DISCUSSING THE TRANSITION FROM CURATIVE CARE TO PALLIATIVE CARE WITH WOMEN WITH ADVANCED BREAST CANCER

EVIDENCE FROM THE LITERATURE AND RECOMMENDED STEPS

PREPARED BY THE NATIONAL BREAST CANCER CENTRE

FUNDED BY THE AUSTRALIAN GOVERNMENT DEPARTMENT OF HEALTH AND AGEING
Discussing the transition from curative care to palliative care - Evidence from the literature was developed by the Peter MacCallum Cancer Centre on behalf of the National Breast Cancer Centre:

The National Breast Cancer Centre
92 Parramatta Road Camperdown NSW 2050 Australia
Locked Bag 16 Camperdown NSW 1450 Australia
Telephone +61 2 9036 3030
Facsimile +61 2 9036 3077
Website www.nbcc.org.au
Email: directorate@nbcc.org.au
© National Breast Cancer Centre 2005

This work is copyright. Apart from any use as permitted under the Copyright Act 1968, no part may be reproduced by any process without prior written permission from the National Breast Cancer Centre. Requests and enquiries concerning reproduction and rights should be addressed to the Communications Manager, National Breast Cancer Centre, Locked Bag 16 Camperdown NSW 1450 Australia.

Recommended citation:

Disclaimer
The National Breast Cancer Centre does not accept any liability for any injury, loss or damage incurred by use of or reliance on the information. The National Breast Cancer Centre develops material based on the best available evidence, however it cannot guarantee and assume no legal liability or responsibility for the currency or completeness of the information.
Copies of this report can be downloaded from the National Breast Cancer Centre website: www.nbcc.org.au
or by telephone: 1800 624 723
The National Breast Cancer Centre if funded by the Australian Government Department of Health and Ageing.
ACKNOWLEDGMENTS

The National Breast Cancer Centre (NBCC) gratefully acknowledges the support of individuals and organisations who contributed to the development of this communication skills module.

**Module developers:**
- Dr Penny Schofield, Peter MacCallum Cancer Centre
- Dr Anthony Love, La Trobe University
- Dr Simon Wein, Peter MacCallum Cancer Centre
- Dr Mariko Carey, Peter MacCallum Cancer Centre

**NBCC Communication Skills Steering Committee:**
- Professor Phyllis Butow, Director, Medical Psychology Unit, University of Sydney (Chair)
- Professor Jill Cockburn, Professor Behavioural Science, University of Newcastle
- Ms Meg Lewis, Specialist Breast Nurse, Royal Adelaide Hospital
- Mr Peter Malycha, Surgeon, Royal Adelaide Hospital
- Ms Pam Robertson, Consumer, Breast Cancer Network Australia
- Dr Jane Turner, Psychiatrist, University of Queensland

**Module reviewers:**
- Professor David Currow, Professor of Palliative & Supportive Services, Flinders University
- Professor David Kissane, Chairman, Department of Psychiatry and Behavioural Sciences, Memorial Sloan-Kettering Cancer Center

**National Breast Cancer Centre Staff**
- Dr Karen Luxford
- Dr Nicole Rankin
- Ms Caroline Nehill
# TABLE OF CONTENTS

**EXECUTIVE SUMMARY**

**INTRODUCTION**

**METHODOLOGY OF THIS REVIEW**

**THE PALLIATIVE APPROACH**

**UNDERSTANDING WOMEN’S EXPERIENCES OF ADVANCED BREAST CANCER**

- Impact of the bad news about advanced breast cancer
- The impact of advanced breast cancer on physical functioning and quality of life
- The impact of advanced breast cancer on psychosocial functioning
- The impact of advanced breast cancer on family functioning
- The Impact of advanced breast cancer on existential issues
- Facilitating the transition from curative to palliative care

**RECOMMENDED STEPS**

- When should I discuss the transition to palliative care?
- How should I prepare for this discussion?
- How do I set-up the consultation?
- How do I begin this discussion?
- How should I approach cultural and linguistic diversity?
- What information do I provide?
- How should I respond to the woman’s emotional reaction?
- How do I bring up palliative care services?
- How can I ensure continuity of care?
- How can I address family concerns?
- How do I conclude the discussion?
- Emotional impact on health professionals

**CONCLUSIONS**

**REFERENCES**
EXECUTIVE SUMMARY

Palliative Care focuses on improving quality of life for patients with life-threatening illness and their families. In practice, a palliative approach tends to be gradually adopted over time as the disease progresses. The challenge is how to facilitate a sympathetic transition from curative to palliative care.

The first step is to understand the woman’s experience of advanced breast cancer.

- This diagnosis is more devastating than the initial diagnosis.
- Patients may continue to want futile, curative treatment.
- Women may experience a range of debilitating physical symptoms, particularly fatigue, pain, dyspnoea and delirium.
- Psychological distress, reduced quality of life and social isolation often result from the diagnosis of advanced disease and the associated symptoms.
- Women are very concerned about the impact of their disease on their family.
- Family distress and caregiver burden increases as the cancer advances.
- Children, particularly adolescent daughters, experience significant distress that may not be detected.
- Women experience existential issues related to facing their own death.

The recommended steps for facilitating the transition from curative to palliative care were based on the best available evidence, however, it should be noted that there is a paucity of research in this area, hence research was also drawn from related areas of enquiry. It is recommended that when discussing this transition these steps are followed:

- Prepare for the discussion by gathering relevant information, ensuring the setting is appropriate, asking the woman to bring family, offering a tape-recording and encouraging the woman and her family to ask questions.
- Elicit the woman’s understanding of her situation and preferences for information and support by asking open-ended questions.
- Be aware of attitudes and information needs of different cultural groups.
- Provide the woman with the information that she requires using lay terms including conveying that more curative treatment would do more harm than good.
- Respond to the woman’s emotional reaction with empathy.
- Negotiate new goals of care by first asking whether the woman wishes to discuss future treatment options, then introducing the role of palliative care services and providing realistic reassurances and hope.
• Maintain continuity of care by referring to the palliative care health professionals as part of the team and reassuring the patient that they will not be abandoned.
• Address family concerns by asking about how they are coping at home and if there are children, asking about their concerns.
• Conclude the discussion by summarising, checking the need for referrals, emphasising the hope-giving aspects and asking for final questions.
• Inform other members of the team about the discussion and document it.
INTRODUCTION

The goal of palliative care has been described as helping people die with dignity\(^1\). Understandably, people find the transition from curative to palliative care a stressful experience. It is recognised as a critical moment in the cancer journey\(^2\). Building health care professionals’ communication skills can assist the transition through this difficult phase and increase the prospect of better outcomes for women with advanced breast cancer and their families. The aim of this communication skills module is to increase health care professionals’ abilities to facilitate discussions about the transition from curative care to palliative care.
METHODOLOGY OF THIS REVIEW

The literature review was synthesised from the best available scientific evidence. A comprehensive literature search was conducted covering the relevant scientific literature from 1990 to 2003. All relevant databases, including MEDLINE, CANLIT, CINAHL, and PSYCHLIT, were searched including the following search terms: cancer, oncology, palliative care, referral, communication, breaking bad news, doctor-patient communication, death, dying and cultural attitudes. As studies in this area are relatively few, and difficult to undertake using randomized controlled trials, all relevant articles in English were collected, and subjected to a methodological review. Further searches were undertaken of references lists, and researchers commonly publishing in this field. In addition, the reference list of the “Clinical practice guidelines for the psychosocial care of adults with cancer” was inspected to ensure no relevant articles cited there had been missed.

The evidence rating system used in this literature review is based on recommendations by the NHMRC$^3$.

- Level I Evidence is obtained from a systematic review of all relevant randomised controlled trials.
- Level II Evidence is obtained from at least one properly designed randomised controlled trial.
- Level III-1 Evidence is obtained from well-designed pseudo-randomised controlled trial (alternate allocation or some other method).
- Level III-2 Evidence is obtained from comparative studies with concurrent controls and allocation not randomised (cohort studies), case control studies or interrupted time series with a control group.
- Level III-3 Evidence is obtained from comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel group.
- Level IV Evidence is obtained from case studies, either post-test or pre- and post-test.
THE PALLIATIVE APPROACH

Palliative care has been defined by the World Health Organisation as “an approach that improves the quality of life of families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” 4. Compared to conventional care, specialist palliative care services improve patient and family satisfaction, reduce family anxiety, provide better pain control and symptom management and increase the likelihood of the patient being cared for his/her place of choice5 (Level 1).

The clinical challenge is how to facilitate a sympathetic transition from curative to palliative care. This transition can imply impending death to the patient and trigger fears of helplessness and abandonment by the medical profession. For advanced breast cancer, chemotherapy can sometimes be used to prolong life in a quasi-curative sense often for many months, even years. In these cases, cancer can be considered a chronic illness6. Hence, the traditional sharp transition point from a curative to palliative goal of care is blurred. In practice, a palliative approach tends to be adopted over time as the disease progresses. This philosophy acknowledges the likelihood of gradual transition, emphasising quality of life considerations and symptom control during the active treatment phase. Treatment goals will evolve from seeking a cure, to control of disease and complications, maintaining physical functioning and quality of life, and ultimately to symptom control7. The concept of dying with dignity moves palliative care beyond symptom control to the consideration of psychological, social, spiritual, and existential issues8.

In this module, the concept of palliative care is defined as encompassing “management during both acute and chronic illness and end-of-life (terminal) care” 4. Hence, use of palliative care varies widely. A woman with breast cancer may be receiving curative treatment such as tamoxifen but with the discovery of metastatic disease may be offered palliative chemotherapy or radiotherapy treatment to prolong her survival. As such, oncologists and general practitioners may prescribe treatments with palliative intent. Patients may see a palliative care physician or nurse for a limited time to resolve a particular issue, such as uncontrolled pain. As the disease advances to the terminal phase, they may be referred to community palliative care services or a hospice for end-of-life care. Each one of these referrals is likely to be distressing as it may confer a new, more serious phase of the illness. These guidelines are intended to have applicability to each of these transition points. Parts of the guidelines may be more relevant to some transitions than others.
UNDERSTANDING WOMEN’S EXPERIENCES OF ADVANCED BREAST CANCER

IMPACT OF BAD NEWS ABOUT ADVANCED BREAST CANCER

While the news of an advanced cancer diagnosis has many similarities to earlier bad news episodes, it also has some unique characteristics.

- It is rated as more devastating than the initial diagnosis of localised disease\(^9\), however, expressing empathy and providing information can facilitate patient adjustment\(^10\).
- A high proportion (61%) of Australian women with advanced breast cancer indicted that they would have liked changes in the way their diagnosis of advanced disease was communicated to them \(^11\).
- Patients with advanced cancer may continue to ask for futile, curative treatment. About a quarter of oncologists say that they occasionally administer a treatment that is not likely to work, in order to bolster the patient’s hope\(^12\).

THE IMPACT OF ADVANCED BREAST CANCER ON PHYSICAL FUNCTIONING AND QUALITY OF LIFE

Optimising quality of life is not only an important outcome in itself but it is also associated with longer survival amongst women with advanced breast cancer\(^13\) (Level III-3). Women may experience a diverse range of physical symptoms, which will require careful assessment and management to alleviate and reduce the associated psychological distress\(^14\,15\). These symptoms commonly include:

- Fatigue; in advanced disease it is the most common and the most challenging to manage\(^16\).
- Pain, both neuropathic and nociceptive; critical to control, not only because of its debilitating effects but also because of its contribution to fear, depression and anxiety\(^17\).
- Dyspnoea, most commonly due to pleural effusion, lymphangitis carcinomatosis, fatigue and lung metastases\(^18\).
- Delirium, which occurs generally in the final stages of disease, can be due to a multitude of causes and can masquerade as anxiety, depression, or psychosis, hence it is frequently under-diagnosed and mismanaged\(^19\).
- Quality of life will be increasingly affected. Between 26% and 30% of Australian women with advanced breast cancer reported poor quality of life in terms of global health status and physical, role, and social functioning\(^20\).

A comprehensive review of symptom management is provided in the Clinical Practice Guidelines for Management of Advanced Breast Cancer (pp 109-112)\(^21\).

**THE IMPACT OF ADVANCED BREAST CANCER ON PSYCHOSOCIAL FUNCTIONING**

Disease phase can have a profound impact on the psychological and social well being of women with breast cancer\(^22\). Specifically:

- As many as a third of women with advanced breast cancer meet diagnostic criteria for psychiatric disorders\(^9\).
- Depression amongst palliative care patients who did not acknowledge their prognoses has been found at rates almost three times that of those who demonstrated partial or complete awareness of their prognosis\(^1\).
- Physical symptoms, such as fatigue and limited mobility, and restricted functioning in social and work-related roles reduce opportunities for social contact that can result in social isolation\(^22\).
- The top two unmet needs of Australian women with advanced breast cancer are psychosocial: “concerns about the worries of those close to you” (70%) and “fears about the cancer spreading” (61%)\(^20\).

**THE IMPACT OF ADVANCED BREAST CANCER ON FAMILY FUNCTIONING**

Not only is a diagnosis of advanced breast cancer devastating for the women, but it also has a profound impact on her family and significant others.

- Caregivers for women with advanced breast cancer report that the task becomes more demanding and difficult as the disease progresses\(^23\).
- Family distress increases as the cancer advances. This burden may be exacerbated by social isolation\(^24\).
- Children of women with advanced breast cancer experience significant psychological distress, particularly adolescent daughters; and parents may not be aware of this distress\(^24\).

Given the impact advanced illness has on family functioning, Palliative Care Australia\(^25\) recommends that the patient and their family should be recognised as the ‘unit of care’.
THE IMPACT OF ADVANCED BREAST CANCER ON EXISTENTIAL ISSUES

A woman who is given the news that her cancer is incurable is likely to face important existential questions related to the meaning of her life and the prospect of facing her own death.

- “Uncertainty about the future” was described as an unmet need by a majority of women (61%) with advanced breast cancer.²⁰
- Kissane and colleagues have developed the concept of ‘demoralisation’ that incorporates the deep emotional pain and existential distress that accompanies loss of meaning and hope and social isolation in the terminally ill.

FACILITATING THE TRANSITION FROM CURATIVE TO PALLIATIVE CARE

There is a paucity of research relating directly to managing the transition to palliative care; hence many of the recommendations are based on findings from related areas of enquiry. Recommendations for discussing transitions from curative to palliative care are presented in Table 1.
# RECOMMENDED STEPS

**Table 1: Recommended Steps for discussing transitions from curative care through to palliative care**

<table>
<thead>
<tr>
<th>Prior to discussion</th>
<th>Source and level of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Recommended steps</strong></td>
<td><strong>Source and level of evidence</strong></td>
</tr>
<tr>
<td>Review all relevant information from records and test results in particular 1) prognosis &amp; 2) therapeutic options</td>
<td>Butow et al.(^{31}); Schofield et al.(^{32})</td>
</tr>
<tr>
<td>Gather any additional information from colleagues about the person’s psychosocial situation</td>
<td></td>
</tr>
<tr>
<td>Ensure discussion takes place in a private place with adequate, uninterrupted time for full discussion</td>
<td>Ptacek &amp; Eberhardt, (^{34}) Schofield, et al.(^{32})</td>
</tr>
<tr>
<td>Offer a tape-recording of consultation</td>
<td>McClement &amp; Hack (^{36}) (Level II)</td>
</tr>
<tr>
<td>Invite the woman to bring kin to the consultation, and encourage questions</td>
<td>Schofield et al. (^{34}) (Level III-3), Roter (^{35}) (Level II)</td>
</tr>
<tr>
<td><strong>Elicit the woman’s understanding of her situation and preferences before discussing clinical decisions</strong></td>
<td></td>
</tr>
<tr>
<td>Ask open questions to determine the woman’s understanding of her disease, the purpose of recent treatment and/or tests</td>
<td>Baile et al. (^{29}) (guidelines), Schofield et al. (^{34}) (Level III-3)</td>
</tr>
</tbody>
</table>
| Ask open questions with a psychological/ existential focus to determine her feelings, concerns, and goals  
- What concerns you most about your illness?  
- What has been most difficult about this illness for you?  
- What are your hopes, expectations and fears about the future?  
- As you think about the future, what is most important to you?  
- Is there any unfinished business in your life that you want to attend to? | Cox et al. \(^{40}\) (Level II)  
Lo et al. \(^{38}\) (guidelines)  
Kissane and Yates \(^{39}\) |
| Assess the person’s preferences for information:  
- How much information would you like?  
- What types of information would you like? I can talk about . . . | Schofield, et al., \(^{32}\) Hagerty et al., \(^{30}\)  
Fallowfield et al., \(^{42}\) Fallowfield, Ford, Lewis \(^{41}\) |
| **Acknowledgement of cultural and linguistic diversity** |  |
| Be aware of attitudes and information needs of different cultural groups especially in relation to discussions of prognosis and death and dying, but not be too confined by them. Individuals can step outside their cultural circle. | Huang et al. \(^{66}\)  
Lickiss \(^{67}\) |
| **Provide information** |  |
| Provide information simply and honestly, using lay terms and no euphemisms. Information may include: disease progression; treatment efficacy; prognosis; symptom management issues | Chapman et al \(^{35}\), Baile et al. \(^{29}\) (guidelines) |
Sensitively convey the information that no curative treatment exists for her disease or that her disease is no longer responding to the current treatment. More of this treatment would do more harm than good. As the seriousness of your cancer increases, it may be that you will achieve better quality of life without further chemotherapy but we continue an active focus on meeting your all of your needs with the best available treatments and support.  

<table>
<thead>
<tr>
<th><strong>Respond to the woman’s emotional reaction</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Allow and encourage the woman to express her feelings</td>
<td>McArdle, et al. 52 (level II) Schofield et al. 34</td>
</tr>
<tr>
<td>Express empathy and listen actively</td>
<td>McArdle, et al. 52 (level II)</td>
</tr>
<tr>
<td>Wait until tears or emotional reaction subsides before moving on</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Negotiate new goals of care</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ask whether the woman would like to discuss future treatment options today or sometime later</td>
<td>Hagerty et al. 30</td>
</tr>
<tr>
<td>Use the term “palliative care” explicitly to maintain open &amp; honest communication Ask what she understands the term palliative care to mean and correct any misperceptions Provide relevant information about the role of palliative care appropriate to her situation i.e. symptom management and maintaining quality of life</td>
<td>Fallowfield et al. 42 Lilly et al. 54 (Level II)</td>
</tr>
<tr>
<td>Positively promote the holistic nature of palliative care and the wide range of services provided i.e. not just symptom control</td>
<td>Baile et al. 29 (guidelines)</td>
</tr>
<tr>
<td>Explain that effective symptom management can be given at the same time as treatment to control the spread of the cancer</td>
<td>Baile et al. 29 (guidelines)</td>
</tr>
<tr>
<td>If a woman continues to ask for curative/current treatment, respond to emotions underlying these requests</td>
<td>Baile et al. 29 (guidelines)</td>
</tr>
<tr>
<td>Provide realistic reassurance and positive hopes for the future eg about positive, achievable goals</td>
<td>Butow et al. 35</td>
</tr>
<tr>
<td>Work from an assumption that “there is never a time when nothing can be done” to rebuild morale.</td>
<td>Kissane and Yates 39</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Continuity of care</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Refer to the palliative care health professionals as part of the woman’s multidisciplinary team</td>
<td>Weissman &amp; Griffe 27</td>
</tr>
<tr>
<td>Explicitly state to the patient that she will receive optimal care at all times and will not be abandoned.</td>
<td>Baile et al. 29 (guidelines)</td>
</tr>
</tbody>
</table>
### Address family concerns

<table>
<thead>
<tr>
<th>Description</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family members and other carers will need to be informed and understand the implications, especially caregiver burden. - What challenges and concerns would exist for you in caring for your ill relative?</td>
<td>Hudson, Aranda, Kristjanson, in press^{54}</td>
</tr>
<tr>
<td>If the women has young or adolescent children, ask about concerns relating to her children and clarify assistance required in discussing these issues with her children</td>
<td>NBCC 1997^{24}</td>
</tr>
</tbody>
</table>

### Concluding the discussion

<table>
<thead>
<tr>
<th>Description</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summarise main points of discussion and check woman’s understanding</td>
<td>Schofield et al. (^{35}) (Level III-3)</td>
</tr>
<tr>
<td>Provide written summary (or audiotape of consultation), other written patient information</td>
<td>Sheard &amp; Maguire (^{48}) (Level I) for psychological interventions</td>
</tr>
<tr>
<td>Check for the need for other referrals - Would you like to talk about how you feel with a counsellor? - Would you like to talk about options for help at home with a social worker - Would you like to explore religious or spiritual issues with someone? - Would your children like to talk to a counsellor?</td>
<td>Butow et al. (^{55})</td>
</tr>
<tr>
<td>Emphasise hope-giving aspects of the discussion eg maximising length and quality of life; availability of up to date treatments</td>
<td>Schofield et al. (^{34}) Roter (^{35}) (Level II)</td>
</tr>
<tr>
<td>Ask if there is anything else the woman or her family wants to ask or discuss</td>
<td></td>
</tr>
<tr>
<td>Organise a follow-up appointment</td>
<td></td>
</tr>
</tbody>
</table>

### After discussion

| Description                                                                 | |
|----------------------------------------------------------------------------||
| Let other members of the treatment team, especially, palliative care health professionals, the woman’s general practitioner and community nurse know about the discussion and your perception of the person’s understanding. | |
| Document discussion in medical records                                       | |

### WHEN SHOULD I DISCUSS THE TRANSITION TO PALLIATIVE CARE?

By making the intent of the treatment clear and introducing notion of specialist palliative care services early after the diagnosis of advanced disease, oncologists, general practitioners and nurses who are providing treatment with palliative intent can facilitate the gradual transition to palliative care. While the palliative approach may be conceptualised as a gradual transition, the introduction of palliative care services is a distinct event. There is very little research on the triggers for a referral to palliative care.
services. One study has suggested that pain control is the most common trigger for referral, and is believed by health professionals to be the symptom most usefully addressed by palliative care services. Perceptions of when is the best time to introduce palliative care services vary markedly between health professional groups, with hospital nurses favouring early referral and hospital doctors and general practitioners later referral. It has been suggested that the introduction of the palliative care team as part of the multidisciplinary team early after the diagnosis of advanced cancer, as opposed to waiting until severe symptoms emerge, may aid in the adjustment process. However, ultimately the timing should be guided by each individual woman’s preferences.

**HOW SHOULD I PREPARE FOR THIS DISCUSSION?**

**Gathering relevant information:** Meeting the information needs of people with cancer is vital at any stage of the disease and this critical transition is no exception. The vast majority of people with cancer want as much information as possible about their diagnosis, their prognosis, and especially their treatment options. Hence, the first task is to review all relevant information prior to the discussion. This may include talking to colleagues involved in the woman’s care to better understand her psychosocial situation or any particular concerns or issues she might have.

**HOW DO I SET-UP THE CONSULTATION?**

**Supportive environment:** It is important to ensure that the discussion takes place in a supportive environment. In a review of breaking bad news recommendations, there was general agreement that ‘bad news’ discussions of this type should take place in a quiet, comfortable and private location, sufficient uninterrupted time should be available to allow time for questions and discussion, and the patient should be encouraged to invite their significant others to be present. Australian cancer patients endorse these recommendations. Moreover, having significant others, usually the spouse, present to hear the bad news has been linked to lower levels of patient anxiety (Level III-3). The woman and her family should be asked throughout the consultation whether they have any questions. Encouraging patients to ask questions has been associated with more patient questions (Level II) and lower levels of anxiety (Level III-3).

**Audiotapes for this consultation:** Studies examining the utility of audio taping consultations have produced mixed results. Overall, it seems that audiotapes are beneficial for most people with cancer, particularly those with high information needs (Level II). However, one study found that people with poor prognoses who received an audiotape reported significantly higher psychological distress than those who did not
receive an audiotape (Level II). The investigators concluded that the audiotape may have precluded the helpful use of 'denial' by some people. Hence, it is advised that in the context of advanced breast cancer, the provision of audiotapes is tailored to the individuals' needs and personal preferences.

**HOW DO I BEGIN THIS DISCUSSION?**

**Understanding the woman’s perspective:** Eliciting the woman's understanding of her situation will establish common bearing for the health professional and woman, and provide direction to the health professional about how to address the issue of palliative care with this particular woman. Baile and colleagues in their guidelines addressing communication issues for end of life care, recommend asking the patient to explain the purpose of recent treatments, procedures or tests so the doctor can verify that they hold a common understanding, and address misunderstandings or gaps in knowledge. Lo and colleagues suggest that prior to discussing palliative care with patients, the doctor should ask a series of open-ended questions to elicit patients' concerns, goals and values. In this way, the doctor can acknowledge and understand the psychosocial, spiritual or existential suffering the person may be experiencing. Research shows that open-ended questions with an emotional content elicit greater expression of feelings than closed questions (Level II).

**Tailoring information:** It is important to tailor information provision to the individual because information preferences do vary and a small proportion of people do not want a lot of information. These people tend to be older and have poorer prognoses. This suggests that for women with advanced breast cancer, it is particularly important to carefully assess how much and what type of information and when it is desired, and not to assume that they wish to be told as much as possible. This is particularly true when introducing palliative care services.

**HOW SHOULD I APPROACH CULTURAL AND LINGUISTIC DIVERSITY?**

Most of these studies discussed above were conducted in developed countries (Australia, UK and USA) with English-speaking participants. However, there is some evidence that there are major cultural and regional differences in communication preferences about palliative care. Bruera and colleagues found that 93% of Canadian doctors said that the majority of their patients wanted to know about the terminal stage of their illness compared with 18% of South American and 26% of European doctors. Canadian doctors were inclined to support 'autonomy' as their
primary guiding ethical principle, whereas South American doctors regarded 'beneficence' as primarily guiding decisions about communication and care.

A qualitative study of Chinese-Australian people with cancer found that non-disclosure of poor prognosis was favoured and there was an emphasis on the family acting as mediators between the health professionals and the patient\textsuperscript{66}. Obviously, there needs to be recognition that communication, particularly in relation to palliative care, involves values and ethical principles, which are influenced by cultural diversity. However, it is prudent not to generalise, as people from a particular cultural background may vary widely in the extent to which they conform to the customs and expectations of that cultural group\textsuperscript{67}.

**WHAT INFORMATION DO I PROVIDE?**

**Prognostic and treatment information:** Limited evidence suggests that people with advanced disease tend to underestimate the extent of their disease\textsuperscript{43,44} and be overly optimistic about their prognosis\textsuperscript{43,44,45,46} (Level III-3). This may be as a result of inadequate communication between health professionals and people with advanced disease. In one study of seriously ill people, only 20\% of clinician/patient pairs agreed that the doctor had communicated that the illness was fatal and in almost half (49\%) the clinicians said that they had told the patients but the patients reported no communication. Better agreement was reached for life expectancy discussions; with 73\% of pairs agreeing the discussion had not taken place\textsuperscript{47}. These misperceptions may also be as a result of health professionals providing a skewed estimate. Lamont and Christakis\textsuperscript{48} found that 23\% of physicians would not give a survival estimate to people with advanced cancer; 37\% would give the survival estimate that they had formulated and 40\% would give an estimate different from the one formulated and most of these estimates were overly optimistic. While it is reasonable to hope for a better than expected outcome, it can be helpful to prepare patients for all eventualities by considering poorer outcomes.

These misperceptions about prognosis are significant because patients who have overly optimistic perceptions of their prognosis are more likely to ask for futile, curative treatments making palliative care referrals more difficult\textsuperscript{46} (Level III-3). Hence, if patients want prognostic information, it is important to provide them with as accurate information as possible. It has been shown in a study of people with incurable cancer that information provision related to prognosis and palliative care treatment options was not associated with increased patient anxiety\textsuperscript{49} (Level III-3). The authors speculated that if information provision is not open, honest and detailed, patients may perceive doctors as withholding potentially frightening information. This sentiment was echoed by Fallowfield...
and colleagues. In their study of 1046 palliative patients, the vast majority (85%) wanted “as much information as possible, good and bad”. Over 90% of people being treated palliatively wanted to know their chances of cure and all possible treatment options. They concluded “misguided evasion or frank dishonesty may add considerably to a patient’s distress”. In keeping with providing open and honest information, Baile and colleagues recommend in their guidelines that the doctor should sensitively convey to the patient that all curative treatment options have been exhausted with statement such as “any more chemotherapy may do you more harm than good”.

Information also needs to be provided using lay terms and euphemisms should be avoided. Recent UK research has shown that a substantial proportion of the general public do not understand words and phrases, such as ‘metastasis’ and ‘spots in the liver’ used in cancer consultations.

**HOW SHOULD I RESPOND TO THE WOMAN’S EMOTIONAL REACTION?**

An open and honest discussion about prognosis is likely to be very upsetting for the woman and her family. Health professionals should encourage emotional expression and respond with empathy. In a qualitative study of being referred to palliative care services, the inexperience and insensitivity of the doctor to patients’ emotions presenting the greatest problems. A sense of security and confidence was generated in the patients when the doctor displayed the characteristics of “the empathic professional” displaying a balance between medical competence and empathy. Empathic encouragement of emotional expression, combined with providing information, and correcting misperceptions, has been found to reduce psychological distress in women with breast cancer (Level II). Another study found that talking about the patient’s feelings and being reassuring has been found to be associated with lower levels of patient anxiety (Level III-3). Expressing empathy involves acknowledging the person’s feelings as valid and appropriate, with statements such as “this must be a really tough time for you”. Active listening can assist the clinician to understand how the woman is feeling and help convey empathy. Active listening involves using eye contact, having an attentive posture, showing interest, such as nodding and making noises of agreement or encouragement, and then summarising what was said.

**HOW DO I BRING UP PALLIATIVE CARE SERVICES?**

Seek the woman’s preferences: In a survey of 126 metastatic cancer patients, Hagerty and colleagues found that 33% wanted to discuss “dying and palliative care services” when first told cancer had spread; 19% said in the next few consultations; 33% said later, upon (their) request; 11% said never; and 10% were unsure. There were also a variety of
opinions about who should initiate the discussion: 45% wanted the specialist just to tell; 20% wanted the specialist to check first if the patient wanted to know; and 24% wanted the specialist to tell only if patient asks. These results indicate that the safest course of action would be to make general enquiries about whether the woman wanted to discuss future care options now or later, before initiating discussions about palliative care services.

**Introduce palliative care options:** In their guidelines, Baile and colleagues recommend that after indicating that further curative treatment has a low chance of being effective, the clinician should introduce the option of effective palliative treatment options that focus not only on symptom control and a range of quality of life issues. They suggest that this transition may take some time with many patients wishing to continue with curative or anti-cancer treatments while also receiving palliative care to control symptoms. Further, he recommended that if a person continues to ask for futile treatment, that the doctor respond with empathy because the patient's emotions, often fear and desperation, need to be understood and acknowledged.

A study of people admitted to intensive care units found that patients and kin who received a series of staged discussions about treatment goals and palliative care options with the critical care team ceased futile active treatment earlier, compared with usual care, with no decrease in survival time (Level III-3).

No research could be found related to introducing palliative care, using the term "palliative care" or the understanding of this term by the general public. However, several authors recommend "open and honest" communication with advanced cancer patients, which suggests the term "palliative care" should be used. The understanding of this term should also be probed and misperceptions corrected. There seems to be a common misconception that palliative care is synonymous with end-of-life or terminal care. While this is an important aspect of palliative care, it should be communicated that palliative care is far broader than care in the final phase of life.

**Maintaining hope:** Hearing the news of incurable disease is understandably devastating for most people. A qualitative study of people with advanced cancer revealed that patients believe it is crucial that doctors communicate hope as well as honest clear information in their discussions of prognosis with them. Fear about loss of hope may underpin the trepidation patients feel about asking for prognostic information. However, avoiding the issue or limiting prognostic information may in itself diminish hope.
Sardell & Trierweiler\textsuperscript{56} found that patients view procedures that disguise a negative prognosis as hope reducing.

Hope has been defined as “the perception that one can reach one’s desired goals”\textsuperscript{57} but that there is some uncertainty still attached to these perceptions. Hence, using this definition hope is not an entity in itself, but is attached to goals or potential outcomes that may change over time as circumstances evolve. Nunn\textsuperscript{58} pointed out that “hope is associated all too commonly with unrealistic expectations” (p.231). Hence, it is critical that the messages of hope that are provided to patients are appropriate. Fostering false hope of a cure when a cure is not possible ultimately can be a source of regret as it may hinder patients and their family making sensible treatment decisions and lifestyle decisions in order to make the best use of the remaining time together\textsuperscript{59}. However, Links and Kramer\textsuperscript{60} have asserted that, in the context of a poor prognosis, it is not necessarily inappropriate for a patient to hope for a cure even if it is highly unlikely, but messages of hope should also include more probable events such as long periods of remission and response to treatments. Strategies that successfully promote appropriate hope may make a critical contribution to discussing the transition from curative to palliative care.

Little research has been performed on how to foster hope in cancer patients. One study\textsuperscript{56} involved 56 cancer patients rating statements describing communication procedures on a hopefulness scale. The top 5 procedures considered most hopeful were the doctor: offering of most up-to-date treatments; insisting that the patient will not be abandoned; offering to be a resource for all questions; being willing to call in other physicians if needed; and stating that there are many treatments available that can cure or slow down a cancer. Another qualitative study\textsuperscript{55} with metastatic cancer patients identified several hope-fostering strategies. These included: the discussion of extraordinary survivors promotes hope; emphasising the positive and achievable outcomes of treatment; discussing a patient’s future in terms of a series of goals and normalising death as a natural event and encouraging preparation for this possibility.

**Rebuilding morale:** Kissane and Yates\textsuperscript{39} have argued that addressing a person’s existential issues is crucial to the successful psychosocial care of a person with advanced disease. They suggest that existential distress can take several forms: death anxiety (fear of process of dying or death); demoralisation (sense of pointlessness and helplessness); grief (intense sadness, anger and sense of unfairness); aloneness (sense of isolation in life); loss of freedom (angst at loss of control; fear of dependence); and loss of dignity (distressed by illness, shame, fear of being a burden). Rebuilding morale requires an assumption by the treatment team that “there is never a time when nothing
can be done” to assist the person in palliative care. This assumption should underpin the discussion of the transition from curative treatment to palliative care.

**HOW CAN I ENSURE CONTINUITY OF CARE?**

Introducing the palliative care health professionals as part of the multi-disciplinary treatment team early can facilitate the transition from curative treatment to palliative treatment. It is important that the palliative care professionals are seen as an integral part of the treatment team, which will enhance the sense of continuity of care and allay any fears of abandonment. This permits women and their families to establish relationships with the palliative care professionals while maintaining a parallel care relationship with their oncologists. In addition, discussion of the palliative intent of life prolonging chemotherapy or radiotherapy treatment on several occasions over time by the oncologist or general practitioner may assist in the transition. Gradually, primary responsibility for care can shift to palliative care health professionals as the disease progresses. Baille and colleagues recommend that when introducing the option of palliative care services, the physician should explicitly state that he/she will not abandon the patient.

**HOW CAN I ADDRESS FAMILY CONCERNS?**

Caregivers, usually a spouse or family member, must deal with unfamiliar situations and demands and many feel inadequately prepared for this role, particularly in relation to receiving guidance, support and information from health professionals. Evidence-based recommendations for information provision to family caregivers to help them assume their care-giving role have recently been developed. It is vital to include family members in the discussions surrounding the transition from curative to palliative care and meet their needs as well as the woman’s needs. In a NBCC review of the needs of children of mothers with advanced breast cancer, it was recommended that clinicians should routinely ask about the family, particularly the children’s adjustment, clarify what assistance might be needed in discussing her illness with her children, and facilitate referrals for family members as necessary.

**HOW DO I CONCLUDE THE DISCUSSION?**

Providing a summary of the main points of the discussion, emphasising the hope giving aspects, checking the woman’s understanding is a useful way to ensure there are no misperceptions and to signal the end of the consultation. A summary of the consultation (written or audio tape) and other patient information is wanted by many patients. The provision of written information in bad news consultations is associated with lower levels
of patient anxiety\textsuperscript{34} (Level III-3). It is also important to check the need for referrals to other health professionals, such as to psychological services, social work or pastoral care. A meta-analysis by Sheard and Maguire\textsuperscript{68} (Level I) showed that psychological interventions have a moderate clinical benefit for anxiety (effect size =0.36) but a weak effect for depression (effect size=0.19). However, interventions targeted at patients experiencing significant clinical distress demonstrated the strongest benefits. The discussion should be concluded by asking the woman and her family whether they have any final questions. Finally, it is important to propose a follow-up appointment to review the situation, address new concerns and questions and to reinforce a commitment to continuity of care.

A summary of the consultation should be documented in the patient’s medical record. In addition, members of the woman’s broader treatment team, especially, palliative care health professionals, general practitioner and community nurse should be informed about the discussion and perceptions of the person’s understanding. This is likely to facilitate the provision of optimal health care and strengthen communication both between the woman and her treatment team and within the team itself.

**EMOTIONAL IMPACT ON HEALTH PROFESSIONALS**

Health professionals generally find it very difficult to introduce the topic of palliative care. Over 40\% of oncologists from western countries reported that they “occasionally” to “almost always” withheld prognosis from patients\textsuperscript{12}. Over half said that they “occasionally” or “frequently” used euphemisms in discussing a grave prognosis, in order to maintain hope; and around a quarter said that they “occasionally” administered a treatment that was not likely to work, in order to bolster the patient’s hope. In comparison to other communication tasks, oncologists tend to feel less confident about “telling patients you are replacing active therapy with symptomatic care only”\textsuperscript{69}. Health professionals also find it difficult to respond to patient emotions. Non-disclosure of feelings by terminally ill patients has been shown to be positively related to blocking behaviours among hospice nurses, while nurses who perceived that their supervisors were supportive of them engaged in less blocking behaviour\textsuperscript{70}. A number of blocking techniques can be used to limit emotional disclosure. These include directing the conversation to focus on medical issues\textsuperscript{71}; changing the topic\textsuperscript{72}; offering reassurance without exploring the issue\textsuperscript{73} and ignoring emotional cues by the patient\textsuperscript{74}.

The stress experienced by health professionals involved in the care of the seriously ill and dying has been increasingly recognised. Not only does the health professional have to deal with patients’ emotions and concerns but potentially their own feelings of failure,
helplessness and frustration arising from advancing illness, which may be compounded by stresses in their private lives. Approximately one third of oncologists report high levels of emotional exhaustion. Burnout amongst oncologists has been found to be associated with a negative attitude towards, and low personal involvement in the organisation or the provision of palliative care for seriously ill patients. Levels of stress experiences by palliative care workers has been found to be lower when the staff have particular personality characteristics, such as high self-esteem and hardiness, have adequate social support, they are actively involved in work-related decision-making and they have a realistic work load. To prevent burnout, it is recommended that health professionals should take an active role in caring for themselves by increasing self-awareness and recognising emotional exhaustion early and taking action. Various mechanisms have been proposed to manage work related stress. These include: sharing concerns with colleagues and developing strong collaborative team relationships, setting realistic work goals, developing a personal philosophy of illness and death, maintaining a balance between one’s personal and professional lives, and engaging in good health habits including diet, exercise and rest. Communication skills training is also recognised as one of the effective mechanisms for addressing this issue.
CONCLUSIONS

The formal introduction of palliative care services is clearly a deeply distressing time for a woman with advanced breast cancer and her significant others. With skill and perceptive sensitivity, the anguish associated with this transition can be eased.
REFERENCES


