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With best wishes,

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Haematology and Palliative Care
Towards an Integrated Practice
Introduction

This booklet addresses well documented concerns that palliative care is still not appropriately integrated into haematology. It presents a trilogy of models, *Functional, Evolving and Refractory*, that outline factors influencing the integration of palliative care and haematology. This booklet points the way forward by sharing the wisdom of those who have successfully identified problems and found solutions. The hope and expectation is that the insights outlined will go some way to ensuring that haematology patients and their families are given the benefits of compassionate, best practice palliative care. This is especially important during the difficult time of dealing with the challenges imposed by the diagnosis of a life-threatening illness.

The insights for this booklet have been generously provided, under the auspices of the *National Health and Medical Research Council (NHMRC)* research grant, by a wide representation of health professionals (including doctors, nurses and allied health), from public and private hospital haematology units, palliative care units, hospices and support organisations throughout Australia. The information was enriched by individuals who shared their experience of caring for a loved one who died of a haematology condition.

The trilogy of models developed from the insights have been subject to rigorous peer review by a national panel of haematology and palliative care experts and also by the publication process of international journals.
This booklet is written for those with a working knowledge of palliative care philosophy and practice; the intent is to apply that knowledge to haematology. The conceptual starting point is the World Health Organisation’s definition of palliative care:

Palliative care is 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. Palliative care:

• provides relief from pain and other distressing symptoms;
• affirms life and regards dying as a normal process;
• intends neither to hasten or 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 patients illness and in 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 illness;

• is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care is about living. It is a compassionate humane response to providing services to those who are confronted by a terminal illness, to ensure that the focus is on their quality of life. The holistic, multi-disciplinary response ensures that patients with a serious illness are able to live life according to their own choices and to their fullest ability.

1. World Health Organisation www.who.int/cancer/palliative/definition/en
Dealing with end-of-life issues will never be easy work. Confronting mortality is inherent in the diagnosis of any life-threatening illness. It will always require a high level of sensitivity, timing, clinical expertise and communication skills.

In order to assist others with the significant event of dying, it is imperative for health professionals to deal honestly with their own feelings, beliefs and attitudes. To be of assistance, health professionals need to enter into the world of the patient and their family; to hear with openness and compassion their needs, fears and hopes.

There are no short cuts or formulaic responses: palliative care by its very nature will always require the sensitive work of confronting and dealing with a difficult life situation.

The evidence indicates that such care is greatly appreciated by the patients and their families, and leaves the bereaved in a much stronger position to re-build their lives.

The present situation of palliative care and haematology in Australia can be understood by a trilogy of overlapping models. A demonstration of best practice is outlined in the Functional Model, which describes experiences and practices that indicate the appropriate integration of palliative care into the acute haematology setting. The Functional Model outlines processes that will ensure satisfying palliative care for patients with haematological malignancies and their families.

At the other extreme is the Refractory Model, detailing factors that block appropriate referral to palliative care. Hospitals operating within the Refractory Model are resistant to the integration of best-practice palliative care provision in haematology. This model has proven negative consequences to patients, their families and staff.

Linking the two is the Evolving Model, which describes the factors that create the possibility of change, either to a Functional, or Refractory Model.

Factors influencing the integration of palliative care into haematology include: recognition of the positive contribution of palliative care by the Head of Haematology; a proactive unit sub-culture; increased participation of all team members in decision processes; the presence of palliative care staff, providing role models for successful service delivery; new staff and graduates who introduce knowledge and practice of the discipline; continuing professional education on best-practice; and exposure of staff to satisfying experiences with hospice and palliative care.
“It is the varying professional perspectives, rather than the unique circumstances of haematology, that create the difference.”

Functional Model

Issues of death and dying are addressed openly and sensitively

Leadership and unit sub-culture - Positive attitudes to palliative care

Organisational issues – Democratic, collaborative, and inclusive multi-disciplinary unit sub-culture

Haematology staff have positive experiences with palliative care

Patient-centred, continuum of care from diagnosis to bereavement

Provision of honest information and respect for patient choice

The complexity of hope and its changes over time is understood

Understanding and use of palliative care expertise for symptom and pain management and psychosocial support from diagnosis to bereavement

Appropriate and timely integration of palliative care

Specific issues regarding patients with haematological malignancies addressed
Refractory Model
A death denying model resistant to palliative care integration resulting in unnecessary hardship for patient and families.

Evolving Model
A model in the process of fluctuation, susceptible to change in either direction, between the Refractory and Functional models.

Functional Model
Provides satisfying continuum of care from diagnosis to bereavement for patient and families.

The Trilogy of Models
Refractory Model

Issues of death and dying denied and/or dealt with bluntly and insensitively

Leadership and unit sub-culture – Negative attitudes to palliative care

Organisational issues – Medico-centric, paternalistic, hierarchical unit sub-culture not inclusive of multi-disciplinary expertise

Absence of positive palliative care experiences by haematology staff

Predominant focus on clinical concerns at the expense of patient/ families psycho-social needs

‘The Spin’ – Doctors communicating with a positive treatment orientated spin that disregards patients psycho-social concerns

Hope – simplistic, with a black and white understanding of ‘hope equals cure’

Lack of understanding of skill and expertise associated with palliative care

Introduction of palliative care delayed until last days of life

Haematology specific issues seen as an obstacle and used to justify non provision of palliative care
Polar opposites in practice

The following is a summary of the important issues posited in the polar opposite perspectives of the Functional and Refractory Models as they translate in practice. It is the varying professional perspectives, rather than the unique circumstances of haematology, that create the difference.

Functional Model

Issues of death and dying are addressed openly and sensitively
- Death and dying are seen as difficult issues, but discussed sensitively and openly

Leadership and unit sub-culture - Positive attitudes to palliative care
- Head haematologist comfortable with death and dying issues and provides leadership for ward sub-culture
- Proactive subculture that supports and integrates palliative care
- Palliative care team provides strong leadership

Organisational issues – Democratic, collaborative, and inclusive multi-disciplinary unit sub-culture
- Flat, democratic structure – emphasis on multi-disciplinary team work with high level of staff satisfaction
- Designated nurses to ensure continuum of care from diagnosis to bereavement within the acute care or community setting.
- Welcomes outside organisations for supportive care.
- Strong inter-professional and inter-organisational co-operation and collaboration

Haematology staff have positive experiences with palliative care
- Doctors have experienced satisfying outcomes from palliative care and recognise the value of this discipline
- Acute care staff are aware that dying at home is a viable option for most haematology patients

Refractory Model

Issues of death and dying denied and/or dealt with bluntly and insensitively
- Denial of death – discussions about dying avoided
- Death seen as failure and palliative treatment seen as ‘giving up’

Leadership and unit sub-culture – Negative attitudes to palliative care
- Head Haematologists uncomfortable with death and dying issues can have a negative influence.
- Unit sub-culture is not sympathetic to palliative care
- Leadership not provided by palliative care team

Organisational issues – Medico-centric, paternalistic, hierarchical unit sub-culture not inclusive of multi-disciplinary expertise
- Dominance of medico-centric and paternalistic relationships limit patient advocacy
- Hierarchical organisational structure that inhibits team input
- Strong professional territory and jealousy – reluctance to ‘let go’ or involve others in care of patient. Patient care spoken of in terms of ‘ownership’
- Nursing advocacy for patients is difficult and marginalised by top-down organisational structure

Absence of positive palliative care experiences by Haematology staff
- Haematology staff are not aware, that with appropriate palliative care, the end-of-life experience can be positive with satisfying outcomes
- Staff have not experienced the benefits of palliative care clinical skill and expertise throughout the continuum from diagnosis to bereavement.
Functional Model

Patient-centred, continuum of care from diagnosis to bereavement

- Staff possess good communication and listening skills
- Patients’ individual care plans are informed by active listening and a holistic approach
- Bereavement follow up always provided
- Carers and family members are satisfied with the experience

Provision of honest information and respect for patient choice

- Honest provision of information - Continuing and open communication on issues of prognosis and side-effects of treatment
- Choice is respected and Quality of life issues are given priority

The complexity of hope and its changes over time is understood

- Hope is seen as a complex issue in which ‘hope for cure’ is only one facet
- It is acknowledged that hope changes over time and with the approach of death is likely to focus on quality of life issues
- Patients and families are able to talk in full about hope in their lives

Understanding and use of palliative care expertise for symptom and pain management and psychosocial support from diagnosis to bereavement

- Respect and integration of palliative care skills and expertise along the continuum of care within the acute or community setting

Appropriate and timely integration of palliative care

- Involvement of palliative care team for pain and symptom control early in treatment to build relationship with patient prior to terminal stage
- Clearly defined referral processes
- Haematology staff may remain involved after referral to palliative care

Specific issues regarding patients with haematological malignancies addressed

- Strategies exist to manage specific issues for palliative care patients with haematological malignancies
- Professional collaboration to enable administration of blood products in the community
- Preparation of patient and family for the possibility of catastrophic bleeds

Refractory Model

Predominant focus on clinical concerns at the expense of patient/families psycho-social needs

- Focus on quantity not quality of life
- Strong reductionist focus
- Lack of infrastructure and resources to provide privacy and support during the emotionally difficult time of death and dying
- No bereavement follow up
- Patients and families distressed by experience. Greater incidence of post-traumatic stress
- Questionable informed consent procedures

‘The Spin’ – doctors communicate with a positive treatment orientated spin that disregards patients’ psycho-social concerns

- Information provided has a ‘positive spin’ towards treatment. This is problematic when a patient’s request to halt treatment is answered by the doctor’s promotion of treatment, without regard to poor prognosis or quality of life issues

Hope – simplistic, with a black and white understanding of ‘hope equals cure’

- Hope is talked about in simplistic, black/white terms, and is only seen as ‘hope for cure’. Practitioners believe that hope is lost unless active treatment or a cure is offered
- Patients and families are not helped to deal with the difficult task of coming to terms with dying – communication focuses only on unrealistic hope

Lack of understanding of skill and expertise associated with palliative care

- Patients and families are not told about palliative care, so cannot advocate for access to such services
- Palliative care staff are not involved in pain or symptom management, so familiarity and relationships with patients do not evolve

Lack of integration of cure and palliation

- Even when the patient is known to be terminal, there is no preparation for the dying trajectory
- Patients die surrounded by increasing curative technology and treatments. The setting for dying is usually the acute ward or intensive care unit, cared for by staff untrained in palliative care

Haematology specific issues seen as an obstacle and used to justify non-provision of palliative care

- Issues, such as community-based provision of blood products and the possibility of catastrophic bleeds, are seen as obstacles to palliative care, especially for patients wanting to die at home
Special considerations for haematology patients

It is important to outline special considerations concerning the provision of palliative care for haematology. These should not be seen as insurmountable obstacles but rather unique circumstances that need to be addressed in developing strategies for patient and family care.

- The considerable number of varied diagnostic groups with different prognosis and treatment options requires different planning and responses. However, as with all palliative care service delivery, the focus is on the individual needs of the patient and their family.
- The high-tech and invasive nature of the treatments offered can include intensive chemotherapy protocols, bone marrow and peripheral blood stem cell transplantations. Significant side effects from treatment can affect quality of life. This makes concerns about the quality versus quantity of life particularly important for haematology patients and their families.
- As treatments can continue over many years, patients and their families usually develop close relationships with the staff of haematology units. Appropriate timing and sensitivity is necessary in negotiating the transition to palliative and/or hospice care. Pain and symptom management and psycho-social support from early in the course of treatment, will build familiarity with palliative care staff. This can build a solid basis for dealing with the transition.
- Patients occasionally show positive signs of recovery when close to death. This necessitates an open and flexible path between acute care and the palliative system.
- There is clinical optimism in haematology based on a myriad of treatment options and outcomes. The positive aspect of such optimism is that it can reflect real advances in haematology. However, such optimism can also drive over-treatment and can obstruct appropriately timed transitions to the palliative system. This results in unnecessary patient and family suffering, exacerbating bereavement difficulties.
- The frequency of blood tests and the need for blood products will require planning to anticipate outpatient care and should be an essential consideration.
- The speed of change to a terminal event needs to be planned for and dealt with, prior to the event.
- The possibility of catastrophic bleeds should be addressed, as the experience can be highly distressing for patients and carers. Proactive strategies include identifying and preparing patients who are likely to experience such bleeds and their families, and discussion of practical measures (such as the use of dark towels in the event of bleeding).
- In the majority of cases there are clinical indications that the patient is nearing or entering the terminal stage. However, at times the distinction between curative and palliative phase may not clear.

Relocation

In most Australian states specialist services for haematology are centralised in the metropolitan areas, so that a significant number of patients have to relocate for treatment. These patients will have to deal with the additional burden of treatment away from the comfort of home, and the supportive networks of family and friends. In addition, they will have to confront such challenges, as the financial costs and practical problems of maintaining two places of residence, extra travel, emotional problems associated with family separation and interruption to work/educational opportunities.

Relocated patients and families require planning and flexible strategies throughout the treatment experience. This is especially so during palliative care, where there can be a strong desire to return home to die in the care of loved ones. Health professionals working within the Functional Model suggest that such strategies include: engaging in proactive, honest conversations to ascertain the wishes of patients and families; comprehensive discharge planning; the maintenance of close relationships with patients’ local general practitioners; networking and collaboration with local palliative care/hospice services, and community based support services. The development of such strategies will go some way towards easing the burden associated with relocation.