

The Importance of Mental Health when Living with a Chronic Disease

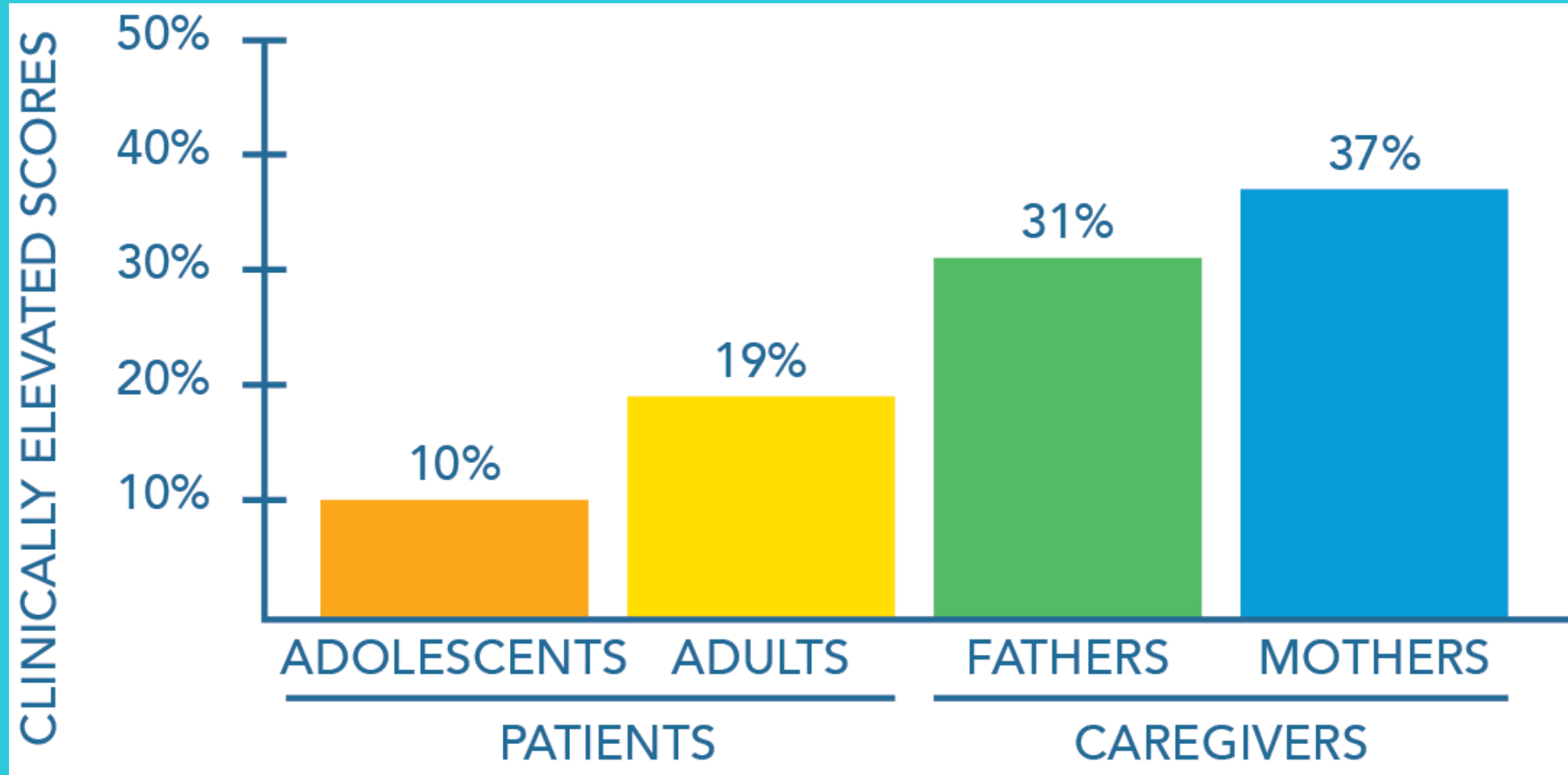
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TIDES Study

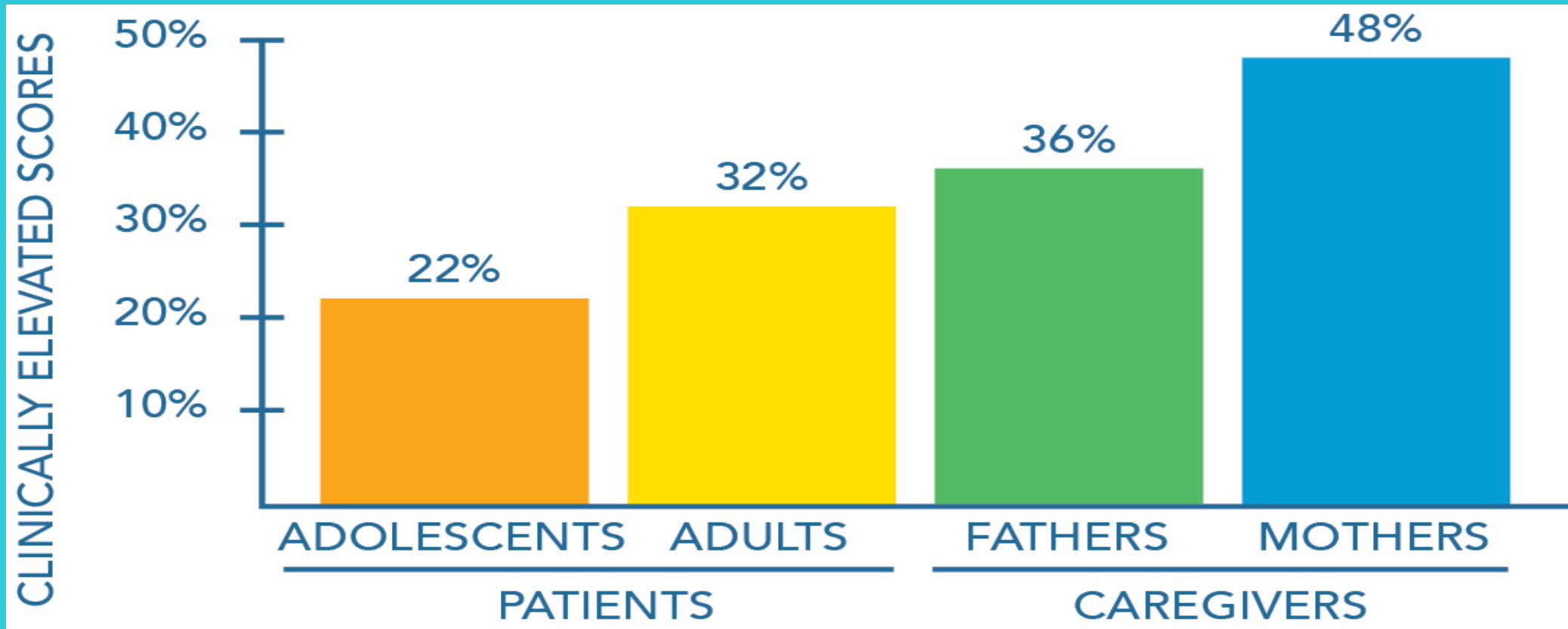
Symptoms of depression and anxiety were elevated in both patients with CF and parents across several European countries and the US.

Prevalence of Depression



Prevalence of Anxiety

2-3 TIMES COMMUNITY PREVALENCE



Why more frequently in CF?

Illness uncertainty

Medical Trauma

Pill swallowing

Needle phobia

Fear of poor performance on PFT

Hospitalization

New Colonization

Exacerbations

Stress

Loss

School/Work problems

Social Isolation

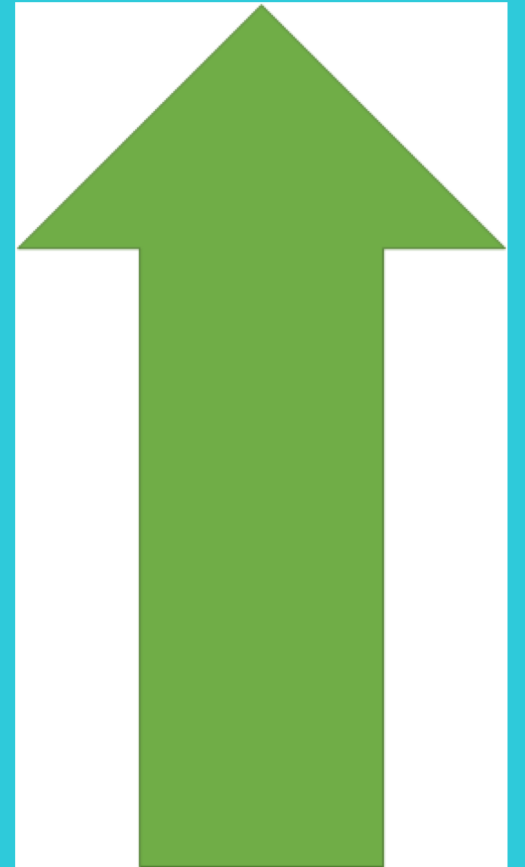
Self-esteem/Bullying

Pain

Burden of care

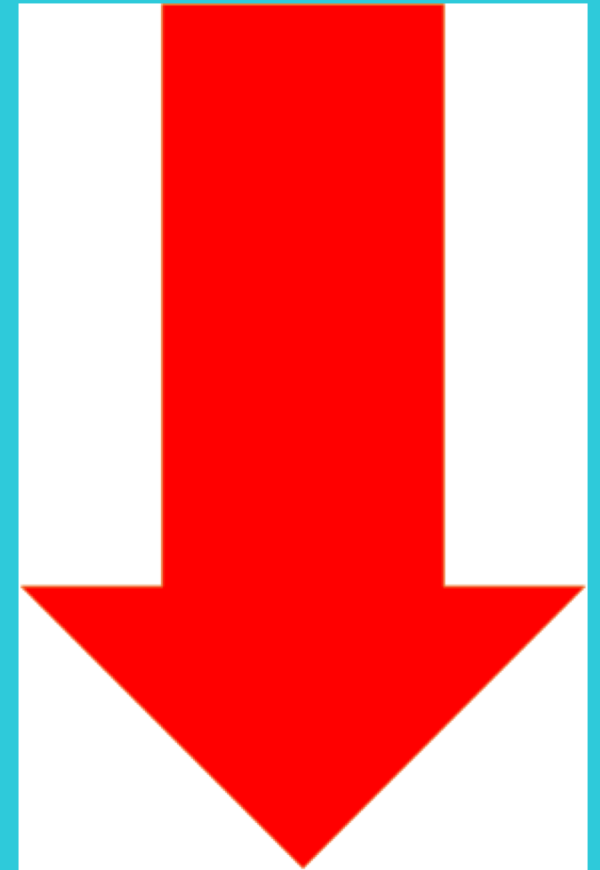
Impact on Health outcomes

- Experience more hospitalizations
- Often have higher healthcare costs
- Risky behaviors (smoking, drinking, etc.)



Impact on Health outcomes

- Less adherent with medical regimens
- Tend to have worse lung function
- Have a lower body mass index (BMI)
- Poor appointment attendance
- Poor quality of life
- Poor family functioning





Symptoms of Anxiety

- Excessive worry
- Feeling restless or “on edge”
- Difficulty concentrating
- Irritability
- Loss of energy
- Muscle tension
- Difficulty sleeping
- Reassurance seeking

GAD-7

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

Total Score — = Add Columns — + — + —

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

Not difficult
at all

☐

Somewhat
difficult

☐

Very
difficult

☐

Extremely
difficult

☐

Symptoms of Depression

- Depressed mood
- Lack of pleasure
- Appetite change
- Sleep change
- Fatigue
- Feelings of worthlessness or guilt
- Poor concentration
- Thoughts of death or self harm



PATIENT HEALTH QUESTIONNAIRE -9

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
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING

0 + + +
 =Total Score:

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

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Depressive Symptoms: What parents should look for



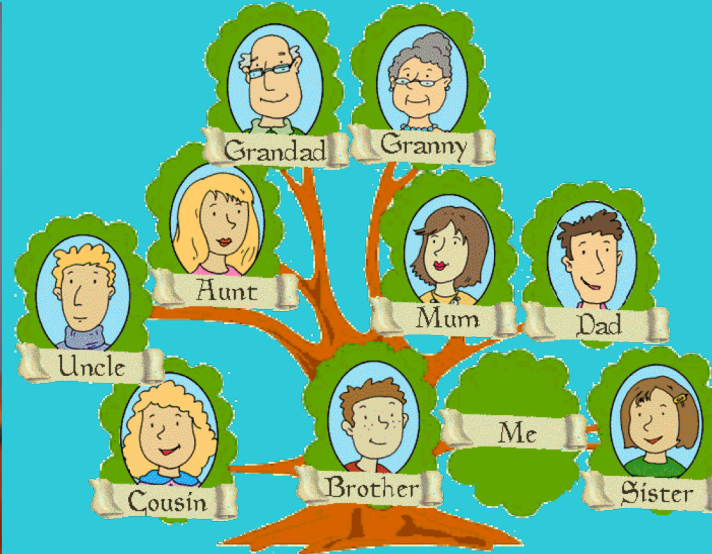
Suicidal Ideation (SI)



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Risk Factors



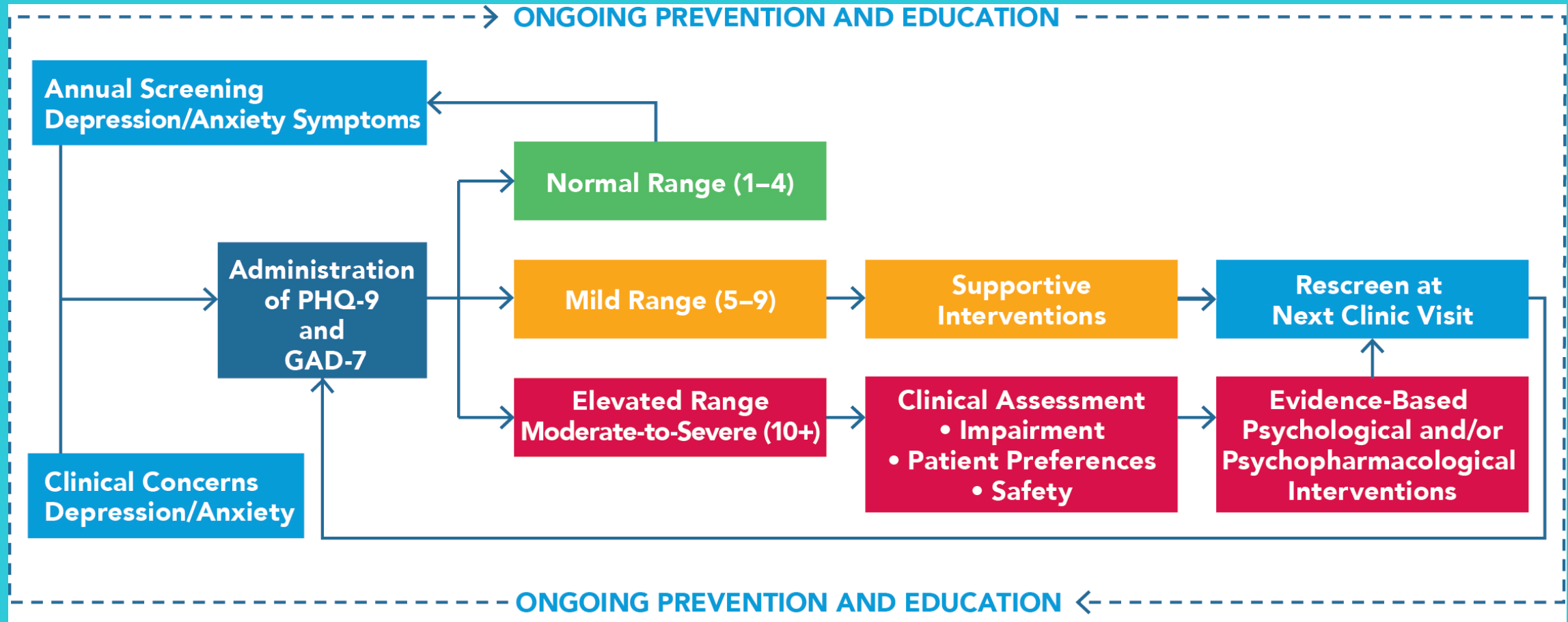


Mental Health Coordinator Role

- Screening
- Education
- Intervention
- Referral



Assessing and referring for treatment



Trikafta

- Increased symptoms of
 - Depression
 - Anxiety
 - Irritability
 - Sleep disturbance
 - Mental slowness
 - Aggression
 - Abnormal temper tantrums



For those eligible for Trikafta

- Fear
- Anxiety
- Guilt
- Stress
- Financial strain
- Disappointment
- Anger
- Difficult adjustments



For those not eligible for Trikafta

- Feeling “left behind”, sadness, worry, anger
- Hope and urgency for a medication that works for them
- Range of emotions or opinions towards those who do benefit from Trikafta



Support for patients

- Screening in clinic
- Individual counseling
- Medication management
 - CF MD, PCP, Psychiatrist
- CFRI
 - Six individual therapy sessions per year up to \$120/visit
 - Support groups for
 - Adults with CF, Teens, Bereavement, Post Transplant, Spanish Speaking

Support for Patients cont'd

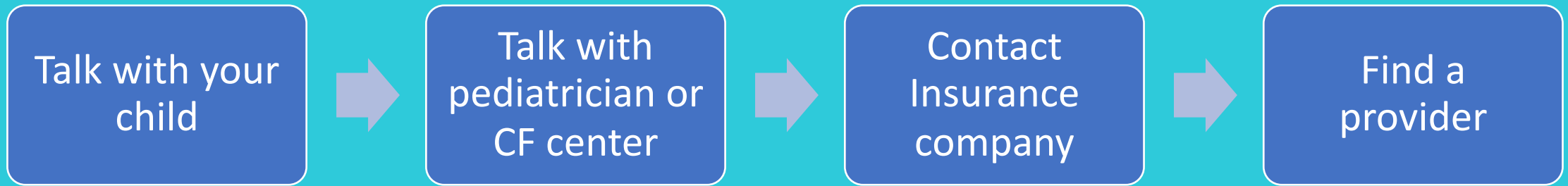
- CF Peer Connect
 - Ages 16 and up (18 & up to be a mentor)
- Attain Health
 - Variety of virtual groups for adults and teens
- Make a Wish
 - Ages 2.5- 18 (eligibility changing 2024)

Helpful Interventions

- Normalize
- Validate
- Promote Coping
- Emphasize and teach coping strategies
- Mood and Anxiety
- Establish routines and build behavioral skills
- Problem-solve difficulties with self-care
 - Airway clearance
 - Medications/enzymes
 - Nutrition
 - Exercise
 - Sleep hygiene
 - Diabetes
- Address body image
- Build social support
- Explore life aspirations and values
- Collaborate with medical team



Finding a therapist



Questions to ask BEFORE the 1st visit

What experience do you have working with children/adolescents?

What experience do you have working with CF or chronic medical conditions?

What are your credentials? How long have you been doing this work?

What kinds of treatment do you use to help people with their condition and concerns? Have they been proven effective for dealing with my child's condition and concerns?

What is your appointment availability? Do you have after work or early morning appointments?

What are your fees? Is there a sliding scale fee policy?

What types of insurance do you accept? Will you accept direct billing to or payment from my insurance company? Do you accept Medicare/Medicaid?

Questions to ask DURING 1st visit

Will you coordinate my child's care with other providers? If yes, how so?

What does successful therapy look like to you?

How often will you meet with my child and/or me? How long will each session be?

What will be the goals of treatment?

What communication methods are preferred? Are emails or phone calls between appointments acceptable?

What Therapists Need to Know

CF AND MENTAL HEALTH: WHAT HEALTH PROVIDERS NEED TO KNOW

A GUIDE FOR
CLINICIANS

WHAT IS CYSTIC FIBROSIS FROM A BIOLOGICAL STANDPOINT?

Cystic fibrosis (CF) is caused by mutations in the cystic fibrosis transmembrane conductance regulator (CFTR) gene, leading sticky mucus to build up in the lungs and cause chronic inflammation, infection, and damage. There are significant differences from one person to the next in how CF impacts the body. Several medications (CFTR modulators) targeting these gene mutations are available, but they do not cure CF or eliminate all symptoms. Approximately 10 percent of people with CF are still waiting for a medication that is matched for their genes. As the disease progresses, individuals face increasing symptoms. Those with end-stage lung disease may pursue lung transplantation to extend their life. Comprehensive information about CF can be found at cff.org.

BODY SYSTEMS THAT MAY BE AFFECTED

- Respiratory system
 - Lungs and sinuses
- Gastrointestinal (GI) system
 - Poor digestion
 - Constipation and obstruction
 - Liver disease
- Endocrine system
 - CF-related diabetes
- Reproductive system
 - 98% of males are infertile
 - Most females can become pregnant

THE BURDEN OF CF DAILY CARE

In addition to typical life stressors, people living with CF manage distinct challenges. Staying healthy involves a complex treatment regimen that can take hours per day and be difficult to sustain. Airway clearance therapy is needed to clear mucus from the lungs. Along with other medications, most people with CF take oral enzymes with meals and snacks to aid digestion and decrease GI discomfort. Many individuals need double the calories required by someone without CF to achieve optimal weight and growth, which might require supplemental tube feedings. During acute illnesses (e.g., pulmonary exacerbations), individuals may stay in the hospital for intravenous antibiotics and miss important activities like school and work. Acute and chronic pain can also impact important daily activities.

WHAT IS CF FROM A PSYCHOSOCIAL STANDPOINT?

The diagnosis of CF is most often made in infancy, after newborn screening results are confirmed by a positive sweat test. This can be a stressful time, as parents plan for their child's complex medical needs. Adjusting can also be difficult for those diagnosed later in life, and as people with CF and their loved ones navigate new challenges during childhood, adolescence, and adulthood. Individuals with CF and their caregivers are at elevated risk for symptoms of depression and anxiety. CF can be a uniquely isolating disease. Symptoms are often invisible to others. In addition, people with CF must avoid close physical contact with each other to avoid cross-infection.

SOME STRESSORS ASSOCIATED WITH CF DIAGNOSIS AND DISEASE

- (Unexpected) diagnosis of lifelong genetic condition
- Keeping up with burdensome daily care regimen
- Social isolation, feeling "different," and disclosure of illness
- Impact on body image and eating behaviors
- Disruption of personal life goals, activities, and relationships
- Financial stress
- Complexity of health care and insurance systems
- Coping with difficult physical symptoms, medical procedures, and pain
- Existential concerns including the uncertainty of illness course and survival

THE KEY ROLE OF THE MENTAL HEALTH PROVIDER

Mental health providers can deliver empirically supported treatments to manage conditions such as depression, anxiety, ADHD, trauma, substance misuse, chronic pain, and distress from medical procedures. There are many ways mental health providers can support people living with CF and their caregivers to cope with stressors and to pursue their life goals.

HOW TO SUPPORT PEOPLE LIVING WITH CF AND THEIR CAREGIVERS



PROMOTE lifelong wellness through healthy sleep, physical activity, nutrition, and understanding mind-body connections.



ENHANCE motivation and skills to sustain complex self-care, with increasing transfer of treatment responsibility as children mature.



ADDRESS the impact of CF throughout the lifespan, especially at developmental milestones such as toilet training, peer relationships and school, transition to college/workplace, planning a family, and disease progression.



BUILD effective communication and trusting relationships within the family, with peers, and with the health care team.

TO LEARN MORE

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

Content adapted with permission from:

Mueller AE, Georgiopoulos AM, Smith BA, Quittner AL, Roach CM, Reno KL, Lomas P, Kvam CM, Filigno SS. (2020). Introduction to Cystic Fibrosis for Mental Health Care Coordinators and Providers: Collaborating to Promote Wellness. Health and Social Work.

Comprehensive mental health guidelines for individuals 12+ years with cystic fibrosis can be found:

Quittner AL, et al. (2014). Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: Results of the international depression epidemiological study across nine countries. *Thorax*, 69(12), 1090-1097.





Resistance

- Utilize CF social worker or MHC
- School resources
- Share own experience
- Encourage coping skills
- Connect with CF community
- Do therapy together or as a family
- Make a deal
- Give it a try
- Open communication
- Be patient and don't give up

Support for Parents/Caregivers

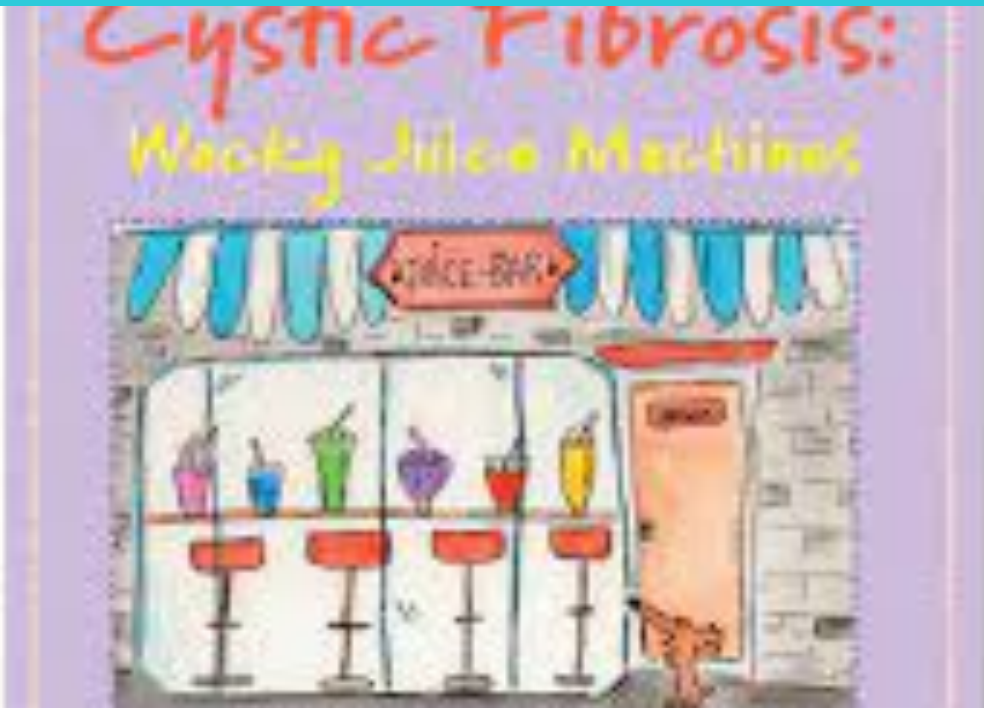
- Screening/self screening offered in some CF clinics
- Self Care
- Engage in individual or family therapy
 - Utilize EAP, CFRI, Psychologytoday.com, Primary Care
- CF Peer Connect
- CFRI CF Caregiver Support Group
- Attain Health- peer support group for caregivers



Siblings



- Involve in treatments
- Bring to an appointment
- Read them “Wacky Juice Machines”
- Open communication about their feelings and questions
- Provide honest information
- Time with each child individually
- Have fun as a family
 - A Kid Again
- Maintain Rules
- Therapy or support group



Who Are The Helpers?

- Child Life Specialists
- Licensed Clinical Social Workers
- Licensed Professional Counselors
- School Counselors
- Clinical Psychologists
- Child and Adolescent Psychiatrists





Questions?

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