

# **Coleman Supportive Oncology Initiative**

## **Distress Training Module**

### **Topic: How to Discuss Practical and Family Concerns with Patients and Families**

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## Learning Objectives

**By the end of this module you should be able to:**

- 1. Communicate with patients and family members about common practical and family concerns**
- 2. Share and discuss resources available to patients reporting mild, moderate and severe levels of distress**
- 3. Describe the documentation needed to communicate your follow-up efforts**

Note: Guidelines on how to talk with patients about their practical and family concerns do not exist. The content in this training module is based on National Comprehensive Cancer Network (NCCN) Distress Guidelines<sup>a</sup> and the Institute of Medicine (IOM) Report, *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*<sup>b</sup> which is a pragmatic approach based on professional experience.

<sup>a</sup> [NCCN Clinical Practice Guidelines in Oncology \(NCCN Guidelines®\) Distress Management](#)

<sup>b</sup> Institute of Medicine, *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*. National Academies Press (US); 2013 Dec.

## Common Practical & Family Concerns Patients Face

- **Childcare issues**
- **Financial issues**
  - Insurance coverage
  - Medication or medical care
  - Food and housing
- **Transportation issues**
- **Work/school issues**
- **Family member concerns**
  - Children
  - Partner
  - Caregivers
  - Other family members
- **Infertility concerns**
- **Treatment decisions**

## Childcare Issues

### Common concerns that patients may have:

- Accessibility or reliability of child care; this may be a barrier to medical treatment
- Having at least one child less than 7 years old
- Logistics or location of childcare
- The financial burden childcare can create
- The fatigue that can be related to childcare

### Possible action steps to take:

- Inquire if the patient has reached out to friends and family, as well as their church/faith/spiritual and school communities.
  - If not, encourage the patient to do so.
- Encourage the patient to discuss pressing issues with their daycare provider or school.
- Refer the patient to a social worker, patient advocate, patient navigator
- Refer the patient to nonprofit cancer organizations and/or cancer support centers
- See the resources listed on slides 24 - 28

## Financial Concerns, Insurance Coverage

### Common concerns that patients may have:

- They have no insurance
- Need assistance to acquire insurance
- Cannot afford their monthly premiums
- Do not have enough funds to cover their deductible

### Possible actions to take:

- Gain a better understanding of the patient's current coverage and any specific concerns related to their coverage being in jeopardy.
- Inquire about any efforts made to contact their insurance provider for assistance.
- Inquire about efforts made to apply for financial assistance anywhere.
- Refer to State Affordable Care Act (ACA) agencies to help with enrolling in insurance plan.
- Refer to a social worker, financial counselor, patient advocate and/or patient navigator.
- Refer to nonprofit cancer organizations and/or cancer support centers.
- See the resources listed on slides 24 - 28

## Financial Issues, Medication or Medical Care

### Common concerns that patients may have:

- Issues paying for medication or medical care, whether or not they have insurance

### Possible actions to take:

- Gain a better understanding of the patient's current health insurance coverage and their specific concerns related to paying for medication and medical care
- Inquire about efforts to contact their insurance provider or treating institutions for assistance
- Inquire about efforts to apply for financial assistance anywhere
- Refer to a social worker, financial counselor, patient advocate and/or patient navigator
- Refer to pharmaceutical manufacturer to apply for drug-related financial aid
- Refer to nonprofit cancer organizations and/or cancer support centers
- See the resources listed on slides 24 - 28

## Financial Issues, Food and Housing

### Common concerns that patients may have are:

- Accessing, preparing or paying for food
- Housing needs, as well as paying their rent or mortgage
- Utility bills including cell phone
- Internet access

### Possible actions to take:

- Gain a better understanding of the patient's current living arrangement and means of paying for food and housing
- Inquire with whom they have shared this concern and what attempts have been made to address
- Suggest to patients to discuss their concerns with friends, family and/or church/faith community
- Refer to a social worker, financial counselor, patient advocate and/or patient navigator
- Refer to nonprofit cancer organizations and/or cancer support centers
- See the resources listed on slides 24 - 28

## Transportation Issues

### Common concerns that patients may have:

- Difficulty with transportation may be a barrier to medical treatment
- Difficulty with physical functioning may interfere with getting to and from medical treatment
- Financial difficulties may be a concern in paying for transportation services

### Possible actions to take:

- Gain a better understanding of the patient's transportation issue(s)
- Refer to a social worker, financial counselor, patient advocate, and/or patient navigator who may be able to assess the situation further and provide transportation resources
- Refer to nonprofit cancer organizations and/or cancer support centers
- See the resources listed on slides 24 - 28



## Work/School Concerns

### **Common concerns that patients may have:**

- Need legal information on job security
- Too ill to work/attend school, or may require reduced hours
- Need documentation of their disability status
- Need financial assistance for tuition

### **Possible actions to take:**

- Gain a better understanding of the patient's specific concerns
- Inquire about efforts to contact their employer's Human Resource Department
- Inquire about efforts to contact school counselor or other school representative
- Inform the patient of the Family Medical Leave Act (FMLA), if the patient works for company of 50 or more employees
- Refer to a social worker or counselor to provide support in addressing these concerns
- Refer to nonprofit cancer organizations and/or cancer support centers
- See the resources listed on slides 24 - 28

## Family Member Concerns: Children

### Behaviors children may exhibit:

- Problem behaviors
- Complaints of pain or illness that have no obvious cause
- Acting or being quieter than normal
- Changes in sleep or appetite
- Change in grades or behavior at school

### Possible actions to take:

- Refer to a family/child psychologist
- Refer to child life specialist, counselor, social worker, cancer support resources, or chaplain
- Encourage patients to discuss concerns, children's needs and parent's medical issues with a teacher and/or school social worker
- Encourage patients to make children aware of their illness if they have not done so already
  - Discuss the patient's concerns about informing children and refer to child/family psychosocial services if needed
  - Develop a plan for discussing illness with the children
  - Discuss how children's lives are being/will be impacted
- Schedule an appointment with social services to identify temporary caretaker availability if the patient feels they are too sick to care for their children. This will ensure that the parent is comfortable with caregiving arrangements

## Family Member Concerns: Partner

### **A few examples of patient concerns about a partner:**

- Patient's relationship with their partner has changed in a way that is concerning to the patient
- Unable to communicate openly with their partner
- How their partner is handling diagnoses
- Partner having caregiver burnout issues

### **Possible actions to take:**

- If seriously concerned about how a partner is handling illness, refer to social worker and/or mental health counselor
- Refer to cancer support resources
- Provide information and material on coping with the stressors commonly experienced by partners
- See the resources listed on slides 24 - 28

## Family Member Concerns: Caregiver

### A few examples of a patient's concerns about a caregiver:

- Caregivers may be in need of additional help giving care *and* caring for themselves
- Concern for caregiver's physical/emotional health
- Feeling unable to openly communicate with caregivers about their health status

### Possible actions to take:

- If concerned about the patient's support team, complete planning to establish such a team for the patient
- Refer to a social worker, cancer resources, and support center resources.
- Provide information on their illness that the patient can give to caregivers
- See the resources listed on slides 24 - 28

## Family Member Concerns: Other Family Members

### Examples of concerns for other family members:

- Own need of care for themselves
- Physical and emotional health and wellbeing
- Understanding of the patient's health status

### Possible actions to take:

- If family member is the caregiver, refer to social worker, counselor or other mental health specialist to discuss family their role as caregiver, as well as the patient's needs.
- If family members are not coping well with the patient's illness, refer to social worker, counselor or spiritual advisor, depending on family members' needs.
- Refer to a social worker, cancer resources, and support center resources
- Refer to nonprofit cancer organizations and/or cancer support centers
- See the resources listed on slides 24 - 28

## **Infertility Concerns: Ability To Have Children**

### **Examples of concerns about having children:**

- Unaware of how treatments could affect their fertility
- Patient or the patient's partner may want more information about fertility
- Patient and/or partner may want the possibility of having children in the future

### **Possible actions to take:**

- Determine if a doctor has spoken to the patient about the effects treatment will have on the patient's fertility. If this has not been done, schedule an appointment for the patient to speak with the primary medical team.
- If available, refer to an onco-fertility nurse or genetic counselor. This may require an external referral.
- If the patient would like information and is experiencing emotional distress, refer to a mental health provider
- If there is a partner, determine the needs of this partner

## Treatment Decisions

### **Common concerns that patients may have:**

- Understanding the diagnosis or stage of the cancer
- Understanding the prognosis or long term outcome
- Treatment options
- Need help discussing their illness with family, friends or children
- Need help with power of healthcare attorney and advance directives

### **Possible action steps to take:**

- Treating physician and/or nurse could suggest an additional appointment to spend more time explaining the cancer and concerns
- Patient could be referred to palliative care for a consultation
- Refer to a social worker, patient advocate or patient navigator
- Refer to nonprofit cancer organizations and/or cancer support centers
- See the resources listed on slides 24 - 28

## Documentation in Medical Records

**For appropriate patient follow-up and care outcomes, it is necessary to document:**

- The practical and/or family concerns that the patient identified as causing distress
- What approaches the patient already has done to address the concern
- What suggestions were made to address the concern
- What referrals were made to address the concern
- Attempts to revisit these concerns and determine if they have been addressed, or in additional support or follow up is needed



## Summary of Points Covered

### **In this training module we addressed:**

- **The most common practical and family concerns that patients face**
- **Possible actions to use when assisting patients with addressing their concerns**
- **What documentation is needed in patients' medical records**

## Next Steps

For more detailed resources for Medical Professionals on these topics, you can go to the following:

### **National Comprehensive Cancer Network®**

➤ [NCCN Clinical Practice Guidelines in Oncology \(NCCN Guidelines®\) for Distress Management Version 1.2017](http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf)

[http://www.nccn.org/professionals/physician\\_gls/pdf/distress.pdf](http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf)

### **American College of Surgeons, Commission on Cancer (CoC)**

➤ [CANCER PROGRAM STANDARDS: Ensuring Patient-Centered Care, 2016 Edition](https://www.facs.org/~media/files/quality%20programs/cancer/coc/2016%20coc%20standards%20manual_interactive%20pdf.ashx)

[https://www.facs.org/~media/files/quality%20programs/cancer/coc/2016%20coc%20standards%20manual\\_interactive%20pdf.ashx](https://www.facs.org/~media/files/quality%20programs/cancer/coc/2016%20coc%20standards%20manual_interactive%20pdf.ashx)

### **Association of Oncology Social Work (AOSW)**

➤ [http://www.nccn.org/professionals/physician\\_gls/pdf/distress.pdf](http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf)

### **American Psychosocial Oncology Society (APOS)**

➤ <https://www.apos-society.org/>

## Next Steps - Resources

For more detailed resources for patients on these topics, you can go to the following:

### Resources for Family/Friends:

- <http://www.cancer.net/coping-with-cancer/talking-with-family-and-friends/family-life>
- <http://www.livestrong.org/we-can-help/guidebook/>

### Resources for Concerns about Childcare:

- <http://www.cancercare.org/financial>
- <http://www.dhs.state.il.us/page.asp?item=30358>
- <http://www.cancer.org>

### Resources for Concerns about Children:

- <http://www.cancer.org/treatment/childrenandcancerhelpingchildrenwhenafamilymemberhascancer/index>
- <http://www.cancercare.org/tagged/children>; <http://kidskonnected.org/>
- <http://www.cancer.net/coping-with-cancer/talking-with-family-and-friends/parenting-while-living-with-cancer>
- <http://www.cancer.net/coping-with-cancer/talking-with-family-and-friends/talking-about-cancer/talking-with-your-children>

### Resources for Concerns about a partner:

- <http://www.cancer.org/treatment/treatmentsandsideeffects/emotionalsideeffects/copingwithcancerineverydaylife/a-message-of-hope-for-spouses-families-friends>
- <http://www.wellspouse.org/>

### Resources for Concerns about Caregiver(s):

- <http://www.caregiving.org/>
- <http://www.caregiving.com/>
- <https://www.caregiver.org/>

### Resources for Concerns about Other Family Members:

- <https://www.cancer.org>; <http://www.cancer.gov/>

## Next Steps - Resources

For more detailed resources for patients on these topics, you can go to the following:

### Resources for Financial Concerns:

- <http://www.cancerfac.org/>
- <http://www.needhelppayingbills.com/>
- <http://www.livestrong.org/we-can-help/insurance-and-financial-assistance/>
- <http://www.cancercare.org/financial>
- [http://www.cancercare.org/publications/211-financial\\_assistance\\_for\\_children\\_and\\_teens](http://www.cancercare.org/publications/211-financial_assistance_for_children_and_teens)
- [http://media.cancercare.org/publications/original/178-helping\\_hand.pdf?1442411382](http://media.cancercare.org/publications/original/178-helping_hand.pdf?1442411382)
- <http://www.cancer.org/treatment/findingandpayingfortreatment/understandinghealthinsurance/>
- <http://www.cancer.org/treatment/findingandpayingfortreatment/understandinghealthinsurance/healthinsuranceandfinancialassistanceforthecancerpatient/health-insurance-and-financial-assistance-outside-sources>

### Resources for Financial Concerns of families with childhood cancer:

- <http://www.cancer.org/treatment/childrenandcancer/whenyourchildhascancer/childrendiagnosedwithcancerfinancialandinsuranceissues/children-diagnosed-with-cancer-financial-and-insurance-issues-help-with-other-expenses>
- [http://www.cancercare.org/publications/211-financial\\_assistance\\_for\\_children\\_and\\_teens](http://www.cancercare.org/publications/211-financial_assistance_for_children_and_teens)
- <http://www.cancer.org/treatment/findingandpayingfortreatment/understandinghealthinsurance/>

## Next Steps - Resources

For more detailed resources for patients on these topics, you can go to the following:

### Resources for Financial Concerns Related to Medication or Medical Care:

- <http://www.cancer.org>; <http://www.livestrong.org/survivorcare>
- <http://www.cancer.net/navigating-care/financial-considerations>
- <https://www.copays.org/>
- <https://www.pparx.org/>
- <http://www.needymeds.org/>
- <http://panfoundation.org/>
- <http://www.livestrong.org/we-can-help/insurance-and-financial-assistance/>
- <http://patientadvocate.org/index.php>
- <http://www.cancer.org/treatment/findingandpayingfortreatment/understandinghealthinsurance/>

### Resources for Financial Concerns Related to Insurance Coverage or lack of:

- <http://www.cancer.net/navigating-care/financial-considerations>; <http://www.healthcare.gov>
- <http://www.cancerandcareers.org/en>
- <http://www.cancerinsurancechecklist.org/>
- <http://www.livestrong.org/we-can-help/insurance-and-financial-assistance/>
- <http://patientadvocate.org/index.php>
- <http://www.cancer.org/treatment/findingandpayingfortreatment/understandinghealthinsurance/>
- <http://www.cancer.org/treatment/findingandpayingfortreatment/understandinghealthinsurance/healthinsuranceandfinancialassistanceforthecancerpatient/health-insurance-and-financial-assistance-options-for-uninsured>

## Next Steps - Resources

For more detailed resources for patients on these topics, you can go to the following:

### Resources for employment concerns:

- <http://www.cancerandcareers.org/en>
- <http://patientadvocate.org/index.php>
- <http://www.cancer.org/treatment/findingandpayingfortreatment/understandinghealthinsurance/>

### Resources for Transportation concerns:

- <http://www.livestrong.org/we-can-help/planning-medical-care/transportation-and-other-cancer-support-services/>
- <http://www.cancer.org/treatment/supportprogramsservices/road-to-recovery>
- <http://www.cancercare.org/financial>

## **Faculty Bio for Anne Bowman, MBA, CHES**

**Anne Bowman, MBA, CHES, is the Associate Executive Director at the Hult Center for Healthy Living and is responsible for leading a staff of 10+ health educators and providing oversight on Hult's four pillars of service: youth prevention health education, mental health awareness and education, senior education programs and cancer programs and services. Prior to working at the Hult Center, Anne worked at the American Cancer Society. For the past 12+ years Anne has been working to help people who have been impacted by cancer.**

**When Anne was 15, she lost her mother to breast cancer at the young age of 39. In 2014 Anne tested positive for the CHEK2 gene mutation, showing her risk for cancer could be as high as 50%. Due to Anne losing her mother to the disease, her own experience in working with cancer patients, and Anne's personal increased risk of developing cancer, she has a passion for helping those who have been impacted by the disease.**

**For additional information:**

<http://www.hulthealthy.org/about/our-team/>

## Faculty Bio for Melissa Minkley, MSW

**Melissa is a social worker with over 20 years of experience in psychosocial oncology and bereavement counseling. She has been a counselor with Stillwaters Cancer Support Services since 1999.**

**Melissa's area of interest and expertise include psycho-social oncology, end of life issues and the grief process. She was actively involved with establishing the *Hope, Healing and Growth* workshop for grieving family members and The Challenges of Cancer Workshop for newly diagnosed cancer patients. These psycho-educational workshops provide information and teach strategies to cope with cancer and the loss of a love one.**

**Melissa has an understanding of the impact that cancer has on a family, and harvests a strong desire to empower those affected by cancer to live life well and confront the issues cancer creates in our life. What Melissa enjoys most about working at Stillwaters is her compassionate co-workers and witnessing the courage cancer patients reveal on their journey.**

**For additional information:**

<http://www.stillwaterscenter.org>



## **Faculty Bio for Megan McMahon, PhD**

**Dr. McMahon has a Ph.D. in Clinical Psychology with an emphasis in health and behavioral medicine. Her specialty is working with couples who are coping with chronic illness. In 2003 Dr. McMahon developed the program Partners Empowered™, a six-week structured intervention aimed at facilitating adjustment and softening the impact a cancer diagnosis has on a couple's relationship. In 2011, Dr. McMahon was named the Cancer Wellness Center Clinical Director.**

**For additional information:**

<https://cancerwellness.org/about/our-staff/>

## References

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