MODULE FIVE

Cancer Supportive Care Principles
Overview
The aim of this module is to develop knowledge of concepts fundamental to the ability of the beginning specialist cancer nurse to demonstrate competence in providing supportive care.

Key concepts
The key concepts associated with cancer supportive care principles are listed below:
- Principles of supportive and palliative care.
- Common supportive care needs.
- Screening and assessment of supportive care needs.
- Experience of transition to palliative care.
- Evidence based approaches to education and information provision.
- Responding to family and carer needs.

Learning activities
At times, you will have learning activities to complete. The questions will relate to the content you’ve just read or the video you’ve just watched.

Videos
You will be prompted to access EdCaN videos throughout this module.

Resource links
Resource links may be included throughout the module. These links lead to interesting resources, articles or websites, and are designed to encourage you to explore other available information.

Estimated time to complete
40 hours

Learning objectives
On completion of this module, you should be able to:
1. Identify key supportive care needs for people during and after treatment for cancer.
2. Demonstrate safe and effective assessment of supportive care needs during and after treatment using evidence based frameworks.
3. Implement supportive care interventions that are tailored to an individual’s clinical, personal and social circumstances.
4. Identify supportive care needs of people affected by advanced and progressing cancer across all domains of health.
5. Implement evidence based interventions to support people affected by cancer to optimise their functional abilities at the end of life, consistent with their preferences and abilities.
Supportive care needs

A diagnosis of cancer can effect a person’s physical, psychological, spiritual, and social well being. Some of these effects will resolve over time due to a person’s personal coping resources and social and professional support. However, unmet needs do not always spontaneously resolve and can result in significant morbidity. Supportive care interventions can prevent or minimise these effects, across all phases of a person’s cancer experience.

Supportive care “embraces the full range of issues that emerge for an individual as the impact of cancer and treatment is felt and the person tries to deal with the situation”. In the context of cancer, supportive care includes services offered during the diagnostic, treatment and follow-up phases of illness. It is aimed at meeting needs in the following domains:

- Physical
- Social
- Emotional / psychological
- Information
- Spiritual.

Nurses contribute to supportive care by:

- Reducing the risk of developing unmet supportive care needs
- Detecting unmet supportive care needs early
- Implementing interventions to address supportive care needs, during and following treatment
- Implementing interventions to address supportive care needs at end of life.

For people affected by cancer, unmet supportive care needs are often associated with significant morbidity and distress. Distress has been defined as an unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. Rates of clinically significant distress have been reported to be between 25% and 45% among people with cancer.

A systematic review of unmet needs of people affected by cancer summarised the most prevalent needs according to time points across the cancer experience. These unmet needs are summarized below.

### Diagnostic phase:

- Physical (includes symptoms such as fatigue, weight loss, breathlessness, pain)
- Social (includes needs such as financial, social support)
- Psychological (includes needs such as anxiety, fear, anger)
- Information (includes needs for information regarding disease, prognosis and planned treatments)
- Spiritual (includes needs regarding feelings of guilt)

### Treatment phase:

- Physical (includes inability to attend to Activities of Daily Living (ADL's), fatigue, pain, mucositis, bowel changes, weight changes, sexuality, poor sleep)
- Social (includes financial issues, transport and accommodation issues, work issues, family support, relationship issues)
- Psychological (includes fear of spread, worry about carers, uncertainty of the future, sadness about loss of health, cognitive impairment, pre-occupation with illness and death, body image changes)
- Information (includes information regarding self-care, treatment benefits, management of side effects of treatment)
- Spiritual (includes needs such as making sense of the experience)

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**Learning Activities**

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<tr>
<td>☑️</td>
<td>1. Search the literature to identify a recent research article on supportive care needs of a person newly diagnosed with cancer:</td>
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<td></td>
<td>• List the common supportive care needs across each of the domains identified above.</td>
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<td></td>
<td>• Identify demographic, cancer related and social factors that might place a person at increased risk of unmet need at this time.</td>
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Learning Activities

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☐ | 1. Review Section 7 of one of the Victorian Patient Management Frameworks: “Specific supportive care needs to consider for patients with...”.
   • List the common psychological, social, informational and spiritual needs of a person undergoing treatment for the identified cancer.

Post treatment, follow up and survivorship phase:

• Physical (includes fatigue, pain, bowel changes, respiratory issues, sexuality, fertility, weight changes)
• Social (includes financial needs, feelings of isolation)
• Psychological (includes anxiety about the cancer returning, cognitive impairments)
• Information (need for information regarding follow up care)
• Spiritual (includes concerns about meaning of life, re-prioritising needs)

Advanced phase:

• Physical (includes inability to attend to ADL’s, nausea, fatigue, pain, bowel changes, respiratory issues, weight changes)
• Social (includes financial needs, expressing wishes such as in wills)
• Psychological (includes depression, anxiety, fear, isolation)
• Information (includes care needs, advanced care planning)
• Spiritual (includes feelings of hopelessness, helplessness, fear of death)

Resource link


Learning Activities

Completed | Activities
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☐ | 1. Search the literature to identify a recent research article on supportive care needs of a person with advanced disease:
   • List the common supportive care needs across each of the above domains
   • Identify demographic, cancer related and social factors that might place a person at increased risk of unmet need at this time
Supportive Care for the Carer

Failure to attend the supportive care needs of the person can have a ripple effect throughout the family and can create additional problems for the person, as they may rely on family and friends to support them during their cancer experience.

Major causes of distress for a carer include:

- The physical care demands of the patient
- Dealing with troublesome symptoms, such as pain
- The uncertainty about the illness trajectory of the person
- Fluctuations in the individual’s mental status, behavior and personality
- Feelings of guilt, unhappiness, depression and emotional upset
- Difficulty remaining positive
- Perceived lack of information and capacity to care for the person
- Changes in body image of the person
- Changes in sexual intimacy

There are risk factors that identify carers at high risk of adverse psychological events including:

- Providing over 20 hours of care per week
- Existing caring responsibilities
- Few supports
- Poor health
- A high level of dependency in a loved one
- Low incomes
- Distressed relationships
- Increased intensity and duration of caring
- A significant change in roles eg. From “cared for” to “carer”.

### Learning Activities

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<tr>
<td>1.</td>
<td>Identify, from your experience, the common supportive care needs for family carers at the following points of a person’s cancer experience:</td>
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<td>• At initial diagnosis</td>
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<td>• During the treatment phase</td>
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<td></td>
<td>• At diagnosis with recurrent metastatic disease</td>
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<td></td>
<td>• At the advanced phase</td>
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Fitch suggests there are five clinical standards of supportive care for people affected by cancer:\textsuperscript{13}

- All individuals receive ongoing supportive care assessment
- All individuals have the opportunity to be referred to an appropriate supportive care resource
- All individuals have the opportunity for self-referral to supportive care resources
- All individuals have access to understandable, relevant information regarding the medical, practical and emotional aspects of their cancer and its treatment
- All individuals receive supportive care that is relevant to their needs and sensitive to their age, gender, language culture, sexual preferences, religion and economic status

A tiered model of supportive care can be useful when undertaking an assessment and deciding on a plan of care (Figure 1).\textsuperscript{3} Using this type of tiered model, it is estimated that approximately 20\% of people will require only an initial assessment with provision of basic emotional support, good communication and information provision and symptom management. Approximately 30\% will require further assessment and help to link with other support services. Another 35\% to 40\% of people will require the next level of specialised information, education and encouragement and only 10\% to 15\% will require intensive intervention.\textsuperscript{13}

\textbf{Figure 1: Model of Supportive Care (adapted from Fitch)\textsuperscript{3}}

<table>
<thead>
<tr>
<th>General needs</th>
<th>All patients</th>
<th>Screening for need and information provision</th>
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<tbody>
<tr>
<td></td>
<td>Many patients</td>
<td>Further referral for assessment and intervention</td>
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<tr>
<td></td>
<td>Some patients</td>
<td>Early intervention tailored to need</td>
</tr>
<tr>
<td>Complex needs</td>
<td>Few patients</td>
<td>Referral for specialised services and programs (for example, psycho-oncology)</td>
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</table>
This model can assist nurses to identify where in the model the supportive care services offered by the health service and the primary care service may fit. For example, the nurse may consider whether there are information resources readily accessible in multimedia format for a person. Figure 2 shows an application of the model to the domain of information needs with examples of some evidence based interventions.

**Figure 2: Application of the Fitch model to information provision**

<table>
<thead>
<tr>
<th>Information needs</th>
<th>Examples of interventions</th>
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<tbody>
<tr>
<td><strong>All people affected</strong> by cancer need tailored information regarding:</td>
<td>• Tailored discussion with the health care team regarding the diagnosis, treatment and responses</td>
</tr>
<tr>
<td>• Diagnosis, treatment and plan for care</td>
<td>• Implementation of a process to screen for supportive care needs</td>
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<tr>
<td>• Risk factors for supportive care issues</td>
<td>• Structured discussion regarding the information obtained from the screening tool, risk factors identified and relevant referrals made</td>
</tr>
<tr>
<td>• Discussion about supportive care needs and possible referral to relevant services</td>
<td>• Provision of information in multimedia format</td>
</tr>
<tr>
<td>• Who is in their care team and the resources available to them</td>
<td>• Nurse led structured interventions such as symptom management clinics</td>
</tr>
<tr>
<td>• Basic emotional support, symptom management and practical assistance.</td>
<td>• Referral to emotional support programs/groups, peer support programs</td>
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</table>

| **Many people** want more specific self management interventions, opportunities to talk with others. Some people may benefit from: | • Specialist interventions such as nurse led brief interventions |
| • specific interventions | • Referral to social worker or psychologist for: |
| • group or individual interventions. |   ◦ Behavioural Training |
| |   ◦ Crisis Intervention (one-to-one) |
| |   ◦ Short - Term Counselling (one-to-one) (family) |
| | • Referral to pastoral care for spiritual counselling |

| **Some people** may benefit from | • Referral to psychologist or psychiatrist for: |
| • specific interventions |   ◦ Psychotherapy (Short-term/Long-term) |
| • group or individual interventions. |     (one-to-one family) |
| | • Complex symptom management |

| **Few people** require intensive therapy. | |

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**Learning Activities**

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<tr>
<td>[ ]</td>
<td>1. Review the Supportive Care Standards suggested by Fitch(^3), and briefly describe examples in your health care service how these standards are met.</td>
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</table>
Identifying supportive care needs

The tiered model of supportive care is based on the assumption that the person’s supportive care needs have been identified. Routine screening for supportive care needs of people is therefore required to achieve the basic standards in the provision of supportive care for people affected by cancer. Nurses have a key role in screening people affected by cancer to identify these supportive care needs.

The roles of the nurse in identifying supportive care needs are:
- understanding and anticipating supportive care needs
- considering the complexity of needs and their interdependency when identifying possible responses
- knowing the risk factors that may impact the person’s response to the diagnosis
- undertaking routine screening for supportive care needs to enable early identification of needs and risk factors

Screening for supportive care needs should take place following a recent diagnosis and on a regular basis using a systematic, evidence-based approach. Screening involves the routine and systematic identification of potential supportive care needs or risk factors before the issue becomes a symptom. Supportive care screening includes:
- the prioritising of needs (relating to the five domains of care)
- providing an immediate response to high level risk
- implementing appropriate follow up referral(s) and support.

The nurse also has a role in identifying carers’ supportive care needs, the level of care required and other carer issues impacting on the person providing the care.

Learning Activities

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<tbody>
<tr>
<td></td>
<td>1. Consider the table “Factors associated with an increased risk of psychosocial problems” on page 98 of Clinical practice guidelines for the psychosocial care of adults with cancer. What process/es do you have in place in your practice to identify these risk factors?</td>
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</tbody>
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Completed Activities

1. Consider the table “Factors associated with an increased risk of psychosocial problems” on page 98 of Clinical practice guidelines for the psychosocial care of adults with cancer. What process/es do you have in place in your practice to identify these risk factors?
Screening tools

There are many supportive care needs screening tools available for use in cancer care.

One example is the Distress Thermometer. The distress thermometer is similar to ratings scales used to measure pain, where the person is asked to rate their distress on a scale from 0=none to 10=extreme distress. The distress thermometer is used to identify distress from any source.

A second example is the SupportiveNeedsScreeningTool. This tool comprises a checklist covering aspects of the individual’s health and wellbeing including:

- Communication and understanding
- Physical health
- Emotional health
- Activities of daily living
- Support and coping
- Use of support services
- Information requirements

It differs to the distress thermometer in that it assesses a more comprehensive list of needs and may be more useful for guiding focused assessment and intervention.

In selecting the most appropriate screening tool, consider whether it meets the following criteria:

1. Does the content of the tool match your population?
2. What is the purpose of the tool? ie. Screening, diagnosis, assessment
3. Is the tool clinically useful?
4. Can it be used in the ambulatory and inpatient settings?
5. Is it reliable, valid and brief?
6. Is it at a reading level that can be understood by the majority of people?
7. Does it link to a process to address the needs identified?

Other considerations when selecting a screening tool include:

- Does the screening tool consider needs in all domains of supportive care, not only psychosocial needs?
- Does the tool offer opportunities to identify risk factors for adverse psychosocial problems? (listed in Clinical practice guidelines for the psychosocial care of adults with cancer)
- Is the tool appropriate for re-screening?
- Can the data be easily documented / collected for both the screening results and any referral or action plans?
- Are versions of the tool available in languages other than English?
- Are there any copyright issues over the use of the tool? (e.g. do you need permission to use it / adapt it)

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<tr>
<td></td>
<td>1. Watch the vignette Jane’s story 1: Meet Jane.</td>
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<td>• Using a screening tool such as the Supportive Needs Screening Tool or the Post Distress Thermometer Discussion Guidelines as a framework for your discussion, outline the questions you would ask and the possible referrals you would suggest to Jane.</td>
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<td>2. Outline the advantages and disadvantages of using a screening tool such as the Distress Thermometer in your practice.</td>
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Supportive Care Assessment

If supportive care needs are identified as part of the screening process, a more focused assessment of these needs or the sources of distress may be appropriate. A range of tools can be used to guide this more focused assessment. Some examples are provided below:

- Tools to assess specific symptoms or concerns, such as:
  - Brief Pain Inventory
  - Spirituality assessment process
  - Bristol stool chart

- Tools to assess specific sources of distress, such as the problem checklist associated with the Distress Thermometer.

- Tools to diagnose specific mental health concerns, such as the Hospital and Anxiety Depression Scale.

- Grading scales identified in the Common Terminology Criteria for Adverse Events (CTCAE) provide a framework for consistent assessment of need.

These more comprehensive assessments are required to enable an understanding of the aetiology or mechanisms underpinning or factors contributing to the identified need, the meaning of the need to the individual, and the impact of need on the person’s day to day life. This understanding is required so that interventions can be appropriately targeted to the cause and tailored to individual needs.

### Learning Activities

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| ☐         | 1. Review the following examples of assessment tools for assessing specific supportive care needs.  
  - Brief pain inventory  
  - Distress thermometer problem checklist  
  For each assessment tool, answer the following:  
  - What dimensions of need are being assessed?  
  - Explain the strengths and limitations of these tools in:  
    - Identifying underlying mechanisms or factors contributing to the unmet need.  
    - Guiding intervention. |
| ☐         | 2. Outline your nursing response if you suspected a person affected by cancer was experiencing anxiety or depression. |
Responding to supportive care needs

The focus of this section is evidence based interventions that are tailored specifically for the person affected by cancer and within the scope of practice of the nurse.

Supportive care interventions need to be specifically matched to the person’s needs. A combination of activities, rather than any single intervention by itself, is also likely to be the approach required.

Effective delivery of supportive care services includes five components:
1. Identifying / screening for supportive care needs (as discussed in previous section)
2. Linking patients to appropriate multidisciplinary services (making referrals)
3. Supporting people to manage their illness (education, development of new skills, preparing for a threatening procedure, brief counseling intervention)
4. Coordination of care
5. Evaluating effectiveness of care

Central to all these components is therapeutic communication.

Therapeutic communication

Intrinsic to communication between the health professional and the person affected by cancer is the notion that communication serves to address particular goals. These goals may include:
- developing a relationship
- giving or receiving information regarding diagnosis, treatment plan
- improving emotional state
- facilitating development of new skills.

For people whose needs sit within the first level of the tiered model for supportive care, it is likely that minimal intervention, such as the provision of information, education and knowing how to access resources, may be all that is required. The main goal of this type of communication includes developing a relationship and provision of summary information.

The strategies and techniques that can be used to assist in effective communication include:
- use of active listening
- open body posture
- identification and responding to verbal and non-verbal cues
- ensuring appropriate timing and environment
- sensitive handling of embarrassing situations
- using open ended questions
- providing the person time to talk
- using silence appropriately
- using discussion prompt sheets
- recognising and acknowledging the clinician’s own distress
- good eye contact
- clarification of the person’s concerns
- responding to cues suggestive of emotional distress
- asking questions about the person’s feelings
- inquiring about the situation at home
- making supportive comments
- handling interruptions well

Learning Activities

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<tr>
<td></td>
<td>1. Reflect on an interaction that you have recently had with a person affected by cancer who was experiencing mild-moderate distress. Using the communication skills list noted above, describe:</td>
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<td>• how you applied these skills in your interaction</td>
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<td>• what you could have done to improve your communication skills</td>
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Developing communication skills

Communication skills training, identifying personal issues, altering the environment and professional clinical supervision are all interventions that may improve communication skills.\(^{26}\)

Good communication skills do not necessarily improve over time or with clinical experience but they are easily learned. There is value in further developing communication skills in clinicians as it has been associated with decreased levels of stress in the workplace. All nurses should have a minimum level of training in communication.

Resource link

- Cancer Australia Frontline Psychosocial Support Tutorial – free of charge, registration required, video tutorial that focuses on anger, distress and depression management
- IPOS Online Curriculum Communication and Interpersonal Skills in Cancer Care - US based online International Psycho-oncology Society (IPOS) presentation
- IPOS Online Curriculum Psychosocial Assessment in Cancer Patients - US based online International Psycho-oncology Society (IPOS) presentation

Learning Activities

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<tr>
<td></td>
<td>• Reflect on an interaction you have had recently with a person you have cared for. Use the tool to rate your performance against each of the criteria.</td>
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<td></td>
<td>• Review the criterion and performance indicators and develop a learning and development plan with your mentor with the aim to develop beginning competence in therapeutic communication (middle band descriptor) by the end of you transition to practice program.</td>
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Communication with specific groups

Communicating with carers

The nurse requires good communication skills to assess the carer’s needs, provide information, and understand preferences for type and level of information provided.

Strategies to enable the eliciting of concerns include:

- Spending time with the carer to obtain information regarding the care required by the person
- Maintaining appropriate hope whilst allowing for expression of concerns regarding the diagnosis and prognosis
- Providing recognition of the importance of the carer’s needs
- Providing information in multiple modalities – verbal, written, family meetings, video, audio tapes, DVDs.

The conceptual model described by Hudson suggests the following strategies may be useful when designing interventions for carers:

- Provide information to improve the carer’s perception of preparedness to undertake the tasks and demands of the carer’s role
- Encourage the carer’s sense of mastery or sense of control the carer believes they have over their situation, with clear discussions regarding aims of treatment and goals of care, and respect of their perspective
- Provided positive reinforcement of the skills of the carer to encourage feelings of competence in overall performance of the role of care giver
- When providing information to the carer, encourage the carer’s sense of self-efficacy in the tasks associated with care giving by modelling and positive reinforcement of actions
- Assess the carer’s level of anxiety and depression and address strategies appropriately
- Remind the carer of the usual support systems the carer has available to encourage a positive perception of available social support

- Check with the carer that they believe they have adequate information to provide care
- Facilitate a discussion with the carer as to the positive aspects or potential benefits they may see from providing care
- Reflect with the carer the degree to which the caregiver finds gratification and meaning in the relationship
- Encourage the carer to maintain existing social interactions.

Family meetings can be useful to assist in clarifying goals of care and site of care options. Family meetings should be offered as part of routine care in palliative care and other situations which require discussion and negotiation of care plans with the family.

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<tr>
<td></td>
<td>1. Review the Clinical Practice Guidelines for Conducting Family Meetings in Palliative Care.</td>
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Special considerations when communicating with parents and children with cancer in the family

The family of a child with cancer has significant supportive care needs throughout the cancer journey, as they cope with a serious physical illness and the fear that their child will not be cured. At diagnosis, parents must adjust to the emotional realisation that their child is living with a life-threatening disease, while simultaneously receiving a large amount of information on how to manage and care for their child during treatment. Parents are very vulnerable during this time, and have an intense need for support from partners, families, friends, employers, hospital staff, and other parents.

How parents respond to their child’s diagnosis and subsequent management can also have a profound effect on how the child develops and responds to his/her illness. Factors which may influence how parents react include:

• reactions to previous crises
• reactions of the child
• child rearing practices and attitudes
• available support systems
• perception of the illness
• previous knowledge or experience with cancer
• cultural and religious beliefs
• beliefs about the cause of the disease
• effects of the disease on the family
• concurrent stresses in the family.

Characteristics which affect children’s responses to cancer include:

• age (most vulnerable - six months to four years)
• development level
• temperament
• social skills and self concept
• pre-existing conditions and previous experiences
• intelligence level
• type of disease
• reactions of significant others.

Primary caregivers, who are important to the well-being of the child during treatment, need to understand the nature of the disease, treatment options and prognosis in order to participate in treatment decisions and to take on the care roles expected of them.

More than one half of all children with cancer can experience moderate to severe cancer related pain. One of the most distressing events for children is pain resulting from diagnostic procedures and treatments. Young children will often view non-invasive procedures such as imaging, radiological tests and radiation treatment as painful and may become distressed prior to and during these procedures. Issues such as lying still for prolonged periods, confined spaces and being separated from parents can also exacerbate this distress. Interventions can include pharmacological and non-pharmacological strategies for the child and their family to reduce procedural distress. These strategies should take account of the child’s age, developmental stage, understanding of their situation and previous responses to stressful situations.

Resource link
## Learning Activities

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|           | 1. Watch the vignette *Ellies story 5: Support during procedures* and complete the following activities.  
 Outline evidence based strategies to:  
• prepare and support Ellie during the accessing of her CVAD  
• support Ellie’s parents during invasive procedures. |
Discussion of issues around prognosis or end of life

Nurses caring for people affected by cancer are often challenged to assist individuals with managing difficult thoughts, feelings and concerns. Existential concerns are normal and common and can be a significant source of distress among individuals facing a life-threatening illness. Individuals who are successfully supported to overcome existential challenges may experience end of life as a time of enhanced relationships with loved ones, a deepened sense of self and heightened psychological growth.36

Guidelines have been developed to support health care professionals to effectively communicate with people with life-limiting illnesses regarding prognostic and end-of-life. Key recommendations include:37

- Prepare for the discussion
- Relate to the person
- Elicit patient and caregiver preferences
- Provide information
- Acknowledge emotions and concerns
- Foster realistic hope
- Encourage questions
- Document

Resource link

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<tr>
<td></td>
<td></td>
<td>1. Observe an experienced health professional discuss end-of-life or poor prognostic information with people affected by cancer. Outline how the guideline recommendations outlined above were implemented in the interaction.</td>
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<tr>
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<td>2. Reflect upon your own life and clinical experiences and describe your thoughts, feelings and attitudes regarding death and dying.</td>
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</table>
Making Appropriate Referrals

Referrals to other health professionals or services are sometimes required to provide specialised support or address more complex issues beyond the capabilities of the team. Recommendations for referrals include:38

- The referral should be made by the health care provider as this is more likely to result in service use.
- Structured referral sheets are useful checklists that can be completed at the time of screening or assessment. The referral checklist can include prompts for the nurse as to the criteria for referral and include suggestions for referral linked to these criteria. Examples of referral tools are available on the Supportive Cancer Care Victoria website.
- The development and dissemination of referral guidelines is a useful strategy for the nurse to clearly identify the internal and external supportive care resources available. The referral guidelines would be more effective if the supportive care services were involved in their development and dissemination.
- The referral guidelines need to be applicable to the local circumstances and address local issues.

Fewer than 10% of people are actually referred for psychosocial help despite having needs identified.6 Reasons for the lack of follow up include:39, 40

- Inappropriate timing of referrals
- Clinicians not knowing the supportive care resources available
- Clinicians not asking about supportive care needs
- Clinicians not able to skillfully introduce the supportive care service.

Inappropriate timing of referrals

Inappropriate timing of the referral can result from issues such as not being ready to acknowledge current difficulties or their current difficulty in coping, not wanting to share their issue with other team members, or focusing attention on the physical treatment first. Strategies relating to this barrier include:15

- Find an acceptable opening by exploring other more acceptable issues first – “I see that you say that you are not sleeping well perhaps we could explore that a bit more.”
- Normalise feelings and the need for help – “Many people I see experience an overwhelming sadness when they have been told they have cancer, this is a normal feeling.”
- Try introducing the referral at another time.

Clinicians not knowing the supportive care resources available

Some strategies that could be attempted include:15

- Mapping available supportive care resources in the area and speaking to the health professionals to identify criteria for referral and your own referral network for supportive and psychological care of their patients. This will generally involve a mix of internal and external resources.
- Initiating local supportive care multidisciplinary team meetings and including supportive care issues in each case discussion.
- Developing a flow chart / care pathway for decision making that reflects the resources available in the area and is agreed to by the multidisciplinary team (see Figure 3).
Effective introduction of supportive care services

The method of introducing referrals to supportive care services can influence their uptake. For example, if a service is introduced as extra to and not as part of the team or care provided, people may see the referral as a burden, or the referral to supportive care services may be seen as a failure as the person is unable to cope.

Strategies to assist include:

- Introduce the other service as part of the team providing care, and advise the person that they will not need to repeat their story over again
- Advise that speaking to someone else and listening to another perspective may assist with developing strategies that may help in their maintaining/improving their overall feeling of health and well-being
- Give illustrations of where such referral has been helpful to another person you have cared for

If a referral is refused, you might ask the person’s permission for you to discuss their problem with relevant colleague(s) and bring suggested strategies into your work with them. This may also lower the barriers to accepting the referral as the individual begins to see the suggestions as helpful.

Learning Activities

<table>
<thead>
<tr>
<th>Completed</th>
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<tbody>
<tr>
<td></td>
<td>1. Identify an individual who has a supportive care need requiring referral:</td>
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<tr>
<td></td>
<td>- Determine what screening is required to identify individuals who have/are at risk of unmet need.</td>
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<td></td>
<td>- Describe the outcomes of any focussed assessment relating to this unmet need.</td>
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<td>- Describe the process of referral.</td>
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<td></td>
<td>- Outline any barriers and enablers experienced throughout the process.</td>
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</tbody>
</table>
Figure 3: Summary of care and referral to psychological care.

Identify and document high risk factors and assess level of distress

Patient not considered ‘high risk’ and not distressed

- Continue to provide care

Assess
- Monitor psychological distress and provide non-specialised interventions as required
  - Emotional support
  - Group support
  - Access to information

Enquire
- Enquire about general psychological and emotional well-being as well as other specific issues (body image, anxiety, concerns about family etc)

Assess degree of psychological distress

Patient not distressed

Patient distressed

- Clarify nature and extent of distress (eg. is it financial, emotional distress, depression)

Self-harm
- Thoughts of self-harm

- Requires urgent psychological consultation

2 weeks history of
- Symptoms of low mood
- Somatic signs of significant distress
- Cognitive symptoms of distress

Distress
- Emotional and financial

Distress
- Requires urgent psychological consultation

Refer to psychologist

Refer to social worker

Adapted from Clinical practice guidelines for the psychosocial care of adults with cancer by Cathie Pigott.
Information provision / education

The provision of information to people affected by cancer is essential to making informed choice, reducing anxiety and participating in decision making. Nurses play an integral role as information providers for people affected cancer, especially relating to treatment. A recent review of the literature indicated that specialist nurses are very effective in providing information.41

Some general steps to include in an education / information session are:15, 42

1. Introduce yourself to the person and their family, and ensure a comfortable environment, minimise interruptions.
2. Assess the anxiety levels of the person and their family, normalise feelings of anxiety. If the person has a history of anxiety disorders such as needle phobia, refer the person to psychologist for extra support.
3. Provide an overview of the session, the structure, timeframe and ensure you allow time for questions.
4. Assess understanding and correct any misconceptions.
5. Assess level of information required.
6. Teach relevant concepts eg. introduce and discuss the treatment.
7. Introduce concept of self care.
8. Review who to contact and role play when to make contact.
9. Provide information in multimedia format, use diagrams or pictures where possible.
10. Encourage the presence of another person.
11. Ask the person to repeat back to you their understanding of the information you have provided.
12. Repeat the important information in a follow up session/ phone call. Send a summary letter as a follow up to the information.

Some of the principles of information and education provision include: 15,43

- Give the most important information first eg antibiotics full course must be taken
- Stress the important messages for eg. “This is important...”
- Provide simple concrete advice and be specific with advice. For example: “You can have one full strength beer with dinner but no more” (as opposed to drink moderately)
- Divide the instructions into categories and announce the categories before giving the person the information in each category. For example “I’m now going to tell you when and how to take the tablets, and the reasons for taking them this way”
- Providing encouraging responses to emotional cues improves recall of the information provided

If the aim of the information or education session is to prepare the person for a threatening procedure or treatment, the nurse needs to consider the ways in the information is presented. Information should describe both sensory and procedural elements of the proposed procedure, and psychological concerns should be addressed, especially for highly anxious people.44 Sensory information is information that describes the sensations that the person is likely to experience as a result of the procedure. Procedural information emphasises the order / sequence in which the procedure will be undertaken.45

When considering coaching or the development of new skills a standardised structured approach to the discussion will maximise the effectiveness of the session. Utilising an evidence based model for tailored education and coaching is a useful approach. One model is the TEC model (tailored education and coaching). The TEC model is a brief, person centered model that is underpinned by social cognitive theory.46
The components of the TEC model include:

- Assessment of current knowledge, attitudes and preferences (values). The first step in skilled information/education provision involves assessing the person’s preference for information. People’s needs vary about the depth of the information about their disease, treatment and prognosis they want to hear. A structured coaching session is more effective if information is tailored to the person’s needs.
- Correction of misconceptions about the disease, treatment and/or side effects. Identification of misconceptions may be achieved by the person completing a questionnaire prior to the interview.
- Teaching of relevant concepts, this could include self-management skills, as well as increasing confidence when communicating with the health team.
- Planning which includes identifying goals, matching strategies to goals.
- Rehearsal using role play exercises.
- Portrayal of learned skills.

### Learning Activities

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<tbody>
<tr>
<td></td>
<td>1. Plan an education session for someone preparing for a cancer treatment. Consider what pre-education questions you would ask, content of the session, access to other resources and the process for follow up would you use.</td>
</tr>
<tr>
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<td>2. Describe how you would evaluate the effectiveness of the education session?</td>
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</table>
Providing a single brief counseling intervention

At the next level of the framework, people affected by cancer can require an intervention such as a once off therapeutic counseling session. Specialist Cancer Nurses with advanced skills in communication and available support processes, such as clinical supervision, may be able to provide this level of intervention.

There are a number of models that can guide these types of therapeutic sessions. One example is the Chronic Illness Self Management 5 A’s model.48

The Five A’s Model of Self-Management Support is used to help people develop action plans particularly focused on their chronic illness. The model has been used by the QUIT program for smoking cessation and is helpful in a range of contexts. The Five A’s are: 48

- **Assess** – the beliefs and knowledge of the person
- **Advise** – provide specific information that will enhance the knowledge of the person and correct any myths, tailored information provision
- **Agree** – work with the person to identify goals and priorities to achieve, develop an action plan for specific behaviour changes
- **Assist** – work with the person to identify barriers and establish some strategies to overcome these, suggest strategies to help achieve the goals
- **Arrange** – arrange a follow up phone call or visit to review achievements against goals set.

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<td>☑</td>
<td>1. Watch the vignette Harold’s Story.</td>
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</table>

- Summarise the evidence regarding smoking cessation for someone with lung cancer.
- Outline the advice would you provide for Harold in relation to his smoking.
Barriers to providing evidence based supportive care

Barriers to providing evidence based supportive care can be categorised into three categories:49

- Predisposing factors
  - Knowledge of what is evidence based practice
  - Attitudes and beliefs about supportive care
  - The value attributed to supportive care
  - The extent to which the person believes they can manage on their own

- Enabling factors include having:
  - Time to discuss supportive care issues
  - Skills in detecting supportive care issues and systems to support the assessment
  - Skills to intervene
  - Reminders come up to remind the clinician to address supportive care issues
  - Resources including environmental and clinicians
  - A clear understanding of roles of each of the multidisciplinary team members
  - Support available to relieve stress of clinicians

- Reinforcing factors include
  - Receiving feedback regarding performance of clinician and outcomes
  - Rewards and negative consequences

Some strategies to help overcome these barriers include:49

- Undertaking communication skills training and education in the use of supportive care tools
- Identifying a person's current supportive care resources, such as family, friends, local doctor or local minister who may reduce the need for other services. Remembering the inverted triangle model and that many people do not require high levels of intervention
- Mapping the resources and developing a service directory of what services are available to provide supportive care in the community

### Learning Activities

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<tbody>
<tr>
<td>1.</td>
<td>Review <em>Barriers to the provision of evidence-based psychosocial care in oncology.</em></td>
</tr>
<tr>
<td></td>
<td>- Appraise current services and practices in your practice setting in light of the barriers to care identified in Table 1.</td>
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<tr>
<td></td>
<td>- Outline strategies which may be useful to consider implementing in your own practice setting to improve supportive care services.</td>
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</table>
Self care for nurses

Healthcare workers participating in cancer control efforts face an increased risk of stress or compassion fatigue.50-52

Causes of stress may include:50, 52
• complex healthcare states and comorbidities
• the high level and intensity of interpersonal relationships
• increasing acuity
• individuals’ expectations of care
• technological advances requiring increasingly sophisticated nursing skills
• decreased length of hospital admission
• the necessity of dealing with the dying process.

In palliative care, unique factors may magnify the risk of compassion fatigue. These include:53
• accumulated losses
• emotionally charged care
• sustained and exclusive focus on terminal illnesses and terminal care
• mortality issues of the clinician (existential, spiritual, or personal).

Cancer nurses must examine their own thoughts, feelings and attitudes regarding death and dying so as to better recognise and understand how to cope with their own aversive thoughts and emotions. Peer support from experienced cancer nurses may facilitate this process in novice nurses.54 Research has shown that nurses who receive death communication education become more comfortable with discussion of life and death concerns with individuals and their families.55

The clinical importance of compassion fatigue has been highlighted through its impact on outcomes such as:
• increased medical errors56
• increased turnover and absenteeism57
• decreased quality of care58
• decreased satisfaction expressed by recipients of care59
• significant impact which burnout has on the professional and personal lives of affected personnel.52, 60

Protective practices for health care professionals are recommended to:53
• help compartmentalise work from the rest of life - identify ways to leave the job behind
• clarify and support staff in establishing professional boundaries
• promote emotional and physical health
• include regular self-care techniques for managing stress.

Resource link

Learning activities

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</table>
|           | 1. Reflect on a situation where a person has asked if medication administered to their loved one will hasten death.  
  • How did / would you respond?  
  • Discuss evidence-based communication strategies you might use in this situation. |
|           | 2. Access self care resources at the following links:  
  • CareSearch53  
  • Cancer Learning  
    o Discuss strategies nurses could implement to protect themselves from workplace stress and compassion fatigue. |
References


16. Peter MacCallum Cancer Centre. Supportive Needs Screening Tool. ND.


