



# Multidisciplinary care principles for advanced disease: a guide for cancer health professionals

Prepared by  
National Breast and Ovarian Cancer Centre



**NATIONAL BREAST  
AND OVARIAN  
CANCER CENTRE**

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# INTRODUCTION

## What is multidisciplinary care (MDC)?

MDC is an integrated team approach to health care in which medical and allied health care professionals consider all relevant treatment options and collaboratively develop an individual treatment and care plan for each patient.<sup>1</sup>

MDC is crucial in assuring that all relevant disciplines contribute to the care planning of patients.<sup>2</sup> As outlined in the National Breast Cancer Centre (NBCC)\* *National Demonstration Project report*,<sup>3</sup> there is evidence to support the benefits of the MDC approach in the management of patients with cancer. These benefits include:

- increased survival for patients managed by a multidisciplinary team
- increased perception by the patient that care is being managed by a team
- greater likelihood of receiving care in accord with clinical practice guidelines, including psychosocial support
- increased patient satisfaction with care
- increased access to information for patients, particularly psychosocial and practical support.

The *Principles of multidisciplinary care*<sup>3</sup> developed by NBCC provide a definition of MDC that is flexible and recognises that implementation will vary according to the size or location and type of service. The NBCC *Principles of multidisciplinary care* are:

- a **team approach**, involving core disciplines integral to the provision of good care, with input from other specialists as required
- **communication** among team members regarding treatment planning
- access to the **full therapeutic range** for all patients, regardless of geographical remoteness or size of institution
- provision of care in accord with **nationally agreed standards**
- **involvement of patients** in decisions about their care.

*\*In February 2008, National Breast Cancer Centre (NBCC) changed its name to National Breast and Ovarian Cancer Centre (NBOCC).*

## Advanced disease

Advanced disease is defined as: *cancer where the goal of treatment and care may not be cure, or where cure is not an option.*

Improvements in cancer treatment mean that there are more patients surviving longer and many receiving treatment and care for advanced disease. It is important to acknowledge that every patient's cancer and care will be different; some patients will live for many more years after a diagnosis of advanced disease, while others may only live for a short time. The needs and issues of these patients with advanced disease include:

- specific psychosocial issues including impact of diagnosis at an advanced stage, poorer prognosis and recurrence<sup>4,5</sup>
- the management of physical symptoms and side effects related to the spread of cancer and cancer treatments<sup>6</sup>
- quality of life issues associated with disease progression<sup>4</sup>
- practical issues and support for patients living with advanced disease.<sup>7</sup>

## MDC principles for advanced disease

The *MDC principles for advanced disease (PAD)* are based on the *Principles of Multidisciplinary Care*<sup>3</sup> developed by the NBCC and adapted to reflect the role of MDC teams in the advanced disease setting.

The PAD stress the importance of continuity of care, coordination, and the involvement of the patient and their nominated caregivers, where appropriate, in the treatment and care planning process. The PAD also highlight the shift from primarily hospital-focused interventions to a more community-based approach to care. The PAD provide a flexible definition of MDC, allowing services to implement MDC in a way that is relevant to the cancer type and service. Multidisciplinary input through MDC treatment planning meetings should be considered for all patients with advanced disease.

The primary goal of the PAD is to improve care and quality of life of patients with advanced disease while maximising comfort and functioning. The MDC approach provides opportunities for multidisciplinary discussion, enabling teams to facilitate effective treatment and care planning for patients with advanced disease.



# THE MDC PRINCIPLES FOR ADVANCED DISEASE (PAD)

## 1 Patient-defined goals of care

Patients and their nominated caregivers, where appropriate, are involved in decisions about their care

### PRINCIPLE OF CARE

- a** Patients with advanced disease and their caregivers, where appropriate, should be encouraged to participate as members of the multidisciplinary team in care planning
- b** The patient and their caregivers, where appropriate, should be fully informed of the treatment and care options, including the benefits, risks and possible complications of treatments offered and how to access appropriate support services to enhance quality of life
- c** The treatment plan for a patient should consider individual patient circumstances and wishes
- d** Patient care is coordinated and not fragmented and the patient and their caregivers, where appropriate, are aware of the communication between team members

### OUTCOME

Patients and their caregivers, where appropriate, are provided with opportunities and supported to have as much input into their care plan as they wish

Consent from the patient prior to communication among team members should be obtained according to local protocols

Appropriate information is offered to assist decision making about treatment and care options and made available in a form that is appropriate to the patient's educational level, language, and culture

The treatment plan is discussed with the patient and their caregivers, where possible, revised as appropriate, and recorded in patient's file

Discussion and decision making about management options is an ongoing and dynamic process

The patient and their caregivers, where appropriate, are regularly informed of the ongoing collaboration and communication between members of the multidisciplinary team about their treatment

Patients' perceived expectations of their care needs are actively sought and met throughout their care

## 2 Team

A team approach involves disciplines integral to the provision of good care, with input from others, as required

### PRINCIPLE OF CARE

- a** A multidisciplinary team approach to care should be considered for all patients with advanced cancer
- b** The cancer care team should be flexible to include health professionals from allied health, palliative and supportive care, community health, nursing and cancer clinicians, as required
- c** The team leader and membership may change with the patient's changing needs over time, while maintaining a focus on optimising patient function and comfort throughout the disease

### OUTCOME

A local protocol is established to ensure multidisciplinary discussion for all patients who present with advanced cancer; the patient and their caregivers, where appropriate, are informed of this

The cancer care team for each patient is established and known by all team members including the patient, their caregivers and the MDC team agreed point of contact

The team leader and membership are reviewed in consultation with patients and their caregivers to ensure appropriate care is offered and provided which meets the patient's changing needs

## 3 Communication and information

Ongoing, timely information and communication is facilitated among all team members, including the patients and their nominated caregivers, throughout the cancer journey

### PRINCIPLE OF CARE

- a** A communications framework should be established which supports and ensures interactive participation from all relevant team members at regular and dedicated case-conference meetings
- b** Timely written communication between all health professionals including GPs is vital to providing optimal care

### OUTCOME

Appropriate communication mechanisms are established to facilitate case discussion by all team members

Systems are in place to ensure patients' results are made available to team members in a timely manner



- |   |  |
|---|--|
| <p><b>c</b> End-of-life (EOL) planning is considered by members of the multidisciplinary team and support services are provided, encouraged and facilitated for all involved</p>  | Health professionals have access to appropriate training and support to enable them to appropriately manage EOL issues   |
| <p><b>d</b> As team membership and care setting (home, hospital, palliative care unit) may change during the course of the disease, communication between the MDC agreed point of contact, patient and caregivers is maintained</p> | The patient and their caregivers are aware of who bears primary responsibility for their care and their agreed point of contact during the course of the disease |

## 4 Standards of care

Provision of medical and supportive care is in accord with nationally agreed standards

### PRINCIPLE OF CARE

- a** All health professionals involved in the management of patients with advanced cancer should practise in accord with guideline recommendations
- b** Maintenance of standards of best practice is supported by a number of activities which promote professional development
- c** Location, type of service or patients' understanding of the health system should not be impediments to patients' access to MDC
- d** The members of the team should support the multidisciplinary approach to care by establishing collaborative working relationships with appropriate local health care professionals
- e** Use of supportive care services, including palliative care, and psychosocial interventions/support should be encouraged and facilitated

### OUTCOME

- Care is demonstrated to be consistent with national evidence-based recommendations and benchmarks, where relevant
- Systems are established and monitored for the support of professional development
- Systems are established to support all patients with advanced disease to have access to MDC
- Systems are established to support collaborative working relationships and referral links
- Systems are established to provide patients with equitable access to all relevant medical and supportive care services

# 1. PATIENT-DEFINED GOALS OF CARE

Patients and their nominated caregivers, where appropriate, are involved in decisions about their care

## PRINCIPLE OF CARE

- a** Patients with advanced disease and their caregivers, where appropriate, should be encouraged to participate as members of the multidisciplinary team in care planning
  
- b** The patient and their caregivers, where appropriate, should be fully informed of the treatment and care options, including the benefits, risks and possible complications of treatments offered and how to access appropriate support services to enhance quality of life
  
- c** The treatment plan for a patient should consider individual patient circumstances and wishes
  
- d** Patient care is coordinated and not fragmented and the patient and their caregivers, where appropriate, are aware of the communication between team members

## OUTCOME

Patients and their caregivers, where appropriate, are provided with opportunities and supported to have as much input into their care plan as they wish

Consent from the patient prior to communication among team members should be obtained according to local protocols

Appropriate information is offered to assist decision making about treatment and care options and made available in a form that is appropriate to the patient's educational level, language, and culture

The treatment plan is discussed with the patient and their caregivers, where possible, revised as appropriate and recorded in patient's file

Discussion and decision making about management options is an ongoing and dynamic process

The patient and their caregivers, where appropriate, are regularly informed of the ongoing collaboration and communication between members of the multidisciplinary team about their treatment

Patients' perceived expectations of their care needs are actively sought and met throughout their care

## Supporting patients and their caregivers to participate

Explaining the concept of the 'MDC team approach' is an important part of introducing MDC to the patient and their caregivers. This is usually done by the lead health professional. All patients and their caregivers should be informed about the members of their MDC team, what and how information is shared between team members, and the treatment plan. It is important to explain to the patient and their caregivers how the meetings work, the meeting structure, whether or not patient names are used in the meeting and issues relating to confidentiality.

Protocols should be in place to ensure that patients' and caregivers' preferences are considered at the MDC treatment planning meeting. The patient and their caregivers do not have to be in attendance at the treatment planning meeting itself, although patients and their caregivers should have input into outcomes of the meeting and treatment plans.

The MDC team should ensure that both the patient's and caregiver's needs are met, wherever possible. Patients' and caregivers' perceptions about their cancer journey and interactions with health professionals may influence the treatment planning and care. Health professionals need to acknowledge this and be aware that the way they relate to, and communicate with, the patient and their caregivers may affect the way the patient and caregivers cope with the cancer. It also can affect the way caregivers resolve their grief following the death of the patient.

## Informing the patient and caregiver

Having relevant information available to the patient and their caregivers not only helps the patient and their caregivers understand the disease, but also helps with decision making and coping with the diagnosis. As health professionals, it is important to elicit the information needs of patients and their caregivers, as these may not always be forthcoming. This includes information related to the nature of the disease, cancer treatments and care options, side effects of treatments, impact on daily life, and patients' and caregivers' psychosocial concerns.

The availability of information in different languages can improve health professionals' ability to effectively communicate with patients and their caregivers from culturally and linguistically diverse backgrounds. Information regarding the use of interpreters should be provided to patients and caregivers, if needed. If an interpreter is required, health professionals should explain to the patient and caregivers that family members and friends are not appropriate translators, as they may not understand medical terminology and may have their own reactions and issues to deal with. A professional interpreter should be used.

## Consent

The patient should be informed that treatment and care planning by the MDC team is part of their care and that their case may be discussed with health professionals whom they have not yet met. Consent from patients should be obtained in line with local protocols regarding consent for the

disclosure and use of personal information in the health environment. It is important to identify the level and type of consent required; for example, who is responsible for obtaining consent and ensuring all team members are aware of consent requirements.

## Caregiver's role

It is important to acknowledge caregivers as vital participants in the cancer journey. Caregivers are family members and/or friends identified by the patient who provide psychosocial and/or physical support to the patient throughout their disease. The role of caregivers should be discussed with the patient to ensure caregivers are involved, where appropriate. Caregivers play a central role in the care and wellbeing of the patient, especially in the later stages of the disease. Attention should be given to the needs and experiences of caregivers as well as patients during this time and caregivers should be offered information and support as required.

## Treatment planning

It is important for teams to establish a process for communicating case discussion outcomes and recommendations to the patient, their general practitioner (GP), and caregivers, where appropriate. The treatment and care plan should be formal, in writing, and should consider the full range of treatment and care options available to the patient, while taking into account the patient's and caregivers' preferences. Where possible, written care plans should be made available to the patient. In addition, patients' access to a second opinion outside the initial team should be respected and facilitated.

Re-evaluating treatment and care plans should be done at critical points during the course of disease including diagnosis, change in treatment, recurrence, or the end of active treatment. It is essential that treatment and care plans are assessed regularly because many changes will occur during the course of the patient's disease. Any changes made to the patient's treatment plan should be discussed with the patient and caregiver and documented.

## Coordination of MDC

The MDC team should designate an agreed point of contact. The agreed point of contact may be fulfilled by a nurse or other supportive care personnel. The team should consider who within their team can fulfil this role, if a designated person is not already in place. The role of this person will be to coordinate administrative aspects of the patient's care, which may include:

- ensuring effective communication between team members, other health professionals and the patient and caregivers
- providing information and referral to services and programs to the patient and caregivers
- providing follow-up and support for the patient and caregivers
- providing written information and resources.

A lead health professional may also be designated to liaise with the patient and their caregivers, where appropriate, regarding treatment and care planning.

## 2. TEAM

A team approach involves disciplines integral to the provision of good care, with input from others, as required

### PRINCIPLE OF CARE

- a** A multidisciplinary team approach to care should be considered for all patients with advanced cancer
- b** The cancer care team should be flexible to include health professionals from allied health, palliative and supportive care, community health, nursing and cancer clinicians, as required
- c** The team leader and membership may change with the patient's changing needs over time, while maintaining a focus on optimising patient function and comfort throughout the disease

### OUTCOME

A local protocol is established to ensure multidisciplinary discussion for all patients who present with advanced cancer; the patient and their caregivers, where appropriate, are informed of this

The cancer care team for each patient is established and known by all team members including the patient, their caregivers and the MDC team agreed point of contact

The team leader and membership are reviewed in consultation with patients and their caregivers to ensure appropriate care is offered and provided which meets the patient's changing needs

### The MDC team

The role of the MDC team for advanced disease is to coordinate and provide treatment and care to patients, and provide information to support the emotional, physical, practical, financial, spiritual and social needs of patients and their caregivers. The needs of patients with advanced disease and their caregivers will need to be regularly assessed, as their needs will change over the course of their disease.

The MDC team for advanced disease should comprise the patient, caregivers, where appropriate, and a range of health professionals integral to the provision of good care. The aim of the PAD is to allow flexibility in the process while ensuring that key underlying principles are in place. Therefore, there is no single correct model of MDC teams. The constitution of the MDC team will vary according to location, type and size of setting and cancer type. The members of the MDC team for advanced disease should reflect both clinical and psychosocial aspects of care. The inclusion of supportive and palliative care in the team and a focus on optimising function and comfort for patients with advanced disease are essential. (For more information about supportive and palliative care see 'Standards of care' page 21).

An effective team approach to care ensures smooth transitions for the patient along the continuum of care. Changes to the team should be communicated to the patient and MDC team members at a time which is appropriate to all. Providing appropriate information to the patient will improve patient understanding about their disease and assist with continuity of care throughout the patient's cancer journey.

The team members and lead health professional are not necessarily fixed and may change throughout the advanced stage of the patient's disease as the needs of the patient change. Changes to team membership should be communicated to patients and their caregivers, where appropriate.

Tables 1–3 provide examples of possible advanced cancer team membership. Other health professionals may be called upon at different times during the patient's treatment course. For example, thoracic surgeons for pleural effusions, orthopaedic surgeons for an impending fracture or neurosurgeons for cord compression surgery.

**TABLE 1: EXAMPLE OF MULTIDISCIPLINARY TEAM MEMBERSHIP: ADVANCED DISEASE**

<p><b>Allied health professionals</b></p> <p>Counsellor Dietitian Occupational therapist Pharmacist Physiotherapist Psychologist Social worker Sexual health counsellor</p>	<p><b>Clinicians</b></p> <p>General practitioner Gynaecological oncologist Medical oncologist Palliative care physician Pathologist Physician Psychiatrist Radiation oncologist Radiologist Registrars Surgeon Urologist</p>
<p><b>Community health</b></p> <p>Community health nurse Community palliative care team</p>	<p><b>Palliative and supportive care</b></p> <p>Palliative care coordinator Palliative care clinical nurse consultant Pastoral care</p>
<p><b>Other health professionals</b></p> <p>Care coordinator Clinical trials coordinator</p>	<p><b>Nursing</b></p> <p>Research nurse Specialist breast nurse Specialist gynaecological nurse</p>

**TABLE 2: EXAMPLE OF MULTIDISCIPLINARY TEAM MEMBERSHIP:  
ADVANCED BREAST CANCER**

<p><b>Allied health professionals</b></p> <p>Counsellor Dietitian Occupational therapist Pharmacist Physiotherapist Psychologist Social worker Sexual health counsellor</p>	<p><b>Clinicians</b></p> <p>General practitioner Medical and radiation oncology registrars Medical oncologist Pathologist Psychiatrist Radiation oncologist Surgeon</p>
<p><b>Community health</b></p> <p>Community health nurse Community palliative care team</p>	<p><b>Palliative and supportive care</b></p> <p>Palliative care coordinator Palliative care clinical nurse consultant Palliative care physician Pastoral care</p>
<p><b>Other health professionals</b></p> <p>Advanced breast cancer team coordinator Occupational therapist Physiotherapist</p>	<p><b>Nursing</b></p> <p>Breast care nurse for advanced breast cancer Chemotherapy nurse Inpatient oncology nurse Research nurse</p>

**TABLE 3: EXAMPLE OF MULTIDISCIPLINARY TEAM MEMBERSHIP:  
ADVANCED OVARIAN CANCER**

<p><b>Allied health professionals</b></p> <p>Counsellor Dietitian Occupational therapist Pharmacist Physiotherapist Psychologist Social worker Sexual health counsellor</p>	<p><b>Clinicians</b></p> <p>General practitioner Gynaecological oncologist Medical oncologist Pathologist Psychiatrist Radiation oncologist Surgeon</p>
<p><b>Community health</b></p> <p>Community palliative care team Community health nurse</p>	<p><b>Palliative and supportive care</b></p> <p>Palliative care consultant/nurse Pastoral care or religious representative</p>
<p><b>Other health professionals</b></p> <p>Occupational therapist Physiotherapist</p>	<p><b>Nursing</b></p> <p>Chemotherapy nurse Gynaecological nurse specialist Research nurse</p>

It will not always be possible for all team members to be present at the one site. In regional sites, it may be appropriate to plan meetings at times when a visiting specialist is due to be present. For other sites, issues of distance may be overcome using teleconference or videoconference.

## The patient's general practitioner (GP)

The patient's GP plays a pivotal role in the care planning for patients with advanced disease. Communication links with the patient's GP and the MDC team are crucial and should be maintained throughout the cancer journey. The GP of patients due to be discussed at an MDC meeting should be informed of the meeting and encouraged to attend in person or via teleconference. If the GP is unable to attend, a member of the team should communicate treatment decisions to the GP in a timely manner.



## EXAMPLE: GPs AND THE MDC TEAM MEETING

**SCENARIO:** The patient's GP initiating an MDC meeting in a rural/regional setting.

**PROCESS:** To ensure the patient's GP is involved in the MDC planning, cancer care coordinators were introduced to a rural/regional health service to provide the link between GPs and other specialists in the care team. The patient's GP works closely with the patient's care team and can initiate a care planning meeting by contacting the lead clinician. The GP is encouraged to attend the meetings in person or participate via teleconference.

**OUTCOME:** Information presented by the GP about the patient's history and psychosocial issues at the MDC planning meeting has influenced decision making around treatment and care planning.

The patient's GP should be actively involved in communicating to the patient and caregivers, where appropriate, information about their treatment and care. This includes when and how the focus of care will change from treatment to optimising function and comfort. The discussion should be documented and all members of the MDC team should be informed.

## EXAMPLE: INVOLVING GPs IN A RURAL SETTING

**SCENARIO:** Involvement of GPs in MDC discussion of breast cancer patients.

**PROCESS:** A representative GP from the local Division of General Practice attends the MDC meeting to represent all the patients' GPs. This representative takes on the role because of an interest in the area and is therefore knowledgeable medically and in regard to the specific care available in the community. The representative GP also liaises with individual GPs before the meeting to provide any useful GP perspective on the patient's situation. After the meeting the GP's role also includes feeding back the meeting recommendations to each patient's GP. This position is funded.

**OUTCOME:** Attending the meeting is one GP's regular commitment and is therefore readily achievable. Their involvement allows both input from a GP perspective, and appropriate and timely feedback to the patient's GP.

## Reviewing team process

Each multidisciplinary team should establish a process to review and audit team functionality. Team functionality refers to how members of the team work together, how the MDC meetings are set up and sustained and how team members support each other. Reviewing functionality can include how meetings are organised, the purpose of the meeting, team membership, attendance, communication among team members, patients and caregivers, and meeting outcomes. Auditing team functionality is an ongoing process which aims to ensure that the team is working in an effective way and there is optimal team interaction.

### 3. COMMUNICATION AND INFORMATION

Ongoing, timely information and communication is facilitated among all team members, including the patients and their nominated caregivers, throughout the cancer journey

#### PRINCIPLE OF CARE

- a** A communications framework should be established which supports and ensures interactive participation from all relevant team members at regular and dedicated case-conference meetings
- b** Timely written communication between all health professionals, including GPs, is vital to providing optimal care
- c** EOL planning is considered by members of the multidisciplinary team and support services are provided, encouraged and facilitated for all involved
- d** As team membership and care setting (home, hospital, palliative care unit) may change during the course of the disease, communication between the MDC agreed point of contact, patient and caregivers is maintained

#### OUTCOME

- Appropriate communication mechanisms are established to facilitate case discussion by all team members
- Systems are in place to ensure patients' results are made available to team members in a timely manner
- Health professionals have access to appropriate training and support to enable them to appropriately manage EOL issues
- The patient and their caregivers are aware of who bears primary responsibility for their care and their agreed point of contact during the course of the disease

## A communications framework

A communications framework should be developed which encourages and supports input into case discussion from all relevant team members. The framework may vary depending on the type and size of service and should acknowledge diversity and flexibility in the way that case discussion is conducted. Seamless care involves effective and timely communication between all health professionals including the patient's GP. For example, informing the patient's GP about discussion and treatment outcomes prior to patient contact will ensure that the GP provides the patient with accurate, relevant and up-to-date information about their treatment and care.

### EXAMPLE: PALLIATIVE CARE

**SCENARIO:** Promoting advanced care planning discussions.

**PROCESS:** Effective and ongoing communication of the patient's clinical care within the team will enable identification of appropriate timing for initiating discussions with the patient and family around goals of care and interventions specific to their individual needs and wishes. The process is incorporated as an integral part of MDC planning and ensures key health care providers are informed and involved and appropriate supports are made available. MDC planning is used to identify who, when, and how these discussions are best managed and enables outcomes to be communicated to other relevant providers.

**OUTCOME:** Timely discussions between patients, families and health care providers ensure goals of care and patient wishes are known and respected at key points in the illness trajectory.

## Communication issues for health professionals

The shift towards palliative care represents a crucial step for patients with advanced cancer and their treatment team. Health professionals may find it challenging to communicate and manage this transition. Introducing palliative care as part of the team approach early after the diagnosis of advanced disease can facilitate this transition.<sup>8</sup> Progression of disease may be rapid or may occur over a number of years with a series of recurrences and remissions. Contingency planning and thinking ahead will help health professionals create opportunities to discuss with their patients potential issues that may arise during the patient's disease. It is important to make clear to the patient that they will receive optimal care at all times and that this transition does not imply discontinuation of care or abandonment by their MDC team. (*For more information about palliative care see 'Standards of care,' page 21*).

Guidelines about discussing disease progression recommend open and honest provision of relevant information.<sup>8,9</sup> For example, the patient and caregiver, where appropriate, should be told about changes to the cancer, treatment efficacy and prognosis, making sure enough time is provided to allow discussion of the implications of this information and the patient's emotional response and support needs. Teams should be encouraged to undertake communication skills training in order to improve the way they relate to other team members, cancer patients and caregivers.

The exchange of knowledge and expertise between larger and smaller teams should be encouraged. This gives health professionals the opportunity to improve outcomes for patients and work towards a best-practice approach to treatment and care.

NBOCC, in collaboration with the Pam McLean Cancer Communication Centre, has developed a number of modules for health professionals to improve their confidence in discussing issues with their patients. Modules include: *'Transition from curative to palliative care,' 'Breaking bad news' and 'Emotional cues'*. For more information see [www.nbocc.org.au](http://www.nbocc.org.au).

## End-of-life (EOL) issues

Attitudes and perceptions about care, including EOL and communication issues, are important aspects beyond clinical educational activities for health professionals. Health professionals involved in the care of people with advanced disease are encouraged to develop professional skills and to participate in regular reflective practice to ensure they can provide optimal care for their patients.

Choosing how and when to raise EOL issues with terminally ill patients can be difficult for health professionals. Overall, findings suggest that it is better to err on the side of ensuring that prognosis and EOL issues are accessible topics for patients and their families. Health professionals need to be sensitive about the way that they raise the subject and first explore the patient's understanding. When discussing EOL issues it is important for health professionals to balance hope and honesty.

Dealing with patients with advanced disease can be stressful for health professionals. This is especially so when managing patients with EOL issues. It is important for health professionals to draw on the expertise of members of the MDC team in dealing with complex clinical problems. Debriefing and opportunities to access support services should also be made available to all team members.

### EXAMPLE: DISCUSSING PALLIATIVE CARE AND EOL ISSUES

**SCENARIO:** Conversation with patients regarding palliative care and EOL care issues.

**PROCESS:** Awareness and 'diagnosis' of a palliative state such as worsening symptoms, failure of treatments due to progressive disease or recurrent disease are important issues to discuss with patients with advanced disease. A discussion with the patient and palliative care team regarding timely assessment of symptom management, ability to manage illness, changing goals, wishes, and future needs is encouraged. Discussions regarding EOL wishes, plans and goals are shared throughout the health care team and may be discussed at MDC meetings as planning processes. It is preferable for the members of the palliative care team who are known by the patient to continue these discussions. The outcomes of conversations are shared with the entire MDC team to continue the communication process. Documentation of this plan is mandatory.

**OUTCOME:** Regular assessment and awareness of individual patient's disease and progression will lead to early and appropriate referral to the palliative care team. This will facilitate smooth transition into the palliative phase, thus allowing planning and respect of patient goals and wishes to be established.

## 'Not for resuscitation' (NFR) orders

Issues relating to NFR orders should also be discussed with the patient and their caregivers, where appropriate, and documented to address issues that may arise. A survey conducted by Kerridge et al<sup>10</sup> found that, while a large proportion of both patients and health care professionals felt that doctors should always ask a patient whether they would like cardiopulmonary resuscitation (CPR) performed, only a very small percentage of patients had actually discussed CPR with their doctors. This study found that many patients want to be involved in CPR decision-making, along with partners and some family members. Many would have liked to put their wishes about life-sustaining treatment in writing or to tell a family member or close friend. Patients and health care professionals generally think that decisions about CPR should be shared by doctors and patients.

For an Indigenous patient, the person or people that a hospital might consult to discuss NFR orders may be different. Particular kinship relationships can identify those who have primary responsibility for making NFR decisions.<sup>11</sup>

'The best CPR decisions will follow preparations that began long before the patient's heart was stilled, this includes discussions about being admitted into intensive care units and emergency departments and discussion about when CPR may not be appropriate. CPR decisions will involve considered consultation between the patient, family, and relevant health care professionals.'<sup>12</sup>

### EXAMPLE: DISCUSSING NFR ORDERS WITH PATIENTS

**SCENARIO:** When appropriate (individually determined by a senior clinician), the patient is told that a discussion on NFR orders is a routine policy for patients with advanced disease who may need admission to hospital.

**PROCESS:** Ideally this initial discussion happens at a time when the patient is not unwell or under stress (e.g. it is not appropriate when diagnosis is first given to them). It is explained to the patient that a discussion about NFR orders is best done before admission occurs. An explanation of the meaning of NFR and the processes involved with resuscitation is given. The issues relating to medical advice, appropriateness of treatment, the patient's right to choice and medical futility can be undertaken as needed. Written information will be provided to all.

Admitting doctors should check the patient's 'NFR status' at each admission and ask the patient if they would like to change their status. It is suggested that their status is included in a card also recording their medications.

**OUTCOME:** The patient and their caregivers have the opportunity to be properly informed about this difficult and emotive topic. As a result, stress is reduced both for the patient and the family, as well as the doctors involved. This also avoids the distressing situation where a doctor unfamiliar with a patient, and their medical history, prognosis and other details, is required to determine the NFR status of a patient, often in the situation of the patient being acutely unwell.



## 4. STANDARDS OF CARE

Provision of medical and supportive care is in accord with nationally agreed standards

### PRINCIPLE OF CARE

- a** All health professionals involved in the management of patients with advanced cancer should practise in accord with guideline recommendations
- b** Maintenance of standards of best practice is supported by a number of activities which promote professional development
- c** Location, type of service or patients' understanding of the health system should not be impediments to patients' access to MDC
- d** The members of the team should support the multidisciplinary approach to care by establishing collaborative working relationships with appropriate local health care professionals
- e** Use of supportive care services, including palliative care, psychosocial interventions/support should be encouraged and facilitated

### OUTCOME

- Care is demonstrated to be consistent with national evidence-based recommendations and benchmarks, where relevant
- Systems are established and monitored for the support of professional development
- Systems are established to support all patients with advanced disease to have access to MDC
- Systems are established to support collaborative working relationships and referral links
- Systems are established to provide patients with equitable access to all relevant medical and supportive care services

### Location of care

Care for patients with advanced disease will take place in a range of community-based settings outside of the hospital. These may include the patient's home, palliative care units, and/or residential care facilities. The MDC team should create links with specialist services and health professionals, especially those based in the community; these include community health nurses and community palliative care specialists. Ideally, community-based services should be locally



available and locally coordinated. Patients from regional and rural locations should benefit from their professional carers' networks to facilitate their MDC. Location, size of the MDC, or patients' understanding of the health system, should not be impediments to patients' access to MDC. Treatment should be flexible to include options that will improve patients' comfort and quality of Life

## Supportive Care

The National Institute for Health and Clinical Excellence (NICE) (UK) defines supportive care as 'an umbrella term for all services, both generalist and specialist, that may be required to support people with cancer and their caregivers'.<sup>13</sup> Supportive care addresses a range of issues and needs for patients with cancer, including informational, emotional, spiritual, psychological, physical, practical, and financial needs. The role of supportive care is crucial in the management of patients with advanced disease. The supportive care needs of patients with advanced disease and their caregivers will be specific to the patient and their caregivers and will change over time.

For more information about psychosocial supportive care refer to NBCC and National Cancer Control Initiative *Clinical practice guidelines for the psychosocial care of adults with cancer*, 2003.<sup>14</sup>

## Palliative care

Palliative care is care provided for people of all ages who have a life-limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life. The World Health Organization defines palliative care as 'an approach that improves the quality of life of patients and their 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'.<sup>15</sup>

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of the illness
- is applicable early in the course of the illness, in conjunction with other therapies intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.<sup>15</sup>

The aim of palliative care is to optimise the patient's comfort and levels of function. Palliative care stresses the importance of advanced planning with a focus on the whole person within their social and emotional context, rather than just the disease. Patients may experience a range of physical symptoms that will need to be managed, as well as the related psychosocial distress associated with having advanced disease. It is important for teams to assess the quality of life of their patients and take this into consideration when planning their treatment and care. MDC teams should aim to maintain function and quality of life for the patient throughout the course of their disease.

## EXAMPLE: PALLIATIVE CARE REFERRAL

**SCENARIO:** Initiating a referral to palliative care.

**PROCESS:** Effective communication within the health care team to help determine appropriate and timely referral to the palliative care team is crucial. The referral is introduced to the patient and their carers by the designated care coordinator explaining the role of palliative care as one of active care that delivers specialised health care to maximise quality of life, whether that be symptom management, pain relief or spiritual, emotional and psychological support.

**OUTCOME:** Introducing the discussion about palliative care is assessed within the multidisciplinary team on an individual basis dependent upon the patient's advancing illness and their hopes for the future.

The term 'palliative care' is confronting for many patients, their caregivers and health professionals. Misconceptions about what palliative care involves, and its role in a patient's care, can influence a patient's decision as to whether they accept palliative care services as part of the MDC approach. Palliative care is often seen as a service that is provided only at the end of life, but early referral can allow patients and their caregivers to benefit from a range of services and support.

## EXAMPLE: PALLIATIVE CARE REFERRAL

**SCENARIO:** When patients are newly diagnosed with advanced breast cancer, they are routinely assessed by an advanced breast care nurse.

**PROCESS:** An advanced breast care nurse explains to the patient the role of key team members as providers of support, information, and symptom control. Once the patient is comfortable and aware of the value of this care, the advanced breast cancer nurse may suggest, if appropriate, that a similar support role can be provided in the community, also by a specialist nurse (from the community palliative care provider).

**OUTCOME:** Patients begin to separate the supportive care role of palliative care services, distinguishing them from terminal care. Patients become more accepting of supportive care provision in the community from palliative care services.

Some people with a life-limiting illness may not need any specialist care, other people may need intermittent specialist palliative care, and others will need on-going care by a specialist palliative care service. A number of access pathways to palliative care services need to be in place for patients, primary carers and families. For many patients receiving primary care, a palliative care approach will be introduced as part of the ongoing and comprehensive care they are already receiving.<sup>16</sup> Patients need not have exhausted all disease-modifying treatments before accepting referral to palliative care.<sup>17</sup> For patients with complex needs the involvement of an interdisciplinary specialised palliative care service, working alongside primary clinical carers, is likely to be of benefit.<sup>18</sup> A referral to palliative care services may be made by the lead clinician, although some services will accept a referral from the patient, a family member or friend, a local community health centre or local hospital. The manner in which the referral is discussed with the patient and caregivers can help to avoid undue stress.

Information about local palliative care services is available from state palliative care associations or from Palliative Care Australia. (See *'Further information'* page 25).



## CONCLUSION

MDC PAD aim to improve the quality of care for patients with advanced disease, and their caregivers. Implemented early, an effective MDC approach will assist patients with their varying needs throughout their disease. By acknowledging and understanding the specific needs of patients with advanced disease and their caregivers, MDC teams for advanced disease can ensure continuity of care while optimising patient function and comfort throughout the disease.



## FURTHER INFORMATION

### Resources:

National Breast Cancer Centre. *Clinical practice guidelines for the management of advanced breast cancer*. Canberra: Commonwealth of Australia, 2001.

National Breast Cancer Centre. *Multidisciplinary meetings for cancer care. A guide for health service providers*. Sydney: NBCC, 2005.

Australian Cancer Network and National Breast Cancer Centre. *Clinical practice guidelines for the management of women with epithelial ovarian cancer*. Sydney: NBCC, 2004.

National Breast Cancer Centre and National Cancer Control Initiative. *Clinical practice guidelines for the psychosocial care of adults with cancer*. Sydney: NBCC, 2003.

Palliative Care Australia. *Standards for providing quality palliative care for all Australians*. Canberra: PCA, 2005.

National Breast Cancer Centre. *Multidisciplinary care – what are the medicolegal implications? Workshop report and recommendations*. Sydney: NBCC, 2007.



## Internet sites:

### **National Breast and Ovarian Cancer Centre (NBOCC)**

NBOCC has a dedicated multidisciplinary component that provides the latest information on implementing and improving sustainable MDC for all cancers in Australia.

For further information: [www.nbocc.org.au/mdc](http://www.nbocc.org.au/mdc)

NBOCC, in collaboration with the Pam McLean Cancer Communication Centre, has developed a range of modules for health professionals on improving communication within the multidisciplinary team. Modules include: *'Transition from curative to palliative care'*, *'Breaking bad news'* and *'Emotional cues'*.

For further information: [www.nbocc.org.au/bestpractice/commskills](http://www.nbocc.org.au/bestpractice/commskills)

### **Palliative Care Australia**

Palliative Care Australia is the national peak body representing the interests of palliative care service providers, including anyone with an interest in palliative care both nationally and internationally.

The site also has contact details and information about **state and territory palliative care associations** including:

Palliative Care New South Wales

Palliative Care Queensland Inc

Palliative Care Victoria

Palliative Care WA Inc

Palliative Care Council of South Australia Inc

Tasmanian Association for Hospice and Palliative Care Inc

ACT Palliative Care Society Inc

Palliative Care NT Inc

For further information: [www.pallcare.org.au](http://www.pallcare.org.au)

### **Carers Australia**

Carers Australia is the national peak carer organisation. This site includes information and resources for carers.

For further information: [www.carersaustralia.com.au](http://www.carersaustralia.com.au)

### **Department of Health and Ageing**

The Australian Government Department of Health and Ageing website provides resources, publications and information about national palliative care program initiatives

For further information: <http://www.health.gov.au/palliativecare>



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## GLOSSARY

**Advanced disease:** cancer where the goal of treatment and care may be not be cure, or where cure is not an option.

**Agreed point of contact:** a designated contact person within the multidisciplinary team who acts as a key contact for the patient and their caregivers.

**Caregivers:** family members and/or friends identified by the patient who provide psychosocial and/or physical support to the patient throughout their disease.

**Multidisciplinary care:** an integrated team approach to health care in which medical and allied health care professionals consider all relevant treatment options and develop collaboratively an individual treatment plan for each patient.

**Multidisciplinary care team:** an established team which comprises all core disciplines integral to provision of good patient care.

**Multidisciplinary care team meeting:** a regular, planned and meeting dedicated to treatment planning for patients with cancer.

**Palliative care:** an approach that improves the quality of life of patients and their 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.

**Supportive care:** an umbrella term for all services, both generalist and specialist, that may be required to support people with cancer and their caregivers. Supportive care addresses a range of issues and needs, including informational, emotional, spiritual, psychological, physical, practical, and financial needs.











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