Cancer supportive care principles

Aim

The aim of this module is to develop specialist cancer nurse knowledge and skills in supportive care screening, assessment and referral.

The module focuses specifically on developing the ability of the SCN to provide an advanced level of supportive care to people affected by cancer.

Rationale

The ability to provide supportive care at an advanced level is a key domain of specialist cancer nursing practice.

This area of practice comprises competencies that reflect the SCN's ability to identify multiple needs across all domains of health throughout the cancer continuum, and includes implementation of evidence-based supportive care interventions in a flexible and responsive manner, in the context of a collaborative multidisciplinary approach to care.

Key concepts

The key concepts associated with cancer supportive care principles include:

- Definition of supportive care.
- Screening and assessment of supportive care needs.
- Evidence based approaches to education and information provision.
- Therapeutic communication skills.
- Promoting self-management.
- Barriers to supportive care provision.
- Self-care for nurses.

Objectives

On completion of this module, you should be able to:

1. Identify key supportive care needs people may experience during and after treatment for cancer.
2. Implement evidence based screening and assessment approaches to identify supportive care needs.
3. Integrate evidence based communication and information provision strategies throughout the supportive care process.
4. Discuss appropriate use of a range of evidence based interventions to address common supportive care needs of people affected by cancer.
5. Identify evidence based resources to make relevant referrals

Learning activities
At times, you will have learning activities to complete. Click on the learning activities button and a list of questions will pop up. The questions will relate to the content you've just read or the video you've just watched.

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

PDF of EdCaN module: Cancer supportive care principles
You can download a PDF version of the module.

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Cancer supportive care needs

A diagnosis of cancer can affect a person's physical, psychological, spiritual, and social well-being. Some of these effects will resolve over time due to individual personal coping resources, social and professional support and some needs emerge later or increase over time.

Supportive care is defined as *"the provision of the necessary services for those living with or affected by cancer to meet their physical, emotional, social, psychological, informational, spiritual and practical needs during the diagnostic, treatment, and follow-up phases, encompassing issues of survivorship, palliative care and bereavement"*.[1]

- **Physical** – "Needs related to physical comfort and freedom from pain, optimum nutrition, ability to carry out one's usual day-to-day functions"[2]
- **Emotional** – "Needs related to a sense of comfort, belonging, understanding and reassurance in times of stress and upset" [2]
- **Social** – "Needs related to family relationships, community acceptance and involvement in relationships"[2]
- **Psychological** – "Needs related to the ability to cope with the illness experience and its consequences, including the need for optimal personal control and the need to experience positive self-esteem" [2]
- **Informational** – "Needs requiring information to reduce confusion, anxiety and fear; to inform the person's or family's decision-making; and to assist in skill acquisition"[2]
- **Spiritual** – "Needs related to the meaning and purpose in life to practice religious beliefs"[2]
- **Practical** – "Needs requiring direct assistance in order to accomplish a task or activity and thereby reduce the demands on the person"[2]

Supportive care interventions can prevent or minimise the adverse effects of cancer and its treatment, across all phases of a person's cancer experience. Nurses contribute to effective supportive care by:[2, 3]

- 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, and at end of life
- timely referral to other professionals, individuals and services if required.

Interventions may include self-management support, information, psychological support, symptom control, social support, rehabilitation, spiritual support, palliative care and bereavement care.[3]

Why is this important?

Early identification and referral of individuals with unmet supportive care needs can result in improved outcomes, such as:[4, 5]

- decreased levels of patient distress
- a decrease in the likelihood of the development of clinical anxiety and depression
- enhanced quality of care and patient satisfaction
- improved communication with the health care team
- increased adherence to cancer treatments
- decreased longer term costs and usage of the health care system.

Unmet supportive care needs can be 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 feelings of vulnerability, sadness and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.[6] Rates of clinically significant distress have been reported to be between 25% and 45% among people with cancer.[7, 8]

A high proportion of unmet supportive care needs are psychological. Individuals need assistance in managing fears about the future and the cancer spreading; lack of control; and feeling sad, depressed or anxious.[9] Fewer than 10% of people are referred for psychosocial help despite having needs identified.[8] Reasons for the lack of follow-up include:[10, 11]

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

The most common unmet needs experienced throughout the cancer journey are summarised in Table 1.

Table 1: Common unmet supportive care needs[4, 12, 13]

Phase of cancer journey	Common unmet supportive care needs
Diagnostic phase:	• Physical (includes symptoms such as fatigue, weight loss, breathlessness, pain, stiffness, movement dysfunction, co-morbidities/injuries) • 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 (ADLs), fatigue, pain, stiffness, mucositis, bowel changes, weight changes, sexual dysfunction, poor sleep, movement dysfunction, co-morbidities/injuries, neurological symptoms) • Social (includes financial, transport and accommodation issues, work issues, family support, relationship issues) • Psychological (includes fear of spread, worry about carers and family, 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).
Post treatment, follow-up and survivorship phase:	• Physical (includes fatigue, pain, stiffness, gastrointestinal and bladder changes, cardiovascular and respiratory issues, sexual dysfunction, fertility issues, weight changes, neurological symptoms, movement dysfunction, co-morbidities/injuries, balance, safety.) • Social (includes financial needs, feelings of isolation, abandonment) • Psychological (includes anxiety about the cancer returning, cognitive impairments) • Information (need for information regarding follow-up care, self-management strategies) • Spiritual (includes concerns about meaning of life, re-prioritising needs)
Advanced and end of life phase:	• Physical (includes inability to attend to ADLs, nausea, fatigue, pain, bowel changes, respiratory issues, weight changes, mobility, balance, safety, falls prevention.) • Social (includes financial needs, expressing wishes such as in wills and advanced care plans, concern related to carer and family coping) • Psychological (includes depression, anxiety, fear, isolation) • Information (includes care needs, advanced care planning) • Spiritual (includes feelings of hopelessness, helplessness, fear of death)

Who is at risk?

Some individuals can be at increased risk of experiencing distress because of a range of social, personal or clinical circumstances (see below). Recognising these risk factors can assist in focusing the discussion with individuals about their concerns and facilitate early intervention and appropriate referrals if required.[4]

Table 2: Factors associated with an increased risk of psychosocial problems[4]

Individual factors	• Younger age and older age • Single, separated, divorced, widowed • Living alone • Having children younger than 21 years • Economic adversity • Lack of social support, perceived poor social support • Poor marital functioning • Past psychiatric treatment especially depression • Cumulative stressful life events • History of alcohol or other substance abuse • Female gender
Disease/treatment factors	• Diagnosis and recurrence • Advanced stages of disease • Poor prognosis • Severe or multiple treatment effects • Greater functional impairment and disease burden • Lymphoedema • Chronic pain • Fatigue

Learning Activities	
Completed	Activities
☐	1. Review one of the *Optimal Care Pathways* for a specific cancer type and list supportive care needs to consider for an individual diagnosed with that cancer. • Describe demographic, cancer related and social factors that might place a person at increased risk of unmet need when newly diagnosed with that cancer.
☐	2. Identify which of the risk factors in Table 2 are common to your patient populations.
☐	3. Outline the process for identifying these risk factors in your clinical practice
☐	4. Watch the vignette Jane's story 1: Meet Jane. • Identify the risk factors which would indicate Jane is at increased risk of experiencing distress. • Consider the supportive care needs Jane may experience throughout her treatment journey: a. physical b. practical c. social d. psychological e. spiritual f. informational.
☐	5. Access the video Understanding the needs of Cancer Survivors, and complete the following: • List the common supportive care needs experienced in the post treatment phase. • Describe 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

Partners / carers and children of people with cancer are also vulnerable to experiencing distress and need support.[4] In particular, spousal caregivers can experience high stress, potential burnout, depressive symptoms, poor health and unmet needs.[14] The distress experienced by carers and patients has been reported as equally significant, but key unmet supportive care needs differ. The majority of patients unmet supportive care needs may be psychological, however carer needs can also relate to access to health services and information. Major causes of distress for a carer include:[15, 16]

- the physical care demands of the person affected by cancer
- dealing with distressing symptoms, such as pain
- uncertainty about the illness trajectory
- 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 undertake carer role
- changes in body image of the person affected by cancer
- changes in intimacy.

Family and carers may have pre-existing concerns affecting their supportive care needs throughout the cancer journey. The following factors are associated with an increased risk of adverse psychological events for carers:[17]

- increased intensity and duration of caring
    - providing over 20 hours of care per week
    - meeting a high level of dependency
- preexisting caring responsibilities in addition to the person affected by cancer (e.g. children, elderly parents)
- female gender[14]
- few supports
- poor health
- unemployment or low income[9]
- distressed relationships
- a significant change in roles e.g. from “cared for” to “carer”.

Carer support may need to be more system focused, setting the intervention in the context of the carer-patient relationship. Strategies to manage the demands of this assumed role can assist.[9]

Learning Activities	
Completed	Activities
☐	1. Access Mrs Li’s story 2. List possible concerns Mrs Li’s daughter may experience following her mother’s diagnosis and into the future.
☐	2. Identify the common concerns experienced by carers of individuals you care for.
☐	3. Outline your response if a relative such as Mrs Li’s daughter came to you, looking fatigued and teary, stating that she wasn’t coping with caring for her mother.

Framework for Supportive Care

A range of skills are needed to provide comprehensive supportive care throughout the cancer trajectory in multiple care settings. Supportive care provision is not the responsibility of one discipline or service. Aspects of supportive care need to be integral to the practice of all health care professionals and demonstrated through actions such as:[2, 18]

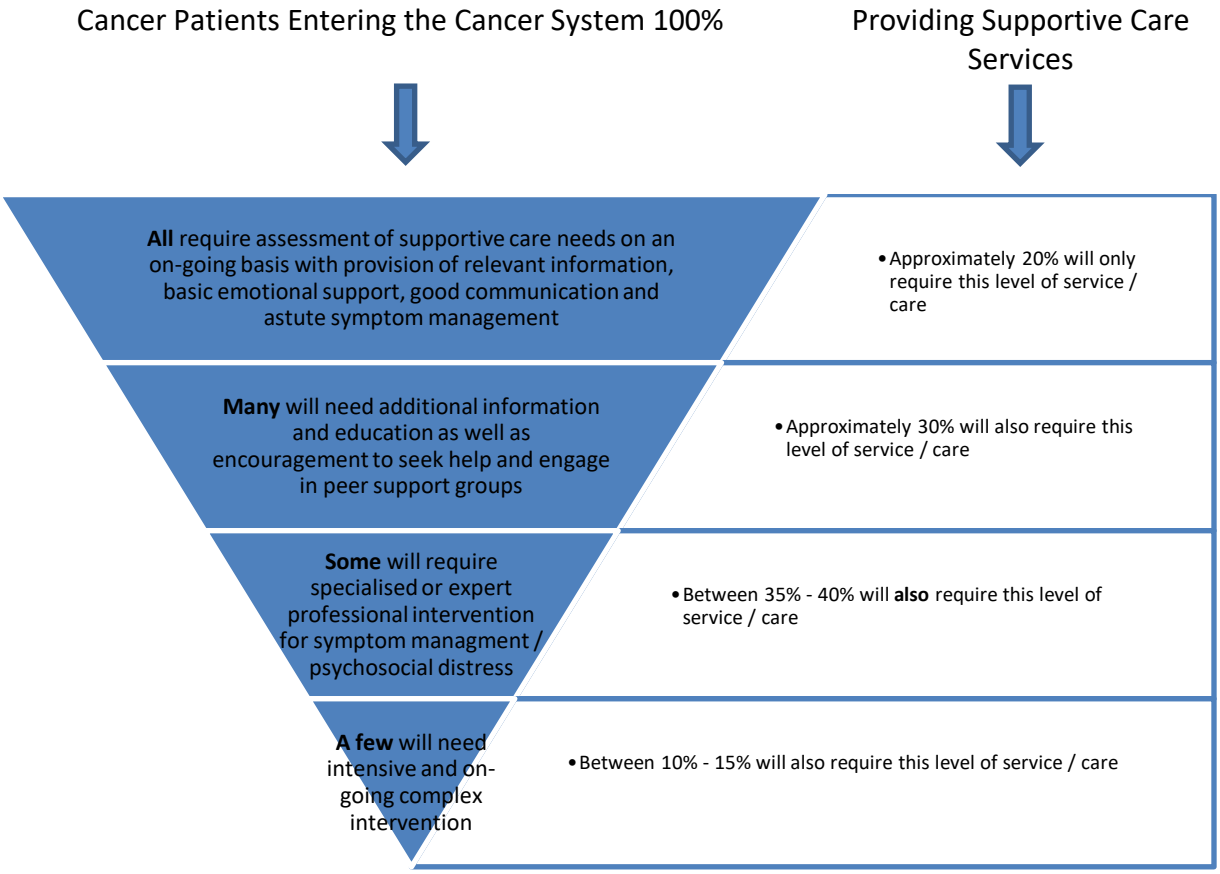
- screening for supportive care needs
- offering emotional support
- providing information in the course of interactions
- alleviating symptoms and complications of cancer
- reducing or preventing effects of treatment
- referring to other providers as necessary.

Fitch (2008), defined five clinical standards of supportive care:[2]

- All individuals receive ongoing supportive care screening and 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.

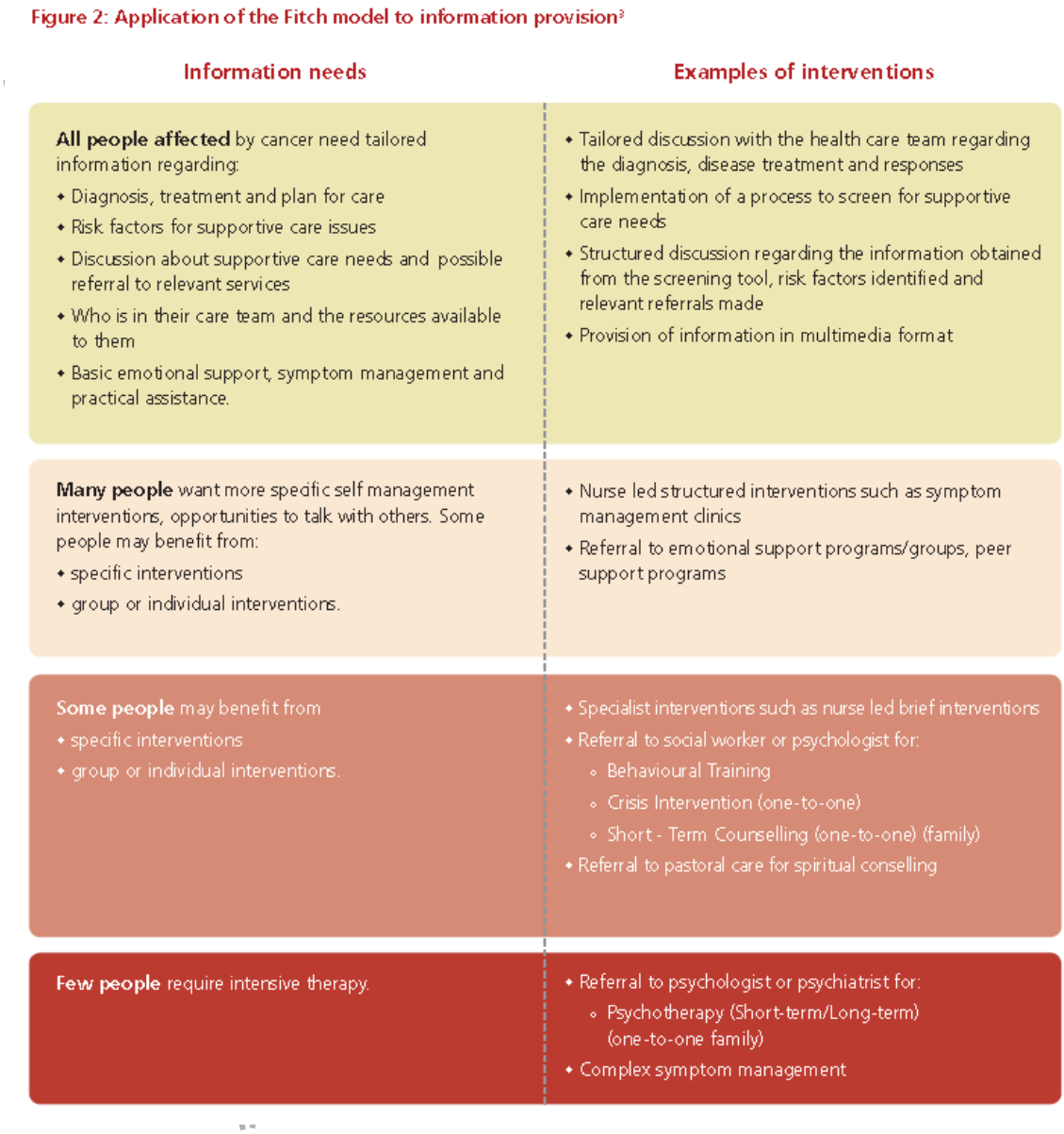
The Supportive Care model in Figure 1 provides a description of the service delivery responses required to meet the supportive care needs of cancer patients. The model recognises that individuals have differing needs and therefore require different levels of response. In all cases, supportive care approaches should be evidence based, and customised to the individual and may not be available in one health care setting.

Figure 1: Model of Supportive Care service provision (Fitch, 2008)[2]



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[3]



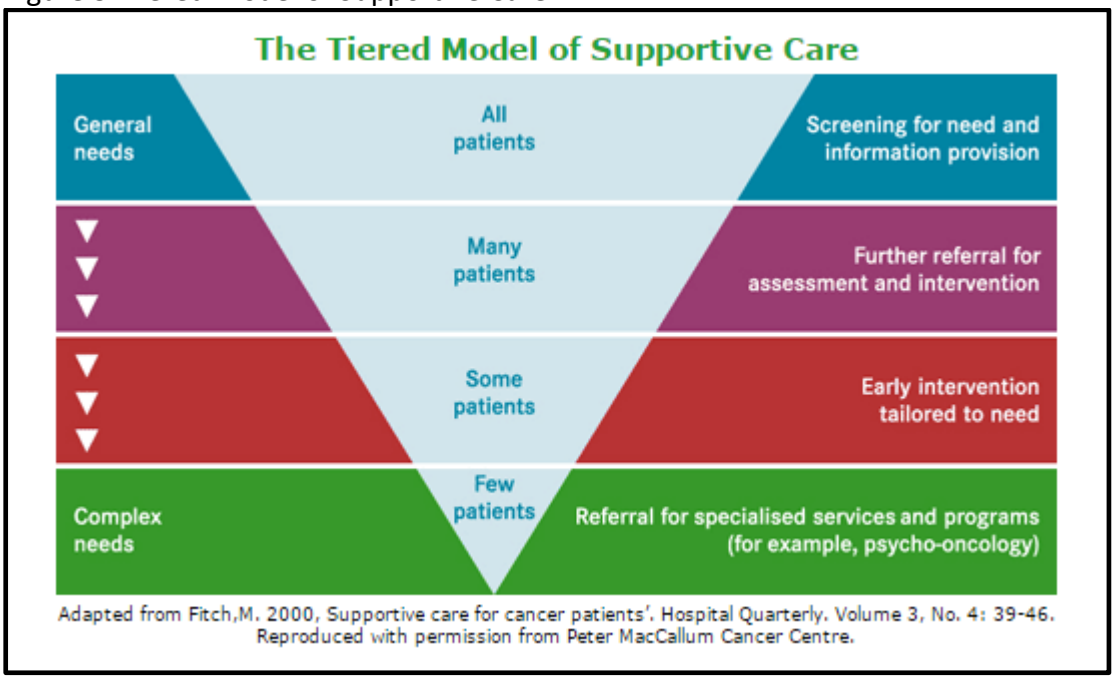
In many cancer care settings, a dedicated cancer care coordinator may be engaged to work with and between multidisciplinary teams to ensure that patients and their families receive holistic supportive care that is relevant and timely. In Australia, the Cancer Nurses Society of Australia (CNSA) contributed to the Clinical Oncology Society of Australia's (COSA) position statement[86] which identifies the functions of the care coordinator as including:

- Assessment and screening for clinical and supportive care needs and patients at risk for adverse clinical and psychosocial outcomes
- Facilitating delivery of cancer care consistent with established evidence based guidelines
- Ensuring prompt referral to specialist, allied health and support services
- Facilitating continuity of care between health professionals and across settings for care delivery
- Providing timely and consistent education and information to patients and their families.

Models of supportive care

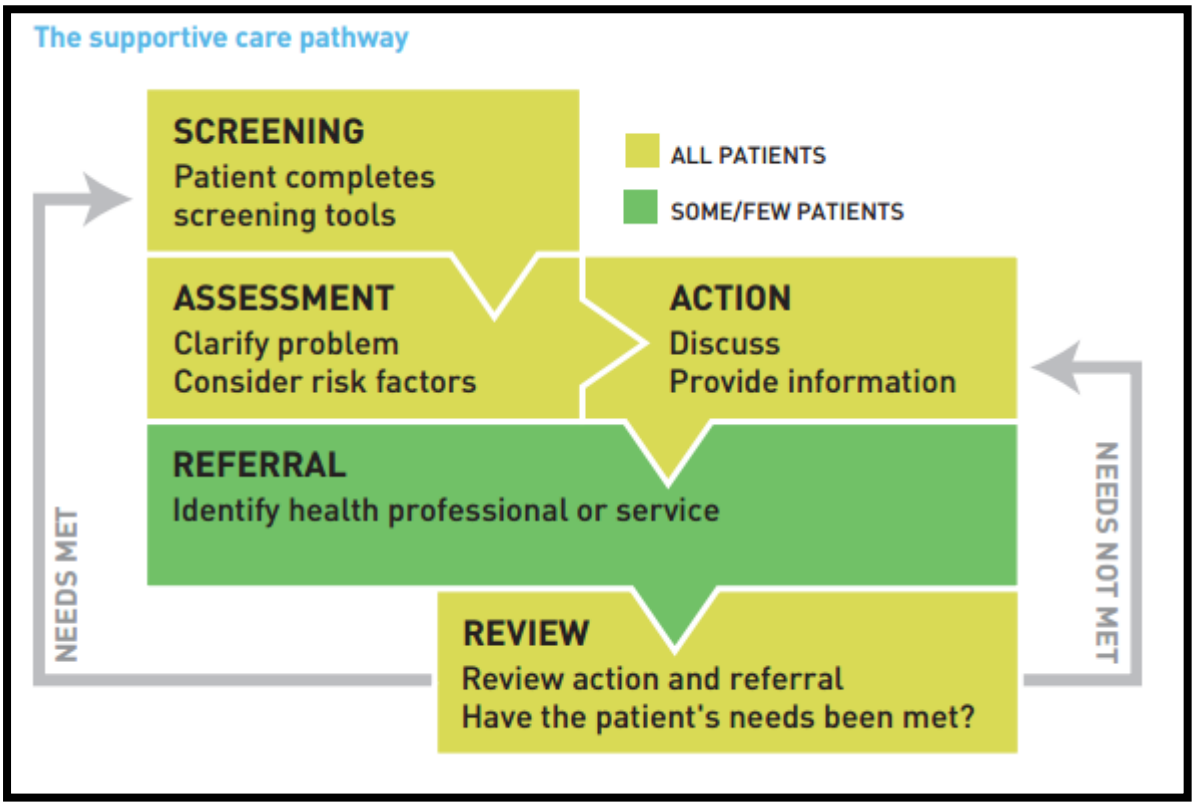
In Australia, models of care applying the principles of supportive care are developing. The Tiered Model of Supportive Care (Figure 3), developed by Supportive Cancer Care Victoria, adapts the approach described by Fitch. It recognises that effective, efficient allocation of resources is required to respond to the diversity of needs of a population.[19]

Figure 3: Tiered Model of Supportive Care[19]



The Supportive Care Pathway[20] (Figure 4), is an example of a model representing the process of supportive care screening, assessment, action and any necessary referral or follow-up. The pathway acknowledges the need for an individualised approach, focussed assessment only when required, and highlights that some needs can be met through clarification and provision of information and supportive communication.[20] The referral stage is either a suggested or recommended step in the process and is relevant for the "Some" and "Few" patients.

Figure 4: The Supportive Care Pathway[20] (© Monash University Department of Rural and Indigenous Health and Gippsland Regional Integrated Cancer Services).



Learning Activities	
Completed	Activities
☐	1. Reflect upon your practice setting. a. How are supportive care needs screened? b. What do you do with the results of screening? c. What types of supportive care interventions can you provide? d. Is there a pathway or resources to guide further assessment or referral?

Supportive care screening

A systematic, evidence-based approach for screening supportive care needs should be routine and periodic practice. It is recommended that that this occurs at various stages of the cancer journey, including:[4, 21]

- following diagnosis (e.g. at the initial visit)
- prior to each new phase of treatment (e.g. surgery, chemotherapy, radiotherapy)
- at appropriate intervals during treatment (e.g. significant changes in symptoms, personal circumstances, treatment plan, prognosis)
- at the conclusion of active treatment
- during follow-up
- at recurrence
- during palliative care.

Screening involves the routine and systematic identification of risk factors and potential supportive care needs before the issue becomes problematic.[3] Through the process of supportive care screening, health professionals facilitate:[3]

- Identification and prioritising of needs.
- An immediate response to high-level risk.
- Appropriate follow-up referral(s) and support.

Guided by health professionals with relevant skills, supportive care screening should, where possible, involve a self-assessment process.[22] Key steps in screening include:[23]

- completion of the screening tool by the person affected by cancer or with assistance by a health professional as required
- discussion between the person and the health professional to:
    - clarify the identified needs
    - evaluate the impact of unmet needs on daily living and quality of life
    - plan for further assessment and referral as needed and / or requested by the person
- document the results of the discussion and the completed screening tool.

The tool used to screen supportive care needs should be reliable and valid. Supportive Cancer Care Victoria has collated a number of Screening Implementation Resources.[24] These include:

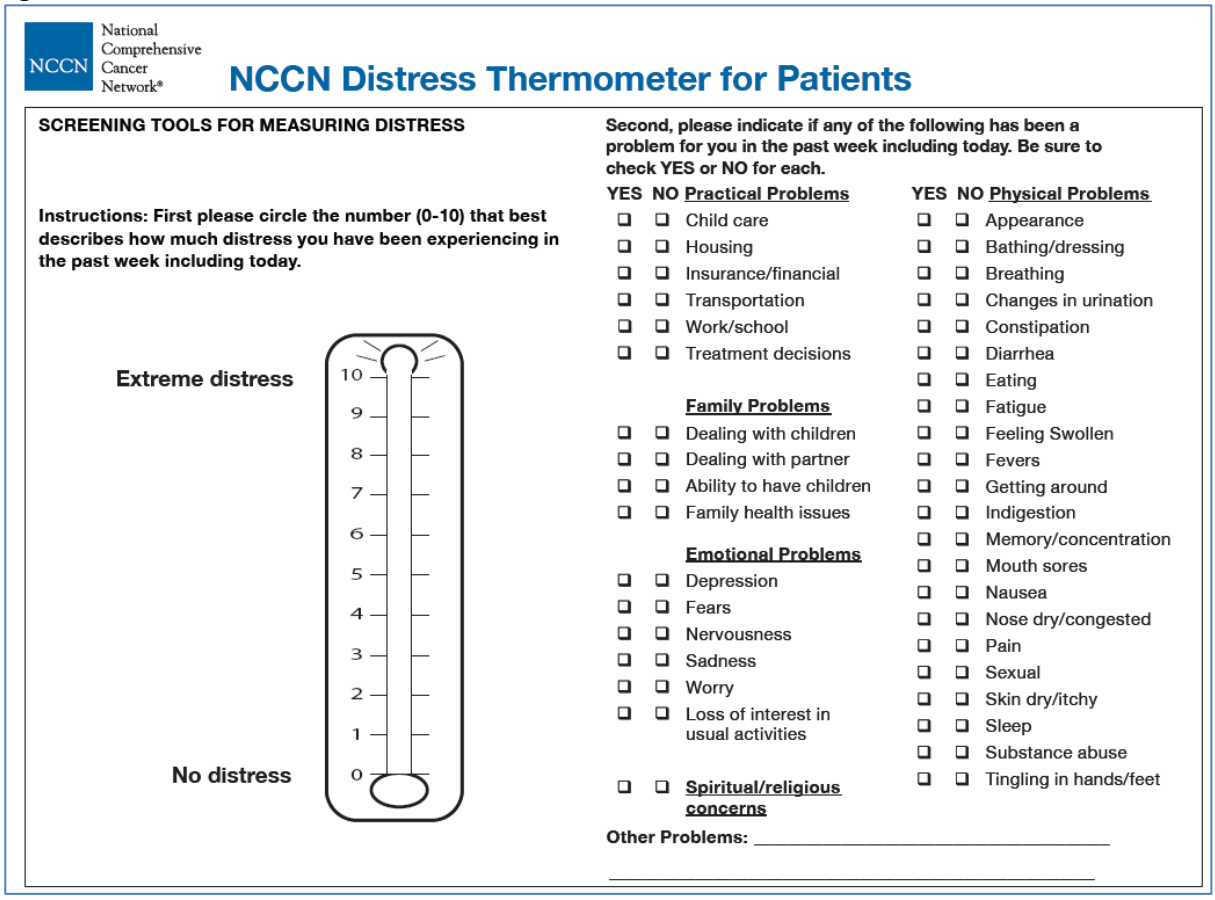
- Supportive Care Screening Tools Summary Guide.
- Points to consider when selecting a screening tool.

A validated and widely used tool, developed by the National Comprehensive Cancer Network, is the Distress Thermometer and Problem List (Figure 5).[21]

The level of distress experienced is identified on a 0-10 scale and the problem list enables identification of issues in the past week related to practical, family, emotional or physical problems and spiritual/religious concerns. The score identified on the distress thermometer may guide clinical decision making. All identified problems should lead to a discussion to explore the individuals' concern/s. If there are a large number of problems identified the health professional could ask the person to prioritise concerns. A score ≥4 may indicate significant distress and warrants discussion. Focused assessment and referral to specialised care may also be required.[21]

The Distress Thermometer and Problem List may be used by any member of the multidisciplinary team within their scope of practice and level of competence.[25] Use of the checklist to facilitate discussion of problems has been associated with enhanced communication and rapport as it encourages patients and clinicians to discuss concerns which they may have otherwise been hesitant to do.[26]

Figure 5: NCCN Distress Thermometer for Patients[27]



NCCN National Comprehensive Cancer Network®

NCCN Distress Thermometer for Patients

SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress

10 9 8 7 6 5 4 3 2 1 0

No distress

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES	NO	Practical Problems
❑	❑	Child care
❑	❑	Housing
❑	❑	Insurance/financial
❑	❑	Transportation
❑	❑	Work/school
❑	❑	Treatment decisions

YES	NO	Family Problems
❑	❑	Dealing with children
❑	❑	Dealing with partner
❑	❑	Ability to have children
❑	❑	Family health issues

YES	NO	Emotional Problems
❑	❑	Depression
❑	❑	Fears
❑	❑	Nervousness
❑	❑	Sadness
❑	❑	Worry
❑	❑	Loss of interest in usual activities

YES	NO	Spiritual/religious concerns
❑	❑	

YES	NO	Physical Problems
❑	❑	Appearance
❑	❑	Bathing/dressing
❑	❑	Breathing
❑	❑	Changes in urination
❑	❑	Constipation
❑	❑	Diarrhea
❑	❑	Eating
❑	❑	Fatigue
❑	❑	Feeling Swollen
❑	❑	Fevers
❑	❑	Getting around
❑	❑	Indigestion
❑	❑	Memory/concentration
❑	❑	Mouth sores
❑	❑	Nausea
❑	❑	Nose dry/congested
❑	❑	Pain
❑	❑	Sexual
❑	❑	Skin dry/itchy
❑	❑	Sleep
❑	❑	Substance abuse
❑	❑	Tingling in hands/feet

Other Problems: _____

_____

Key resources

The consumer resource, Cancer – how are you travelling?[28], contains several copies of the Distress Thermometer that individuals may use independently or prior to a follow-up appointment.

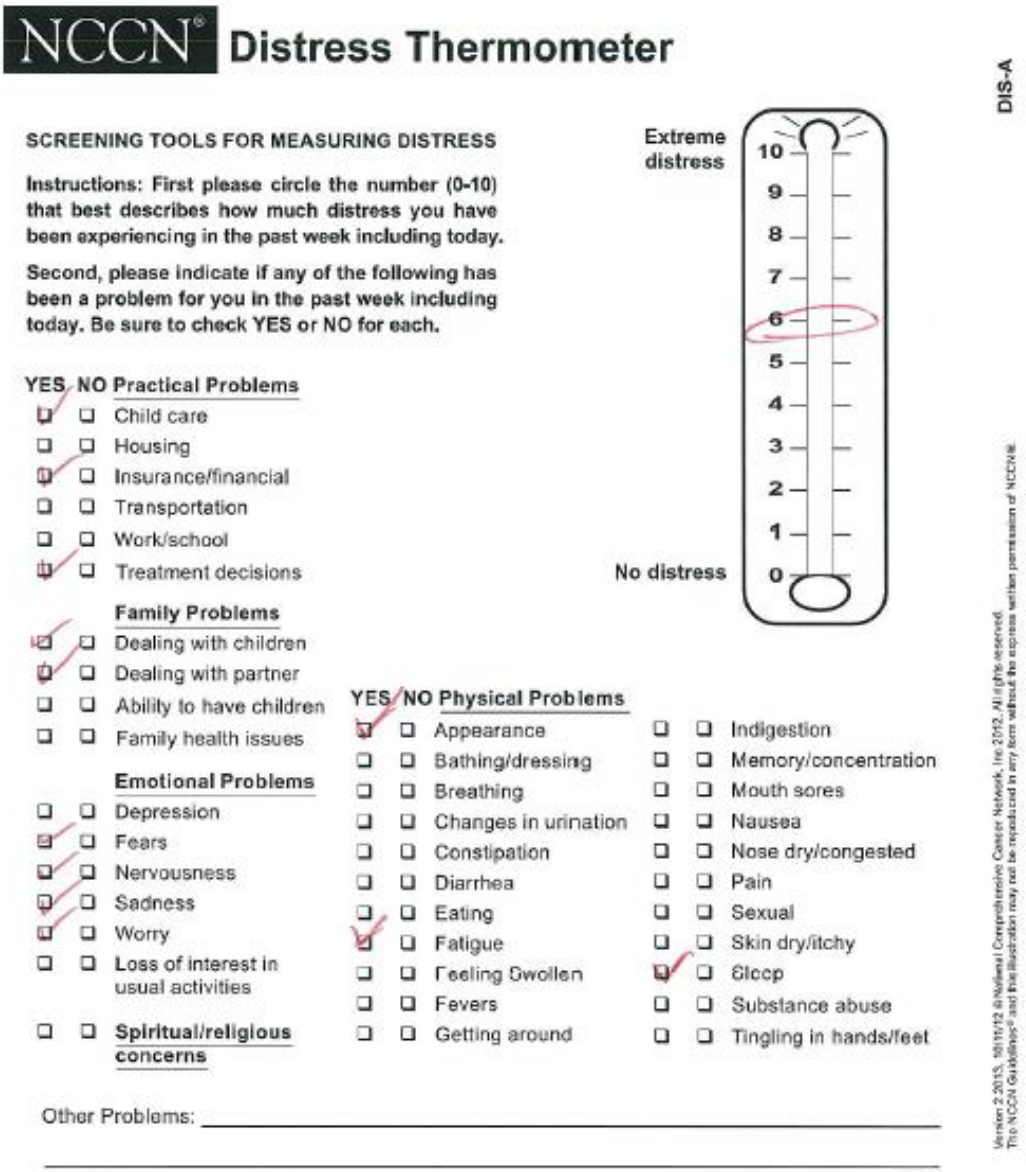
NCCN Distress Thermometer for Patients. National Comprehensive Cancer Network, 2013.[27]

Targeted supportive care needs assessment tools have been developed for some specific populations.

- Garvey, G., et al. (2012). The development of a supportive care needs assessment tool for Indigenous people with cancer. BMC Cancer, 12: 300
- Waller, A., et al. (2010). Validity, reliability and clinical feasibility of a Needs Assessment Tool for people with progressive cancer. Psychooncology, 19(7): 726-733.
- Girgis, A., et al. (2011). The next generation of the supportive care needs survey: a brief screening tool for administration in the clinical oncology setting. Psychooncology, 21(8): 827-835.
- Breen, S., Ristevski, E., & Regan, M. (2012). Enabling supportive care screening and evidence-based referrals for patients with cancer: Patient acceptability and clinician implementation of the supportive care resource kit (SCRK). The Australian Journal of Cancer Nursing, 13(1): 20-31.

Learning Activities	
Completed	Activities
☐	1. Watch the vignette Jane's Story 3, to meet Jane. Follow her journey as she presents for her first treatment in the case study below: It is a busy morning in the day therapy unit. Jane is presenting for her first cycle of chemotherapy for ovarian cancer post-surgery. You notice her in the waiting area… tapping her feet, nervously holding a child's soft toy in her hands. You approach Jane in the waiting area. " Hi Mrs Cooper, My name is Sara. I will be one of the nurses caring for you today. I see from your patient record that today is your first day of treatment." "Oh, yes, yes it is. To tell you the truth I'm feeling a little nervous. I don't know what to expect with this treatment. I'm thinking about my boys. The little one, so sweet, he gave me his favourite toy to keep Mummy company at the hospital today." "That is very sweet. Well, I can give you information about the treatment you are going to have and what to expect along the way. While we wait for a quiet room to be available for us to speak further, would you mind filling in this questionnaire which asks about you and your health, and how you might be feeling and any concerns you may have. It will help us provide the best support and care for you. It will only take about five minutes and most of the questions are tick boxes. There is also room on the form to add anything else of concern. Is that ok for you to fill it in?" "Sure, what will you do with it after I complete it?"

	"Once you have completed it, we can sit together and talk about your concerns and determine the best ways to support you during treatment. "Okay, there are a few things on my mind, so this might be useful to me." You review Jane's patient file. She is 36 years old and has had a total abdominal hysterectomy and bilateral salpingo-oopherectomy 16 days ago. She has been diagnosed with Stage III ovarian cancer. She is married with a young family. After five minutes you go to collect the questionnaire. "Thanks for completing the form. I have organised a comfortable room for us to discuss your responses."



NCCN® Distress Thermometer

DIS-A

SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

Extreme distress — 10 9 8 7 6 5 4 3 2 1 0 — No distress

YES	NO	Practical Problems
☐	☐	Child care
☐	☐	Housing
☐	☐	Insurance/financial
☐	☐	Transportation
☐	☐	Work/school
☐	☐	Treatment decisions

		Family Problems
☐	☐	Dealing with children
☐	☐	Dealing with partner
☐	☐	Ability to have children
☐	☐	Family health issues

		Emotional Problems
☐	☐	Depression
☐	☐	Fears
☐	☐	Nervousness
☐	☐	Sadness
☐	☐	Worry
☐	☐	Loss of interest in usual activities
☐	☐	Spiritual/religious concerns

YES	NO	Physical Problems
☐	☐	Appearance
☐	☐	Bathing/dressing
☐	☐	Breathing
☐	☐	Changes in urination
☐	☐	Constipation
☐	☐	Diarrhea
☐	☐	Eating
☐	☐	Fatigue
☐	☐	Feeling Swollen
☐	☐	Fevers
☐	☐	Getting around
☐	☐	Indigestion
☐	☐	Memory/concentration
☐	☐	Mouth sores
☐	☐	Nausea
☐	☐	Nose dry/congested
☐	☐	Pain
☐	☐	Sexual
☐	☐	Skin dry/itchy
☐	☐	Sleep
☐	☐	Substance abuse
☐	☐	Tingling in hands/feet

Other Problems: _____

_____

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Learning Activities	
Completed	Activities
☐	Review the Distress Thermometer and Problem List completed by Jane. 1. What level of distress has Jane indicated on the Distress Thermometer? 2. What is the significance of this level of distress? 3. Based on the Problem List, what issues will be the focus of your discussion with Jane?

Communicating about concerns

Strategies to increase patients' willingness to discuss and disclose concerns include:[29-33]

- using a screening tool as a prompt
- taking a positive approach to communication of supportive care issues
- normalising the person's experience
- encouraging open communication.

Key person-centred communication skills facilitate the process:[25]

- Empathy – acknowledging and understanding a person's feelings using verbal and non-verbal strategies
- Active listening – listening in an understanding way using verbal and non-verbal strategies
- Actively encouraging questions and checking understanding – clarifying the message of the person affected by cancer
- Asking open ended questions – encouraging the person to talk
- Not interrupting
- Encouraging the presence of a support person (when appropriate) – can help the person's understanding, recall and/or satisfaction
- Checking the person's preference for receiving information – to tailor the information for the persons needs
- Using plain language – concise questions and comments without jargon
- Noticing non-verbal cues – observing a person's body language, particularly if it is incongruent with the verbal messages
- Checking that the person understands what you have said – explaining adequately.

Health professionals can find it challenging to discuss psychological difficulties. The following general question prompts have been suggested to start a conversation about emotional well-being:[4]

- "In addition to looking at the physical issues, I am interested in hearing how things are going more generally for you"
- "How have you been feeling emotionally"
- "Could you tell me how your mood is?"
- "How would you say the diagnosis and treatment has affected you?"
- "I see you have ticked sadness on this tool can you tell me a little more about why you have ticked this".

Key resources

Communication skills training for health professionals has been identified as a strategy to support meeting the supportive care needs of patients. Examples of programs and resources within Australia include:

- Communication skills training, Cancer Australia[34]
- Communication for Cancer Clinicians, Cancer Council Victoria.[35]
- Managing cancer pain – communication skills for health professionals, Cancer Council NSW[36]
- Communication Skills Video Training Resources, Supportive Cancer Care Victoria[37]
- Communication skills, BMJ Learning[38]

Learning Activities	
Completed	Activities
☐	You undertake a discussion with Jane to explore her needs identified on the Distress Thermometer and Problem List. To begin your discussion with Jane, you clarify whether she is still comfortable to discuss the questionnaire. "Jane, I've had a brief look at your responses and would like to discuss a number of issues you have raised. Is that okay with you?" You open your discussion by looking at the Distress Thermometer and Problem List. "Jane, I've noticed that you have scored a six on the distress thermometer. That tells me that you are feeling fairly distressed today. I can also see that you have ticked fear, nervousness, sadness and worry on the problem list. Can you tell me a bit more about what you are worried and scared about?" To help Jane feel comfortable to tell her story you use some of the following probing questions: "Tell me more about that…." "Can you explain this further to me…." "What do you think has led you to be worried and fearful?" You find out from Jane that she is feeling overwhelmed with the prospect of starting chemotherapy. She is not sure what to expect from the treatment. Her mother had chemotherapy and was very nauseated and experienced intractable vomiting. She is also scared the treatment won't work. She hopes she has made the right decision not to enter the clinical trial. It was just too hard a decision. Jane is trying to remain positive for her two young children and husband. Whilst juggling home life and hospital is a challenge, keeping the children in their normal routine and feeling supported is a priority. She admits this is exhausting though. She hasn't been sleeping well since her surgery. She indicates that she has had difficulty relaxing and "turning off my brain at night". She has some ongoing pain but hasn't been taking regular analgesia. She has been given medication but is reluctant to take it regularly. "Jane, there are some things that I can help you with today, and I can also refer you to other people / places for assistance, can we look at some options for you today?" Jane responds, "Yes, that would be very helpful."

☐	1. Consider approaches you could take to discuss the problems Jane identified. Practical problems: • Childcare • Insurance / financial • Treatment decisions. Family problems: • Dealing with children • Dealing with partner. Emotional problems: • Fears • Nervousness • Sadness • Worry. Physical problems: • Appearance • Fatigue • Sleep.
☐	2. Review the EdCaN Competency Assessment Tool for Therapeutic Communication 2009. • 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. • Develop a professional development plan to achieve competence in therapeutic communication.
☐	3. Complete the Cancer Learning Frontline Psychosocial Support Tutorial and for each scene complete the following: • Appraise the interaction with the health professional and Felicity. • Outline how you would respond to Felicity.

Providing support and information

For some individuals, the opportunity to raise and discuss issues at the time of the consultation might be enough. For others, provision of verbal advice, written information and contact details for a service or support group may resolve their concerns.

When providing treatment information and supporting decision making with people with cancer, the following issues should be considered:[4]

- Individuals will vary in their needs for information and their needs may change as treatment proceeds, requiring individualised responses by clinicians
- Individual preferences for communication styles vary, and clinicians need to tailor the format of information provision
- Information recall can be increased by simplifying the language, dividing the information into key issues, and repeating key messages
- Time information provision appropriately
- Individual preferences for the amount, detail and content of information varies and should be tailored to the individual and their circumstances and need
- Provision of a question prompt sheet may promote questions, reduce anxiety, improve recall and shorten the consultation
- Provision of reputable written, audio-visual, and/or online resources can support individual understanding and reinforce information provided.

Consider some of the general principles relevant to education/information sessions which have been identified in the literature.[4, 39] Use this list as a checklist to appraise your interactions.

- □ Introduce yourself to the person and their family, and ensure a comfortable environment, minimise interruptions.
- □ 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.
- □ Provide an overview of the session, the structure, timeframe and ensure you allow time for questions.
- □ Assess understanding and correct any misconceptions.
- □ Assess level of information required.
- □ Teach relevant concepts e.g. introduce and discuss the treatment.
- □ Introduce concept of self-care.
- □ Review who to contact and role play how and when to make contact.
- □ Provide information in multimedia format, use diagrams or pictures where possible.
- □ Encourage the presence of another person.
- □ Ask the person to repeat back to you their understanding of the information you have provided.
- □ Repeat the important information in a follow up session/phone call. Send a summary letter as a follow up to the information.

Learning Activities	
Completed	Activities
☐	1. Jane requires information about the treatment she is going to start for ovarian cancer. Identify strategies you would use to ensure an effective education session.

Considerations when discussing 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.[40]

Guidelines have been developed to support health care professionals to effectively communicate with people with life-limiting illnesses regarding prognostic and end-of-life issues. Key recommendations include:[41]

- 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:

Clayton, J.M., Hancock, K.M., Butow, P.N., Tattersall, M.H.N., & Currow, D.C. (2007). Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness and their caregivers. MJA, 186(12): S77-S108.

Cancer Australia has developed a new resource called "Finding the words: Starting a conversation when your cancer has progressed"[87] to assist health professionals and patients in communicating about changes in prognosis.

Learning Activities	
Completed	Activities
☐	1. Reflect upon an interaction where you discussed end-of-life or poor prognostic information with people affected by cancer. Appraise the interaction in light of the guideline recommendations outlined above.
☐	2. Reflect upon your own life and clinical experiences and describe your thoughts, feelings and attitudes regarding death and dying.

Providing therapeutic communication

Health professionals with advanced skills in communication and psycho-education, and available support processes, such as clinical supervision, may be able to provide therapeutic strategies to meet specific supportive care needs.

There are a number of models that can guide these types of therapeutic sessions. Examples include:

- Chronic Illness Self-Management 5 A's model.[42]
- Motivational Interviewing.[43]

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:[42]

- 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.

Key resource

Hall, K, Gibbie, T., & Lubman, D.I. (2012). Motivational interviewing techniques. Facilitating behaviour change in the general practice setting. Australian Family Physician, 41(9): 660-667[43]

Learning Activities	
Completed ☐	Activities 1. Watch the vignette Harold's Story (or reflect upon an individual you have cared for in your local care setting and adapt the learning activity to meet their supportive care need) • Summarise the evidence regarding smoking cessation for someone with lung cancer. • Outline the components of a single brief counseling intervention you could provide for Harold in relation to his smoking.

Promoting self-management

Cancer is increasingly being acknowledged as a chronic condition. Evidence is building to support the use of self-management programs in chronic disease populations such as cancer survivors.[44, 45] An example of a self-management program for cancer in Australia is the Living with Cancer Education Program (LWCEP).

Supporting self-management skills, encourages an awareness and active participation by the person in their cancer experience to minimise the consequences of treatment, and promote survival, health and well-being.[46] It involves a collaborative partnership between the person and the health professional to empower individuals to take on responsibility for their health and well-being.[47] Further information on self-management can be found in the Cancer Survivorship module: Promoting self-management.

Nurses have a role in promoting self-management behaviours in all people affected by cancer. The following key resource may assist Specialist Cancer Nurses to develop capacity this area:

- Capabilities for Supporting Prevention and Chronic Condition Self-Management. A Resource for Educators of Primary Health Care Professionals[48]

Learning Activities	
Completed	Activities
☐	1. Access Self-Management: Enabling and empowering patients living with cancer as a chronic illness[44], and • Discuss the role of self-management in supportive care.
☐	2. Access the video Developing Person Centred Capabilities, and complete the following: • Describe the knowledge, skills and attitudes required to promote changes which promote self-management behaviours of people affected by cancer. • Outline the strategies a health professional may use to effectively assess the self-management capacity of a person affected by cancer.
☐	3. Access the video Developing Behaviour Change Capabilities, and complete the following: • Describe the knowledge, skills and attitudes required to promote changes which promote self-management behaviours of people affected by cancer. • Outline how health professionals support the establishment of self-management goals that are appropriate for a person affected by cancer. • List barriers which might exist to achieving sustained health behaviour change for a person affected by cancer.
☐	4. Access the video Developing Organisational and System Capabilities, and complete the following: • Describe the knowledge, skills and attitudes required to utilise organisational and system level supports to promote self-management of people affected by cancer. • Outline the key components of an effective team approach to supporting self-management for people affected by cancer.

	• Identify community resources you may draw on to support self-management strategies for people affected by cancer in your local area.
☐	5. Access the video Integrating into Practice, and complete the following: • Using the core skills identified in the Capabilities for Supporting Prevention and Chronic Condition Self-Management resource for health professionals as a checklist, identify your own areas of strength and areas for further development. • Develop your own professional development plan to enhance your ability to promote self-management of people affected by cancer. • Develop a quality improvement strategy that would support health professionals to promote self-management of people affected by cancer in your organisation.

Focused Assessment

All health professionals can work collaboratively with people affected by cancer to identify their existing resources and capacity for self-management and identify need for further assessment to guide information provision, supportive care interventions and referral to additional specialist services and resources.

Further assessment focussing on problems identified in screening, which have not been addressed with therapeutic communication, may be appropriate to clarify the extent and burden of problems.[3] If required a range of evidence-based tools can be used by members of the multidisciplinary team to undertake this more focused assessment. Examples of tools to assess specific symptoms or concerns include:

- Brief Pain Inventory[49]
- Spirituality assessment – HOPE Questions[50]
- Bristol stool chart[51]
- Kessler Psychological Distress Scale (K10) [52]
- Hospital and Anxiety Depression Scale[53]
- Common Terminology Criteria for Adverse Events (CTCAE)[54] Grading scales for physical symptoms are identified and provide a framework for consistent assessment of need.

For example, the Kessler Psychological Distress Scale (K10)[52] has been recommended by some to assist in decision making when referring patients who have a score ≥ 4 on the Distress Thermometer.[20] The K10 is a measure developed to detect psychological distress. The K10 has been shown to be a valid measure of psychological distress when compared to other measures. A limitation of the tool is that it is not cancer specific. It is commonly used by General Practitioners referring patients for counselling or psychological services.[55]

Each question on the K10 has a five point response scale. The response options are scored from five (All of the time) to one (None of the time). The final score will be between 10 and 50. The final scores should be interpreted as follows:[55]

A score of < 16:	Indicates people with no increased likelihood of anxiety of depressive disorder
A score of 16 – 30:	Indicates people with three times the population risk of having a current anxiety or depressive disorder
A score of 31 – 50:	Indicates people with ten times the population risk of having a current anxiety or depressive disorder.

K10 ASSESSMENT QUESTIONNAIRE

Date: _____ Patient ID Number: _____

For all the questions below please indicate the response which best describes your mood over the past 4 weeks.

In the past 4 weeks	All of the time	Most of the time	Some of the time	A little of the time	None of the time
1 About how often did you feel tired out for no good reason?					
2 About how often did you feel nervous?					
3 About how often did you feel so nervous that nothing could calm you down?					
4 About how often did you feel hopeless?					
5 About how often did you feel restless or fidgety?					
6 About how often did you feel so restless you could not sit still?					
7 About how often did you feel depressed?					
8 About how often did you feel that everything is an effort?					
9 About how often did you feel so sad that nothing could cheer you up?					
10 About how often did you feel worthless?					

Key resources

Assessment Tools. eviQ Cancer Treatments Online. Cancer Institute NSW, 2014. (Requires login)
MASCC Guidelines and Assessment Tools. MASCC Multinational Association of Supportive Care in Cancer. 2013[56]
Symptom Assessment and Management Tools. Cancer Care Ontario. 2014[57]

Learning Activities	
Completed	Activities
☐	Jane identified three problems in the emotional domain. Whilst she feels less anxious after learning more about her treatment, she indicates that she would like some further help to manage her feelings. You identify a number of resources that Jane may wish to access: • Cancer council helpline • Hospital or community-based support programs, eg psycho-education programs, peer support programs • Social worker • Psychologist • General Practitioner. Jane has a close relationship with her GP, and feels it would be good to follow up her concerns with someone familiar. Jane's GP gets her to complete the K10 checklist. Her results are below. **Anxiety and depression checklist (K10)** **This simple checklist aims to measure how you may have been affected by depression and anxiety in the past four weeks.** Your answers and results remain confidential. We don't keep any information on file. After you take the test, you can print the results for your records or to give to your GP. These questions concern how you have been feeling over the past 4 weeks. Tick a box next to each question that best represents how you have been.

In the past 4 weeks...	None of the time	A little of the time	Some of the time	Most of the time	All of the time
About how often did you feel tired out for no good reason?	○	○	○	◉	○
About how often did you feel nervous?	○	○	◉	○	○
About how often did you feel so nervous that nothing could calm you down?	○	◉	○	○	○
About how often did you feel hopeless?	○	○	◉	○	○
About how often did you feel restless or fidgety?	○	◉	○	○	○
About how often did you feel so restless you could not sit still?	○	◉	○	○	○
About how often did you feel depressed?	○	○	◉	○	○
About how often did you feel that everything was an effort?	○	○	○	◉	○
About how often did you feel so sad that nothing could cheer you up?	○	○	◉	○	○
About how often did you feel worthless?	○	◉	○	○	○

1. What is Jane's final score?
2. What does this indicate?

Provision of appropriate levels of interventions and/or referral

Supporting people with cancer to manage the concerns they identify may involve provision of supportive care interventions within a health professional's scope of practice or referral to other disciplines and services for specialised intervention.

There are a number of resources available to guide health professionals when providing appropriate levels of intervention and referral. These include frameworks, clinical guidelines, and evidence summaries.

Psychosocial interventions

Interventions which have established roles in managing significant distress in people affected by cancer are summarised below.[58]

Cognitive behavioural therapy

- Includes cognitive, cognitive behavioural and behavioural therapies. Teaches skills in problem-solving, reframing attitudes, e.g. challenging "black and white" thinking, coping with stress and anxiety. Relaxation therapy, guided imagery or cognitive skills might be used in dealing with stressful situations such as particular treatments, or to reduce nausea associated with chemotherapy. Techniques to enable gradual adaptation might also be included.
- Improvement in emotional distress, coping, anxiety, depression and a psychiatric morbidity; Decrease in nausea, vomiting and insomnia; increase in control over illness.

Supportive psychotherapy

- Encourages the expression of emotions, validates the experiences of the individual, and offers support through empathetic listening and encouragement, and provision of information. Reflects on the strengths of the individual and encourages use of adaptive coping techniques. Sometimes called supportive, existential or supportive-expressive.
- Improvement in mood, coping and physical and functional adjustment.

Group therapy

- Places emphasis on sharing of experiences among patients with a comparable stage of disease. Participants feel that their experiences are validated, and they can contribute in a meaningful way to the well-being of other members of the group. Can use cognitive behavioural or supportive psychotherapy, and include educational and information components.
- Improvement in mood, coping and adjustment, anxiety and depression; Positive immune function changes.

Family therapy

- Enhances improved communication, cohesion and conflict resolution within the family system, including the needs of children. Can use cognitive behavioural or supportive psychotherapy.

Couples therapy

- Targets problems and issues within the couple relationship. Can use cognitive behavioural or supportive psychotherapy.
- Reduces levels of depression and psychological distress. Beneficial in increasing sexual satisfaction.

Telephone counselling

- Provides geographically-isolated patients with an opportunity for cognitive behavioural or supportive psychotherapy interventions. Also useful for providing casework support, e.g. reassurance, information provision and referral.

Other therapies

- Other therapies may include art therapies, e.g. music, painting, reading and poetry, wellness programs, medication, hypnosis, acupuncture, relaxation, exercise, prayer, laughter etc.
- Improvement in mood, coping, anxiety, depression, breathing; Reduction in nausea and pain.

Other specialist services

- Includes speech therapy, physiotherapy, occupational therapy, dentistry, endocrine therapy, plastic surgery, reconstructive surgery, nutritionist, fertility services, specialized pain services.
- Target specific physical symptoms or impairment resulting from the disease or treatment. Assists in reducing pain, restoring or improving physical functioning or appearance.

The Tiered Intervention Model for Psychosocial Interventions provides a framework which can guide the implementation of psychosocial care (Hutchison, Steginga and Dunn,2006).[59] This framework, adapted in Table 3, is based on the concept of triage or treatment matching following screening to match the level of distress and expressed need to an appropriate level and provider of care. This generic approach can be adapted to any cancer setting through a scoping of existing services to meet the needs at the various levels of the model.[59]

Table 3: Tiered Intervention Model for Psychosocial Interventions
Adapted from Hutchison, Steginga & Dunn (2006, p.534)[59] and Department of Health, Western Australia (2008, p. 21)[60]

Level of Distress / Complexity of Need	**Level of Intervention**	**Methods**	**Appropriate services**	**Possible target areas / Example of psychosocial issue**
For all people affected by cancer and minimal to mild distress	**Universal care** Information and advice	General information Information about treatment and specific or common problems	Primary care team Tele-based cancer help-lines Print, electronic and audio-visual patient education resources	Information about medical treatments Coping with treatment side-effects How to talk to / assist a family member with cancer Practical concerns
Mild to moderate distress	**Supportive care** Psycho-education, emotional support and / or triage	Psycho-education combined with emotional support for mild distress Peer support Decision support	Tele-based cancer help-lines Hospital or community-based support programs, e.g. psycho-education programs, peer support programs, cancer social worker, cancer nurse	Treatment decision making Communicating with health professionals Problem solving specific issues Coping with emotions Social isolation
Moderate distress	**Extended care** Focused counselling with psycho-education and coping skills training	Focused individual, couple, family or group counselling including psycho-education and support	Programs / therapy provided by trained health professional e.g. Social worker, psychologist, psychiatrist, nurse with specific training in supportive care interventions	Adjustment to cancer / grief Stress management Communication skills Partner support skills Coping skills
Moderate to severe distress	**Specialist care** Narrow focus with skilled therapist	Psychotherapy, couple and relationship therapy, or family therapy with mental health practitioner	Cognitive behavioural, interpersonal and supportive expressive therapy by mental health professionals with experience in oncology e.g. Psychologist, psychiatrist, sex therapist, grief therapist Pharmacotherapy by primary care physician or psychiatrist	Mood and anxiety disorders Trauma, relationship and sexuality problems
Severe distress	**Acute care** Broad focus, specialist services or multidisciplinary team	Therapy with specialist mental health professional to deal with multiple problems	Specialist community or hospital based mental health or psycho-oncology team e.g. Psychologist, psychiatrist, family therapist,	Multiple, complex or severe problems Suicide ideation Personality issues

			multidisciplinary mental health services	Severe couple problems Family system problems

Learning Activities	
Completed	Activities
	1. Based on the screening and assessment undertaken with Jane, consider which supportive care interventions may be appropriate to support her psychological wellbeing.

Interventions to manage symptoms and treatment effects

A number of clinical guidelines, evidence summaries and algorithms have been developed to support evidence based approaches to providing appropriate supportive care interventions and reduce variations in care.[61] There is limited data that suggests implementation of palliative and supportive care guidelines can improve patient outcomes.[62]

Examples of resources which have been developed in Australia and internationally have been collated in Table 4.

Clinicians are cautioned to consider possible limitations when utilising resources:

- Guideline efficacy may not have been evaluated.[62]
- Dissemination into standard care is variable in practice.[62]
- Standards for guideline development are variable.[63]

Table 4: Examples of resources to guide appropriate supportive care interventions

Key resources	Key content
Cancer Learning Evidence Summaries.	Symptom management: evidence summary (EdCaN) • Nausea and vomiting • Adult cancer pain • Dyspnoea • Distress • Mucositis • Altered bowel habits • Fatigue • Lymphoedema • Peripheral neuropathy • Alopecia Cancer Survivorship factsheets providing evidence based information about key symptoms and factors affecting survivorship wellness. • Alcohol • Diet and Nutrition • Distress • Exercise • Fatigue • Smoking
ESMO Clinical Practice Guidelines: Supportive Care. European Society for Medical Oncology. 2014	The ESMO Clinical Practice Guidelines (CPG) are intended to provide the user with a set of recommendations for the best standards of cancer care, based on the findings of evidence-based medicine. ESMO published Clinical Practice Guidelines on the management of a variety of issues: • Management of refractory symptoms at the End of Life and the use of palliative sedation • Advanced care planning • Bone health • Prevention of chemotherapy and radiotherapy-induced nausea • Erythropoiesis-stimulating agents in the treatment of anaemia in cancer patients • Management of cancer pain

	• Management of oral and gastrointestinal mucositis • Cancer, fertility and pregnancy • Management of venous thromboembolism (VTE) in cancer patients • Cardiovascular toxicity induced by chemotherapy, targeted agents and radiotherapy • Management of chemotherapy extravasation.
MASCC Guidelines and Assessment Tools. MASCC Multinational Association of Supportive Care in Cancer. 2013	Evidence-based clinical practice guidelines • **Mucositis Guidelines** • **Antiemetic Guidelines** • **MAT-** MASCC Antiemesis Tool© • **MOATT-** MASCC Oral Agent Teaching Tool© • **MOATT**- User Guide© • **MESTT-** MASCC EGFR Inhibitor Skin Toxicity Tool© MASCC Endorsed Guidelines Partnerships • Acute AINV Guideline. "Guideline for the Prevention of Acute Nausea and Vomiting due to Antineoplastic Medication in Pediatric Cancer Patients (April 2014)" • International Pediatric Fever and Neutropenia Guideline. "Guideline for the Management of Fever and Neutropenia in Children With Cancer and/or Undergoing Hematopoietic Stem-Cell Transplantation" (September, 2012).
Symptom Management Guidelines. BC Cancer Agency. 2014	Consensus guidelines include: • Anorexia and Cachexia • Constipation • Diarrhoea • Dyspnoea • Fatigue • Fever and Neutropenia • Intimacy and Sexuality • Lymphoedema • Malignant wounds • Nausea and Vomiting • Oral Mucositis

	• Pain • Palmar Plantar Erythodysesthesia • Peripheral Neuropathy • Radiation Dermatitis • Sleep-Wake Disturbances • Xerostomia
Symptom Assessment and Management Tools. Cancer Care Ontario. 2014	The Symptom Management Guides help healthcare professionals assess and appropriately manage a person's cancer-related symptoms. Available as: • condensed summaries in Pocket Guide format PDF • 2-page Algorithms for each symptom PDF • Guide-to-Practice PDF These symptoms can include: • pain • dyspnoea • nausea and vomiting • delirium • loss of appetite • bowel care • oral care • anxiety • depression • fatigue • sleep disturbances.

eviQ Cancer Treatments Online. Cancer Institute NSW. 2014	eviQ provides nurses with evidence based information and treatment protocols with the aim of promoting best practice, improving standards and ultimately, patient outcomes.
	
	• Management of Radiation Induced Side Effects
	  ○ Management of Radiation Induced Nausea and Vomiting
	  ○ Management of Radiation Induced Proctitis
	  ○ Management of Radiation Induced Skin Reactions
	  ○ Management of Radiation Induced Xerostomia

	○ Oral Mucositis - Assessment and Treatment ○ Treatment Induced Diarrhoea • Immediate Management of Neutropenic Fever • Prevention and Management of Tumour Lysis Syndrome • Hand Foot Syndrome (HFS) - Palmar Plantar Erythrodysaesthesia (PPE) Associated with Chemotherapeutic Agents • Hepatic Sinusoidal Obstruction Syndrome (HSOS) associated with Haemopoietic Stem Cell Transplantation (HPCT) • Prevention of Chemotherapy Induced Nausea and Vomiting
Putting Evidence Into Practice (PEP) resources. Oncology Nursing Society. 2014	ONS PEP resources are designed to provide evidence-based interventions for patient care and teaching. PEP topic teams of nurse scientists, advanced practice nurses, and staff nurses summarize and synthesize the available evidence in PEP topic areas. PEP topics include: • Anorexia • Anxiety • Caregiver Strain and Burden • Chemotherapy-Induced Nausea and Vomiting • Cognitive Impairment • Constipation • Depression • Diarrhoea • Dyspnoea • Fatigue • Hot Flashes • Lymphoedema • Mucositis • Pain • Peripheral Neuropathy • Prevention of Bleeding • Prevention of Infection • Radiodermatitis • Skin Reactions

	• Sleep-Wake Disturbances
Supportive Care and Quality of Life Guidelines. Survivorship Guidelines. ASCO. American Society of Clinical Oncology. 2014.	Using the best available evidence, ASCO expert panels identify and develop practice recommendations for specific areas of cancer care that would benefit from using practice guidelines. Examples of ASCO supportive care and survivorship guidelines include: • central venous catheter care for the patient with cancer (2013) • antimicrobial prophylaxis and outpatient management of fever and neutropenia in adults treated for malignancy. (2013) • antiemetics: ASCO Clinical Practice Guideline Update (2011) • screening, assessment, and care of anxiety and depressive symptoms in adults with cancer (2014) • prevention and management of chemotherapy-induced peripheral neuropathy in survivors of adult cancers (2014) • Fertility preservation in patients with cancer (2013).
NCCN Guidelines for Supportive Care, National Comprehensive Cancer Centre. 2014	The NCCN guidelines detail interventions and treatment algorithms based on best available evidence providing tools and knowledge that can help guide decision-making in the management of cancer. Supportive care guidelines include: • adult cancer pain • antiemesis • cancer- and chemotherapy-induced anaemia • cancer-associated venous thromboembolic disease • cancer-related fatigue • distress management • myeloid growth factors • palliative care • prevention and treatment of cancer-related infections • survivorship.

Referral for specialised services and programs

Referrals to other health professionals or services are sometimes required to provide specialised support or address more complex issues beyond the capabilities of health professionals within multidisciplinary team. A combination of activities, rather than any single intervention by itself, is also likely to be the approach required.[64] Referral may be indicated to meet a need for specialist intervention or to help manage specifically identified risk factors or needs such as:[22]

- People socially or financially at risk
- People from culturally and linguistically diverse backgrounds
- People from Aboriginal and Torres Strait Islander backgrounds
- People experiencing:
    - Perceptions of hopelessness
    - Persistent physical symptoms
    - Pre-morbid mental health issues.

Referral should be evidence-based and contextualised to the individual's needs and situation. Protocols and/or guidelines may assist clinicians make evidence-based referrals.[20, 26, 65, 66] Structured referral sheets are useful checklists that can be completed at the time of screening or assessment. The referral checklist can include prompts regarding the criteria for referral and include suggestions for referral linked to these criteria. The Psychosocial Care Referral Checklist[67] is an example of a tool to identify factors contributing to the distress experienced by the individual and to document a referral plan. Further examples of referral resources are available on the Supportive Cancer Care Victoria website.[68]

It has been recommended that services establish referral networks and develop contact lists of local services and resources in line with evidence-based principles to support referrals. Referral opportunities may also be dependent on regional and site specific constraints, training of staff and availability of resources.[58]

Clinical example:	
Supportive Care Resource Kit[20] Protocols developed in the Supportive Care Resource Kit[20] include recommendations related to assessment, referral and information provision for the 35 issues listed in the Distress Thermometer and Problem List (2010).	

General Practitioners (GPs) are in a key position to make referrals to supports in the community and to facilitate access to services covered by Medicare through the GP mental health care plan or chronic and complex care plan. For further information, access:

- Chronic Disease Management (CDM) Medicare Items
- Allied Health Services Under Medicare – Fact Sheet

Specific considerations / strategies to facilitate the process of effective referral include:[20, 69]

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- the patient must consent to the referral. They must have a choice if they want to be referred and where they would like to be referred (within the boundaries of service availability)
- prioritise referrals – some patients may be experiencing worry and fears which are exacerbated by other concerns.
- consider risk factors when referring – e.g. If the patient is experiencing financial problems, you may consider referral to a private psychologist inappropriate due to associated costs.
- introduce the concept of the multidisciplinary approach to care as an accepted standard
- normalise the need for referral to other disciplines
- provide individually tailored information about the benefits of referral
- coordinate appointments if able
- consider the timing of the referral and suggest referral at another appropriate time if not accepted initially.

Learning Activities	
Completed	Activities
☐	Watch Scenario 3: Making referrals and complete the following. 1. Identify the communication strategies the clinician used.
☐	2. Identify two referrals you would suggest for Jane? How are these referrals supported by the evidence?
☐	3. Identify factors you need to consider in making appropriate referrals for Jane?
☐	4. Access Examining the introduction of a supportive care screening and referral process for cancer patients: how does practice compare with protocols? and complete the following: • Identify key recommendations to promote effective supportive care screening and referral. • Discuss how these research findings may inform processes in your practice setting.

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Implementing evidence based supportive care

There are a number of challenges to meeting the supportive care needs of people affected by cancer. Factors influencing provision of effective evidence based supportive care can be organised into three categories:[70]

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:

- 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:

- Receiving feedback regarding performance of clinician and outcomes
- Rewards and negative consequences.

Some strategies to improve provision of supportive care include:[71]

- 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	
Completed ☐	Activities 1. Review Barriers to the provision of evidence-based psychosocial care in oncology[71] and Incorporating supportive care into routine cancer care: the benefits and challenges to clinicians' practice[72], and: • Appraise current supportive care practices in your practice setting in light of the challenges identified. • Develop a plan to implement a supportive care screening and referral process in your practices setting. In your plan, consider training and support mechanisms, resources and organisational challenges and enablers.

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Troubleshooting

1. What would you do if a patient ticks 14 items on the problem lists?

   - Ask the patient to prioritise their top three needs.
   - Check if the patient was referring to the last seven days only when they filled in the tool.
   - Group the problems according to the fields on the tool.
   - Refer to a GP or other health professional as appropriate.
   - Prioritise the patient's needs and make a later time to discuss the other issues with the patient.

2. What would you do if a patient's expression is not focused and it is not easy to identify their concerns?

   - Gently bring the patient back to the topic by saying something like "that is really interesting. Now, I wonder if you can tell me right here and now what is your number one concern?" Or if they appear to be jumping from one concern to another you could summarise the points they have outlined and ask them which one is the main concern.
   - Let them know at the start that the purpose of the discussion is to consider their priority needs and that it will take no more than 20 minutes. (Setting an agenda allows the person to know the purpose of the discussion).
   - Balance the patient's need to be comfortable to disclose with your need to get the job done.
   - Make time to talk.

3. What if there is no psychologist or social worker to refer to?

   - Refer to a GP who has access to mental health schemes.
   - If you are concerned about suicide risk, and the person is in the ambulatory setting, ring the Psychiatric Crisis Assessment Team.
   - Consider referral to local specialist cancer nurse.
   - Access your organisations referral recommendations such as the Supportive Care Service Directory.[20]

4. What if you are unsure about making an action or referral?

   - Discuss the options with the patient.
   - Seek peer support from other members of the team.
   - Access your organisations referral recommendations such as the Supportive Care Service Directory.[20]

5. What would you do if the patient indicates a high level of distress but ticks no items on the Problem list?

   - Discuss the nature of the patient's distress as they may not articulate it in the same way as Problem List.

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Self-care for nurses

Healthcare workers supporting people affected by cancer face an increased risk of stress or compassion fatigue.[73-75]

Causes of stress may include:[73, 75]

- 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:[76]

- 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.[77] 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.[78]

The clinical importance of compassion fatigue has been highlighted through its impact on outcomes such as:

- increased medical errors[79]
- increased turnover and absenteeism[80]
- decreased quality of care[81]
- decreased satisfaction expressed by recipients of care[82]
- significant impact which burnout has on the professional and personal lives of affected personnel.[75, 83]

Protective practices for health care professionals are recommended to:[76]

- 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.

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Resource link

Aycock, N., & Boyle, D. (2009). Interventions to manage compassion fatigue in oncology nursing, Clinical Journal of Oncology Nursing. 13(2):183-191[84]

Wenzel, J., Shaha, M., Klimmek, R., & Krumm, S. (2011). Working Through Grief and Loss: Oncology Nurses' Perspectives on Professional Bereavement, Oncology Nursing Forum. 38(3): E272-E282[85]

Learning activities	
Completed	Activities
☐	1. Access Justin's story 7: end of life and complete the following: 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 current literature (see resource link) and self-care resources at the following links: CareSearch[76] • Discuss strategies you could develop and promote in your practice setting to support your self-care and that of nursing colleagues to reduce the impact of workplace stress and compassion fatigue.

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