



Best Practice Guideline  
for the Management of  
**Cancer-Related  
Distress in Adults**

Full Version

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## Executive Summary and Recommendations

Individuals affected by cancer face many psychosocial, physical, practical, and financial challenges throughout their cancer experience (1). Evidence indicates that clinically significant levels of cancer-related distress are experienced by at least 35%-45% of those affected by cancer (2-4). Risk factors for cancer-related distress include (2,5-8):

- Pre-existing psychological problems or history of substance abuse
- Advanced illness, poor prognosis, greater disease burden and physical disability
- Poorly controlled symptoms (e.g., pain)
- Lower levels of social support
- Other concurrent psychosocial/life stressors (e.g., young children, financial stress, family concerns)
- Communication difficulties (e.g., language, literacy, interactions with health care team)
- Existential/spiritual issues
- Younger age
- Female gender

Supporting individuals affected by cancer requires an interprofessional health care team, effective communication, a process for identifying when clinically significant levels of cancer-related distress are present and an awareness of the individual's unique needs or challenges so that appropriate interventions may be offered. The identification and management of cancer-related distress is an integral part of cancer care (7).

The results from the Ambulatory Oncology Patient Experience Survey conducted for *Cancer Care Nova Scotia* by NRC-Picker Canada highlights the need to focus on improving patient experience in regard to emotional and psychosocial care (9). These findings support the development of this guideline focused on the identification and management of cancer-related distress to improve the experience of adults with cancer. The unique perspective of this guideline is to address cancer-related distress in its broadest form, from common normal feelings to problems with anxiety and depression that can become disabling (See 1.10.4). Use of the Screening for Distress Tool (Table 4.4) and the therapeutic conversation, the Screening for Cancer-Related Distress Algorithm (Figure 4.2) and the Cancer-Related Distress Management Referral Pathway (Figure 5.3) facilitate a person-centred approach to care. Through this process the person's specific circumstances are considered and assistance is offered for all types of cancer-related distress (Figure 5.3).

The purpose of this guideline is to provide guidance and assist health care providers (HCPs) to screen, identify and manage cancer-related distress experienced by individuals diagnosed with cancer and their families. The health questions addressed in this guideline focus on: the type of psychosocial health care persons affected by cancer need (Chapters 2, 3, 4, 5, 6); the nature of cancer-related distress and associated risk factors (Chapters 2, 4, 6); the process of screening for cancer-related distress (Chapter 4 (e.g., when to screen, recommended screening tool, and use of therapeutic conversation)); and management of cancer-related distress (Chapter 4 and 5).

This guideline is based on:

- 1) a trial of the ADAPTE methodology with The Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer as developed and published in 2003, by the National Breast Cancer Centre (NBCC) (Australia) and the National Cancer Control Initiative (NCCI) (10);
- 2) comprehensive evidence update and systematic search of the published literature ;
- 3) Delphi process with health care providers (HCPs) and cancer patients and families;
- 4) a trial of the algorithms through the Screening for Distress Initiative in Nova Scotia;
- 5) expert consensus in regard to the recommendations (including levels and strength of evidence);

This guideline establishes a minimum standard of psychosocial care for screening and management of cancer-related distress, such that all adults diagnosed with cancer will be screened for distress throughout the cancer continuum and offered appropriate management and care. The guideline and quick reference version provide a valuable clinical resource to HCPs working with people affected by cancer and dealing with cancer-related distress. Implementation of the guideline has the potential to facilitate practice change, and to improve patient experience and patient care.

The recommendations stated below apply to all adults affected by cancer unless otherwise noted and relate to screening for and management of cancer-related distress. The majority of the recommendations are supported by Level I or Level II evidence (see section 1.11.2) and are rated as Strong Recommendations (see section 1.12).

| <b>Recommendations</b>   |  |
|--|--|
| <p>1. Cancer services will ensure that persons affected by cancer and health care providers (HCPs) understand that identification and management of cancer-related distress is an integral part of cancer care (Section 2.1)</p> <p>Level I* (2,10)<br/>Level III-3* (7)</p>   |  |
| <p>2. Psychosocial health services focused on meeting the individual's physical, social, emotional, nutritional, informational, psychological, spiritual, and practical needs is recommended throughout the cancer experience and into survivorship (Section 2.1)</p> <p>Level 1* (7)<br/>Level II* (10-12)</p>  |  |
| <p>3. It is recommended that adults diagnosed with cancer be screened for cancer-related distress by HCPs (Section 4.3).</p> <p>Level I (13)<br/>Level II (11)<br/>Level III-3 (7,12)</p>  |  |
| <p>4. Screening for cancer-related distress should occur within two months following diagnosis. Re-screening should occur at critical times and times of transition throughout the cancer continuum. (Section 4.3).</p> <p>Level III-3 (7,12)</p>  |  |
| <p>5. Screening will be done with the Screening for Distress Tool (adapted for Nova Scotia). The tool consists of (Refer to Section 4.4 and Table 4.4) :</p> <ul style="list-style-type: none"> <li>• The Edmonton Symptom Assessment System-revised (ESAS-r) (14,15);</li> <li>• The Canadian Problem Checklist (CPC) (16);</li> <li>• The Distress Thermometer® (DT) (7,12).</li> </ul> <p>Level I** (13)<br/>Level II** (7,11,12,16)<br/>Level III-3** (16)<br/>**The references cited relate to specific parts of the Screening for Distress Tool (i.e., DT, ESAS-r, CPC).</p> |  |
| <p>6. Adults with one or more distress scores on the ESAS-r and/or DT of 8 or greater are in high distress and require an urgent decision by the health care team to either manage the distress directly or make a referral to an appropriate health care specialist for specialized assessment and care. (Section 4.6)</p> <p>Level I*** (2,12)<br/>Level II*** (11)<br/>Level III-1*** (12)</p>  |  |

| <b>Recommendations</b>  |  |
|---|--|
| <p>7. Individuals in moderate distress with one or more scores on the ESAS-r and/or DT between 4 and 7 may be managed by the health care team or referred to an appropriate health care specialist for specialized assessment and care. (Section 4.6 and Figure 4.2)</p> <p style="padding-left: 40px;">Level I *** (2,12)<br/>Level II*** (11)<br/>Level III-1*** (2,12)</p>                                 |  |
| <p>8. Individuals in mild distress, with all scores on the ESAS-r and/or DT less than 4, can be managed by the health care team. If distress does not improve, referral to an appropriate health care specialist for specialized assessment and care should be considered. (Section 4.6 and Figure 4.2 )</p> <p style="padding-left: 40px;">Level I*** (2)<br/>Level III-1*** (2)<br/>Level III-3*** (17)</p> |  |
| <p>9. When the adult affected by cancer needs specialized care (i.e. assessment and/or treatment), referral to the health care specialist with expertise relevant to the identified distress problem is recommended. (Section 5.1 and Figure 5.3)</p> <p style="padding-left: 40px;">Level I (2,7)<br/>Level II (11)</p>  |  |
| <p>10. Health care providers should provide information on available resources tailored to the person’s specific needs and situation. (Section 5.7)</p> <p style="padding-left: 40px;">Level I (10)<br/>Level II (10,18)<br/>Level IV (7)</p>   |  |
| <p>11. Health care providers screening individuals for cancer-related distress must address the needs of people from diverse communities. (Section 6.11)</p> <p style="padding-left: 40px;">Level III (19)<br/>Level IV (20)</p>  |  |
| <p>12. Health care providers seeing persons for management of cancer-related distress should provide service in an inclusive and sensitive manner. (Section 6.11)</p> <p style="padding-left: 40px;">Level III (19)<br/>Level IV (20,21)</p>  |  |

## Chapter 1 - Introduction and Background

### 1.1 Practice Guidelines

Practice guidelines are intended to provide guidance and assist health care providers (HCPs) with decisions throughout the spectrum of the cancer experience. This guideline is intended to assist HCPs to screen, identify and respond to adults with cancer-related distress. Management of cancer-related distress should be tailored to meet the unique needs of adults and their families and in accordance with evidence-based care (22).

Guidelines should not replace specific health care decisions for adults affected by cancer, and do not substitute for the shared person-centred decisions between the person affected by cancer and his/her health-care professional. Guidelines do provide evidence-based information, expert consensus-based recommendations for similar problems, and a context for individual decisions.

Development of this guideline is described in Appendix I. The evidence-based literature for this guideline is fully described in Appendix II, available on request or at the *Cancer Care Nova Scotia (CCNS)* website. This guideline will be reviewed in three years from publication date or earlier if important new evidence becomes available. Current versions of this guideline will be available on the *CCNS* website ([www.cancercare.ns.ca](http://www.cancercare.ns.ca))

### 1.2 Target Population

This clinical practice guideline applies to adults with cancer who may experience distress at some point during the cancer continuum (i.e., from the time of diagnosis through to survivorship and death and dying).

### 1.3 Target Users

This guideline is primarily intended for HCPs, working in a variety of clinical and care settings. For front-line HCPs, the quick reference version of the guideline will be a practical clinical guide for screening and management of distress. Clinical educators, researchers and administrators will also benefit from this guideline.

Patients, families and members of the public are referred to relevant materials written for lay people, through the Canadian Cancer Society [www.cancer.ca](http://www.cancer.ca) or 1 888 939-3333 and provincial cancer care organizations such as *Cancer Care Nova Scotia (CCNS)* ([www.cancercare.ns.ca](http://www.cancercare.ns.ca)).

### 1.4 Structure of the Guideline

This guideline is based on the patient's experience of cancer-related distress across the cancer continuum which includes the time of diagnosis, through treatment to survivorship and palliation. The focus is on the generic experience of cancer rather than specific cancer sites. Cancer site specific issues are noted in the guideline to describe specific patient experiences.

The recommendations that are described in the executive summary are embedded throughout the text as specific content is presented. In Chapter 1 relevant background, terminology, scope and the development of the guideline are presented. Chapter 2 focuses on cancer-related distress and the many challenges of cancer experienced by adults such as psychosocial, physical, informational, practical, end of life and survivorship. Principles of care and communication skills that support patients throughout the cancer continuum are described in Chapter 3. In Chapter 4 the focus is on the screening process including the Screening for Distress Tool (adapted for Nova Scotia) and the Screening for Cancer-Related Distress Algorithm including mild, moderate and high distress. Specialized care for the management of cancer-related distress based on best available evidence is provided in Chapter 5. The Cancer-Related Distress Management Referral Pathway is included in Chapter 5. The final chapter highlights some barriers, concerns and considerations relevant to adults with cancer from diverse communities.

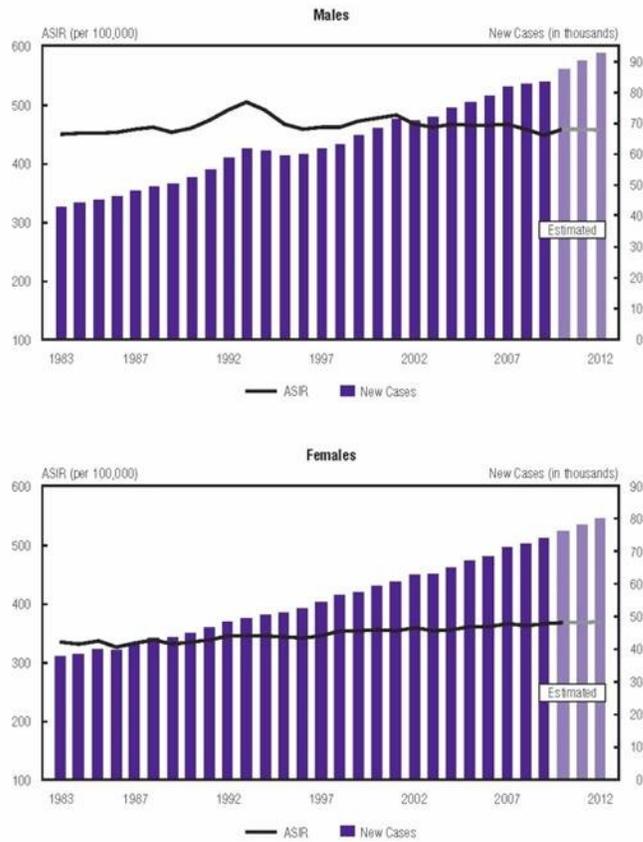
## **1.5 Background**

Cancer is a leading cause of morbidity and mortality in our society and most individuals diagnosed with cancer will experience cancer-related distress at some time during their cancer experience. In Canada, it is estimated there will be 186,400 new cases and 75,700 deaths from cancer in 2012 (23). Men outnumber women for both new cases and deaths (Figure 1.1). The numbers of new cases continue to rise steadily as the Canadian population increases and ages, with age being a primary factor. These numbers reflect the burden of cancer in Canada (23-25). It is important to note that “mortality is declining for males in most age groups and for females under 70” (23). In Nova Scotia, 28,100 people were diagnosed with invasive cancer between 2005 and 2009 (26). On average, approximately 5,500 cases were registered annually (27). More than two-thirds of all new invasive cancer cases in Nova Scotians occur after the age of 60 years (24,28) and approximately 5% more males than females were diagnosed annually in the 2005 to 2009 period (26). Slightly more than 31,000 people were living in Nova Scotia in 2010 with an invasive cancer diagnosed in the previous 15 years. Individuals diagnosed with breast and prostate cancer account for the highest proportions in this group, representing approximately 2% of the total population of Nova Scotia (26). According to 2012 estimates Atlantic Canada and Quebec, generally have higher incidence and mortality rates (23).

**Figure 1.1**

Canadian Cancer Society's Steering Committee on Cancer Statistics: Canadian Cancer Statistics (2012) (23)

**New Cases and Age-Standardized Incidence Rates (ASIRs) for All Cancers, Canada, 1983–2012**



**Note:** "All cancers" excludes non-melanoma skin cancer (basal and squamous). Rates are age-standardized to the 1991 Canadian population. Actual incidence data were available to 2009 except for Quebec (2007). Please refer to *Appendix II: Data sources and methods* for further details.

**Analysis by:** Chronic Disease Surveillance and Monitoring Division, CCDPC, Public Health Agency of Canada.

**Data source:** Canadian Cancer Registry and National Cancer Incidence Reporting System databases at Statistics Canada.

Adults affected by cancer, those diagnosed with cancer and their loved ones will face many psychosocial, physical, practical, and financial challenges throughout their cancer experience (1). Evidence indicates that clinically significant levels of cancer-related distress are experienced by at least 35%-45% of those affected by cancer (2-4).

Family members are also affected by their loved one's cancer diagnosis and the evidence suggests that for partners, the cancer-related distress is as severe as it is for patients (1,29-32).

Supporting individuals affected by cancer requires an interprofessional health care team, effective communication, a process for identifying when clinically significant levels of cancer-related distress are present and an awareness of the individual's unique needs or challenges so that appropriate interventions may be offered. The identification and management of cancer-related distress is an integral part of cancer care (7).

The findings from the NRC-Picker Canada Ambulatory Oncology Patient Experience Survey conducted for *Cancer Care Nova Scotia* in early 2010 (unpublished) were consistent with previous survey results in regard to patient satisfaction on Physical Comfort Domain and Emotional Support Domain. Specifically, 84% of patients were satisfied with Physical Comfort received, whereas 58.6% of patients were satisfied with Emotional Support (9). Although the Emotional Support score was significantly higher than the Canadian average (50.4%) during the survey period, there are several areas that should be addressed to improve the patient's experience. Some of the specific areas that require work include provision of information to patients on emotional, relationship, sexual activity, and work changes, and putting patients in touch with services to help with anxiety and depression (9). These findings support the establishment of a guideline focused on the identification and management of cancer-related distress to improve the experience of adults with cancer.

## 1.6 Scope and Purpose

The scope and purpose of this guideline is to provide guidance and assist health care providers (HCPs) to screen, identify and manage cancer-related distress experienced by individuals diagnosed with cancer and their families (first level care). More specifically, this guideline will:

- Assist HCPs to become aware/sensitive to cancer-related distress
- Educate HCPs about management strategies for cancer-related distress (prior to referral to psychosocial health care specialists)
- Identify referral options for management of cancer-related distress by front-line HCPs
- Provide direction for cancer-related distress management and treatment options (local and tertiary)
- Assist front-line HCPs to identify and access appropriate specialist psychosocial care referral
- Support the provision of person-centred care with a focus on cancer-related distress.

## 1.7 Health Questions Addressed

- What level of supportive care can all persons affected by cancer expect?
- What is the nature and incidence of cancer-related distress?
- What are the risk factors contributing to clinically significant distress?
- Who should be screened for cancer-related distress?
- When should screening for cancer-related distress occur?
- What tool(s) are recommended to screen for cancer-related distress?
- When cancer-related distress is identified, how should it be managed?
- What are the limitations to screening?

## 1.8 Methodology

The ADAPTE methodology (Canadian Partnership Against Cancer (CPAC)) case series study from 2008- Dec 2009) was trialed to inform the development of the current guideline (33). An evidence update was required for The Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (10) as the document was endorsed in 2003 (Refer to Section 1.11.1). The guideline committee agreed that content revisions were needed and further information was required to address the health questions identified in Section 1.7. This led to a hybrid adaptation and de novo methods to develop the current guideline (33). In 2008, the quality of The Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer was rated in accordance with the AGREE I © (34) tool by the guideline committee.

Concurrent with the evidence review, a formal consensus process was used to obtain broader input to answer, “What would you like to see in a distress management guideline for adult cancer patients and families?” The Delphi Process was initiated with HCPs across all nine health districts within Nova Scotia and circulated three times for ideas and comments and then once for rating. Of the 152 HCPs representing a range of disciplines who were invited to participate, 35 (23%) participated in some part of the Delphi Process. The guideline committee reviewed the ratings and comments for inclusion in the current guideline and reached consensus on the following themes. The primary themes identified by the HCPs to be included in a distress management guideline consisted of:

- User friendly
- Communication
- Screening and assessment of cancer-related distress
- Resources to manage cancer-related distress

To provide an opportunity for citizen engagement and to inform the guideline, the Delphi Process was implemented with a sample of patients and families. A convenience sample of 22 patients and families was obtained through the CCNS Cancer Patient Family Network. The Delphi Process was concluded earlier than anticipated as the focus shifted from the Delphi question to discussing personal concerns. The themes identified through the patient and family Delphi Process included:

- Communication
- Patient/Family education

- Resources to manage cancer-related distress
- Meeting supportive care needs (e.g., support groups, parking fees)

The guideline committee took the opportunity to trial the algorithms through the innovative Screening for Distress Initiative in Nova Scotia from Oct 2009 to mid-2011. This provided helpful and constructive feedback on the referral pathways from the HCPs involved in the screening initiative. The guideline committee revised the algorithms based on this feedback.

The recommendations were developed by the committee based on the evidence and expert consensus. Consensus conference, with a subgroup of four members of the committee (Janice Howes, Ph.D., R.Psych. (Chair), Deborah McLeod R.N., Ph.D., Judith Cleary, BScN, Larry Broadfield, MHSc) was used to determine the levels of evidence for, as well as rate the strength of the evidence. Refer to Section 1.11.

## **1.9 Expected Outcomes from Implementation of this Guideline**

To establish a minimum standard of psychosocial care, such that:

- People diagnosed with cancer will be screened for cancer-related distress throughout the cancer continuum, and
- People experiencing cancer-related distress will be offered appropriate management and care.

## **1.10 Terminology**

### **1.10.1 Psychosocial Health Services**

CCNS has adopted the CAPO 2010 Standards of Psychosocial Health Services for Persons with Cancer and their Families. As a result we have accepted the umbrella definition of psychosocial health services and its components: psychosocial oncology and supportive care. “Psychosocial health services are psychological, social and spiritual care services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioural, social and spiritual aspects of illness and its consequences so as to promote better health. (Adapted from Adler & Page, 2008, pgs 359-360)<sup>1</sup> ((22), pg 2).

### **1.10.2 Psychosocial Oncology**

Psychosocial Oncology “is a specialty in cancer care concerned with understanding and treating the social, psychological, emotional, spiritual, quality of life and functional (practical) aspects of cancer, from prevention through bereavement. It is a whole-person approach to cancer care that addresses a range of human needs. Psychosocial Oncology focuses on the emotional distress aspects of cancer care and is particularly concerned with the assessment and treatment of distress (as supported by its identification internationally as the 6th Vital Sign of cancer care) and the management of complex issues. Psychosocial Oncology offers care to persons with cancer who have specific unmet needs related to coping with their illness, emotional distress, changes in relationships

and planning for the next phase of their lives and is addressed by professionals trained in this sub-specialty (e.g., psychologists, social workers, spiritual care specialists, psychiatrists and psychiatric/mental health advanced practice nurses [APNs]). Psychosocial oncology professionals offer assessment, treatment and follow up that is consistent with Clinical Practice Guidelines published by CAPO” ((22), pg 2

### **1.10.3 Supportive Care**

“Supportive care services address a range of needs, including informational and counselling needs related to the management of symptoms and specific practical or functional issues. A variety of disciplines may be involved in provision of supportive care, such as nursing, medicine, nutrition and rehabilitation services. Supportive Care services address unmet needs of persons with cancer who require information, education, support, financial advice, or other practical advice.” ((22), pg 2)).

### **1.10.4 Cancer-Related Distress**

Cancer-related distress is defined according to the NCCN as “...a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation and existential and spiritual crisis.” (7), pg DIS-2) Distress affects not only the person with the cancer but also his or her loved ones.

### **1.10.5 Person/Individual Affected by Cancer**

This includes both the individual diagnosed with cancer and his/her family.

### **1.10.6 Family**

Family is defined by the individual diagnosed with cancer. Thus, the make-up of an individual’s family can be varied.

### **1.10.7 Psychosocial Challenges**

Individuals diagnosed with cancer and their families deal with a myriad of psychosocial issues and concerns related to their experience of cancer. Psychosocial refers to the psychological, emotional, physical, social, body image, sexuality, relationship, family, spiritual and existential, quality of life, vocational, financial, and practical challenges that persons affected by cancer may experience. Examples of some of the challenges that individuals may experience include: fear of cancer recurrence, living with the uncertainty of cancer, anxiety, depression, dealing with the physical effects of cancer and cancer treatment, disfigurement and body image difficulties, functional limitations, interpersonal problems, marital and family difficulties, loss of work and associated financial stress, struggling with meaning and purpose, and challenges

to one's faith. Some of these challenges may be experienced by all individuals affected by cancer (e.g., fear of cancer recurrence), whereas others are relevant to specific cancer site groups (e.g., an individual with a head and neck cancer who is struggling with communication problems post-laryngectomy). (See Chapter 2)

### **1.10.8 Evidence-based Care**

"The psychosocial care of persons affected by cancer is informed by evidence/best practice informed by clinical judgment" ((22), pg 9). "Evidence-Based care is a person-centred integration of best research evidence and clinical judgment (Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000)...Health professionals advocate for improvements in practice in accordance with best research evidence and the definition of evidence-based care" ((22), pg 9).

## **1.11 Evidence Base**

### **1.11.1 Review of Evidence**

- Two relevant guidelines were identified: the National Comprehensive Cancer Network Distress Management Guideline (7) and The Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (10). The Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer was selected as a model for the development of the Best Practice Guideline for the Management of Cancer-Related Distress in Adults due to its comprehensive coverage of psychosocial concerns and care of adults with cancer. The rating of the Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer with the AGREE I © was found to have acceptable scores on domains of relevance (e.g., "systematic methods were used to search for evidence", "criteria for selecting the evidence were clearly described") (34). The NCCN guideline was selected given its focus on brief screening for distress and distress management algorithms (e.g., use of Distress Thermometer for screening – see Chapter 4). The NCCN was unanimously regarded by the guideline committee as a reputable source and recognized as a pioneer in this standard of care.
- A systematic search of the published literature was conducted in 2009 to identify systematic reviews, cohort studies and RCTs that focus on the identification and management of cancer-related distress in adults, and the provision of supportive care. This was completed using a recognized search filter by a library scientist through the funding support of CPAC.
- The following data bases were searched: Medline, PsychInfo, Psychextra, Embase, CINAHL, EBP including Cochrane Library databases up to early 2009.
- The searches focused on three concepts: cancer patient, distress and supportive care. Relevant subject headings were identified and additional key words were used to supplement the subject headings.
- The search limits were humans and English language.
- Initially, all retrieved articles (N= 779) were screened by abstract by two independent reviewers in regard to relevance. Articles were excluded if they

were beyond the scope of the guideline (e.g., focused on prevention of cancer, pediatric focus), biomedical in nature, published prior to 2002, or case studies). Any disagreements were resolved through discussion between the two raters.

- The articles (N=393) were pulled and reviewed by two independent raters for relevancy to the health questions and consistency to the draft guideline.
- Upon article review, some lower levels of evidence had not been eliminated by abstract alone. When these articles were relevant to and consistent with the guideline and in the absence of higher level evidence, they were used as a reference for the guideline.
- Relevant additional publications from 2009-2012 were included as identified by the committee.
- Based on external review, additional primary research articles were identified, these were then reviewed for inclusion, relevance and consistency with the guideline by two reviewers.

### **1.11.2 Levels of Evidence**

- Recommendations are based on the highest level of evidence, as found through the evidence review process (Refer to Appendix II). The level of evidence is provided for each recommendation.
- There is limited research in some areas and when this is the case any major deficiencies are noted.
- The evidence used in the guideline is rated using the system developed by the Australian National Breast Cancer Centre and National Cancer Control Initiative (NBCC-NCCI) as described in the *Clinical practice guidelines for the psychosocial care of adults with cancer* (10). The levels of evidence are as follows:

|                    |  |
|--------------------|--|
| <b>Level I</b>     | Based on a systematic review of randomized controlled trials (RCT).  |
| <b>Level II</b>    | Based on a minimum of one properly designed RCT.   |
| <b>Level III-1</b> | Based on well-designed pseudo- randomized controlled trials.   |
| <b>Level III-2</b> | Based on “comparative studies with concurrent controls and allocation not randomized (cohort studies), case control studies, or interrupted time series with a control group”. ((10), pg 4). |
| <b>Level III-3</b> | Based on “comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel group”. ((10), pg 4).                                   |
| <b>Level IV</b>    | Based on “case studies, either post-test or pre- and post-test”. ((10), pg 4).   |

- Level I evidence is the gold standard for recommendations related to clinical interventions. In the absence of this level of evidence, some recommendations have been made based on lower levels of evidence and expert consensus.

### **1.11.3 Strength of Recommendation**

The strength of recommendation ratings are based on the system described by the American Academy of Pediatrics (AAP) for classifying recommendations for clinical practice guidelines (35). The purpose of this rating system is to convey the importance of following a specific recommendation by taking into account the quality of the supporting evidence, as well as the evaluation of the potential benefit or harm. The four strength ratings are as follows:

- **Strong Recommendation** – Consensus of guideline committee that the benefits of the recommendation “clearly exceed the harms of that approach and that the quality of the evidence supporting this approach is either excellent or impossible to obtain. Clinicians should follow such guidance unless a clear and compelling rationale for acting in a contrary manner is present”. (35), pg 876.
- **Recommendation** - Consensus of guideline committee that the benefits of the recommendation “exceed the harms but the quality of the evidence on which the recommendation is based is not as strong. Clinicians also generally should follow such guidance but also should be alert to new information and sensitive to patient preferences” (35), pg 876-877.
- **Option** - Consensus of guideline committee “that the evidence quality that exists is suspect or that well-designed, well-conducted studies have demonstrated little clear advantage to one approach versus another” (35), pg 877.
- **No Recommendation** - Consensus of guideline committee that “there is both a lack of pertinent evidence and an unclear balance between benefits and harms” (35), pg 877.

## 1.12 Summary of Recommendations with Levels of Evidence and Strength Ratings

| Recommendations   | References  | Strength of Recommendation<br>(35)   |
|---|---|--|
| 1. Cancer services will ensure that persons affected by cancer and health care providers understand that identification and management of cancer-related distress is an integral part of cancer care (Section 2.1)  | Level I* (2,10)<br>Level III-3* (7)                             | <b>Strong Recommendation</b><br>Some strong evidence<br>Benefits clearly exceed harm |
| 2. Psychosocial health services focused on meeting the individual's physical, social, emotional, nutritional, informational, psychological, spiritual, and practical needs is recommended throughout the cancer experience and into survivorship (Section 2.1)  | Level 1* (7)<br>Level II* (10-12)                               | <b>Strong Recommendation</b><br>Some strong evidence<br>Benefits clearly exceed harm |
| 3. It is recommended that adults diagnosed with cancer be screened for cancer-related distress by HCPs (Section 4.3).   | Level I (13)<br>Level II (11)<br>Level III-3 (7,12)             | <b>Strong Recommendation</b><br>Some strong evidence<br>Benefits clearly exceed harm |
| 4. Screening for cancer-related distress should occur within two months following diagnosis. Re-screening should occur at critical times and times of transition throughout the cancer continuum. (Section 4.3).  | Level III-3 (7,12)  | <b>Recommendation</b><br>Strength of evidence is mixed<br>Benefits exceed the harm   |
| 5. Screening will be done with the Screening for Distress Tool (adapted for Nova Scotia). The tool consists of (Refer to Section 4.4 and Table 4.4) : <ul style="list-style-type: none"> <li>• The Edmonton Symptom Assessment System-revised (ESAS-r) (14,15);</li> <li>• The Canadian Problem Checklist (CPC) (16);</li> <li>• The Distress Thermometer® (DT) (7,12)).</li> </ul> | Level I** (13)<br>Level II** (7,11,12,16)<br>Level III-3** (16) | <b>Recommendation</b><br>Strength of evidence is mixed<br>Benefits exceed the harm   |

| Recommendations  | References   | Strength of Recommendation<br>(35)   |
|--|--|--|
| 6. Adults with one or more distress scores on the ESAS-r and/or DT of 8 or greater are in high distress and require an urgent decision by the health care team to either manage the distress directly or make a referral to an appropriate health care specialist for specialized assessment and care. (Section 4.6) | Level I <sup>***</sup> (2,12)<br>Level II <sup>***</sup> (11)<br>Level III-1 <sup>***</sup> (12)   | <b>Strong Recommendation</b><br>Some strong evidence<br>Benefits clearly exceed harm                                 |
| 7. Individuals in moderate distress with one or more scores on the ESAS-r and/or DT between 4 and 7 may be managed by the health care team or referred to an appropriate health care specialist for specialized assessment and care. (Section 4.6 and Figure 4.2)  | Level I <sup>***</sup> (2,12)<br>Level II <sup>***</sup> (11)<br>Level III-1 <sup>***</sup> (2,12) | <b>Strong Recommendation</b><br>Some strong evidence<br>Benefits clearly exceed harm                                 |
| 8. Individuals in mild distress, with all scores on the ESAS-r and/or DT less than 4, can be managed by the health care team. If distress does not improve, referral to an appropriate health care specialist for specialized assessment and care should be considered. (Section 4.6 and Figure 4.2 )                | Level I <sup>***</sup> (2)<br>Level III-1 <sup>***</sup> (2)<br>Level III-3 <sup>***</sup> (17)    | <b>Recommendation</b><br>Strength of evidence is mixed<br>Benefits exceed the harm                                   |
| 9. When the adult affected by cancer needs specialized care (i.e. assessment and/or treatment), referral to the health care specialist with expertise relevant to the identified distress problem is recommended. (Figure 5.3)   | Level I (2,7)<br>Level II (11)   | <b>Strong Recommendation</b><br>Some strong evidence<br>Benefits clearly exceed harm                                 |
| 10. Health care providers should provide information on available resources tailored to the person's specific needs and situation. (Section 5.7)   | Level I (10)<br>Level II (10,18)<br>Level IV (7)   | <b>Strong Recommendation</b><br>Some strong evidence<br>Benefits clearly exceed harm                                 |
| 11. Health care providers screening individuals for cancer-related distress must address the needs of people from diverse communities. (Section 6.11)  | Level III (19)<br>Level IV (20)  | <b>Recommendation</b><br>Overwhelmingly consistent evidence from descriptive studies<br>Benefits clearly exceed harm |

| Recommendations  | References                         | Strength of Recommendation<br>(35)   |
|--|------------------------------------|--|
| 12. Health care providers seeing persons for management of cancer-related distress should provide service in an inclusive and sensitive manner. (Section 6.11) | Level III (19)<br>Level IV (20,21) | <b>Recommendation</b><br>Overwhelmingly consistent evidence from descriptive studies<br>Benefits clearly exceed harm |

\*Recommendation is supported by evidence synthesized in the source document.

\*\*The references cited relate to specific parts of the Screening for Distress Tool (i.e., DT, ESAS-r, CPC).

\*\*\*Evidence for intervention varies; with strong evidence for some interventions. Although there is limited evidence for exact cut-off scores, the recommended cut-off scores are evidence informed and have the unanimous support of the guideline committee.

### 1.13 Acknowledgements

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### **1.14 Guideline Approvals**

- Supportive Care Cancer Site Team – Initial: February 2014. Final: December 2014
- Department of Health and Wellness – February 2015

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## Chapter 2 - Understanding the Challenges of Cancer

### 2.1 Understanding the Challenges of Cancer

Each person diagnosed with cancer and their family will experience a range of psychosocial, physical and practical challenges and needs related to their diagnosis and treatment (1,8). Cancer can affect every aspect of a person's life and is a traumatic experience for many individuals and their families.

#### ***Recommendation***

Psychosocial health services focused on meeting the individual's physical, social, emotional, nutritional, informational, psychological, spiritual and practical needs is recommended throughout the cancer experience and into survivorship (refer to 1.9.1).

Level 1\* (7)

Level II\* (10-12)

\*Recommendation is supported by evidence synthesized in the source document.

Challenges of cancer include:

- Psychosocial Challenges, consisting of one's emotional and psychological response to cancer (emotional responses to cancer and clinically significant distress), sexuality and body image concerns, existential and spiritual concerns, and family and social challenges;
- Common Physical Challenges;
- Informational Needs;
- Practical Concerns (i.e., financial and resource challenges);
- Concerns Near End of Life; and
- Survivorship.

Some challenges are common across all cancers (e.g. adjusting to the diagnosis); whereas other challenges (e.g. infertility) are associated with specific cancers. Individual difference factors may affect the cancer-related distress experienced by each person dealing with specific challenges. It is important for HCPs to be sensitive to and explore the unique challenges and needs experienced by those affected by cancer.

***Recommendation***

Cancer services will ensure that persons affected by cancer and health care providers understand that identification and management of cancer-related distress is an integral part of cancer care.

Level I\* (2,10)

Level III-3\* (7)

\*Recommendation is supported by evidence synthesized in the source document.

In the following tables many of the challenges of cancer are described as well as associated distress.

## 2.2 Psychosocial Challenges

### Emotional and Psychological Responses and Challenges

The emotional and psychological responses (fear, worry, anxiety, irritability, sadness, loss, anger, guilt, fear of cancer recurrence) to cancer described in Table 2.2A are understandable and normal reactions to diagnosis/ management of cancer and dealing with associated adjustments and uncertainty.

**Table 2.2A Emotional and Psychological Responses to Cancer**

| Emotional and Psychological Responses  | Description   |
|--|---|
| <b>Feelings of fear, worry, anxiety, irritability, sadness, loss, anger and/or guilt</b> | <ul style="list-style-type: none"> <li>• For the majority of cancer patients and their families, these emotions wax and wane, and are generally manageable (36).</li> <li>• Emotional responses often increase at times of transition in medical treatment (e.g., end of active treatment; shift to palliation) and disease progression (7).</li> <li>• Many individuals display a high level of emotional/psychological resiliency when dealing with stressful and traumatic events such as cancer (36).</li> <li>• Most benefit from acknowledgement and support within the context of their cancer treatment and follow-up, psycho-education and information (5).</li> </ul>   |
| <b>Fear of cancer recurrence and the uncertainty of living with cancer</b>               | <ul style="list-style-type: none"> <li>• Persons affected by cancer often experience: uncertainty about the disease course and the future; fear and worry about recurrence/metastasis; and ongoing concern about life threat and dying (37,38).</li> <li>• For some individuals, fears of disease recurrence are persistent, whereas for other individuals and their families this fear and related uncertainty reduces over time as the individuals' progress through cancer treatment, cancer-free medical follow-ups, and survivorship. Refer to Section 2.7.</li> <li>• High fear of cancer recurrence has been associated with higher emotional distress and more intrusive thinking about cancer (39, 40).</li> <li>• Several factors have been related to elevated fear of cancer recurrence (39,41) (e.g., difficulty assessing the meaning/significance of ongoing or new physical symptoms, learned reminders of the experience, death of fellow survivors, less positive meaning of illness, more concurrent family stressors, age).</li> <li>• Family members/care givers also experience worries and fear of cancer recurrence. (39).</li> </ul> |
| <b>Self-Esteem/Self-Concept</b>  | <ul style="list-style-type: none"> <li>• One's self-esteem and sense of self can be affected by the experience of cancer. Many of the challenges discussed in this chapter impact self-esteem, such as: emotional distress, body image, physical effects of cancer and treatment, sense of loss of control, social and family challenges, meaning and purpose, vocational issues, and financial stresses.</li> </ul>  |
| <b>Guilt/Survivor Guilt</b>  | <ul style="list-style-type: none"> <li>• Guilt is a difficult emotion that can negatively affect persons with cancer. Guilt can be related to developing cancer, putting one's partner/family through the stress of cancer, past unhealthy lifestyle choices (e.g., cigarette smoking, alcohol abuse), surviving when others have not, and surviving longer than expected, life choices and unresolved issues.</li> </ul>   |

## Clinically Significant Distress

35%-45% of individuals affected by cancer struggle emotionally and display clinically significant cancer-related distress such as anxiety and depression as described in Table 2.2B. Refer to section 4.4 for discussion of risk factors for clinically significant cancer-related distress (i.e., anxiety and depression).

**Table 2.2B Clinically Significant Distress**

| Clinically Significant Distress   | Description  |
|---|--|
| <ul style="list-style-type: none"> <li> <b>Clinically Significant Depression and Anxiety</b><br/>                     At least 35%-45% of individuals affected by cancer display clinically significant levels of emotional distress and meet criteria for a DSM-IV-TR (2000) Anxiety Disorder, Depression, or Adjustment Disorder (2-4).                 </li> </ul> | <ul style="list-style-type: none"> <li>Prevalence estimates of anxiety (e.g., Generalized Anxiety, Panic Disorder, Post-Traumatic Stress Disorder) and depression in adults with cancer vary (2,42).</li> <li>Anxiety and depression can occur at any point during the cancer care continuum.</li> <li>Physical effects of medical treatment, type of cancer, and/or other medical problems can contribute to/cause anxiety and/or depression (e.g., hormonal changes).</li> <li>Estimated rates of Anxiety Disorders and Major Depression may vary related to point in the illness trajectory (e.g., higher rates of anxiety in the newly diagnosed, higher rates of depression in individuals with advanced disease) (2,43,44).</li> <li>Emerging evidence suggests that hospitalized persons with cancer have high levels of distress (45).</li> <li>Family members also experience difficulties with anxiety and depression (1, 29-32).</li> </ul> |
| <ul style="list-style-type: none"> <li> <b>Sub-syndromal Presentations of Anxiety and Depression</b> </li> </ul>  | <ul style="list-style-type: none"> <li>Many individuals diagnosed with cancer may display anxiety and depressive features at a lower level and do not meet full criteria for a diagnosis of Anxiety Disorder, Depression, and/or Adjustment Disorder.</li> <li>High frequencies of individual symptom clusters (e.g., re-experiencing symptoms consisting of intrusive thoughts/memories) related to cancer, diagnosis and treatment have been reported (46, 47).</li> </ul>   |
| <ul style="list-style-type: none"> <li> <b>Suicide Risk</b><br/>                     There is an increased risk of suicide among cancer patients relative to the general population.                 </li> </ul>  | <ul style="list-style-type: none"> <li>In addition to the usual risk factors, other factors associated with higher risk in individuals diagnosed with cancer include: advanced disease, little social or cultural support, limited treatment options, more likely to be male, lack of hope (48).</li> </ul>  |

## Challenges to Sexuality and Body Image

Cancer and treatment can have a significant effect on body image and sexual health and function. Altered body image affects self-concept and self-esteem to varying degrees, potentially affecting sexual health, relationships, social and vocational functioning and cancer-related distress.

**Table 2.2C Challenges to Sexual Health and Body Image**

| Challenges to Sexual Health and Body Image   | Description  |
|--|--|
| <p><b>Sexual Health</b></p> <ul style="list-style-type: none"> <li>• Cancer and treatment can have significant impact on sexual function and sexuality and negative effects can persist for years</li> </ul> | <ul style="list-style-type: none"> <li>• Concerns related to sexual dysfunction and sexual health are present for many people with cancer (49). Changes in physical appearance as well as general weakness can lead to alterations in self-image that may interfere with sexual intimacy (49).</li> <li>• Chemotherapies often induce menopause. Sudden menopause can be particularly difficult to adjust to and may be particularly problematic for young women. Impacts include shifts in sexual response cycle, dyspareunia, and severe vaginal dryness (50).</li> <li>• Men treated with androgen deprivation therapy for prostate cancer will experience erectile dysfunction and decreased libido secondary to treatment (51).</li> <li>• Pelvic radiotherapy is likely to affect sexual function, including: vaginal dryness, fibrosis and stenosis; dyspareunia; and erectile dysfunction. The effects of radiotherapy increase in the months following treatment.</li> <li>• Radical prostatectomy can lead to erectile dysfunction and for many men this is moderately to extremely distressing (self-rated) (52,53).</li> <li>• Surgical interventions for women with gynecological cancers (e.g., radical hysterectomy) have been shown to affect sexual functioning and this side-effect is very distressing for many women (54).</li> <li>• Infertility can be a concern for both men and women. Research indicates that women dealing with cancer-related infertility may experience enduring distress (55).</li> <li>• Some studies report that couples have difficulty discussing these concerns with each other and in finding appropriate support or counseling to address difficulties (e.g., (56,57))</li> <li>• There is evidence that HCPs do not adequately assess sexual concerns, resulting in inadequate access to resources for those affected by cancer (58)</li> </ul> |
| <p><b>Body Image</b></p>   | <ul style="list-style-type: none"> <li>• Many people experience some changes in body image with cancer treatments (e.g.,</li> </ul>  |

| <b>Challenges to Sexual Health and Body Image</b> | <b>Description</b>   |
|---|--|
|   | <p>alopecia, weight loss) (59).</p> <ul style="list-style-type: none"><li>• Altered body image affects self-concept and self-esteem to varying degrees, potentially affecting sexual health, relationships, social and vocational functioning and cancer-related distress.</li><li>• Some tumours and their treatment are highly visible and disfiguring, with major implications for body image (e.g. head and neck cancers) (49).</li><li>• Other cancers/surgeries are less visible but still have significant impact on the individual's body image, sense of self and intimate relationships (e.g. colo-rectal, prostate and breast cancer) (49,60,61).</li></ul> |

### Common Existential and Spiritual Challenges

For many individuals the cancer experience can raise existential and spiritual concerns (e.g., meaning and purpose, life threat and uncertainty of life, loss of sense of control, fears of death and dying, challenges to one’s faith). Hope can help people with cancer cope and adjust to uncertainty, loss and suffering (62).

**Table 2.2D Common Existential and Spiritual Challenges**

| Common Existential and Spiritual Challenges   | Description  |
|---|--|
| <p>The cancer experience can raise existential and spiritual concerns such as meaning and purpose, life threat and uncertainty of life, loss of sense of control, fears of death and dying, and challenges to one’s faith.</p>  | <ul style="list-style-type: none"> <li>• Psycho-spiritual well-being has been described as including emotional health and meaning-in-life concerns (63)</li> <li>• Life-threat, uncertainty of life, loss of control and self-determination, existential and spiritual concerns may include re-examination of belief system/faith, adherence to faith-based rituals and concerns about death.</li> <li>• Spiritual concerns may be expressed in religious language, but often are worded in terms of hope, love, belonging, and purpose.</li> <li>• Spiritual despair may be reflected through: alienation (e.g., sense of injustice or abandonment), loss of self (e.g., why me?), and dissonance (e.g., fear of pain and suffering, avoidance of death) (64)</li> <li>• Religious coping is described as the “use of cognitive and behavioural techniques, in the face of stressful life events, that arise out of one’s religion or spirituality” (65).</li> <li>• 34%-86% of medically ill people use religious coping to help deal with their illness (65)</li> <li>• Research has shown that active faith (including participation in a church community) can reduce overall distress and depression. (63, 66).</li> </ul> |
| <p><b>Hope</b></p> <ul style="list-style-type: none"> <li>• Hope is a somewhat ambiguous concept across the cancer continuum that can be conceptualized as looking toward the future in an adaptive, positive and personally significant way (e.g., symptom control, maintaining dignity, meaning, relationships) (62,67).</li> </ul> | <ul style="list-style-type: none"> <li>• The balance between distress and hope changes through the course of the disease (67) .</li> <li>• Hope can vary throughout the cancer experience from hope for cure of disease, to hope for quality of life when the disease is not curable, to “hope for dignity, comfort, and closure as well as for growth at the end of life” (69)</li> <li>• A sense of hope is supported through a therapeutic relationship with the HCP and use of the general interactional skills described in Chapter 3 (62) .</li> <li>• An empathic, honest approach by HCPs can contribute to an individual’s hope (62,67)</li> <li>• Hope can help people with cancer cope and adjust to uncertainty, loss and suffering (62).</li> </ul>   |

## Family Challenges

The experience of cancer is a significant stressor for most families and all family members, including children, are affected to various degrees (70-73). Partners are often as distressed as the person with cancer. The family’s experience with cancer is influenced by several contextual factors (See Table 2.2E).

**Table 2.2E Family Challenges**

| Family Challenges  | Description   |
|--|---|
| <ul style="list-style-type: none"> <li>• The experience of cancer is a significant stressor for most families and all family members are affected to various degrees (70-73).</li> <li>• It is important to note that research focusing on families that are non-traditional, from low socio-economic status, or dealing with a cancer diagnosis other than breast cancer (mother) is limited (1,73).</li> </ul> | <ul style="list-style-type: none"> <li>• The family’s experience is influenced by many contextual variables including: developmental stage; concurrent stressors, nature of relationships, previous experience with illness and cancer (1,71,73) and ethnic or cultural background (73).</li> <li>• Challenges that families experience include:                         <ul style="list-style-type: none"> <li>• Disruption to roles and responsibilities (1, 74).</li> <li>• Managing strong emotions (guilt, anger, grief).</li> <li>• Maintaining open communication, mutual support and productive problem solving in the face of high stress and fatigue (1, 74, 75).</li> <li>• Managing practical and emotional support from their extended family and friends that may vary over time.</li> </ul> </li> <li>• Partners are typically as (or more) distressed than the person with cancer but receive less support, and acknowledgement while struggling to manage additional responsibilities (1, 29-32, 53, 61, 75).</li> <li>• Knowing how to help children through the cancer experience is a concern for many parents. Children appear to cope better with adequate and appropriate information and routine (76).</li> <li>• Children also experience cancer-related distress with some research suggesting that older children may be more distressed about a parent’s cancer, with adolescent daughters of a mother with cancer showing the most distress (71-73, 77). The research regarding children is limited.</li> <li>• Persons affected by cancer may have worries/fears about their children’s risk of developing cancer secondary to genetic or environmental risk factors (78, 79).</li> <li>• Families with a history of difficult relationships, including abuse, are likely to struggle more with the cancer experience.</li> </ul> |

## Challenges of Caregiving

Caring for a family member with cancer is challenging, but many caregivers report satisfaction from providing this support (80). Factors associated with caregiver cancer-related distress include, higher care needs, high level of dependency on the caregiver, pessimistic expectations and practical problems (1,81,82). For example, caregivers of people with laryngectomies describe a high level of stress and burden during the immediate post-operative period (83) and then ongoing adjustments to the loss of voice, financial concerns and changes in intimacy (83). Evidence the partners of elderly individuals with cancer may be more likely to suffer negative effects from caregiving secondary to their own age-related changes and emotional connection to their partner (1).

Evidence suggests that caregivers generally have a need for informational support related to competence in their role as caregivers (e.g., symptom management), although each caregiver may have unique needs and preferences for information (80,84).

Further research is needed to understand the longitudinal effects of caregiver burden and the caregiving experiences of specific family members (1).

## 2.3 Physical Challenges

Several physical challenges are experienced by those dealing with cancer. The cancer-related distress associated with physical challenges is affected by the meaning of the symptom, the effectiveness of the management of the symptom and the impact of the symptom on activities of everyday life.

**Table 2.3 Common Physical Challenges**

| Common Physical Challenges  | Description   |
|---|---|
| Temporary and permanent physical changes/symptoms may develop secondary to treatment or cancer progression. | <ul style="list-style-type: none"> <li>Any uncontrolled physical symptom may lead to cancer-related distress (7,82).</li> <li>Physical changes may be a source of embarrassment and/or affect self-esteem, body-image, sexuality, and performance of daily activities and lead to cancer-related distress (8, 53, 59, 60, 85-87).</li> </ul>  |
| Pain (acute and chronic)  | <ul style="list-style-type: none"> <li>The meaning of pain affects an individual's tolerance for or ability to cope with this symptom (88).</li> <li>Uncontrolled pain may cause distress, limit mobility, affect sexual health and affect psychological adjustment (10, 89, and 90). Younger and older adults with cancer and experiencing pain display similar levels of depression (91).</li> <li>When pain results from a side-effect of treatment, the person's ability to tolerate and continue with cancer therapy may be affected (60).</li> </ul>  |
| Cancer-Related Fatigue  | <ul style="list-style-type: none"> <li>"Cancer-related fatigue is a distressing persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning" (92), p FT-1.</li> <li>Fatigue can be a side effect of chemotherapy, radiotherapy, combined therapy, targeted therapy, biotherapy, surgery, and stem cell transplantation that often persists beyond the completion of treatment (82,92-95).</li> <li>Fatigue is the most common (75 to 90%) and one of the most distressing symptoms reported by individuals diagnosed with cancer (92,94,95).</li> <li>The specific pathophysiologic mechanisms are unclear but the etiology of cancer-related fatigue is likely multifactorial (e.g., pain, anemia, medication side-effects, depression) (93, 94, 96, 97).</li> <li>Fatigue can interfere with sleep, mood, physical and social functioning, job performance, quality of life and may be a source of cancer-related distress (82,92-94,96).</li> </ul> |
| Sleep/Wake Disturbances   | <ul style="list-style-type: none"> <li>Problems sleeping at night and/or sleepiness during the day are a common problem for people with cancer and their caregivers (98-100).</li> <li>Many factors are associated with sleep/wake disturbances, such as gender (female), psychological factors, and disease- and treatment- related variables (e.g., pain, hot flashes, corticosteroids) (98,100).</li> </ul>  |
| Cognitive problems  | <ul style="list-style-type: none"> <li>Neuropsychological changes have been described for some people following cancer treatment and may be related to the disease and/or effects of treatment (101-103).</li> <li>May be experienced post treatment and described as "brain fog" or "chemotherapy brain" (101,104). Although cognitive changes (changes to concentration and memory) are often mild to moderate, they can impact activities of daily living, quality of life, be a source of cancer-related distress, and persist (29,102-105).</li> </ul>   |

| Common Physical Challenges   | Description   |
|--|---|
|  | <ul style="list-style-type: none"> <li>Individuals with primary brain cancer or metastasis to the brain may experience global cognitive and personality changes (29).</li> </ul>  |
| Nutritional/ Gastrointestinal Concerns (e.g., nausea, constipation, anorexia, cachexia, dysphagia) | <ul style="list-style-type: none"> <li>Difficulty eating can be a challenge for people diagnosed with cancer due to gastrointestinal symptoms or effects of cancer treatment (e.g., head and neck cancers that can lead to malnutrition and reduced quality of life for some) (85,106).</li> </ul>  |
| Communication problems   | <ul style="list-style-type: none"> <li>Temporary and permanent changes in voicing/speech may be caused by cancer and/or its treatment. For example, surgical resection for some head and neck cancers may lead to changes in voicing or loss of voicing resulting in significant life adjustments (85,107). The incidence of depression is high throughout the illness trajectory for people with head and neck cancers (108).</li> </ul> |

## 2.4 Information Needs

Information needs of those affected by cancer vary across the cancer continuum and are impacted by many factors (e.g., coping style, life circumstances, values and beliefs, see Chapter 6 for discussion of some of these factors) (18). Individuals diagnosed with cancer and their families may feel they have not received sufficient information about diagnosis, treatment, resources, or prognosis in order to effectively cope, communicate with their health care team, and feel confident in decision-making (109-111). Further, persons may not recall information provided about their illness, treatment, and prognosis as several factors can affect retention of information (e.g., cancer-related distress, personal relevance, and the timing of when information is given) (112,113). Communication and educational approaches to meet the informational needs of individuals affected by cancer are presented in Chapter 3.

## 2.5 Practical Concerns

Frequent practical concerns experienced by individuals and families affected by cancer include financial worries and strain (e.g., changes in employment and income), instrumental challenges (e.g., treatment costs and concerns, getting to and from appointments, getting groceries and meal preparation) and awareness of and access to available resources.

**Table 2.5 Common Practical Challenges**

| Common Practical Challenges   | Description   |
|---|---|
| <p><b>Financial Challenges</b><br/>                     Family income can be reduced suddenly and unexpectedly with the onset of illness/treatment (114) and may relate to:</p> <ul style="list-style-type: none"> <li>• Interruption or changes in employment (115);</li> <li>• Availability of alternate sources of income during illness (e.g., sick benefits, long term disability benefits) (115);</li> <li>• Treatment costs that are not covered (e.g., medications, supplies, travel, accommodations) (115);</li> </ul> | <ul style="list-style-type: none"> <li>• Worries related to ability to work and finances are major concerns for people with advanced cancer (63) and are also commonly reported by people with earlier stages of cancer (106,114).</li> <li>• A need for increased financial support has been reported by families, especially those with lower incomes (114,115).</li> <li>• Research is limited that describes the cancer-related distress associated with the financial challenges of diagnosis and treatment (114).</li> <li>• Findings from the National Population Health Survey (1994-2007) reported by Orpana et al. indicate that lower income is associated with a higher risk of becoming distressed in the general population, but other concurrent stressors mediate this relationship and account for part of the increased risk (116).</li> <li>• A person may have to take time off work, travel great distances to treatment, adjust daily commitments, and take on additional medical costs, as examples. Higher demands from the environment (job strain, unemployment, job insecurity, lack of ability to meet basic needs) in combination with lack of resources are taxing to an individual's ability to adapt and cope (116).</li> </ul> |
| <p><b>Instrumental Challenges</b><br/>                     People affected by cancer may require adjustments and support to meet their everyday practical needs (e.g., childcare, getting groceries, meal preparation).</p>   | <ul style="list-style-type: none"> <li>• Cancer-related emotional distress (e.g., clinical depression, anxiety) and physical challenges (e.g., fatigue, cognitive problems, communication problems, and pain) can affect a person's everyday functioning, and ability to navigate the cancer system and access resources.</li> </ul>  |
| <p><b>Resource Concerns</b><br/>                     People affected by cancer may experience difficulties in accessing resources to meet their financial and instrumental challenges.</p>  | <ul style="list-style-type: none"> <li>• People may experience insufficient resources (e.g., to cover travel, meals, accommodations, pre-treatment necessities, dental, childcare) .</li> <li>• There is often a lack of awareness/knowledge of available resources.</li> <li>• There are a variety of barriers to access resources (e.g., poverty, literacy, marginalized groups, and eligibility criteria of government programs). Refer to Chapter 6.</li> <li>• All of these factors may affect how the individual makes decisions about his or her cancer care.</li> </ul>   |

## 2.6 Concerns Near the End of Life

As the adult’s disease progresses and they hope for a peaceful death there are several concerns experienced by the person and their loved. Frequent concerns include existential/spiritual, anticipatory grief and loss, and addressing practical and legal issues. Caregivers deal with personal and role strain while also dealing with anticipatory grief as they support their family member with cancer.

**Table 2.6 Concerns Near the End of Life**

| Concerns Near the End of Life  | Description   |
|--|---|
| Disease progression  | <ul style="list-style-type: none"> <li>• Quality of life is affected by increased symptoms, reduced functional ability and increased cancer burden (10).</li> <li>• Individuals with cancer may experience distress related to uncertainty about his/her illness and care plan, and fears related to the dying process (117).</li> <li>• Depression and anxiety are experienced by many individuals during palliative cancer care (118).</li> </ul>   |
| Existential /Spiritual Concerns  | <ul style="list-style-type: none"> <li>• Existential and spiritual concerns are important for terminally ill individuals (63,119).</li> <li>• Spiritual and psychosocial needs may be reprioritized near the end of life as physical and functional deterioration progresses (64).</li> <li>• End of life spiritual health is influenced by spiritual despair (e.g., fear of suffering, loss of self); spiritual work/processing (e.g., creating meaning, forgiveness) and spiritual well-being (e.g., transcendence, self-love) (64).</li> <li>• Spiritual work is hindered when individuals have unrelieved symptoms such as pain and anxiety (64).</li> <li>• Finding meaning and hope was associated with improved psycho-spiritual well-being (63, 64).</li> </ul> |
| Comfort  | <ul style="list-style-type: none"> <li>• Provision of comfort care to individuals near the end of life should reflect the individual’s needs and preferences (e.g., place of death, level of alertness and degree of pain control) (120).</li> <li>• According to the NCCN Guidelines™ Palliative Care a “peaceful death” is: “Free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patient’s and family’s wishes; consistent with clinical, cultural, and ethical standards” ((69), pg MS 16).</li> </ul>   |
| Relationships and Socialization  | <ul style="list-style-type: none"> <li>• Worries about their families were a major concern for people with advanced cancer (63).</li> <li>• Socialization has been identified by some individuals as important during the final year of life and is associated with the perception of a “good death” by the person dying (10, 63) .</li> <li>• Refer to Section 2.2 – Common Family and Social Challenges</li> </ul>  |
| Caregivers <ul style="list-style-type: none"> <li>• Demands of the role</li> </ul> | <ul style="list-style-type: none"> <li>• Caregivers report high levels of personal and role strain as well as overall burden, which is often the greatest during the terminal phase of the illness (1, 10).</li> <li>• Caregivers want to provide good care but may not know how to (80).</li> <li>• The ability to provide care may be affected by their experience of loss and grief.</li> <li>• Refer to Chapter 6, Section 6.11.</li> </ul>   |
| Grief and Bereavement  | <ul style="list-style-type: none"> <li>• Cancer is associated with numerous losses for those diagnosed with cancer and their families.</li> </ul>   |

| Concerns Near the End of Life  | Description   |
|--|---|
| <ul style="list-style-type: none"> <li>• Anticipatory grief and loss, grief and complicated bereavement</li> </ul>   | <ul style="list-style-type: none"> <li>• Grief responses are varied, including physical, emotional, cognitive, behavioural and existential symptoms.</li> <li>• The surviving partner or bereaved caregiver(s) is also at risk for sleep/wake disturbances. The risk may be greater when the person diagnosed with cancer experienced unrelieved symptoms during the final three months of his/her life (100).</li> <li>• Complicated bereavement is a severe grief response associated with significant functional impairment.</li> <li>• Predictors of complicated bereavement include: sudden or traumatic death, feelings of shame or guilt surrounding the death, poor social supports, and co-morbid psychiatric conditions ((10).</li> </ul> |
| <p>Practical and Financial</p> <ul style="list-style-type: none"> <li>• Preparation of will and financial planning</li> <li>• Memorial/funeral planning</li> </ul> | <ul style="list-style-type: none"> <li>• A number of individuals reach the end of their life without having legal issues addressed (e.g., power of attorney, will, advanced care plan). Addressing these issues may be distressing.</li> <li>• Funeral/memorial planning may be helpful and adaptive for some and distressing for others.</li> <li>• Financial concerns related to the high cost of memorials/funerals, escalating health-care costs (e.g., home care), nursing homes and reduced pension income can cause great stress for families (114).</li> </ul>  |

## 2.7 Survivorship

It is recognized that individuals that survive cancer can experience emotional, psychological and physical sequelae. For some adults these effects may be more limiting and persist over time whereas others are able to achieve a more satisfying quality of life (e.g., able to return to their regular work). Assisting patients in navigating their long term follow-up care is a focus of ongoing clinical development.

**Table 2.7 Common Challenges of Survivorship**

| Common Challenges of Survivorship     | Description  |
|---------------------------------------|--|
| Emotional and Psychological           | <ul style="list-style-type: none"> <li>• It has been reported that up to 29% of cancer survivors display anxiety and/or depression (121).</li> <li>• Cancer-related distress is associated with the challenges of survivorship (e.g., fear of cancer recurrence; reduced medical and social support at completion of cancer treatment; vocational, financial and physical concerns; changes to self-esteem and body-image; sexual health changes) and periods of vulnerability (e.g., annual screenings, medical follow-up, new physical symptoms) (7,121).</li> <li>• Feelings of guilt for having “survived” cancer or feelings of fear related to the risk of cancer recurrence may be experienced (78).</li> <li>• Some psychological effects are positive (73,121). For example, some survivors may experience an increased appreciation of life.</li> <li>• Many long term survivors display improved quality of life over time (122), for others cancer-related distress may be a problem years after treatment (121,123).</li> <li>• Family members of survivors experience stress, anxiety, worry and fears about recurrence (8, 73) (See Table 2.2E).</li> </ul> |
| Vocational and Educational Challenges | <ul style="list-style-type: none"> <li>• Return to work can be affected by type of cancer and long-term effects (e.g., facial disfigurement or severe lymphedema), nature of work and job security (115). The rate of return to work for people diagnosed with cancer is variable (e.g., 30-93%) (124).</li> <li>• A flexible work environment and having co-workers with positive attitudes has been associated with return to work (124).</li> <li>• Not returning to work may lead to reduced income and negatively affect socialization and self-esteem (8,124).</li> <li>• Difficulties accessing health and life insurance programs have also been described (124).</li> </ul>   |
| Long Term Follow-Up Care              | <ul style="list-style-type: none"> <li>• Feelings of fear and uncertainty are present when survivors do not understand their post treatment care and do not know how to navigate their follow-up (78) (i.e., when to report certain symptoms and what doctor they should see when issues arise).</li> <li>• Long-term follow-up care is a priority issue that was identified through a survey of individuals associated with the cancer care system in Nova Scotia (i.e., survivors and families, HCPs, government partners and cancer organizations) (125).</li> </ul>  |
| Sexual Health                         | <ul style="list-style-type: none"> <li>• As noted in Section 2.2 Challenges to Sexual Health and Body Image, changes such as alterations to body image, pre-mature menopause or erectile dysfunction may lead to permanent changes in sexual functioning and are distressing for cancer survivors (50,121-123).</li> </ul>   |
| Fatigue                               | <ul style="list-style-type: none"> <li>• Fatigue may persist even years after cancer treatment (8, 92-95, 97,121).</li> <li>• Refer to Section 2.3.</li> </ul>   |
| Physical concerns                     | <ul style="list-style-type: none"> <li>• Physical symptoms of cancer can be acute and/or chronic. The late or long-term physical effects of cancer and/or treatment can</li> </ul>   |

| <b>Common Challenges of Survivorship</b> | <b>Description</b>   |
|--|--|
|  | <p>be devastating (121).</p> <ul style="list-style-type: none"><li>• Physical concerns such as pain and lymphedema may lead to physical limitations, may negatively affect social functioning and are distressing for cancer survivors (89, 90,121,126,127).</li></ul> |

## 2.8 Challenges for HCPs Caring for Persons Affected by Cancer

As noted in the Canadian Association of Psychosocial Oncology Standards of Psychosocial Health Services for Persons with Cancer and their Families, “cancer care takes a toll on health providers” (pg 15, (22)). The following section offers an introduction to this important topic. A systematic search of the literature in this area was not conducted as managing the distress of HCPs is outside the scope of this guideline. Burnout is a psychological reaction related to high levels of work-related stress, characterized by emotional and physical exhaustion, and sense of lower levels of accomplishment, that is associated with the staff considering leaving the stressful work environment or reducing their hours of work (128). Distress and burnout appear to be high among oncology HCPs, although not necessarily higher than levels experienced by HCPs in non-cancer clinical settings (10,129). The distress experienced by HCPs may result in part from the context of their clinical practice and the emotional presence required in caring for individuals with cancer and their families. Some factors that have been associated with this distress include: feeling overloaded, caring for people who are suffering or dying, dealing with treatment toxicities, worries about medical errors and lack of job satisfaction/personal accomplishment (10,129). HCPs who feel inadequately trained in therapeutic communication and management skills also seem to be at risk for burnout (129).

Psychosocial problems experienced by oncology HCPs may include: emotional over-involvement, emotional exhaustion, feeling doubtful of his/her abilities or that of health sciences to make a difference, detachment, cynicism, frustration, stress and tension, psychiatric morbidity (e.g., anxiety), low job satisfaction, physical complaints (e.g., headaches) and alterations in personal/family life (129).

Burnout is affected by factors related to the context of practice (e.g., clinical demands) as well as personal characteristics (e.g., coping). Current research is too limited to provide evidence-based recommendations for the prevention or treatment of work-related distress and burnout (129); however, preliminary research is focused on influencing personal factors (e.g., communication skills training, emotional support, stress management, and self-care) and organizational factors (e.g., adequate staffing, scheduling and team building) (129). Formal and informal peer support can be helpful to staff in managing distress. Creating an awareness of and sensitivity to distress experienced by oncology HCPs facilitates staff communication and support and seeking appropriate treatment when needed. A guideline in this area would be helpful.

## **Chapter 3 – General Principles**

### **3.1 Overview**

Central to the care of a person diagnosed with cancer and his or her family is skilled communication and an awareness of the specific cancer-related challenges they may experience (Refer to Chapter 2). Effective communication can assist with: the ongoing adjustment to the diagnosis and treatment of cancer; education about cancer-related issues and challenges; decision-making; adherence to treatment; and satisfaction with care (10, 36,130). Ineffective communication, on the other hand may lead to limited or lack of identification of the individual’s needs, preferences and concerns. As described in the Australian Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (10) and the Provider-Patient Communication: A Report of Evidence-Based Recommendations To Guide Practice in Cancer published by Cancer Care Ontario (CCO) in 2008 (130), there are interactional skills and approaches to care that facilitate a supportive and therapeutic relationship between the HCP and the person affected by cancer .

In this chapter, principles of care as well as evidence-based interactional approaches are presented to aid communication by the HCP at various points throughout the cancer continuum. The approaches presented are an integration of the CCO evidence-based recommendations, the NBCC-NCCI recommended steps for provider-patient communication and by expert consensus. For a more detailed discussion of evidence-based recommendations of provider-patient communication, please refer to Provider-Patient Communication: A Report of Evidence-Based Recommendations To Guide Practice in Cancer published by CCO in 2008.

### **3.2 Principles of Care**

#### **3.2.1 Person and Family Centred Care**

As defined by Gerteis, Edgman-Levitan, Daley, and Delbanco, 1993 (131) and cited by CAPO, 2010 (pg 7, (22)), patient-centred care is “an approach that consciously adopts the patient’s perspective about what matters. It includes the following elements:

- Respecting the patient's values, personal dignity, preferences, and needs
- Providing physical comfort and emotional support
- Coordinating and integrating care
- Ensuring information, education, and communication
- Involving family and friends
- Ensuring transition and continuity
- Providing access to care
- Facilitating individuals and families to use their own resources to promote wellbeing.”(22), pg 7)

#### **3.2.2 Collaborative Person-Centred Practice**

Given the challenges of cancer, the care of individuals affected by cancer may be best provided by an interprofessional team (10, 22,132). Collaborative person-centred practice is an approach to care that, “involves the continuous interaction of two or more

professionals or disciplines, organized into a common effort, to solve or explore common issues with the best possible participation of the patient” (133), pg 2) The health care team includes all HCPs providing care such as nurses, cancer patient navigators, social workers, psychologists, radiation therapists, surgeons, oncologists, hematologists, family physicians, and others.

Various frameworks, models and determinants of successful collaborative practice are reported in the literature (134,135). For successful collaborative practice, four elements need to exist within a team: a willingness to collaborate; communication; mutual trust and respect (135).

### **3.2.3 Ensuring Continuity of Care**

The provision of diagnostic, therapeutic and psychosocial health services for persons affected by cancer involves many members of the interprofessional health care team working collaboratively with the person at different points of time, both within and outside of the hospital setting. Effective communication is necessary to avoid duplication or gaps in service and ensure that people feel supported throughout their cancer experience. The health care team is responsible for specific areas of care and ensuring follow up so that people continue to feel supported throughout the cancer continuum.

Limited research exists to provide direction on how best to provide this continuity (136). Patient navigation has developed in Nova Scotia over the past several years. This service involves a HCP who helps guide people affected by cancer through the cancer care system and provides individualized support and information as needed. More detailed information available through the following link:

[www.cancercare.ns.ca/en/home/nscancerservices/cancerpatientnavigation/help.aspx](http://www.cancercare.ns.ca/en/home/nscancerservices/cancerpatientnavigation/help.aspx) .

There is some clinical and research evidence focused on nurse-led care (137).

Advanced practice nurses coordinating care has shown promise within the management of care for persons affected by breast or prostate cancers (10,138,139). This idea has been expanded to oncology nurses caring for persons affected by other types of cancers (10,140). Based on a systematic review of palliative care/end of life interventions, there is evidence to support interprofessional interventions to improve continuity of care (141).

### **3.2.4 Shared Decision-Making**

The preferred level of involvement in decision-making varies among individuals affected by cancer (110,130). Level of involvement in shared decision-making may range from a very passive role to a very active role in decision-making. To understand each person’s preferences in this area, the HCP should directly ask how the person would like to be involved in decision-making, including the role of his/her family (130). The individual’s involvement in decision-making about his/her care may increase satisfaction with care (10). It is recognized that a person’s preferences regarding this collaboration may change across the cancer continuum (10,110,130). (See Table 4.1)

It is important to consider the individual’s ability to be involved in shared decision-

making and to provide assistance as needed. In some cases, anxiety can be increased by offering treatment options without providing assistance to make the choice (10).

### 3.3 General Interactional Skills

The therapeutic relationship is facilitated by interactional and clinical skills that enhance empathy, understanding and communication (130). The goal is to help the person affected by cancer feel comfortable/safe to ask questions, explore and address his/her needs and feelings to manage cancer-related distress. The use of open-ended questions is an effective way to initiate this discussion and allow for a range of responses by the individual affected by cancer (10).

Expressing empathy and listening actively may improve the person affected by cancer’s psychological adjustment. (10) Empathy is displayed through the use of emotional words that convey an appreciation of the person’s feelings (142). It is important for HCPs to individualize their approach to communication to be consistent with the person’s values and beliefs, background, stage of life, and individual preferences (e.g., his/her preferred role in decision- making (10,130,143,144). (See Table 3.1) All HCPs are guided by their standards of practice and ethical guidelines in regard to therapeutic relationships.

**Table 3.1. Summary of General Interactional Skills\***

| <b>Evidence-Based Approaches</b>   |
|--|
| <p><u>To convey support and establish trust:</u></p> <ul style="list-style-type: none"> <li>• Ask if he/she would prefer to have someone with them for the visit/consult/discussion.</li> <li>• Ensure a comfortable and private space.</li> <li>• Demonstrate concern by sitting attentively and actively listening.</li> <li>• Use verbal and non-verbal behaviours that are respectful of the person’s values and beliefs, background, stage of life and individual preferences (e.g., preferred role in decision-making (143,145). Refer to Chapter 6.</li> <li>• Express empathy by using words that relate to the person’s feelings (67,146).</li> <li>• Facilitate the expression of feelings by the person affected by cancer (145).</li> <li>• Discuss difficult topics directly but with sensitivity.</li> </ul> |

**\* Based on the CCO evidence-based recommendations and the NBCC-NCCI recommended steps for provider-patient communication (10,130).**

These general interactional skills apply throughout the cancer experience when providing information about disease and treatment, emotional and social support, practical and financial support, support at times of transition, and support near the end of life.

## **3.4 Providing Information**

### **3.4.1 General Information Needs and Preferences**

Research indicates that anxiety and depression may be reduced, coping enhanced, participation in decision-making and satisfaction with treatment choices increased, and communication within the family improved when people have had their needs for health-information met and are able to discuss their concerns (10,109). Since information needs vary across the cancer continuum, HCPs should ask individuals about their specific needs at different times (18,147). Evidence does not support one method of information provision as more effective than another. Some strategies (e.g., decision aids, question prompt sheets and summaries of the consult) may be helpful to some people affected by cancer and not others (113,130,148,149).

Information is provided by HCPs in a way that reflects the person's values and beliefs, background, stage of life, and individual preferences (130,143). It is important to address any barriers such as language and low literacy. It is helpful to ask what the person has understood from the discussion, to clarify any misunderstandings and allow time to address further questions and concerns (130). Refer to Table 3.2 for evidence-based approaches.

**Table 3.2. Provision of Medical Information\***

| <b>Evidence-Based Approaches</b>   |
|--|
| <p><u>To provide medical information (diagnosis, prognosis, treatment options and disease progression):</u></p> <ul style="list-style-type: none"> <li>• Ask about the person’s preference for information, prior knowledge, level of understanding, and meaning (67).</li> <li>• Provide specific information in a clear manner (67,111) .</li> <li>• Use medical terms and explanations only as needed and check for understanding.</li> <li>• Relate information to the individual’s specific situation (67,111).</li> <li>• Tailor information to each person’s preference for information and preferred level of involvement in decision-making (29,67,111,146,150).</li> <li>• Support adaptive hope (62,67,130,146)</li> <li>• Reassess the person’s understanding of information throughout the discussion as new information is provided (146,150).</li> <li>• Attend to and consider the individual’s emotional presentation (e.g., visibly anxious) (112,150).</li> <li>• Provide guidance to individuals who are actively seeking further information (e.g., offering names of reputable websites).</li> <li>• Attend to the needs of persons from diverse communities.*</li> <li>• Address barriers (e.g., language, low literacy, visual impairment)*</li> <li>• Use professional interpreting services when possible.*</li> </ul> <p style="text-align: center;">*Refer to Chapter 6 for more detailed discussion</p> |
| <p><u>To improve understanding and retention of information:</u></p> <ul style="list-style-type: none"> <li>• Facilitate questions and confirm understanding (146).</li> <li>• Use simple diagrams/pictures as appropriate with verbal explanation (112).</li> <li>• Repeat and summarize important points.</li> <li>• Some people may benefit from important points being reinforced in writing or by providing an audio recording or written summary of the consult (111-113,148,149,151).</li> <li>• Regularly assess the person’s need for more information.</li> </ul>  |

**\* Based on the CCO evidence-based recommendations and the NBCC-NCCI recommended steps for provider-patient communication (10,130).**

### **3.4.2 Diagnosis of Cancer**

Delivering the diagnosis of cancer to a person is an unpleasant and difficult part of practice for most clinicians. The way this information is provided can affect the person's understanding of his/her disease, as well as his/her long term psychological adjustment (10).

Information is best given in a private space when there is enough time for the person to discuss his/her feelings and the treatment options (10,130,130). The decision to have a support person present is the preference of the person receiving the diagnosis (10,130). (See Tables 3.1 and 3.2 for detailed evidence-based approaches)

### **3.4.3 Prognosis**

The provision of prognostic information usually flows from the diagnosis of cancer and from the discussion of various treatment options (130). It is important to ask questions to find out what the person knows already, what his/her major concern is and how much information he/she would like about his/her illness and prognosis (130). It is also important to check that the person has had all of his/her questions or concerns addressed and offer avenues to have questions/concerns that come up later addressed (130). Lin and Bauer-Wu's literature review supports the provision of prognostic information for people with advanced cancer, to help with coping and "living well in the present moment" (63)(See Tables 3.1 and 3.2)

### **3.4.4 Treatment Options**

A person's decision about treatment is affected by both the communication style of the clinician, as well as the way treatment options are presented (10,130). Identify the person's preference for involvement in decision-making (Refer to Section 3.4) and facilitate this (130)) (See Tables 3.1 and 3.2) The likelihood of an individual accepting a particular treatment may increase when information about prognosis is positively framed (i.e., presented as chances of survival) (10). It is important to recognize the uncertainty of treatment outcome and encourage the person to discuss any questions or concerns (130). HCPs provide individualized and specific information that addresses the person's need for information related to treatment options (including no treatment), expected results, side-effects, and alternative and complementary therapies (130).

### **3.4.5 Disease Progression**

For some persons affected by cancer, hearing that their cancer has recurred is even more distressing than being diagnosed with cancer for the first time (10). Further to the general interactional skills described previously, it is essential that HCPs make every effort to provide clear and specific information about disease progression, in person, in a private, comfortable space with enough time scheduled to allow the person to express his/her feelings and concerns and ask questions (130). HCPs are reminded of the potential benefits of having a support person present (if the person wishes), to help recall information and provide emotional support (130). The person's preferences for information and involvement in decision making should be respected (130). It is important that HCPs specifically ask about these again at this time as both information needs and decision making preferences change over time (130). It is also important to

reassure the person affected by cancer that supports will be available to actively treat symptoms and provide ongoing care (130). Offering to help discuss difficult topics with the family and to be available for further questions and concerns are important supportive roles for the HCP (130). Continuity of care is essential as care may be transitioned from one HCP (e.g., oncologist) to another (e.g., family physician, palliative care team). Documentation and communication of what information was provided to the person, what the person seemed to understand and his/her reaction to the information will help others continue care (130).  
(See Tables 3.1 and 3.2)

When disease progression leads to end of life care, discussions around the person's priorities, care wishes, role changes and the anticipation of greater family involvement in decision making are needed (130). Ongoing assessment of how the person and his/her family are coping is important. Refer to Section 3.11, Support towards the End of Life for a more detailed discussion of this topic.

#### **3.4.6 Medical Procedures**

Research indicates that individuals who receive information prior to a medical procedure have less anxiety and emotional distress and recover faster with fewer complications (10,130). Prior to providing information about a medical procedure, ask how much detail the person would like to know about the procedure. Information may be provided through a discussion with the HCP, and/or written material and/or recorded material and should include the following: why the procedure is needed, what the procedure will involve (e.g., any preparation required prior and what will occur before, during and after the procedure) and how they may feel before, during and after the procedure (10,130). Address any questions or concerns (e.g., anxiety) (130). Psychosocial support is effective in assisting individuals to cope with required procedures or treatment (10,130). It may be helpful to encourage the use of adaptive coping strategies before, during and after (e.g., relaxation). Please see Table 3.3 for specific approaches for medical procedures and also refer back to Tables 3.1 and 3.2.

**Table 3.3. Managing Medical Procedures\***

| <b>Evidence-Based Approaches</b>  |
|---|
| <p><u>Before a medical procedure</u></p> <ul style="list-style-type: none"> <li>• Prior to the procedure ask how much detail and what information they would like to know about the procedure. Explain purpose of the procedure and what will be involved. Allow time for discussion of any questions or concerns.</li> </ul> |
| <p><u>During a medical procedure</u></p> <ul style="list-style-type: none"> <li>• During the procedure offer psychosocial support and provide information about what will happen and how he/she may feel. Allow the person their preferred level of control when possible and as appropriate.</li> </ul>                      |
| <p><u>After a medical procedure</u></p> <ul style="list-style-type: none"> <li>• Post procedure continue to offer psychosocial support and address any additional informational needs or concerns such as post-procedure care.</li> </ul>   |

\* Based on the CCO evidence-based recommendations and the NBCC-NCCI recommended steps for provider-patient communication (10,130).

### 3.5 Emotional and Social Support

Emotional and social supports are important to the care of persons diagnosed with cancer and their family. Having support and feeling supported are major factors affecting how one adjusts to the disease (10). Refer to Chapter 2 “Understanding the Challenges of Cancer”. It is helpful for people affected by cancer to be made aware of psychosocial supports early in treatment. Individuals who receive support cope better and adjust better psychologically (152). Various sources of support may include the health care team, psychosocial health care professionals, HCP-led support groups, peer-led support groups, peer support and on-line support, in addition to family and friends.

HCPs need to anticipate and enquire specifically about concerns or unmet needs as most persons affected by cancer, including family members, will not raise them spontaneously (1,10,36,143,145,153). People who have been given an “opportunity to explore feelings with a member of the treatment team” have less cancer-related distress than those not given this opportunity (10). Psycho-spiritual well-being for people with advanced cancer has been shown to improve through open communication and a therapeutic relationship with the HCP (63). Further, asking individuals about their feelings communicates that psychosocial concerns are important aspects of their cancer experience and that HCPs are interested in attending to these needs throughout the cancer continuum. To provide ongoing support, ask regularly about how he/she is feeling emotionally and encourage expression of any fears and/or concerns (130). Ask about current support systems and offer additional resources and/or referral to specialists as appropriate (130). The approaches to emotional and social support include the general points described in Tables 3.1 and 3.2 as well as specific points in Table 3.4.

**Table 3.4 Provision of Psychosocial Support\***

| <b>Evidence-Based Approaches</b>  |
|---|
| <p><u>To provide emotional and social support:</u></p> <ul style="list-style-type: none"><li>• Ask how they are doing, how they feel about their treatment, and encourage expression of any fears and concerns (36).</li><li>• Assess current support systems (level of emotional and practical support received, how partner and family are coping) (1,80).</li><li>• Provide contact information for additional resources, support services and peer support programs (36).</li><li>• Refer to specialists for treatment as needed.</li></ul> |

\* Based on the CCO evidence-based recommendations and the NBCC-NCCI recommended steps for provider-patient communication (10,130).

### **3.6 Practical and Financial Support**

Practical or financial concerns (See Chapter 2 - Section 2.5) may make it difficult for a person to cope with his/her cancer experience. Persons affected by cancer may be reluctant to raise their practical/financial concerns due to personal boundaries, feelings of shame or worries about stigma. It is important for HCPs to enquire directly about these concerns using the general supportive interactional skills. (See Tables 3.1, 3.2 and 3.4) Normalizing these challenges and making the person aware of resources may be helpful. Recognizing that practical implications can add significantly to cancer-related distress and ensuring these elements are incorporated into assessment and care is essential.

### **3.7 Managing Transitions**

Transitions occur throughout the cancer continuum related to disease status, medical treatment, setting of care, functional ability, dying, death, bereavement and survivorship. (Refer to Chapter 2 for challenges) Generally, times of transition can be distressing and require adjustment. Communication approaches covered in Tables 3.1, 3.2 and 3.4 apply when managing transitions.

### **3.8 Support towards the End of Life**

As the goals of medical treatment change from cure, to disease control, to palliation, psychosocial care focuses on assisting persons diagnosed with cancer and their family prepare for dying and death and bereavement. As discussed in Chapter 2 (see section 2.6), challenges occur related to disease progression, existential concerns, comfort, advanced care, relationships, caregivers and anticipatory grief and bereavement (154). For example, work by Chochinov and colleagues ( e.g.,(117,155,156)) proposes directions for clinical practice focused on dignity-conserving perspectives (e.g., continuity of self, maintenance of pride) and dignity-conserving practices (e.g., living in the moment, seeking spiritual comfort), as well as social dignity (e.g., privacy boundaries, social support, care team, burden to others, aftermath concerns).

Clinical practice guidelines published by the NCCN aim to provide patients with satisfaction “with response to anticancer therapy, adequate pain and symptom control, reduction of patient/family distress, acceptable sense of control, relief of caregiver burden, strengthened relationships, optimized quality of life, personal growth and enhanced meaning” (69). For adults affected by cancer with distress scores greater than or equal to four, early referral to palliative care specialist should be considered (69).

### **3.8.1 Communication**

Towards the end of life, HCPs utilize the general interactional skills noted in Tables 3.1, 3.2, and 3.4, to enquire about specific concerns, feelings, fears and information needs, while respecting patient’s boundaries and individuality (117,130). The style of health professional communication is even more important than the content, with families identifying the need for empathic honesty, hope and encouragement to ask questions as highly important to them (67,146). Allowing individuals to express their grief may improve adjustment (10).

### **3.8.2 Provision of Information**

“Education sessions can improve adjustment, knowledge, death awareness and increase positive self-concept” (10). HCPs utilize the general interactional skills to assess information needs related to the person’s illness, care plan, dying process and supports and the provision of timely information (117). Refer to Tables 3.1, 3.2, and 3.4. Family members desire information with regard to end of life care, symptom management, and anticipatory guidance with regard to what they might expect during the dying process (80,146).

### **3.8.3 Family Relationships**

Open communication, education about cancer and opportunities to express emotions within families is usually helpful for all family members, taking into consideration developmental stage and comprehension (71,72). Family members may benefit from counseling (e.g., individuals, couples or family) to facilitate open communication, coping with strong emotions and to assist with end of life care and planning. Empirical research is limited in regard to specific interventions that may assist children and adolescents to cope (71, 72, 74). Expert opinion suggests that at a minimum children/adolescents benefit from being informed about the illness in developmentally appropriate ways and being given an opportunity to have input into their participation at the end of a loved one’s life (e.g., say goodbye to their parent) (76).

## **3.9 Specific Psychosocial, Physical and Practical Concerns**

When the healthcare team encourages the adults expression of feelings, challenges and needs related to the cancer experience, specific psychosocial, physical and practical concerns may need further exploration and follow-up. (Refer to Chapter 4) The general interactional skills noted in Tables 3.1, 3.2, and 3.4 provide techniques that can be used to facilitate this discussion.

## Chapter 4 - Screening for Cancer Related Distress

### 4.1 Overview

The use of a standard approach to screening for cancer-related distress may facilitate early recognition, assessment and management of distress (157). As noted in Chapter 2, there are many sources of distress and challenges experienced by people affected by cancer.

Screening for cancer-related distress in adults with cancer throughout the cancer continuum using a standard tool provides a means for HCPs to identify individuals' specific challenges and distress. The Screening for Distress Toolkit Working Group (Cancer Journey Action Group (CJAG) of the Canadian Partnership Against Cancer (CPAC) recommended that screening include three domains: psychosocial, practical, and physical (12). The following two self-report tools completed by the patient were recommended to form the national minimum common data set: The Edmonton Symptom Assessment System (ESAS), and the Canadian Problem Checklist (CPC). In 2012 the ESAS-r replaced the ESAS as the recommended tool. The establishment of a minimum common data set for screening for cancer-related distress will ultimately improve person-centred cancer care and patient experience, as well as facilitate clinical research (158,159). The guideline committee unanimously agreed to use the Distress Thermometer® in addition to the national minimum common data set. See Distress Thermometer heading under Section 4.4.

Following completion of the standard screening tool by the patient, the HCP then has a therapeutic conversation focusing on understanding of his/her cancer-related distress and management/treatment options. (See Sections 4.7, 4.8, 4.9)

### 4.2 Screening versus Assessment

The objective of screening for cancer-related distress is to efficiently identify those people experiencing distress and their specific concerns. Screening allows the HCP to determine the need for assessment and referral to an appropriate health care specialist for diagnosis and treatment as appropriate (160). Assessment is a thorough examination of the individual's concerns, conducted after screening (12).

*As stated in A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient (12), "Screening for distress is recommended for use as an initial "red flag" indicator of psychosocial health care needs that should be followed by a more comprehensive and focused assessment to ensure that interventions are targeted, appropriate, and relevant to the needs and specific problems identified by the individual and family." ((12), pg 18)*

In a comprehensive assessment the various aspects of an individual's psychosocial health are considered. A focused assessment is tailored to the specific concerns identified through the screening process and follows the comprehensive assessment (12). Refer to "A Pan-Canadian Clinical Practice Guideline: Assessment of Psychosocial Health Care Needs of the Adult Cancer Patient" (12) for further

information concerning comprehensive and focused assessments.

### **4.3 Who should be Screened for Cancer-Related Distress and When?**

Evidence shows that cancer-related distress is displayed by 35-45% of adults with cancer and can occur throughout the cancer continuum, from the time of initial diagnosis, through to survivorship or end of life (See Figure 4.1). For example, rates of depression in people with head and neck cancer are high at diagnosis, during cancer treatment and for several months post treatment, and that mild to moderate depression can persist up to six years following diagnosis (108). (Refer to Chapter 2)

#### ***Recommendation***

It is recommended that adults diagnosed with cancer be screened for cancer-related distress by HCPs.

Level I (13)

Level II (11)

Level III-3 (7,12)

### **4.3.1 Initial Screening following Entry to the System**

The time of the initial screen will vary depending on the individual's diagnosis, type and stage of cancer, and health care services available. It is important to screen as early as feasible following initial diagnosis. Initial screening is recommended during the person's initial few cancer-related appointments, within two months following initial diagnosis (consensus of guideline committee). HCPs must use their clinical judgement when determining the most appropriate time to have the person complete the screen. Thus, the initial screen could occur when the person is seen by:

Surgical/Radiation/Medical Oncologist, Hematologist, cancer patient navigator, family physician or upon admission to hospital. It is not recommended to screen on the day of diagnosis as distress at time of receiving diagnosis is understandably expected to be very high and will dissipate to some degree as the person adjusts to the diagnosis and receives disease management information.

It is noteworthy that some patients may choose to not complete the Screening for Distress Tool for several reasons (e.g., patient may be too stressed/too tired to complete; does not feel the question(s) apply to him/her) (6,161). In these situations, it is advisable to present the screening tool to the person affected by cancer at a later time.

#### ***Recommendation***

Screening for cancer-related distress should occur within two months following diagnosis. Re-screening should occur at critical times and times of transition throughout the cancer continuum.

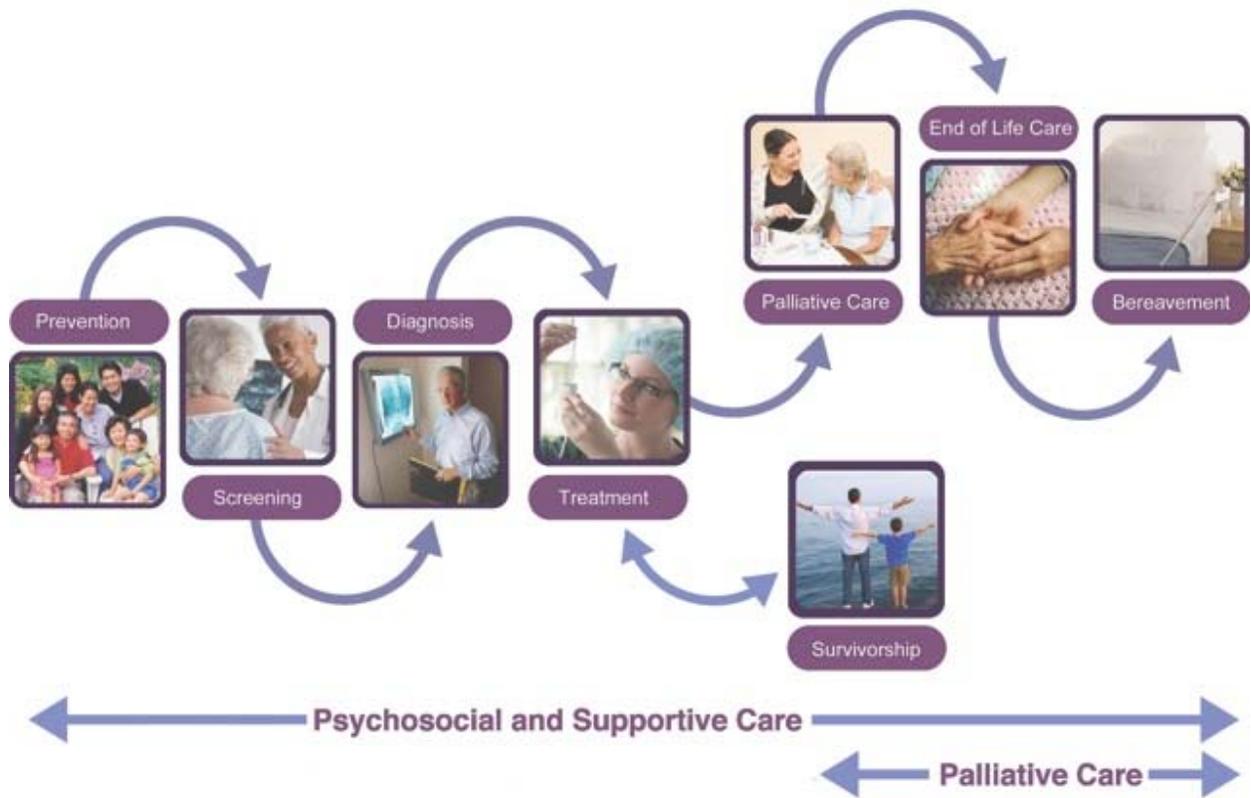
Level III-3 (7,12)

### **4.3.2 Re-screening at Critical Times or Times of Transition**

Re-screening should occur at critical times or times of transition throughout the cancer continuum, such as at the time of medical/surgical procedures, start and end of cancer treatment, transition to survivorship, changes in disease status (e.g. disease progression or recurrence), advanced disease, during end of life care, times of personal transition or re-appraisal, and other stressful times (12). These critical times may be associated with increased feelings of vulnerability and cancer-related distress (7). (See Figure 4.1 for depiction of the cancer continuum). When re-screening during active treatment, the time elapsed between screens should not exceed four months. During survivorship, it is reasonable to consider re-screening on an annual basis.

Since family members also experience cancer-related distress, HCPs should consider screening family members for distress, if possible, or at a minimum, inquiring (71-74) about how family members are coping (e.g., partners, and children/partners may experience adjustment issues in response to parental cancer, respectively).

**Figure 4.1 Cancer Continuum ((22), pg7)**



### **4.3.3 Risk factors for cancer-related distress**

HCPs should be aware of risk factors for cancer-related distress, specifically clinical levels of anxiety and depression. In summary, these include (2,5-7,162):

- Pre-existing psychological problems or history of substance abuse
- Advanced illness, poor prognosis, greater disease burden and physical disability (8)
- Poorly controlled symptoms (e.g., pain)
- Lower levels of social support
- Other concurrent psychosocial/life stressors (e.g., young children, financial stress, family concerns)
- Communication difficulties (e.g., language, literacy, interactions with health care team)
- Existential/spiritual issues
- Younger age
- Female gender

Early referral of people at risk for psychological problems may help reduce the chance of significant disorders developing (10).

#### 4.4 Screening for Distress Tool

The Screening for Distress Tool (adapted for Nova Scotia) includes the Edmonton Symptom Assessment System, The Canadian Problem Checklist and The Distress Thermometer®. Each is described.

##### **Recommendation**

**Screening will be done with the Screening for Distress Tool (adapted for Nova Scotia). The tool consists of:**

- **The Edmonton Symptom Assessment System-revised (ESAS-r)** (14,15);
- **The Canadian Problem Checklist (CPC)** (16);
- **The Distress Thermometer® (DT)** (7,12)

Level I\*\* (13)

Level II\*\* (7,11,12,16)

Level III-3\*\* (16)

(See Table 4.4).

\*\*The references cited relate to specific parts of the Screening for Distress Tool (i.e., DT, ESAS-r, CPC).

**Edmonton Symptom Assessment System (ESAS).** The ESAS (14) is a commonly used screening tool in Canada. It has sound psychometric properties and has been validated with cancer groups, although predominantly within palliative care (12,163,164). The ESAS consists of 10 symptoms/items; each rated by the individual on a scale from 0 (absent/best) to 10 (worst possible). The items focus on specific physical and emotional concerns that can be experienced by people with cancer. The ESAS is included in Table 4.1a.

A revised version of the ESAS (ESAS-r recently published) retains the same symptom items/elements of the ESAS (i.e., 9 specific symptoms and optional 10<sup>th</sup> symptom) with revisions (i.e., item order, terminology, and format) (15). The ESAS-r is included in Table 4.1b. Watanabe et al. (2011) report that although most patients (sample of palliative patients) rated the ESAS and ESAS-r as easy to understand, significantly more patients preferred the ESAS-r as it was easier.

In the revised version of the screening for distress implementation manual that was released in 2013 (159), the ESAS-r rather than the ESAS, was recommended for use as part of the minimum common data set. In Nova Scotia, the ESAS-r has been unanimously recommended by the guideline committee to replace the use of the ESAS in the Screening for Distress Tool.

**Table 4.1 a – Edmonton Symptom Assessment System**

| Edmonton Symptom Assessment System (ESAS)            |   |   |   |   |   |   |   |   |   |   |  |
|--|---|---|---|---|---|---|---|---|---|---|--|
| <b>Please circle the number that best describes:</b> |   |   |   |   |   |   |   |   |   |   |  |
| No pain  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Worst possible pain                 |
| Not tired  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Worst possible tiredness            |
| Not nauseated  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Worst possible nausea               |
| Not depressed  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Worst possible depression           |
| Not anxious  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Worst possible anxiety              |
| Not drowsy   | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Worst possible drowsiness           |
| Best appetite  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Worst possible appetite             |
| Best feeling of wellbeing                            | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Worst possible feeling of wellbeing |
| No shortness of breath                               | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Worst possible shortness of breath  |
| Other problem  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10                                     |

**Table 4.1 b The Edmonton Symptom Assessment System-revised**



**Edmonton Symptom Assessment System:  
(revised version) (ESAS-R)**

**Please circle the number that best describes how you feel NOW:**

|   |   |   |   |   |   |   |   |   |   |   |    |                                    |
|---|---|---|---|---|---|---|---|---|---|---|----|------------------------------------|
| No Pain   | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Pain                |
| No Tiredness<br><i>(Tiredness = lack of energy)</i>         | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Tiredness           |
| No Drowsiness<br><i>(Drowsiness = feeling sleepy)</i>       | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Drowsiness          |
| No Nausea   | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Nausea              |
| No Lack of Appetite   | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Lack of Appetite    |
| No Shortness of Breath                                      | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Shortness of Breath |
| No Depression<br><i>(Depression = feeling sad)</i>          | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Depression          |
| No Anxiety<br><i>(Anxiety = feeling nervous)</i>            | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Anxiety             |
| Best Wellbeing<br><i>(Wellbeing = how you feel overall)</i> | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Wellbeing           |
| No _____<br>Other Problem <i>(for example constipation)</i> | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible _____               |

Patient's Name \_\_\_\_\_

Date \_\_\_\_\_ Time \_\_\_\_\_

Completed by (check one):

- Patient
- Family caregiver
- Health care professional caregiver
- Caregiver-assisted

**BODY DIAGRAM ON REVERSE SIDE**

**ESAS-r**  
Revised: November 2010

1

<sup>1</sup> As included in Screening for Distress the 6<sup>th</sup> Vital Sign: A Guide for Implementing Best Practices in Person-Centred Care.(159),page 71.

**Canadian Problem Checklist (CPC).** The Canadian Problem Checklist (16) was developed by the Screening for Distress Toolkit Working Group to capture practical, psychosocial, and physical concerns, and complements the information collected in the ESAS (164). This checklist was informed from the Problem List from NCCN (7). The Canadian Problem Checklist is part of the minimum common data set and includes 21 items. At a national level, it has been agreed that items can be added by any jurisdiction using this tool. In Nova Scotia, the following items have been added: **Medication Coverage**, under Practical Concerns; **Relationship Difficulties**, under Social/Family Concerns; and **Swallowing**, under Physical Concerns. When completing this checklist, the person affected by cancer checks all of the items that have been a concern or problem for him/her during the past week. The Canadian Problem Checklist is included in Table 4.2.

**Table 4.2 Canadian Problem Checklist**

Please check all of the following items that have been a concern or a problem for you in the past week including today:

**Practical:**

- Work/School
- Finances
- Getting to and from appointments
- Accommodation
- Medication Coverage

**Social/Family:**

- Feeling a burden to others
- Worry about friends/family
- Feeling alone
- Relationship difficulties

**Emotional:**

- Fears/Worries
- Sadness
- Frustration/Anger
- Changes in appearance
- Intimacy/Sexuality

**Spiritual:**

- Meaning/Purpose of Life
- Faith

**Informational:**

- Understanding my illness and/or treatment
- Talking with the health care team
- Making treatment decisions
- Knowing about available resources

**Physical:**

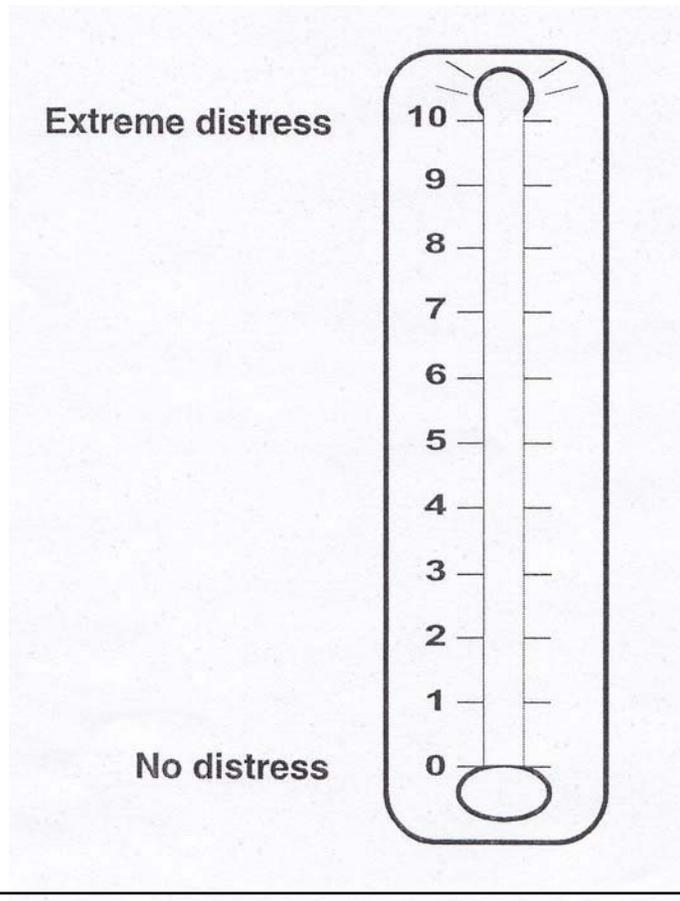
- Concentration/Memory
- Sleep
- Weight
- Swallowing

Nova Scotia Version - 2010

**Distress Thermometer® (DT).** The Distress Thermometer® was developed by the NCCN and has been found to be a valid and reliable tool to screen for cancer-related distress (7, 13,165). It has been used with various cancer populations in several countries (e.g., Dolbeault et al., 2008, Wang et al., 2011) (6, 82,166,167). This visual analogue scale which appears as a thermometer is a rapid user-friendly means to measure cancer-related distress. Given the strengths of the DT and its wide use with varied cancer populations across cultures the guideline committee unanimously agreed to use the DT in the Screening for Distress Tool. The person diagnosed with cancer is asked to rate the amount of distress he/she has experienced over the past week, from 0 (no distress) to 10 (extreme distress). The NCCN Guideline indicates that a score of 4 or greater is considered to identify a moderate or severe level of distress and requires assessment (7). According to the NCCN Guidelines for Distress Management, individuals should be referred for specialized care (for diagnosis and treatment, as appropriate) when there is evidence of moderate to severe distress (7,160). The Distress Thermometer is depicted in Table 4.3.

**Table 4.3 Distress Thermometer**

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

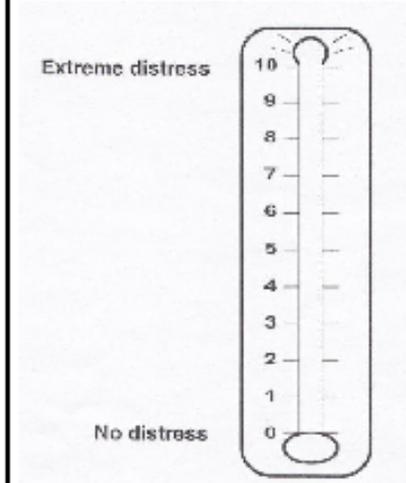


### **The Screening for Distress Tool**

The recommended tool is depicted in Table 4.4. This tool is being used in the Nova Scotia Screening for Distress Program, in partnership with CCNS and the Nova Scotia District Health Authorities. This work was initially made possible with the support of CPAC, by a financial contribution from Health Canada. It is a self-report tool completed by the patient. HCP feedback on the use of this tool in identifying the concerns of individuals experiencing distress has been generally positive (161).

In the Nova Scotia Screening for Distress Initiative, most persons offered the screen agree to complete the tool and the refusal rate has been low (161). Further, preliminary feedback from a sample of patients completing the screen is positive.

**Table 4.4 The Screening for Distress Tool**

|   |  |   |
|---|--|---|
|  <b>To be completed by patient</b>   |  | Place patient label here  |
| <h2 style="margin: 0;">Screening for Distress</h2>  |  |   |
| MSI #: _____<br>Date (DD/MM/YYYY): _____  |  |   |
| <b>1. Canadian Problem Checklist</b>  |  | <b>2. Distress Thermometer</b>  |
| Please check all of the following items that have been a concern or problem for you in the past week, including today:  |  | Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week, including today: |
| <b>Practical:</b><br><input type="checkbox"/> Work/School<br><input type="checkbox"/> Finances<br><input type="checkbox"/> Getting to and from appointments<br><input type="checkbox"/> Accommodations<br><input type="checkbox"/> Medication Coverage<br><br><b>Social/Family:</b><br><input type="checkbox"/> Feeling a burden to others<br><input type="checkbox"/> Worry about friends/family<br><input type="checkbox"/> Feeling Alone<br><input type="checkbox"/> Relationship difficulties<br><br><b>Emotional:</b><br><input type="checkbox"/> Fears/Worries<br><input type="checkbox"/> Sadness<br><input type="checkbox"/> Frustration/Anger<br><input type="checkbox"/> Changes in Appearance<br><input type="checkbox"/> Intimacy/Sexuality | <b>Spiritual:</b><br><input type="checkbox"/> Meaning/Purpose of Life<br><input type="checkbox"/> Faith<br><br><b>Informational:</b><br><input type="checkbox"/> Understanding my illness and/or treatment<br><input type="checkbox"/> Talking with the health care team<br><input type="checkbox"/> Making treatment decisions<br><input type="checkbox"/> Knowing about available resources<br><br><b>Physical:</b><br><input type="checkbox"/> Concentration/memory<br><input type="checkbox"/> Sleep<br><input type="checkbox"/> Weight<br><input type="checkbox"/> Swallowing |    |
| <b>3. Edmonton Symptom Assessment System (ESAS- R):</b>   |  |   |
| Please circle the number that best describes how you feel NOW:  |  |   |
| No Pain   | 0 1 2 3 4 5 6 7 8 9 10   | Worst Possible Pain   |
| No Tiredness<br><small>(Tiredness= lack of energy)</small>  | 0 1 2 3 4 5 6 7 8 9 10   | Worst Possible Tiredness  |
| No Drowsiness<br><small>(Drowsiness= feeling sleepy)</small>  | 0 1 2 3 4 5 6 7 8 9 10   | Worst Possible Drowsiness   |
| No Nausea   | 0 1 2 3 4 5 6 7 8 9 10   | Worst Possible Nausea   |
| No Lack of Appetite   | 0 1 2 3 4 5 6 7 8 9 10   | Worst Possible Lack of Appetite   |
| No Shortness of Breath  | 0 1 2 3 4 5 6 7 8 9 10   | Worst Possible Shortness of Breath  |
| No Depression<br><small>(Depression= feeling sad)</small>   | 0 1 2 3 4 5 6 7 8 9 10   | Worst Possible Depression   |
| No Anxiety<br><small>(Anxiety= feeling nervous)</small>   | 0 1 2 3 4 5 6 7 8 9 10   | Worst Possible Anxiety  |
| Best Wellbeing<br><small>(Wellbeing= how you feel overall)</small>  | 0 1 2 3 4 5 6 7 8 9 10   | Worst Possible Wellbeing  |
| No _____  | 0 1 2 3 4 5 6 7 8 9 10   | Worst Possible _____  |
| Other Problem (for example constipation)  |  |   |

#### **4.5 HCPs Screen for Cancer-Related Distress**

Any member of the health care team providing care to persons diagnosed with cancer can conduct screening for distress. The health care team includes all HCPs providing care to an individual with cancer. HCPs well positioned to screen for cancer-related distress may include nurses, cancer patient navigators, social workers, psychologists, radiation therapists, surgeons, oncologists, hematologists, family physicians, and others. Each team must identify the HCPs who are responsible to screen for cancer-related distress.

#### **4.6 Levels of Cancer-Related Distress and Referral Pathway**

When utilizing the recommended Screening for Distress Tool, HCPs will identify people experiencing varying levels of distress. As illustrated in the Screening for Cancer-Related Distress Algorithm (See Figure 4.2), HCPs use the individual's responses on the Screening for Distress Tool and have a therapeutic conversation (See Section 4.7 for discussion of therapeutic conversation) with the person affected by cancer to determine the best approach for cancer-related distress management.

As indicated in Table 4.5, mild distress is defined as DT or ESAS-r item scores less than 4. "The ESAS cut-off scores are assumed to mirror the NCCN DT cut-offs (mild less than 4, moderate to high 4 to 10), but this requires further research to fully validate." ( (2), p30). Moderate distress is defined as DT or ESAS-r item scores of 4 to 7. High distress is defined as DT or ESAS-r item scores of 8 or greater. Although the CPC responses are not used as cut-off scores for level of distress, the information on the CPC alerts the HCP to the individual's specific concerns. It should be noted that individuals will most likely identify some concerns on the CPC, regardless of their distress level on the ESAS-r and DT, and it is important that these be attended to. See Sections 4.8 and 4.9 for discussion of management of mild, moderate and high distress.

**Table 4.5 Levels of Distress**

| <u>Levels of Distress</u> |  |
|---------------------------|--|
| Mild Distress             | <ul style="list-style-type: none"><li>• Distress Thermometer or ESAS-r Score &lt; 4 and/or concerns identified on Canadian Problem Checklist</li></ul> |
| Moderate Distress         | <ul style="list-style-type: none"><li>• Distress Thermometer or ESAS-r Score ≥ 4 to 7</li></ul>  |
| High Distress             | <ul style="list-style-type: none"><li>• Distress Thermometer or ESAS-r Score ≥ 8</li></ul>   |

***Recommendations to respond to and manage high, moderate and mild cancer-related distress are as follows:***

**Adults with one or more distress scores on the ESAS-r and/or DT of 8 or greater are in high distress and require an urgent decision by the health care team to either manage the distress directly or make a referral to an appropriate health care specialist for specialized assessment and care (See Figure 4.2)**

Level I\*\*\* (2,12)  
Level II\*\*\* (11)  
Level III-1\*\*\* (12)

**Individuals in moderate distress with one or more scores on the ESAS-r and/or DT between 4 and 7 may be managed by the health care team or referred to an appropriate health care specialist, for specialized assessment and care.**

Level I \*\*\*(2,12)  
Level II\*\*\* (11)  
Level III-1\*\*\* (2,12)

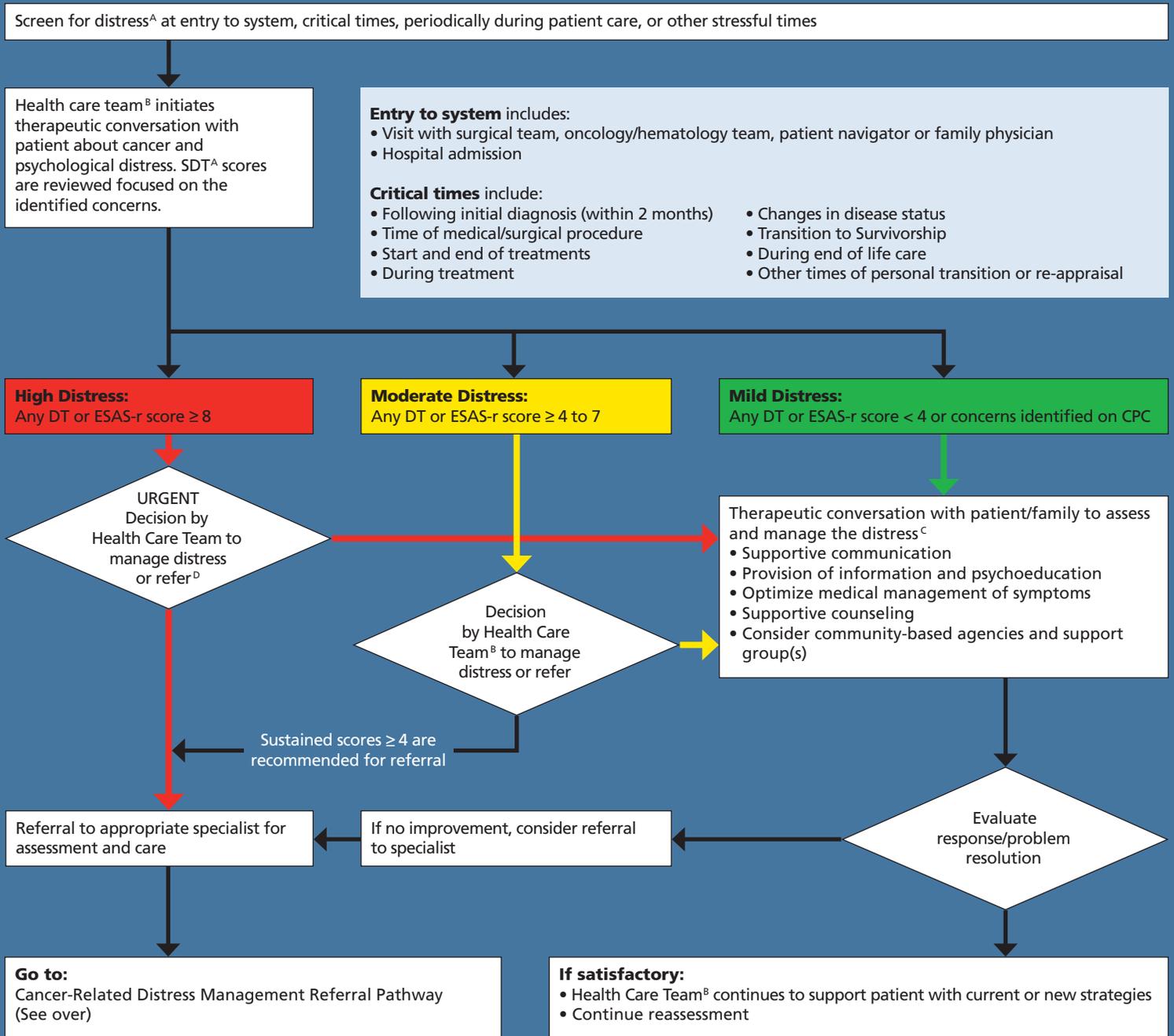
**Individuals in mild distress, with all scores on the ESAS-r and/or DT less than 4 can be managed by the health care team. If distress does not improve, consider referral to an appropriate health care specialist, for specialized assessment and care (See Figure 4.2)**

Level I\*\*\* (2)  
Level III-1\*\*\* (2)  
Level III-3\*\*\* (17)

\*\*\* Evidence for intervention varies; with strong evidence for some interventions. Although there is limited evidence for exact cut-off scores, the recommended cut-off scores are evidence informed and have the unanimous support of the guideline committee.

# Screening for Cancer-Related Distress Algorithm

Quick Reference Card



A. Patient completes Screening for Distress Tool (SDT), which includes Distress Thermometer (DT), Edmonton Symptom Assessment System-revised (ESAS-r) and Canadian Problem Checklist (CPC). In some circumstances, the patient may need assistance to complete the SDT (see Chapter 6).

B. The Health Care Team may include surgeons, oncologists, hematologists, family physicians, nurses, social workers, psychologists, patient navigators, and other health care professionals (HCPs).

C. See Chapters 3 and 4 for communication approaches.

D. Most patients with HIGH distress will require referral.

#### 4.7 Therapeutic Conversation to Discuss Results of Screening for Cancer-Related Distress

As noted by Jacobsen et al., and Mitchell et al., (168,169), screening alone is unlikely to lead to improved patient outcomes. Exploration of the person’s cancer-related distress through a therapeutic conversation is essential (See Chapter 3 for evidence-based interactional skills) to help the HCP to understand the individual’s distress and to provide the person the opportunity to discuss their concerns (82,170). **Regardless of the level of distress on screening, the HCP must have a therapeutic conversation with the person affected by cancer** (See Screening for Distress Algorithm, Figure 4.2).

After the individual affected by cancer completes the screening for cancer-related distress tool, the HCP reviews the screening for distress scores and the Screening for Distress Algorithm. The HCP has a brief therapeutic conversation with the person affected by cancer to review the screening for distress responses. In order to determine the nature, severity and duration of the cancer-related distress, and what services may be helpful to the individual, HCPs ask specific, focused questions. When several problems have been endorsed on the Screening for Distress Tool (i.e.; the CPC, DT and ESAS-r), the HCP is encouraged to start by asking the person what is troubling them the most, and then focus on this patient identified concern. In Nova Scotia, feedback from HCPs indicates that this screening process leads to more focused, more supportive and more meaningful therapeutic conversations (161). The therapeutic conversation is consistent with the “Assessment to clarify nature and extent of depressive /anxiety symptoms” as described in “A Pan-Canadian Practice Guideline: Screening, Assessment and Care of Psychological Distress (Depression, Anxiety) in Adults with Cancer” (2).

The use of drill down questions in the therapeutic conversation helps the HCP explore/understand the individual’s concerns. Therapeutic conversation also provides an opportunity for the HCP to acknowledge and normalize the person’s feelings and provide support.

The BATHE developed by Stuart and Lieberman is a useful framework for the therapeutic conversation concerning the Screening for Distress results (171). This framework was adapted by McLeod et al., (172), for use with screening for distress. BATHE-RS stands for the following (172):

|          |  |
|----------|--|
| <b>B</b> | Collect Relevant <b>Background</b> Information             |
| <b>A</b> | Find Out About the Person’s <b>Affect</b>                  |
| <b>T</b> | What is <b>Troubling</b> the Person Most                   |
| <b>H</b> | How is the Person <b>Handling</b> This Concern             |
| <b>E</b> | Express <b>Empathy</b>                                     |
| <b>R</b> | Health Care Provider’s <b>Response</b> and <b>Referral</b> |
| <b>S</b> | <b>Screening</b> Follow-up                                 |

It is important to use the person’s screen results to help focus the conversation.

A useful opening question is, “**You have checked a number of concerns on the tool, what concern(s) is/are bothering you the most?**” Examples of questions that correspond with the BATHE-RS model are as follows:

|          |   |
|----------|---|
| <b>B</b> | <b>Background</b><br>“Tell me about this concern”   |
| <b>A</b> | <b>Affect</b><br>“How do you feel about that?”<br>“Tell me how you feel.”<br>“How does this (specific emotion identified by the patient) feel”?   |
| <b>T</b> | <b>Trouble</b><br>“What about this symptom/situation troubles you the most?”<br>“How is this symptom/situation affecting your day to day life?”   |
| <b>H</b> | <b>Handling</b><br>“How are you managing/handling this?”<br><br><b><u>Drill down questions</u></b><br>“What have you tried to do to cope with this concern?”<br>“Is this helping?”<br>“What supports are helpful to you?”<br>“How have you coped with concerns/stress in the past?” |
| <b>E</b> | <b>Empathic Approach ( See Chapter 3)</b>   |
| <b>R</b> | <b>Response/Referral</b> – Use the Screening for Cancer-Related Distress Algorithm and Referral Pathways(See Figures 4.2 and 5.3)   |
| <b>S</b> | <b>Screening Follow-up</b> - Services/treatment provided and plan to re-screen in the future.   |

## **Examples of Therapeutic Conversations**

**Example 1: Anxiety.** An individual was screened with the Screening for Distress Tool and rated his/her distress as 6 on the DT, rated anxiety and well-being as 4 and 6 respectively on the ESAS-r; and endorsed concerns of fears /worries, concentration/memory and finances on the CPC.

- *You have checked a number of concerns on the tool. What concern is bothering you the most?*
- The person responds, “I am feeling anxious and scared”.  
Drill down questions focus on anxiety and fear:
- *Tell me about the anxiety and fear. (Background)*
- *What does this feel like? (Affect)*
- *What about the anxiety and fear troubles you the most? (Trouble)*
- *How are the anxiety and fears affecting how you function? (Trouble)*
- *How long have you been feeling this way? (Background)*
  - *Briefly explore mental health history if relevant*
- *What have you tried to do to manage this? (Handling)*
  - *How helpful is this?*
- *What supports are helpful for you? (Handling)*
  - *Are you reaching out to your supports (family, friends, co-workers)?*
- *How have you coped with anxiety/fears in the past? (Handling)*
- *This must be difficult and stressful for you. (Empathy)*

**Example 2: Depression.** An individual was screened with the Screening for Distress Tool and rated his/her distress as 8 on the DT, rated depression as 4 and appetite as 8 on the ESAS-r, and endorsed concerns of sadness and feeling alone, getting to and from appointments, meaning and purpose, and worry about friends/family on the CPC.

- *You have checked a number of concerns on the tool. What concern is bothering you the most?*
- Person responds, “I am feeling sad and alone”.  
Drill down questions focus on the sadness and feeling alone:
- *Tell me about the sadness and feeling alone. (Background)*
- *What does the sadness feel like? (Affect)*
- *What is troubling you the most about the sadness and feeling alone? (Trouble)*
- *How is your sadness affecting how you are functioning day to day? (Trouble)*
- *How long have you been feeling this way? (Background)*
  - *Briefly explore mental health history if relevant*
- *Do you have thoughts of harming yourself or suicide? (Affect/Trouble)*
- *What have you tried to do to manage this? (Handling)*
  - *How helpful is this?*
- *What supports are helpful for you? (Handling)*
  - *Are you accessing your supports (family, friends, co-workers)*
- *How have you coped with sadness in the past? (Handling)*

- *You seem to be struggling emotionally. This must be hard. (Empathy)*

In both of these examples, some of the other endorsed concerns may be discussed by the patient in response to specific drill down questions. Also, depending on the patient's responses to the drill down questions, the HCP may need to ask more specific questions (e.g., inquire about suicidal ideation, if patient indicates this or alludes to it).

#### **4.8 Management of Mild to Moderate Cancer-Related Distress by the Health Care Team**

The Screening for Distress Algorithm, depicted in Figure 4.2 provides information about when to refer based on the screen scores and the therapeutic conversation between the HCP and the person affected by cancer.

##### **Mild Distress**

For most cases of **mild distress**, the HCP/health care team will be able to manage the person's concerns through supportive communication, normalization, provision of information, supportive counseling, and making the person aware of support services and community-based agencies. See Figure 4.2

**Supportive communication** consists of evidence-based communication approaches and interactional skills that most HCPs are familiar with (e.g., expressing empathy, reassurance and encouragement as appropriate). Refer to Chapter 3 for further information.

When using **supportive counseling** (173,174) the HCP would:

- Support the person and enhance his/her strengths, coping skills and capacity to use supports;
- Help person to manage anxiety, anger, sadness or other difficult emotions;
- Help person manage symptoms associated with cancer and treatment;
- Enhance the person's function, and quality of life; and
- Reduce psychosocial distress.

In cases where mild distress does not decrease over time or increases, referral to a specialist should be considered (See Figure 4.2).

##### **Moderate Distress**

In cases of moderate distress, the HCP/health care team makes a decision to manage the cancer-related distress or refer. If the health care team manages the cancer-related distress, the response is similar to that for mild cancer-related distress. In situations where the HCP/health care team decides to refer the person, the HCP then follows the Cancer-Related Distress Management Referral Pathway (See Figure 5.3).

For people experiencing mild or moderate cancer-related distress (as in Example 1, Section 4.7), the HCP should provide information about the disease, medical treatment, basic coping strategies, available supports, and specialist treatment, as appropriate.

Example statements from HCP:

- *“I am going to give you some written information about your medical treatment in addition to what we have discussed, as I think this will be helpful.” (Response/Referral)*
- *“You seem to be doing okay right now but I am here if you run into any difficulties.” (Response/Referral)*
- *“You expressed an interest in joining a support group; here is some information about what is available.” (Response/Referral)*
- *“Many people dealing with cancer experience distress. This must be difficult for you, but it sounds like you have some strategies and supports that are working for you.” (Response/Referral)*
- *“I will continue to check in with you when you are seen in the clinic.” (Screening Follow-up)*
- *“If at any time you feel you would benefit from further help, please let me know. There are additional supports we can offer you.” (Screening Follow-up)*

As indicated in the Screening for Cancer-Related Distress Algorithm (Figure 4.2), when distress does not decrease over time or worsens referral to a specialist is advisable (See Chapter 5). This is particularly important for those who are moderately distressed.

#### **4.9 Management of High Cancer-Related Distress by the Health Care Team**

In cases of high distress an urgent decision by the HCP/health care team to manage the cancer-related distress or refer the person for specialized care is recommended. In many cases where the patient displays high distress, referral will be indicated. This is consistent with “A Pan-Canadian Practice Guideline: Screening, Assessment and Care of Psychological Distress (Depression, Anxiety) in Adults with Cancer” for patients displaying severe anxiety or severe depression (2, 11, 17). For individuals with high distress, there may be some situations where the team and the individual affected by cancer make a decision to manage the cancer-related distress without specialist referral (17). This would be influenced by the nature of the cancer-related distress and the HCP’s clinical judgment and skills (members of the health care team may have training and skills related to specific interventions). For example, a person who is highly distressed after diagnosis due to misinformation or lack of information concerning diagnosis and prognosis may have his/her distress reduced by conversation with his/her HCP focused on clarification of information about his/her diagnosis and prognosis. Psychoeducation may also be provided by the HCP/health care team related to symptom management and procedural anxiety, as examples. It is beyond the scope of this guideline to comprehensively address specific care approaches for physical symptoms. For further information concerning evidence-based clinical practice guidelines for specific physical symptoms refer to CCNS Symptom Management Guidelines (Pain, Oral Complications, Nausea and Vomiting), <http://www.cancercare.ns.ca/en/home/healthprofessionals/resourcestools/cancermanagementguidelines/allapprovedguidelines/supportivecare.aspx>

and to Pan-Canadian Symptom Guidelines (Fatigue, Pain, Sleep), <http://www.cancerview.ca> .

When responding to patients in high distress (as in Example 2, Section 4.7) who require referral, normalization and the benefits of referral should be noted.

Example: Statement from HCP

- *“Many people dealing with cancer experience sadness and distress, and find it helpful to talk about their concerns with a psychologist. I would like to refer you to Dr. \_\_\_\_\_ (Psychologist) to help you deal with your sadness.” (Response/Referral)*

#### **4.10 Screening for Distress Summary Sheet**

Regardless of the patient’s level of distress, the HCP who has the therapeutic conversation with the patient completes the summary sheet (See Table 4.6). In the summary sheet, the HCP documents the outcome and plan of the screen and therapeutic conversation (e.g., no screening follow-up needed; health care team following; specialist referral made). Both the completed tool and summary sheet are part of the patient’s health care record.

#### **4.11 Implementing Screening for Cancer-Related Distress**

Several lessons have been learned about the implementation of screening for distress from The Nova Scotia Screening for Distress Initiative and the other Canadian jurisdictions who have implemented screening with the support of CPAC by a financial contribution from Health Canada.

Some of the key components for successful implementation include:

- high level administrative and clinical leader support (e.g., provision of time for learning for HCPs; recognition of the psychosocial as well as the physical impact of cancer on patients and their families; support need for psychosocial services)
- education for administrators, clinical leaders, educators, HCPs, an clerical staff
- identification of champions to facilitate/support implementation
- recognition and support of practice change associated with implementation of screening
- identification of HCPs responsible for screening
- integration of screening and re-screening into routine practice
- phased approach to implementation
- open communication and feedback concerning successes and challenges of implementation
- identification of barriers or challenges to implementation and problem solving
- reviewing available resources to determine resource strengths and gaps (e.g., psychosocial resource inventory in Nova Scotia)
- reviewing delivery of clinical services to meet identified needs

For further information about implementing screening for distress, please refer to Screening for Distress, the 6th Vital Sign: A Guide to Implementing Best Practices in Person-Centred Care (159).



## **Chapter 5 - Specialized Care for Management of Cancer-Related Distress**

### **5.1 Overview**

Feelings of fear, worry, anxiety, irritability, sadness, loss, being overwhelmed, guilt and/or anger are understandable and normal emotional/stress responses to the cancer experience. As discussed in Chapter 2, many individuals display a high level of emotional/psychological resiliency throughout their cancer experience and are able to effectively use, adapt or expand their usual coping strategies to manage the stress caused by their cancer. However, 35-45% of individuals will experience clinically significant distress at some point during their cancer experience (3,4) and may require referral for specialist care.

As discussed in Chapter 4, identification of cancer-related distress involves screening for distress, therapeutic conversation with the HCP and assessment of symptoms such as worries, fear, sadness, despair, concentration problems, family problems, spiritual crisis and/or practical concerns. A variety of interventions and counseling approaches are effective in reducing distress of people affected by cancer. Some benefits of specialized care include decreased anxiety and depression, improved communication, and improved adjustment and coping. Refer to Section 5.2 and Table 5.1.

When it is determined that the person affected by cancer is experiencing a high or ongoing level of distress and needs specialized care (as noted in the Screening for Cancer-Related Distress Algorithm, Figure 4.2), referral to an appropriate psychosocial oncology health care specialist is recommended (see Figure 5.3 Cancer- Related Distress Management Referral Pathway). It is important to explain the nature and potential benefits of the referral to the individual, understanding that the decision to accept or decline the referral is his or hers. The person's decision to accept or decline the referral may be affected by several factors such as his/her psychological orientation, his/her coping style, limited information about the service, and misperceptions. Given this, it would be beneficial to re-offer the referral if the person declines and continues to be distressed. When seen for specialized assessment and care, the individual has personal responsibility to address and work on his/her concerns in counseling or psychotherapy.

### **Recommendation**

**When the adult affected by cancer needs specialized care (i.e., assessment and/or treatment), referral to the health care specialist with expertise relevant to the identified distress problem is recommended. (See Referral Pathway, Figure 5.3)**

Level I (2,7)

Level II (11)

Implementation of this recommendation for specialist care may be affected by local circumstances such as limited resources and/or availability of psychosocial oncology specialists. When a psychosocial oncology HCP is not available, then referral to the most appropriate HCP should be offered. Practitioners, such as family physicians or advanced practice nurses with training in specific interventions, may be an alternative (2). Family physicians or cancer patient navigators should be consulted to identify locally available resources and/or expertise.

### **5.2 Types and Benefits of Psychotherapeutic and Counseling Approaches**

In the following table, some of the psychotherapies and counseling approaches that can be used to treat individuals with cancer-related distress are noted. This table is only a cursory summary and not an exhaustive listing. The most constructive therapeutic approach will be determined by an assessment of the difficulties and needs of the individual affected by cancer, the available community resources, and the best available evidence. It is beyond the scope of this guideline to comprehensively address specific care approaches for physical symptoms. For further information concerning evidence-based clinical practice guidelines for specific physical symptoms refer to CCNS Symptom Management Guidelines, (Pain, Oral Complications, Nausea and Vomiting) <http://www.cancercare.ns.ca/en/home/healthprofessionals/resourcestools/cancermanagementguidelines/allapprovedguidelines/supportivecare.aspx> and to Pan-Canadian Symptom Guidelines, (Fatigue, Pain, Sleep) <http://www.cancerview.ca> .

**Table 5.1 General Types of Interventions and Examples of Potential Benefits for Individuals Affected by Cancer**

| Type  | Description  | Potential Benefits   |
|---|--|--|
| <p><b>Individual Psychotherapy</b></p> <ul style="list-style-type: none"> <li>• Cognitive-Behavioural therapy; Behavioural therapy; Stress Management; Coping skills training.</li> <br/> <li>• Supportive; Supportive – Expressive; Existential Therapy</li> </ul> | <p>Focuses on teaching/expanding skills and coping strategies such as problem-solving, cognitive reframing, challenging cognitive distortions, relaxation therapy, and imagery techniques to help cope with stress, anxiety, fears, depression, adjustments, and living with uncertainty.</p><br><p>Encourages emotional expression, validation of feelings, empathic listening, support, encouragement, and provides information. Helps to identify the individual's strengths and supports adaptive coping strategies.</p> | <ul style="list-style-type: none"> <li>• Decrease distress</li> <li>• Improvement in anxiety and depression</li> <li>• Improvement in coping</li> <li>• Helpful in managing pain and sleep difficulties</li> <li>• Improvement in quality of life (5,42,105,175-180)</li> <li>• Improvement in Physical Functioning (181)</li> <li>• Management of cancer-related fatigue (92)</li> <br/> <li>• Improvement in anxiety, depression, adjustment, and coping (42,119)</li> </ul> |
| <p><b>Group Psychotherapy</b></p>   | <p>Focuses on sharing experiences and listening to the experiences of others. Can incorporate cognitive-behavioural therapy, supportive psychotherapy and other therapy approaches, as well as an educational component.</p>   | <ul style="list-style-type: none"> <li>• Improvement in anxiety, depression, emotional well-being, coping, and/or adjustment (46,70,105,177,182-185).</li> </ul>   |
| <p><b>Psychoeducation/Education</b></p>   | <p>Consists of a brief intervention (1 to 6 sessions) administered on an individual or group basis. Focuses on the provision of information concerning aspects of the cancer experience (e.g., education about cancer, medical treatment, symptom management and emotional reactions).</p>   | <ul style="list-style-type: none"> <li>• Effective in reducing anxiety and depression. (5, 42,170).</li> <li>• Management of cancer-related fatigue (92).</li> <li>• Assistance with sexual health concerns (54,186).</li> <li>• Management of hot flashes in breast cancer survivors (187).</li> </ul>  |
| <p><b>Hypnotherapy</b></p>  | <p>Therapy of a hypnotic process that consists of techniques for induction, deepening, therapy (e.g., suggestions, regimens), post hypnotic suggestions and ego boosting.</p>  | <ul style="list-style-type: none"> <li>• Limited evidence for effectiveness of hypnotherapy for pain and nausea (188).</li> <li>• Cognitive-behavioural therapy and hypnosis combined was helpful in controlling fatigue relative to a control group for</li> </ul>  |

| Type   | Description   | Potential Benefits  |
|--|---|---|
|  |   | <p>breast cancer patients during radiotherapy (189)</p> <ul style="list-style-type: none"> <li>• The poor quality of some studies limits conclusions concerning the efficacy of hypnotherapy in managing other symptoms (190).</li> </ul>   |
| <p><b>Family Therapy</b></p>   | <p>Facilitates communication within the family, promotes family cohesion and conflict resolution, including needs of children. Approaches may include cognitive-behavioural therapy, supportive psychotherapy, systems therapy or other forms of psychotherapy.</p>                   | <ul style="list-style-type: none"> <li>• Decrease distress (191,192)</li> </ul>   |
| <p><b>Couples Therapy</b></p>  | <p>Provides an opportunity for couples to enhance dyadic support, communication and problem solving. Supports couples adjustment and coping with stressors (e.g., cancer diagnosis, living with cancer, illness-related problems)</p>   | <ul style="list-style-type: none"> <li>• Decrease distress (in patients with various cancers) (193-195)</li> <li>• Improve communication (194,195)</li> <li>• Improve relationship quality (193)</li> <li>• Gains in sexual function for prostate cancer patients and partners (186) .</li> <li>• Sexual adjustment (195)</li> </ul>  |
| <p><b>Remote Counselling</b></p> <ul style="list-style-type: none"> <li>• <b>Telephone, video-conferencing and internet-based</b></li> </ul> | <p>Provides individuals, who are unable to attend face-to-face services due to geographic distances, transportation problems, or physical problems and declining health, with counselling (e.g., cognitive-behavioural, supportive therapy, provision of information and support)</p> | <ul style="list-style-type: none"> <li>• Support for psychological support, information, services for individuals diagnosed with cancer by telephone (140).</li> <li>• Videoconferencing and internet are encouraging but limited studies with cancer patients (196).</li> <li>• Meta-analysis by Barak et al. (2008) of internet-based psychotherapy provides support for online psychological interventions, especially for adults between the ages of 19-39 years and for anxiety and stress problems. Only one of 64 studies included cancer patients (197).</li> <li>• Internet-based support groups are being studied for cancer patients (198-200).</li> </ul> |

| Type   | Description   | Potential Benefits  |
|--|---|---|
| <b>Physical Exercise</b>                         | <p>Home-based or institution-based exercise.</p> <ul style="list-style-type: none"> <li>• Evidence is limited to prescribe a specific exercise intervention.</li> <li>• When recommending physical exercise to patients, their age, gender, fitness, cancer diagnosis and health status should be considered (92).</li> </ul> | <ul style="list-style-type: none"> <li>• Physical exercise leads to reduced fatigue during and post-cancer treatment (97,201,202).</li> <li>• Physical exercise can improve quality of life, depression, anxiety, and sleep problems (203-205).</li> </ul>  |
| <b>Massage Therapy</b>                           | <p>Various types of massage (e.g., focused touch)</p>   | <ul style="list-style-type: none"> <li>• There is some evidence that massage therapy is beneficial in the short-term for anxiety, distress, pain and nausea (206-208).</li> </ul>   |
| <b>Prayer</b>                                    | <p>An expression of faith that supports hope and strengthens the sense of connection to a higher power.</p>   | <ul style="list-style-type: none"> <li>• Prayer has been cited as a need for some people with advanced cancer (209).</li> <li>• For those for whom spirituality is important, prayer has been shown to have some positive effects on psychological and physical well-being for people with certain types of cancers (210).</li> </ul>   |
| <b>Music Therapy</b>                             | <p>Music Therapy</p>  | <ul style="list-style-type: none"> <li>• Music Therapy has been shown to be helpful in managing pain, distress, mood and other physical symptoms in adults with cancer (211,212).</li> </ul>  |
| <b>Complementary/Alternative Therapies (CAM)</b> | <p>Refers to supportive care/methods to complement mainstream treatments (e.g., supplements, yoga, meditation, therapeutic touch/energy therapy, acupuncture, art therapy) to help control symptoms and improve well-being (213-216).</p>   | <ul style="list-style-type: none"> <li>• Limited evidence, but it is estimated that almost one third of individuals diagnosed with cancer use some form of CAM (217).</li> <li>• Some treatments (e.g., acupuncture, healing touch, Tibetan yoga) have shown promise (preliminary support for efficacy in cancer-related fatigue, (96).</li> <li>• Some evidence that therapeutic touch helps reduce pain and anxiety in persons with cancer (218).</li> <li>• Limited evidence that yoga can modulate chemotherapy symptoms (219).</li> <li>• Limited evidence that art therapy</li> </ul> |

| Type | Description | Potential Benefits  |
|------|-------------|---|
|      |             | <p>contributes to reduced depression, anxiety, and somatic concerns; and improved quality of life in women with breast cancer (216,220) and that mindfulness-based art therapy can lead to reduction in distress (depression and anxiety) in women with a variety of cancers (221).</p> |

### **5.3 Examples of Evidence-Based Therapies and Interventions for Specific Problems in Adults with Cancer**

Examples of evidence-based therapies and interventions for specific problems displayed by adults with cancer, such as anxiety and depression, are summarized in Table 5.2. The generalizability of some of these findings is restricted due to limited research focusing on psychosocial interventions with men, specific ethnic and minority groups, younger and older adults and specific cancer diagnoses (42).

**Table 5.2 Examples of Evidence-Based Therapies and Interventions for Specific Problems in Adults with Cancer**

| Problem   | Examples of Psychosocial/Psychological Evidence-Based Interventions *  |
|---|--|
| Anxiety   | <ul style="list-style-type: none"> <li>• Psychoeducation (42)</li> <li>• Relaxation, Guided Imagery (42,222)</li> <li>• Cognitive-Behaviour Therapy (46,179)</li> <li>• Psychotherapy (105,182)</li> <li>• Supportive Therapies (42)</li> <li>• Anxiolytics</li> <li>• Crisis Intervention (223)</li> <li>• Mindfulness-Based Stress Reduction (224,225)</li> <li>• Physical exercise (205)</li> </ul>   |
| Depression  | <ul style="list-style-type: none"> <li>• Psychoeducation (42)</li> <li>• Behavioural Therapy Counselling/Psychotherapy alone or combined with Education (5)</li> <li>• Cognitive-Behaviour Therapy (42,226)</li> <li>• Relaxation Therapy</li> <li>• Psychotherapy (105,227)</li> <li>• Supportive Therapies (42)</li> <li>• Antidepressants for treatment of moderate to severe depression (91,228,229)</li> <li>• Combined psychological and pharmacologic interventions for patients diagnosed with major depression (2,228,229)</li> <li>• Mindfulness-Based Stress Reduction (224,225)</li> <li>• Physical exercise (205,230)</li> </ul>  |
| Sexual Health Concerns  | <ul style="list-style-type: none"> <li>• Literature is available concerning the provision of interventions for sexual difficulties, but few results from randomized clinical trials (49)</li> <li>• Some evidence that a combined approach of exercise, counseling, education and medications may improve sexual functioning for women with breast cancer (49)</li> <li>• Psychoeducation may be beneficial for women with gynecological cancers who are experiencing Female Sexual Arousal Disorder and for men with prostate cancer (54,186)</li> <li>• Sexually assistive aids can be effective for some men post radical prostatectomy. Many discontinue use despite effectiveness (52,186)</li> </ul> |
| Physical Symptoms (e.g., uncontrolled symptoms, pain, fatigue, cognitive problems and communication problems) | <ul style="list-style-type: none"> <li>• Cognitive-behaviour Therapy resulted in less pain (Breast Cancer; (180))</li> <li>• Multimodal exercise and walking programs and psychological treatments (e.g., cognitive-behavioural, restorative approaches, activity management (93)) reduced cancer-related fatigue (97,168)</li> <li>• Aerobic exercise can lead to improved physical function and may limit cancer-related fatigue in breast cancer patients during adjuvant treatment (231,232)</li> </ul>  |



## 5.4 Treatment of Anxiety and Depression

As described in Chapter 2, anxiety and depression are common psychosocial challenges experienced by individuals affected by cancer. Howell et al. recommend assessment to understand the relevant history, psychosocial factors and disease status as related to the occurrence of anxiety and depression. It is important for HCPs to be aware of evidence-based psychosocial/psychological and pharmacological interventions for people affected by cancer with anxiety and depression. (Summarized in Table 5.2). For current recommendations for assessment and treatment of anxiety and depression, and more in depth discussion, refer to “A Pan-Canadian Practice Guideline: Screening, Assessment and Care of Psychological Distress (Depression, Anxiety) in Adults with Cancer” (2).

**Anxiety:** There is evidence to support the use of the following psychological, non-pharmacological interventions in the treatment of anxiety (See Table 5.2): psychoeducation (42), relaxation and guided imagery (42,222), cognitive-behaviour therapy (179), supportive therapies (42), crisis intervention (223).

The treatment of moderate to severe anxiety may require pharmacotherapy in addition to psychosocial/psychological therapies (2). There are several medications available to treat anxiety. Individual patient-specific variables and needs, as well as other factors (e.g., nature of anxiety, psychological-mindedness, co-morbid medical conditions, potential side effects of medications, and patient preference) should be considered in choosing pharmacological and/or psychological interventions (2).

**Depression:** Psychological and pharmacological interventions have shown efficacy in treating individuals diagnosed with major depression (228,229). Some examples of evidence-based psychological interventions for depression are psychoeducation (42) and behavioural therapy alone or combined with education (5). (Refer to Table 5.2 for further information). Antidepressants are beneficial in the treatment of depression (2,228,229). Many types of anti-depressants are available. The choice of antidepressant will be affected by several factors such as potential side-effects of the medications, co-morbid medical conditions, and patient preference (2,229).

Antidepressants are not usually indicated in the treatment of subsyndromal or mild depressive symptoms (228,229). Psychological treatment is indicated for patients having difficulty managing these symptoms. For moderate depression, psychological intervention and/or pharmacotherapy are recommended (2,229). For severe depression, combined pharmacotherapy and psychological therapy is recommended (2,229).

## 5.5 When and Who to Refer to

As discussed in Chapter 4, (see recommendations to respond to and manage high, moderate and mild cancer-related distress, section 4.6), adults experiencing high, moderate, and at times mild cancer-related distress may require referral to a health care specialist for specialized assessment and care (see Screening for Cancer-Related Distress Algorithm - Figure 4.2)

When referral is deemed necessary the Cancer-Related Distress Management Referral Pathway should be used (See Figure 5.3). Responses on the Screening for Distress Tool and the therapeutic conversation can identify specific distress problems. For example, The Canadian Problem Checklist allows for patients to endorse specific concerns such as finances or faith, the ESAS-r may indicate difficulties with anxiety or depression. These specific distress problems are then used to direct the referral according to the flowchart, Cancer-Related Distress Management Referral Pathway (Figure 5.3). The referral options identified for each of the cancer-related distress problems have taken into account the need for qualified health care providers to provide the specialized assessment and treatment, as well as the availability of various health care providers throughout the province with expertise in cancer-related distress management. Communication between the specialist and health care team is helpful in optimizing care and adjusting treatment plan as needed.

There may be more than one health care provider qualified to provide the specialized care for persons with cancer-related distress. For example, individuals with clinically significant distress may be treated by psychiatrists, psychologists, social workers or advanced practice nurses in specific cases. It is important for people affected by cancer to have access to effective, skilled psychosocial care (42) and access to evidence-based therapies and interventions for specific cancer-related distress problems. (See Table 5.2) HCPs providing psychological interventions must be adequately trained, as there is the possibility of such interventions causing harm (183). In specific situations, particular therapies and interventions may be best provided by specific HCPs (2,170) . For example, if an individual displays high/imminent suicidal risk, an urgent psychiatric consult is recommended.

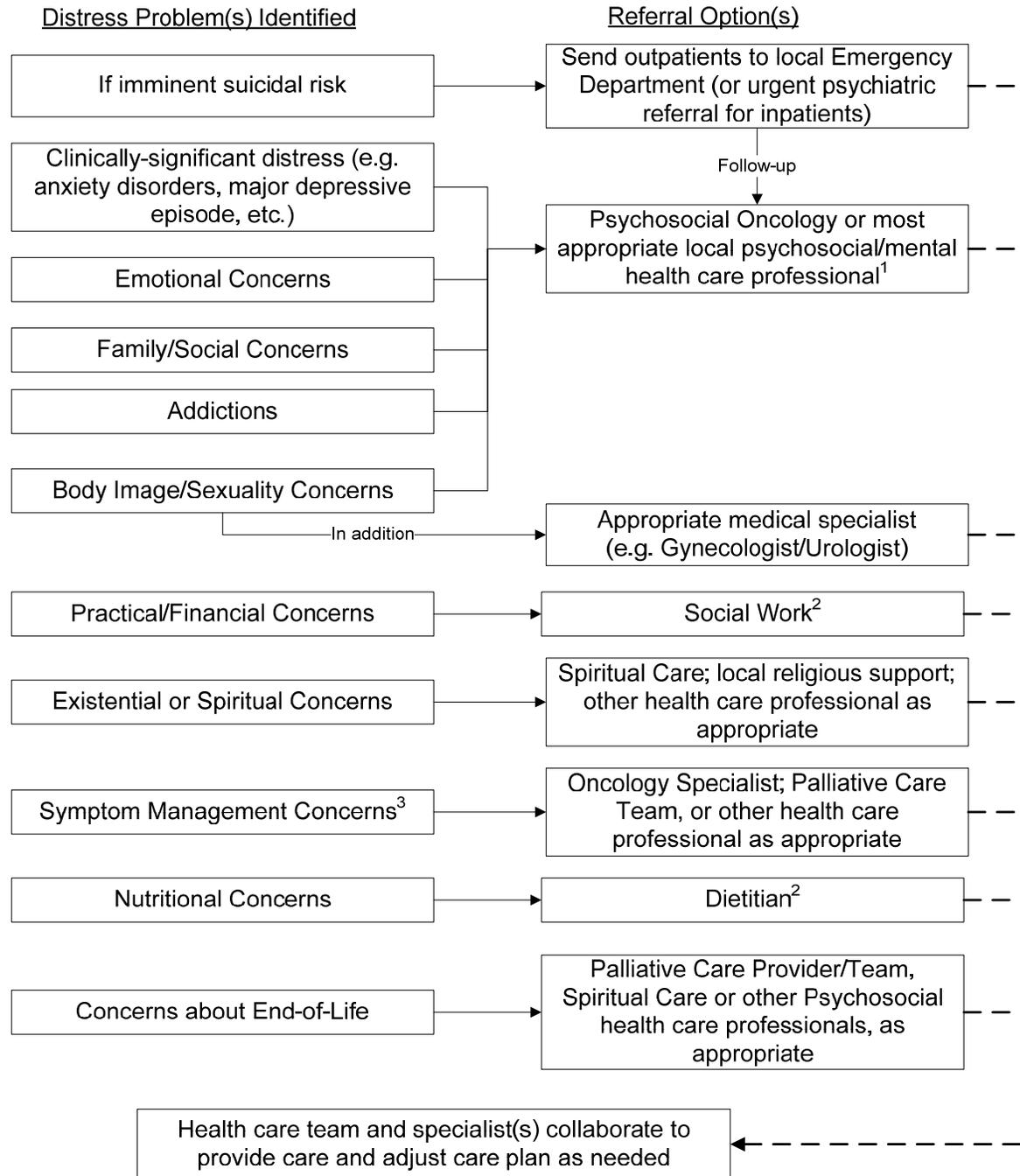
## **5.6 Discussing Referral with the Person Affected by Cancer**

When discussing the referral with the individual affected by cancer, advise the individual of services available, the potential benefits of referral, normalize the referral and need for support, be culturally sensitive, and discuss barriers/stigma to accessing services. If referral is declined and distress level continues to be elevated, raise the referral again when the person is seen in follow-up. However, it is noteworthy that some people may be more willing to discuss or focus on psychological concerns when their medical treatment for cancer is finished (10).

To address possible personal barriers to referral for specialized care, the HCP may use the following strategies when communicating with individuals (10).

- Initiate discussion about a physical concern and then move the discussion to a more sensitive psychosocial issue.
- Provide education concerning the psychosocial effects of cancer, and benefits of treatment, and normalize as appropriate.
- Discuss the interaction between some physical concerns and psychological concerns (e.g., unmanaged pain is stressful and contributes to cancer-related distress; similarly high levels of distress can aggravate pain).
- When necessary, offer to assist the person with possible negative reactions to the referral (e.g., talking to the family may help to address any concerns the family may have).

**Figure 5.3 Cancer-Related Distress Management Referral Pathway**  
**Cancer-Related Distress Management Referral Pathway**



1. Psychiatrist, Psychologist, Social Worker, Patient Navigator, Advanced Practice Nurse, Spiritual Care, etc.  
 2. If identified health care professional not available, referral to the district Patient Navigator or family physician  
 3. Pain, Fatigue, Nausea/Vomiting and sleep for example, refer to symptom management clinical practice guidelines

### **5.7 Accessing Resources (awareness and availability)**

HCPs should provide information on available resources to people affected by cancer. Psychosocial HCPs vary throughout the province. Refer to the Inventory of Psychosocial Resources in Nova Scotia on the CCNS website

<http://www.cancercare.ns.ca/en/home/healthprofessionals/resourcestools/psychosocial.aspx>

to find public and private resources categorized by health districts, as developed by the Supportive Care Cancer Site Team.

#### ***Recommendation***

**Health care providers should provide information on available resources tailored to the person's specific needs and situation.**

Level I (10)

Level II (10,18)

Level IV (7)

## Chapter 6 - Adults with Cancer from Diverse Communities

### 6.1 Introduction

All Canadians should have equal access to health care of the same quality. However, when a person is not part of the cultural majority/dominant culture (e.g., language, culture, socio-economic status, and sexual orientation), his/her access to health care as well as the quality of the health care he/she receives is likely to be affected (237). “Five factors that most influence health disparities are: low socio-economic status, Aboriginal identity, ethnic identity, gender and geographic location” in Canada (19) , p18).

People from the following groups experience barriers in regard to health care: multicultural; elderly; women/children/youth in disadvantaged circumstances; those living with poverty, those with low literacy levels; those challenged by mental or physical problems; not fluent in English or French; less educated; and people belonging to marginalized groups (e.g., the homeless, sex trade workers). Individuals are often part of more than one of these groups and may experience multiple barriers (19,238). These underserved groups are at risk of poorer health outcomes as a result of the barriers to health care they experience (19,239).

Systematized (institutionalized) discrimination can form barriers to optimal health care for members of these communities (240,241). This is exemplified by the experiences of some African Canadians who have reported: communication difficulties with primary health care providers; being under-represented amongst HCP; racial profiling and assumptions related to racial/ethnic background (241). Some members of immigrant communities have experienced: racial profiling; insufficient access to professional cultural health interpreters; and a need for health outreach (241). Some Aboriginal Peoples have experienced a range of barriers: jurisdictional barriers to accessing health care (e.g., some home care nursing services may be unavailable); “historical bi-cultural tension”; stereotyping and biases; and primary HCP who appeared disrespectful among others (241).

Within the cancer care system similar barriers to care have been reported (19). It has been noted that cancer pain may be less well controlled for individuals who are members of racial/ethnic minority groups (242). Also, people affected by cancer who are members of underserved groups are more likely to experience distress from their situation than others (19,43).

Cultural competency “refers to the abilities of caregivers and organizations to respond respectfully and effectively to the unique needs of culturally and linguistically diverse patients and families” from, the Proceedings from A National Forum on Cancer Care for All Canadians, as cited in Promoting Equity and Diversity in Cancer Care Settings, CPAC Toolkit, Slide 4, 2009. Cultural competence is viewed as a necessary approach to decrease health disparities for underserved populations and contribute to outcomes (19,237).

In this chapter, several issues are discussed that require consideration in regard to

health care and specifically in regard to screening for cancer-related distress and cancer-related distress management for adults with cancer. These issues include: culture, race, ethnicity<sup>2</sup>, language, literacy, age/stage of life, gender, gender identity, geography, sexual orientation, socio-economic status, religiosity/spirituality<sup>3</sup>, communication, and intellectual and physical abilities. These issues may be inter-related as an individual may identify with more than one diverse group/community.

## 6.2 Culture, Race and Ethnicity

Sociocultural and behavioural factors can affect decision-making, adherence to treatment, outcomes and the ability to practice appropriate surveillance and follow healthy lifestyle habits post-treatment (243,244). There is also some evidence that the incidence of cancer and the mortality rate for cancer amongst some ethnic minority groups and underserved populations may be higher than the average (73,152,243,244). There is a lack of psychosocial health intervention studies focused on distress management that are inclusive of people from underserved groups (19,244).

Culture can affect beliefs related to health and illness (e.g., culture can affect beliefs related to health and illness such as fear, fatalism, consequences of initial treatment and lack of knowledge about disease symptoms) (19,143,240). Cultures may differ in beliefs regarding communication styles, such as: asking fewer questions improves health care; increased family involvement in decision-making; or it is undignified to complain/ask for help (143,144,245). Particularly relevant to screening for and managing distress is to understand how cancer-related distress and pain are expressed (241), p14) and understanding emotional responses/terms. Asking the person about the meaning of their cancer how their spiritual/religious beliefs affect decision-making, care and treatment can assist the HCP in providing culturally sensitive person-centred care. For example, Knobf (2007) noted that spirituality plays an important role for some Black women in dealing with breast cancer (152).

When attending to the ethnocultural experience of the adult affected by cancer, it is important that HCPs recognize individual differences and be cautious to not reduce the individual to a representative of a specific ethnic type (143,240,246). Within all of these populations diversity exists. Therefore, each person affected by cancer is considered as an individual and his/her unique needs and preferences must be recognized (19,143,240,241). Factors other than one's ethnicity, such as gender, age, and family history, may be as or more relevant to care (240). As noted above religious beliefs and socio-economic level are also important considerations. Evidence is lacking that describes the experiences of people from underserved groups throughout the cancer

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<sup>2</sup> Nova Scotia's Aboriginal communities include members of the Mi'kmaq Nation, Inuit and Métis People, with the majority being of the Mi'kmaq Nation. The largest population of Aboriginal Peoples is in Capital District Health Authority followed by Cape Breton District Health Authority. The majority of African Canadians living in Nova Scotia, live in Capital District Health Authority. Acadian and Francophone Nova Scotians are largely concentrated in Capital District Health Authority, followed by Cape Breton District Health Authority and South Western Nova Scotia. Most members of Nova Scotia's diverse immigrant population reside in Capital District Health Authority, although smaller communities are present throughout the province (241,250).

<sup>3</sup> There is diversity in religious faith and spiritual beliefs across Nova Scotia with Christianity being the religious faith of the majority, and Islam and Judaism being the next most common faiths (241).

continuum (19,243,244) . One recent study involving 58 oncologists, found that the time physicians spent communicating (e.g., teaching, building rapport) with people with newly diagnosed breast cancer was influenced by race, income level, education, and age of the person with cancer (144) . Statistically significant racial differences were observed with more time spent counseling white than non-white patients. Racial differences were observed in almost all types of communication (e.g., more utterances by white than non-white people with breast cancer) (144). Refer to Table 6.1 for approaches that are useful in provision of culturally sensitive clinical services.

### **6.3 Language**

In Canada, groups who face language/communication barriers are: minority official language speakers; newcomers (i.e., immigrants and refugees); members of Aboriginal communities, and the Deaf/hard-of-hearing and the Deaf Blind (refer to Section 6.9). Nova Scotians who are not fluent in English, such as members of Francophone, Acadian and non-English speaking immigrant communities may face language barriers related to health care (241). Misunderstandings secondary to language barriers can lead to significant problems with health care, including: disparities in health care provided, longer hospitalizations, and medical errors (19). Some research suggests that Canadians with cancer from non-English first language countries are more likely to experience higher levels of cancer-related distress (244).

Evidence highlights the benefit of professional interpreters, over ad hoc untrained persons (e.g., family members, friends, other HCP etc.) (19,247), in facilitating the exchange of information and communication between the individual and the HCP. Refer to Table 6.1 for information about working with interpreters. It is noteworthy that when the treating HCP speaks the same language as the individual affected by cancer, the language barrier can be overcome, and this has resulted in high patient-satisfaction (19). Thus, it is reasonable to consider language and cultural background when linking particular HCPs with individuals affected by cancer as this can reduce the need for interpretation and help address cultural barriers.

Efforts should be made to try to find educational materials in the individual's language, if possible (e.g., providing information to the person to manage his/her cancer-related distress).

### **6.4 Literacy and Health Literacy**

People with low levels of literacy have been identified as an underserved population. Difficulties understanding written materials about disease and treatment may leave an individual unable to participate in his/her own health care to the level he/she prefers (243,248). For example, more than 80% of Nova Scotia's seniors surveyed for the 1994 Adult Literacy Survey scored less than three; the minimum literacy level considered adequate for day-to-day living (e.g., reading newspapers, completing forms, and scheduling medications) (249).

“Health literacy is the ability to find, understand, and use health information, services and supports that help us make informed choices about how to be

healthy.<sup>1</sup> Health literacy requires communication, math and reading skills, and an ability to navigate forms and health systems.” (250), pg 1. Health literacy can affect one’s ability to participate in one’s health care and manage cancer-related distress (248).

Individuals with low literacy and/or health literacy will require flexibility in the administration of the Screening for Distress Tool, such that the HCP may have to read the tool to the person. In situations where the HCP or a family member reads the tool to the person, it is important to try to minimize influencing the person’s responses.

**Table 6.1: Evidence-based approaches in attending to culture and language**

\*

|   |
|---|
| <p><b>Working with interpreters</b></p> <ul style="list-style-type: none"> <li>• Arrange for professional interpreter for individuals for whom English is not their first language and who are not fluent in English.</li> <li>• Obtain consent for use of an interpreter by the person affected by cancer.</li> <li>• Speak directly to the person affected by cancer rather than the interpreter, use short sentences and pause following to allow for interpretation.</li> <li>• Request interpreter to translate patient response as closely as possible.</li> </ul>  |
| <p><b>Provision of culturally sensitive services and support</b></p> <ul style="list-style-type: none"> <li>• Ask how the person affected by cancer feels about his/her disease and treatment, and what meaning it has for him/her, including any cultural or religious issues which may influence care and treatment.</li> <li>• Assess the person’s understanding of his/her disease, treatment and prognosis.</li> <li>• Attend to culturally-specific and individually-specific values, beliefs and modes of behaviour (e.g., non-verbal behaviour that is interpreted differently in various cultures (247); how distress and pain are expressed (241, p14); what distress and emotional response/terms mean).</li> <li>• Utilize culturally-appropriate health care providers, if possible (e.g., women with access to a female HCP).</li> <li>• Review with the person how confidentiality is maintained within the health care setting.</li> <li>• Discuss issues and treatment options with the family of the person diagnosed with cancer, if the person requests this.</li> <li>• Discuss the value of social support and encourage the person affected by cancer to ask for support from family, friends, support services and local cancer organizations.</li> <li>• Arrange follow-up and support as needed.</li> </ul> |
| <p><b>Provision of information</b></p> <ul style="list-style-type: none"> <li>• Provide all information relevant to the person’s care and treatment in the appropriate language, if possible.</li> </ul>  |

\* Based on the NBCC-NCCI recommended steps involved in dealing with cultural issues (10).

## 6.5 Age/Stage of Life

Two-thirds of all new cancer cases in Nova Scotians occur after the age of 60 years (28). Younger and older patients may face different social, vocational and economic challenges (78,152). Young adults may be focused on establishing careers, starting a family, and raising a young family, whereas seniors may be dealing with the death of a spouse or caring for an ailing spouse, as well as dealing with their own age-related health changes (1,251,252). The Canadian Problem Checklist assists the adult with cancer and their HCP to identify the particular psychosocial, practical and physical concerns irrespective of age/stage of life. Once identified, it is important for the HCP to attend to the age specific needs of their patients.

Younger Adults. Some studies suggest that younger adults (less than 69 years Thomas et al.) may experience higher levels of cancer-related distress (10,244,251). Evidence indicates that younger women with breast cancer display higher distress and identify more unmet needs than older women (152). Younger men with prostate cancer may have a greater need to discuss sensitive issues than older men (145). See Chapter 3 for a review of general interactional skills. Support groups may not provide peer support to younger adults if the majority of the group is older with different experiences and concerns (78).

Families with young children have the additional demands related to the care and nurturing of their children (72), as well as information needs related to explaining serious illness to children and understanding coping behaviours of children (71,72,74). Providing relevant information to this group can be beneficial (74, 76). A parent's ability to communicate about his/her illness seems to help children's adjustment (72). The Canadian Association of Psychosocial Oncology with the support of the de Souza Institute, has launched a web based resource to assist HCPs and educators to support children and adolescents when a family member has cancer ([www.startthetalk.ca](http://www.startthetalk.ca)).

Older Adults. The experience of some symptoms, such as cancer-related fatigue, by older adults may be exacerbated by age-related changes and comorbidities (253,254). When providing care to seniors with cancer, it is important not to make assumptions about quality of life or treatment choices based on age-related stereotypes (10,254). Some physicians may rate an older adult's quality of life lower than they would, and there are concerns that seniors may be under treated (10). For some older individuals with cancer, stoicism or "not wanting to be a bother" may require that HCPs ask directly and with sensitivity about particular psychosocial challenges or concerns (10). There is some evidence that older individuals with cancer prefer intrapsychic coping mechanisms (e.g., optimism, religious beliefs) compared to younger individuals who seem to use problem-oriented coping (1).

## 6.6 Gender

The gender of the person affected by cancer may impact his/her cancer experience (32) (Refer to section 6.7 for gender identities (e.g., transgender)). Evidence suggests that women experience more cancer-related distress than men, irrespective of whether they are the adult with cancer or the partner of someone diagnosed with cancer (32).

Women in disadvantaged circumstances (e.g., immigrants and refugees) are recognized as an underserved population, and therefore, may face additional challenges related to cancer treatment, care and support (19).

Men with urogenital cancers may feel uncomfortable raising sensitive issues. For some, peer support may be beneficial (145,153). The HCPs use of effective communication techniques, consideration of the setting and gender of the HCP may help address this barrier (145).

Men with breast cancer represent a minority group within the population of individuals diagnosed with this disease (255). The availability of written information specific to men with breast cancer is limited, which may result in unmet information needs. This may be greater for younger men with breast cancer (255).

## **6.7 GLBT Community**

GLBT Community includes gay, lesbian, bisexual, transgender/transsexual/two-spirit, individuals. Unfortunately, some members of this community may have already suffered some effects of discrimination and social isolation, and in some cases violence, prior to their experience with cancer. Research in health care settings indicates that a lack of sensitivity or homophobic attitudes by HCPs may contribute to: delays in seeking health care and follow-up; reduced access to information, education and interventions; and frequent changes in practitioners (10). Many individuals may hide their sexual orientation or gender identity because of fears that their care will be negatively affected (10). Elder members of the GLBT Community may experience greater personal barriers than younger members due to their past health care experiences and aging.

The following interactional skills may assist the HCP in developing a trusting and supportive relationship with persons of diverse sexual orientations and gender identity based on the NBCC-NCCI Guideline (10) and clinical consensus of the writing group ).

- Be supportive and non-judgmental.
- Communicate with sensitivity.
- Use an inclusive approach.
- Recognize that family is defined by the person diagnosed with cancer (see 1.11.5)
- Maintain a non-homophobic, open attitude.
- Use gender neutral terms.
- Be aware that attitudes of the HCP may affect clinical judgment.
- Acknowledge previous experiences/barriers with care the individual may have encountered.
- Provide a safe environment where sexual orientation and identity can be openly discussed.
- Separate sexual behaviour from sexual identity.

## **6.8 Geography**

The practical and financial needs of individuals, who are isolated, live in rural

communities and far away from the health care centre may be increased as there is more time away from family, home and work, and costs associated with travel (115,243). Details related to travel, accommodations, potential changes to family life and how to access financial assistance are examples of information needs of people required to leave their community for cancer treatment (256). The Screening for Distress Tool can help to identify these concerns and associated distress. Specific types of psychosocial/medical support may also be more limited in rural communities relative to urban areas, even though the support needs of individuals in both rural and urban areas are similar (196). These are issues to consider in Nova Scotia and throughout Canada.

## **6.9 Socioeconomic Factors**

Socioeconomic factors such as employment status, reduced or low income, and lack of resources can impact the well-being and distress level of a person affected by cancer, (257,258). Bennett et al., (2009) reported that 37% of their participants experienced a decrease in household income following cancer diagnosis (259).

In a literature review by Spelten et al., (2002) the rate of return to work for cancer survivors ranged from 30-93% (124). Some factors that have been negatively associated with return to work include: non-supportive work environment, physically demanding work, and specific types of cancer such as head and neck, and brain, with high disease and treatment burden (124,258). Some persons affected by cancer who return to work may require job modifications (e.g., reduced work hours) (258). Decreased ability to work is also influenced by the type of medical treatment, treatment side-effects (e.g., fatigue), and co-morbidities (260).

The Screening for Distress Tool includes items such as work/school and finances, and can be helpful in identifying socio-economic factors that require consideration.

## **6.10 Communication**

Disease Related Communication Issues. As described in chapter 2, temporary or permanent changes in voicing/speech may be caused by the disease and/or its treatment. Further, voicing and speech problems affect the individual socially, vocationally and emotionally. For example, people with some head and neck cancers (especially cancer of the larynx) are more likely to have communication problems. The incidence of depression is high throughout the illness trajectory for people with head and neck cancer (108). Communication may also be compromised in individuals dealing with brain cancer (primary/metastatic) (167). Thus, the ability of the person diagnosed with cancer to ask questions and express his/her concerns through usual verbal means may be compromised by the changes in voicing/speech (108) or by the effects of primary or metastatic brain lesions.

When working with persons who have these types of communication issues, a more flexible approach is needed (e.g., use of written notes and non-verbal communication with an individual post-laryngectomy; use of straightforward questions and simple

language with a person who is experiencing difficulty expressing him/herself verbally or processing verbal information).

**Deaf Community.** *“Within the Deaf culture, deafness itself is a non-issue”* (261). Deaf persons rely on visual means of communication such as Sign language, lip-reading, speech reading, and reading and writing versus auditory means of communication such as voice, and hearing, with or without aids or devices (261). The Deaf community is a diverse group, inclusive of people with differing racial/ethnic backgrounds, socio-economic status, sexual orientation, English language proficiency and Signing proficiency (261,262). Communication barriers with HCPs have been identified as problems for many members of the Deaf community (261,262). The use of Sign language interpreters can help to overcome this language barrier. However, access to this resource may be a challenge within the health care system (261,262). Functional illiteracy levels (English language) are high amongst this group and may form an additional barrier to accessing written health information/education (261,262). Therefore, it is important to ask about and understand the Deaf person’s communication preferences and ability to read English, when screening for and helping to manage cancer-related distress. Refer to Table 3.1 for a Summary of General Interactional Skills.

### **6.11 Intellectual, Physical and Other Challenges**

People with mental or physical challenges represent an underserved population in regard to health care (19). Although comprehensive discussion of these challenges is beyond the scope of this guideline, two examples of challenges are presented that are important to address when screening for and managing cancer-related distress.

There is evidence that individuals who are intellectually challenged and dealing with cancer may have unique information requirements that are not usually addressed through the health care system (263). Total communication techniques use signs, symbols, objects, pictures, photographs, facial expression and body language to support or relay a verbal message (263). This approach can be used by HCPs to help individuals express and manage symptoms such as pain (263). It is important for HCPs to learn about the person’s capacity to understand health information and manage his/her care, as well as participate in treatment decisions, and cope with disease and treatment. Collateral information from identified family/support persons can be helpful.

A significant physical challenge is vision loss. According to The Canadian National Institute for the Blind (CNIB), one in eleven Canadians 65 years of age or over have a significant visual impairment and this number is expected to rise substantially as the population ages (264). Challenges associated with living with vision loss include but are not limited to difficulties with daily living, higher rates of clinical depression, higher social dependence and more medication errors (264,265). Younger people with vision loss often face economic and employment challenges. CNIB research has found that “only 35% of working-age people with vision loss are employed” and 50% of adults with vision loss have gross annual incomes of \$20,000 or less (264,265). When screening individuals with vision loss for cancer-related distress, a family member or the HCP will

be needed to assist the patient in completing the tool.

HCPs (and health centres) must be flexible in their approach to be inclusive of people with intellectual or physical challenges when screening for and managing cancer-related distress throughout the cancer care continuum.

***Recommendation***

**Health care providers screening individuals for cancer-related distress must address the needs of people from diverse communities.**

Level III (19)

Level IV (20)

***Recommendation***

**Health care providers seeing persons for management of cancer-related distress should provide service in an inclusive and sensitive manner.**

Level III (19)

Level IV (20,21)

## **APPENDIX I - Guideline Development Process**

The development of this guideline was overseen by CCNS' Supportive Care Cancer Site Team with original leadership from Judy Simpson, CCNS Manager of Palliative and Supportive Care, until her retirement, and then Janice Howes, CCNS Psychosocial Oncology Clinical Lead.

A guideline committee was established with representatives from key disciplines in the province. Each member was asked to report any conflict of interests. None were reported. The list of guideline committee members can be found in Section 1.13 of the guideline document. In addition, the guideline committee would like to acknowledge the contribution of Norma Kennedy, Ph. D., Psychologist, during the very initial stage of the guideline development process.

The decision was made that the guideline would not be developed de novo from original literature but would be adapted from existing guidelines from credible sources. Concurrently, the Canadian Partnership Against Cancer (CPAC) was looking for guideline adaptation projects to trial its ADAPTE methodology, and this project was accepted as one of the case studies.

After review of candidate guidelines by the guideline committee, it was agreed to adapt The Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer as developed and published in 2003, by the National Breast Cancer Centre (NBCC) (Australia) and the National Cancer Control Initiative (NCCI) (10). In 2008, the quality of The Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer was rated in accordance with the AGREE I © (34) tool by the guideline committee. An evidence update was required as the original evidence review was more than 5 years old by this time. (Refer to Section 1.11.1). The guideline committee also identified that content revisions were needed and further information was required to address all the health questions to be addressed by the guideline. This led to a hybrid adaptation and de novo methods to develop the current guideline (33).

Concurrent with the evidence review, a formal consensus process was used to obtain broader input to answer, "What would you like to see in a distress management guideline for adult cancer patients and families?" The Delphi Process was initiated with Health Care Providers (HCP) across all nine health districts within Nova Scotia and circulated three times for ideas and comments and then once for rating. Of the 152 HCPs representing a range of disciplines who were invited to participate, 35 (23%) participated in some part of the Delphi Process. The guideline committee reviewed the ratings and comments for inclusion in the current guideline and reached consensus on the following themes. The primary themes identified by the HCPs to be included in a distress management guideline consisted of:

- User friendly
- Communication

- Screening and assessment of cancer-related distress
- Resources to manage cancer-related distress

To provide an opportunity for citizen engagement and to inform the guideline, the Delphi Process was implemented with a sample of patients and families. A convenience sample of 22 patients and families was obtained through the CCNS Cancer Patient Family Network. The Delphi Process was concluded earlier than anticipated as the focus shifted from the Delphi question to discussing personal concerns. The themes identified through the patient and family Delphi Process included:

- Communication
- Patient/Family education
- Resources to manage cancer-related distress
- Meeting supportive care needs (e.g., support groups, parking fees)

The guideline recommendations were developed by the committee based on the evidence and expert consensus. A consensus conference, with a subgroup of four members of the committee (Janice Howes, Ph.D., R.Psych. (Chair), Deborah McLeod R.N., Ph.D., Judith Cleary, BScN, Larry Broadfield, MHSc) was used to determine the levels of evidence for, as well as rate the strength of the evidence. Refer to Section 1.11.

The guideline committee took the opportunity to trial the algorithms through the innovative Screening for Distress Initiative in Nova Scotia from Oct 2009 to mid-2011. This provided helpful and constructive feedback on the referral pathways from the HCPs involved in the screening initiative. The guideline committee revised the algorithms based on this feedback.

Once the draft document was complete, it underwent an external review. For details see Appendix II.

The guideline was revised based on feedback from the external review and was returned to the guideline committee and the Supportive Care Cancer Site Team for final review and approval. The guideline will be reviewed three years after approval or revised as new evidence becomes available.

The approved guideline is published in both a Full Version and a Quick Reference Version. The full version is available online on the *Cancer Care Nova Scotia (CCNS)* website ([www.cancercare.ns.ca](http://www.cancercare.ns.ca))

The development of this guideline was supported by CCNS. CCNS staff supported the guideline development process. CCNS provided a stipend for the guideline writer and funded the design, printing and dissemination of the guideline survey as well as the approved guideline. The views and interests of CCNS have not influenced the guideline committee's recommendations.

*CCNS* acknowledges the support of the Canadian Partnership Against Cancer (CPAC) through a financial contribution from Health Canada in completion of this guideline. This project was one of the case studies for the CPAC Can-Implement project (33).

## **Appendix II – External Review**

An external review of the final draft version of this guideline was conducted throughout the summer of 2013. Areas of interest included the guideline in general and specific topic areas, such as the recommendations and development methods (See Table I below). Several health care professionals involved in cancer care from across Canada were identified by the guideline committee to potentially provide feedback on the guideline. Of the original list of possible reviewers, eight HCPs agreed to review the guideline and of those, five responded including a representative from the National Advisory Group.

### **Methods**

Eight HCPs were sent a draft version of the guideline with an accompanying survey to complete. Five completed surveys were received by the deadline, one reminder had been sent. The survey responses were collated by CCNS and forwarded to the Chair of the guideline committee. The results of the external review were shared with the guideline committee, comments were addressed and revisions made to the guideline as required.

### **Results**

The majority of responses were very positive and supportive of the draft guideline. Some respondents provided specific positive feedback through written comments, such as “I was extremely impressed with this guideline - can't wait for it to be finalized so that I can reference it in my province!”, “the guideline was comprehensive and covered all of the important areas and was clearly written”.

The survey items and ratings are detailed in Table I. The lowest rating was neutral and this was endorsed on only three items out of seven, each time by one respondent. The written comments section offered some insight as to the reason for these ratings.

The written comments focused on four main areas of the guideline, recommendations, search methodology, evidence base and specific content related suggestions (i.e., adding examples to support text). Each comment/suggestion was reviewed and actions were drafted by a subgroup of the guideline committee with actions reported back to the guideline committee. See Table II for a summary of written comments that required action/response.

**Table I - Responses from the Distress Management Guideline External Review**

| Survey Item  | Response Total (Response Percent) |        |         |          |                   |
|--|-----------------------------------|--------|---------|----------|-------------------|
|  | Strongly Agree                    | Agree  | Neutral | Disagree | Strongly Disagree |
| The guideline development methods are of high quality. Consider whether the appropriate stakeholders were involved in the development of the guideline, was the evidentiary base developed systematically, are recommendations consistent with the literature, whether consideration of alternatives, health benefits, harms, risks, and costs was made. | 2(40%)                            | 2(40%) | 1(20%)  | 0        | 0                 |
| The guideline is well organized.   | 3(60%)                            | 2(40%) | 0       | 0        | 0                 |
| The recommendations were easy to find.   | 4(80%)                            | 1(20%) | 0       | 0        | 0                 |
| The completeness of reporting is of high quality. Consider whether the guideline development process was transparent and reproducible and was the information complete to inform decision making.  | 2(40%)                            | 3(60%) | 0       | 0        | 0                 |
| The guideline recommendations are appropriate for the target population.   | 2(40%)                            | 2(40%) | 1(20%)  | 0        | 0                 |
| Overall, I agree with the recommendations as stated. If you have specific suggestions for modifications, an opportunity is provided at the end of the survey for you to make them.   | 3(60%)                            | 1(20%) | 1(20%)  | 0        | 0                 |
|  | Response Total (Response Percent) |        |         |          |                   |
|  | Excellent                         | Good   | Neutral | Fair     | Poor              |
| Please rate the overall quality of the guideline.  | 3(60%)                            | 2(40%) | 0       | 0        | 0                 |

**Table II - Summary of Written Comments Requiring Action/Response**

| General Comments on Rankings  | Action / Response   | Theme   |
|---|---|---|
| <p>One reviewer commented that the guideline focused too much on screening versus management of cancer-related distress. More information on resources needed to implement these guidelines could help secure funding and access to a variety of HCPs.</p>  | <p>The scope and purpose of the guideline “to provide guidance and assist health care providers (HCPs) to screen, identify and manage cancer-related distress” supports inclusion of this topic area. Expanded text in Chapter 4 to include reference to psychoeducational approaches and specific symptom management guidelines that may be used by the primary team to manage cancer-related distress (previously only discussed under specialized care). Text added to highlight needs related to implementation such as high level administration support, education for administrators, educators and HCPs and guidance related to resources required. The need for reviewing resources available and collaborating to determine resource gaps and strengths (e.g., psychosocial resource inventory in Nova Scotia) was additionally described. (See Section 4.11)</p>   | <p>Content (resources)</p>                                      |
| <p>One reviewer commented on the literature review and evidence base for the recommendations and guideline. Noted that the search terms and strategy were not clear, absence of recently published primary research papers and questioned some of the evidence ratings used to support the recommendations, cut off scores specifically. Also, noted that there was a lack of clarity between what was practice in Nova Scotia versus an evidence based recommendation.</p> | <p>Follow-up consensus conferences, with a subgroup of five members of the committee (Janice Howes, Ph.D., R.Psych. (Chair), Carol Digout, Executive Director, APPHON, Deborah McLeod R.N., Ph.D., Judith Cleary, BScN, Larry Broadfield, MHSc) to re-examine the levels of evidence for, as well as the strength of the recommendations. Clarification was made to Section 1.11 (Evidence Base). “The rating of the Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer with the AGREE I © was found to have acceptable scores on domains of relevance (e.g, “systematic methods were used to search for evidence”, “criteria for selecting the evidence were clearly described”) (34) .... The NCCN was unanimously regarded by the guideline committee as a reputable source and recognized as a pioneer in this standard of care.”<br/>                     “Upon article review, some lower levels of evidence had not been eliminated by abstract alone. When these articles were relevant to and consistent with the guideline and in the absence of higher level evidence, they were used as a reference for the guideline.”<br/>                     “Based on external review, additional primary research articles were identified, these were then reviewed for inclusion, relevance and consistency with the guideline by two reviewers.”<br/>                     Clarification made to the asterisk notation that describes the evidence used to support cut-off scores in Table 1.12. “Evidence for intervention varies; with strong evidence for some interventions. Although there is limited evidence for exact cut-off scores, the recommended cut-off scores are evidence informed and have the unanimous support of the guideline committee”. (See Table 1.12)</p> | <p>Systematic Search<br/>Evidence Base<br/>Evidence Ratings</p> |
| <p>One reviewer found discrepancy between the operational definition of the levels of evidence and the actual evidence ratings for some references.</p>   | <p>The sub-group reviewed the operational definitions and evidence ratings, no changes were made as the group felt the asterisk notations explained the discrepancy. (See Table 1.12)</p>   | <p>Evidence Ratings</p>   |

| <b>Would you consider endorsement or adaptation of this guideline report for use in your own provincial jurisdiction? If maybe, what would you need to consider endorsement?</b> | <b>Action / Response</b>  | <b>Theme</b>             |
|--|---|--------------------------|
| Adaptation of guideline would require an update of evidence  | The initial detailed systematic review was conducted in 2009. Between 2010 to 2013 the committee continued to scan the literature for relevant articles. Relevant articles were added to the review. Further to this the expert external review process also identified some articles for inclusion; these were also reviewed and included as appropriate. No further published literature between 2010 and 2013 contradicted any of the recommendations. | Evidence Base (currency) |
| More information on resources  | Text added to highlight needs related to implementation such as high level administration support, education for administrators, educators and HCPs and guidance related to resources required. The need for reviewing resources available and collaborating to determine resource gaps and strengths (e.g., resource inventory in Nova Scotia) was additionally described.   | Content (resources)      |

| <b>Is there anything that should be added to the guideline?</b>  | <b>Action / Response</b>   | <b>Theme</b>      |
|--|--|-------------------|
| One respondent would like to see a specific reference to nausea under the physical challenges section.   | Nutritional Concerns section of Chapter 2 re-titled Nutritional/Gastrointestinal Concerns and expanded with examples of nausea, constipation, anorexia and cachexia, recognizing these symptoms are bothersome to many patients.   | Content           |
| One reviewer suggested adding a recommendation to cover content of Chapters two and three “For consistency in structure and organization suggest adding recommendations about all health care professionals needing to engage in education about distress and communication/counselling strategies”. Also, recommendations (even expert opinion) would be of benefit regarding distress of HCPs. | Recommendations regarding the management of HCP distress were beyond the scope of this guideline. Thus this topic area was not fully addressed by the literature search. This point was clarified in the document. ( See section 2.8)<br>Follow-up consensus conference discussed the possibility of additional recommendations. The group felt that the need for ongoing learning was adequately addressed through the HCP’s professional standards.                  | Recommendations   |
| One reviewer commented that the rationale for the recommended distress screening tools was not sufficient. “In particular, what the rationale/evidence base for including both ESAS and DT?”   | Text was expanded under Distress Thermometer, in Section 4.4. “...is a rapid user-friendly means to measure cancer-related distress. Given the strengths of the DT and its wide use with varied cancer populations across cultures the guideline committee unanimously agreed to use the DT in the Screening for Distress Tool.”   | Content           |
| One reviewer commented that “recent evidence suggests that patients with lower levels i.e. a score as low as 2 or 3 may have clinical depression; which is why further focused assessment is necessary based on DSM criteria as some patients may require specialist intervention at lower score levels”   | After thoughtful review, no changes were made as the guideline allows for individuals with lower DT or ESAS-r screening scores to be referred for specialist assessment/intervention as determined through the therapeutic conversation with the HCP or by the ongoing nature of the distress. This is consistent with “A Pan-Canadian Practice Guideline: Screening, Assessment and Care of Psychological Distress (Depression, Anxiety) in Adults with Cancer” (2) . | Content           |
| One reviewer noted that the methodology of the literature search was not clear enough and that the language used to describe it was inconsistent (i.e., systematic review versus systematic search of the literature).   | Revisions made to the guideline to describe the methodology as a systematic search of the literature. ( See Section 1.11.1)  | Systematic Search |

| <b>Is there anything that should be removed from the guideline?</b>  | <b>Action / Response</b>   | <b>Theme</b>           |
|--|--|------------------------|
| <p>One reviewer questioned the value of Chapter 2, and Health Questions 2 and 3. (See Chapter 1)</p>   | <p>Part of the scope and purpose of the guideline was to “Assist HCPs to become aware/sensitive to cancer-related distress”(section 1.6) and the second and third Health Questions support this aspect of the scope and purpose. Therefore no changes were made to the guideline.</p>  | <p>Content</p>         |
| <p>One reviewer did not find the flowchart, Figure 5.3 useful or well linked to the screening tool.</p>  | <p>Text was adjusted in Section 5.5 to link better with referral pathway.</p>  | <p>Content</p>         |
| <p>“ I did have some concerns about recommendation number 8 which states that mild to moderate distress can be addressed by the primary oncology team; recent research by Madeline Li and colleagues suggest that some patients may be clinical depressed at low levels of ESAS distress scores, which is why further focused assessment is required as per the CAPO depression guideline as these patients should be referred earlier for specialist intervention.”</p> | <p>After thoughtful review, no changes were made to the recommendations as the guideline allows for individuals with lower DT or ESAS-r screening scores to be referred for specialist intervention as determined through the therapeutic conversation with the HCP or by the ongoing nature of the distress. This is consistent with “A Pan-Canadian Practice Guideline: Screening, Assessment and Care of Psychological Distress (Depression, Anxiety) in Adults with Cancer” (2) . Clarification was made in Chapter 4 to better link the therapeutic conversation section to the anxiety and depression guideline.</p> | <p>Recommendations</p> |

| <b>Is there anything you think should be changed in the Guideline?</b>   | <b>Action / Response</b>  | <b>Theme</b>  |
|--|---|---------------|
| One reviewer suggested adding a couple of examples at specific points in Chapter 5.  | Examples were added to support the text.  | Content       |
| One reviewer felt the referrals made list (See Table 4.6) had overlap and could benefit with the addition of community supports the patient was referred to.         | The Distress Management Summary Sheet provided a block for support groups the patient was referred to, as well as an “other” block which could be used to capture community supports recommended. Therefore, no changes were made.                            | Content       |
| One respondent found Figure 4.2 too busy with so many crossing lines.  | Throughout the guideline development process several versions of the flowchart were drafted, this was the least busy version and performed well in clinical settings. There will be opportunities for revisions based on more widespread clinical experience. | Content       |
| One reviewer suggested only citing the highest level of evidence for a particular recommendation.  | This point was discussed at the follow-up consensus conference. The group decided to continue to fully describe the breadth of evidence as different levels of evidence describe different aspects of a particular recommendation.                            | Evidence Base |
| One respondent found the language inconsistent regarding the cancer continuum and whether it included death and dying versus use of palliative and end of life care. | The cancer continuum was defined several places throughout the guideline and consistently included end of life care. The section on transitions, Section 3.7 had not included dying, death and bereavement so these were added.                               | Content       |

| <b>Is there anything else you want to tell us about the guideline?</b>   | <b>Action / Response</b>  | <b>Theme</b>                       |
|--|---|------------------------------------|
| <p>One reviewer noted the rationale for the development of the guideline was not clear and perhaps a change to scope and practice should be made to address the fact that it was a useful synthesis of other guidelines without offering anything new.</p>   | <p>Revisions made to Executive Summary to better highlight the unique aspect of this guideline. "The unique perspective of this guideline is to address cancer-related distress in its broadest form, from common normal feelings to problems with anxiety and depression that can become disabling. (See 1.10.4) Use of the Screening for Distress Tool (Table 4.4), the Screening for Cancer-Related Distress Algorithm (Figure 4.2) and the Cancer-Related Distress Management Referral Pathway (Figure 5.3) facilitate a person-centred approach that considers the person's specific circumstance and offers assistance with cancer-related distress from mild to severe levels, for all types of cancer-related distress.(Figure 5.3)</p> | <p>Content</p>                     |
| <p>One reviewer asked for clarification as to who can perform CBT, psycho-education and other specialist interventions such as properly trained members of the front-line team. It was also noted that there were no recommendations related to the front-line team providing these interventions.</p>   | <p>Changes made to guideline, specifically Section 4.9 to clarify this point.</p>   | <p>Content<br/>Recommendations</p> |
| <p>One reviewer asked for clarification regarding strong recommendations and the level of evidence that supports a strong recommendation.</p>  | <p>Upon careful review of the literature base and reconsideration of consistency for the strength of all recommendations, the consensus conference group decided to change the strength of recommendation of number 11 to a "Recommendation" from a "Strong Recommendation" (Sections 1.12 and 6.11).</p>   | <p>Recommendations</p>             |
| <p>One reviewer noted the need for clarification regarding the systematic search and how lower levels of evidence were identified. Clarification of definitions of specific levels of evidence such as, "quality RCT in level 2 evidence if a quality appraisal was not conducted or if this was a trial of a particular size--could it be more explicit".</p> | <p>Clarification added to Section 1.11.1 to describe inclusion of lower levels of evidence. "The psychosocial care of persons affected by cancer is informed by evidence/best practice informed by clinical judgement" ((22), pg 9). "Evidence-Based care is a person-centred integration of best research evidence and clinical judgement (Sackett, Straus, Richardson, Rosenberg, &amp; Haynes, 2000)...Health professionals advocate for improvements in practice in accordance with best research evidence and the definition of evidence-based care" ((22), pg 9).</p>   | <p>Systematic Search</p>           |

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