

Psychosocial Care Referral Checklist

FOR PATIENTS WITH CANCER

AIM

National Breast and Ovarian Cancer Centre's *Psychosocial care referral checklist* provides a simple way for health professionals to identify patients at higher risk of psychosocial distress who may benefit from additional assessment and appropriate referral for psychosocial care.

The purpose of the *Psychosocial care referral checklist* is not to diagnose psychiatric disorders.

Explanatory notes

National Breast and Ovarian Cancer Centre has developed explanatory notes to assist health professionals in completing the *Psychosocial care referral checklist*.

How to use the checklist

The *Psychosocial care referral checklist* is divided into two sections. The first section is to be completed at initial presentation and the second at follow-up. Any information identified after initial presentation can be recorded at follow-up.

Ideally the *Psychosocial care referral checklist* is to be completed in consultation with the patient, but can be completed post-consultation.

Patient supportive care needs can change with time. It is important to monitor each patient and make appropriate referrals for further assessment and support as necessary.

National Comprehensive Cancer Network (NCCN) Distress thermometer screening tool

It is recommended that the NCCN *Distress thermometer screening tool* be used in conjunction with the *Psychosocial care referral checklist*.

The NCCN *Distress thermometer screening tool* is designed to be completed by the patient to support the information recorded on the checklist. By completing the screening tool patients will be able to identify their present level of distress and any concerns they have that may be impacting on their distress.

EXPLANATORY NOTES

The *Psychosocial care referral checklist* is divided into two sections. The first section is to be completed at initial presentation and the second at follow-up. Disease and treatment factors will change with time. Information may not be available during the initial treatment planning meeting – known or anticipated factors should be recorded. Any information identified after initial presentation can be recorded at follow-up. Ideally the *Psychosocial care referral checklist* is to be completed in consultation with the patient, but can be completed post-consultation.

The items listed on the checklist are those identified in the *Clinical practice guidelines for the psychosocial care of adults with cancer*¹ as being important indicators of psychosocial distress for a patient with cancer. When considering the psychosocial or support needs of a patient it is important to include an appraisal of individual patient circumstances, including past experiences of bereavement or loss and family history of cancer or mental health problems, which can impact on a patient's coping mechanisms.

The following information and prompts have been provided to assist you in completing the *Psychosocial care referral checklist*.

PATIENT CHARACTERISTICS

Younger than 55 years?

Research shows that younger patients are more vulnerable to emotional distress and are more likely to experience poorer adjustment and show more symptoms of depression. This may be due to concerns about the impact of cancer on their partner and children, including practical issues such as income and childcare, the untimely nature of the diagnosis, and a sense of isolation. There is an accepted definition of 'young' as it applies to cancer patients. For the purpose of this checklist younger patients are defined as those younger than 55 years. In general, the younger the age of the patient, the higher the risk of distress.

Single/separated/divorced/widowed?

Being single has been associated with an increased risk of psychosocial problems. Single patients may be more likely to experience emotional distress associated with establishing new relationships, a sense of isolation and inadequate support, and fears about disclosing their cancer.

Lives alone/marital/family problems/lack of social support?

Patients who perceive they have poor social support are more likely to experience greater psychosocial distress. The following open-ended questions may be helpful in eliciting the extent to which social support issues are relevant for the patient:

"Who do you feel you have helping you at the moment?"

"Are you getting the emotional support you feel you need?"

"Are family and friends giving the sort of help that you would like?"

"Do you ever feel that you are having to cope with the emotional side of things pretty much on your own?"

¹ National Breast Cancer Centre and National Cancer Control Initiative. 2003, *Clinical practice guidelines for the psychosocial care of adults with cancer*. National Breast Cancer Centre, Camperdown, NSW.

Children younger than 21 years?

Patients with children must cope not only with the effects of cancer, but also with concerns about the emotional impact on their family. In addition parents with children have practical demands on their time and concerns about issues of childcare, which can have a major impact on their health. There is evidence that having children younger than 21 years places the person with cancer at increased risk of psychosocial distress, and this is especially so if the parent feels guilty or worried about the impact of the cancer on their family. These issues can be explored using questions such as:

“What sort of impact do you think cancer has had on your family?”

“Do you have any concerns about the emotional impact on your children?”

“Are there any practical issues affecting how your family is coping?”

Financial concerns/issues?

Patients with cancer may incur considerable costs as a result of cancer treatments, as well as the financial burden resulting from loss of income. Financial concerns may affect their treatment and well-being. Health professionals can explore financial concerns by asking questions like:

“Cancer treatment and care can be expensive for you and your family. Is finance a concern for you?”

“Do you feel that the cancer has put pressure on you financially? How much do you worry about that?”

Previous episodes of depression/psychiatric illness/mental health problems?

Any person who has experienced depression is at risk of experiencing further episodes. Experiences of loss, such as becoming unemployed, can precipitate further episodes and the diagnosis of cancer is also a common precipitant for episodes of depression. In general, if a person has an extensive history of depression or psychiatric illness they are at increased risk of psychosocial distress following the diagnosis and treatment of cancer.

These issues can be explored using questions such as:

“It is important to ensure that we have all of the information for us to provide the best possible care. One of the areas we need to be aware of is any emotional issues you have faced in the past.”

“Have you ever had counselling or seen a psychologist or psychiatrist? Can you tell me some more about that?”

“Problems like anxiety and depression are common in the community. Have you ever been affected by problems like that?”

History of stressful life events?

Stressful life events and patient’s coping styles can impact on their current psychosocial distress. How patients have coped in the past during stressful times in their life can predict their ability/inability to cope with their current diagnosis and the potential stress associated with cancer and treatments. In addition, there is evidence that multiple current stressors can add to pose a cumulative burden and undermine coping. Because the individual events are not enormous, patients may not reveal the extent of the life events with which they are coping, and specific questions about this are necessary.

Explore the patient’s coping mechanisms by asking open-ended questions, such as:

“Can you tell me about past stressful experiences in your life and how they have affected you?”

“People cope with stressful situations in different ways. Some people seek out information to help them handle the situation; whilst some people avoid thinking about it. What strategies have you used in the past?”

Explore current life stressors by general questions such as:

“Even though individual problems might be small, if there are enough of them they can add up to have a large effect on anyone. Can you tell me if there are a lot of things happening in your life apart from the cancer at present?”

“Are there things happening in your life that complicate how you are able to deal with the cancer?”

“Do you feel that there are issues other than the cancer that are weighing you down?”

Problems related to drugs or alcohol?

Health professionals commonly omit to elicit a history of alcohol ingestion, and this represents a significant lost opportunity for preventive health interventions, particularly in patients with cancer. Previous or current high alcohol intake or drug use is associated with increased psychosocial distress in patients with cancer. It is important to approach this topic sensitively, and to explain to your patient that the questions you are asking are to help you provide the best possible care. In general, patients will underestimate their alcohol consumption. Asking about the amount of alcohol intake by giving ‘top-down’ examples is a useful technique. Some suggested approaches include:

“Do you ever drink alcohol?”

“On average, how many times a week would you drink alcohol? Are there any days in the week when you don’t have a drink?”

“On average, how many drinks would you have most days?” If the patient is not specific, could ask: *“How often would you have more than 10 glasses of wine per day?”* or similar and adjust according to patient response.

“Can you tell me if you have taken drugs in a larger dose than prescribed?”

“There are certain drugs that are commonly used for anxiety or stress such as benzodiazepines, diazepam, or paroxetine hydrochloride. These drugs can affect people’s health. Have you ever taken one of these drugs for more than a few weeks at a time?”

“Can you tell me if you have ever used any drugs other than prescribed?” Most patients who have used illicit substances will respond openly if the question is asked directly.

“Are there times when you think that alcohol (or drugs) might have affected your health?”

“Have you ever worried about drinking (or taking drugs) and tried to cut down?”

“Have any drugs or medications ever been a problem for you?”

Female?

A number of studies have examined the incidence of psychosocial distress for women with cancer. They have shown that women are at higher risk of experiencing anxiety and/or depression, sexual difficulties, and other problems related to body image.

DISEASE/TREATMENT FACTORS

The nature and severity of psychosocial distress can vary over time; hence it is worthwhile to elicit and record emotional concerns regularly during treatment. Each patient will experience a range of practical, psychosocial, and emotional challenges as a result of their cancer diagnosis and treatment-related adverse effects.

Initial diagnosis and diagnosis of recurrence are times of increased psychosocial vulnerability and active assessment of coping is important at these times.

Patients who are diagnosed with cancer with a poor prognosis are especially vulnerable to psychosocial distress. Coping with grief and concerns associated with disease progression may be very difficult for patients. Many patients report that distress increases as the cancer progresses.

Distress caused by physical symptoms?

People with cancer can experience distress caused by a number of physical symptoms. Research shows that when physical symptoms are less well controlled, psychosocial distress increases and physical and social functioning decreases. Patients may not reveal symptoms if they feel that they are to be expected, or they feel that nothing can be done to help.

The following prompts may be useful:

“Sometimes the treatment can be hard going and side effects can be tough. How would you say the treatment is going for you?”

“How have physical symptoms impacted on your life and ability to do the things that matter to you?”

“Are there any physical symptoms you have experienced that have been particularly worrying or upsetting?”

Distress caused by disease burden?

It is important to monitor the emotional and psychosocial impact of the cancer on patients. Many patients, although not experiencing severe difficulties with one specific aspect of their cancer, may experience minor difficulties across a number of areas. While each problem in itself may not be severe, the cumulative effect may significantly affect their psychosocial well-being. The following questions can be used to frame questions which elicit the patient's concerns:

“How are things going overall?”

“Many people who have been treated for cancer feel that their outlook on life has changed. Changes to your body and how it functions mean having to make some adjustments. Are there any particular issues that concern you?”

“Even though symptoms might be small themselves, having a number of symptoms from the cancer can make life difficult. Would you say that your life is affected by ongoing symptoms?”

Impaired ability to perform daily activities?

Cancer symptoms and side effects of treatment can impact on a patient's ability to perform everyday tasks. The following questions can be used to determine the emotional impact of cancer on the patient's everyday life.

“Experiencing cancer symptoms can affect the way we feel emotionally. It is important to have a sense of whether symptoms are troubling you, and whether they are affecting your day-to-day life.”

“How do you think cancer is affecting your ability to perform everyday activities?”

“Is the cancer making doing things much more of an effort for you?”

Lymphoedema?

Lymphoedema can be debilitating, impairing a patient's ability to perform ordinary tasks and resulting in increased psychosocial distress. It is important to enquire about the presence of limb or other swelling. The degree to which lymphoedema causes limitation in function is a more important determinant of psychosocial risk than the extent of the lymphoedema.

Chronic pain?

Enquiring about pain is part of routine clinical care. Pain has an emotional dimension and for patients with cancer, the interpretation of the meaning of pain may influence the way the patient deals with it. It is important to assess the degree of psychosocial distress resulting from physical symptoms. Try an approach such as:

"Having pain can affect how we feel mentally and emotionally. Can you tell me how your pain is affecting you?"

Fatigue?

Many patients fail to discuss fatigue with their treating team because of the belief that nothing can be done to help. Signs of fatigue may include tired eyes, whole body tiredness, inability to concentrate, weakness, boredom or lack of motivation, sleepiness, and increased irritability. When discussing fatigue with your patient the following comments may be helpful:

"Fatigue is a common complaint of patients with cancer and it can sometimes interfere with everyday life. Since being diagnosed with cancer, how have your energy levels been?"

"How have your energy levels been affecting you?"

"We know that fatigue can last well after treatment has been completed. Is fatigue having an impact on your life?"

THE NATIONAL COMPREHENSIVE CANCER NETWORK (NCCN) DISTRESS THERMOMETER SCREENING TOOL²

The NCCN *Distress thermometer screening tool* is designed to be filled out by the patient to support the information recorded on the *Psychosocial care referral checklist*. By completing the screening tool patients will be able to identify their present level of distress and any concerns they have which may be impacting on their distress. Patients should be screened for distress at initial presentation, at follow-up and at other times of significant change to their disease and/or treatment status.

REFERRAL INFORMATION AND OPTIONS

This *Psychosocial care referral checklist* is intended to highlight the extent of psychosocial and supportive care needed by patients being treated for cancer in your centre or unit. In some circumstances, there may be a need to think flexibly about who can provide such care.

Before using this checklist it is important to consider:

- What specialist expertise in psychological and/or supportive interventions are available at your local cancer centre or unit? If specialist services are not available at you local centre, who else could you refer to? It may be useful to discuss the patient's needs with their GP.
- Are there local cancer support groups that could help?

Before making a referral it is important to consider:

- Does this patient want to be referred to specialist services at this time?
- Does this patient prefer individual or group-based psychosocial intervention?

² The NCCN 1. 2005 *Distress Management Guidelines*. *The Complete Library of NCCN Clinical Practice Guidelines in Oncology* (CD-Rom) Jenkintown, Pennsylvania.

The following table outlines possible service providers with demonstrated effectiveness for specific problems experienced by people with cancer. It will be useful for services to establish a referral network and develop a contact list for possible psychosocial care referrals.

Table 1: A guide to appropriate referral for specific problems

Problem	Discipline to refer to
Depression/psychiatric illness/mental health problems	Clinical psychologist/Psychiatrist
Interpersonal problems	Clinical psychologist/Psychiatrist/Social worker
Financial concerns	Social worker/Welfare worker
High alcohol intake/drug use	Clinical psychologist/Psychiatrist/Drug & alcohol counsellor
Distress caused by physical symptoms	Clinical psychologist/Psychiatrist/Social worker
Distress caused by disease burden	Clinical psychologist/Psychiatrist
Impaired ability to perform daily tasks	Occupational therapist/Support services/ Physiotherapist
Lymphoedema	Physiotherapist/Occupational therapist
Chronic pain	Specialist pain services/Clinical psychologist/ Psychiatrist
Fatigue	Occupational therapist/Dietitian

Adapted from National Breast Cancer Centre and National Cancer Control Initiative, 2003. *Clinical practice guidelines for the psychosocial care of adults with cancer*. National Breast Cancer Centre, Camperdown, NSW: Pg, 103.