

# From Distress Screenings to Solutions





January 1, 2015, marked the implementation date for several new standards required of cancer programs seeking accreditation from the American College of Surgeons Commission on Cancer (CoC), including Standard 3.2, psychosocial distress screening. This standard requires that “the cancer committee develops and implements a process to integrate and monitor onsite psychosocial distress screening and referral for the provision of psychosocial care.”<sup>1</sup> The CoC permits for some flexibility in the screening process by allowing cancer programs to select their own screening tool and to determine the best time to screen, as long as cancer patients are screened at least once during a pivotal medical visit. If the screening identifies distress, the cancer program must provide a link to psychosocial services, either onsite or by referral.<sup>1</sup>

The Institute of Medicine (IOM) in its 2008 report *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* revealed that between 29 to 43 percent of cancer patients report psychosocial distress.<sup>3</sup> One of the issues in recognizing distress as a concern for cancer patients is that distress is discounted as being a normal consequence of a cancer diagnosis.<sup>4</sup> Additionally, the topic of distress is not usually a topic of conversation during a medical visit. “Communication regarding psychosocial issues may be hampered by competing expectations as to who should take the lead in initiating such discussions”—the physician or the patient.<sup>5</sup>

At the Edward and Marie Matthews Center for Cancer Care, Plainsboro, N.J., the process for developing and implementing Standard 3.2 began in January 2013. The Matthews Center for Cancer Care is the community cancer program of the Princeton Healthcare System. Two medical oncologists and one radiation oncologist deliver outpatient oncology care with 950 abstracted cases annually. The center houses radiation oncology and an outpatient infusion room. The cancer program is supported by an FTE oncology nurse navigator, an American Cancer Society patient-navigator (8 hours a week), and a reg-

## dis•tress (dĭ-strĕs')

an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment. It extends along a continuum, from common normal feelings of vulnerability, sadness, and fears, to problems that are disabling, such as true depression, anxiety, panic, and feeling isolated or in spiritual crisis.

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istered dietitian (2 hours per week); outpatient social service referrals are made to CancerCare®.

### Developing a Distress Screening Tool

The first step in developing the distress screening process was to form a workgroup from members of the Cancer Committee. The workgroup included the cancer program director, the outpatient infusion room assistant nurse manager, the cancer program manager, the oncology practice nurse, the breast health nurse, the inpatient clinical nurse leader, the inpatient nurse manager, the oncology nurse navigator, and the radiation oncology nurse; the inpatient social worker (who is the psychosocial representative on the Cancer Committee) was available as a consultant.



Top: University Medical Center of Princeton at Plainsboro, Plainsboro, N.J.  
Bottom: The entrance to the Edward and Marie Matthews Center for Cancer Care.

The workgroup’s underlying goal: to design a process for distress screening that could be easily incorporated into daily routine, across the entire healthcare system, and using the support resources currently available to be compliant with CoC standard 3.2. Despite the ease of using the NCCN Distress Thermometer, which has already been validated, the planning team felt that the tool itself was redundant with questions pertaining to physical symptoms. These questions are already reviewed at medical appointments, and while patients could clearly indicate their degree of distress on the thermometer, there was no way of knowing what was causing the distress unless patients only mark one symptom. The workgroup quickly made the decision to develop its own distress screening tool.

The workgroup started by conducting a literature review to see how other cancer programs were incorporating distress screening. The literature review revealed a 2012 article written by Kendall, Hamann, and Clayton, “Oncology Distress Screening: Distress Prevalence, New Standards, and Implementation,”

published in *Oncology Issues*.<sup>6</sup> The article reviewed the process that was established at the Simmons Cancer Center in Dallas, Tex. The oncology nurse navigator, who was the team lead for the project, contacted the lead author, Jeffrey Kendall. Their subsequent phone conversation helped guide the workgroup in the development of its own distress screening tool.

With permission from Kendall, the workgroup remodeled the tool used by the Simmons Cancer Center into a format that would allow for the best use of our support services. Our final product was a paper and pencil distress screening tool (Figure 1, pages 41 and 42). After learning from our literature review that having the definition of distress on the tool itself is helpful,<sup>7</sup> the workgroup added the definition to the top of its tool.

The distress screening tool identifies six areas most likely to cause distress in our patients:

1. Weight
2. Sadness
3. Anxiety
4. Concerns about children and/or family
5. Concerns about significant others
6. Financial concerns.

There is also an area where patients can identify an “other” concern that is not represented on the distress screening tool.

The workgroup decided to use a 0-5 Likert-type scale rather than a 0-10 scale. While some programs have established a referral process for lower scores on the scale, such as written information for a response of 3-5, referral to the appropriate professional within 48 hours for a response of 6-8, and immediate referral for a response of 9-10, we were looking to offer referrals to patients with significant levels of distress—a 4 or 5 on our scale. That said, patients have the option to refuse a referral or to request a referral without an identified distress trigger. The nurse who administers the distress screening tool is responsible for making the appropriate referrals. Therefore, the back of the tool has space for the staff to document who administered the tool and what educational materials or referrals were made. Our goal: to contact patients within 24 hours.

The workgroup’s next step involved establishing referral pathways to the appropriate professional and timing protocols for administering the tool.

To make the referral process as seamless as possible, the workgroup worked with support services to create an algorithm with parameters for potential referrals (Figure 2, page 44). The algorithm guides the clinician who administers the distress screening tool to the appropriate support service. A second algorithm addresses when distress screening should take place (Figure 3, page 45). As timing is critical, the workgroup made the decision not to administer screening during “high points” of patient

*(continued on page 43)*

**Figure 1. Matthews Center for Cancer Care Distress Screening Tool (continued on back)**

**Distress:** “An unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment. It extends along a continuum, from common normal feelings of vulnerability, sadness, and fears, to problems that are disabling, such as true depression, anxiety, panic, and feeling isolated or in spiritual crisis.”

*(NCCN practice guidelines for the management of psychosocial distress. National Comprehensive Cancer Network. Oncology (Williston Park)13(5A): 113-47, 1999. [PUBMED Abstract]*

The staff of the Matthews Center for Cancer Care recognizes that cancer care is more than just receiving treatments. Peace of mind and a sense of well-being are essential for you to achieve long-term success. Please tell us how you are doing today by completing this screening tool.

Check this box if there are no changes since the last time you completed this survey.

**STEP 1. Please circle the number for each symptom that best describes how you feel now:**

(0=no complaints; 5=severe complaints).

No weight loss	0	1	2	3	4	5	Significant weight loss
No sadness	0	1	2	3	4	5	Significant sadness
No anxiety	0	1	2	3	4	5	Severe anxiety
No concerns about children/family	0	1	2	3	4	5	Significant concerns about children/family
No concerns about your significant other	0	1	2	3	4	5	Severe concerns about your significant other
No financial concerns	0	1	2	3	4	5	Severe financial concerns
Other problems	0	1	2	3	4	5	Tell us: _____

**STEP 2. If you want to be contacted by one of our professionals, please check the box next to the professional and he or she will contact you.**

Cancer Dietitian     UMCP Chaplain     Nurse Navigator     Financial Services

Check this box if you do not want to be contacted by a support service staff member.

Your name: *(please print)* \_\_\_\_\_ Date: \_\_\_\_\_

Best contact method *(phone or email address)*: \_\_\_\_\_

Name of your treating physician: \_\_\_\_\_

*(continued on page 42)*

**For Staff Use Only:**

Date of Assessment	Provider Signature	(Any Response) Educational Materials	(Response of 4 or 5) Patient Referred to:	MD Notified and Date
			Referred to:  Facility name:	
			Referred to:  Facility name:	
			Referred to:  Facility name:	

**Referral Contact Information**

**Cancer Dietitian**

*(Name, phone number, and email)*

**UMCPP Chaplain Office**

*(Name, phone number, and email)*

**CancerCare Social Worker**

*(Name, phone number, and email)*

**Breast Navigator**

*(Name, phone number, and email)*

**Breast Resource Center**

*(Name, phone number, and email)*

**Nurse Navigator**

*(Name, phone number, and email)*

**American Cancer Society Patient Navigator**

*(Name, phone number, and email)*

**UMCPP Financial Counselor**

*(Name, phone number, and email)*

**Support Groups**

*(Name, phone number, and email)*

\*For referrals to homecare, palliative care, and/or hospice, contact treating physician.

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distress, for example, the day patients are given their cancer diagnosis. The workgroup also took into consideration the workflow of the areas where the distress screening tool would be administered; nursing units with more than 15 minutes face-to-face time with patients were identified as the primary administrators of the distress screening tool.

The distress screening tool was piloted from March 2013 through August 2013. The workgroup wanted an opportunity to work out any issues surrounding the implementation or referral process prior to presenting its work. The final product was presented to the Cancer Committee for approval in October 2013.

Once the distress screening tool is complete, the oncology nurse navigator collects copies of the distress screening tool and enters the responses and referrals into a spreadsheet. Original copies of completed tools are kept in the patient's medical chart. When distress screening is conducted in radiation oncology, the collaborating medical oncologist is notified when patients report any distress level of 4-5, including what interventions were initiated. The oncology nurse navigator reports distress screening metrics quarterly to the Cancer Committee.

Once the workgroup felt that the distress screening process was complete, staff received face-to-face education about their responsibilities for completing the distress screening tool, as well as a list of "helpful hints" for introducing the distress screening tool into conversations with patients (see page 46).

### **Pilot Outcomes**

Over a six-month period, the oncology nurse navigator collected the distress screening tool from departments that participated in the pilot, including radiation oncology, outpatient infusion, the Breast Health Center, the inpatient oncology unit, and the medical oncologist practice. She checked for completion and that appropriate referrals had been made. The oncology nurse navigator then followed up with patients—either in person or by phone—to confirm that patients had completed the referral process. It quickly became apparent that patients were not taking the initiative to contact the support staff on their own, and the decision was made to have cancer program staff initiate contact with support staff, providing the patient's contact information.

Our data revealed that 41 percent of our patients required referrals for distress symptoms, which is concordant with the 2008 IOM report. The workgroup was satisfied that it had accomplished its goal.

Anecdotally, our patients reported that the distress screening tool is user-friendly. Nurses who reviewed the completed tool with the patients reported that the distress screening tool only added about 15 minutes to their daily routine.

One result we did not anticipate: an additional 20 percent of



The oncology nurse navigator discusses financial resources with a patient.

the patients who took the distress screening tool self-referred to our support services, which included the chaplaincy department, a department that had not previously seen outpatient cancer patients.

### **Improving the Process**

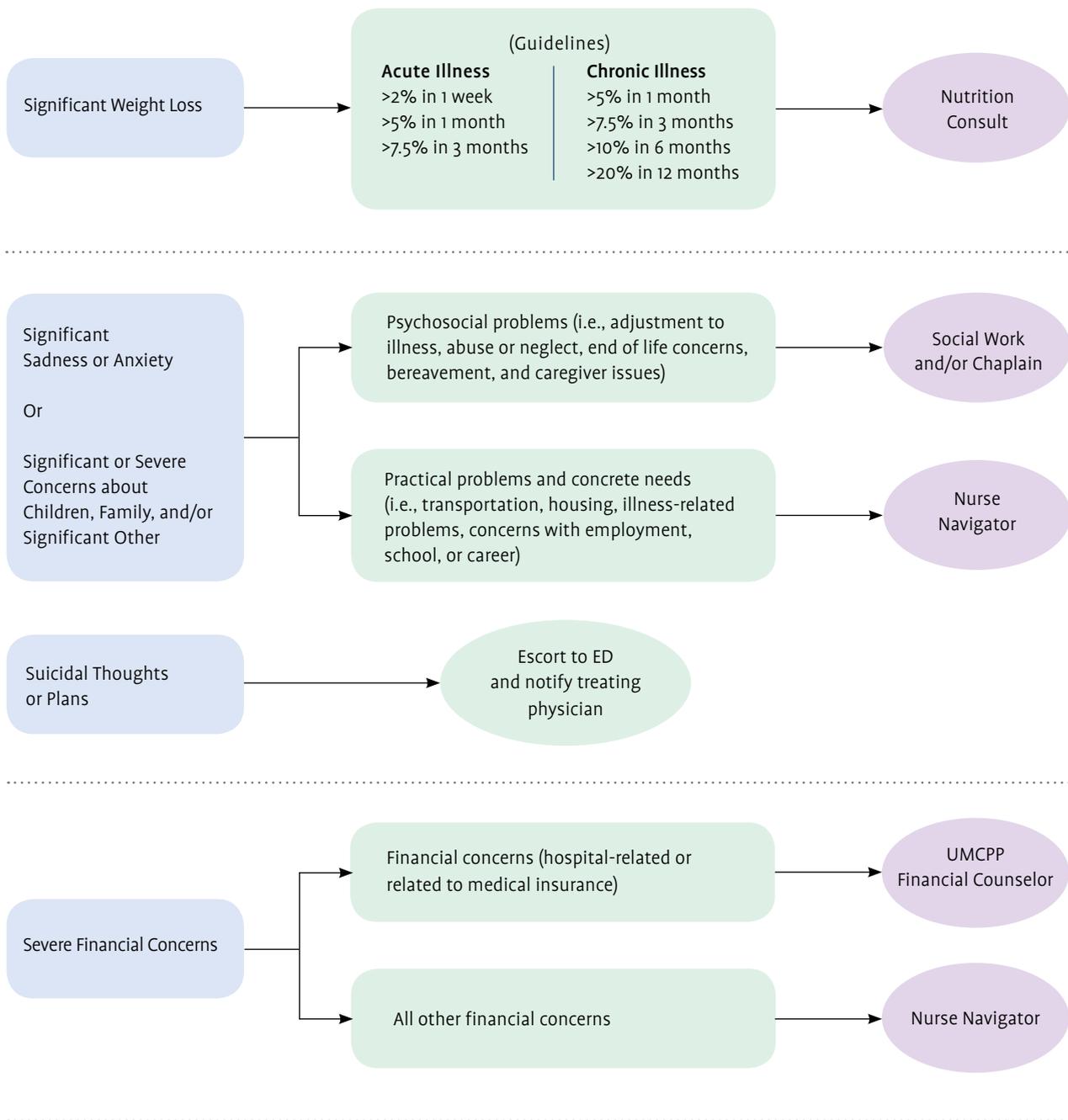
The workgroup's final task was to write a policy and procedure for administration of the distress screening tool. Since Princeton Healthcare System is a Magnet facility, the policy was reviewed and approved by the Clinical Practice Committee, as well as the Cancer Committee. (View this policy online at [www.accc-cancer.org/oncology\\_issues/MA2015.asp](http://www.accc-cancer.org/oncology_issues/MA2015.asp)).

Inpatient staff who administered the distress screening tool identified one challenge: the tool is paper and pencil, and inpatient staff chart exclusively in an EHR. The inpatient nurses who were part of the workgroup took on this challenge, working with the IT department to make the distress screening tool part of the EHR. In April 2014, following a hospital-wide education program, the distress screening tool was launched as part of the EHR. Now the distress screening tool is entered into the system by the staff as a direct order when the patient is identified as a cancer patient. This process improvement has made it possible for a cancer patient admitted anywhere in the Princeton Healthcare System to be screened for distress, if appropriate.

A second challenge was educating staff to take full ownership of the distress screening tool, including completing the tool and identifying the appropriate referrals to support services. In the first month of the pilot, the oncology nurse navigator found that 25 percent of distress screening tools were incomplete. Our solution: identifying a staff member to act as "volunteer champion."

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**Figure 2. Matthews Center for Cancer Care Distress Tool Pathways**



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The author of this article was part of the initial interdisciplinary team that developed and implemented the distress screening tool. She would like to thank her fellow workgroup members: Judy Neuman, CTR, cancer program director; Deborah Richey, RN, MSN, OCN, nurse manager, cancer program; Beth Beckett, RN, BSN, OCN, OPI assistant nurse manager; Sheryl Smolesky, RN, OCN,

radiation nurse; Monica Lyle, RN, BSN, OCN, clinical practice nurse; Inez Brandon, MSN, RN, OCN, CHPN, CNL, MNO, clinical nurse leader; Audrey Amir, MSN, RN, CNL, PCCN, MNO, clinical nurse leader; Humility Samayang, RN, BSN, BC, nurse manager; Britni Walton, BSN, RN, OCN, WCC; Nune Mehrabyan, RN, BC, MS, IT Department; and Mary Kiensicki, RN, CBCN, breast health nurse.

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This individual was then tasked with ensuring that all distress screening tools placed in the folder for the oncology nurse navigator to collect were complete with appropriate referrals. (Fortunately, the volunteer champion was able to “retire” from her position at the conclusion of the pilot.)

### Patient-Centered Care

Although implementation of the distress screening tool required a commitment of time from Princeton Healthcare System nursing staff, we have successfully implemented psychosocial distress screening to become compliant with CoC standard 3.2 without adding an FTE to our budget.

Staff who are responsible for administering the distress screening tool have observed that it has improved our delivery of patient-centered care. For example, screening patients for distress has created an opportunity to open dialogue and engage our patients beyond their clinical needs. This benefit is apparent in the number of referrals to support services and resources that are triggered as a result of distress screening. Since the distress screening tool is usually first administered just after diagnosis or early in the treatment process, concerns are identified and communicated to the care team, allowing for prompt interventions that can promote a positive effect before these concerns become insurmountable or paralyzing.

The distress screening tool has also improved care coordination by expanding the circle of multidisciplinary support for our patients. For example, both the registered dietitian and social worker have reported an increase in referrals since distress screening was implemented. 

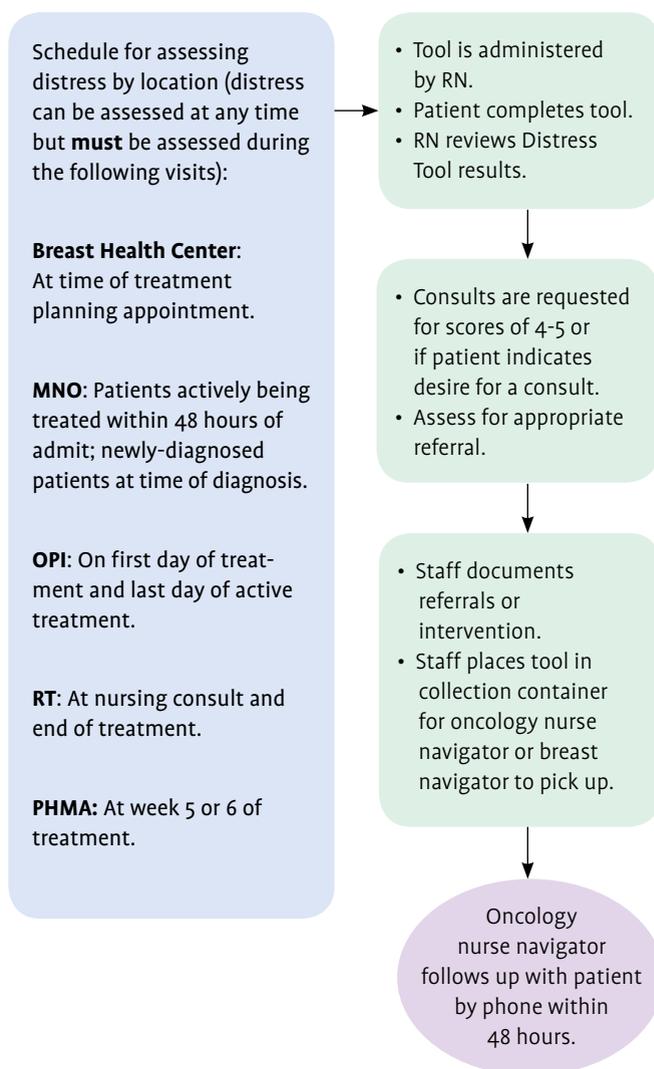
*Lori McMullen, RN, MSN, OCN, is senior oncology nurse navigator, University Medical Center of Princeton at Plainsboro, Edward and Marie Matthews Center for Cancer Care, Plainsboro, N.J.*

### References

1. American College of Surgeons. Cancer Program Standards 2012: Ensuring Patient-Centered Care, Version 1.1.2, Standard 3.2 Psychosocial Distress Screening. Chicago, IL, 2012 Available online at: [www.facs.org/cancer](http://www.facs.org/cancer). Last accessed Oct. 6, 2014.
2. National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines Version 2.2014, Distress Management. Available online at [www.nccn.org](http://www.nccn.org). Last accessed March 7, 2014.
3. Institute of Medicine. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. Washington, DC: The National Academies Press; 2008. Available online at: [http://www.nap.edu/openbook.php?record\\_id=11993](http://www.nap.edu/openbook.php?record_id=11993). Last accessed Sept. 7, 2014.
4. Fallowfield L, Ratcliff D, Jenkins V, Saul J. Psychiatric morbidity and its recognition by doctors in patients with cancer. *British J Cancer*. 2001;84 (8):1011-1015.

5. Detmar SB, Aaronson LDV, Weaver M, Muller, Schornagel, J H. How are you feeling? Who wants to know? Patients’ and oncologists’ preferences for discussing health-related quality-of-life issues. *J Clin Oncol*. 2000;18(18):3295-3301.
6. Kendall J, Hamann H, Clayton S. Oncology distress screening: Distress prevalence, new standards, and implementation. *Oncol Issues*. 2012; 27(6): 22-28.
7. Fulcher C, Gosselin-Acomb T. Distress assessment: Practice change through guideline implementation. *CJON*. 2007;11(6): 817-821.

**Figure 3. Matthews Center for Cancer Care Distress Tool Administration Pathway**



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# FACTS AND HELPFUL HINTS FOR ADMINISTERING THE DISTRESS TOOL (DT)

**T**he American College of Surgeons (ACoS) Commission on Cancer (CoC), the accrediting body for cancer programs, has added standard 3.2 Psychosocial Distress Screening as a requirement for achieving accreditation. The standard promotes patient-centered care with the goal of improving the quality of cancer care.

## Why is Distress Screening Important?

- 20 to 47 percent of newly-diagnosed and recurrent cancer patients show significant levels of distress
- Failure to recognize and treat distress can lead to:
  - Trouble making decisions about treatment
  - Extra visits to the ED or physician's office
  - Poor quality of life and have a negative impact on survival.
- Early evaluation and screening of distress:
  - Improves medical management
  - Ensures appropriate referrals to psychosocial resources that can lead to lower levels of stress in three months compared to those without screening and referral
  - Better adherence to treatment
  - Better communication
  - Fewer calls and visits to MD office
  - Avoidance of anger and development of severe anxiety or depression.

## Suggestions for Introducing Distress Screening

In screening patients for distress, our goal is to provide them with the best resource to address their problem(s). As you introduce the tool:

- Build rapport and trust before expecting the patient to talk about something personal and revealing.
- Make it clear that this is a normal, routine assessment rather than something unusual.

- Take your time and talk generally about how things are going before introducing the distress screening tool. For example, "How have you been managing with your diagnosis and treatment?"
- If the patient identifies a distressing issue, move from the general to the specific. For example, "You've put down weight loss. Can you tell me a bit more about this?" And then follow up with, "What do you think is causing you to lose weight?"
- Explore how the patient is using their own resources in managing their distressing issue. For example, "Can you tell me what you are doing at home to manage your weight loss?"
- Acknowledge achievements and build on things that are going well.
- Focus on a solution to the problem rather than the problem itself.
- Offer (and encourage) appropriate referrals.

## Resources

1. American Cancer Society. Distress in People with Cancer; 2012. Available online at: [www.cancer.org/acs/groups/cid/documents/webcontent/002827-pdf.pdf](http://www.cancer.org/acs/groups/cid/documents/webcontent/002827-pdf.pdf). Last accessed Jan. 28, 2015.
2. Brennan J. A Manual for Screening and Responding to Cancer Distress using the Distress Thermometer and Problem Checklist; 2009. Available online at: [www.ncsi.org.uk/wp-content/uploads/DT-Instruction-Manual-Bristol-method.pdf](http://www.ncsi.org.uk/wp-content/uploads/DT-Instruction-Manual-Bristol-method.pdf). Last accessed Jan. 28, 2015.
3. National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines Distress Management, Version 2.2013. Available online at: [www.nccn.org](http://www.nccn.org).



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