MODULE 4 – SYMPTOM MANAGEMENT: DYSPNEA

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IMPROVING LIFE WITH CF
A Primary Palliative Care Partnership

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Symptom Management: Dyspnea

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Dyspnea: Webinar

- Dyspnea Management for the Cystic Fibrosis Professional
  - *Denis Hadjiliadis, MD, MHS, FCCP, FRCP(C)*

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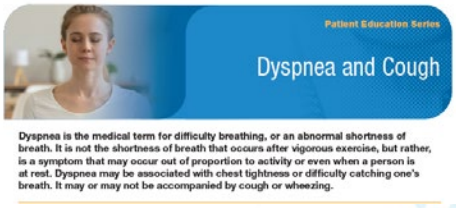
Dyspnea: Patient and Family Education



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Dyspnea: Best Practice Guide

Access through the **Provider Education** page on our project portal:

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Dyspnea Symptom Management: Objectives

- The ***Dyspnea Best Practice Guide*** covers key content for primary palliative care of people with CF
- The guide covers three topics:
  - Symptoms to consider
  - Diagnostic testing
  - Management
- Teaching objectives
  - Review the topics as they are presented in the Best Practice Guide
  - Illustrate their practical application with a case description

Dyspnea Symptom Management: Key Content in the Best Practice Guide

- Physical symptom management is one component of palliative care—with a goal to reduce distress and improve quality of life
- The management section of the *Dyspnea Best Practice Guide* includes a range of primary palliative care interventions to consider in co-developing a comprehensive treatment plan:
  - Lifestyle modification
  - Psychosocial interventions
  - Integrative interventions
  - Medical management
  - When to refer to a specialist

Dyspnea Symptom Management: Assessment

- Principles introduced in the Pain Best Practice Guide apply to dyspnea symptom management as well
- Competent treatment planning requires a competent assessment, guided by its ***objectives: The 3 "C's"***
  - ***Character***: ***Characterize the symptom*** to guide work-up and selection of therapies
  - ***Cause***: ***Identify the etiology***, if possible, to clarify the potential for disease-modifying therapy
  - ***Context***: ***Understand the impact and context*** to integrate symptom management into the broader palliative plan of care

Multidimensional Symptom Description

- ***"P-Q-R-S-T"***
  - ***"P"*** = Provocative and palliative factors
  - ***"Q"*** = Quality of the symptom
  - ***"R"*** = Region → Localized (where?), multifocal, or generalized
  - ***"S"*** = Severity → Verbal rating scale or a numeric scale "on average during the past week" and "at its worst during the past week"
  - ***"T"*** = temporal features → Onset, course, and fluctuation

What Is Dyspnea? Symptoms to Consider

- Dyspnea is a subjective feeling, with components of both
  - ***Sensation***, i.e., neural activation from stimulation of a receptor and
  - ***Perception***, i.e., a reaction of the individual to that sensation
- American Thoracic Society Consensus Statement

  "… a subjective experience of breathing discomfort that comprises qualitatively distinct sensations that vary in intensity.… Derives from…multiple physiological, psychological, social, and environmental factors and may induce secondary physiological and behavioral responses."

  Parshall MB et al., *AJRCCM* 2012;185(4):435.

Dyspnea: Symptoms to Consider

- **Typical symptoms of dyspnea**
  - Shortness of breath, with or without
    - Cough
    - Increased sputum production
    - Chest tightness
    - Wheezing
    - Worsening with exertion
- **Atypical manifestations of dyspnea**
  - Pleuritic pain
  - Chest wall discomfort
  - Palpitations
  - Sleep disturbances (waking up short of breath)

Dyspnea: Symptoms to Consider

- **Key elements of dyspnea assessment**
  - **Chronicity and alarm signs** are the most important assessments influencing urgency of diagnosis and management of dyspnea
  - Dyspnea is considered **acute** when it develops over hours to days and **chronic** when it occurs for more than 4-8 weeks
  - Overlap of acute on chronic symptoms ***from different diagnoses*** is common and should always be considered

Dyspnea: Symptoms to Consider

- **Alarm signs: Signs and symptoms requiring immediate attention**
  - Severe chest pain (may or may not be associated with pleurisy)
  - Hemoptysis
  - Shortness of breath present at rest
  - Hypoxemia (i.e., increasing oxygen supplementation needs)
  - Excessive coughing causing chest pain and/or emesis, lightheadedness, confusion, inability to complete sentences

Dyspnea: Symptoms to Consider

- **Signs and symptoms requiring further evaluation**
  - Weight loss, poor appetite
  - Poor sleep
  - Worsening from baseline of chronic shortness of breath

Dyspnea: Diagnostic Testing

- **Key elements of diagnostic testing**
  - Lung function tests
    - Spirometry is commonly available
    - Can help diagnosis of the most common cause, pulmonary exacerbation
  - Pulse oximetry
  - Heart rate
  - Other tests, especially when alarm symptoms present

Focused Differential Diagnosis of Acute & Subacute Dyspnea in CF

Acute or subacute dyspnea	Common underlying risk factors	Diagnostic tests to consider at onset and follow-up	Management considerations	Special considerations
Pulmonary exacerbation	• Known CF pathogens (PA, MRSA)	• Sputum culture • Pulse oximetry • CXR or CT chest • Spirometry	• Oral/IV antibiotics • In-hospital versus in-home treatment • If severe or new oxygen requirement, admit to hospital • If hypercapnia, initiate noninvasive ventilation	• Antibiotic for minimum of 10-14 days • Follow-up spirometry
	• Viral pneumonia	All of the above plus: • Respiratory viral panel PCR • Influenza PCR • COVID-19 PCR	• Supportive care • Antiviral therapy when appropriate • Hypoxemia related to COVID-19: Treatments rapidly evolving; consider corticosteroids	• May require antibiotics for superimposed CF pathogens • COVID-19: Assess D-dimer, thrombus if indicated
Pneumothorax (PTX)	• Advanced lung disease (FEV1<50%) • Bullae	• Pulse oximetry • Immediate CXR or CT chest • Immediate lung US if available	• ER visit • 100% O2 supplement for small PTX if hemodynamically stable • Pigtail chest tube for moderate/large PTX	• Early referral to lung transplant program • Pleurodesis after discussion with transplant program

Dyspnea Case: Next-Step Interventions

Intervention type	Examples
Lifestyle modifications	• Reduce stress • Regular sleep schedule
Psychosocial interventions	• Relaxation techniques • Cognitive Behavioral Therapy (CBT)
Integrative interventions	• Yoga breathing • Meditation
Medical management	• Revisit evaluation for underlying causes: 6-minute walk test, nocturnal oximetry, echocardiogram for PH, venous blood gas • Continue NTM therapy • Consider pulmonary rehabilitation • Add SSRI (e.g., fluoxetine) to CBT • Lorazepam as needed for severe panic while initiating SSRI, or if refractory anxiety • May consider low dose opioid for activity
Refer to a specialist	• If ID consultation needed for NTM management • If CF team does not have capacity for skilled mental health assessment/treatment

Benzodiazepines for Anxiety

- Benzodiazepines are ***not*** effective for depression
- SSRIs are first-line for chronic anxiety
- Benzodiazepines such as lorazepam are preferable to SSRIs primarily
  - When rapid onset of action is needed (e.g., panic attack)
  - When serotonergic agents are relatively contraindicated (e.g., serotonin syndrome)
  - For episodic procedure-related anxiety
  - For refractory symptoms, including at end of life

Benzodiazepines for Anxiety

- Benzodiazepines require additional caution and monitoring for those with
  - History of substance abuse
    - Controlled substance, risk of misuse, physical dependence with chronic use
  - Depression
  - Elevated risk for respiratory depression

Case: Dyspnea & Panic

- 18-year-old woman with CF, *M. abscessus*, and generalized anxiety with panic attacks

What about the caregiver?

- Identifies mother as primary support
- Offer Brief Assessment Scale for Caregivers (BASC)

BASC Responses From Mother

Over the past month, because of your relative or friend's illness, how much have you:	Not at all	A little	Some	A lot
Worried about your relative or friend even when you are not with him/her?	1	2	3	4
Been upset about not having enough time for yourself because of caring for your relative or friend?	1	2	3	4
Been overwhelmed by the responsibility of caring for your relative or friend?	1	2	3	4

Rate your distress during this past month:	Not at all distressed	A little distressed	Some distress	A lot of distress	Does not apply
At not having enough time to do your job, other responsibilities, and chores	1	2	3	4	0

What else would you like to know?
What are your next steps in assessment?
What resources or interventions might you offer?

MODULE 5 – SYMPTOM MANAGEMENT: DEPRESSION AND ANXIETY

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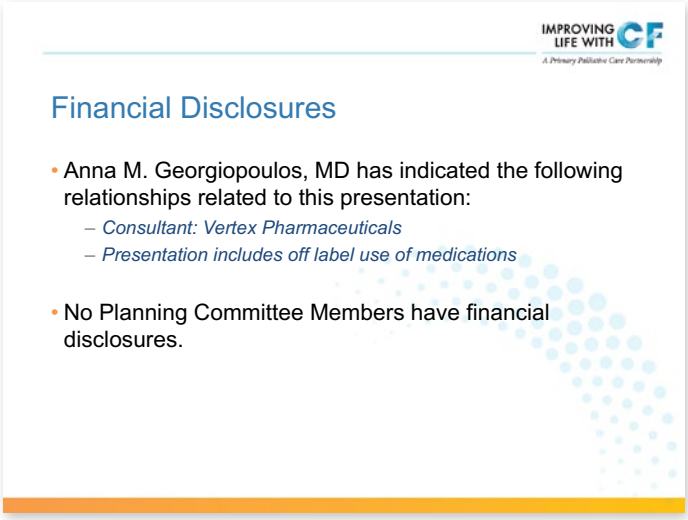


Depression & Anxiety: Best Practice Guide

Access through the **Provider Education** page on our project portal:
ImprovingLifewithCF.org

Depression & Anxiety Symptom Management: Objectives

- The ***Depression & Anxiety Best Practice Guide*** covers key content for primary palliative care of people with CF
- The guide covers three topics:
  - Symptoms to consider
  - Assessment & diagnostic tools
  - Management
- Teaching objectives
  - Review the topics as they are presented in the Best Practice Guide
  - Illustrate their practical application with a case description

Depression & Anxiety Symptom Management: Key Content in the Best Practice Guide

- Psychological symptom management is one component of palliative care—with a goal to reduce distress and improve quality of life
- The management section of the *Depression & Anxiety Best Practice Guide* includes a range of primary palliative care interventions to consider in co-developing a comprehensive treatment plan:
  - Lifestyle modification
  - Psychosocial interventions
  - Integrative interventions
  - Medical management
  - When to refer to a specialist

Depression: Symptoms to Consider

Type	Examples
Core depression symptoms	• Sad, depressed or irritable mood • Lack of interest or pleasure
Additional symptoms	• Trouble sleeping or sleeping too much • Decreased or increased appetite; weight change • Impaired concentration • Decline in academic or work performance • Fatigue, low energy • Guilt, worthlessness, feel like a burden on others • Low libido • Sensitivity to criticism • Trouble making decisions • Feeling helpless/hopeless • Thoughts of death or suicide

Anxiety: Symptoms to Consider

Type	Examples	
Core anxiety symptoms	• Anxious, worried, fearful or irritable mood • Avoids anxiety-provoking stimuli	
Additional symptoms	**Generalized anxiety**	• Excessive, uncontrollable worry in multiple situations
	Panic attack	• Intense fear with abrupt onset
	Social anxiety	• Excessive fear in social situations
	Specific phobia	• Excessive fear of object or situation • In people with CF, medical traumatic stress (e.g., medical procedures, hypoglycemia, hemoptysis)
	Separation anxiety	• Separation distress, excessive for developmental stage
	Post-traumatic stress disorder (PTSD)	• Intrusion (nightmares, flashbacks) • Avoids reminders of trauma • Hyperarousal or reactivity (startle, hypervigilance)
	Obsessive-compulsive disorder (OCD)	• Obsessions: Specific intrusive thoughts causing anxiety • Compulsions: Rituals aimed at reducing anxiety

Depression & Anxiety: Symptoms to Consider

Requiring immediate attention (alarm signs)	• Wish to be dead, thoughts of self-harm or suicide • Self-injurious or reckless behavior • Extreme irritability, anger, or aggression • Minimal oral intake • Rapidly fluctuating mental status, autonomic changes – Delirium – Medication side effect – Substance intoxication or withdrawal – Serotonin syndrome • Psychotic symptoms (delusions, hallucinations) • Catatonia (stillness or extreme restlessness)

Depression & Anxiety: Symptoms to Consider

Requiring further evaluation	• Rapid worsening from baseline • Psychomotor slowing or agitation • Poor self-care • Missing work or school • Rapidly shifting or elevated/irritable mood with increased energy and impulsivity – Bipolar disorder – Borderline personality disorder – Medication side effect – Substance intoxication or withdrawal

Depression & Anxiety: Assessment

To evaluate urgency, type, and setting of treatment, consider:

- Symptom characteristics
  - Rapidity of onset, frequency, severity, duration
- Distress and impairment
- Safety
- Biopsychosocial context
  - Precipitating and exacerbating factors
  - Patient/family strengths, resilience, and resources
  - Patient/family understanding of the problem

Depression & Anxiety: Assessment

Factors important in differential diagnosis and treatment planning:

- Psychiatric history
  - What has helped so far?
- Family psychiatric history
- Medical status
  - Change in medical condition or medications
  - Drug-drug interactions
  - Impact of psychiatric treatment on CF symptoms
- Patient/family preferences for addressing the problem
- Access to care

Depression & Anxiety: Assessment Tools

Condition	Assessment tool
Depression	• Annual PHQ-9 screening for ages ≥12 years • Consider CES-DC (Center for Epidemiologic Studies Depression Scale for Children) in children ages 6-17
Anxiety	• Annual GAD-7 screening for ages ≥12 years • Consider SCARED (Screen for Child Anxiety Related Emotional Disorders) in children ages 8-17
Suicidality and self-harm	• Columbia Suicide Severity Rating Scale (CSSRS) – Wish to be dead (passive suicidal ideation) – Non-specific suicidal thoughts – Presence of plan and intent to act – History of self-harm, suicide attempt

Depression & Anxiety: Diagnostic Testing

- **Neuropsychiatric/neuropsychological testing**
  - Sometimes helpful when differential is complex
    - Learning, attentional, or cognitive disorders
  - Bedside attentional testing if concern for delirium
    - Confusion Assessment Method (CAM)
    - MoCA (Montreal Cognitive Assessment)
    - Mini-Mental State Examination (MMSE)

Depression & Anxiety: Diagnostic Testing

- **Laboratory testing to consider**
  - CBC, electrolytes, creatinine, LFTs, HgbA1c
  - B12, folate, fat-soluble vitamins
  - TSH (hypothyroidism, hyperthyroidism)
  - Iron panel (restless leg syndrome, anemia)
  - Heavy metal screen, HIV, RPR
    - Especially if psychotic or cognitive symptoms
  - Toxicology screen
  - EKG (chest pain, palpitations)

Focused Differential Diagnosis of Anxiety & Depression in CF

Selected psychiatric differential & comorbidities	Implications
Bipolar disorder—Manic, depressed, or mixed episode	• Typically requires mood stabilizer, not antidepressant
Substance misuse	• Treat withdrawal syndromes • Impacts choice of intervention
Attention deficit hyperactivity disorder (ADHD)	• Overlaps symptoms of depression, anxiety • Poor concentration • Difficulty initiating and completing tasks • Stress due to impaired daily functioning • Dysregulated emotions, sleep and self-care
Emotion dysregulation due to personality disorder	• Risk for non-suicidal self-injury, suicide • Evidence-based psychotherapy such as dialectical behavioral therapy (DBT)

Focused Differential Diagnosis of Anxiety & Depression in CF (Cont'd)

Selected CF-specific differential & comorbidities	Implications
Delirium	• Hypoactive delirium may mimic depression • Hyperactive delirium may mimic anxiety/panic • Elevated mortality in hospitalized patients • Treatment includes correcting medical triggers
CF-related sleep disturbance (e.g., from cough) or fatigue	• Can trigger or exacerbate anxiety or mood changes • Sleep study for sleep apnea or restless legs syndrome
CF-related dyspnea	• Can mimic or exacerbate panic
Pain	• Can trigger or exacerbate anxiety or mood changes • May impact choice of intervention (e.g., CBT; SNRI or gabapentin/pregabalin)
Vitamin D deficiency	• Depression, psychosis associated with vitamin D deficiency
Neuropsychiatric side effect (e.g., albuterol, CFTR modulator, immunosuppressants, steroids)	• Consider reducing dose or discontinue to assess relatedness to the CF therapy • Treat neuropsychiatric manifestations symptomatically

Depression & Anxiety: Non-Medical Management

Approach	Type	Examples
Non-medical management	Lifestyle modifications	• Monitor and address stressors • Engage social support (family, friends, faith community) • Maintain structure • Pleasurable, meaningful activities • Sleep hygiene • Optimize nutrition • Physical exercise • Spend time in nature, with animals, or listening to music

Depression & Anxiety: Non-Medical Management

Approach	Type	Examples
Non-medical management	Psychosocial interventions	• Brief intervention in CF clinic • Psychoeducation • Relaxation techniques • Problem solving • Case management of problems related or unrelated to CF (school, work, financial, legal) • Psychotherapy is generally recommended as first-line treatment --Many evidence-based approaches are available

Depression & Anxiety: Non-Medical Management (Cont'd)

Approach	Type	Examples
Non-medical management	Integrative interventions	• Acupuncture • Meditation/mindfulness • Yoga

Depression & Anxiety: Medical Management

- **Use combination psychotherapy and pharmacotherapy as initial therapy for severe depression**
  - More effective than either modality alone
- Add pharmacotherapy when there is no or partial response to psychological interventions
- Pharmacotherapy may be used alone, especially for adults
  - When evidence-based psychotherapy is unavailable
  - Per patient/family preference

Depression & Anxiety: Medical Management (Cont'd)

- **Employ sequential trials with close monitoring of response to intervention**
  - Consider serial PHQ-9/GAD-7 measures
- Consider strategies if incomplete response to pharmacotherapy
  - Dose adjustment
  - Switch
  - Augmentation
- Monitor for new suicidality, agitation, or mania when antidepressants are used
  - Especially in young people
  - Weigh against risk of untreated depression/anxiety

Depression & Anxiety: Medical Management (Cont'd)

Approach	Type and examples	Comments
Medical management: **Selected medications for both anxiety and depression**	**Selective Serotonin Reuptake Inhibitors (SSRIs)** • Citalopram • Escitalopram • Fluoxetine • Sertraline	• First-line medications in children, adolescents and adults • Recommended by CFF/ECFS guidelines • Start low and titrate slowly to minimize initiation and discontinuation syndromes—headache, dizziness, GI distress, jitteriness or fatigue • Sexual side effects • Risk of serotonin toxicity • Citalopram may prolong QTc, especially with other QTc-prolonging meds (azithromycin) • Use with lumacaftor/ivacaftor may require dose increase of citalopram, escitalopram, sertraline

SSRI Dose Titration in CF

SSRIs	Start Low Low starting dose for individuals with CF	Go Slow Titrate up every 1-4 weeks if no/partial response	Treat to Target Normal PHQ-9/GAD-7 & functioning for 1 year prior to taper	Higher if Needed (Off label)
Citalopram	5-10 mg/day	By 5-10 mg	20-40 mg/day	80 mg/day
Escitalopram	2.5-5 mg/day	By 2.5-5 mg	10-20 mg/day	40 mg/day
Fluoxetine	5-10 mg/day	By 5-10 mg	20-60 mg/day	80 mg/day
Sertraline	12.5-25 mg/day	By 12.5-25 mg	50-200 mg/day	250 mg/day

Depression & Anxiety: Medical Management (Cont'd)

Approach	Type and examples	Comments
Medical management: **Selected medications targeting both anxiety and depression**	**Serotonin Norepinephrine Reuptake Inhibitors (SNRIs)** • Duloxetine • Venlafaxine • Milnacipran	• May also treat comorbid pain (e.g., diabetic neuropathy, chronic headache) • Side effect profile similar to SSRIs • Consider checking LFTs before starting duloxetine • Venlafaxine may elevate blood pressure and carries higher risk of discontinuation syndrome
	Mirtazapine	• Useful when weight gain and nocturnal sedation are welcome • Few drug-drug interactions • No sexual side effects

Depression & Anxiety: Medical Management (Cont'd)

Approach	Type and examples	Comments
Medical management: **Selected medications targeting depression only**	**Bupropion**	• Low appetite • Insomnia/vivid dreams • No sexual side effects
	Stimulant (off label) • Methylphenidate	• When rapid response is needed • When ADHD is comorbid • Low appetite • Insomnia • Irritability, increased anxiety • Caution with history of substance misuse

Depression & Anxiety: Medical Management (Cont'd)

Approach	Type and examples	Comments
Medical management: **Selected medications targeting anxiety only**	**Gabapentinoids** (off-label) • Gabapentin • Pregabalin	• May also address comorbid neuropathic pain • Requires renal dosing
	Hydroxyzine	• Sedation, dryness • Requires renal dosing
	Benzodiazepines • Lorazepam	• For acute panic, anxiety related to medical procedures, refractory anxiety • Physical dependence; withdrawal seizures • Minimize length of therapy and taper slowly • Caution with depression, substance misuse, respiratory depression, opiates, peri-transplant • Monitor for cognitive side effects, delirium, tachyphylaxis, misuse

Depression & Anxiety: Medical Management (Cont'd)

- **When to refer to a specialist**
  - Psychiatric diagnosis is uncertain
  - CF team does not have capacity to initiate or provide ongoing treatment
  - Complexity of the case exceeds the CF team's level of training and experience
  - Depression or anxiety appear treatment-resistant
  - Urgent safety risk is identified

Case Discussion: Depression & Anxiety in a Model of Palliative Care for CF

- 27-year-old man with CF and poorly controlled CF-Related Diabetes
- Annual palliative care needs assessment

Case Discussion: Depression & Anxiety

- The patient completes the Integrated Palliative Care Outcome Scale (IPOS) as part of the annual needs assessment

Over the past week:	Not at all	Occasionally	Sometimes	Most of the time	Always
Have you been feeling anxious or worried about your illness or treatment?	0	1	2	3	4
Have any of your family or friends been anxious or worried about you?	0	1	2	3	4
Have you been feeling depressed?	0	1	2	3	4

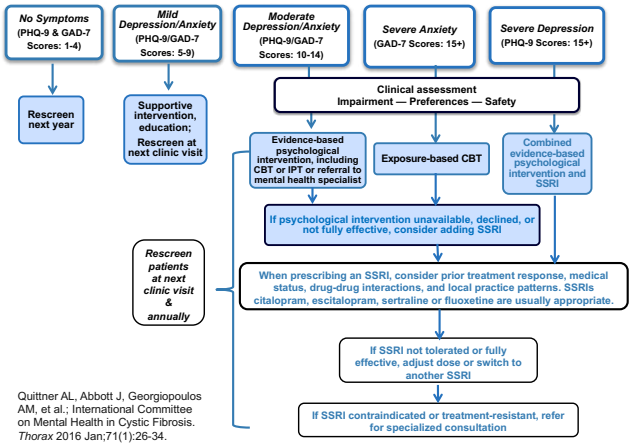
What else would you like to know?
What are your next steps in assessment?

Positive Screen: Now What?

- CFF Models of Palliative Care Guidelines: Optional measures for depression and anxiety in people with CF ≥12 years
  - Generalized Anxiety Disorder 7-Item Scale (GAD-7)
  - Patient Health Questionnaire-9 (PHQ-9)
- Align with measures used for routine screening in CFF/ECFS mental health guidelines
- Also may be used for caregivers of children and adults with CF

Quittner AL, Abbott J, Georgiopoulos AM, et al.; International Committee on Mental Health in Cystic Fibrosis. *Thorax*. 2016 Jan;71(1):26-34.

Screening & Treatment for Depression & Anxiety: Algorithm for Individuals with CF (Ages 12-Adulthood)

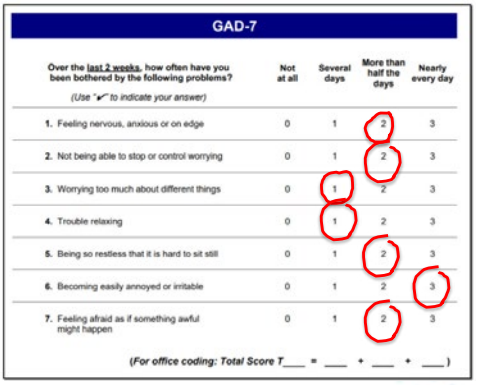


Quittner AL, Abbott J, Georgiopoulos AM, et al.; International Committee on Mental Health in Cystic Fibrosis. *Thorax* 2016 Jan;71(1):26-34.

GAD-7

- Optional anxiety measure
- Total score: 13
- Moderate anxiety symptoms

What else would you like to know?
Next steps?



GAD-7

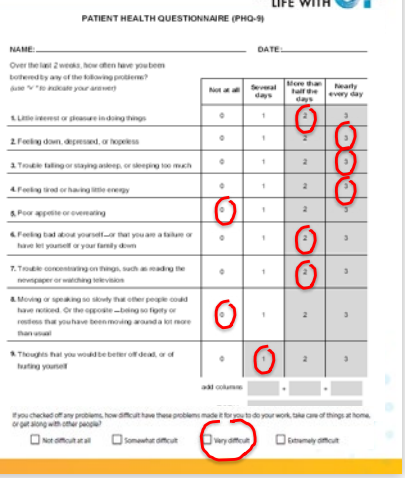
Over the last 2 weeks, how often have you been bothered by the following problems? (Use ✓ to indicate your answer)	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

(For office coding: Total Score T___ = ___ + ___ + ___ + ___)

PHQ-9

- Optional depression measure
- Total score: 16
- Severe depressive symptoms:
- Passive suicidal ideation on Q9
  - Wish to be dead without intent or plan
- Impact on functioning "very difficult"

What else would you like to know?
Next steps?


PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

NAME: DATE:

Over the last 2 weeks, how often have you been bothered by any of the following problems? (use "√" to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite—being so figety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself	0	1	2	3
add columns				

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

☐ Not difficult at all ☐ Somewhat difficult ☐ Very difficult ☐ Extremely difficult

Case: Depression & Anxiety

- 32-year-old man with CF and poorly controlled CFRD
- No prior mental health treatment
- Moderate anxiety
  - IPOS "sometimes"; GAD-7 Score: 13
- Severe depression with passive suicidal ideation
  - IPOS "most of the time"; PHQ-9 Score: 16

What are you most worried about?
What are your next steps?
How urgent is further diagnostic assessment and intervention?

Depression & Anxiety Case Discussion: Management

The Depression & Anxiety Best Practice Guide includes a range of primary palliative care interventions to consider in co-developing a comprehensive treatment plan

What interventions might you suggest?

- Lifestyle modifications
- Psychosocial interventions
- Integrative interventions
- Medical management
- When to refer to a specialist

Consider simultaneous vs. sequential interventions.
Some may not be appropriate or acceptable to the patient.
Which CF team members might be helpful to engage?

Depression & Anxiety Case: Initial Interventions

Intervention type	Examples
Lifestyle modification	• Increase time outdoors
Psychosocial intervention	• Start evidence-based psychotherapy such as Cognitive Behavioral Therapy (CBT) or Interpersonal Therapy (IPT) urgently
Integrative intervention	• Yoga
Medical management	• Start SSRI urgently (e.g., citalopram)
Refer to a specialist	• If CF team does not have capacity for skilled assessment/treatment, including for suicidality

Are there other unmet palliative care needs that might change the treatment plan?

Case Discussion: Depression & Anxiety

How has the following symptom affected you over the past week?	Not at all	Slightly	Moderately	Severely	Over-whelmingly
Pain	0	1	2	3	4
Weakness or lack of energy	0	1	2	3	4

What if these symptoms were <u>also</u> endorsed on IPOS?

What else would you like to know?

Case Discussion: Depression, Anxiety, & Pain

- **32-year-old man with CF and poorly controlled CFRD**
  - No prior mental health treatment
  - Moderate anxiety, severe depression, passive suicidal ideation
- **Pain and paresthesias in feet—diabetic neuropathy**
  - Severe impact of pain and lack of energy
  - Intermittent but daily, worse at night, up to 8/10
  - Interferes with sleep, activities, enjoyment

What are your next steps?
Does this new information change management?

Depression, Anxiety, & Pain Case: Interventions

Intervention type	Examples
Lifestyle modification	• Increase time outdoors
Psychosocial intervention	• Start Cognitive Behavioral Therapy (CBT) urgently to target depression, anxiety, and coping with pain • Interpersonal Therapy (IPT) less preferred given pain
Integrative interventions	• Yoga • Acupuncture
Medical management	• Start SNRI urgently (e.g., duloxetine) • Consider insulin pump to improve glycemic control
Refer to a specialist	• If CF team does not have capacity for skilled assessment/treatment, including for suicidality or refractory pain

Case Discussion: Depression, Anxiety, & Pain

- **32-year-old man with CF, poorly controlled CFRD, depression, anxiety, neuropathic pain**
  - IPOS: *Have any of your family or friends been worried or anxious about you?*
    - *"Not at all"*

What about the caregiver?

- Identifies live-in girlfriend as primary support
- Offer Brief Assessment Scale for Caregivers (BASC)

BASC Responses From Partner

Over the past month, because of your relative or friend's illness, how much have you:	Not at all	A little	Some	A lot
Worried about your relative or friend even when you are not with him/her?	1	2	3	4
Been depressed because of your relative or friend's illness?	1	2	3	4
Been upset about not having enough time for yourself because of caring for your relative or friend?	1	2	3	4
Been overwhelmed by the responsibility of caring for your relative or friend?	1	2	3	4

What else would you like to know?
What are your next steps in assessment?
What resources or interventions might you offer?

Alternate Case Scenarios: Depression & Anxiety

- **Would this case present or be managed differently in a school-aged child or adolescent?** How?
- **Would this case be managed differently in a college student who identifies his mother as his primary support?** How?
- **Would this case be managed differently if the patient had recently initiated highly effective modulator therapy?** How?

Key Concepts From the *Depression & Anxiety Best Practice Guide*

- **Use PHQ-9 and GAD-7 to supplement IPOS and BASC**
  - Aligns with CFF/ECFS mental health guidelines
  - May offer to caregivers of adults, not just children
- **Lifestyle modifications and psychotherapy are first line**
  - Consider integrative interventions
- **Consider medication depending on preferences, access, response to treatment**
- **Start with *combined* psychological intervention and pharmacotherapy (usually SSRI) for severe depression**
- **Co-occurring symptoms such as pain may impact the choice of first-line medication for depression & anxiety**

MODULE 6 – SERIOUS ILLNESS DISCUSSIONS

Presented by:

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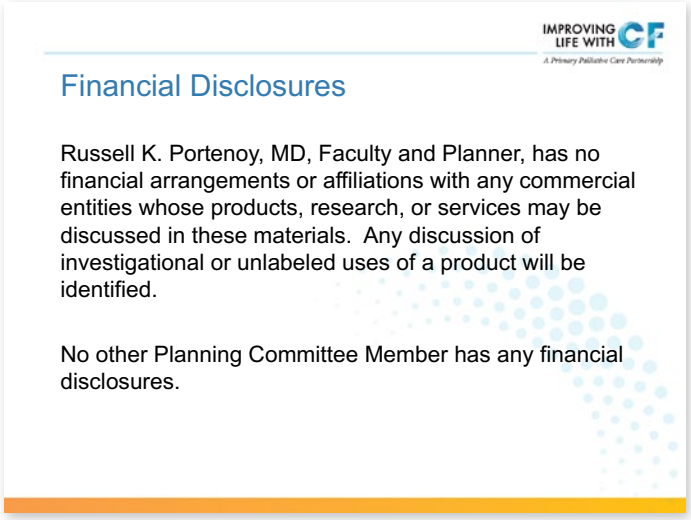
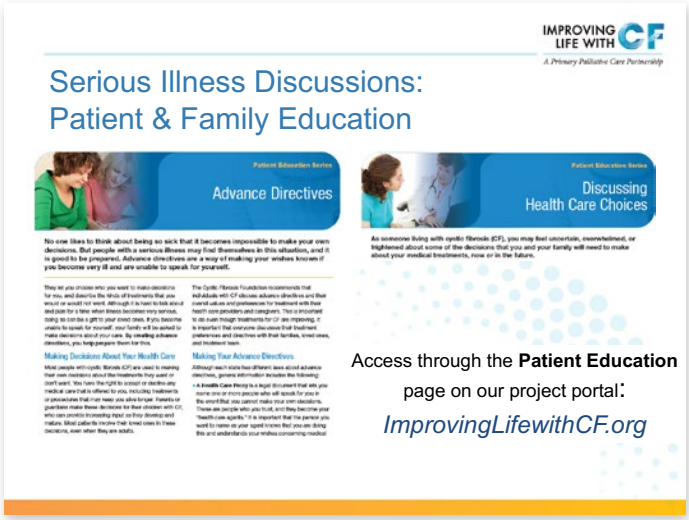
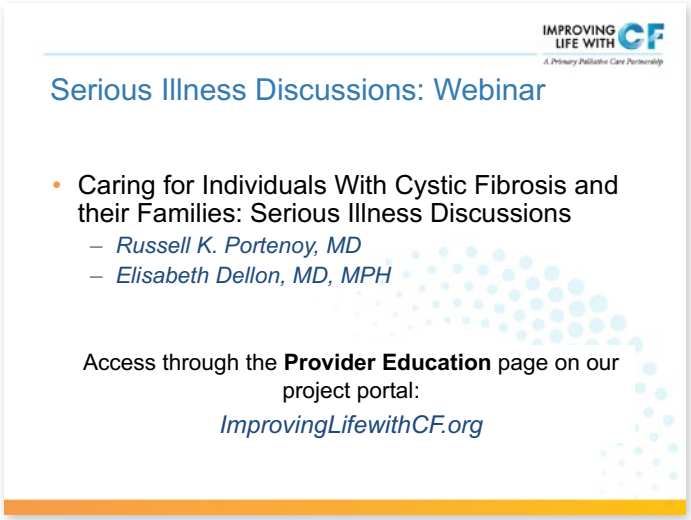
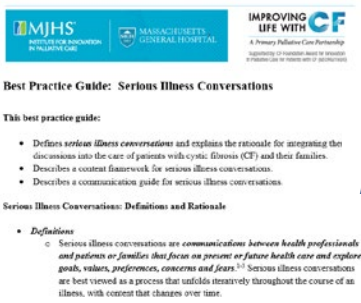






Serious Illness Discussions: Best Practice Guide


Best Practice Guide: Serious Illness Conversations

This best practice guide:

- Defines *serious illness conversations* and explains the rationale for integrating these discussions into the care of patients with cystic fibrosis (CF) and their families.
- Describes a content framework for serious illness conversations.
- Describes a communication guide for serious illness conversations.

Serious Illness Conversations: Definitions and Rationale

- *Definitions*
  - Serious illness conversations are *communications between health professionals and patients or families that focus on present or future health care and explore goals, values, preferences, concerns and fears.*[1-3] Serious illness conversations are best viewed as a process that unfolds iteratively throughout the course of an illness, with content that changes over time.

Access through the **Provider Education** page on our project portal:

ImprovingLifewithCF.org

Serious Illness Discussions for the CF Professional

- Competent and timely serious illness discussions may be associated with positive outcomes for patients, families and providers of care
- The ***Best Practice Guide*** covers two topics: ***content framework*** and ***a communication approach***
- Teaching objectives
  - Review the topics as they are presented in the *Best Practice Guide*
  - Illustrate their practical application with a case description

Serious Illness Discussions: Key Concept in the BPG

- Serious illness discussions are very diverse but have common elements
  - They relate to ***expectations or preferences*** about the illness or its management
  - They are perceived as potentially inciting patient/family distress because they commonly include 'bad news', end-of-life preferences, or difficult decisions with implications for prognosis
  - They elicit clinician discomfort because of uncertainty about the best language and tone, unpredictability of the response, concern about how to manage a negative response, and the time required

Serious Illness Discussions: Key Concept in the BPG

- A systematic approach to serious illness discussions includes
  - Identifying **appropriate patients** at **appropriate times**
  - Preparing for a discussion by having **specific objectives** in mind
  - Using a **structured approach to communication**

Serious Illness Discussions: Key Concept in the BPG

- A systematic approach to serious illness discussions includes
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Serious Illness Discussions: Key Concept in the BPG

- **Who** is the appropriate patient/family?
  - All patients/families living through serious chronic illness—all patients with CF and their families
- **WHEN** to have a discussion?
  - Some types of serious illness conversations are appropriate at any time
  - Some are appropriate when progression of disease or complications occur
  - Some are appropriate when the end of life appears to be approaching

Serious Illness Discussions: Key Concept in the BPG

- **WHEN** to have a discussion?
  - Periodically during stable periods—during an annual evaluation
  - When signs indicate progressive illness or a recent hospitalization has occurred
  - When decline suggests that prognosis may be limited

Serious Illness Discussions: Key Concept in the BPG

- A systematic approach to serious illness discussions includes
  - Identifying **appropriate patients** at **appropriate times**
  - Preparing for a discussion by having **specific objectives** in mind
  - Using a **structured approach to communication**

Serious Illness Discussions: Key Concept in the BPG

- Whenever a clinician is planning to discuss a 'sensitive' issue—i.e., whenever a serious illness discussion will be initiated with a patient or family
  - One or more ***objectives***—what information should be obtained or provided—should be considered ***in advance***
  - Although discussions may diverge from expectations, the clinicians should always start a discussion with clarity about the objectives that would be favored

Serious Illness Discussions: Key Concept in the BPG

- The objectives of a serious illness discussion, from the perspective of the clinician, can be categorized as "general" or "specific"

Serious Illness Discussions: Key Concept in the BPG

General objectives

To acquire information about:

- Values and preferences
  - 'Decisional control preferences'
  - Desire for information
  - View of 'trade-offs'
  - Views about treatments
- Prognostic awareness
- Immediate and longstanding life goals
- Fears and concerns

Specific objectives

Advance care planning

To exchange information about:

- Treatment decisions
  - CFTR modulators, lung transplantation, hospitalizations, ICU stays, respiratory support, artificial nutrition
- Hospice

Serious Illness Discussions: Key Concept in the BPG

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Specific objectives

Advance care planning

To exchange information about:

- Treatment decisions
  - CFTR modulators, lung transplantation, hospitalizations, ICU stays, respiratory support, artificial nutrition
- Hospice

General Objectives: Values and Preferences

- **'Decisional control preferences'**: Who makes health care decisions for the patient
  - Patients may be more active (self) vs. more passive (physician or family) vs. shared (mixed approach)
- **Desire for information**
  - Patients may prefer more or less detail
- **View of trade-offs**
  - Patients vary in the way they view 'quantity' vs. 'quality' of life or 'efficacy' vs. 'burden' of treatments
- **General views about specific treatments**
  - Consider transplantation, hospitalization, artificial nutrition, others

Values and Preferences: Direct Questioning

- **What type of question would assess 'decisional control preferences'?**

Values and Preferences: Direct Questioning

- What type of question would assess 'decisional control preferences'?

"When it comes to a decision about an important treatment for your illness, are you the kind of person who likes to make her own decisions, or do rely on your family or your doctor to make the right decision for you?"

Values and Preferences: Direct Questioning

- **What type of question would assess the desire for information?**

Values and Preferences: Direct Questioning

- What type of question would assess the desire for information?

"Are you the kind of person who wants to hear the details about your illness, or do you usually like more general information, with details only when the doctor feels that it is really important for you to know?"

Values and Preferences: Direct Questioning

- **What type of question would assess the patient's views on trade-offs?**

Values and Preferences: Direct Questioning

- What type of question would assess the patient's views on trade-offs?

"People who have chronic illnesses differ in how they judge what is important. For example, some people say that quality of life is the most important thing, while others say that controlling the disease and living as long as possible is most important. Although this comparison doesn't reflect how complicated these decisions really are, it is still helpful to know how you think about these kinds of trade-offs?"

General Objectives: Prognostic Awareness

- **Prognostic awareness**
  - May refer to ***life expectancy*** or ***course of illness***
  - Patients and families have varying 'states' of awareness: 1) **Accurate;** 2) **Inaccurate;** 3) **Unknown and not wanting to know;** and 4) **Unknown and wanting to know**
  - ***Discussion*** and ***disclosure*** of prognosis
    - Begins with ***assessment of understanding*** and the ***desire for information***
    - Is done to correct inaccuracies, and provide information to those who want it

Prognostic Awareness: Direct Questioning

- **What type of question could be used to initiate a discussion about prognosis?**

Prognostic Awareness: Direct Questioning

- What type of question could be used to initiate a discussion about prognosis?

"How much do you know about your illness, about how serious it is or what might occur in the future?"

"Some people benefit from having more information about what to expect. Some want to know about the prognosis. Do you feel the need for more information?"

Prognostic Disclosure

- **Course of illness**
  - May be described in terms of symptoms or functioning, effect on the individual or effects on the family
- **Life expectancy**
  - May be discussed with a time horizon (e.g., "weeks to months") or without a time horizon ("terminal illness")

General Objectives: Goals, Concerns, and Fears

- **Life goals:** Some patients experience benefit or share clinically important information by discussing
  - Near-term goals (things that have not been done and may still be possible)
  - Past events or achievements (memories that bring joy, connectedness, or meaning)
  - Legacy (what would be remembered after we are gone)
- **Fears and concerns:** Some patients experience benefit or share clinically important information by discussing
  - Concerns or fears that may be specific or general
  - Concerns or fears may focus on the self or the family

Goals, Fears, and Concerns: Direct Questioning

- **What type of question would assess concerns or fears?**

Goals, Fears, and Concerns: Direct Questioning

- What type of question would assess concerns or fears?

"Given how things have been going during the past few months, it wouldn't be surprising if you were having some concerns, or fears, about your illness or the treatments we are using. Tell me, what are your concerns?"

Serious Illness Discussions: Key Concept in the BPG

General objectives

To acquire information about:

- Values and preferences
  - 'Decisional control preferences'
  - Desire for information
  - View of 'trade-offs'
  - Views about treatments
- Prognostic awareness
- Immediate and longstanding life goals
- Fears and concerns

Specific objectives

Advance care planning

To exchange information about:

- Treatment decisions
  - CFTR modulators, lung transplantation, hospitalizations, ICU stays, respiratory support, artificial nutrition
- Hospice

Specific Objectives: Advance Care Planning

- Advance care planning may be viewed as a ***type*** of serious illness discussion
  - Focuses on ***expectations or preferences*** about ***future*** care
  - Should establish the means to direct future care consistent with values and preferences (the advance directive)
  - Should include information that addresses other objectives, e.g., prognostic awareness
  - Advance directives can be used to select a spokesperson/decision maker (Durable Power of Attorney for Health Decisions) AND/OR to give specific instructions about future care (Living Will, MOLST)

Specific Objectives: Treatment Decisions

- The model for serious illness discussions applies to treatment-related discussions that
  - Carry high risk or burden
  - Have limited probability of meaningfully positive outcomes
  - May not align with the patient's/family's values or preferences, as they are understood
  - Imply conclusions about prognosis that may not be understood by the patient or family (e.g., hospice)

Serious Illness Discussions: Key Concept in the BPG

- To conduct discussions intended to meet either general or specific objectives, a systematic approach to the communication is valuable
- Various communication training models have been developed—they share many elements

Communication Approaches for Serious Illness Discussions

- ***Partnership Enhancement Program (PEP)***
  - Cystic Fibrosis Foundation and the Academy of Communication in Healthcare
  - CF-specific communication guide
  - For more information about PEP training, contact PEP@cff.org
- ***Serious Illness Conversation Guide***
  - Ariadne Labs
  - https://www.ariadnelabs.org/areas-of-work/serious-illness-care
- ***Vital Talk***
  - https://www.vitaltalk.org
- The ***OPUS Model***

The *OPUS Model*

- Serious illness discussions are iterative and may focus on an array of issues
- Prepare for each discussion by deciding on the objectives to be pursued
- All discussions may be structured with key elements summarized by the mnemonic ***OPUS***

O = *"Opener"*
P = *"Permission"*
U = *"Understanding"*
S = *"Support"*

The *OPUS Model*

O = *"Opener"*
- Setting the stage
- Neutral opening statement
- Main objective, in general terms

P = *"Permission"*
- Is it OK to proceed
- Should others be present for this discussion?

U = *"Understanding"*
- What does the patient or family know?
- Can more information be elicited?
- What information should be provided?
- What more does the patient or family want to know?

S = *"Support"*
- Allow emotion
- Empathize
- Offer a plan

The *OPUS Model*

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Consider using the **"ask-tell-ask"** technique:
1) give information in short sentences and without medical jargon,
2) repeatedly stop and ask if the individual understands or has questions, and
3) periodically ask the individual to repeat a key point and correct any misunderstanding.

Consider using **"hope/worry statements"** or **"hope for the best/prepare for the worst"** statements

Case Discussion: Serious Illness Discussions

- Case
  - 49-year-old man with advanced CF lung disease was recently referred for lung transplant evaluation
  - Palliative care needs assessment triggered by rapid decline in FEV1 & lung transplant referral
  - Screening suggests the need for discussions to clarify the care plan

CF Palliative Care Needs Assessment Includes Non-Symptom Domains

The Integrated Palliative Care Outcome Scale (IPOS) screens Spiritual, Communication & Practical Problems

Over the past week, have you:	Always	Most of the time	Some-times	Occa-sionally	Not at all
Felt at peace?	0	1	2	3	4
Been able to share how you are feeling with your family or friends as much as you wanted?	0	1	2	3	4
Had as much information as you wanted?	0	1	2	3	4

Over the past week:	Addressed/ no problems	Mostly	Partly	Hardly	Not addressed
Have any practical problems resulting from your illness been addressed (such as financial or personal)?	0	1	2	3	4

Murtagh FE, et al. *Pall Med*. 2019 Sep;33(8):1045-57.

CF Palliative Care Needs Assessment Includes Non-Symptom Domains

- In addition to the IPOS for the patient:
  - **Brief Assessment Scale for Caregivers (BASC)** used to screen the caregiver
- According to the CFF Palliative Care guidelines, these scales can be supplemented by optional measures:
  - **Spiritual Needs Assessment for Patients (SNAP)** tool for people with CF ≥12 years, or caregivers
  - **PG-13** to assess caregiver complicated grief

IPOS Responses

What have been your main problems or concerns over the past week?
I changed my mind about transplant.

Over the past week, have you:	Always	Most of the time	Some-times	Occa-sionally	Not at all
Felt at peace?	0	1	2	3	4
Been able to share how you are feeling with your family or friends as much as you wanted?	0	1	2	3	4
Had as much information as you wanted?	0	1	2	3	4

Over the past week:	Addressed/ no problems	Mostly	Partly	Hardly	Not addressed
Have any practical problems resulting from your illness been addressed (such as financial or personal)?	0	1	2	3	4

Murtagh FE, et al. *Pall Med*. 2019 Sep;33(8):1045-57.

Case Discussion: Serious Illness Discussions

- Is the screening result worthy of follow-up?
  - If so, when?
  - If so, what is the next step?

Case Discussion: Serious Illness Discussions

- Next steps require an assessment
  - What would worry the CF clinician?
  - What other information would be valuable?

Case Discussion: Serious Illness Discussions

- The CF clinician asks the patient to complete the **Spiritual Needs Assessment for Patients (SNAP)**
  - Assesses 5 psychosocial needs, with a focus on coping and communication
  - Assesses 13 spiritual needs
    - Finding meaning, finding hope, prayer/meditation, overcoming fears, coping with suffering, forgiveness; relationships with family, friends, God
  - Assesses 5 religious needs
    - Visits from clergy or members or faith community, rituals, spiritual texts

Case Discussion: Serious Illness Discussions

- Based on the record review, conversation with members of the CF team and the SNAP, the assessment reveals
  - He may feel alone; he has not discussed his condition with his partner and is estranged from his family
  - He has told a team member that the possibility of lung transplant has been “sprung” on him and he expressed a lack of clarity about what might happen if he declines this

Case Discussion: Serious Illness Discussions

- Based on the record review, conversation with members of the CF team and the SNAP, the assessment reveals
  - The SNAP identifies concerns about "Sharing your thoughts and feelings with people close to you" and "Finding meaning in your experience of illness"
  - His record reveals no advance directives, no documentation of ACP discussions, and no documented prior discussions about his preferences for care, his level of prognostic understanding, or any concerns or fears he has expressed about his illness

Case Discussion: Serious Illness Discussions

- The assessment suggests that the **patient's decision to decline transplant**, expressed on the IPOS screening**, may reflect a lack of knowledge, concerns and fears, and a perceived lack of social support**
- One or more discussions are warranted to better understand the **patient's thinking about transplant**, his **understanding of his illness and prognosis**, and his overarching **preferences for care**
- Discussions also are needed to document his **preferences for future care** and **provide an advance directive** that will increase the likelihood that future care will be concordant with these preferences

Case Discussion: Serious Illness Discussions

- Next steps
  - What should the clinician consider in planning the approach to the serious illness discussions that might benefit the patient at this time?

Serious Illness Discussions: Key Concept in the BPG

General objectives

To acquire information about:

- Values and preferences
  - 'Decisional control preferences'
  - Desire for information
  - View of 'trade-offs'
  - Views about treatments
- Prognostic awareness
- Immediate and longstanding life goals
- Fears and concerns

Specific objectives

Advance care planning

To exchange information about:

- Treatment decisions
  - CFTR modulators, lung transplantation, hospitalizations, ICU stays, respiratory support, artificial nutrition
- Hospice

Case Discussion: Serious Illness Discussions

- Next steps
  - Having considered the objectives of the initial discussion, what should the clinician choose as the area or areas of focus?

Case Discussion: Serious Illness Discussions

- The CF clinician decides to tell the patient that 2-3 visits are needed to clarify the treatment plan at this time
- The clinician intends to collect some information about **decisional control preferences**, **desire for information**, and **prognostic awareness**, and ask the patient about **goals**, **concerns and fears** during the first discussion
- She intends to re-visit the decision about the transplant and discuss ACP during the second visit

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- What information should be provided?
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Consider using **"hope/worry statements"** or **"hope for the best/prepare for the worst"** statements

Case Discussion: Serious Illness Discussions

- The patient brought up the decision about lung transplantation at the start of the visit
- The CF clinician determined that the decision was fraught—he wanted to please the CF team, did not fully understand the rationale or prognosis, and feared talking to his partner about the procedure

Case Discussion: Serious Illness Discussions

- The CF clinician indicated a desire to talk more about this at the next session then turned the conversation to other areas:
  - ***Decisional control***: He prefers to make own decisions
  - ***Desire for information***: He is a "detail" person and responds to unknowns with worry
  - ***Prognostic awareness***: When asked about his understanding of his illness, he made an inaccurate statement about the likelihood that his lung disease would be stable -- as long as he avoided infections. He expressed that he would value more information
  - ***Concerns and fears***: He is very fearful of being dependent on his partner. He admits that concern about his partner's response to his worsening illness is one reason he did not discuss the transplant surgery with him

Case Discussion: Serious Illness Discussions

- Next steps
  - The CF clinician decides to hold off on further interventions until the patient returns for another visit focused on clarifying goals and preferences
  - She intends at this visit to focus on the lung transplant and ACP

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- Neutral opening statement
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Case Discussion: Serious Illness Discussions

- The patient states that he wants his partner to be his agent
  - The CF clinician responds that the partner needs to know this, and ideally, also should understand the patient's preferences about future treatments
  - She offers to meet with them together before the patient signs the health care proxy, and he agrees

Case Discussion: Serious Illness Discussions

- The discussion about the lung transplant addresses the nature of the procedure, the usual postoperative course, and the impact on prognosis and quality of life of a successful transplant
- The patient asks about his life expectancy if he declines the transplant and the CF clinician describes the course of advanced lung disease in terms of progressive care needs and a prognosis of "perhaps a few years"
  - The patient states that he would like to discuss the procedure with his partner before agreeing

Case Discussion: Serious Illness Discussions

- Next steps
  - The CF clinician sets up a date to meet with the patient and his partner
  - She will discuss this case with the lung transplant team to determine next steps if the patient now agrees
  - She offers the patient a referral for ongoing psychotherapy, and the patient agrees

Case Discussion: Serious Illness Discussions

- **What if's…**
  - What if the patient were a 16-year-old girl?
  - What if the patient declined information about his illness, his prognosis, and his treatment options?
  - What if the patient became very distressed during the first discussion, weeping and criticizing the CF team for pressuring him to get the transplant?