aware this option could be considered?
 - Is my patient aware that palliative care does not have to be a last option?
- **Is everyone on the same page?**
 - Does the patient know what palliative care will entail?
 - Am I fully aware of what palliative care will mean for my patient?
 - Have the other members of the MDT been briefed that this is what the patient has decided?
 - Has the patients' family been fully briefed on what palliative care will mean for them/their loved one?

Offering support

Other than talking to your patient and using this guide, it's important to note that not all of the patient's questions and concerns regarding palliative care can be answered purely from a medical perspective. It's a good idea to have some details of local professionals/organisations that you recommend for the following:

- Support groups to talk about palliative care with others;
- Psychologists for more professional help;
- Physical support;
- Carers;
- Respite care;
- Household help e.g. cleaners;
- Financial care;
- Funeral arrangement – to help alleviate the burden on the family/loved ones;
- Bereavement care – for family.

Addressing patient concerns

Once the questions have been considered and the decision has been taken to start palliative care, it's most likely that the patient be worried about the next steps. The points following highlight some of the potential questions and concerns you may encounter. They are intended to be used as a guide so you preempt your conversations with your patient and reassure them about what the future may hold and offer appropriate support during this difficult stage in their life.



1. Concerns for self: Deterioration. It's important to reassure the patient as much as possible and help them come to terms with the mental and physical changes they will experience as they transition to palliative care. They will want their quality of life to remain unaffected. The patient could be concerned about how their body and mind will deteriorate.

These concerns may include:

MENTALLY

- Decline in the socially based aspects of one's identity;
- Feeling a loss of control;
- Worries about mental awareness;
- Achieving a sense of completion.

PHYSICALLY

- Being unable to fulfil normal roles;
- Deterioration of physical appearance;
- Needing help with intimate personal care and routine activities of daily living;
- Achieving a sense of completion;
- Pain and management of symptoms.

2. Concerns for self: Dying. Most patients are inevitably concerned about their end of life care and/or how they're going to die.

These concerns could include:

- Venue of death;
- Pain and management of symptoms;
- Quality of end of life care;
- Dignity in dying;
- Achieving a sense of completion;
- Family and caregivers involvement;
- Having a 'good death' e.g. family present, being at home (if desired);
- Feelings of abandonment.

3. Concerns for others. Finally, the patient could be thinking of the people they will leave behind; their children and loved ones.

These concerns could include:

- Ensuring pets / children / loved ones are provided for financially;
 - How they're going to talk to children / loved ones about what is happening;
 - Fear of burdening loved ones;
 - Fear of abandoning others;
 - Fear of a lack of support for the family.
- These concerns could be addressed by providing the patient with information they can easily understand and pass on to others, or by welcoming their children/loved ones to book a group appointment, where they can voice their concerns and questions in a safe environment.

