Mental Health in Cystic Fibrosis (CF):

Mental health guidelines in CF and mental health care in practice

Learning Outcomes

At the end of this module, you should be able to:

- **Differentiate** and **discuss** the consensus statement principles developed by the International Committee on Mental Health in Cystic Fibrosis
- **Coordinate** and **work within** a multidisciplinary team to achieve effective mental health care of patients with CF throughout their lifespan.
- **Navigate** the mental health services and resources available for patients with CF

Module Overview

There are two components of this module:

- **Part 1:** The mental health guidelines in CF
- **Part 2:** Mental health care in practice: a response framework for all CF team members

Expert steering committee

Dr. **Anna M. Georgiopoulos**, *Associate Professor of Psychiatry, Harvard Medical School and Consulting Psychiatrist, Massachusetts General Hospital Cystic Fibrosis Program*

Dr Georgiopoulos is an adult, child and adolescent, and consultation-liaison psychiatrist who has been working with the Massachusetts General Hospital CF Program (Boston, USA) since 2005 to promote psychiatric resilience and optimal medical outcomes. Dr. Georgiopoulos chaired workgroups for the CF Foundation/European CF Society consensus statements for screening and treating depression and anxiety and the CF Foundation models of palliative care delivery guidelines, and is co-principal investigator for clinical trials in CF mental health and palliative care. She leads the education and training subgroup of the CF Foundation Mental Health Advisory Committee, co-chairs the Junior Investigator Award for Clinical Research at the North American CF Conference, and serves on the CF Foundation Data Safety Monitoring Board and European CF Society Mental Health Working Group. In 2018, she received the CF Foundation's Mattingly Leadership in Mental Health Care Award. Dr. Georgiopoulos had the great pleasure of meeting members of the CF community and CF care teams in 6 Australian cities during the CF Australia Mental Health Roadshow.

Dr. **Lucy Holland** (PhD). *Adjunct Fellow, Queensland University of Technology. Accredited Social Worker, Professional Coach & Consultant, Simplify Consulting, Australia.*

Lucy is an accredited social work clinician, professional coach, consultant and academic who has worked in health and adolescent health for over 15 years. As a Senior Social Worker, Lucy has worked with individuals and families across tertiary and community health sectors, in acute, trauma and community settings. Lucy also works as a professional coach and adolescent health consultant through her business Simplify Consulting. Lucy has significant academic teaching and research experience in adolescent health, integrated care, professional education, mixed methods and health systems research and evaluation. Lucy has recently completed a PhD in Public Health that examined the optimisation of care for adolescents and young adults living with cystic fibrosis. Lucy is passionate about the working at the interface between practice and research to drive effective health service development, delivery and evaluation. She is committed to ensure meaningful, consumer-led, humanistic approaches to research and care that prioritise true consumer partnership.

Anthony Talbot, *Clinical psychologist, Melbourne, Victoria, Australia*

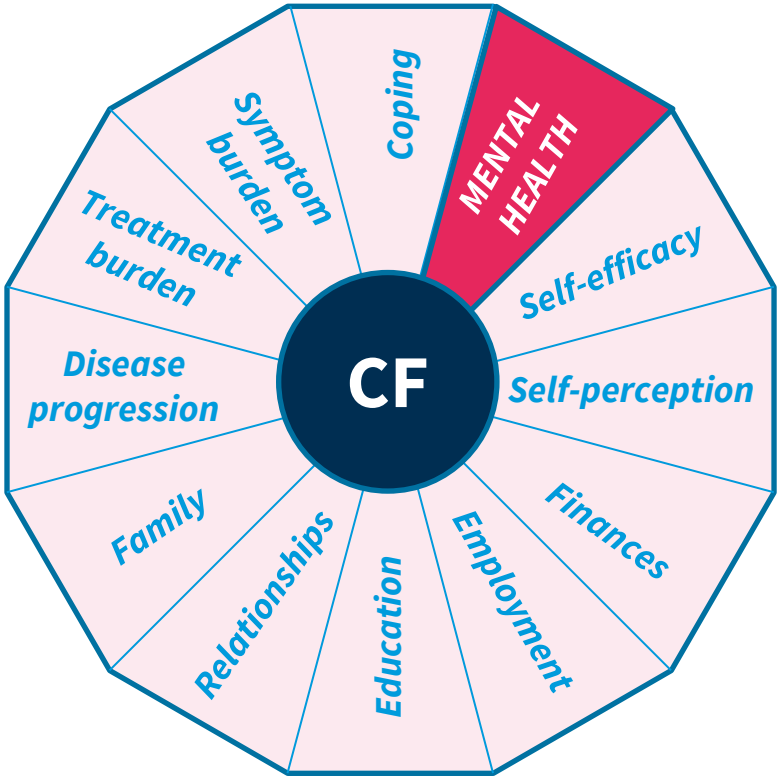
Anthony is a clinical psychologist who has worked in CF care at the Alfred for 10 years. He works with CF patients presenting with a range of psychological concerns, often in the context of significant illness, loss and understandable distress. His approach is to explore a person's own goals for achieving physical and mental wellbeing in the larger context of their life, relationships, values and strengths. Psychotherapy ideally supports adaptation, improved behavioural management of chronic illness, new coping skills and strengthened confidence to make changes. His approach integrates cognitive behavioural therapy, mindfulness, lifespan development and existential psychotherapy. He has a background in smoking cessation. Other interests include loss and grief, motivational interviewing, developmental transitions and sexual identity.

The mental health guidelines in CF

Part 1

Mental health is integral to overall health outcomes in CF

- **People with CF are impacted by an extensive range of closely interrelated biopsychosocial factors** that evolve throughout their lifespan and influence their physical health and wellbeing.[1-3]
- Mental health is one of these factors.[1-3] **The prevalence and impact of mental health issues in the CF community has been increasingly recognised in recent years.[2]**
- CF continues to be one of the most difficult chronic conditions to manage, and those living with it face a higher risk of psychological distress.[2] Conversely, psychological symptoms in those with CF are associated with poorer health outcomes, worse health-related quality of life and higher mortality.[2,4]



1. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283. 2. Muther EF, et al. Pediatr Pulmonol 2018;53(S3):S86-S92 3. Withers AL. Pulm Med 2012;2012:134132.
4. Reno K, et al. Mental Health in Cystic Fibrosis Quality Improvement Change Package. Aug 2020.

Mental health guidelines are available for CF

The Mental Health Guidelines in CF were developed in response to the higher prevalence of depression and anxiety in the CF community.[1]

"Investigations examining depression and anxiety in individuals with [CF] *and their caregivers indicate elevated symptoms of these mental health issues in this population. To address this concern, a multidisciplinary group of experts convened to develop consensus recommendations for identifying and treating depression and anxiety in the context of CF care."[1]*

- Cystic Fibrosis Foundation

1. Cystic Fibrosis Foundation. Screening & Treating Depression & Anxiety Guidelines [Internet]. Available at: https://www.cff.org/Care/Clinical-Care-Guidelines/Screening-and-Treating-Depression-and-Anxiety-Guidelines [Accessed June 2023].

Mental health guidelines are available for CF (cont.)

The **International Committee on Mental Health in CF (ICMH)** was comprised of a panel of experts including physicians, psychologists, psychiatrists, nurses, social workers, pharmacists, patients and parents.[1] Their objective was to change clinical practice to improve mental health outcomes for those with CF.[2]

As one of many components of effective mental health care, the guidelines contribute by:

- Helping CF teams identify patients/parents in need of help and allowing timely intervention[1]
- Helping CF teams feel assured that psychosocial wellbeing is evaluated, at least on a basic level, once a year[1]
- Being a valuable addition to available psychosocial care services, including the continuous and individual interactions psychosocial health providers already have with patients.[1]

1. Havermans T, Staab D. Thorax 2016;71(1):1-2. 2. Quittner AL, et al. Thorax 2016;71(1):26-34.

The guidelines comprise of fifteen recommendations across four themes[1]

Use the buttons below to explore these themes further. The home button  will return you to this menu:

- **Prevention**
- **Screening**
- **Clinical assessment**
- **Intervention**

1. Quittner AL, et al. Thorax 2016;71(1):26-34.

Guideline recommendations: PREVENTION

The recommendations on **prevention** focus on providing sufficient information and education to help those in the CF community to develop coping skills and disease management. Examples and further detail will be explored in the following screens.

Recommendations[1]	
1	For all **individuals with CF and caregivers**, provide **ongoing education and preventative/ supportive interventions** suitable for their age and disease state *e.g. training in stress management and the development of coping skills*
2	For all **individuals with CF undergoing medical procedures**, offer **behavioural approaches** to reduce the risk of distress

1. Quittner AL, et al. Thorax 2016;71(1):26-34.

Prevention efforts help stop emerging mental health issues from developing into clinical disorders

Individuals with CF and their caregivers should be offered education and supportive interventions to promote effective coping skills and disease management.[1,2] This can be as simple as an educational handout.[1,2]

Prevention strategies should **encourage individuals to understand and know how to manage** both their physical and mental health.[1,2]

Use a sensitive and empathetic approach, paying attention to individual and family functioning.[1]

1. Quittner AL, et al. Thorax 2016;71(1):26-34. 2. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

Examples of strategies for preventing mental health issues[1,2]

Engage in their medical care
Complete CF treatments and address physical symptoms early, since they have a two-way connection with depression/ anxiety

Practice good sleep hygiene

Exercise every day
Physically active people are at reduced risk of depression/ anxiety

Take steps to control stress
e.g. controlled breathing, meditation, yoga

Go outside in the sunlight
Daily exposure can lessen depression/ anxiety symptoms

Reach out to trusted family and friends

Eat a well-balanced diet

Schedule enjoyable activities and stay engaged

Promote open communication with the CF team
It's important to understand what challenges are being faced

1. Quittner AL, et al. Thorax 2016;71(1):26-34. 2. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

Improving resilience can contribute significantly to positive coping skills

Resilience: the process of adapting well under adverse circumstances or significant stress.[1,2]

Resilience can be a powerful tool in confronting the uncertainty that comes with living with CF.

Building resilience helps to buffer against the biopsychosocial risk factors associated with CF and sustain long-term quality of life for both patients and their caregivers.[1]

Resilience involves behaviours, thoughts and actions that can be learned and developed with time and intentionality.[2]

1. Muther EF, et al. Pediatr Pulmonol 2018;53(S3):S86-S92. 2. American Psychological Association. Building Your Resilience [Internet]. Available at: https://www.apa.org/topics/resilience [Accessed June 2023].

Examples of strategies for improving resilience[1,2]

- **Building connections** – prioritising relationships, accepting support, joining groups
- **Fostering wellness** – self-care, meditation or meditative movement (e.g. Tai Chi)
- **Embracing healthy thinking** – optimism, positive self-perception, accepting change, focusing on what can be controlled, big picture perspective, looking for evidence of learning and personal growth
- **Finding purpose** – volunteering, decisive action (e.g. acting on problems rather than wishing them away), developing realistic goals and taking consistent action towards them
- **Positive spiritual coping** – using spiritual beliefs to find comfort/support and make meaning of experiences (has been associated with improved treatment adherence and better health outcomes for both patients and caregivers).

1. Muther EF, et al. Pediatr Pulmonol 2018;53(S3):S86-S92. 2. American Psychological Association. Building Your Resilience [Internet]. Available at: https://www.apa.org/topics/resilience [Accessed June 2023].

A coping plan can be a helpful preventative measure for procedural anxiety

Developing a coping plan can help reduce stress and anxiety associated with potentially painful medical procedures.[1] This may include relaxation, imagery, massage or pharmacological interventions.[1,2]

For parents or children with CF, strategies can include:[1,2]

- **Learning details of the procedure** to prepare the child, with information tailored to their age and understanding
- For younger children, **'playing' a procedure beforehand** can be beneficial
- Providing **distraction**, like games or a favourite toy
- Teaching children **slowed or controlled breathing** and other calming techniques
- **Role modelling calm, coping behaviour** – younger children especially will take cues from their parents
- **Progressively involving children in the medical decision-making process** as they get older.

Children need clear and honest information – as a health professional, you can help parents find the right words that are appropriate for the child.[2]

1. Cystic Fibrosis Western Australia. Procedural Anxiety Factsheet [Internet]. Available at: https://www.cfwa.org.au/news/optimising-resilience/ [Accessed June 2023]. 2. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-S78.

Guideline recommendations: SCREENING

The second recommendation area provides guidance on how and when to provide mental health screening for people in the CF community. Further detail will be explored in the following screens.

	Recommendations[1]
3	**Children with CF ages 7–11 to be clinically evaluated** for depression and anxiety **when caregiver depression or anxiety scores are elevated**, or when **significant symptoms of depression or anxiety in the child are reported or observed** by patients, caregivers or members of the CF multidisciplinary team
4	Provide **screening every year for depression and anxiety** with the PHQ-9 and GAD-7 **for adolescents and adults** with CF (ages 12–adulthood)
5	Offer **annual screening** for depression and anxiety to **at least one primary caregiver of children and adolescents with CF (ages 0–17)** using one of the following approaches: ▸ Screening with the PHQ-9 and GAD-7 ▸ Screening with the PHQ-8 and GAD-7 ▸ Screening with the PHQ-2 and GAD-2

1. Quittner AL, et al. Thorax 2016;71(1):26-34.

Systematic screening with the PHQ-9 and GAD-7 ensures reliability and standardisation of care[1]

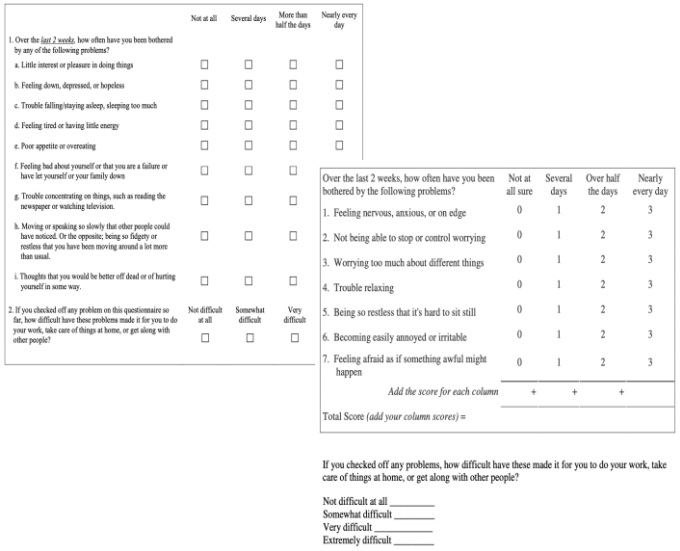
These screening tools are **free, brief and reliable** with optimal cut-off scores for detecting psychological symptoms.[1,2]

Screening should generally be done by a mental health specialist (e.g. registered social worker, psychologist, psychiatrist); however, it could also be done by other providers (e.g. nurse, GP) with additional training.[1]

Prior to administration, be sure the patient understands the rationale for screening mental health issues.[1]

DEPRESSION:
Patient Health Questionnaire 9 (PHQ-9)

ANXIETY:
General Anxiety Disorder 7-item (GAD-7)



1. Over the *last 2 weeks*, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
a. Little interest or pleasure in doing things	☐	☐	☐	☐
b. Feeling down, depressed, or hopeless	☐	☐	☐	☐
c. Trouble falling/staying asleep, sleeping too much	☐	☐	☐	☐
d. Feeling tired or having little energy	☐	☐	☐	☐
e. Poor appetite or overeating	☐	☐	☐	☐
f. Feeling bad about yourself or that you are a failure or have let yourself or your family down	☐	☐	☐	
g. Trouble concentrating on things, such as reading the newspaper or watching television.	☐	☐	☐	
h. Moving or speaking so slowly that other people could have noticed. Or the opposite; being so fidgety or restless that you have been moving around a lot more than usual.	☐	☐	☐	
i. Thoughts that you would be better off dead or of hurting yourself in some way.	☐	☐	☐	
2. If you checked off any problem on this questionnaire so far, 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	
	☐	☐	☐	

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all sure	Several days	Over 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's 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
Add the score for each column	+	+	+	
Total Score *(add your column scores)* =				

If you checked off any problems, how difficult have these 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 _____

1. Quittner AL, et al. Thorax 2016;71(1):26-34. 2. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

PHQ-9

To use the PHQ-9, assign scores to each response based on the values indicated below, then add these to create the patient's total score.

- Not at all = 0
- Several days = 1
- More than half the days = 2
- Nearly every day = 3

Interpreting scores:[1]

- **0-4:** no/minimal symptoms
- **5-9:** mild depression
- **10-14:** moderate depression
- **≥15:** severe depression

Patient Health Questionnaire (PHQ–9)

1. Over the last two weeks how often have you been bothered by any of the following problems?

	Not at all (0)	Several days (1)	More than half the days (2)	Nearly every day (3)
a. Little interest or pleasure in doing things.	☐	☐	☐	☐
b. Feeling down, depressed, or hopeless.	☐	☐	☐	☐
c. Trouble falling/staying asleep, sleeping too much	☐	☐	☐	☐
d. Feeling tired or having little energy	☐	☐	☐	☐
e. Poor appetite or overeating.	☐	☐	☐	☐
f. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down.	☐	☐	☐	☐
g. Trouble concentrating on things, such as reading the newspaper or watching TV.	☐	☐	☐	☐
h. Moving or speaking so slowly that other people could have noticed. Or the opposite; being so fidgety or restless that you have been moving around more than usual.	☐	☐	☐	☐
i. Thoughts that you would be better off dead or of hurting yourself in some way.	☐	☐	☐	☐

Total Score: _____

2. If you checked off any problem on this questionnaire so far, 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

Adapted from https://camh.ca/-/media/files/form-phq-9-pdf.pdf. [Accessed June 2023]

1. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

GAD-7

To use the GAD-7, add the numbers based on the patient's response to create their total score.

Interpreting scores: [1]

- **0-4:** no/minimal symptoms
- **5-9:** mild anxiety
- **10-14:** moderate anxiety
- **≥15:** severe anxiety

Generalized Anxiety Disorder (GAD–7) Scale

1. Over the last two weeks how often have you been bothered by any of the following problems?

	Not at all (0)	Several days (1)	More than half the days (2)	Nearly every day (3)
a. Feeling nervous, anxious or on edge	☐	☐	☐	☐
b. Not being able to stop or control worrying	☐	☐	☐	☐
c. Worrying too much about different things	☐	☐	☐	☐
d. Trouble relaxing	☐	☐	☐	☐
e. Being so restless that is hard to sit still.	☐	☐	☐	☐
f. Becoming easily annoyed or irritable	☐	☐	☐	☐
g. Feeling afraid as if something awful might happen	☐	☐	☐	☐

Total Score: _____

Adapted from https://camh.ca/-/media/files/formgad7-pdf.pdf. [Accessed June 2023]

1. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

When screening caregivers, two alternative approaches can also be considered

If resources are limited within a CF centre, the guidelines recommend using shortened versions of the PHQ-9 and GAD-7 for caregiver screening.[1]

Option 1:

- Screen for depression with **PHQ-8** – omits the question on self harm (if scores are elevated, this can be inquired about during clinical assessment).
- Screen for anxiety with **GAD-7**.

Option 2:

- Screen for depression with **PHQ-2** – only covers items on low mood and anhedonia.
- Screen for anxiety with **GAD-2** – only covers items on feeling anxious/nervous and not being able to stop/control worrying.
- These are designed as 2-step processes which screen core features only. Elevated scores may warrant full screening by the CF team or referral to a primary care doctor for evaluation.

1. Quittner AL, et al. Thorax 2016;71(1):26-34

The approach to screening will depend on each CF team and available resources

Every CF team will have a different system that works best for them, and this will often depend on the availability of specialist mental health resources.[1] Some may perform screening as part of a wider CF assessment, while others may perform it as a consultation with referral outside the CF team as needed.

It is critical that care and referral pathways be established *prior* to implementing a screening program.[1]

This involves identifying roles and responsibilities, developing educational materials, creating and maintaining a list of referral sources, and establishing a suicide safety plan.[1]

1. Quittner AL, et al. Thorax 2016;71(1):26-34

It is important not to screen just for the sake of it

Regardless of the approach, screening should not simply be implemented as a ‘tick the box’ exercise – there is no point screening someone without a clear plan of what to do with the results.

As well as implementing routine mental health assessment into CF care, the opportunity to build ongoing mental health monitoring into existing patient-provider interactions should also be considered.

Guideline recommendations:
CLINICAL ASSESSMENT

The third recommendation area advises next steps for those who reveal elevated symptoms during the screening process:

	Recommendations[1]
6	Any treatment for depression and anxiety in individuals with CF and caregivers must be based on clinical diagnosis ▸ A healthcare provider with appropriate training and expertise should evaluate the clinical significance of elevated screening scores and presenting symptoms to **perform a differential diagnosis before initiating treatment**
7	**For caregivers of individuals with CF** who have clinically significant symptoms of depression/anxiety, **refer for treatment to primary care or mental health services** after initial assessment with the CF team.

1. Quittner AL, et al. Thorax 2016;71(1):26-34.

Following an elevated mental health screen, clinical assessment must be done prior to initiating treatment[1]

An appropriately trained and registered mental health professional should complete the clinical mental health diagnosis.[1]

The goal is to identify the **presence, duration and severity of mental health symptoms**, plus **prior history** and **risk factors** for depression/anxiety.[1]

They should assess:[1]

- Physical health, including CF and other conditions
- Prior history of depression or anxiety
- Previous treatment and response
- Family history of psychiatric illnesses
- Comorbid psychiatric diagnoses.

Those with a positive suicide risk should be followed up immediately by a designated mental health expert.[1]

Suicide safety planning will be covered in the following section.

1. Quittner AL, et al. Thorax 2016;71(1):26-34.

Consider a CF-specific differential diagnosis during assessment

Differential diagnosis refers to the process of ruling out other potential conditions that share symptoms similar to those identified during screening. A psychiatric differential diagnosis may include bipolar disorder, post-traumatic stress disorder, delirium or substance abuse.[1,2]

Some symptoms can be attributable to CF itself, and can exacerbate or mimic depression and anxiety. It's important to consider the individual context of disease-related factors such as **pain**, **vitamin D deficiency**, **low energy/fatigue**, **dyspnoea**, **weight loss** and **sleep disturbance.**

What about caregivers?

Caregivers are recommended to be assessed and treated outside of the CF team. This is because the ICMH acknowledges that the majority of CF centres will not have the resources to treat parental depression and anxiety.[1]

1. Quittner AL, et al. Thorax 2016;71(1):26-34. 2. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

Guideline recommendations:
INTERVENTION (1/4)

The fourth and final recommendation area endorses interventions based on severity of symptoms:

	Recommendations[1]
8	For all individuals with CF and symptoms of depression/anxiety, **provide a flexible, stepped care model of clinical intervention** developed and implemented in close collaboration with: ▸Patients and caregivers, ▸The multidisciplinary CF team and ▸Other treatment providers or consultants, such as primary care or mental health specialists. → CF teams must identify who will be responsible to initiate and coordinate care and monitor treatment effects.
9	**For children with CF ages 7–11**, who have clinically significant depression or anxiety, **evidence-based psychological interventions** should be provided as first-line treatment.

1. Quittner AL, et al. Thorax 2016;71(1):26-34.

Guideline recommendations:
INTERVENTION (2/4)

The fourth and final recommendation area endorses interventions based on severity of symptoms:

	Recommendations[1]
10	For individuals with CF ages 12–adulthood and **mild** depression or anxiety symptoms, **provide education** about depression/anxiety, **preventative or supportive interventions** and **rescreening** at the next clinic visit.
11	For individuals with CF ages 12–adulthood and **moderate** depression or anxiety, offer or provide a **referral for evidence-based psychological interventions**, including Cognitive Behavioural Therapy (CBT) or Interpersonal Therapy (IPT). ▸When psychological intervention is unavailable, declined or not fully effective, **antidepressant treatment** should be considered.
12	For individuals with CF ages 12–adulthood and **severe depression**, use **combined evidence-based psychological interventions and antidepressant pharmacotherapy**.

1. Quittner AL, et al. Thorax 2016;71(1):26-34.

Guideline recommendations:
INTERVENTION (3/4)

The fourth and final recommendation area endorses interventions based on severity of symptoms:

	Recommendations[1]
13	**For individuals with CF ages 12–adulthood and severe anxiety, offer exposure-based CBT.** **▸ When exposure-based CBT is unavailable, declined or not fully effective antidepressant medications can be considered**
14	The selective serotonin reuptake inhibitors (SSRIs) **citalopram, escitalopram, sertraline and fluoxetine** are appropriate first-line antidepressants **for most individuals with CF, ages 12–adulthood, requiring pharmacotherapy** **▸ In selecting an antidepressant and adjusting its dosage, close monitoring of therapeutic effects, adverse effects, drug–drug interactions and medical comorbidities is recommended**

1. Quittner AL, et al. Thorax 2016;71(1):26-34.

Guideline recommendations:
INTERVENTION (4/4)

The fourth and final recommendation area endorses interventions based on severity of symptoms:

	Recommendations[1]
15	**Lorazepam** can be considered for short-term use in individuals with CF with **moderate-to-severe anxiety symptoms associated with medical procedures**, who have not responded to behavioural approaches.

1. Quittner AL, et al. Thorax 2016;71(1):26-34.

Care plans should be developed collaboratively and tailored to the individual[1]

The care plan should be delivered by appropriately trained mental health providers and based on the following patient factors:[1]

Age	**Functional impairment**	**Medical status**	**Access to treatment**
Safety	**Screening scores**	**Treatment history**	**Psychiatric comorbidities**
Preferences	**Clinical assessment**	**Resource availability**	

Concomitant CF symptoms should be actively treated while addressing depression and anxiety.[1] Be aware that pulmonary exacerbations can worsen or mimic depression/ anxiety via multiple biopsychosocial mechanisms including demoralisation, stress and inflammation.[1]

1. Quittner AL, et al. Thorax 2016;71(1):26-34.

Recommended interventions are based on the severity of symptoms – psychotherapy is always first-line[1,2]

Provisional Diagnosis	PHQ-9 / GAD-7	First-line Treatment Recommendation
No/minimal symptoms	0-4	**Rescreen next year**
Mild depression or anxiety	5-9	**Preventive/supportive interventions, education + rescreen at next visit** • The clinician actively encourages the patient to discuss life stressors, reinforces effective problem solving and coping strategies, and provides education, suggestions and advice

1. Quittner AL, et al. Thorax 2016;71(1):26-34. 2. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

Recommended interventions are based on the severity of symptoms – psychotherapy is always first-line (cont.)[1,2]

Provisional Diagnosis	PHQ-9 / GAD-7	First-line Treatment Recommendation
Moderate depression or anxiety	10-14	**Evidence-based psychotherapy, such as Cognitive Behavioural Therapy or Interpersonal Therapy** • Antidepressants can be considered when psychological interventions are inaccessible, not desired or ineffective
Severe depression	≥15	**Combined antidepressant and evidence-based psychotherapy**
Severe anxiety	≥15	**Exposure-based Cognitive Behavioural Therapy** • Antidepressants can be considered when psychological interventions are inaccessible, not desired or ineffective

1. Quittner AL, et al. Thorax 2016;71(1):26-34. 2. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

Cognitive Behavioural Therapy (CBT)[1,2]

- Addresses dysfunctional emotions by targeting interrelated thoughts and behaviours
- Combines cognitive interventions (challenging/replacing negative cognitions) with principles of behaviour modification (skills training)
- Extensive evidence base for use in paediatric and adult patients, and in some chronically ill populations
- Demonstrated efficacy in treating comorbid depression and anxiety
  - Behavioural activation (planning pleasurable activities) is a core component for treating depression
  - Relaxation training and graduated exposure are core components for treating anxiety
  - Education and cognitive restructuring are standard for both depression and anxiety.

Psychotherapy should take a person's context and family needs into account, especially for children and adolescents.[2]

1. Quittner AL, et al. Thorax 2016;71(1):26-34. 2. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

Interpersonal Therapy (IPT)[1,2]

- Time-limited intervention focusing on loss, conflicts with others or changes in social roles
- Encourages patients to regain control of mood and functioning
- Based on treatment alliance where the therapist engages the patient to express feelings and improve communication skills and behaviour patterns
- Not indicated for anxiety
- Less empirical support and adoption vs CBT.

Psychotherapy should take a person's context and family needs into account, especially for children and adolescents.[2]

1. Quittner AL, et al. Thorax 2016;71(1):26-34. 2. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

The PHQ-9 and GAD-7 can be used to assess and monitor response to treatment[1]

The goal is for symptoms to return to a normal range and for functioning to improve.[1]

If symptoms continue to be elevated **after 12 weeks, additional or alternative interventions should be offered** by appropriate mental health professionals and continued until they return to within normal range.[1]

1. Quittner AL, et al. Thorax 2016;71(1):26-34.

For pharmacotherapy, evidence supports selective serotonin reuptake inhibitors (SSRIs) first-line

Pharmacological interventions form part of a comprehensive treatment plan for moderate to severe depression and anxiety.[1,2]

SSRIs are effective for both depression and anxiety.[1,2] They are well studied in medically ill populations and contraindications for use in people with CF are rare.[1,2]

Appropriate initial choices usually include:[1,2]

- **Citalopram**
- **Escitalopram**
- **Sertraline**
- **Fluoxetine.**

For children 7-11 years old, psychotherapy is always first-line and specialist consultation should be obtained if pharmacotherapy is being considered.[1]

1. Quittner AL, et al. Thorax 2016;71(1):26-34. 2. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

Pharmacokinetics can be altered in CF[1]

Optimal dose adjustment requires close monitoring.[1]

Since individuals with CF may be young, low weight, medically complex and taking other medications, **gradual titration starting from a low dose** is recommended.[2]

Impaired absorption, enhanced hepatic metabolism, genetic variation, drug-drug interactions, and patient-reported mental health events in some cases may support adjustment(s) to pharmacotherapy.[2]

See next slide for a guide to SSRIs in CF

1. Quittner AL, et al. Thorax 2016;71(1):26-34. 2. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

Using SSRIs for depression and anxiety in adolescents and adults with CF[1]

SSRIs in CF	Start low	Go slow	Treat to target	Higher if needed	Watch for interactions
	Low starting dose suggested for individuals for CF	Titrate up every 1-4 weeks if partial or no response	When GAD-7, PHQ-9 and functioning return to normal, continue target dose for 1 year, then consider taper off SSRI	Off-label high dose may be useful in some circumstances	Examples in CF:
	Hepatic impairment?	Side effects?	Recurrent symptoms off SSRI?	No response or worsening?	Risk of serotonin syndrome with linezolid and SSRIs; use only if no safer alternatives
	Keep dose lower	Maintain dose longer or reduce dose	Consider longer-term treatment	Assess adherence; consider medication change or consultation	
Citalopram	5-10 mg/day	By 5-10 mg	20-40 mg/day	80 mg/day	Increase dose with lumacaftor Risk of additive QTc prolongation with antifungals, macrolides, quinolones, methadone
Escitalopram Fluoxetine Sertraline	2.5-5 mg/day 5-10 mg/day 12.5-25 mg/day	By 2.5-5 mg By 5-10 mg By 12.5-25 mg	10-20 mg/day 20-60 mg/day 50-200 mg/day	40 mg/day 80 mg/day 250 mg/day	Increase dose with lumacaftor Reduce dose with lumacaftor Increase dose with lumacaftor

1. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

Pharmacokinetics can be altered in CF (cont.)[1]

Optimal dose adjustment requires close monitoring.[1]

When pharmacotherapy for depression or anxiety is required, it is important for health providers to:

- **Monitor** for therapeutic benefits, adverse effects and medical status.[1]
  - Pulmonary, gastrointestinal, hepatic, renal and nutritional changes are particularly salient in CF.
  - Supplement clinical monitoring with blood level monitoring where available.
- **Inform** prescribing clinicians of all medications used daily, regularly cycled or used periodically for CF exacerbations, to reduce the risk of drug-drug interactions.[1]
- **Taper** SSRIs gradually after an extended period of symptom remission (~1 year), to decrease the risk of relapse and physical discontinuation symptoms.[2]

1. Quittner AL, et al. Thorax 2016;71(1):26-34. 2. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

Appropriate CF team members can be trained to prescribe pharmacotherapy

As treatment of depression or anxiety with SSRIs is relatively straightforward to manage, appropriate CF team members can readily learn to prescribe and monitor them.[1]

This is consistent with a model of Collaborative Care (to be explored in the next section) and **promotes access to psychiatric treatment**, **continuity of care** and **pre-existing understanding of non-psychiatric aspects of CF management**.[1]

Psychiatric consultation should continue to be made available for more complex patients.

1. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

Benzodiazepines can be considered for moderate-to-severe episodic procedural anxiety[1,2]

If there is no response to behavioural approaches, **lorazepam can be considered as a useful short-term adjunct** to reduce procedural anxiety.[1,2] Key benefits include rapid onset and short duration of action. [1,2]

Patients should be advised on the **serious consequences of misuse**, particularly in combination with alcohol.[1,2]

Close monitoring and caution is required in individuals with:[1,2]

- History of substance abuse
- History of depression
- Elevated risk of respiratory depression.

Other considerations:

- Given renal excretion, dose reduction may be necessary in patients who develop renal insufficiency.[1]
- Sudden cessation following chronic use can result in withdrawal symptoms.[2]

1. Quittner AL, et al. Thorax 2016;71(1):26-34. 2. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

When is specialised psychiatric consultation required?[1]

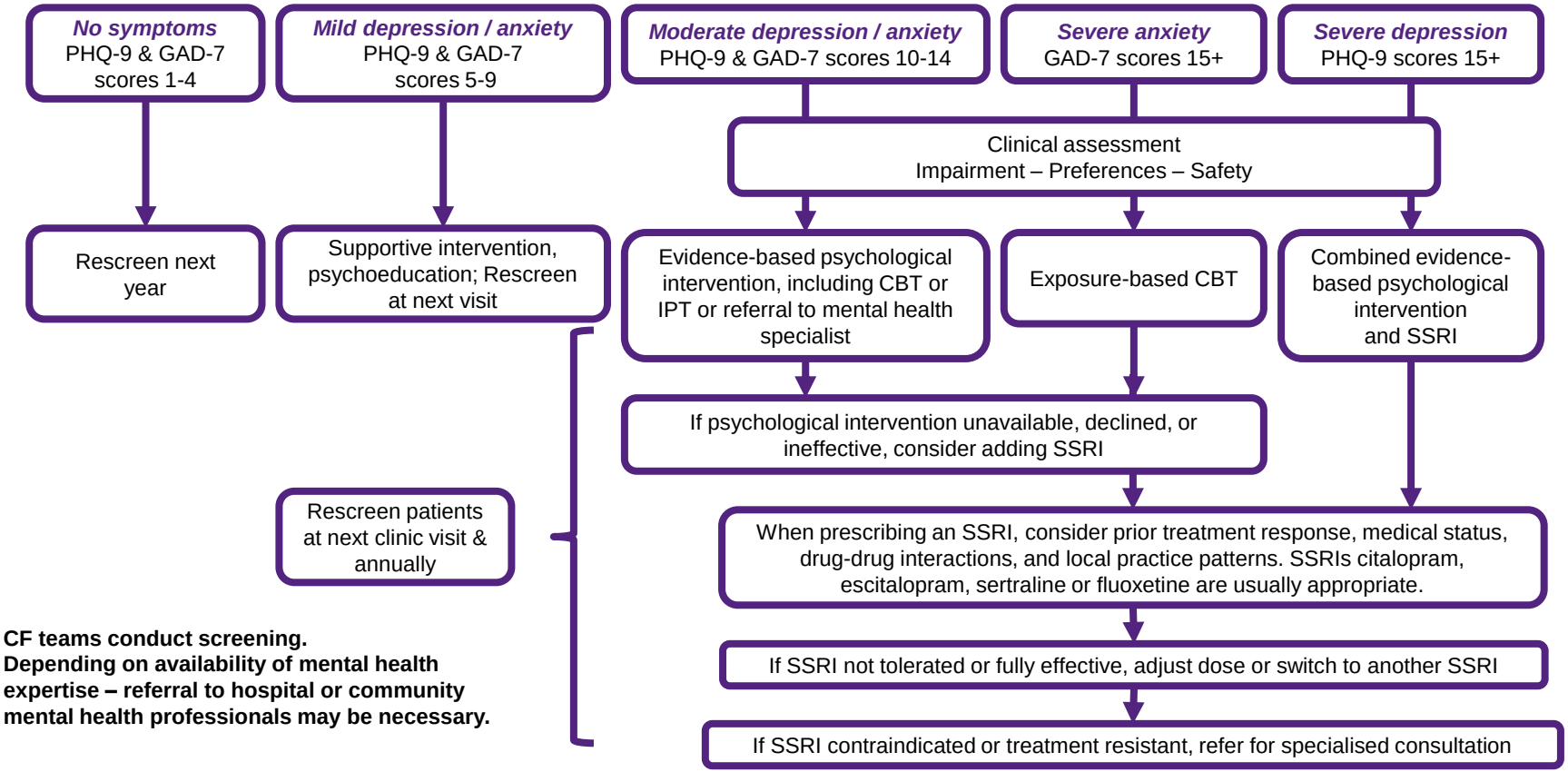
- When the psychiatric **diagnosis is uncertain**.
- When **complexity** of the case exceeds the CF team's level of training or experience.
- When an **urgent safety risk** is identified.
- When depression or anxiety is **resistant to treatment.**

CF teams should always work in close collaboration with specialists and help educate mental healthcare providers unfamiliar with CF.[2]

This ensures established psychotherapeutic techniques are adapted to the biopsychosocial needs of those with CF.

1. Quittner AL, et al. Thorax 2016;71(1):26-34. 2. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

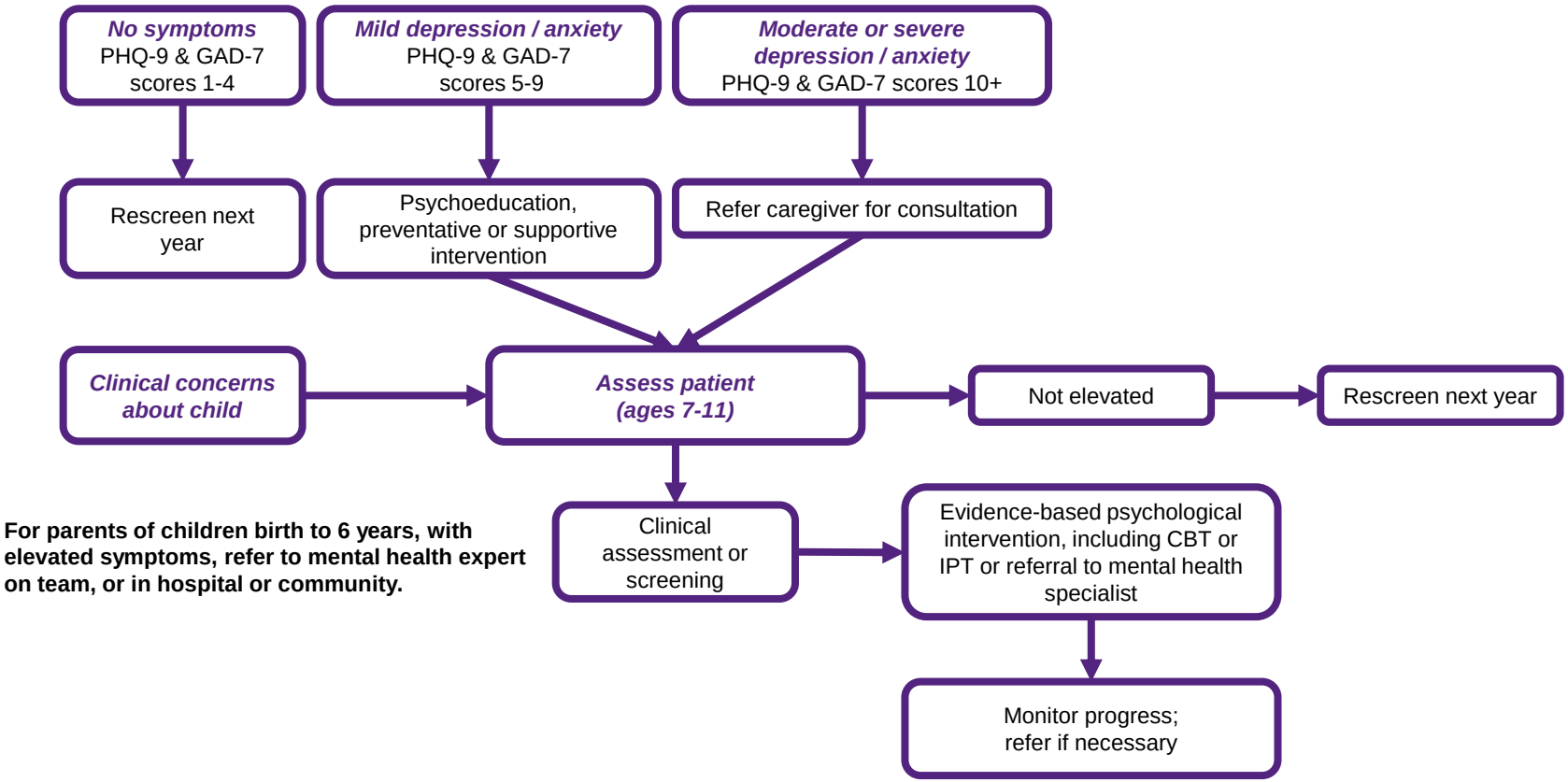
Summary: screening and care algorithm for individuals with CF (12 YO+)[1]



Screening and treatment of depression and anxiety: algorithm for individuals with CF (ages 12-adulthood). Adapted from Quittner et al, 2016.[1]

1. Quittner AL, et al. Thorax 2016;71(1):26-34.

Summary: screening and care algorithm for parents/caregivers[1]



For parents of children birth to 6 years, with elevated symptoms, refer to mental health expert on team, or in hospital or community.

Screening and treatment of depression and anxiety: algorithm for parents/caregivers. Adapted from Quittner et al, 2016.[1]

1. Quittner AL, et al. Thorax 2016;71(1):26-34.

Mental healthcare in practice: a response framework for all CF team members

Part 2

Mental health screening actions don’t need to be limited to a screening program

As recommended by the guidelines, formal annual screening is essential for addressing the mental wellbeing of individuals with CF and their caregivers. It provides the opportunity for open discussions, providing education and support, and eliminating mental health stigma.[1]

However, mental health care in CF does not fall squarely on the shoulders of those immediately involved in the screening program.

Given the complexity of CF medical care and its large treatment burden, everyone in the CF care team has a unique opportunity to holistically assess and treat patients and their families, and ensure their psychological as well as physical health needs are being met.[1]

Appreciating the two-way connection between mental and physical health, this section will explore how preventing and monitoring for mental health issues can be embedded within overall CF care.

1. Reno K, et al. Mental Health in Cystic Fibrosis Quality Improvement Change Package. Aug 2020.

It’s not just about screening – it’s about the quality of the conversation and what happens next

Regardless of whether screening is done formally or informally, it’s not enough to simply ask how the patient (or caregiver) is feeling.

Screening should be seen as a catalyst for discussion – **the focus should be on building positive relationships so that individuals living with CF feel they have someone in the care team they can be open with**.[1] This is particularly relevant for health providers who are in frequent contact with the patient and/or caregiver.

Remember, you don’t need to be a skilled counsellor to have effective conversations related to mental wellbeing. That said, **clinicians should aim to hone their communication skills to effectively engage with patients and know how to respond if concerns arise.**

1. ECFS Mental Health Working Group, CFF Mental Health Advisory Committee. Cystic Fibrosis Patient and Caregiver Mental Health Survey. Data collected Nov 2019 to Feb 2020.

It’s important to optimise communication between clinicians and patients with CF[1,2]

In a multi-centre study analysing patient-clinician communication amongst individuals/families living with CF, eliciting psychosocial concerns was identified as a key need and preference during clinic interactions.[1]

Findings point to the value of developing advanced communication skills that foster trust-building, negotiating agendas, active listening and collaborative goal-setting.[1]

See next slide for some tips for effective engagement

1. ECFS Mental Health Working Group, CFF Mental Health Advisory Committee. Cystic Fibrosis Patient and Caregiver Mental Health Survey. Data collected Nov 2019 to Feb 2020. 2. Cooley L, et al. Pediatr Pulmonol 2020;55(4):948-958.

Effectively engaging with people with CF[1]

- **Show interest in the person's broader life so they feel more open to share** –
  open-ended questions can help uncover areas where they may need support.
  - *"What's something that's been hard for you since the last time we saw you?"*
  - *"How are your family/friends supporting you?"*
  - *"How are you feeling about...?"*
- **During treatments, make the exchange less transactional by asking them "what is this like for you?"** – this can help build rapport and elicit any negative feelings.
- **Wait for one-to-one moments to discuss their wellbeing** – they may feel less inclined to open up in front of their family or a large group.
- **Stay committed and remember conversations get more comfortable with practice** – part of the goal is to normalise negative feelings and reduce the stigma around mental health issues.
- Even if the patient doesn't report any symptoms of depression or anxiety, **take time to discuss what's going well and positively reinforce those factors.**

1. ECFS Mental Health Working Group, CFF Mental Health Advisory Committee. Cystic Fibrosis Patient and Caregiver Mental Health Survey. Data collected Nov 2019 to Feb 2020.

Use inpatient care as an opportunity to enhance psychosocial support

Research suggests that 2 out of 3 chronically ill children who are frequently admitted to hospital have major psychosocial factors contributing to the admission.[1]

For both children and adults, psychosocial assessment and counselling can be made a routine part of inpatient CF care to:[1,2]

- Specifically address the impact of hospitalisation on school and home life
- Continue education on coping and self-management for patients and their families
- Encourage patients to discuss psychosocial issues
- Offer psychological interventions to manage stress, pain, sleep and other health-related challenges, and to promote treatment adherence.

1. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283. 2. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023].

Use inpatient care as an opportunity to enhance psychosocial support (cont.)

While inpatient stays are a great time to build rapport with patients, hear their stories and offer psychosocial support, **it is important to respect whether the patient wants/accepts this and their right to decline.**

Psychosocial care for inpatients should be sensitive to need, medical indication, patient preference and pacing around medical status. Stressful or confronting topics may be better left for the outpatient channel.[1,2]

1. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283. 2. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023].

A systematic framework can help ensure an appropriate response to conversations about mental health

Conversations where a patient's psychosocial wellbeing is discussed can happen anytime, not only during annual mental health screening.

While it is good for regular psychosocial assessment to be embedded into CF care, **it's important that CF team members know what to do when they are confronted with signs and symptoms of mental health issues in their everyday interactions with patients**.

This is especially true for CF teams that may not have the resources to fully implement international mental health standards discussed previously.

A systematic framework can help ensure an appropriate response to conversations about mental health (cont.)

A systematic response framework that all CF team members are trained in can help with this. This framework should be underpinned by two important principles:

1. Every team works in different ways – it should be tailored to what works best for your centre.
2. Team members need to be forthcoming about sharing their concerns to the wider team – this will allow the patient to get the support they need.

A suggested response framework:
Reassure, Reinforce, Respond

With guidance from our **independent steering committee**, we have developed the following simple framework on how to respond and offer help when you suspect a mental health concern in your patient.

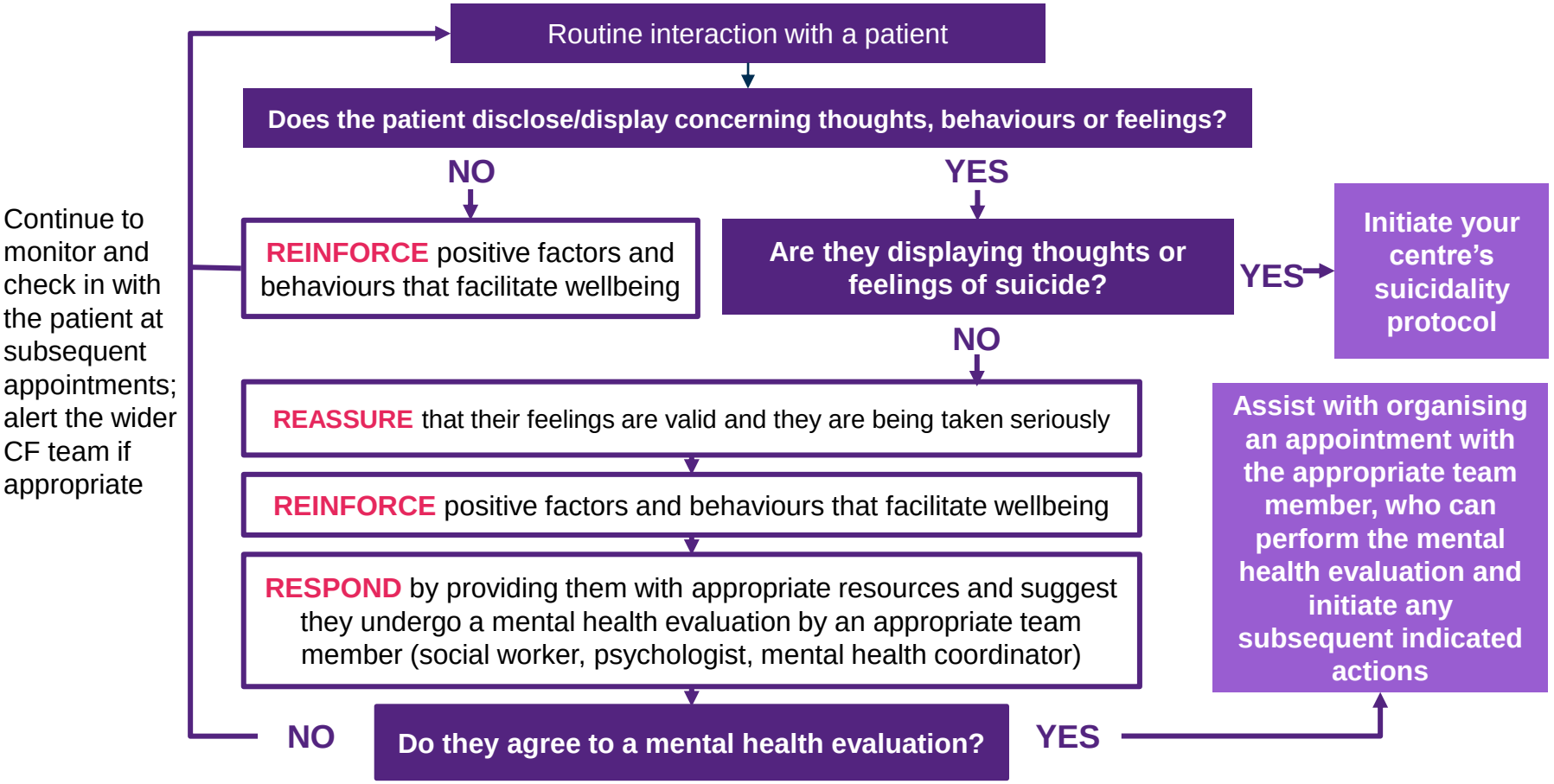
REASSURE – Normalise rather than dismiss their thoughts and feelings. Let them know you care, are taking them seriously and that how they feel is important. Practice listening without judgment or the need to solve their issues. Acknowledgement and validation are key interventions at this point.

REINFORCE – Emphasise that opening up about their feelings is the right thing to do, and highlight any other positive actions they have already taken.

RESPOND – Provide them with educational and/or support resources appropriate to their immediate needs (e.g. handout, websites, helplines), and discuss whether they would be interested in having a mental health evaluation with an appropriate member of the CF team who will be able to give them further support (e.g. social worker, psychologist, mental health coordinator). If they agree, **it is important to follow through with this consultation in a timely manner so formal screening, assessment and treatment can be initiated if needed.**

The framework can be used by any CF team member

The **Reassure, Reinforce, Respond** framework can be used by any team member during the course of clinical care, in conjunction with their CF centre's other mental health and suicidality protocols.



Be aware of the signs and symptoms that may prompt evaluation for mental health issues

DEPRESSION[1]

- Depressed mood
- Loss of interest or pleasure; reduced engagement in normal activities
- Changes in appetite or weight
- Problems with sleep
- Agitation or retardation of movements
- Fatigue
- Feelings of worthlessness and guilt
- Decreased concentration
- Suicidal feelings
- Increased irritability, anger or hostility
- Boredom
- Vague, non-specific physical complaints

ANXIETY[1]

- **Cognitive:** Unwanted thoughts, excessive negative predictions, harsh self-criticism
- **Somatic:** Fight or flight response, muscle tension, fatigue, sleep disturbance, feeling on edge
- **Behavioural:** Avoidance, clinginess (in children), reassurance seeking, disruptive behaviour
- **Emotional:** Nervousness, panic, fear or dread, irritability, hopelessness
- **Physical:** Headaches or stomach aches

1. Smith BA, et al. Pediatr Pulmonol 2016;51(S44):S71-78.

Supporting mental health & wellbeing at each stage of life

Beyond screening and treatment, effective mental health care requires the health providers' approach to be person-centred and evolve with changing psychosocial needs.

We will now revisit the five broad life stages marking key changes in psychosocial needs for people with CF and explore how the CF team might work together to recognise changing needs and coordinate care.[1-5]

1. **Perinatal**
2. **Early childhood**
3. **School age**
4. **Adolescence**
5. **Adulthood**

See next slide for some tips for a summary of psychosocial needs across life stages

1. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023]. 2. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023]. 3. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283. 4. Muther EF, et al. Pediatr Pulmonol 2018;53(S3):S86-S92. 5. Withers AL. Pulm Med 2012;2012:134132.

Life-stage psychosocial care needs[1-5]

Perinatal	Genetic counselling for parents; parental management education and skills; understanding CF; commencing lifelong care and daily therapies; family support
Early childhood	Support for normal childhood development; childcare support; acceptance of daily therapies; managing procedural anxiety; family support
School age	Commencing school, ‘fitting in’, learning self-management, family support
Adolescence	Attaining independence; negotiating puberty; relationships; sexual and reproductive health; managing risk taking behaviours; moving towards self-care and autonomy; preparing for transition; coping with disease progression; transplantation
Adulthood	Adapting to adult care team; tertiary education; employment; moving out; balancing work, life and CF; relationships; family planning; travel; coping with disease progression; transplantation; goal planning; end-of-life planning

1. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023]. 2. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023]. 3. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283. 4. Muther EF, et al. Pediatr Pulmonol 2018;53(S3):S86-S92. 5. Withers AL. Pulm Med 2012;2012:134132.

Strategies for engagement:
The perinatal stage[1-3]

This is a critical time for the mental health of parents and caregivers as they come to terms with their child's diagnosis.

Psychosocial Objectives:

Maximise parental ability to engage meaningfully and positively with their child; mitigate unhelpful parental behaviours to prevent long-term negative impacts.

See following slides for psychosocial interventions the CF team could focus on, and some practical tips and resources.

1. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283. 2. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023]. 3. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023].

Interventions at the perinatal stage should focus on supporting parents and caregivers with their new reality[1-3]

Action	Lead responsibility
Provide genetic counselling to help parents understand what the mutation means and options for future pregnancies.	Genetic counsellor
Monitor the parents' emotional response to the CF diagnosis to minimise self-blame (associated with significantly worse emotional adjustment for both the child and parents).	CF Medical Physician, CF Nurse, Social Worker, Psychologist, Genetic Counsellor , General Practitioner
Provide intensive education and parental management support to enable them to become confident with daily treatments; encourage them to seek advice whenever needed and link them to additional community and support services.	CF Medical Physician, CF Nurse, CF Physiotherapist, CF Dietitian Social Worker
Assist in implementing routines around general daily activities and CF-specific treatment tasks.	CF Nurse, Social Worker, Psychologist

1. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283. 2. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023]. 3. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023].

Perinatal stage: practical tips and useful resources

Both the **Cystic Fibrosis Foundation (CFF)** and **Cystic Fibrosis Australia (CFA)** websites contain a wealth of information about CF in general, as well as resources specific to parents and caregivers:

- **Parent and Guardian Guidance** *(CFF website)*
- **What About Siblings? Helping My Family Cope** *(CFF Fact Sheet Download)*
- **Newborns** *(CF Western Australia website)*
- **Parents and Other Carers** *(CF Western Australia website)*

Baby Steps Cystic Fibrosis is another online Australian resource developed to help parents cope with a newborn diagnosis of CF. It includes sections on **Emotions After Diagnosis** and **Getting Support**.

*__Purple text__ *are hyperlinks*

What about adolescent/adult diagnosis?

These individuals tend to have phenotypic characteristics of a ‘milder’ CF mutation or ‘atypical’ CF, including better nutritional status, pancreatic sufficiency, milder lung disease and lower rates of chronic *P. aeruginosa* infection.[1]

Reactions to a late diagnosis can include:[1]

- Relief, if coming after multiple medical investigations
- Shock, anger or denial – desire for the ‘instant cure’
- Unwillingness to attend an adult CF centre (e.g. for fear of infection, allegiance to a previous physician, reluctance to identify as a CF patient)
- The family also suffers considerable psychological distress and concerns about the future (e.g. genetic implications and life/medical insurance).

1. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023].

What about adolescent/adult diagnosis (cont.)?

To address their needs:[1]

- Appropriate counselling, support and education need to provided, with sensitive discussion to help them understand and embrace the established principles of CF care.
- A spirit of optimism and hope should be conveyed very strongly by the CF team to encourage continued clinic attendance and engagement in self-care.

When CF is suspected but not proven?[1]

Diagnostic uncertainty can sometimes occur when diagnostic testing is non-confirmatory or unavailable. Effective clinical treatment is still available for this presentation even without a formal diagnosis, with a focus on reassurance, empowerment of the patient, and regular individualised treatment regimens.

Because of the psychological impact associated with the uncertainty of their diagnosis, psychological monitoring and support for patients and family is indicated.

1. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023].

Strategies for engagement:
Early childhood[1-3]

There can be an increased burden on family dynamics in this life stage, as parents attempt to promote normal childhood development in the context of CF.

Psychosocial Objectives:

Maintain healthy family functioning; maximise favourable disease-related experiences for the child.

See following slides for psychosocial interventions the CF team could focus on, and some practical tips and resources.

1. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283. 2. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023]. 3. Muther EF, et al. Pediatr Pulmonol 2018;53(S3):S86-S92

Interventions during early childhood should focus on supporting parents and caregivers with their new reality[1-3]

Action	Lead responsibility
Provide tailored family-based support to help ensure normal developmental opportunities/ milestones.	CF Medical Physician, CF Nurse, Social Worker, General Practitioner
Offer behavioural modification strategies for improving eating behaviours and broad adherence across CF-related tasks.	Psychologist, CF dietitian
Assist with accessing childcare or respite services to ensure an appropriate level of CF-specific knowledge and skills.	Social Worker

1. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283.2. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023]. 3. Muther EF, et al. Pediatr Pulmonol 2018;53(S3):S86-S92

Early childhood: practical tips and useful resources

Many of the resources noted for the perinatal stage are useful in early childhood as well. Others include:

CFF Guides for parents with CF

- **Parent and Guardian Guidance** *(CFF website)*

Day-care related resources

- **Going to Day Care with CF Fact Sheet** *(CFWA)*
- **A Guide to Cystic Fibrosis for Early Childhood Educators** *(CFSmart Education Program)*

Nutrition related resources

- **Nutrition for Children Fact Sheet** *(CFWA)*
- **A Guide for Feeding Infants Aged 0 to 2 Years** *(CFFood Nutrition Program)*
- **Managing Meal Time Behaviour** *(Baby Steps Cystic Fibrosis)*

Resources for procedural anxiety

- **Procedural Anxiety in Children Fact Sheet** *(CFWA)*
- **Clinical Holding Fact Sheet** *(Keeping Kids in No Distress by Perth Children's Hospital)*
- **Developmental Stress & Comfort Fact Sheet** *(Keeping Kids in No Distress by Perth Children's Hospital)*

**Purple text are hyperlinks*

Strategies for engagement:
School age[1,2]

The child with CF is developing their sense of identity and competence as they start focusing more on peer relationships.

Psychosocial Objectives:

Encourage self-efficacy; develop effective strategies to navigate social situations; enhance adherence.

See following slides for psychosocial interventions the CF team could focus on, and some practical tips and resources.

1. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283. 2. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023].

Interventions at school age should focus on engaging the child to improve their self-efficacy and social adjustment[1,2]

Action	Lead responsibility
Provide tailored family-based support to help ensure good integration into the school environment and development of social skills.	CF Medical Physician, CF Nurse Social Worker, General Practitioner
Provide developmentally-appropriate education to the child to help them understand the relationship between their illness and treatment.	CF Medical Physician, CF Nurse
Offer behavioural interventions (e.g. weekly monitoring, successive approximation) to improve adherence and self-efficacy.	CF Nurse, Psychologist, Social Worker, CF Physiotherapist, CF Dietitian
Work with the child to understand what is personally motivating to promote goal-driven behaviour and self-efficacy.	All Multi-disiplinary Team members

1. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283. 2. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023].

School age: practical tips and useful resources

"It's important for children to develop areas of mastery or competence in things like school, sports, activities, strong friendships… CF is just one aspect of developing identity."

– Dr Georgiopoulos

- There are many resources available on the **CFF and CFWA websites** about navigating life with children with CF, including school, travel, hospital admissions and more.
- To support development of self-care skills during appointments, try **directing questions to the child instead of their parent** and encourage them to answer themselves.
- Help parents with developmentally-appropriate expectations for their child's behaviour, and advise them to **give their child the opportunity to learn from their mistakes** (e.g. when administering treatments themselves) as part of building self-care skills.[1]
- As part of providing age-appropriate education, **give the child opportunities to ask questions** and **be honest in answering them** in a developmentally-appropriate way.
- Give the child and/or parents **strategies on how to handle awkward social situations related to their CF.**[1]

*Purple text *are hyperlinks*

1. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283.

Strategies for engagement:
Adolescence[1-4]

The rapid, profound and complex changes that signify adolescence can increase the risk of mental health issues in teenagers with CF.

Psychosocial Objectives:

Encourage autonomy and self-management skills; build resilience and protective behaviours.

See following slides for psychosocial interventions the CF team could focus on, and some practical tips and resources.

1. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283. 2. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023]. 3. Withers AL. Pulm Med 2012;2012:134132. 4. Muther EF, et al. Pediatr Pulmonol 2018;53(S3):S86-S92

Interventions during adolescence should focus on support and education, with ongoing check-ins on their wellbeing[1-3]

Action	Lead responsibility
Screen for psychosocial risk and resilience factors using HEADSS (*see slide 69)	CF Nurse, Social Worker, Psychologist
Tailor treatments and offer behavioural interventions to improve adherence and self-efficacy.	All Multi-disciplinary Team members
Provide access to support such as health coaching and peer-led programs, plus for social needs such as tertiary education, employment, income support and housing	Social Worker
Provide sexual and reproductive health education.	CF Medical Physician General Practitioner
Prepare for transition from paediatric to adult care.	Joint responsibility of Adult and Paediatric teams

1. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283. 2. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023]. 3. Withers AL. Pulm Med 2012;2012:134132.

Engaging with adolescents requires specific skills and approaches

- **Use sensitive and reassuring communication** to build rapport and trust, and help them feel understood.[1]
- **Focus on immediate rather than future consequences**, particularly regarding risky behaviours.[1]
- **Apply a strengths-based approach** to help internalise healthy behaviours.[2]
- **Use collaborative strategies** starting with only them first, then involve their wider support network with their consent (unless there is risk identified).[1]
- **Be open, transparent and set clear boundaries about confidentiality** with them and their parents to sustain engagement and trust. Clear communication and expectation setting is important.[1]
- **Use older patients as a role model**, particularly regarding body image issues.[1]
- **Support healthy peer connections**
- **Offer a variety of ways in which they can communicate** and receive support from members of the CF team.[3]

1. Withers AL. Pulm Med 2012;2012:134132. 2. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283. 3. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023].

Screening adolescents with HEADSS[1]

From 12-13 years old, it can be useful for CF team members to start seeing adolescents on their own for at least part of the consultation.

During one-to-one discussions, the CF nurse, social worker or psychologist may perform an adolescent screen for risk and resilience factors using the HEADSS acronym.[1-4*] This helps ensure new medical problems don't overshadow mental health and wellbeing, and helps identify areas in need of further support.[1]

Home environment

Education & employment

Activities

Drug use

Sexual activity & relationships

Suicide risk/risk taking behaviours*

**Variations of this acronym exist; e.g. HEEADSSS[5]*

Couple use of HEADSS with normalisation of the questioning process and the situation being discussed, e.g. *"We ask everyone your age these questions"and "Lots of people your age experiment with alcohol – Do your friends drink? How about you?"*

Use the links in the reference section below to learn more about HEADSS and how to use it.

1. Withers AL. Pulm Med 2012:134132. 2. Goldenring, JM & Rosen DS. Contemporary Pediatrics 2004;21:64-90. 3. Government of Western Australia. HEADSS Adolescent Psychosocial Assessment [internet]. Available at https://www.cahs.health.wa.gov.au/-/media/HSPs/CAHS/Documents/Community-Health/CHM/HEADSS-adolescent-psychosocial-assessment.pdf?thn=0 [Accessed June 2023]. 4. University of Washington. HEADSS for adolescents [internet]. https://depts.washington.edu/dbpeds/Screening%20Tools/HEADSS.pdf [Accessed June 2023]. 5. NSW Health. Psychosocial assessment - adolescents. Available at https://www.health.nsw.gov.au/kidsfamilies/youth/Documents/youth-health-resource-kit/youth-health-resource-kit-sect-3-chap-2.pdf [Accessed June 2023].

Transition from paediatric to adult care can be a significant source of concern for adolescents with CF[1-3]

Transition from paediatric to adult care is a major milestone, but can be a significant source of concern for an adolescent with CF and a risk factor for mental health issues.

- Loss of familiarity can be upsetting.
- An infantilised self-image and/or facing the significance of their health care needs can create fear of independence.
- Anxiety can lead to non-compliance in attempts to delay transition.
- Transition may be interpreted as ‘rejection’ by the paediatric team, especially if sustaining daily care has been challenging.

1. Withers AL. Pulm Med 2012;2012:134132. 2. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023]. 3. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023].

Moving from paediatric to adult care

Transition is defined as "*the purposeful, planned movement of adolescents and young adults with chronic conditions from child-centred care to adult-oriented health care systems.*"[1]

Transition is a process, not an event.[2] It involves a joint judgment on the optimal time for the young person to transfer to an adult centre, and is an individual process that must not be rushed.[3] There should not be an expectation that transfer must occur by a certain age or life event.[1]

The concept of transition and transfer to adult services should be raised at diagnosis, with more active discussions beginning when they enter secondary school.[1-3] The annual review is an ideal opportunity to assess maturity and understanding of adult CF issues and to identify any barriers to transfer of care.[2] Responsibility for decision-making should be increased gradually, and by the time they transfer, **the young person should be independent enough to appropriately manage all aspects of their medical care and have a clear understanding of the structure of the adult clinic.**[1,3]

Find more transition information and resources at CF R.I.S.E, a transition program endorsed by the Cystic Fibrosis Foundation.

1. Withers AL. Pulm Med 2012;2012:134132. 2. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023]. 3. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023].

Success factors for transfer from paediatric to adult care[1-3]

- A **well-established transition program** designed to prepare young people for transfer to adult care (this includes formal guidelines/policies, and may involve a designated team member partnering with families to facilitate the process)
- Specific, written **educational materials** about the transition process and facilities/services available at the adult centre
- **Clear communication** between centres, the young person and their family
- A **tour of the adult centre** with a trusted member of the paediatric team within 12 months of planned transfer, including **orientation with the adult team**
- **1-to-1 meeting** between the patient and CF medical specialist prior to transfer
- **Joint clinic sessions** in the lead up to transfer
- Additional support and assistance from **local CF associations**
- **Follow-up by the paediatric team post-transfer** to ensure the young person is effectively engaging with adult health services.

1. Withers AL. Pulm Med 2012;2012:134132. 2. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023]. 3. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023].

Strategies for the CF team to support successful transition from paediatric to adult care [1-3]

The CF team can support successful transition by:

- **Including discussions about transition as part of the annual review**, starting from 12-15 years old.
- **Regularly revisiting the topic**, using every consultation as an opportunity to improve self-management.
- Using **gentle and sensitive exploration** to tease out fears and identify barriers.
  - Acknowledge and affirm their concerns: *"I can see how this would be scary for you".*
- Using a **strengths-based approach** to foster self-management capabilities over time
- Providing the **opportunity to contact relevant staff at both centres** to answer questions.
- **Positioning transition as a non-threatening routine** part of medical care.
- **Being guided by the individual** on the gradual attainment of self-management capabilities and the optimal time of transfer.

1. Withers AL. Pulm Med 2012;2012:134132. 2. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023]. 3. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023].

Strategies for engagement:
Adulthood[1,2]

Adulthood for those with CF involves fostering meaningful independence and nurturing mental health as they manage their disease and address life milestones - including those they may not have expected to face.

Psychosocial Objectives:

Maintain high quality of life; balance ‘normal’ life with managing their progressing disease.

See following slides for psychosocial interventions the CF team could focus on, and some practical tips and resources.

1. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023]. 2. Muther EF, et al. Pediatr Pulmonol 2018;53(S3):S86-S92

As in adolescence, interventions in adulthood should focus on support, education and wellbeing[1,2]

Action	Lead responsibility
Regularly monitor for psychosocial issues and provide ongoing education and preventive strategies.	CF specialist team, Social Worker, General practitioner
Provide support for social needs such as tertiary education, employment, income support and housing.	Social Worker
Tailor treatments and offer behavioural interventions to improve adherence and self-efficacy.	All Multi-disciplinary Team members
Assist with family planning.	CF Medical Specialist, General Practitioner, Genetic Counsellor
Manage end-stage lung disease and end-of-life care.	CF specialist team, Palliative Care

1. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023]. 2. Muther EF, et al. Pediatr Pulmonol 2018;53(S3):S86-S92

Adulthood: practical tips and useful resources

Online resources for adults with CF include:

- **CFF Website – Managing CF** is a useful webpage developed by the CFF, containing tips and resources related to navigating life with CF.
- **CFWA Website – Adults Section** contains a wealth of information about living with CF, including parenting, employment and mental health resources. Similar resources can be found on other CF Australia state-based websites.
- **CFreSHC Cystic Fibrosis Sexual and Reproductive Health Guide** serves to educate clinicians and patients about issues affecting adult females with CF.
- **CFStrong** is a newly launched website by Cystic Fibrosis Community Care, designed as a resource hub specifically for adults living with CF.

*Purple text *are hyperlinks*

Insights shared by the steering committee

"CFF is a good resource with comprehensive information. Usually my interventions are personalised from conversations with adult patients about their personal experience and wider contexts of their life."

– Mr Talbot

"HEADDSS can and should be used into the late 20s as social role transitions and neuro-cognitive developmental processes continue."

– Ms Holland

"Some US CF centres are providing copies of Facing Cystic Fibrosis to their adult patients, and also to families with a new CF diagnosis. It has lots of mental health information and it's free with Amazon Kindle."

– Dr Georgiopoulos

Lung transplantation: psychosocial support is needed for both the patient and their family[1]

Early discussions can help normalise transplantation in the context of managing end-stage lung disease.

Patients and their families need sufficient education to make decisions around transplantation, including written information covering:

- Symptoms and feelings
- Additional support and services
- Personal stories from other people with CF
- Options vs benefits vs risks
- Preparation for decision making
- Goal planning

Patients and carers need support after 'false alarms' – when the promise of a transplant doesn't come through.

Carers need to be given information about potential health crises and what to do and who to contact.

1. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023].

Specific support is indicated when initiating lung transplantation[1]

- Additional supportive care provided by **Palliative care services** can be beneficial even at an early stage.
- A **Social worker** can assist with dealing with the progressive loss of independence, changing financial needs and Centrelink entitlements, and establishing ongoing support mechanisms for the patient and their family.
- The **Transplant coordinator** liaises with the transplant referral centre and helps to manage psychosocial support, including regular assessment for anxiety/depression and referral as appropriate.

1. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023].

Attending to spiritual and psychological needs is essential to end-of-life care[1,2]

Lowered mood and anxiety are commonly experienced by patients as their health declines significantly and/or they attend their last admission.[1] The uncertainty of their health can understandably lead to feelings of hopelessness and helplessness.[1]

Monitoring of psychological and spiritual wellbeing of both patients and caregivers at end-of-life is indicated with appropriate interventions and specialist support as needed.[1]

Several valid screening tools are available for assessing psychosocial needs in the context of palliative care, and consultation with palliative care services can provide valuable expertise.[1,2]

1. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023]. 2. Kavalieratos D, et al. J Palliat Med 2021;24(1):18-30.

Palliative care delivery in CF[1]

Palliative care is focused on relieving suffering and improving quality of life for individuals living with serious illness, and for their caregivers. It should be delivered throughout the entire course of illness and modulated to the patient's needs.

While CF team members are well suited to provide continuous first-line monitoring and basic palliative care, both CF and transplant care teams can consult **specialist palliative care clinicians** to address care needs beyond their expertise, including:

- **Complex symptoms or advanced illness**
- **Existential or spiritual distress**
- **Family conflict regarding goals of care**
- **Concerns during the transplant evaluation process.**

Early integration of palliative care teams is important for ensuring rapport and comfort when a patient eventually transitions to end of life care.

1. Kavalieratos D, et al. J Palliat Med 2021;24(1):18-30.

Annual screening for psychosocial palliative care needs is recommended[1]

The Cystic Fibrosis Foundation Consensus Guidelines on Palliative Care Delivery recommend screening for palliative care needs annually, and at times of disease progression.

- Some of the recommended screening tools cover psychosocial domains and can be used in conjunction with PHQ-9 and GAD-7
- **Integrated Palliative Care Outcome Scale (IPOS**) – captures needs regarding pain, communication, spiritual and financial concerns.
- **Spiritual Needs Assessment for Patients (SNAP)** – assesses for unmet psychosocial, spiritual/existential and religious needs; may be offered based on IPOS responses or if concerns about spiritual distress arise.
- **CFQ-R Emotional Functioning subscale** – can help with eliciting psychological symptoms in children ages 6-11 who are too young to complete PHQ-9 and GAD-7.
- **Brief Assessment Scale for Caregivers (BASC)** – designed to identify caregiver concerns; includes items related to family functioning.

1. Kavalieratos D, et al. J Palliat Med 2021;24(1):18-30.

The CF team has an important role to play after a patient with CF dies[1-3]

Following death of a patient, members of CF team should have the opportunity to meet with the family and provide ongoing bereavement support.[1-3]

- Practical advice and assistance regarding funeral arrangements can be provided by the social worker.
- Loss and grief support can be provided by the broader CF team and and/or by referral to appropriate agencies outside the CF centre.
- Consider screening with the Prolonged Grief Questionnaire PG-13 to assess for persistent complex bereavement disorder.

1. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023]. 2. Kavalieratos D, et al. J Palliat Med 2021;24(1):18-30. 3. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023].

Mental health in CF includes the mental health of the CF team too

Chronic illness can also be emotionally exhausting for health providers, as they are exposed to the cumulative suffering and losses experienced by patients and their families.[1]

Members of the CF team may face:[1]

- Feelings of anxiety and professional inadequacy
- Distress when patients they have known well approach the terminal phase
- Guilt about side effects of certain treatments
- Conflicts about proposed treatments
- Patients who are angry, demanding or resentful
- Complex ethical issues around prolonging end of life or allocating resources
- Stress about providing emotional support to patients, especially for those who haven't been trained in communication skills.

1. Turner J, Kelly B. West J Med 2000;172(2):124-128.

Mental health in CF includes the mental health of the CF team too (cont.)

Health providers cannot provide excellent clinical care if they ignore their own physical, emotional and spiritual needs.[1]

All members of the CF team should be encouraged to:

- Share the burden of care with the wider team and be open about discussing difficult clinical problems[1]
- Nurture relationships and activities outside of work to provide balance[1]
- Access local services and facilities for support, particularly following the death of a patient.[2]
  - Group mindfulness-based cognitive therapy, delivered onsite during work hours, has been shown to be feasible and effective in decreasing stress for multidisciplinary CF team members.[3]

Some thoughtful general resources are also available at the Pandemic Kindness Movement website, which was developed in recognition of the need for health professionals to strengthen their self-care during the COVID-19 pandemic.

1. Turner J, Kelly B. West J Med 2000;172(2):124-128. 2. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023]. 3. Hente E, et al. J Pediatr 2020;224:87-93.e1.

In summary

- The Mental Health Guidelines in CF aim to ensure psychosocial wellbeing is routinely evaluated and that patients/parents in need of help are identified and access timely intervention.[1,2]
- Treatment plans should be tailored to the individual with interventions dependent on symptom severity – psychotherapy is always first-line, and close monitoring of pharmacotherapy if required.[1]
- All members of the multidisciplinary CF care team play a role in embedding prevention and screening for mental health within overall CF care[3-5] – the Reassure, Reinforce, Response framework helps ensure patients at risk are always met with an appropriate response.
- The CF care team must adopt different engagement strategies to meet the evolving psychosocial needs of people with CF across life stages.[4-8]

1. Quittner AL, et al. Thorax 2016;71(1):26-34. 2. Havermans T, Staab D. Thorax 2016;71(1):1-2. 3. Reno K, et al. Mental Health in Cystic Fibrosis Quality Improvement Change Package. Aug 2020. 4. Agency for Clinical Innovation. Cystic Fibrosis Model of Care. 2016. Available at: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0003/338124/ACI16125_Cystic_Fibrosis_MoC_F_web.pdf[Accessed June 2023]. 5. Cystic Fibrosis Australia. Cystic Fibrosis Standards of Care. 2008. Available at: https://www.cysticfibrosis.org.au/what-we-do/clinical-improvement [Accessed June 2023]. 6. Ernst MM, et al. Child Adolesc Psychiatr Clin N Am 2010;19(2):263-283. 7. Muther EF, et al. Pediatr Pulmonol 2018;53(S3):S86-S92. 8. Withers AL. Pulm Med 2012;2012:134132.