Supportive Care Resource Kit

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A Training & Resource Kit for Health Practitioners

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TheSupportiveCareResourceKit

A Training and Resource Kit for Health Practitioners

contents

contents

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CHAPTER 1

About the Supportive Care Resource Kit

The Supportive Care Resource Kit (SCRK) has been designed to:

- train health professionals to undertake supportive care with their patients
- be a practical resource kit for health professionals involved in the supportive care of cancer patients.

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What does the Supportive Care Resource Kit contain?

The Kit is divided into three sections:

Section 1: Learning how to undertake supportive care screening, action and referral

The first section of the SCRK contains the training workbook (Chapter 2) which can be completed during the training workshop or as a self-directed learning activity. Activities and a case study are provided to illustrate the principles of supportive care screening and action and referral for cancer patients. The training explores how to undertake supportive care screening, what tools to use and the process of taking actions and making referrals.

Section 2: The action and referral protocols

The second section of the SCRK is divided into six chapters (3-8) and provides the evidence-based action and referral protocols which health practitioners can use to address identified patient needs in the screening discussion.

The protocols are divided into the following:

- Distress Thermometer assessment
- practical
- family
- emotional
- spiritual
- physical.

The protocols are based on the 'Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer' and were developed in collaboration with the Regional Supportive Care Advisory Group.

Section 3: Resources

The third section of the SCRK (Chapter 9) contains the screening tools:

- the Distress Thermometer and Problem List
- Kessler Psychological Distress Scale
- Risk Factor Checklist.

A copy of the National Breast Cancer Centre & National Cancer Control Initiative, *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer: A Summary Guide for Health Professionals* has also been included as a useful resource. Further in-depth information about supportive care provision for cancer patients can be found in the full guidelines available at **http://www.nhmrc.gov.au/publications/synopses/cp90syn.htm**.

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CHAPTER 2

Training Workbook

02

Overview of training

This training workbook will give you the knowledge and skills to undertake supportive care screening and provide advice, information and referrals for cancer patients. By the end of the training you will have a good understanding of what supportive care involves and be able to undertake supportive care of cancer patients.

Cancer supportive care is a relatively recent area of research. The training and the SCRK have been developed using currently available evidence-based research and clinical practice guidelines.

The training will take approximately four hours to complete and will be conducted as a face-to-face workshop incorporating facilitator instruction, group discussion, learning activities and a case study.

Icons you will see throughout the training are:

Activities

You will be asked to do certain activities to assist in your understanding of the topic.

Case study

The case study is an opportunity for you to apply your learning to a practical example.

Training objectives

At the end of this training you will be able to:

- understand the role of supportive care in the treatment and management of cancer patients
- undertake supportive care screening of cancer patients
- use the protocols to take action and make evidence-based referrals
- incorporate supportive care into routine clinical practice.

Training agenda

Introductions	10 mins
Topic 1: What is supportive care?	**30 mins**
Topic 2: Screening	**30 mins**
Break	10 mins
Topic 3: Action and referral	**90 mins**
Break	10 mins
Topic 4: Supportive care in routine practice	**30 mins**
Conclusion and questions	**30 mins**
TOTAL TIME ALLOCATION	**4 hours**

TOPIC 1: What is supportive care?

Introduction

Providing optimal supportive care to cancer patients is gaining a higher priority for the cancer multidisciplinary team as an increasing evidence base becomes available for this area. Understanding what supportive care is and why it is important are the first steps toward integrating best practice supportive care into routine, everyday care.

In this topic you will examine:

- what supportive care is
- the importance of supportive care
- Department of Human Services' directions for cancer care in Victoria
- risk factors for psychological distress
- the model for supportive care.

What is supportive care?

Supportive care is an umbrella term that describes all services required to support people with cancer throughout their journey. Supportive care needs include:

- physical (e.g. pain, fatigue)
- emotional (e.g. distress, anxiety, depression)
- family (e.g. child care)
- practical (e.g. help around the home, financial issues)
- information (e.g. services, self-management)
- spiritual (e.g. religious and other spiritual needs).

Supportive care is provided by the entire specialist and generalist multidisciplinary team as well as by family and community services.

Why is supportive care necessary?

Current research suggests that the early identification and referral of patients with unmet supportive care needs can result in better outcomes for patients such as:

- decreased levels of patient distress
- a decreased 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.[1-2]

Research in the last 15 years suggests that health professionals often inadequately identify patient distress and other supportive care needs.[3-7]

Evidence suggests that patients are often reluctant to raise issues with health professionals, yet clinicians defer to patients to initiate discussion about their supportive care needs.[8-9] In addition some of the issues most troubling patients, such as emotional and sexual concerns, are often those issues clinicians are least comfortable and feel least equipped to deal with.[10]

Directions for cancer care in Victoria

The impetus for addressing supportive care needs for cancer patients addresses the following strategic directions provided by the Department of Human Services Victoria (DHS) in the Victorian Cancer Action Plan 2008–2011:

- identifying the supportive care needs of people affected by cancer
- capacity building for optimal supportive care
- implementing supportive care screening into routine practice
- addressing supportive care needs (referral and linkage).

Screening patients along with training staff will bring cancer health care provision in line with the new Victorian Cancer Action Plan's targets of providing evidence of workforce training in supportive care screening processes and documenting supportive care screening for 50 percent of newly diagnosed cancer patients by 2012.
http://www.health.vic.gov.au/cancer/docs/vcap/vcactionplan.pdf

Risk factors for psychological distress

When considering a patient's supportive care needs it is important to consider the patients' particular life circumstances, past experiences and current responsibilities. Research suggests that certain factors can particularly impact on a person's ability to cope and increase the likelihood that a person with cancer will experience a high level of emotional distress.[1]

People with cancer who are experiencing any of the following issues may be at greater risk of developing emotional distress:

RISK FACTOR	WHY CAN IT CONTRIBUTE TO PSYCHOLOGICAL DISTRESS?
Younger than 55 years	The perceived untimely nature of the diagnosis can be a shock for people under 55 years of age.
	People under 55 years of age often have more commitments in terms of dependent children and work.
Lack of social support (e.g. single, widowed, living alone)	People who live alone may experience isolation and inadequate support.
	People who perceive themselves to lack social support are also more likely to experience emotional distress.
Caring for children or other dependants	People with cancer may not always be able to attend to the usual practical and emotional demands of family.
	They may also be dealing with the impact of cancer on their families.
	Sometimes parents with cancer may feel guilty about the impact of their cancer on children.

RISK FACTOR	WHY CAN IT CONTRIBUTE TO PSYCHOLOGICAL DISTRESS?
Financial problems	People with cancer may have to take time off work and may incur extra financial costs as a result of their treatment.
Previous episodes of depression, anxiety or other psychiatric illness	Any person who has experienced depression or anxiety in the past will be at greater risk of developing it again.
	A diagnosis of cancer can precipitate a recurrence of psychological problems.
History of stressful life events	Multiple stressors can be a cumulative burden on people with cancer which can increase distress.
High alcohol or drug intake	High levels of alcohol or drug use is associated with increased emotional distress in people with cancer.
	Most people, when asked, underestimate their alcohol intake.
Female	Women are at a higher risk than men of experiencing anxiety and depression, sexual problems and issues relating to body image.

In addition to these eight identified risk factors you might be able to identify additional issues which you believe may significantly increase the risk of psychological distress in cancer patients.

activity 1

Risk factors for psychological distress

Discuss which of the above risk factors are common to your own patient populations.

The model of supportive care used in this Kit

A supportive care model should recognise the variety and the level of intervention required for individual patients. It is recommended that patients be screened at various stages of their treatment,[11,12] including:

- 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. as clinically indicated)
- at the conclusion of active treatment
- during follow-up
- at recurrence
- during palliative care.

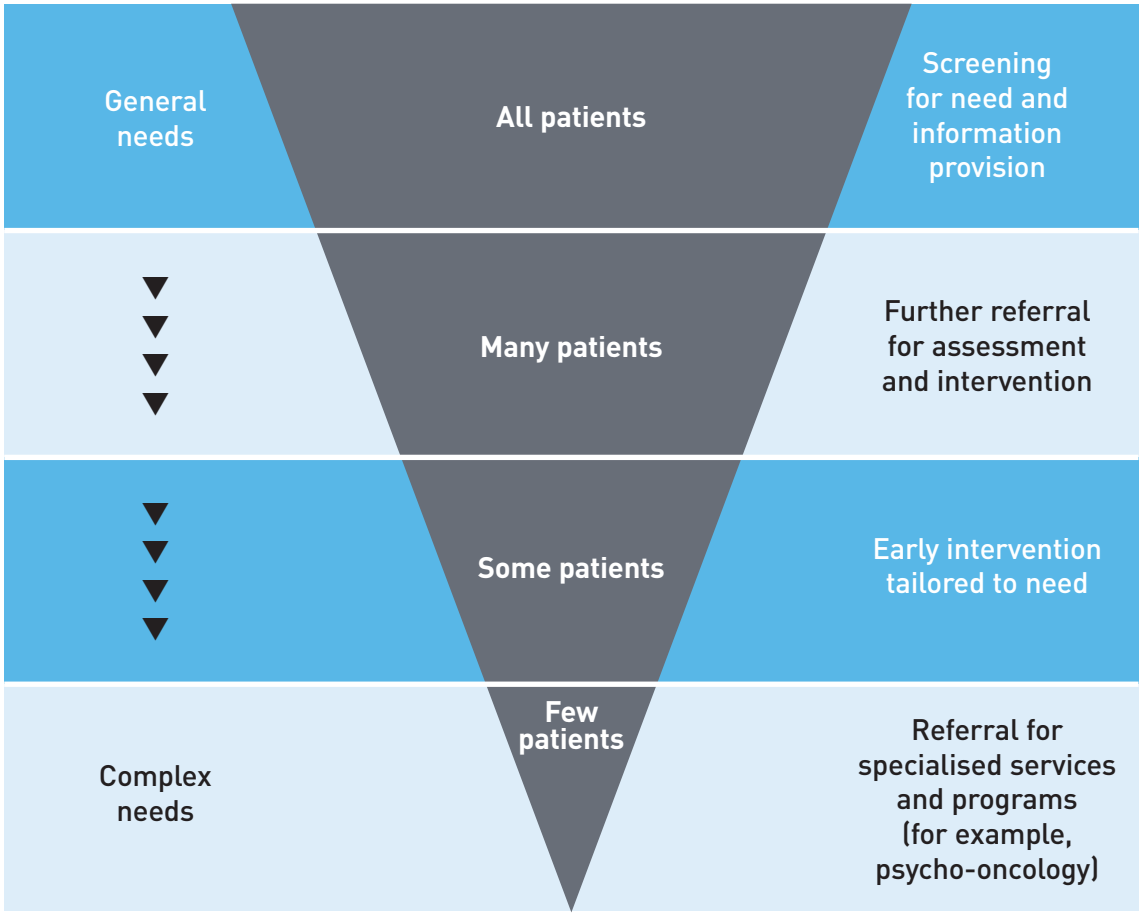
Every time a patient comes in for their treatment (e.g. chemotherapy) they will not need to be screened. Examples of times when you could undertake screening include:

- significant changes in symptoms
- if patients are looking or acting distressed
- if they have had a change in their treatment plan or their prognosis.

NOTE: Supportive care screening does not in any way replace routine medical assessments completed by clinical staff.

The following diagram (adapted from Fitch[13]) is a visual model of the process of improved supportive care used in this Kit. Note that while screening and information provision is necessary for all patients, more specialised interventions such as referrals are required for only a few patients.

Model for improved supportive care



Evidence-based actions

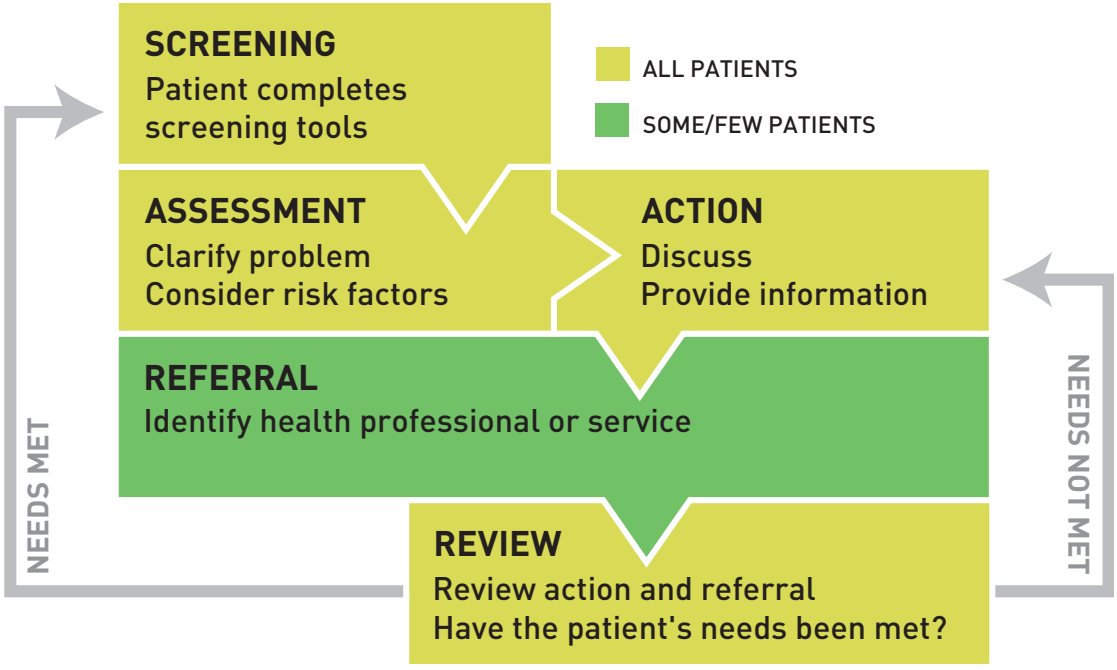
Although screening patients for supportive care needs is a vital component of supportive care, past research has shown that screening *alone* is not sufficient to improve overall supportive care. The identification of supportive care needs must be combined with clear, evidence-based referral protocols and guidelines (e.g. *The Psychosocial Guidelines for the Treatment of Adults with Cancer*).

Whilst patients in metropolitan areas may have access to the full range of supportive care practitioners and services, access to these services is often limited in rural areas.[1] Supportive care action and referral protocols must not only be evidence-based, but must also be adapted to rural areas by being flexible and by identifying a range of particular strategies for patients' needs. A flexible referral protocol also benefits patients who want a greater active choice in the types of care they are offered, and allows the tailoring of supportive care to individual patients' needs, preferences and beliefs.

Overview of the supportive care process

The following diagram represents the process of supportive care screening, action and any necessary referral or follow-up. Each stage represented in this diagram is discussed in more detail in Topic 2 (screening), Topic 3 (referral) and Topic 4 (supportive care in routine practice). The stages of Screening, Assessment, Action, Referral and Review are all essential steps in the process and are representative of the 'All Patient' category of Fitch's model. The Referral stage is either a suggested or recommended step in the process and is representative of the 'Some Patients' and 'Few Patients' categories of Fitch's model.

The supportive care pathway



activity 2

Test your knowledge questionnaire

This questionnaire asks you to reflect on your current knowledge of supportive care and your existing experience in applying supportive care to your practice.

The answers and scoring information follow the quiz.

SUPPORTIVE CARE QUIZ

1. **Name two supportive care needs common to cancer patients.** ***(2 marks)***

   1. _____

      _____

   2. _____

      _____

2. **Complete the following three sentences.** ***(3 marks)***

   "The early identification of unmet supportive care needs can help to . . .

   a) decrease _____

      _____"

   b) increase _____

      _____"

   c) enhance _____

      _____"

3. **List 3 risk factors for psychological distress in cancer patients.** ***(3 marks)***

   1. _____

      _____

   2. _____

      _____

   3. _____

      _____

4. **Circle true or false for the following statements.** ***(4 marks)***

   It is recommended that patients be screened for their supportive care needs:

   - Following diagnosis True False
   - Each time they visit for a treatment True False
   - With significant changes in symptoms True False
   - At the end of treatment True False

5. **Screening for supportive care needs should be conducted with . . .** Circle one option. ***(1 mark)***

   a) All patients

   b) Many patients

   c) Some patients

   d) Few patients

6. **Referrals for specialised services/programs should be offered to some patients.** Circle true or false. ***(1 mark)***

   True False

7. **Which statement is false?** ***(1 mark)***

   Supportive care assessment, actions and referrals need to incorporate:

   a) Evidence based protocols and guidelines

   b) Practitioner knowledge of all local services

   c) Patient preferences for services

   d) The availability of services in the local area

8. **The best referrals are those made to local services.** Circle true or false. ***(1 mark)***

   True False

9. **Complete the following statement.** ***(3 marks)***

   Screening, assessment, action and review are essential steps for _____ patients. The referral stage is a _____ or recommended step for _____ and few patients.

10. **A specialist cancer nurse is the best person to provide supportive care to cancer patients.** Circle true or false. ***(1 mark)***

    True False

SUPPORTIVE CARE QUIZ ANSWERS

1

Any of the following can be listed
- **Physical (e.g. pain, fatigue)**
- **Practical (e.g. help around the home, childcare, & financial issues)**
- **Family (e.g. relationship issues)**
- **Psychological (e.g. distress, depression, anxiety)**
- **Spiritual (e.g. hopelessness, despair)**
- **Information (e.g. diagnosis, treatment, prognosis)**

2

a) Decrease … **levels of patient distress … likelihood of developing clinical anxiety and depression … long term costs and usage of the health care system**
b) Increase … **adherence to cancer treatment**
c) Enhance … **quality of care and patient satisfaction … communication with the health care team**

3

Any of the following can be listed:
- **Younger than 55 years**
- **Lack of social support**
- **Caring for children or other dependents**
- **Financial problems**
- **Previous episodes of depression, anxiety or other psychiatric illness**
- **History of stressful life events**
- **High alcohol or drug intake**
- **Female**

4

a) **True**
b) **False**
c) **True**
d) **True**

Patients do not need to be screened every time they come in for treatment.

It is recommended that patients be screened at various stages of their treatment, including:
- 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. as clinically indicated)
- at the conclusion of active treatment
- during follow-up
- at recurrence
- during palliative care.
- significant changes in symptoms
- if patients are looking or acting distressed
- if they have had a change in their treatment plan or their prognosis.

5	**(a) All patients** Refer to the model 'Model for improved supportive care' in Topic 1. Supportive care provision can be improved by strategies which routinely and systematically screen all cancer patients for unmet supportive care needs using an appropriate measure.
6	**False** Refer to the model 'Model for improved supportive care' in Topic 1. Referral for specialised services and programs is offered to few patients, usually patients with complex needs.
7	**(b) Practitioner knowledge of local services** Practitioners are not expected to know all the health and community services and programs that exist in their local area. In fact, some patients will live in different local government areas to where they receive treatment, therefore, it is not feasible to know all the supportive care services that exist in the region. To assist you in your planning and referral to services the a Supportive Care Directory is provided by the Regional Integrated Cancer Service which lists available services and programs.
8	**False** Not always. Referrals will depend on the patient's preference, issues of access for the patient, issues of service availability, waiting times, and the need for specialised care.
9	Screening, assessment, action and review are essential steps for **ALL** patients. The referral stage is a **SUGGESTED** or **RECOMMENDED** step for **SOME** and **FEW** patients.
10	**False** The responsibility of supportive care screening and referral should not fall onto one person or discipline of care/practice. It is recommended that supportive care be provided by the by the entire patient treatment team which should include surgeons, oncologists, radiotherapists, nurses, allied health, social work, psychologists GPs, as well as community services, religious and charitable organisations.

HOW DID YOU SCORE?

Score 0-4 This training is perfect for you.
Score 5-10 I need to know more about supportive care.
Score 11-15 I'm nearly there, but tell me more.
Score 16-20 Too easy, but I'll stay for the training as there's more I could learn!

case study part A

Mary Simpson

A case study has been developed to illustrate the concepts of screening, action and referral as described throughout this Kit. Read part A of the case study and then answer the questions which follow.

It's a busy morning at the cancer centre. You are preparing the patient records and lists for patients arriving for their ten o'clock radiotherapy appointment. The centre provides radiotherapy and chemotherapy services to people from all areas of the region. The diversity of patients receiving treatment at the centre is great; including dairy farmers and timber workers, teachers from the local secondary school and colleagues from other health services. In some instances you know some of these people outside of your work.

As the patients arrive the receptionist takes their names and asks them to take a seat in the waiting room. You notice one patient standing nervously at the reception desk.

You overhear her say to the receptionist, "Oh, I am really nervous about coming here today. I'm not sure if I was supposed to have breakfast before the radiation or not, and I couldn't organise for someone to pick me up today. Can you ring me a taxi later?"

"Certainly Mrs Simpson, I can do that for you."

"Actually, it's Ms; I'm recently separated from my husband."

"I apologise. Take a seat and I will ask one of the nursing staff to come and speak with you."

Anne, the receptionist, has sensed that Mary Simpson is feeling agitated and has alerted you to this. You approach Mary in the waiting area.

"Hi, Ms Simpson, I'm Jackie O'Brian, I will be the nurse assisting with your treatment 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 how I will respond to the treatment and I couldn't get someone to pick me up today."

"Okay, I will help you arrange something for your travel home. While you are waiting, would you fill in this questionnaire which asks some questions about you and your health, and how you might be feeling or any concerns you may have? We are trialling a new way to provide support and care for our patients. It will only take you about five or ten minutes and most of the questions are tick boxes. Would you fill this in?"

"Mmm, what will you do with it after I complete it?" asks Mary.

"Once you have completed it, we will arrange a time for us to sit together and see if you have any concerns about your health or your care that I can help you with. I can also refer you to other people to help you with your care."

"Okay, this sounds like something that might be useful to me."

You review Mary's patient file. She is 50 years old and has had a lumpectomy for a Stage IIA, early breast cancer. She has completed her chemotherapy. It is noted that she only briefly saw a Breast Care Nurse before her surgery. It is also noted that she has been diagnosed with fibromyalgia.

After ten minutes you go to collect the questionnaire.

"Did you have any problems or questions you want to ask me about the questionnaire?"

"Oh no, it seemed pretty straightforward, but there are some other things that are not listed here that I would like to mention."

"That's not a problem, either list them in the 'other problems' section of the form, or let me know when we look at the form together. I'll just arrange a room for us to discuss this privately; I'll be back in a few minutes."

Question to consider

From the scenario, what are the key issues to note about Mary and her personal situation?

TOPIC 2: Screening

Introduction

Screening patients for supportive care needs is an essential step in the overall process of providing holistic cancer care. Screening and referral will usually occur as one process. For the purpose of familiarising you with the steps involved in the whole process, it has been separated into two topics; however, in practice it will usually occur together.

In your own work, you might already informally screen and refer patients. The process discussed here is formalising this process.

In this topic you will examine:

- the screening tools that are used
- an overview of the tools
- how to assess the tools.

What screening tools are used?

This Kit uses the following tools:

- Risk Factor Checklist
- the Distress Thermometer and Problem List
- Kessler Psychological Distress Scale (K10).

A copy of each screening tool has been included in the Resources section of the Kit.

Risk Factor Checklist

A risk factor checklist has been developed from the *Clinical Practice Guidelines for Psychosocial Care of Adults with Cancer*[1] to help you decide if a patient is at significant risk of developing psychological distress. It is designed for completion by health professionals.

The Risk Factor Checklist should be completed for each patient prior to the action stage. You can begin checking this list off while the patient is completing the Distress Thermometer and Problem List. Using your knowledge of the patient, information from the patient's medical record, and/or through clarification from the patient, tick any of the risk factors which are applicable to the patient you are screening.

Ticked items on the checklist are a 'red flag' to alert you to the fact that this patient may be at increased risk of experiencing psychological distress. Understanding which of these factors apply to the patients you are screening will:

- help you understand the patient better
- suggest clarification or follow-up questions you might need to ask in your discussion
- assist you in decision making regarding appropriate action and/or referrals.

CHECKLIST OF RISK FACTORS FOR PSYCHOLOGICAL DISTRESS

If the patient is experiencing any of the following they may be at greater risk of developing emotional distress:

- ☐ Younger than 55 years
- ☐ Lack of social support (e.g. single, widowed, living alone)
- ☐ Caring for children or other dependants
- ☐ Financial problems
- ☐ Previous episodes of depression, anxiety or other psychiatric illness
- ☐ History of stressful life events
- ☐ High alcohol or drug intake
- ☐ Female

activity 3

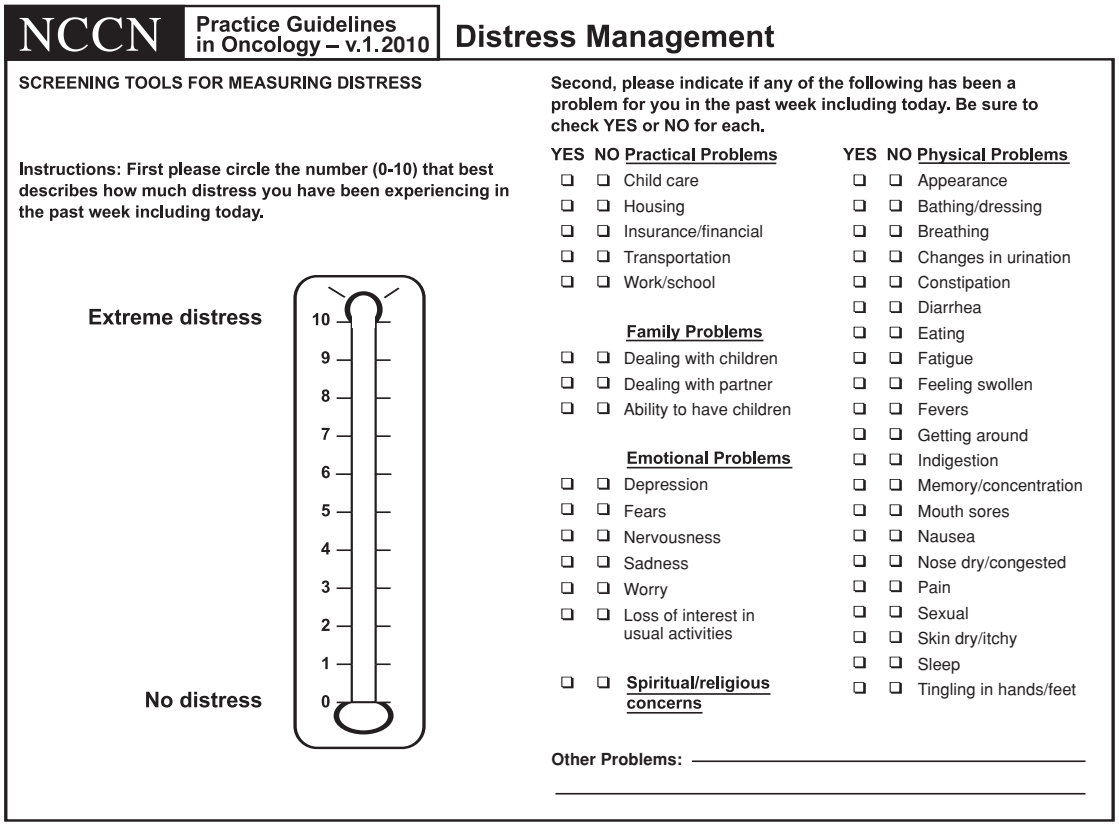
Completing the Risk Factor Checklist

Looking back at case study part A, fill in the checklist above for Mary's risk factors.

The Distress Thermometer and Problem List

The Distress Thermometer and Problem List is a one page screening tool developed by the National Comprehensive Cancer Network.[11] It is used in cancer treatment centres as a supportive care needs screening tool in the United States,[14,15,16] United Kingdom and more recently in Australia.[17] It has been validated to be effective in detecting distress in patients with cancer.[14,15,16]

The Distress Thermometer and Problem List has been designed to be self-administered by patients. If the patient prefers, the questions can also be read aloud to the patient.



NCCN Practice Guidelines in Oncology – v.1.2010

Distress Management

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
		Family Problems
❑	❑	Dealing with children
❑	❑	Dealing with partner
❑	❑	Ability to have children
		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
❑	❑	Tingling in hands/feet

Other Problems: _____

The Distress Thermometer and Problem List is made up of:

The Distress Thermometer: a single item question measuring patient distress on a scale of 0–10. The thermometer has been modelled on the pain scale. The patient indicates the level of distress they have been experiencing from any source (even if unrelated to their cancer) in the past seven days (including today) by marking the scale.

The Problem List: this is a list of supportive care issues or needs, grouped into five domains that may be contributing to the patient's distress. The patient indicates problems that have been causing them concern by ticking the appropriate box. At the bottom there is an opportunity for patients to add additional areas of concern not included in the list.

Assessing the Distress Thermometer

Assessment of the Distress Thermometer falls into two categories:

- A score of less than 4 (< 4) indicates the patient has mild distress.
- A score of greater than or equal to 4 (≥ 4) indicates the patient has moderate to severe distress.

There is an action and referral protocol for each of these two categories. (Refer to DistressThermometer Assessment protocol.)

Assessing the Problem List

Assessing the Problem List is straightforward as the patient ticks 'Yes' or 'No' when they fill out the screening tool. For each item that the patient has indicated 'Yes', the corresponding action and referral protocol needs to be followed.

NOTE: Activities for assessing the Distress Thermometer and Problem List are in Topic 3.

The Kessler Psychological Distress Scale (K10)

The K10 is a measure developed to detect psychological distress. It can be completed by the patient in a pen and paper format or the questions can be read aloud. The K10 has been shown to be a valid measure of psychological distress when compared to other measures such as the SF-12 and the GHQ.[18] It is also used by GPs referring patients for counselling or psychological services.

The K10 has been included in this Kit to assist in decision making when referring patients who have a score of greater than or equal to 4 on the Distress Thermometer.

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?					

Assessing the K10

Each question on the K10 has a 5 point response scale. These response options are scored from 5 to 1 respectively as illustrated in the table below.

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
About how often did you feel tired out for no good reason?	5	4	3	2	1

Scoring the K10

Once the K10 has been completed by the patient, add up the scores according to the points indicated above. The final score will be between 10 and 50. The final scores should be interpreted as follows:

A score of <16: indicates people with no increased likelihood of anxiety or 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

activity 4

Practice scoring the mock K10

Look at the completed K10 below and answer the following question.

What is the final K10 score for this patient and what does this indicate?

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?					✓

case study part B

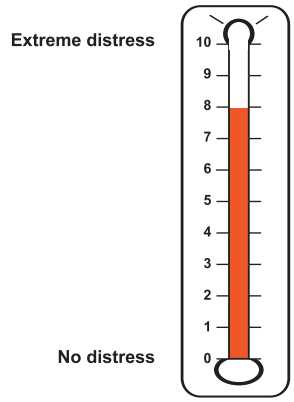
Using the Distress Thermometer

Mary has completed the Distress Thermometer and Problem List and you have collected it from her. You take a few minutes to review it before calling her into the room.

NCCN Practice Guidelines in Oncology – v.1.2010 **Distress Management**

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.

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

YES	NO	Family Problems
☐	☐	Dealing with children
☐	☐	Dealing with partner
☐	☐	Ability to have children

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
☐	☐	Tingling in hands/feet

Other Problems: When to take prescription medicine - Fibromyalgia - can't walk much

Questions to consider

1. What level of distress has Mary indicated on the Distress Thermometer? Does she have mild, or moderate to severe distress?
2. In what domains does Mary indicate problems?
3. In what way could Mary's risk factors be relevant to her problems?

TOPIC 3: Action and referral

Introduction

Appropriate action and referral must be matched to the identified supportive care needs of the patient. Once you have reviewed the patient's responses on the Distress Thermometer and Problem List, and considered any risk factors relevant to the patient, you will have a discussion with the patient about their responses.

In this topic you will examine:

- the key principles of action and referral
- the review process
- using the action and referral protocols.

Key principles of action and referral

Discussion and action

The discussion with the patient will involve clarifying the problems with the patient to make an initial assessment. The actions you take depend on the discussion and the nature of the issue the patient highlighted.

For some patients, the opportunity to raise and discuss issues at the time of the consultation might be enough.

For others, you may be able to resolve the patient's problems with provision of verbal advice, some written information or contact details for a service or support group.

For some patients you will need to take additional action. Some examples of additional action include:

- making a phone call to get some additional information for the patient
- clarifying an issue with the patient's oncologist
- obtaining application forms for an assisted transport scheme.

Does the patient get a choice in the referral?

YES, the patient **MUST** have a choice if they **WANT TO BE REFERRED** and **WHERE** they would like to be referred (within the boundaries of service availability).

For example, if a patient lives in a rural town and requires a social worker it might be more appropriate to refer them to their local service. However, the person might feel they do not want to see somebody locally who might know them. Instead, they might want to consult the social worker in the regional centre. Or the patient might find the idea of a social worker too stigmatising and might prefer to join a support group or call the Cancer Connect Service. Discuss the options with the patient and establish their needs and desires for their supportive care. Sometimes it may be enough for a patient to know that a service is available for them to use should they need it in the future.

A range of referral options is given in the protocols because:

- not all practitioners/services/information may be available in your area
- a patient may not feel they want to take up one particular kind of referral and would prefer another.

Note: the referrals are NOT always listed hierarchically or in any order of preference but provide a range of options that you may consider. For physical problems, a medical assessment is also required.

Prioritising referrals

Some patients may be experiencing worry and fears which are exacerbated by other concerns (e.g. practical problems like lack of transport). In these cases you could look up the referral protocols for both issues and select the most appropriate place to start helping the patient.

Considering risk factors when referring

When suggesting referrals for the patient you need to consider if their risk factors are relevant. For example, if you know that the patient is experiencing financial problems, you may consider referral to a private psychologist inappropriate. Or if the patient is living alone, you may need to factor this in when suggesting actions.

Knowing when to refer

In many situations referrals are suggested. Offering a referral will depend upon clarifying the problem identified by the patient, and the patient's choice. In some situations referrals are recommended rather than suggested. These are situations where the level of distress determines the nature of the referral.

All problems in the family, emotional and spiritual domains as well as memory/concentration in the physical domain have a strong link to the patient's level of distress. As such the referrals for these problems are **suggested** if the patient's distress level is less than 4 and are **recommended** if the patient's distress level is greater than or equal to 4.

Referrals are essential if a patient expresses thoughts of suicide or self-harm. An URGENT referral to Psychiatric Services is required.

Problems in the physical domain require assessment by the treating medical team prior to deciding on subsequent supportive care referrals.

Note: Patients must continue to receive their usual clinical care. The supportive care process does NOT replace routine medical care or assessment.

The Supportive Care Service Directory

If you are referring a patient to a supportive care service or practitioner, you can check the location of available services/practitioners. These are listed in the Supportive Care Service Directory available from your local Integrated Cancer Services.

Documenting your discussion, action and referral

The final step in the action and referral process is documentation. It is recommended that you make an entry into the patient's medical record or complete the relevant recording or documentation system used by your department/unit/organisation. To enable easy identification by other members of the team, consistent documenting is advisable. Documentation under the following headings is recommended:

Assessment	. . . . .
Action	. . . . .
Referral	. . . . .

Review

The final essential step of the supportive care process is review. Recommended intervals for screening were described in Topic 1, therefore re-screening should ideally occur at these intervals. The outcomes of the recommended actions and referrals will be reviewed at the next visit. Further discussion on reviewing the patient occurs in Topic 4.

The action and referral protocols

The Distress Thermometer and each problem on the Problem List has one or more pages devoted to suggested actions you could make to help the patient. These are the action and referral protocols. Some problems have more than one protocol. For example the problem of 'eating' has several protocols for different aspects associated with: lack of appetite/weight loss; difficulty chewing; difficulty swallowing; and taste changes/dry mouth.

Each protocol is categorised under three subheadings for ease of use. These subheadings are:

- Assessment
- Action
- Referral

The action and referral protocols in the SCRK can be accessed by:

a) Looking up each problem in the table of contents at the front of the Kit, or
b) Turning to the broad category of the issue (e.g. physical problems). All individual issues are listed alphabetically within each of these sections.

Using the protocols

As explained above, referrals for the Distress Thermometer score and problems identified on the Problem List can be **suggested** or **recommended**. In this section you will practice using the protocols in each instance.

activity 5

Protocols for the Distress Thermometer score

Practice using the Distress Thermometer action and referral protocols to find out what to do for a patient in these instances:

a) Distress Thermometer Score of 2

b) Distress Thermometer Score of 7, K10 score of 12

c) Distress Thermometer Score of 9, K10 score of 26

activity 6

Action and suggested referrals

Practice using the action and referral protocols to find out what to do for a patient who indicates on the Problem List they are having problems with:

a) Fatigue

b) Transportation

activity 7

Action and suggested or recommended referrals

Look at the two examples of the Distress Thermometer and Problem List below. Practice using the action and referral protocols to find out what to do for a patient in these instances.

Example 1

NCCN Practice Guidelines in Oncology – v.1.2010 **Distress Management**

SCREENING TOOLS FOR MEASURING DISTRESS

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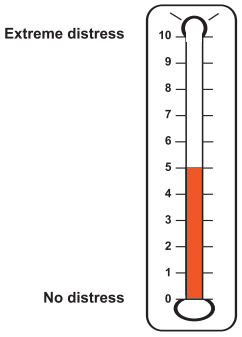


Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

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

YES	NO	Family Problems
☐	☐	Dealing with children
☐	☐	Dealing with partner
☐	☐	Ability to have children

YES	NO	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
☐	☐	Tingling in hands/feet

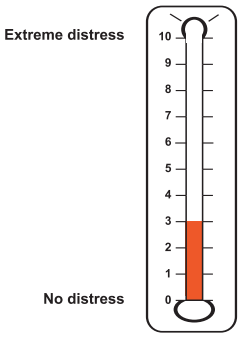
Other Problems: _____

Example 2

NCCN Practice Guidelines in Oncology – v.1.2010 **Distress Management**

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.



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☐	☐	Work/school

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☐	☐	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
☐	☐	Tingling in hands/feet

Other Problems: _____

case study part C

The screening interview

Read part C of the case study below and answer the questions.

NCCN Practice Guidelines in Oncology – v.1.2010 **Distress Management**

SCREENING TOOLS FOR MEASURING DISTRESS

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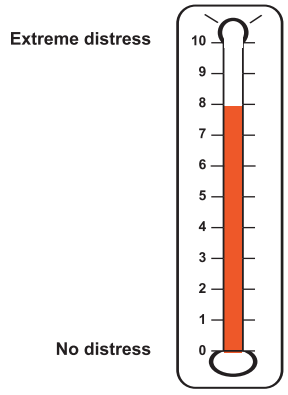

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

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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
☐	☐	Tingling in hands/feet

Other Problems: When to take prescription medicine - Fibromyalgia - can't walk much

To begin your discussion with Mary, clarify whether she is still comfortable to discuss the questionnaire.

"Mary, 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.

"Mary, I've noticed that you have indicated that you are feeling distressed today. I can also see that you have ticked fear and worry on the Problem List. Can you tell me a bit more about what you are worried and scared about?"

To help Mary 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 Mary that she is feeling unsupported and alone, especially when she was undergoing her chemotherapy as no one in her family was there to provide her support. She lives on her own, as she is separated from her husband. She has two sons; one lives nearby, although she doesn't see him very often and the other lives in the city, about three hours drive away.

She still has these feeling now that she is entering into a new treatment phase.

Mary indicates that she is slightly anxious and needs emotional support. She still has very uncertain feelings about her breast cancer diagnosis and is continually asking "why me?". Mary is looking for "something" to help support her emotionally.

From the discussion you also find out that Mary experiences pain and fatigue, and has issues with mobility due to her fibromyalgia. She has been given medication but is confused about how often to take it and how much to take.

After the discussion you decide it is necessary to make suggestions for further action.

"Mary, 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?"

Mary responds "Yes, that would be very useful."

Mary has agreed for you to help her by making some referral suggestions.

Questions to consider

1. Using the action and referral protocols, what referrals do you think would be appropriate for you to suggest?
2. What factors do you need to consider in making the appropriate referrals for Mary?

TOPIC 4: Supportive care in routine practice

Introduction

The process of screening, action and referral as discussed in this Kit must be implemented into routine cancer care to achieve best practice supportive care. Some of the practical issues of implementing these processes into your everyday practice will be covered in this topic.

In this topic you will examine:

- how to encourage uptake of referrals, advice and self-management
- communicating about supportive care issues with the patient
- trouble shooting and practical suggestions to help you incorporate supportive care into your work – overcoming the barriers.

Encouraging uptake of referrals, advice and self-management

Many clinicians experience difficulty encouraging patients to take up referrals or other advice. This is particularly true for issues related to the emotional and family domains of the Problem List.

A study of the uptake of referrals by patients in a large Australian cancer centre found that 38% of services for emotional issues offered to patients were declined by the patient.[19] This study found that men were more likely to decline to take up the service than women and people with mild symptoms of distress were more likely to fail to take up the service than people with more severe symptoms.

Reasons for declining to take up referrals or services for emotional issues included:

- 'not now', maybe later, have other priorities to deal with first
- prefers to deal with it themselves
- prefers an alternative, nonclinical support such as family members
- considers help unnecessary or doesn't want to discuss referral or assistance
- prefers an alternative formal support such as home carers
- primary concern is cancer treatment and physical issues
- previous support not positive, doesn't have faith in psychological support
- distress improving
- distress not important.

Sometimes clinicians hesitate to discuss psychological distress with patients or to make these referrals because they feel the patient may not be receptive to it or feel it is beyond their scope of practice to discuss or assess for these issues.

Strategies to encourage uptake

If patients decline to take up or attend referrals for emotional issues, possible actions are:

a) Discuss and clarify the issue further with the patient. During this discussion consider the following points:

- If the patient's past experience of a particular service is negative, you could consider referring to another service or health professional.
- The 'not now' or 'prefer self-management' type of response could really mean 'no, I don't want a referral'.
- The K10 is a tool used by many psychological and health professionals to gauge whether emotional distress is severe and needs follow up.
- Check whether another issue such as transport to the suggested service or financial issues have discouraged the patient from taking up the referral.
- Check that the patient is not feeling shame or guilt that they are not coping.
- Sometimes discussion alone (taking into account the patients' known risk factors) has alleviated the problem and the patient believes that attending the referral is now not necessary.
- Review and follow up with the patient at a later stage.
- If the patient has the 'not now' response they may be more receptive to referral at a later stage.
- You may want to screen the patient again using the Distress Thermometer and Problem List at a later stage or organise it to be done by the appropriate unit.

b) Give the patient information about a service or practitioner in a form they can use later when they are ready.

c) Referrals made by a patient's routine service provider can increase the level of uptake of referral.

d) If a patient really doesn't want to take up a referral it isn't always desirable to pressure them. Document in the usual way the discussion, action and the patient's reluctance to take up or attend the referral.

activity 8

Discuss other appropriate action

What other actions could you suggest to encourage patients to take up or attend referrals?

case study part D

Patient review

Read part D of the case study below and answer the questions.

During the supportive care screening discussion you had with Mary Simpson you discussed the issues she had highlighted on the Distress Thermometer and Problem List. As a result of that discussion you made a number of suggestions for action and referral:

- You gave her a brochure about fibromyalgia medication to help her to understand the medication regime.
- You gave her information about a 'Living with Cancer' education program at the local hospital.
- You referred her to the hospital social worker to assist her with some of the practical and emotional problems she was experiencing.
- You also recommended and discussed with her the advantages of attending the local leisure centre for exercise and pain management but she seemed reluctant to attend the leisure centre and had not been interested in discussing it further.

Three weeks after this discussion, Mary returns to the cancer centre for her routine radiotherapy appointment. As you are treating Mary you ask her if she has followed up any of the actions and referrals suggested.

Mary replies, "I think I've sorted out my medication now. That's good."

You ask her about the 'Living with Cancer' program.

"Oh, yes, that was OK, I don't really know yet," she replies.

You ask her if she has attended the appointment which you made with the social worker.

"Um, no, I might leave that one until later. I'll see what I feel like in a few weeks. I don't want counselling – talking isn't going to help".

Questions to consider

1. What else might you say to Mary?
2. Do you take any further action or make any further suggestions? If so, what?

Communication about supportive care needs

Many clinicians highlight communicating with patients about emotional and psychological issues as a difficult area. Research has shown that clinicians feel more comfortable talking about physical problems and attending to physical and practical problems than emotional issues. Clinicians also report they believe they haven't developed enough rapport with their patients to have personal conversations. Other practical barriers to communication included skills, time and access to private discussion areas. Patients also report not wanting to raise their issues/concerns with the clinician as they see the clinicians as 'too busy' and don't want 'to bother them'. It has also been found that patients and clinicians will often both wait for the other to initiate discussion. [1, 20-22]

activity 9

Barriers to communicating with patients

Identify the factors that prevent you from becoming engaged in discussion with a patient about emotional and/or psychological issues. Try to identify two personal factors and two workplace/situational or patient factors.

'Golden rules' for supportive communication

As a response to the identified barriers to communicating with patients, the following 'Golden rules' for supportive communication are presented in the tables below. Each table provides a short explanation of the 'Golden rules' including key elements and examples of each of the principles.

Good nonverbal communication skills

Good nonverbal communication skills to use in a discussion with the patient include:

ELEMENTS	EXAMPLES
Maintaining eye contact	
Listening carefully	
Providing visual evidence of listening	Nod, 'hmmm', facial expressions
Positioning your body toward the patient in an open position	

Blocking

Many health professionals (often unknowingly) prevent patients from disclosing emotions by blocking actions. Blocking actions can include:

ELEMENTS	EXAMPLES
Ignoring signs a person is upset or wishes to talk	
Changing the subject	
Selectively focusing on physical issues or turning the conversation to physical or practical concerns	
Offering premature or false reassurance	'You're lucky you have a very treatable type of cancer.' 'I'm sure you'll be fine.'
Trivialising issues	
Asking closed questions to prevent disclosure of emotional issues	
Having an air of being 'too busy' to attend to emotional issues	

Setting up the conversation

The way you set up the conversation with the patient can encourage them to discuss sensitive issues. Try to:

ELEMENTS	EXAMPLES
Be clear about how much time you have and be prepared to make another time if necessary	
Be friendly and open when approaching the patient	
Ask the patient's permission to discuss sensitive issues	'I noticed you ticked sexual issues. Can I talk to you about these?'
Position furniture to maximise communication	Place your chair facing the patient, away from others and on the same level as the patient

Good verbal communication skills

Good verbal communication skills to use in a discussion with the patient include:

ELEMENTS	EXAMPLES
Asking open questions	'What have you been feeling like this week?'
Carefully assessing what a patient wants to know	
Avoiding jargon and medical terminology, without explanation	
Empathising with the patient's situation and emotional responses	
Using 'educated guesses' about a patient's feelings [21]	
Giving feedback to the patient and summarising what they have said	

Encourage an environment of supportive communication

You can help to cultivate an environment of supportive communication in your work area by:

ELEMENTS	EXAMPLES
Trying to challenge bias towards technical and physical tasks	
Documenting communication about supportive care needs	
Considering your own support needs	Debriefing with other staff
Balancing knowledge of your limitations with openness to discuss supportive care issues	

Further resources: Cancer Council Victoria offers regular communication skills training courses. Phone: 13 11 20 or see **http://www.cancervic.org.au**.

activity 10

Practising the 'Golden rules' for supportive communication

Choose 1-2 of the 'Golden rules' and complete the examples section of the table.

Trouble shooting and practical suggestions for supportive care

You may come across some barriers in implementing supportive care within your own work and your organisation. The most common barriers experienced by health professionals are listed in the tables. The tables also provides some strategies for you to use in overcoming these barriers.

BARRIER: TIME, WORKLOAD AND ORGANISATIONAL DEMANDS
Most common barrier raised by all health professionals. [23-27, 29] Clinicians may feel that talking is not a valid part of essential care. [22]
STRATEGIES
Discuss issues while attending to other tasks, e.g. changing a dressing.
Prepare and structure time for supportive care.
Be clear with the patient how much time you have and, if necessary, arrange a time to return to the issues raised.
Prioritise problems for discussion – some now, some later.
Clarify the problem, e.g. has the patient interpreted the question correctly. Is it a new problem or an on-going issue? [22]
The patient can complete the screening tool while waiting for their treatment, i.e. in the waiting room or in the chemotherapy chair. [28]
To focus the discussion ask "how can I help you today" or "what are the two most troubling problems for you today?" [28]

BARRIER: SCOPE OF PRACTICE

Clinician's report feeling more confident in dealing with physical problems and practical tasks rather than with psychological issues. [25, 29-30] (e.g. focusing on the treatment agenda of investigating, diagnosing and treating cancer).

They may be uncertain about what to say in some situations, [22] fear of opening a Pandora's Box which they might not know how to deal with [25] or worried about upsetting the patient or making things worse. [22, 25, 29] Clinicians may hesitate to be drawn into the emotional world of the patient [26] and feel an emotional burden of caring for the cancer patient. [24]

STRATEGIES

Resist the temptation to put everything right for patients and instead demonstrate an understanding of their distress. [22]

Undertake communication skills training. [25]

Use a multidisciplinary approach and involve other members of the treatment team. [28]

Seek out peer support.

BARRIER: SKILLS, KNOWLEDGE & TRAINING

Some clinicians report a lack of practical/clinical skills and training in the detection of supportive care [25] and managing distress. [22]

STRATEGIES

Consider further training in this area. [25]

Use a multidisciplinary approach and involve other members of the treatment team. [28]

BARRIER: BELIEFS, ATTITUDES & VALUES

Some clinicians report that they do not feel confident in communication skills or knowledge about the emotional impact of cancer and how to deal with the situation. [29]

Some clinicians report low personal skills or confidence about caring for a patient with a cancer diagnosis. [23]

Clinicians who have a positive attitude towards supportive care tend to have more "open communication with their patients and their patients are more inclined to initiate questions and express opinions". [25]

STRATEGIES

Clinicians' confidence and self-efficacy (belief in being able to perform a particular task) can empower patients to talk about supportive care issues. [25]

Initiate discussion and be confident in dealing with supportive care issues.

"the process of exploring your own feelings can allow you to better understand and separate your own issues from those of patients" [22]

Consider further training in this area. [25]

BARRIER: RESOURCES

Lack of private interruption-free spaces. [25]

Lack of referrals to appropriate allied health professionals (notably psychologists) [25] and access to other specialist service providers. [29]

STRATEGIES

Ask the patient if they feel comfortable discussing the screening tool in their current location.

Refer to another appropriate health professional according to the action and referral protocols.

activity 11

Trouble shooting

Discuss practical strategies that could be used to overcome some of these common issues in supportive care.

1. What would you do if a patient ticks 14 items on the Problem List?

2. What would you do if a patient begins to tell you their life story?

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

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

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

ANSWERS

Question 1

- 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.
- Prioritise the patient's top three needs.
- Refer to a GP or other health professional as appropriate.
- Prioritise the patient's needs and make a time later in the day or week or at the next visit to discuss the other issues with the patient.

Question 2

- What do you normally do?
- Balance the patient's need to be comfortable to disclose with your need to get the job done.
- Gently bring the patient back to the topic.
- Make time to talk.

Question 3

- Refer to a GP who has access to mental health schemes.
- Use the Supportive Care Service Directory.

Question 4

- Discuss the options with the patient.
- Seek peer support from other members of the team.
- Use the Supportive Care Service Directory.

Question 5

- Check that the patient has filled out the Distress Thermometer correctly.
- Discuss the nature of the patient's distress as they may not articulate it in the same way as Problem List.
- Follow the protocols accordingly.

Hypericum perforatem (St. John's Wort)

CHAPTER 3

Distress Thermometer Assessment

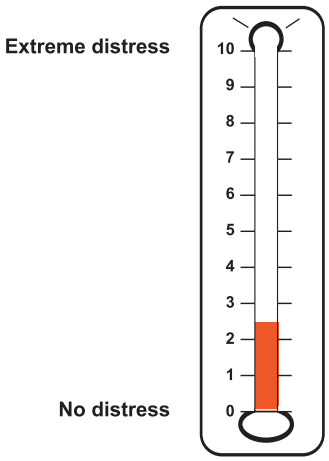
The Distress Thermometer is a single-item screen to identify distress that could be from any source, including unrelated to cancer.

A score of less than 4 indicates mild or no distress; a score of greater than or equal to 4 indicates moderate to severe distress.

There is one action and referral protocol each for a score of < 4 and a score of ≥ 4.

03

Thermometer score < 4



A score of 0 on the Distress Thermometer indicates no distress. Let the patient know that they can talk to you if they become distressed.

If the patient has noted that their level of distress is above 0 and less than 4 on the Thermometer, then they are considered to have mild distress. These patients may show signs and symptoms of normal fear and worry about their illness and the future. They may experience some of the problems identified on the checklist.

ASSESSMENT

- Clarify the exact nature of the distress/problem with the patient.
- Assess the patient's family and social support structure.
- Consider if the patient's risk factors are relevant to the problem.

ACTION

- Discuss the distress with the patient utilising the 'golden rules' of supportive communication.
- Address any identified problems on the Problem List using the protocols in this Kit.
- Provide verbal and/or written information.
  - Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:

- Psychologist/Counsellor
- GP
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse.

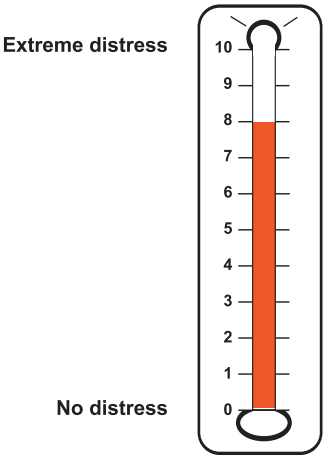
To one of the following supportive care services:

- Cancer Connect Service (The Cancer Council Victoria; ph. 13 11 20)
- Cancer Support Groups.

Reassess the distress level at the next visit. If it is stable or diminishing, then continue to support and monitor. If the distress level rises to 4 or above, then follow the protocol for Thermometer score ≥ 4.

ALL PATIENTS SOME/FEW PATIENTS

Thermometer score ≥ 4



If the patient indicates that their level of distress is greater than or equal to 4 then their level of distress is considered to be moderate to severe. Further action is required.

ASSESSMENT

- Clarify the exact nature of the distress/problem with the patient.
- Consider contribution to distress by the problems ticked on the Problem List.
- Assess the patient's family and social support structure.
- Consider if the patient's risk factors are relevant to the problem.
- Ask patient to complete the Kessler Psychological Distress Scale (K10).

ACTION

- Discuss the distress with the patient utilising the 'golden rules' of supportive communication.
- Address any identified problems on the Problem List using the protocols in this Kit.
- Provide verbal and/or written information.
- Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

Referral for distress based on K10 score:
If the patient scores < 16 on the K10 scale **suggested** referrals to one of the following:

- Cancer Care Coordinator/Breast Care Nurse
- Social Worker
- Psychologist/Counsellor.

If the patient scores ≥ 16 on the K10 scale **recommended** referrals:

- Psychologist and/or GP.

NB. If the patient expresses thoughts of suicidal ideation or self harm, an URGENT referral to Psychiatric Services is required.

ALL PATIENTS SOME/FEW PATIENTS

Verbascum

CHAPTER 4

Practical action and referral protocols

The Problem List asks patients whether or not they have experienced any of five practical problems within the last week. There is one action and referral protocol for each problem, except for work which has two protocols, one for paid work and one for work around the home.

04

Child care

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse.

To one of the following supportive care services:
- Local Council
- Community Health Centre.

For financial assistance with child care:
- Family Assistance Office (ph. 13 61 50).

Housing

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse.

ALL PATIENTS SOME/FEW PATIENTS

Insurance/Financial

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Consider if the patient's risk factors are relevant to the problem. • If the patient is currently employed, enquire about patient leave status (e.g. sick, annual or long service).	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information. • Ask the patient if they are comfortable discussing leave options with their employer (if not, refer as outlined below).

REFERRAL

To one of the following supportive care practitioners:
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse
- Financial Counsellor.

For information and discussion of leave entitlements:
- Social Worker.

To supportive care services:
- for information on sickness allowances – Centrelink (ph. 13 27 17).
- for information on travel allowances – Victorian Patient Transport Assistance Scheme (VPTAS) **(http://www.health.vic.gov.au/ruralhealth/aservices/vptas.htm).**

ALL PATIENTS SOME/FEW PATIENTS

Transportation/Travel

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse.

To one of the following supportive care services:
- Local Council
- Community Health Centre.

For information on travel allowances:
- Victorian Patient Transport Assistance Scheme (VPTAS) **(http://www.health.vic.gov.au/ruralhealth/aservices/vptas.htm).**

ALL PATIENTS SOME/FEW PATIENTS

Work – paid work

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information. • Ask the patient if they are comfortable discussing leave options with their employer (if not, refer as outlined below).

REFERRAL

To one of the following supportive care practitioners:
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse.

For information and discussion of leave entitlements:
- Social Worker.

For information on patient declaration of health clauses in contracts, loans or insurance policies:
- Social Worker.

To supportive care services:
- for information on sickness allowances – Centrelink (ph. 13 27 17).

ALL PATIENTS SOME/FEW PATIENTS

Work – work around the home

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- Social Worker OR;
- Cancer Care Coordinator/Breast Care Nurse.

To supportive care services:
- to one of the following for Home Help or Meals on Wheels services:
  – Local Council
  – Community Health Centre.

ALL PATIENTS SOME/FEW PATIENTS

School – patient's child

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information. • Ask the patient if they are comfortable discussing the issue with a school counsellor or their child's teachers (if not, refer as outlined below).

REFERRAL

To one of the following supportive care practitioners:
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse
- School Counsellor.

To one of the following supportive care services
- Canteen (ph. 1800 226 833 or **http://www.canteen.org.au**)
- OnTrac @PeterMac (ph. 9656 1744 or **http://www.petermac.org/ontrac/**)

If the child may benefit from talking to someone confidentially about their problems:
- Kids Helpline (ph. 1800 55 1800 or **http://www.kidshelpline.com.au**).

ALL PATIENTS SOME/FEW PATIENTS

Papaver somniferum (Opium Poppy)

CHAPTER 5

Family action and referral protocols

The Problem List asks patients whether or not they have experienced any of two family problems within the last week. There is one action and referral protocol for each problem, except for in the case of dealing with partner which has two protocols, one for interpersonal problems and one for sexual problems. There is an additional protocol for dealing with family and friends.

05

Dealing with children

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

If the patient's Distress Thermometer score is less than 4 then the following referrals are suggestions to consider offering to the patient.

If the patient's Distress Thermometer score is greater than or equal to 4 then the following referrals are recommended.

To one of the following supportive care practitioners:
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse.

If problem continues and/or is causing significant patient distress family counselling may be needed from one of the following:
- Psychologist
- Family Counsellor.

To supportive care services:
- Canteen (ph. 1800 226 833 or **http://www.canteen.org.au**).

If the child may benefit from talking to someone confidentially about their problems:
- Kids Helpine (ph. 1800 55 1800 or **http://www.kidshelpline.com.au**).

ALL PATIENTS SOME/FEW PATIENTS

Dealing with partner – interpersonal problems

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Assess the family and social support structure. • Assess the family roles. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

If the patient's Distress Thermometer score is less than 4 then the following referrals are suggestions to consider offering to the patient.

If the patient's Distress Thermometer score is greater than or equal to 4 then the following referrals are recommended.

To one of the following supportive care practitioners:
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse.

If problem continues and/or is causing significant patient distress family or couples counselling may be needed from one of the following:
- Psychologist
- Counsellor
- Psychiatrist.

To supportive care services:
- Relationships Australia (ph. 1300 364 277 or **http://www.relationships.com.au**).

ALL PATIENTS SOME/FEW PATIENTS

Dealing with partner – sexuality/ sexual problems

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease, treatment and sexuality. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

If the patient's Distress Thermometer score is less than 4 then the following referrals are suggestions to consider offering to the patient.

If the patient's Distress Thermometer score is greater than or equal to 4 then the following referrals are recommended.

To one of the following supportive care practitioners:
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse
- Women's Health Nurse
- Sexual Health Counsellor
- GP.

For longer term problems or in the case of significant patient distress, to one of the following:
- Psychologist
- Family Counsellor
- Psychiatrist.

If erectile dysfunction or hormonal problems are suspected:
- GP.

To supportive care services:
- Relationships Australia (ph. 1300 364 277 or **http://www.relationships.com.au**).

ALL PATIENTS SOME/FEW PATIENTS

Dealing with family and friends

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Assess the family and social support structure. • Assess the family roles. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information. • Encourage setting priorities with family members and social activities.

REFERRAL

If the patient's Distress Thermometer score is less than 4 then the following referrals are suggestions to consider offering to the patient.

If the patient's Distress Thermometer score is greater than or equal to 4 then the following referrals are recommended.

To one of the following supportive care practitioners:
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse.

If problem continues and/or is causing significant patient distress family counselling may be needed from one of the following:
- Psychologist
- Counsellor
- Social Worker.

To supportive care services:
- Cancer Connect Service (The Cancer Council Victoria ph. 13 11 20).

ALL PATIENTS SOME/FEW PATIENTS

Ability to have children

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

If the patient's Distress Thermometer score is less than 4 then the following referrals are suggestions to consider offering to the patient.

If the patient's Distress Thermometer score is greater than or equal to 4 then the following referrals are recommended.

To one of the following supportive care practitioners:
- Specialist Physician
- GP
- Cancer Care Coordinator/Breast Care Nurse

For contraceptive and pregnancy concerns:
- Gynaecologist

For women who have concerns at conclusion of treatment:
- Endocrinologist

For preservation of oocytes, ovarian tissue, embryos or sperm:
- Fertility clinic (prior to treatment).

If problem continues or is causing significant patient distress couples and/or personal counselling may be needed from one of the following:
- Psychologist
- Couples/Personal Counsellor
- Psychiatrist

ALL PATIENTS SOME/FEW PATIENTS

Comfrey

CHAPTER 6

Emotional action and referral protocols

The Problem List asks patients whether or not they have experienced any of six emotional problems within the last week. There is one action and referral protocol for each problem.

06

Depression

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Assess the patient's family and social support structure. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

If the patient's Distress Thermometer score is less than 4 then the following referrals are suggestions to consider offering to the patient.

If the patient's Distress Thermometer score is greater than or equal to 4 then the following referrals are recommended.

To one of the following supportive care practitioners:
- Psychologist/Counsellor
- GP
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse.

To one of the following supportive care services:
- Cancer Connect Service (The Cancer Council Victoria; ph. 13 11 20)
- Cancer Support Groups.

ALL PATIENTS SOME/FEW PATIENTS

Fears

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Assess the patient's family and social support structure. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

If the patient's Distress Thermometer score is less than 4 then the following referrals are suggestions to consider offering to the patient.

If the patient's Distress Thermometer score is greater than or equal to 4 then the following referrals are recommended.

To one of the following supportive care practitioners:
- Psychologist/Counsellor
- GP
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse.

To one of the following supportive care services:
- Cancer Connect Service (The Cancer Council Victoria; ph. 13 11 20); OR
- Cancer Support Groups.

ALL PATIENTS SOME/FEW PATIENTS

Nervousness

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Assess the patient's family and social support structure. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

If the patient's Distress Thermometer score is less than 4 then the following referrals are suggestions to consider offering to the patient.

If the patient's Distress Thermometer score is greater than or equal to 4 then the following referrals are recommended.

To one of the following supportive care practitioners:
- Psychologist/Counsellor
- GP
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse.

To one of the following supportive care services:
- Cancer Connect Service (The Cancer Council Victoria; ph. 13 11 20)
- Cancer Support Groups.

ALL PATIENTS SOME/FEW PATIENTS

Sadness

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Assess the patient's family and social support structure. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

If the patient's Distress Thermometer score is less than 4 then the following referrals are suggestions to consider offering to the patient.

If the patient's Distress Thermometer score is greater than or equal to 4 then the following referrals are recommended.

To one of the following supportive care practitioners:
- Psychologist/Counsellor
- GP
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse.

To one of the following supportive care services:
- Cancer Connect Service (The Cancer Council Victoria; ph. 13 11 20)
- Cancer Support Groups.

ALL PATIENTS SOME/FEW PATIENTS

Worry

ASSESSMENT

- Clarify the exact nature of the problem with the patient.
- Assess the patient's family and social support structure.
- Consider if the patient's risk factors are relevant to the problem.

ACTION

- Discuss the problem with the patient utilising the 'golden rules' of supportive communication.
- Provide verbal and/or written information.
- Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

If the patient's Distress Thermometer score is less than 4 then the following referrals are suggestions to consider offering to the patient.

If the patient's Distress Thermometer score is greater than or equal to 4 then the following referrals are recommended.

To one of the following supportive care practitioners:

- Psychologist/Counsellor
- GP
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse.

To one of the following supportive care services:

- Cancer Connect Service (The Cancer Council Victoria; ph. 13 11 20)
- Cancer Support Groups.

ALL PATIENTS SOME/FEW PATIENTS

Loss of interest in usual activities

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Assess the patient's family and social support structure. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

If the patient's Distress Thermometer score is less than 4 then the following referrals are suggestions to consider offering to the patient.

If the patient's Distress Thermometer score is greater than or equal to 4 then the following referrals are recommended.

To one of the following supportive care practitioners:
- Psychologist/Counsellor
- GP
- Social Worker
- Cancer Care Coordinator/Breast Care Nurse.

To one of the following supportive care services:
- Cancer Connect Service (The Cancer Council Victoria; ph. 13 11 20)
- Cancer Support Groups.

ALL PATIENTS SOME/FEW PATIENTS

07

Allium sativum (Garlic)

CHAPTER 7

Spiritual action and referral protocols

The Problem List asks patients whether or not they have experienced any spiritual or religious concerns within the last week. There is one action and referral protocol for this concern.

07

Spiritual/Religious concerns

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Consider if the patient's risk factors are relevant to the problem.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information. • Where appropriate, explain the role of Palliative Care Services as part of holistic care.

REFERRAL

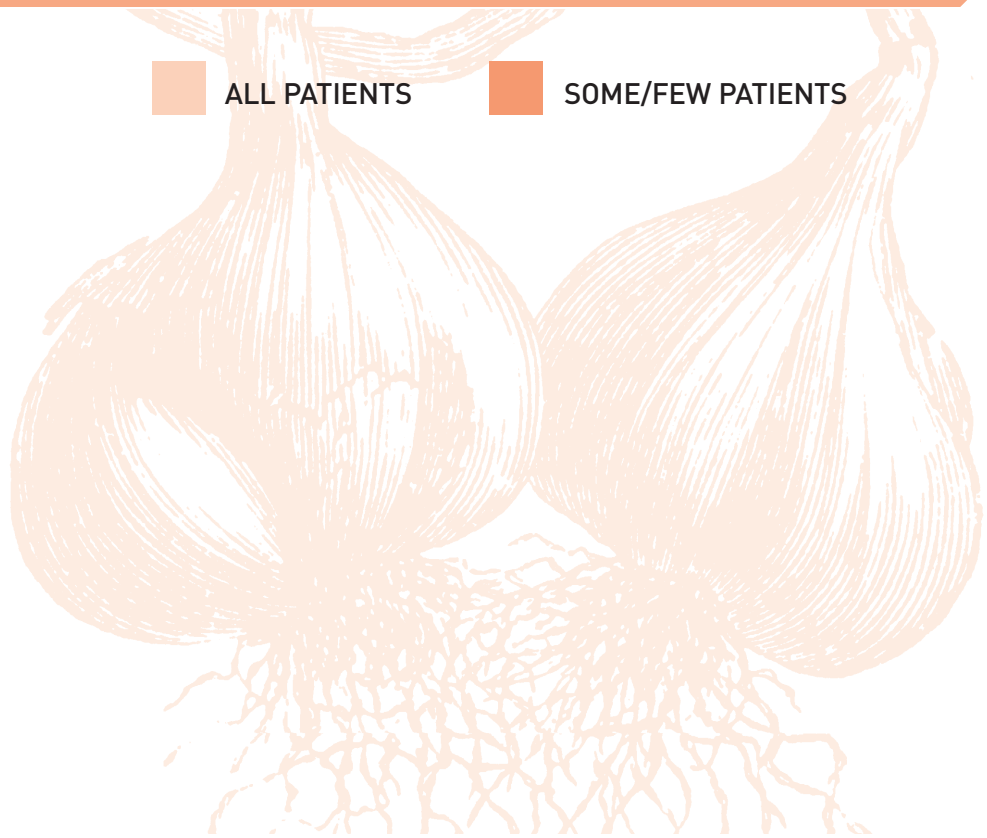
If the patient's Distress Thermometer score is less than 4 then the following referrals are suggestions to consider offering to the patient.

If the patient's Distress Thermometer score is greater than or equal to 4 then the following referrals are recommended.

To one of the following supportive care practitioners:

- Patient's own spiritual/religious advisor (e.g. parish minister)
- Pastoral Care call-in service (if available)
- Social Worker
- Psychologist
- Cancer Care Coordinator/Breast Care Nurse
- Palliative Care Service (if applicable).

ALL PATIENTS SOME/FEW PATIENTS



Digitalis (Foxglove)

CHAPTER 8

Physical action and referral protocols

The Problem List asks patients whether or not they have experienced any of 21 physical problems within the last week. There is one action and referral protocol for each problem, except for changes in urination which has two protocols, one for incontinence and one for urgency, frequency and pain. The problems of constipation and diarrhoea have been combined with one general protocol and one for bowel incontinence. Eating has four protocols, one each for lack of appetite or weight loss, difficulty chewing, difficulty swallowing and taste changes/dry mouth. Feeling swollen has two protocols, one for generalised oedema and one for lymphoedema.

Appearance

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment. • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information; • Provide information on wigs, prostheses, fittings and retailers as appropriate.

REFERRAL

To one of the following supportive care practitioners:
- Cancer Care Coordinator/Breast Care Nurse
- Social Worker.

In the case of severe patient distress, to one of the following:
- Psychologist
- Counsellor
- Psychiatrist.

If patient is interested in reconstructive surgery:
- GP
- To supportive care services:
- Look Good Feel Better Workshops (phone: 1800 650 960 or **http:///www.lgfb.org.au)**

ALL PATIENTS SOME/FEW PATIENTS

Bathing/Dressing

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's family and social support structure. • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- Cancer Care Coordinator/Breast Care Nurse
- Social Worker
- Occupational Therapist
- Physiotherapist
- Community Nurse.

To supportive care services:
- for information regarding Home Help services, to one of the following:
  – Local Council
  – Community Health Centre.

ALL PATIENTS SOME/FEW PATIENTS

Breathing

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment. • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- GP
- Specialist Physician
- Cancer Care Coordinator/Breast Care Nurse
- Occupational Therapist
- Physiotherapist
- Psychologist
- Counsellor
- Palliative Care Service.

If an assessment for home oxygen is required, to one of the following:
- Community Nurse
- District Nurse.
- To supportive care services:
- Community Health Centre.

ALL PATIENTS SOME/FEW PATIENTS

Changes in urination – incontinence

ASSESSMENT

- Clarify the exact nature of the problem with the patient.
- Establish the patient's understanding of disease and treatment.
- Consider if the patient's risk factors are relevant to the problem.
- If onset of the problem is sudden – arrange immediate physical assessment and follow-up by the treating medical team.

ACTION

- Discuss the problem with the patient utilising the 'golden rules' of supportive communication.
- Provide verbal and/or written information.
- Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:

- Continence Nurse
- Continence Physiotherapist
- Cancer Care Coordinator/Breast Care Nurse.

To supportive care services:

- Community Health Centre.

ALL PATIENTS SOME/FEW PATIENTS

Changes in urination – urgency, frequency or pain

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment. • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- GP
- Cancer Care Coordinator/Breast Care Nurse.

ALL PATIENTS SOME/FEW PATIENTS

Constipation/Diarrhoea

ASSESSMENT	ACTION
Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment. • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- GP
- Cancer Care Coordinator/Breast Care Nurse
- Dietician
- Palliative Care Service (where appropriate).

ALL PATIENTS SOME/FEW PATIENTS

Constipation/Diarrhoea – bowel incontinence

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment. • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:

- GP
- Specialist Physician
- Continence Nurse
- Continence Physiotherapist
- Cancer Care Coordinator/Breast Care Nurse
- Stomal Therapist
- Physiotherapist
- Occupational Therapist.

To one of the following supportive care services:

- Community Health Centre.

ALL PATIENTS SOME/FEW PATIENTS

Eating – lack of appetite or weight loss

ASSESSMENT

- Clarify the exact nature of the problem with the patient.
- Establish the patient's understanding of disease and treatment.
- Consider if the patient's risk factors are relevant to the problem.
- Arrange immediate physical assessment and follow-up by the treating medical team.

ACTION

- Discuss the problem with the patient utilising the 'golden rules' of supportive communication.
- Provide verbal and/or written information.
- Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:

- Cancer Care Coordinator/Breast Care Nurse
- Dietician.

In the case of weight loss exceeding 5kg, to one of the following:

- Dietician
- GP
- Specialist Physician
- Palliative Care Service (where appropriate).

ALL PATIENTS SOME/FEW PATIENTS

Eating – difficulty chewing

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment. • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- Occupational Therapist
- Dietician
- Dentist
- Speech Therapist
- Cancer Care Coordinator/Breast Care Nurse
- GP.

ALL PATIENTS SOME/FEW PATIENTS

Eating – difficulty swallowing

ASSESSMENT

- Clarify the exact nature of the problem with the patient.
- Establish the patient's understanding of disease and treatment.
- Consider if the patient's risk factors are relevant to the problem.
- If onset of the problem is sudden – arrange immediate physical assessment and follow-up by the treating medical team.
- If there is a previous history of the problem, arrange assessment by a Speech Therapist.

ACTION

- Discuss the problem with the patient utilising the 'golden rules' of supportive communication.
- Provide verbal and/or written information.
- Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:

- Speech Therapist
- Dietician
- Occupational Therapist
- Physiotherapist
- Cancer Care Coordinator/Breast Care Nurse
- GP.

ALL PATIENTS SOME/FEW PATIENTS

Eating – taste changes/dry mouth

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment. • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- Cancer Care Coordinator/Breast Care Nurse
- Dietician
- GP.

ALL PATIENTS SOME/FEW PATIENTS

Fatigue or feeling tired

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment. • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- Cancer Care Coordinator/Breast Care Nurse
- Occupational Therapist
- Physiotherapist
- Dietician
- Psychologist
- Palliative Care Service (where appropriate).

ALL PATIENTS SOME/FEW PATIENTS

Feeling swollen – generalised or specific oedema

ASSESSMENT

- Clarify the exact nature of the problem with the patient.
- Establish the patient's understanding of disease and treatment.
- Consider if the patient's risk factors are relevant to the problem.
- Arrange immediate physical assessment and follow-up by the treating medical team.

ACTION

- Discuss the problem with the patient utilising the 'golden rules' of supportive communication.
- Provide verbal and/or written information.
- Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:

- GP
- Specialist Physician.

ALL PATIENTS SOME/FEW PATIENTS

Feeling swollen – lymphoedema

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment. • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:*

- Cancer Care Coordinator/Breast Care Nurse
- Occupational Therapist
- Physiotherapist
- Specialist Lymphoedema Nurse.

To one of the following supportive care services:

- Lymphoedema Support Group
- Lymphoedema Association of Victoria (ph. 1300 852 850 or **http://www.lav.org.au**)
- Lymphoedema Clinics.

* Only practitioners with specific training in complex decongestive physiotherapy should be referred to here. These practitioners are listed under the heading of 'lymphoedema specialists' in the Supportive Care Service Directory.

ALL PATIENTS SOME/FEW PATIENTS

Fevers

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment. • Consider if the patient's risk factors are relevant to the problem. • If patient is receiving or has recently received chemotherapy or radiotherapy treatment and fever is greater than 38°C, refer to nearest hospital emergency department OR the treating medical team immediately for assessment and follow- up; in accordance with local febrile neutropenia protocol. • If fevers have been a chronic problem, refer to the treating medical team for assessment and follow-up.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

ALL PATIENTS SOME/FEW PATIENTS

Getting around

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment. • Assess the family and social support structure. • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- Cancer Care Coordinator/Breast Care Nurse
- Social Worker
- Occupational Therapist
- Physiotherapist.

To supportive care services:
- For information regarding Home Help services, to one of the following:
  – Community Health Centre
  – Local Council.
- If patient is having continuing problems with balance and/or falls:
  – Mobility Clinic.

ALL PATIENTS SOME/FEW PATIENTS

Indigestion

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- Cancer Care Coordinator/Breast Care Nurse
- Dietician
- GP.

ALL PATIENTS SOME/FEW PATIENTS

Memory/Concentration

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

If the patient's Distress Thermometer score is less than 4 then the following referrals are suggestions to consider offering to the patient.
If the patient's Distress Thermometer score is greater than or equal to 4 then the following referrals are recommended.

To one of the following supportive care practitioners:
- GP
- Specialist Physician
- Cancer Care Coordinator/Breast Care Nurse
- Occupational Therapist
- Psychologist
- Palliative Care Service (where appropriate).

ALL PATIENTS SOME/FEW PATIENTS

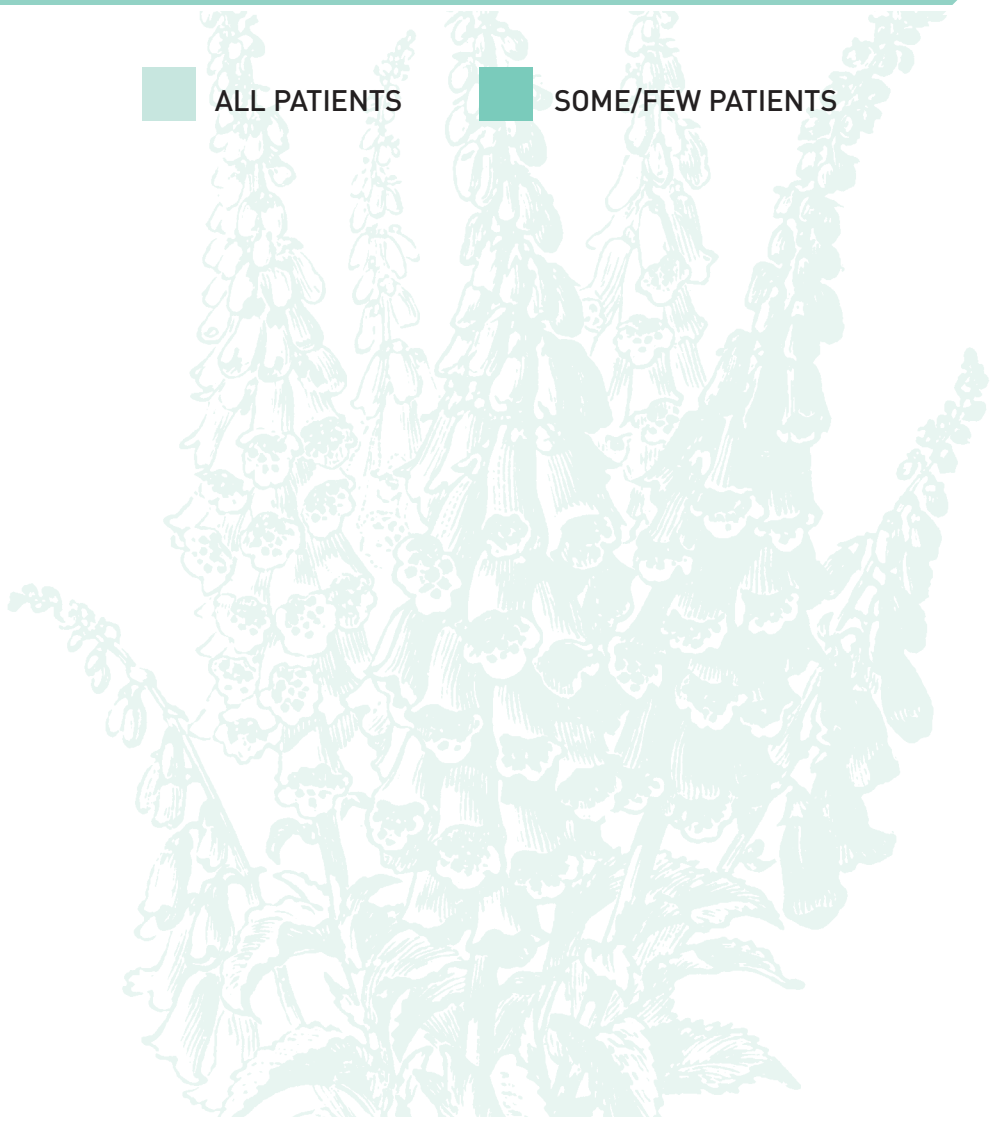
Mouth sores

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- GP
- Specialist Physician
- Dietician.

ALL PATIENTS SOME/FEW PATIENTS



Nausea/Vomiting

ASSESSMENT

- Clarify the exact nature of the problem with the patient.
- Establish the patient's understanding of disease and treatment
- Consider if the patient's risk factors are relevant to the problem.
- Arrange immediate physical assessment and follow-up by the treating medical team.

ACTION

- Discuss the problem with the patient utilising the 'golden rules' of supportive communication.
- Provide verbal and/or written information.
- Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:

- GP
- Specialist Physician
- Dietician
- Cancer Care Coordinator/Breast Care Nurse
- Palliative Care Service (where appropriate).

If the problem continues and causes significant distress following treatment,
to one of the following:

- Social Worker
- Psychologist
- Counsellor.

ALL PATIENTS SOME/FEW PATIENTS

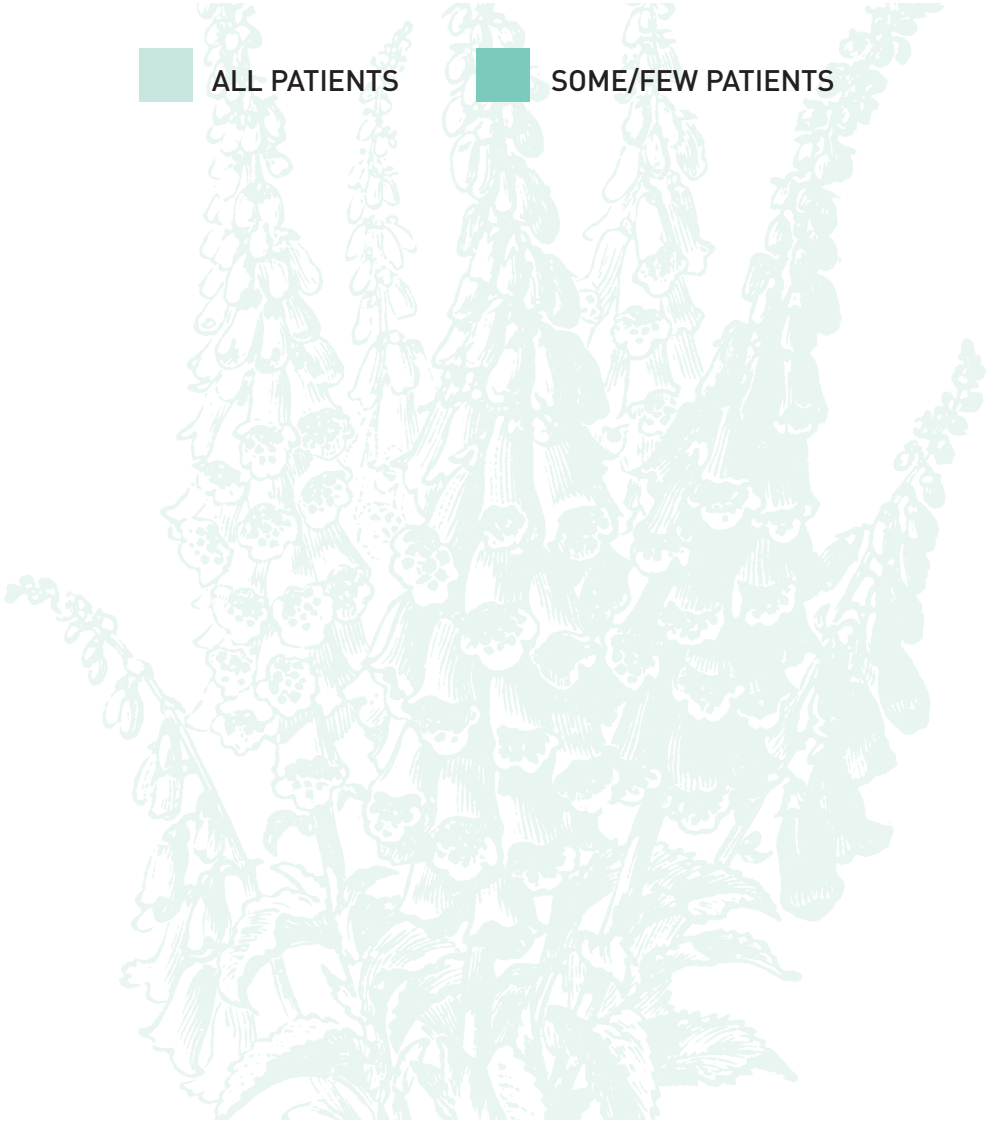
Nose dry/Congested

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment. • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- GP
- Pharmacist
- Cancer Care Coordinator/Breast Care Nurse.

ALL PATIENTS SOME/FEW PATIENTS



Pain

ASSESSMENT

- Clarify the exact nature of the problem with the patient.
- Establish the patient's understanding of disease and treatment.
- Consider if the patient's risk factors are relevant to the problem.
- Arrange immediate physical assessment and follow-up by the treating medical team.

ACTION

- Discuss the problem with the patient utilising the 'golden rules' of supportive communication.
- Provide verbal and/or written information.
- Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:

- GP
- Specialist Physician
- Cancer Care Coordinator/Breast Care Nurse
- Occupational Therapist
- Physiotherapist
- Psychologist
- Social Worker
- Palliative Care Service.

ALL PATIENTS SOME/FEW PATIENTS

Sexual

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease, treatment and sexuality. • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- Cancer Care Coordinator/Breast Care Nurse
- Social Worker
- Women's Health Nurse
- Sexual Health Counsellor.

For longer term problems or in the case of significant patient distress, to one of the following:
- Psychologist
- Counsellor
- Psychiatrist.

In the case of erectile problems:
- GP.

To supportive care services:
- Relationships Australia (ph. 1300 364 277 or **http://www.relationships.com.au**).

ALL PATIENTS SOME/FEW PATIENTS

Skin dry/Itchy

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- GP
- Pharmacist.

ALL PATIENTS SOME/FEW PATIENTS

Sleep

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:

- GP
- Specialist Physician
- Cancer Care Coordinator/Breast Care Nurse
- Occupational Therapist
- Social Worker
- Psychologist
- Counsellor
- Palliative Care Service (where appropriate).

ALL PATIENTS SOME/FEW PATIENTS

Tingling in hands/feet

ASSESSMENT	ACTION
• Clarify the exact nature of the problem with the patient. • Establish the patient's understanding of disease and treatment • Consider if the patient's risk factors are relevant to the problem. • Arrange immediate physical assessment and follow-up by the treating medical team.	• Discuss the problem with the patient utilising the 'golden rules' of supportive communication. • Provide verbal and/or written information. • Consider recommending the Cancer Helpline (ph. 13 11 20) for further verbal/written information.

REFERRAL

To one of the following supportive care practitioners:
- GP
- Specialist Physician
- Cancer Care Coordinator/Breast Care Nurse
- Physiotherapist.

ALL PATIENTS SOME/FEW PATIENTS

Vinca rosea

CHAPTER 9

Resources

The resources chapter of this Kit contains copies of:

- the Distress Thermometer and Problem List
- Instructions for clinicians in using the Kessler Psychological Distress Scale (K10)
- Kessler Psychological Distress Scale (K10)
- Risk Factor Checklist
- National Breast Cancer Centre & National Cancer Control Initiative (2005) *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer: A Summary Guide for Health Professionals*, Camperdown, NSW: National Breast Cancer Centre.
- References

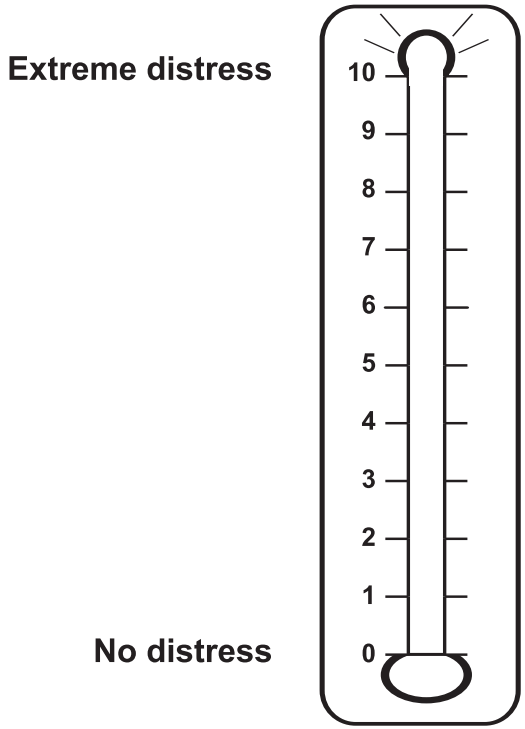
09

Distress Management

Guidelines Index,
Distress Management TOC,
Discussion, References

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.

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

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

YES	NO	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
❑	❑	Tingling in hands/feet

Other Problems: _____

_____

Instructions for clinicians in using the Kessler Psychological Distress Scale (K10)

* This cover sheet is for clinician use only. Do not give cover sheet to patients.

Background

The Kessler Psychological Distress Scale (K10) is a measure developed to detect psychological Distress. It can be self-completed by the patient in a pen and paper format or the questions read aloud to the patient. It has shown to be a valid measure of psychological distress when compared to other measures such as the SF-12 and the GHQ.[1] There is no cost associated with the use of this scale and it is seen to be an instrument which can be used in routine clinical practice. [1]

Scoring

The K10 is a 10-item scored scale with possible scores ranging from 10–50. Each question has a 5 point response scale: all of the time; most of the time; some of the time; a little of the time and none of the time. These response options are scored from 5 to 1 respectively as illustrated below.

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**
About how often did you feel tired out for no good reason?	5	4	3	2	1

Once the final score for a questionnaire has been completed scores should be interpreted as follows:

A score of < 16: indicates persons with no increased likelihood of anxiety or depressive disorder.

A score of 16–30: indicates persons with three times the population risk of having a current anxiety or depressive disorder.

A score of 31–50: indicates persons with ten times the population risk of having a current anxiety or depressive disorder.

1. Andrews, G., & Slade, T. (2001). Interpreting scores on the Kessler Psychological Distress Scale (K10). *Australian & New Zealand Journal of Public Health*. 25:494-497

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?					

Risk Factor Checklist

CHECKLIST OF RISK FACTORS FOR PSYCHOLOGICAL DISTRESS

If the patient is experiencing any of the following they may be at greater risk of developing emotional distress:

- ☐ Younger than 55 years
- ☐ Lack of social support (e.g. single, widowed, living alone)
- ☐ Caring for children or other dependants
- ☐ Financial problems
- ☐ Previous episodes of depression, anxiety or other psychiatric illness
- ☐ History of stressful life events
- ☐ High alcohol or drug intake
- ☐ Female

Clinical practice guidelines for the psychosocial care of adults with cancer

A summary guide for health professionals

This summary has been developed to assist health professionals in providing optimal evidence-based psychosocial care for adults with cancer, and their families. Prepared by the National Breast Cancer Centre and the National Cancer Control Initiative with funding from the Australian Government, Department of Health and Ageing, this summary provides an overview of the key emotional issues to consider when treating patients with cancer. It includes practical recommendations about specific interventions to promote adjustment, and detect and treat emotional disorders.

The complete guidelines can be downloaded from the National Health and Medical Research Council website:
http://www.nhmrc.gov.au/publications

NATIONAL BREAST CANCER CENTRE
Incorporating the Ovarian Cancer Program

NATIONAL CANCER CONTROL INITIATIVE

Psychosocial issues facing people with cancer

Emotional issues
Episodes of intense, unpleasant and distressing emotions (such as anger, feeling out of control, fear and helplessness) are normal responses to a cancer diagnosis.

Social issues
The extent to which a person with cancer feels supported affects their adjustment to the disease. Partners and children are also vulnerable to experiencing distress.

Psychological issues
Psychological issues requiring special treatment include:
- Depression or anxiety
- Traumatic symptoms
- Difficulties in relationships (including establishing new relationships)

Issues relating to self concept, body image and sexuality are common causes of distress, even affecting those whose cancer and/or treatment does not directly involve sexual organs.

Physical issues
Illness and treatment-related physical symptoms/side effects significantly affect quality of life and increase the risk of developing more serious levels of anxiety and depression. Issues to consider include:
- Fatigue
- Pain
- Fertility

Practical needs and financial issues
Concerns about finances can affect adjustment. Common financial and practical concerns include:
- Access to and cost of prostheses
- Travel and accommodation
- Access to home help and child care
- Access to and costs of supportive treatments and services

Survival issues
Issues often faced by cancer survivors include:
- Changes in life priorities
- Coping with residual disease or treatment side-effects
- Feeling a sense of being different in social situations
- Changes in employment and financial status
- Concern that the cancer could recur

Cancer survivors can experience difficulty in relationships if others fail to recognise the issues they face.

Towards end of life issues
The meaning attached to cancer will vary between patients. It is important to explore specific concerns, and remember that there is a strong link between physical symptoms and emotional adjustment.

Specific issues worth exploring:
- Social issues such as ability to maintain social relationships
- Existential and spiritual issues including confrontation with mortality and the meaning of life
- Concerns about impact on family and caregivers

Issues requiring special consideration
Issues such as culture, geography, sexual orientation and age need to be considered when dealing with cancer patients and their families.

Communication skills

The following recommendations are designed to enhance patient recall and understanding, improve patient satisfaction and reduce emotional distress.

Telling a person they have cancer, a recurrence or metastases

- Ensure the information is given in a quiet, private place and allow enough uninterrupted time
- Encourage a second person to be present if appropriate
- Assess the person's understanding of their condition and preference for information
- Briefly explain the process by which the diagnosis was reached
- Provide varied methods to convey the information, e.g. written materials, video
- Encourage the person to talk about the impact of the illness and offer appropriate support
- Clearly indicate that the person has the final decision regarding their care

Discussing prognosis

Patients require information about prognosis to make treatment decisions. Most patients want specific, honest information about prognosis. It is best to negotiate the timing, format and amount of detail they want.

Depending on the patient this might be:

- Specific, e.g. median survival
- General, e.g. 'I think your chances are good'
- Statistical, e.g. average time gained
- Exceptional cases, e.g. survival against the odds

Where possible, emphasise hopeful aspects appropriate to the person's situation.

Treatment decisions

Patients' treatment decisions will be influenced by factors other than the information given by health professionals, including:

- Demographic factors such as age, sex and culture
- Media, family and friends
- Body image concerns
- Personal beliefs about treatment

Discussing treatment options: providing information and choice

Patients vary in their need for information and their needs will change as treatment proceeds.

It is necessary to:

- Determine the patient's preference regarding the format, timing and amount of information they would like to receive
- Check the patient's desire for involvement in decision-making
- Provide information about the specific cancer, treatment options, the likelihood that treatment will be successful, possible adverse effects of treatment and practical issues
- Assess if the patient has received an adequate amount of information and has understood the nature, benefits and risks of the procedure or treatment
- Discuss the patient's interest in, and use of, alternative and complementary therapies

Preparing patients for potentially life-threatening procedures and treatment

Providing patients with information about the procedure they are about to undergo significantly reduces their emotional distress and improves their psychological and physical recovery.

The specific information demonstrated to assist includes:

- Procedural information – practical details about what will happen before, during and after a procedure
- Sensory information – what the person is likely to experience physically, feelings in response to treatment, and the amount and type of pain to be expected
- Coping strategies – relaxation strategies, education about exercises, information and available resources

Preparing patients for progression from curative to palliative treatment

The movement from curative to palliative treatment is emotionally difficult for both patients and health professionals.

Points to consider when managing the transition to palliative care include:

- Introduce palliative care workers early
- Explore the patient's understanding of palliative care and emphasise its role
- Incorporate all health professionals involved in the patient's care as a team
- Reassure the patient that they will receive optimal care and will not be abandoned

The following open-ended prompts may be helpful:

"What concerns you most about your illness?"

"What are your hopes, expectations and concerns about the future?"

Identifying and responding to psychosocial distress

For full details, refer to Chapter 4, page 101 of the complete guidelines.

Risk factors for psychosocial distress

The following checklist can be used to identify cancer patients at a higher risk of psychosocial distress.

Individual features	Disease/treatment factors
✓ Younger age ✓ Single, separated, divorced, widowed ✓ Living alone ✓ Having children younger than 21 years ✓ Economic adversity ✓ Poor marital functioning ✓ Past psychiatric treatment especially depression ✓ Cumulative stressful life events ✓ History of alcohol or other substance abuse ✓ Female gender ✓ Disease/treatment factors	✓ Advanced stages of disease ✓ Poorer prognosis ✓ More treatment side-effects ✓ Greater functional impairment and disease burden ✓ Lymphoedema ✓ Chronic pain ✓ Fatigue

Referral for specialised care

Improved physical function usually leads to improved psychosocial adjustment.

People with cancer who are experiencing significant psychological distress, significant physical impairment or severe physical symptoms can benefit from specialised interventions such as counselling, psychotherapy, physiotherapy, speech pathology, occupational therapy, plastic or reconstructive surgery, fertility services, nutritional advice or specialised pain services.

Referral for psychological intervention

If you or the patient are concerned about their emotional well-being, consider a referral for specialised psychosocial care and:

- Inform the patient about the benefits of individual and group counselling or psychotherapy and ask them if they have any questions
- Provide the patient with information about available individual or group counselling or psychotherapy services
- Ask the patient if they would like a referral and assistance arranging the appointment
- Consider endocrine assessment if a treatment-induced hormonal dysfunction is likely

Discussing referral for specialised psychosocial care

People may refuse referral because of shame or guilt that they are not coping or because of a lack of understanding of the benefits of psychosocial treatment.

It is helpful to find an acceptable opening by exploring physical issues like pain before moving to emotional issues. For example:

> *"I notice you said you are fine, but that you are not sleeping at night. That is an important problem. Perhaps we could help you with that."*

Remember that the timing of the referral may not be right and it may be necessary to try again at another time.

Reluctance to accept a referral for specialised psychosocial care can be reduced by explaining that psychosocial distress is common and no less worthy of treatment than a physical condition.

Psychosocial professionals should be part of the multidisciplinary treatment team and introduced as an available resource from the beginning.

It may be necessary to obtain advice about what is culturally appropriate for the particular patient and their family.

Establishing a referral network

Some practitioners, particularly those in private practice, may need to actively establish a referral network for psychosocial care.

Types of psychosocial interventions and treatments

Psychological therapies usually involve attention to the meaning of the person's experience, and can include structured problem-solving, cognitive techniques to cope with distress and relaxation training. Treatment can be helpful for individual patients, couples and families.

The usual drug treatments for anxiety and depression are generally well tolerated and effective in patients with cancer, however attention needs to be paid to:

- The risk of drug interactions
- Possible exacerbation of existing symptoms
- The side-effect profile of the drug

Exploring and responding to specific concerns

For full details, refer to Chapter 3, page 85 of the complete guidelines.

Ask the patient about their general psychological and emotional well-being, and explore any specific concerns or sources of distress.

Check on clinical issues including:

- Anxiety
- Depression
- Interpersonal functioning
- Coping with physical symptoms
- Body image and sexuality

The following prompts have been provided to assist you when raising specific concerns with people with cancer.

Body image concerns

"Cancer certainly changes how we feel about ourselves, and I would like to hear if you have particular concerns about the way the cancer and treatments might affect your body – how you look and how you feel?"

Sexual difficulties

"Cancer affects so many aspects of life including our body image and sexuality. Can you tell me a little about the way cancer has affected those issues for you?"

Interpersonal problems

"The diagnosis and treatment of cancer affects everyone in the family."

"I was wondering how things have been going for your family … How do you feel your partner and family are handling things?"

Physical symptoms or difficulties

"Having pain or other symptoms certainly makes a big difference to the way we feel emotionally as well. It is important to have a sense of how troublesome these symptoms are for you, and how much they are affecting your life."

Existential concerns

"It is enormously painful for any of us to contemplate our own death. Are there particular fears or issues troubling you about facing death and what that means?"

Psychological problems

"How do you think the cancer has affected you emotionally?"

Anxiety

"Anxiety is understandably common in people who have been treated for cancer. Would you say that anxiety is an issue for you?"

Depression

"Coping with cancer isn't just about physical issues, the emotional impact is important too."

This prompt could be followed with open-ended questions, such as:

"Could you tell me about what the cancer has meant emotionally?"

"Would you say that you had ever felt really sad or depressed?"

Asking about suicidal thoughts

"Sometimes people feel so overwhelmed by things that they feel everything is 'just too much'. Would you say you have ever felt like that?"

"Have you ever felt that you can't keep going?"

"Do you feel that things will ever get better?"

Traumatic symptoms

"How much do you feel that thoughts about the cancer intrude on your life?"

"Have you found that you are feeling jumpy and easily upset?"

The *Clinical practice guidelines for the psychosocial care of adults with cancer* were produced by the National Breast Cancer Centre and National Cancer Control Initiative with funding from the Australian Government and can be downloaded from the National Health and Medical Research Council website: http://www.nhmrc.gov.au/publications/pdf/cp90.pdf

References

1. National Breast Cancer Centre and National Cancer Control Initiative. (2003). **Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer.** Camperdown, NSW: National Breast Cancer Centre.
2. Carlson, L.E., & Bultz, B.D. (2003). Cancer distress screening: needs, models and methods. **Journal of Psychosomatic Research**, 55, 403-409.
3. Kruijver, I.P.M., Garssen, B., Visser, A.P., & Kuiper, A.J. (2006). Signalising psychosocial problems in cancer care: the structural use of a short psychosocial checklist during medical or nursing visits. **Patient Education and Counseling**, 62(2), 163-77.
4. Hedstrom, M., Skolin, I., & von Essen, L. (2004). Distressing and positive experiences and important aspects of care for adolescents treated for cancer. Adolescent and nurse perceptions. **European Journal of Oncology Nursing**, 8(1), 6-17.
5. Keller, M., Sommerfeldt, S., Fischer, C., Knight, L., Riesbeck, M., Lowe, B., Herfarth, C., & Lehnert, T. (2004). Recognition of distress and psychiatric morbidity in cancer patients: a multi-method approach. **Annals of Oncology**, 15(8),1243-1249.
6. Fallowfield, L. (2001). Participation of patients in decisions about treatment for cancer: desire for information is not the same as a desire to participate in decision making. **BMJ**, 323(7322), 1144.
7. Newell S., Sanson-Fisher, R.W., Girgis A., & Bonaventura, A. (1998). How well do medical oncologists' perceptions reflect their patients' reported physical and psychosocial problems? **Cancer**, 83(8), 1640–1651.
8. Detmar, S.B., Aaronson, N.K., Wever, L.D., Muller, M., Schornagel, J.H., & Wever, L.D. (2000). How are you feeling? Who wants to know? Patients' and oncologists' preferences of discussing health-related quality-of-life issues. **Journal of Clinical Oncology**, 18, 3295-3301.
9. Maguire P., Walsh S., Jeacock J., & Kingston, R. (1999). Physical and psychological needs of patients dying from colo-rectal cancer. **Palliative Medicine**, 13(1), 45-50.
10. Snyder, C., Dy, S., Hendricks, D., Brahmer, J., Carducci, M., Wolff, A., & Wu, A. (2007). Asking the right questions: investigating needs assessments and health-related quality-of-life questionnaires for use in oncology clinical practice. **Supportive Care in Cancer**, 15(9), 1075-1085.
11. National Comprehensive Cancer Network. (2008). **Distress Management Clinical Practice Guidelines**. Fort Washington, PA, USA: National Comprehensive Cancer Network.
12. National Comprehensive Cancer Network. (2003). Distress Management Clinical Practice Guidelines. **Journal of the National Comprehensive Cancer Network**, 1, 344-374.
13. Fitch, M. (2000). Supportive Care for Cancer Patients. **Hospital Quarterly**, 3(4), 39-46.
14. Jacobsen, P.B., Donovan, K.A., Trask, P.C., Fleishman, S.B., Zabora, J., Baker, F., & Holland, J.C. (2005). Screening for psychological distress in ambulatory cancer patient: a multi-centre trial of the Distress Thermometer. **Cancer**, 103(7),1494-1502.
15. Hoffman, B.M., Zevon, M.A., Darrigo, M.C., & Cecchini, T.B. (2004). Screening for distress in cancer patients: the NCCN rapid screening measure. **Psycho-Oncology**, 13,792-799.
16. Ransom, S., Jacobsen, P.B., & Booth-Jones, M. (2006). Validation of the Distress Thermometer with bone marrow transplant patients. **Psycho-Oncology**, 15, 604-612.
17. Au, G., Pryor, A., Griffin, A., McCarthy, C., Dall'Armi, L., Wilcox, N., Cassar, S., Delaney, G., Moylan, E., & Barton, M. (2006). Putting a model of psycho-social service for cancer patients into practice in an oncology centre – The Liverpool Cancer Therapy Centres' experience. **Asia Pacific Journal of Clinical Oncology**, 2(S2), A10.

18. Andrews, G., & Slade, T. (2001). Interpreting scores on the Kessler Psychological Distress Scale (K10). **Australian and New Zealand Journal of Public Health**, 25, 494-497.

19. Curry, C., Cossich, T., Matthews, J.P., Beresford, J., & McLachlan, S.A. (2002). Uptake of psychosocial referrals in an outpatient cancer setting: improving service accessibility via the referral process. **Supportive Care in Cancer**, 10, 549-555.

20. Arora, N. (2003). Interacting with cancer patients: the significance of physicians' communication behaviour. **Social Science and Medicine,** 57, 791-806.

21. Maguire, P. & Pitceathly, C. (2003). Improving the psychological care of cancer patients and their relatives. The role of specialist nurses. **Journal of Psychosomatic Research**, 55, 469 – 474.

22. Towers, R. (2007). Providing psychological support for patients with cancer. **Nursing Standard,** 22(12), 50-57.

23. Mitchell, A., Kaar, S., Coggan, C., & Herdman, J. (2008). Acceptability of common screening methods used to detect distress and related mood disorders – preferences of cancer specialists and non-specialists. **Psycho-Oncology,** 17, 226-236.

24. Mohan, S., Wilkes, L.M., Ogunsiji, O., & Walker, A. (2005). Caring for patients with cancer in non-specialist wards: the nurse experience. **European Journal of Cancer Care**, 14, 256-263.

25. Schofield, P., Carey, M., Bonevski, B., & Sanson-Fisher, R. (2006). Barriers to the provision of evidence-based psychosocial care in oncology. **Psycho-Oncology**, 15, 863-872.

26. Botti, M., Endacott, R., Watts, R., Cairns, J., Lewis, K., & Kenny, A. (2006). Barriers in providing psychosocial support for patients with cancer. **Cancer Nursing**, 29(4), 309-316.

27. Willard, C., & Luker, K. (2005). Supportive care in the cancer setting: rhetoric or reality? **Palliative Medicine**, 19, 328-333.

28. Vitek, L., Quinn Rosenweig, M., & Stollings, S. (2007). Distress in patients with cancer: definition, assessment and suggested interventions. **Clinical Journal of Oncology Nursing**, 11(3), 413-418.

29. Turner, J., Clavarino, A., Yates, P., Hargraves, M., Connors, V., & Hausmann, S. (2007). Oncology nurses' perceptions of their supportive care for parents with advanced cancer: challenges and educational needs. **Psycho-Oncology,** 16, 149-157.

30. Kenny, A., Endacott, R., Botti, M., & Watts, R. (2007). Emotional toil: psychosocial care in rural settings for patients with cancer. **Journal of Advanced Nursing**, 60(6), 663-672.

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