1

OBJECTIVES

At the conclusion of this presentation, the participant will be able to:

- Review the differences of palliative care and hospice care
- Review legal components of the advance directive
- Describe a comprehensive assessment approach to include areas sensitive to serious illness (SI) end-stage conditions
- Describe care plan review, addressing the patient's values and goals while incorporating behavioral, medical, and social aspects impacting care
- Describe appropriate referral touchpoints to connect SI biomedical assessment and care planning with palliative or hospice care services

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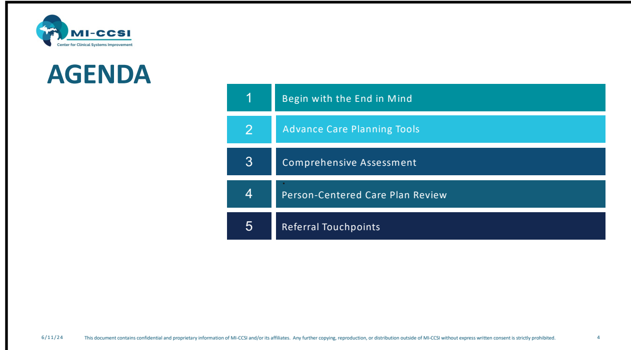

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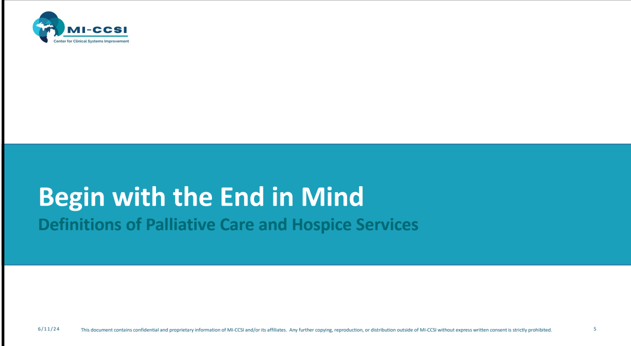

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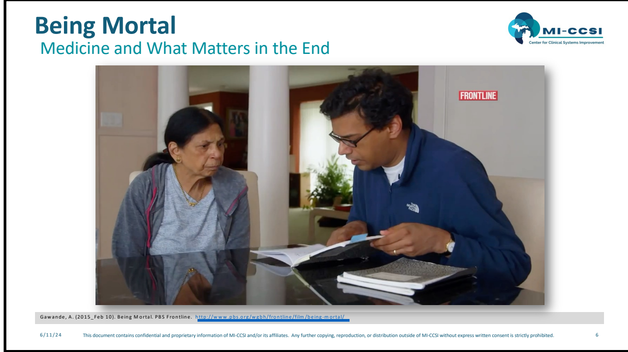

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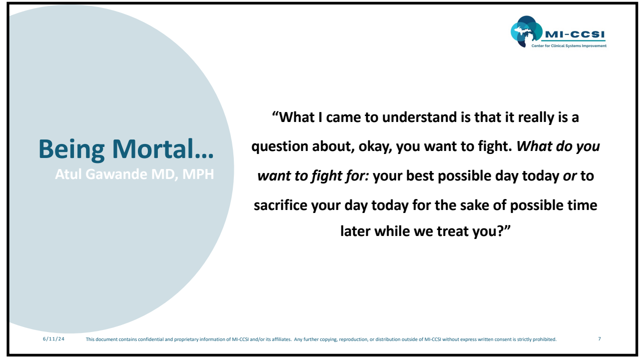

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Public Barriers:

Language "Triggers"

- **Palliative Care**
  - *Symptom management* of disease or treatments related to disease
- **Hospice**
  - Care focused on comfort *when cure is no longer possible*

"All hospice patients need palliative care, but not all palliative care patients need hospice!"

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Palliative/Serious Illness Care definition

- Specialized medical care for people with serious illness
- Care providing relief from pain and other symptoms, supports quality of life, and is focused on patients with serious illness and their families. (IOM, 2015; CAPC, CMMS)
- May begin early in the course or treatment for serious illness, across the continuum of health care settings (IOM, 2015; CMMS)
- Appropriate at any age and at any stage in serious illness (NCHPC 2018, p. iii)
- Can be provided along with curative treatment (NCHPC 2018, p. iii)
- Not time-limited
- Covered by insurance
- Can be delivered across the continuum of care (home, hospital, clinic, various living facilities)

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Hospice Care definition

- Philosophy of care, versus a place.
- Focused on quality of life when cure is no longer possible.
- Treats the whole person, not just the disease.
- An interdisciplinary team that works with the person and family to design & implement a plan of care unique to each person's diagnosis.
- The person's wishes are always a priority.
- Hospice care continues, providing bereavement support up to 13 months post-death for the family and loved ones.

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Hospice Services

- Manage a person's pain and symptoms
- Provide emotional support
- Provides needed medications, medical supplies and equipment associated with the terminal diagnosis
- Instructs and coaches loved ones on how to care for the person
- Delivers special services as needed (e.g., speech & physical therapy)
- Grief support to loved ones and friends (including 13 months post death)
- Short-term inpatient care if pain or symptoms can't be managed at home, or caregiver needs respite time

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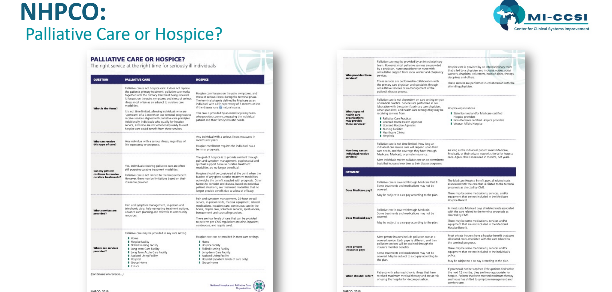
NHPCO:

Palliative Care or Hospice?



https://www.nhpco.org/patients-and-caregivers/about-palliative-care/palliative-care-faqs/

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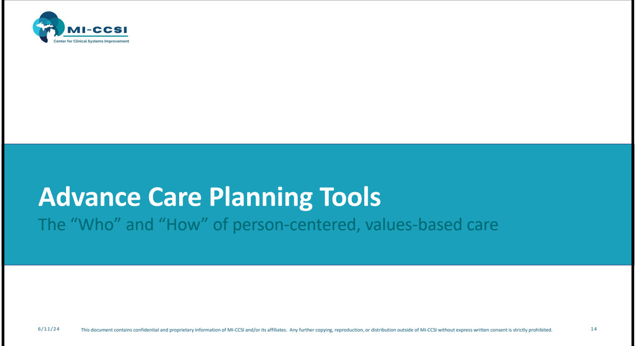

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The PROCESS

Advance Care Planning (ACP)

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Discuss

- Reflect on your values and beliefs

Decide

- Choose your Patient Advocate(s)
- Decide on your treatment preferences

Document

- Write your wishes in an Advance Directive (Durable Power of Attorney for Healthcare or DPOAH)
- Share your plan

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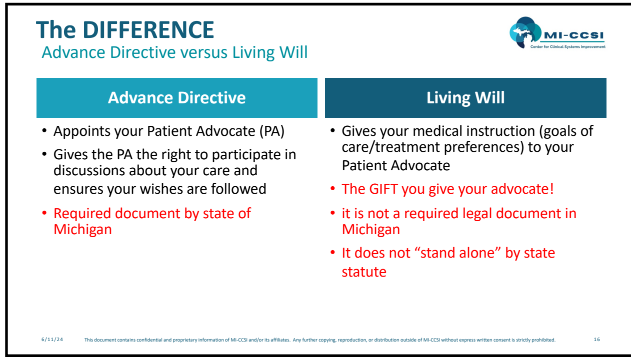

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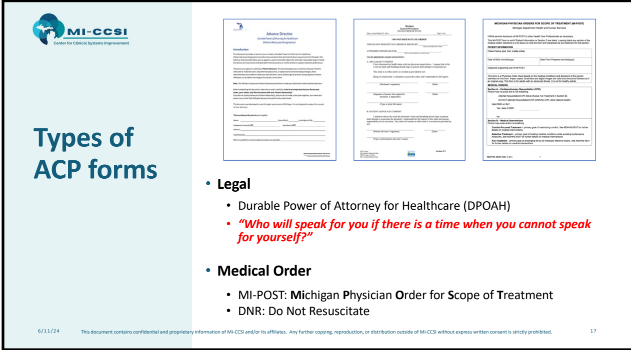

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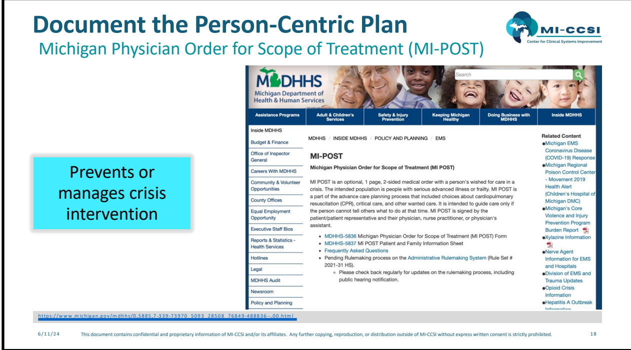

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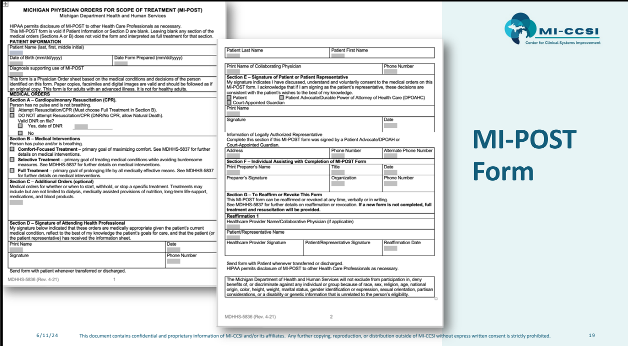

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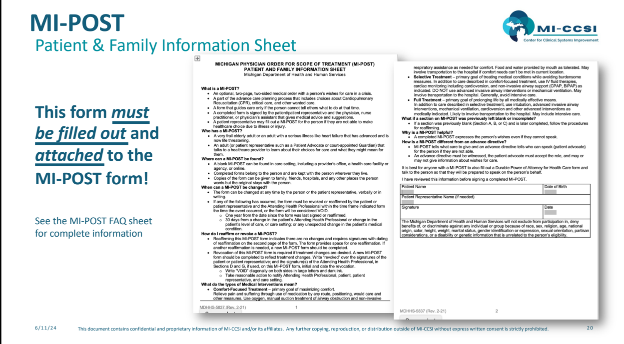

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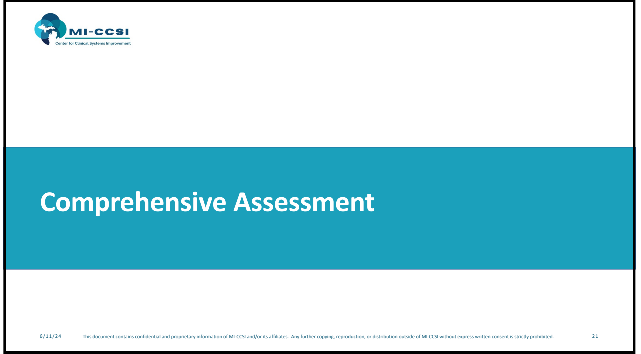

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Comprehensive Assessment

"To get to my body, my doctor has to get to my character. He has to go through my soul…I'd like my doctor to scan me, to grope for my spirit as well as my prostate. Without such recognition, I am nothing but my illness."

- Anatole Broyard

- Maximize listening skills
- Minimize quick judgments
- How would patient like to be addressed? Mr. Smith? John?
- Who is with the person? What are their names?
- Who is legally authorized to speak for the person if they cannot speak for themself (Patient Advocate/Durable Power of Attorney for Healthcare)?

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Domains of Palliative Care

An interdisciplinary approach to holistic care

1. **Structure & Practice of Care**
   - Comprehensive IDT assessment; identified & expressed need of person & family
   - Emotional impact of the work on the Team Members
2. **Physical**
   - Pain & other symptoms
   - Treatment alternatives for person/family to make informed choices
3. **Psychologic and Psychiatric**
   - Pharmacologic, non-pharmacologic, Complementary and Alternative Medicine (CAM) as appropriate
   - Grief & Bereavement programming available to person & family

National Consensus Project for Quality Palliative Care (2018)

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Domains of Palliative Care

An interdisciplinary approach to holistic care

4. **Social**
   - Family structure, relationships, medical decision-making, sexuality, caregiver availability, access to meds/equipment
   - Individualized comprehensive care plan to lessen caregiver burden and promote well-being
5. **Spiritual, Religious, Existential**
   - Assess and address spiritual concerns
   - Recognize and respect religious beliefs - provide spiritual support
   - Connect with community and spiritual groups or individuals important to person &/or family
6. **Cultural**
   - Assess and aim to meet cultural-specific needs of person and family
   - Respect and accommodate range of language, dietary, habitual and religious practices of person and family

National Consensus Project for Quality Palliative Care (2018)

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Domains of Palliative Care

An interdisciplinary approach to holistic care

7. Imminently Dying Person
- IDT recognizes imminent death; provides appropriate care to the person and family, including planning for after-death care
- Introduce hospice referral as person declines
- Educate family on signs/symptoms of approaching death in developmentally, age and culturally appropriate manner; including, but not limited to, pain, dyspnea, nausea, agitation, delirium, and terminal secretions

8. Ethics & Law
- Family structure, relationships, medical decision-making, sexuality, caregiver availability, access to meds/equipment
- Individualized comprehensive care plan to lessen caregiver burden and promote well-being

National Consensus Project for Quality Palliative Care (2018)

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The Interdisciplinary Team

- The Person's Attending Physician
  MD, DO, NP, PA and is identified by the person, at the time they elect to receive hospice care, as having the most significant role in the determination and delivery of the individual's medical care.
- Hospice Physician (if on service)
- Nurses
- Home Health Aides
- Social Workers
- Trained volunteers (if on service)
- Physical &/or Occupational Therapists
- Chaplain (if on service)
- Bereavement Counselors (if on service)

20.1 Timing and Content of Certification, Rev. 246, Issued 09-14-18

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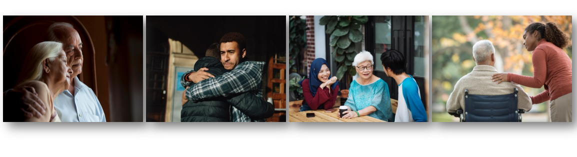
The Interdisciplinary Team

Includes family or friends, or others, either paid or unpaid



NCPQPC, 2018

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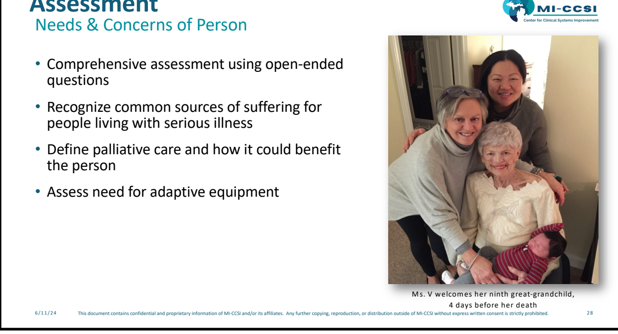

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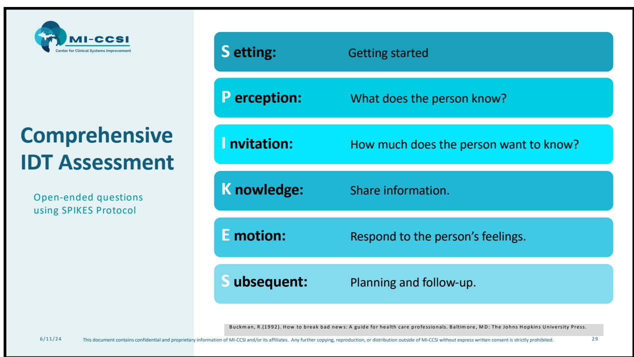

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Comprehensive Assessment
Stated and observed needs & concerns

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Person's knowledge of disease

- What can you tell me about your illness/disease?
- How does your illness affect your daily activities?
- What symptoms bother you the most?
- What concerns you the most?
- How much of your day do you spend resting? Is it more or less than 50%? Has it changed recently?
- Has anyone talked with you about what to expect?
- How have your religious or spiritual beliefs been affected by your illness?
- Many people wonder about the meaning of all this - do you?
- Do you have a sense of how much time is left? Is this something you would like to talk about?

Medical College of Wisconsin (n.d.). Communication phrases in palliative care.

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Managing Pain & Symptoms

Identifying Serious Illness/Hospice Care Needs

- For ongoing patients, conduct regular symptom assessment and success in controlling troubling symptoms
- Initiate steps for symptom management when person is in distress
  1. Pain
  2. Breathing: shortness of breath/dyspnea/air hunger/respiratory distress
  3. Nausea/vomiting
  4. Bowel management
  5. Appetite
  6. Fatigue
  7. Sleep
  8. Emotional/Psychosocial Distress
  9. Spiritual Distress

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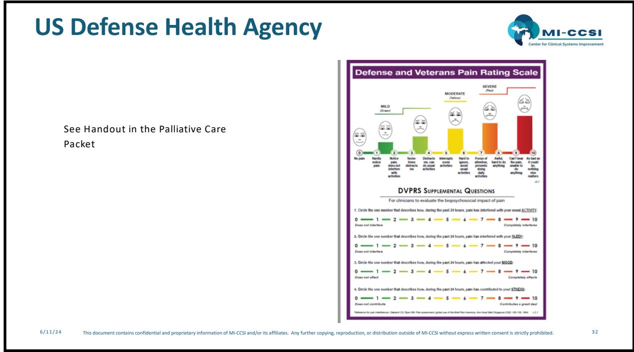

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Pain & Symptom Management

Decision aids for referral to Specialty Palliative Care

- Karnofsky Performance Status Scale http://www.npcrc.org/files/news/karnofsky_performance_scale.pdf
- Palliative Performance Scale https://eprognosis.ucsf.edu/pps.php
- Edmonton Symptom Assessment Scale https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5337174/
- Respiratory Distress Observation Scale© https://www.floridahospices.org/archives/Press%20Releases/Forum%20links/Meg%20Campbell%20Article.pdf
- Heart Failure: Partnering in Your Treatment (American Heart Assn, 2019) https://www.heart.org/en/health-topics/heart-failure/what-is-heart-failure/classes-of-heart-failure
- End-Stage Renal Disease (ESRD). https://www.kidney.org/kidneydisease/siemens_hcp_quickreference
- FICA Spiritual Assessment Tool© https://smhs.gwu.edu/spirituality-health/sites/spirituality-health/files/FICA-Tool-PDF-ADA.pdf

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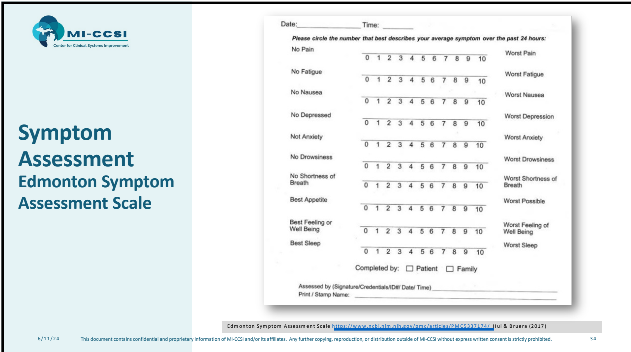

Date:________________ Time:________

Please circle the number that best describes your average symptom over the past 24 hours:

No Pain	0 1 2 3 4 5 6 7 8 9 10	Worst Pain
No Fatigue	0 1 2 3 4 5 6 7 8 9 10	Worst Fatigue
No Nausea	0 1 2 3 4 5 6 7 8 9 10	Worst Nausea
No Depressed	0 1 2 3 4 5 6 7 8 9 10	Worst Depression
Not Anxiety	0 1 2 3 4 5 6 7 8 9 10	Worst Anxiety
No Drowsiness	0 1 2 3 4 5 6 7 8 9 10	Worst Drowsiness
No Shortness of Breath	0 1 2 3 4 5 6 7 8 9 10	Worst Shortness of Breath
Best Appetite	0 1 2 3 4 5 6 7 8 9 10	Worst Possible
Best Feeling or Well Being	0 1 2 3 4 5 6 7 8 9 10	Worst Feeling of Well Being
Best Sleep	0 1 2 3 4 5 6 7 8 9 10	Worst Sleep

Completed by: ☐ Patient ☐ Family

Assessed by (Signature/Credentials/ID#/ Date/ Time)________________
Print / Stamp Name: ________________

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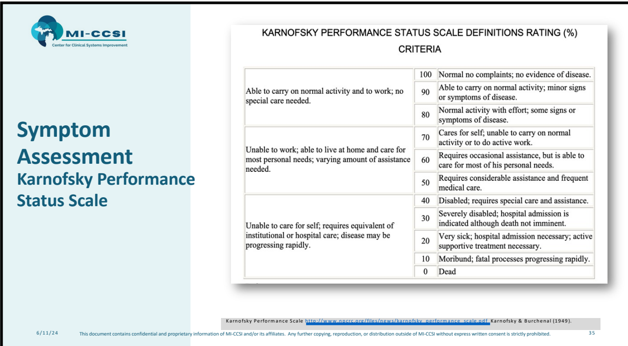

KARNOFSKY PERFORMANCE STATUS SCALE DEFINITIONS RATING (%) CRITERIA

Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead

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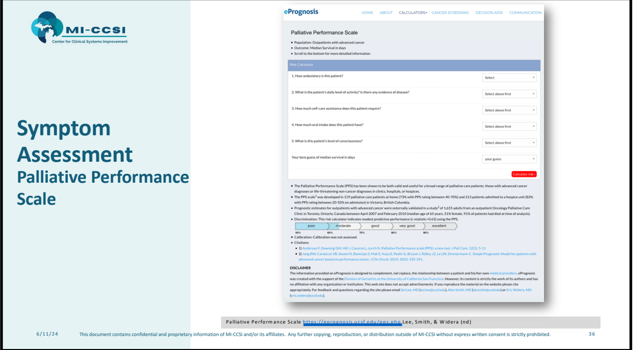

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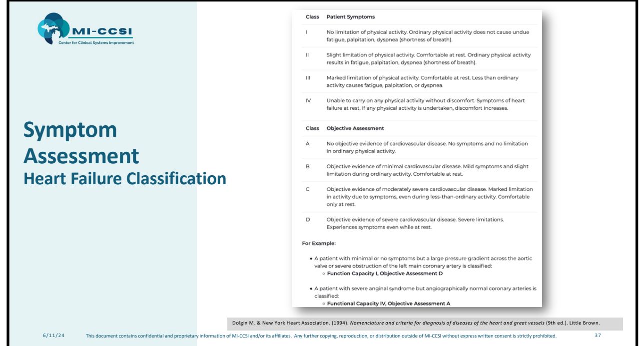

Class	Patient Symptoms
I	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea (shortness of breath).
II	Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea (shortness of breath).
III	Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnea.
IV	Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases.

Class	Objective Assessment
A	No objective evidence of cardiovascular disease. No symptoms and no limitation in ordinary physical activity.
B	Objective evidence of minimal cardiovascular disease. Mild symptoms and slight limitation during ordinary activity. Comfortable at rest.
C	Objective evidence of moderately severe cardiovascular disease. Marked limitation in activity due to symptoms, even during less-than-ordinary activity. Comfortable only at rest.
D	Objective evidence of severe cardiovascular disease. Severe limitations. Experiences symptoms even while at rest.

For Example:

- A patient with minimal or no symptoms but a large pressure gradient across the aortic valve or severe obstruction of the left main coronary artery is classified:
  - **Function Capacity I, Objective Assessment D**
- A patient with severe anginal syndrome but angiographically normal coronary arteries is classified:
  - **Functional Capacity IV, Objective Assessment A**

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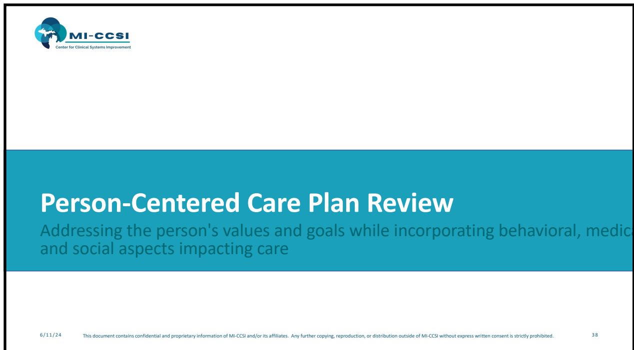

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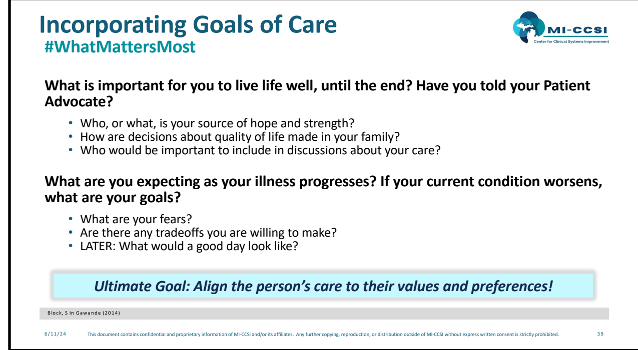

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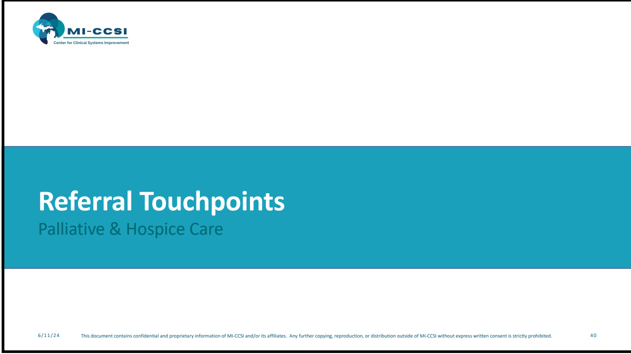

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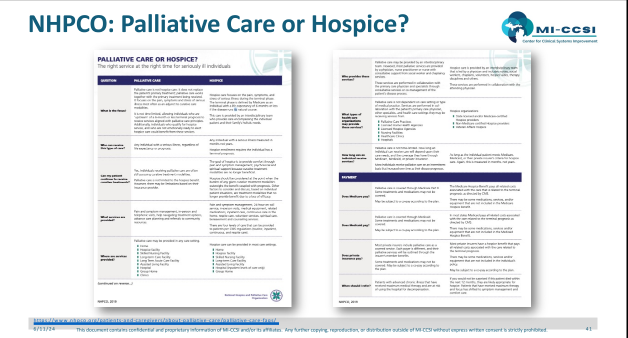

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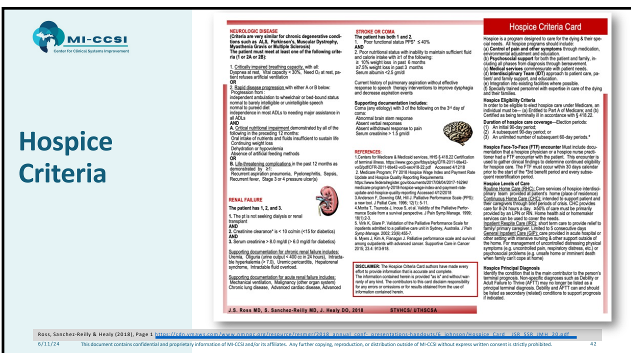

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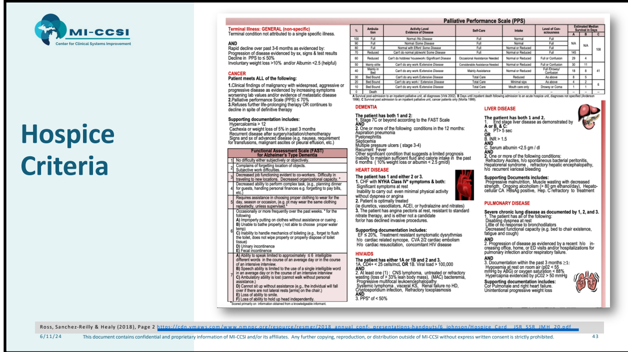

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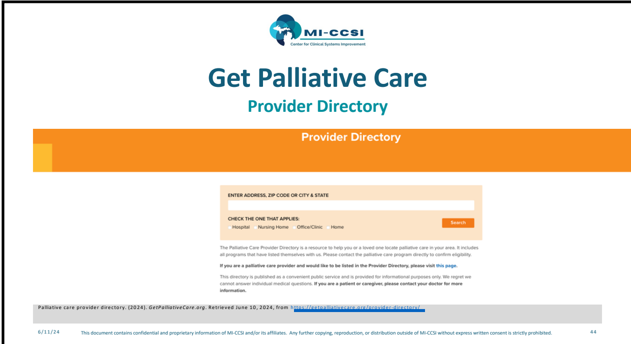

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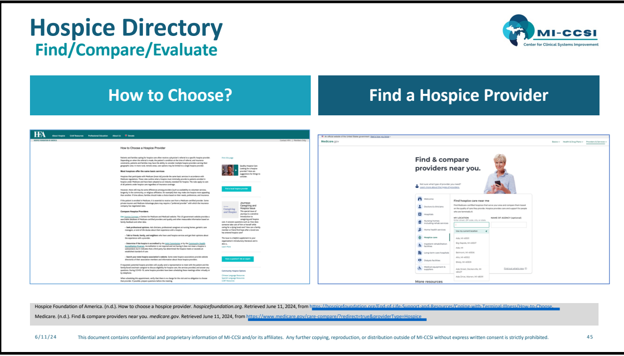

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