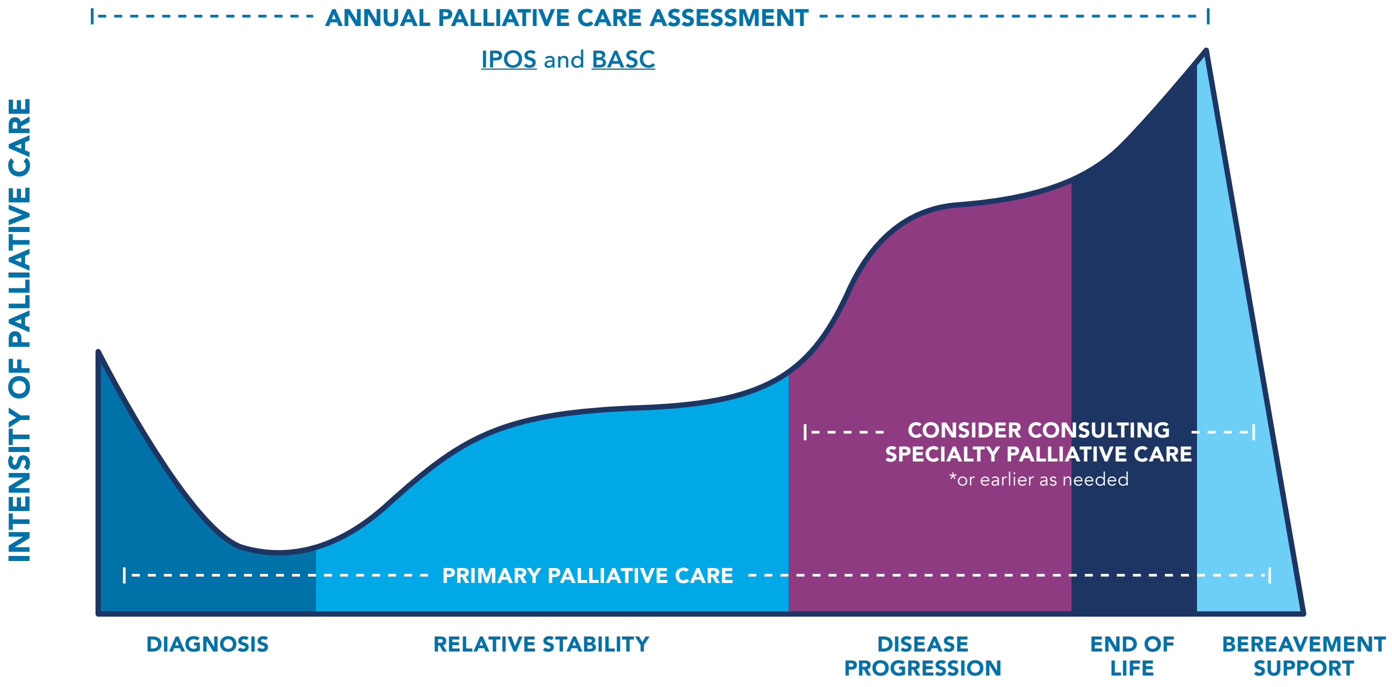
CYSTIC FIBROSIS
FOUNDATION®

PALLIATIVE CARE and CYSTIC FIBROSIS

A GUIDE FOR CF CLINICIANS

WHAT IS PALLIATIVE CARE?

Palliative care focuses on reducing physical and emotional symptoms and improving quality of life for people with cystic fibrosis throughout their lives. Palliative care occurs alongside usual treatments and is individualized according to the unique goals, hopes, and values of each person with CF.



GUIDELINES ON THE MODELS OF PALLIATIVE CARE IN CYSTIC FIBROSIS

The Cystic Fibrosis Foundation developed guidelines on models of care around addressing palliative care needs[1]. These guidelines provide recommendations for addressing palliative care needs and opportunities to improve quality of life for individuals with CF at all stages of illness and development, as well as for their caregivers.

WHAT ABOUT INSURANCE FOR PALLIATIVE CARE COVERAGE?

CF Foundation *Compass* is a free, confidential, and personalized service available to anyone with CF, their family, and their care team to help them navigate complex insurance, financial, legal, and other issues related to life with CF. This service is available regardless of income or insurance status. *Compass* is available to help the community understand their insurance options and connect them with helpful resources to make an informed decision about health insurance coverage.

Call **844-COMPASS** (844-266-7277) or email **compass@cff.org**

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1. Kavalieratos, D, Georgiopoulos A, Dhingra L et al., *Models of Palliative Care Delivery for Individuals with Cystic Fibrosis: Cystic Fibrosis Foundation Evidence-Informed Guidelines*

PRIMARY PALLIATIVE CARE PROVIDED BY THE CF CARE TEAM

- Continuous monitoring and management of basic palliative care needs
- Discussion of goals of care and advance care planning across the lifespan
- Identification and addressing of caregivers’ concerns, and providing support and resources from diagnosis through bereavement
- Comprehensive, timely, compassionate end-of-life care

HOW THE CF CARE TEAM CAN PROVIDE PRIMARY PALLIATIVE CARE

COMMUNICATION AND ADVANCE CARE PLANNING

- Provide education about CF as a chronic, progressive condition
- Discuss prognostic uncertainty and hope
- Communicate distressing news related to CF
- Discuss goals of care with patients and caregivers
- Describe options for life-sustaining treatments for respiratory failure and other critical illnesses
- Identify surrogate decision-makers or health care proxies
- Guide documentation of advance directives
- Provide education and support around transplantation

SYMPTOM MANAGEMENT

- Provide basic management of anxiety and depression
- Provide basic pain and symptom management
- Provide education and resources on coping with chronic illness

CAREGIVER SUPPORT

- Listen supportively and empathetically
- Screen caregivers for anxiety and depression
- Identify resources for emotional support
- Address financial needs and identify resources
- Screen caregivers using the Brief Assessment Scale for Caregivers (BASC)

CARE COORDINATION

- Communicate with other relevant health care providers
- Refer to community resources such as ***Compass***

SPECIALTY PALLIATIVE CARE

Palliative care specialists offer expert management of palliative care needs beyond the comfort level or skill set of the CF care team.

Consults should be considered when:

- The palliative care needs are beyond the expertise or comfort level of the CF care team
- An individual with CF is considering or declines transplant
- A palliative care referral is requested

SERVICES A PALLIATIVE CARE SPECIALIST CAN PROVIDE

COMMUNICATION AND ADVANCE CARE PLANNING

- Address code status and advance directives
- Navigate discordance among patients, caregivers, and health care providers
- Address concerns about misalignment of goals and treatment decisions
- Address fears about future illness and preferences for communication
- Act as third party for conversations about transplantation
- Provide additional exploration of wishes and address concerns around preferences for end-of-life care
- Encourage advance care planning and documentation around respiratory support, life-sustaining treatments, and transplantation

SYMPTOM MANAGEMENT

- Assist with managing physical symptoms refractory to primary palliative care interventions
- Assist with managing emotional symptoms refractory to primary palliative care interventions
- Address existential and spiritual distress

CAREGIVER SUPPORT

- Address needs that exceed the expertise of the CF care team
- Address spiritual and existential distress
- Explore grief and bereavement needs
- Assist with community referrals
- Support caregiver coping
- Address legacy and bereavement care

CARE COORDINATION

- Communicate with CF care team and other relevant health care providers
- Introduce and revisit hospice and community palliative care resources
- Conduct hospice eligibility review
- Address emotional needs of community around the patient, including the CF care team

When to Consider Palliative Care Referral

- During transition planning
- During spiritual and existential distress
- When concerned about medical decision-making
- When in need of assistance with planning for limitation or withdrawal of life-sustaining interventions
- When experiencing distress related to CF or treatment
- When experiencing uncontrolled symptoms*
- When determining goals of care
- When transplant is considered or declined

*Pain (physical, spiritual, and/or emotional) and non-pain

WHY SCREEN?

Screening can identify unmet palliative needs and facilitate improvements in quality of life.

HOW TO SCREEN PATIENTS

Step 1: Establish a care pathway.

Establish care and referral pathways prior to the initiation of screening to:

- Identify palliative care champions on the CF care team
- Become familiar with screening measures and interpretation of screening results
- Develop or use recommended educational materials that can be found on My.CFF: Search "Palliative Care Toolkit," or find under the "Palliative Care" category
- Develop and maintain a list of referral sources for individuals with CF and caregivers within the hospital and community

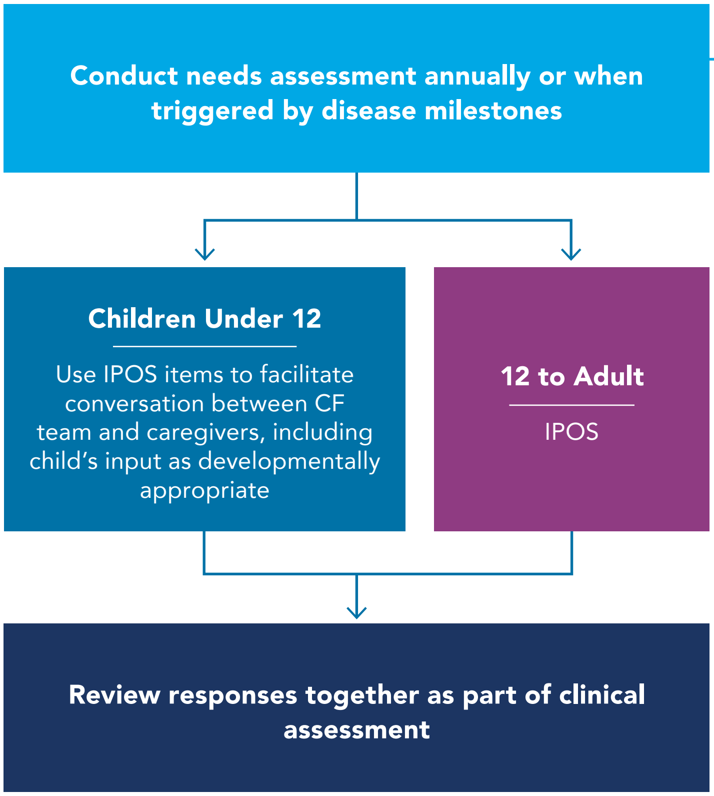
Step 2: Screen patients.

Children with CF under age 12 years: Use the Integrated Palliative Care Outcome Scale (IPOS) to guide conversations with children and caregivers, annually and at disease milestones, to identify unmet palliative care needs.

Individuals with CF ages 12-adulthood: Use the Integrated Palliative Care Outcome Scale (IPOS), annually and at disease milestones, for screening and clinical assessment of unmet palliative care needs.

Palliative Care Screening Tools:
IPOS - Patients
BASC - Caregivers

SCREENING PATHWAY



Conduct needs assessment annually or when triggered by disease milestones

Children Under 12

Use IPOS items to facilitate conversation between CF team and caregivers, including child's input as developmentally appropriate

12 to Adult

IPOS

Review responses together as part of clinical assessment

TRIGGERS FOR SCREENING

- Inpatient hospitalization
- Meeting the definition of advanced CF lung disease
- Rapid decline of FEV_1% predicted
- Development of new CF complications or serious co-occurring disorders
- Referral for evaluation for transplant
- Decision not to pursue transplant

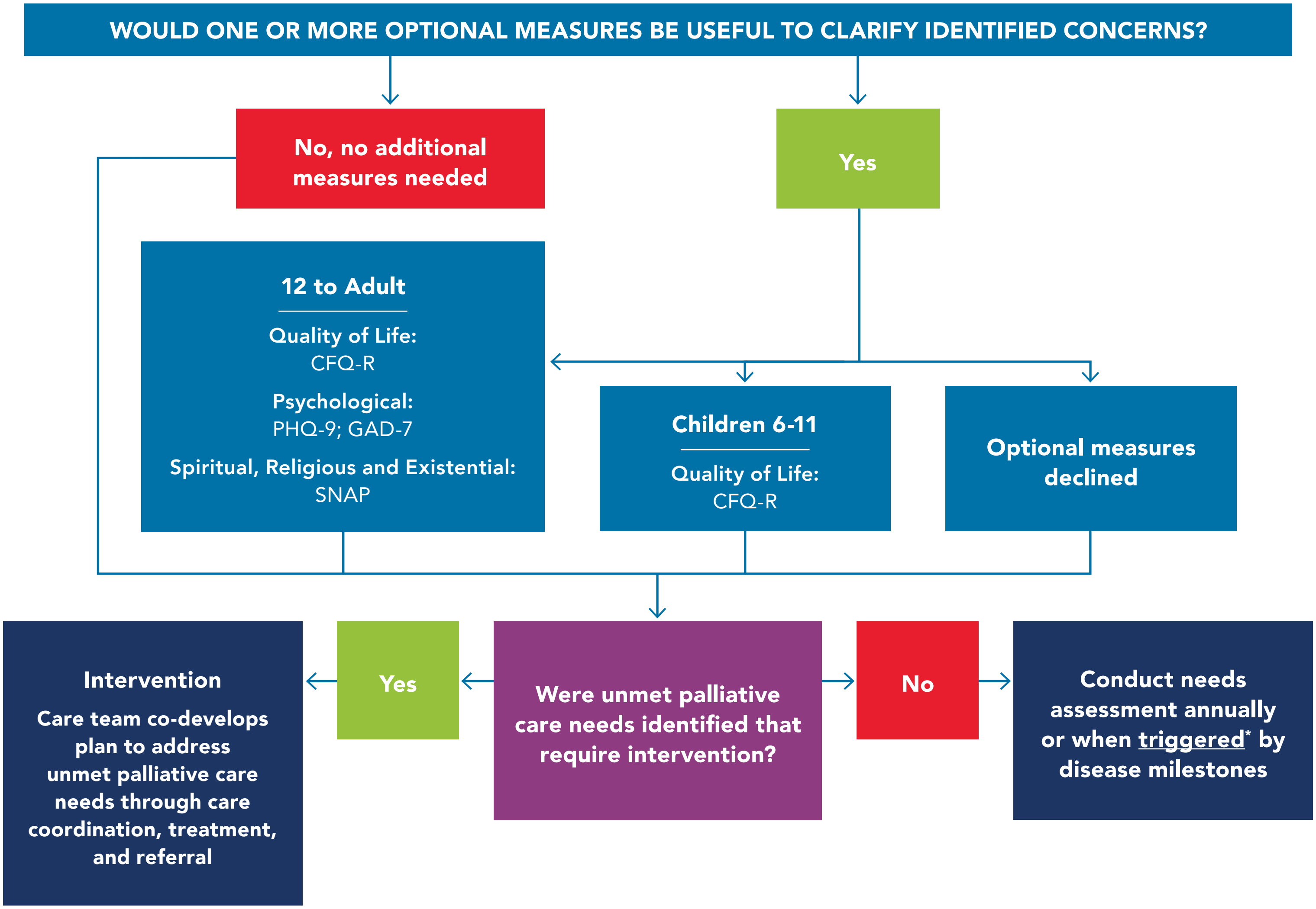
Step 3: Consider additional screens when concerns are found.

Discuss reported concerns, paying special attention to:

- Most severe ratings on any IPOS (>3)
- Needs identified by individuals, caregivers, or the CF team as most important

Additional Screening Tools:

CFQ-R
PHQ9 and GAD7
SNAP



WOULD ONE OR MORE OPTIONAL MEASURES BE USEFUL TO CLARIFY IDENTIFIED CONCERNS?

No, no additional measures needed

Yes

12 to Adult

Quality of Life:
CFQ-R

Psychological:
PHQ-9; GAD-7

Spiritual, Religious and Existential:
SNAP

Children 6-11

Quality of Life:
CFQ-R

Optional measures declined

Were unmet palliative care needs identified that require intervention?

Yes

Intervention

Care team co-develops plan to address unmet palliative care needs through care coordination, treatment, and referral

No

Conduct needs assessment annually or when triggered* by disease milestones

INTERVENTION MAY TARGET

- Physical or psychological symptoms
- Rehabilitation to improve functioning
- Spiritual/existential concerns
- Psychosocial, legal, or financial needs
- Clarification of goals, values, and preferences for treatment

PRACTICAL CONSIDERATION

Include the annual IPOS and BASC alongside your annual Anxiety and Depression Screening.

**See page 4 for triggers*

HOW TO SCREEN CAREGIVERS

Step 1: Screen caregivers.

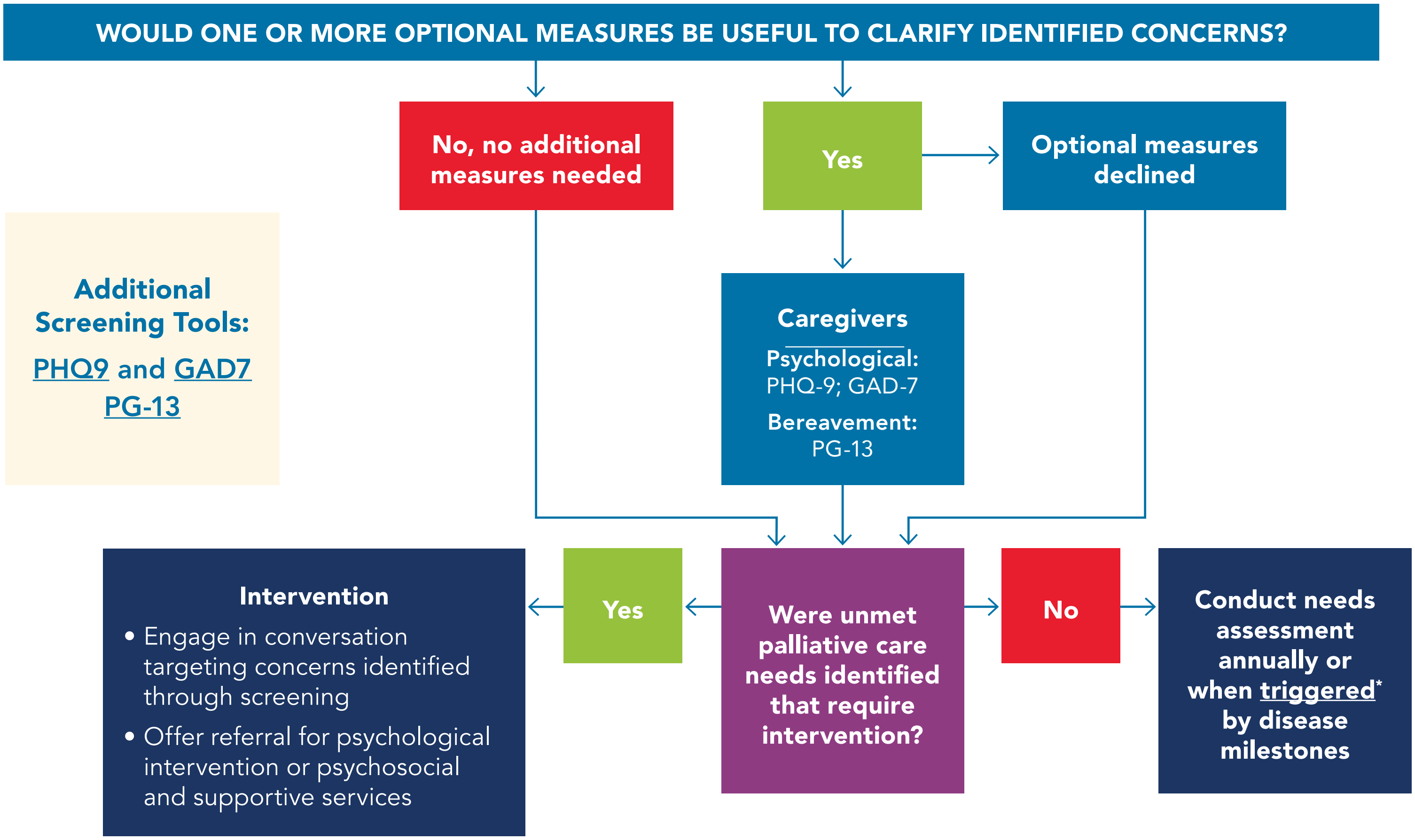
Offer screening annually to at least one primary caregiver of individuals with CF of all ages and when disease milestones trigger repeated screening, using the Brief Assessment Scale for Caregivers (BASC).

Conduct needs assessment annually or when triggered by disease milestones → **Caregivers** Offer BASC → **Review responses together as part of clinical assessment**

Step 2: Consider additional screens for caregivers when concerns are found.

Discuss reported concerns, paying special attention to:

- Most severe ratings on any BASC item
- Needs identified by individuals with CF, caregivers, or the CF team as most important



WOULD ONE OR MORE OPTIONAL MEASURES BE USEFUL TO CLARIFY IDENTIFIED CONCERNS?

No, no additional measures needed

Yes → **Optional measures declined**

Caregivers
Psychological: PHQ-9; GAD-7
Bereavement: PG-13

Additional Screening Tools:
PHQ9 and GAD7
PG-13

Were unmet palliative care needs identified that require intervention?

Yes → **Intervention**
- Engage in conversation targeting concerns identified through screening
- Offer referral for psychological intervention or psychosocial and supportive services

No → **Conduct needs assessment annually or when triggered* by disease milestones**

INTERVENTION MAY TARGET

- Physical or psychological symptoms
- Rehabilitation to improve functioning
- Spiritual/existential concerns
- Psychosocial, legal, or financial needs
- Clarification of goals, values, and preferences for treatment

For questions, call 1-800-FIGHT-CF (800-344-4823) or email info@cff.org

**See page 4 for triggers*