

section 2.5: palliative care for advanced malignant diseases

living with advanced cancer

Cancer is the leading cause of death in South Australia, resulting in 22 new diagnoses and between 8-9 deaths every day.¹ Currently almost 4 out of every 5 patients seen by specialist palliative care teams have some form of cancer.²

Initial goals of care for patients with cancer are directed to pursuing disease modifying therapy options, often with the goal of cure. However when these options are exhausted, goals of care focus on high quality control of symptoms such as pain and breathlessness, psychosocial support and assessment for and coordination of community supports. At this stage malignancy is usually advanced, progressive and with distant metastatic spread. This is frequently associated with an increased burden of disease, a decrease in functional status and a subsequent increase in the use of health care resources.³

The challenge of living with cancer may be met with a range of reactions from patients and families. It is frequently accompanied by fears and anxieties which may be motivated by the difficulty in making the initial diagnosis, the uncontrolled nature of disease within the body, potentially lengthy and debilitating treatment regimens (the “getting worse before getting better” scenario), the possibility of pain and suffering and the associated stigma of a disease which in the past had no cure.

Advanced disease brings particular challenges for patients which require sensitive and compassionate responses from health professionals. These include the weighing up of treatment benefit versus burden, concerns about the length of time remaining, loss of control of aspects of life and the psychological, emotional and social implications of maintaining both self and other relationships in a setting of declining physical health. The impact for family and caregivers is far reaching as they begin to consider life without the patient and to balance the practical details of caregiving with their own concerns and anxieties.

essential information required by patients and families:

Patients and families require information about the usual behaviour of specific cancers including:

- the likely trajectory and pattern of spread of disease
- the predictable complications and symptoms of disease, which in advanced cancer will relate to the particular site of origin and the degree of spread⁴
- options for treatment and possible limitations to treatment due to significant co-morbid conditions
- advice about managing symptoms at home:
 - symptoms in cancer may change rapidly – advising patients to contact the most appropriate health professional promptly (likely to be their GP) is critical to managing symptoms well
 - advise the patient that symptoms will be managed actively
 - every pain or other symptom may not be related to the cancer, but still requires thorough assessment and appropriate investigation

- details about supports that are available which can cater for specific patient's needs, both in hospital, at home and in their workplace – information and contact details numbers should be provided and supports are available in flexible ways, eg telephone, internet, pamphlets
- the critical role the patient's family and friends play in providing practical and emotional support but will require information from health professionals to assist them in undertaking these tasks

Assisting the patient and particularly their family to reflect on the past and to project forward in time may be an extremely useful way for them to consider the rate of decline, eg "if you look back 6 months ago and 1 month ago, how have things changed?" – if little has changed in that time then projecting forward may indicate that the situation could remain stable; if however major decline has occurred, particularly in the last 1 month and forward projection suggests that should this continue at the same rate, then time remaining may be shorter rather than longer.

important patient-centred goals to consider in advanced cancer:

Encouraging a focus on wellness can be a positive approach for patients, allowing them to articulate how "wellbeing" looks to them – what are the important aspects of their life and ways in which health professionals can support these wishes. This type of discussion assists in allocating priority to specific goals and a targeted plan that is directed by the patient.

Practical strategies which focus on caring for self include⁵:

- maintaining oral comfort and good nutrition – considering the role of the dietician
- getting the right amount of rest
- maintaining mobility and use of the driver muscles – this may be as simple as moving from a sitting position to standing regularly throughout the day – consider input from a physiotherapist
- focusing on normal daily goals of "living as well as possible".

The capacity to respond to changing needs is crucial – a decrease in the patient's functional status will prompt the need for increasing community supports or the evidence of psychological, emotional or financial stressors should signal the need for appropriate allied health, specialist or counselling input. Facing progressive disease can be confronting and frightening. In some situations accepting changing circumstances or the statement "I've had enough" can be more difficult for family members than for the patient and supportive input may be required.

Assisting patients to reframe goals is often valuable. These may be short term goals such as "I would like to be pain free today" or "I would like to be able to get around my home easily" and it may become important to bring ahead significant occasions within the family such as weddings, birthdays or specific wishes that have already been identified by the patient.

Many patients may have a number of co-morbidities as well as their primary diagnosis of cancer. Some chronic illnesses that require active management include hypertension, atrial fibrillation, hypercholesterolaemia osteoporosis, diabetes mellitus and arrhythmias. Deciding whether to continue medications or not must take into account the balance of diminishing benefits with increasing side effects, take weight loss into account and consider the patient's prognosis.⁶

Adopting a palliative approach to all aspects of management of advanced or rapidly progressive malignant disease is required (see Section 1 - Introducing palliative care) with input from the specialist palliative care team when symptoms for the patient or caregiver become complex and difficult to manage.

Detailed management of specific cancers and common complications is outlined in *Therapeutic Guidelines – Palliative Care, Version 2* (2005).

related resources and information for staff

Cancer nursing

Cancer nursing online courses see <http://www.cancernursing.org/>

Ci-Scat

Cancer Institute NSW Standard Cancer Treatments- provides information on evidence-based cancer treatments and protocols, see www.treatment.cancerinstitute.org.au/

Emergencies in Palliative and Supportive Care (2006) Currow D, Clark K. Oxford University Press, Oxford.

Oxford Textbook of Palliative Medicine. (1999) – 2nd edn. Eds Doyle D, Hanke G, MacDonald, N. Oxford University Press, Oxford, UK.

Palliative Medicine (2004) Evidence-based symptomatic and supportive care for patients with advanced cancer. Woodruff R. Oxford University Press, Oxford.

Therapeutic Guidelines – Palliative Care, Version 2 (2005). Therapeutic Guidelines Ltd, Victoria.

The National Health & Medical Research Council (NHMRC) publications for health professionals which are located at their website:

- *Clinical practice guidelines for the management of advanced breast cancer*
- *Clinical practice guidelines for the management of colorectal cancer*
- *Clinical practice guidelines for the management of cutaneous melanoma*
- *Clinical practice guidelines for the psychosocial care of adults with cancer*
- *Psychosocial Clinical Practice Guidelines: providing information, support and counselling for women with breast cancer*

Haematology and palliative care – Towards an integrated practice

A booklet which specifically deals with palliative care issues in relation to the haematology setting and addresses issues related to timing of referrals to palliative care services. From the International Program of Psycho-Social Health Research, Central Queensland University. Can be downloaded from <http://www.ipp-shr.cqu.edu.au>.

related resources and information for patients and families:

The Cancer Council of South Australia phone (08) 8291 4111

Provides a comprehensive website with information for health professionals and patients and caregivers related to cancer: <http://www.cancersa.org.au/>.

Includes information relating to specific cancers, details of clinical trials from Australian and international sites and use of complementary and alternative therapies. Specific topics of interest include:

- comprehensive guide to cancer services and treatment centres in Adelaide & SA
- supports available for people with cancer including brief counselling interventions, booklets relating to specific cancers and treatment
- **Cancer Council Helpline** – telephone support – phone **13 11 20**
- cancer on the internet – information to help with safe surfing
- questions to ask about clinical trials.

Colostomy Association – phone **(08) 8354 2618**

Ileostomy Association – phone **(08) 8234 2678 or 8268 3645**

Infertility support – contact The Cancer Council SA

Laryngectomy Association – contact The Cancer Council SA

Leukaemia Foundation of Australia – phone **(08) 8357 7656 or 1800 620 420**

Supporting patients diagnosed with leukaemia, lymphomas, myelomas or related disorders

Look Good Feel Better - phone **1800 650 960**

Community service for women undergoing cancer treatment aimed at supporting or restoring self image

Lymphoedema Support Group – phone **(08) 8336 7748**

National Continence helpline phone **1800 330 066**

The National Health & Medical Research Council (NHMRC) has the following consumer guidelines: *A guide for women with metastatic breast cancer.*

references

¹ Cancer in South Australia 2004 with incidence projections to 2007. Department of Health, Epidemiology Branch, Cancer Registry.

² A Snapshot of Palliative Care in Australia, Department of Health and Ageing (2003), Commonwealth of Australia.

³ Stuart B (1999). Advanced Cancer and Co morbid Conditions: Prognosis and Treatment. *Cancer Control Journal* 6:2, 168-175.

⁴ Barbato M (2005) Caring for the palliative care patient McGraw Hill, Sydney, Australia.

⁵ Advanced Cancer. Brochure compiled by The Cancer Council of South Australia. See www.cancersa.org.au

⁶ Stevenson J, Abernathy A, Miller C, Currow D (2004) Managing comorbidities in patients at the end of life. *BMJ*.329:909-912.