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 psychosocial issues requiring special treatment and of the complete guidelines.

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

Psychosocial issues

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.

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

- “Have you found that you are feeling jumpy and easily upset?”
- “Could you tell me about what the cancer has meant to you?”
- “How much do you feel that thoughts about the cancer intrude on your life?”
- “Have you felt that you can’t keep going?”
- “Do you feel that things will ever get better?”

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?”

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

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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:
“Why are you here today?”
“Does the pain bother you?”
“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
- Younger age
- Single, separated, divorced, widowed
- Living alone
- Having children younger than 21 years
- Economic adversity
- Poor mental functioning
- Past psychiatric treatment especially depression
- Cumulative stressful life events
- History of alcohol or other substance abuse
- Female gender
- Disease/treatment factors

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.

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- Disease/treatment factors
- Age
- Sex
- Culture
- History of alcohol or other substance abuse
- Living alone
- Single, separated, divorced, widowed
- Emotional stability
- 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
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:
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• Depression
• Interpersonal functioning
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Sexual difficulties
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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?”

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