



CF Quality of Life Program

A collaboration of
STANFORD FAMILY MEDICINE
and
Community Center for Health & Wellness



Informational Packet Overview

The Cystic Fibrosis Quality of Life Program: A Living Legacy of Peter Judge (CFQoLP) is part of the Peter Judge CF Program at the Stanford Center for Education and Research in Family & Community Medicine (CERFCM) which was started with a small private grant and donations from Peter's family and friends after he died of cystic fibrosis. The CFQoLP is currently a collaboration between CERFCM and the Institute of Transpersonal Psychology (ITP) to train therapists and psychologists to provide specialized support and counseling to the Cystic Fibrosis Community. ITP's counseling center is the Community Center for Health and Wellness (CCHW).

The contents of information represent this unique and important collaborative effort. The aim of these informative pages is to further educate and encourage you and/or others you may know to the importance of emotional wellbeing and let you know of resources available to address these often crucial aspects in managing CF. This information has been sent out to CF treatment centers throughout California to supplement the physical treatments provided for CF. Consider the CF Quality of Life Program at Stanford Family Medicine and CCHW a strategic ally toward your health and wellness.

The following topics:

- [Cystic Fibrosis: Helping Families Cope](#)
- [Peer Support, Loneliness, and Personal Autonomy: Issues for Adolescents with CF](#)
- [Cystic Fibrosis: Brief Guide to Depression](#)
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We thank Cystic Fibrosis Research, Inc. (CFRI) and the Stanford CF Units for their advice and encouragement.

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Cystic Fibrosis: Helping Families Cope

We know that families are the primary caretakers for patients with cystic fibrosis. They are the ones that help most with the daily physical demands of treatment. They are also the primary sources of emotional and social support. Caring for a loved one with CF can be extremely stressful. How well each family adapts can influence the course of the illness, as well as the relationship between the patient and other family members. Less stress within the family system has been shown to create better patient outcomes.

Some important things to remember are:

- Chronic illness, regardless of severity, presents emotional health risks to the entire family. Some of the stresses of care giving include chronic worry about expenses, the loss of privacy and spontaneity, concerns about the future, and communications with healthcare providers. Depression is common in addition to grief, anxiety, isolation, and maladaptive behaviors.
- Individual family members may have different experiences or challenges when coping with a family member's illness. It is important to learn how to respect each other's experiences.
- Siblings who do not suffer from the disease may get less time or attention from parents. Sometimes behavioral problems will arise as these siblings attempt to receive more attention. These are "normal problems" given what families with CF face.
- Chronic illness in a family can shift relationships within a family as well as with their community. Families often need to maintain intensely personal relationships with many "outsiders", including doctors, teachers, nurses, and hospital staff. This is expected with CF.
- Families coping with illness are usually very capable and resilient. It is important to appreciate each other's competencies and create a family identity that does not involve CF, but is greater than the disease.
- Strive for balanced coping. Manage cystic fibrosis within the context of total family needs, protect family integration, nurture self-esteem, and use professional support, and try not to sacrifice the needs of individual family members, including your primary needs.
- Rather than viewing a family as being affected by CF, realize that family members can positively impact CF's course, process, and outcome. The family system is a tool against CF.

If you can find support in your community do not hesitate to use it. If what you need is not available, the professional staff at the Community Center for Health & Wellness knows the importance of how a healthy family as a whole can be utilized in confronting CF. Our staff is trained in family therapy and knows that CF affects the whole family. This is why we not only offer help to individuals with CF, we offer support to the entire family. We know that each family faces CF differently and that all family members cope differently. Supporting the family takes stressors off everyone and can allow for healthier relationships and coping skills for the member with CF. We can provide consultation by phone and by Skype for those who can not come to our Community Center for Health & Wellness.

Peer Support, Loneliness, and Personal Autonomy: Issues for Adolescents with CF

Adolescence is a challenging time for anyone. As we move toward adulthood, we develop a stronger sense of ourselves as individuals and begin to form important peer connections. For adolescents with cystic fibrosis (CF), there are a number of special issues that can arise. These issues have to do with finding their place in a community of peers, dealing with the potential for loneliness and isolation, and developing their independence in a way that serves their psychological and physical health. The following are some important points:

- Most adolescents with CF can participate in school and in after-school activities like sports, helping them to stay connected to their peer community. Many adolescents with CF find it helpful to be open with others, and especially with close friends, about cystic fibrosis as a health condition and how it affects their lives.
- Adolescence is a time when we feel a strong need to be liked and accepted by our peers. Some adolescents with CF may feel “different” from others, leading to a sense of loneliness and isolation. This problem is especially difficult in today’s environment of real concern about cross-contamination between CF patients.
- Loneliness is not just an unpleasant emotion—it affects adolescents with CF in every way including mind, body, and spirit. It can lead to a higher rate of physical symptoms and result in adolescents having a less positive outlook on their own potential for good health. Staying connected with others who have CF, perhaps via the internet, and maintaining a strong social support system is an important part of whole-person health care.
- Adolescence is a time of testing limits and developing a sense of identity apart from parents and family members. In adolescents with CF, this can sometimes appear as resistance to doing their treatments—a type of rebellion that can have serious negative consequences for their physical health.
- A positive way for adolescents with CF to develop a sense of autonomy is to begin to take more responsibility for their health, including communicating directly with their health care providers and ensuring that they are keeping up with CF treatments. In this way they gain greater independence while improving their health at the same time!

Looking for support in your community is important and helpful. However, if community support is not available, the Community Center for Health and Wellness (CCHW) can offer another and equally important type of support in providing counseling that addresses mind, body and spirit for adolescents with CF, as well as for their families and caregivers. Such counseling helps adolescents get and stay connected to their community while also assisting adolescents in the development of a healthy sense of independence as they look forward to participating in school, career, and their own adult lives.

Cystic Fibrosis: Brief Guide to Depression

Given the stressors associated with Cystic Fibrosis, patients often experience depression and anxiety. Depression and anxiety are serious illnesses that can impact a person’s mind, body, and spiritual well-being, as well as their capacity for daily functioning. The effects of depression and anxiety may also extend beyond the person and influence the well-being of those close to the person. Fortunately, depression and anxiety are treatable conditions with many people successfully achieving recovery. Treatment may involve medication, psychotherapy, or a combination of both. Popular therapies for depression and anxiety include cognitive behavior therapy and other behaviorally-based therapies specific to the person’s symptoms. Professional treatment is required for depression and anxiety disorders.

Depression Symptom Checklist – take this list to your doctor

Symptom	√	Symptom	√
Persistent sad, anxious or "empty" feelings		Loss of interest in activities or hobbies once pleasurable including sex	
Feelings of hopelessness and/or pessimism		Fatigue and decreased energy	
Feelings of guilt		Difficulty concentrating remembering details and making decisions	
Worthlessness and/or helplessness		Insomnia	
Irritability		Early–morning wakefulness, or excessive sleeping	
Restlessness		Overeating, or appetite loss	
Thoughts of suicide, suicide attempts		Persistent aches or pains	
Headaches, cramping, or digestive problems separate from CF that do not ease even with treatment			

Source: National Institute of Mental Health (NIMH, 2008).

In addition to professional treatment, it is advisable for individuals to get involved in their recovery with activities like: (a) engaging in mild physical activity or exercise; (b) going out to a movie, a ballgame, or another event or activity that you once enjoyed; (c) participating in religious, social or other activities; and (d) spending time with other people, confiding in a trusted friend or relative. Start small and gradually increase the time or level of activity. Remember that positive thinking will replace negative thoughts as your depression responds to treatment.

Having a professionally trained person to talk with about your feelings and concerns and getting helpful advice can bring the joy back into life for individuals and families coping with the challenges of CF. Several types of “talk therapy” have been shown to be successful. If you can not find support in your local community, depression is commonly and successfully treated at the Community Center for Health and Wellness (CCHW).

Cystic Fibrosis: Brief Guide to Anxiety

Everyone experiences anxiety as it is a normal reaction to life stressors. Patients with CF, families, and care givers normally experience stressors and concerns that can easily elevate to the level of disruptive anxiety. In general, an adaptive amount of anxiety actually provides one with the motivation to complete important activities such as work or school projects. However, a person or family dealing with CF may experience an amount of anxiety that is disproportionate to “normal” life stressors and interferes with their everyday functioning. In this case, the person may be suffering from an anxiety disorder. Help is available.

Anxiety Symptom Checklist – take this list to your doctor

Symptom	✓
Constantly tense, worried, or on edge	
Anxiety interferes with work, school, or family responsibilities	
Experience irrational fears that will not go away	
Have the belief that something bad will happen unless certain things are completed in a specific way	
Anxiety provoking everyday situations or activities are avoided	
Heart-racing panic is suddenly & unexpectedly experienced	

In general, anxiety disorders are treated with medication, specific types of psychotherapy, or both. Treatment choices depend on the problem and the person’s preference. Before treatment begins, a doctor must conduct a careful diagnostic evaluation to determine whether a person’s symptoms are caused by an anxiety disorder or a physical problem. It is critical that persons who received previous treatment for anxiety advise their physician of this in order to ensure that no drug interactions occur and ineffective treatments are not repeated. If an anxiety disorder is diagnosed, the type of disorder or the combination of disorders that are present must be identified, as well as any coexisting conditions, such as depression or substance abuse. Sometimes alcoholism, depression, or other coexisting conditions have such a strong effect on the individual that treating the anxiety disorder must wait until the coexisting conditions are brought under control.

Why suffer in silence with anxiety when effective help is available? Life presents so many challenges to all of us, coping with CF adds to those stressors. There are many effective ways to overcome anxiety but it starts first by reaching out confidentially for professional support. If you can not find appropriate help and support in your community, patients with CF are successfully treated at the Community Center for Health and Wellness (CCHW) for anxiety. CCHW trained staff is aware of the many stressors facing those coping with CF.

Exercise and Managing CF

At one time, exercise was considered dangerous for CF patients because some patients had difficulty managing their breathing with their limited lung capacity. Over time, this view of physical exercise and particularly those exercises that involve “cardio” has changed dramatically.

Today, exercise is considered a valuable tool for CF patients because it is a natural form of chest physiotherapy. Running, jogging, aerobics, bicycling, swimming, and tennis are all examples of exercise that can be of benefit to a person with CF. The movements involved in exercise, creates a natural vibration that helps loosen mucus in the lungs so it can be coughed up more easily. Exercise stimulates coughing, helping to remove mucus from the lungs. Finally, exercise improves cardiovascular health by strengthening the heart and improving blood pressure.

From a psychological perspective, exercise can improve mental attitude and impart a sense of well-being and “normalcy”. Becoming part of a team when involved with sporting activities fights isolation. By participating in some physical activity, some children may feel that CF no longer makes them stand out from the rest of their friends. Exercise has also been shown to help alleviate depressive symptoms in many patients too.

Please make sure to discuss all exercise activities with your doctor before beginning a new regimen. It is especially important that a person's health care team recommend an appropriate exercise program. The program should take into account the patient's interests and limitations. It is also important to start an exercise program slowly and work up to a comfortable level.

When beginning a new exercise program, remember to stay properly hydrated since you will be losing additional water and salt through perspiration. Patients will also be losing extra calories from exercise and may need to make up for the loss.

At the Community Center for Health & Wellness, we know that physical exercise underlies a holistic perspective on wellness. We work with persons with CF and their care givers to customize an exercise schedule that is just right for the right person. It is exciting how this view of whole person or holistic health we promote is supported by much current research highlighting the clear benefit of exercise for common mental health ailments such as depression.

Check with your local physician about what is right for you and seek resources in your community. If you want specific exercise coaching for CF, a possible resource is Julie Desch, MD. Julie has CF herself, and has coached many people with CF to improve several areas of wellness, including adding moderate exercise to their health regimen. She can be reached by email at Julie@newdaywell.org.

Cystic Fibrosis: Spirituality, Religion and Well Being

The ability to find meaning, refuge, and comfort through spirituality and religion, can be very helpful when dealing with a chronic disease such as Cystic Fibrosis. Many patients, family members, and caregivers, rely on spiritual or religious beliefs and practices to help them live with chronic diseases. Studies indicate that spiritual and religious beliefs and practices help people to improve their quality of life through finding greater meaning, decreasing anxiety, depression, anger and discomfort, decreasing the sense of isolation, and can help patients and others adjust to the effects of chronic disease and its treatment.

- Spirituality can be generally described as an awareness of something beyond the material or greater than the individual self.
- Spirituality can be expressed through religion, although there are many other paths of spiritual pursuit and expression.
- Spiritual practices such as meditation, prayer, or silence have been shown to improve psychological and physical health.
- Other practices such as silent observation, listening, or gratitude can become part of an open-ended spirituality that can infuse everyday life with greater wellbeing, depth, and meaning.
- Some people express spirituality by spending time with nature, doing creative work, or by serving others.
- Spiritual and religious communities, including churches, temples, mosques, meditation centers, etc., may be a valuable resource that provides a place to get comfort and community support.
- Through spirituality people sometimes find meaning in their suffering and develop increased compassion for their own and other people's pain.
- Serious illnesses like Cystic Fibrosis may cause patients and family caregivers to have doubts about their spiritual beliefs or religious values. This can cause much personal distress. Seeking spiritual counseling from a skilled spiritual guide, a trained pastoral counselor, or a minister, priest, or rabbi, etc., may provide spiritual reconciliation and comfort from distress.

The Community Center for Health & Wellness (CCHW) is rooted in Transpersonal Psychology, widely recognized as the modern bridge between psychology and spirituality. We acknowledge the role and healing potential of spirit in the lives of our CF patients and their families. We are very careful in not promoting any one specific religion but are clinically trained in supporting individuals with CF and their families in any spiritual or religious practice they have or wish to develop.