

Outline for PT Annual Exam:

Population	Why
<p>Children diagnosed with cystic fibrosis</p>	<p>Cystic fibrosis is a chronic condition characterized by hypersecretion of various body tissues, including the lungs.¹ In addition, secretions are typically thicker and prone to infectious organisms.¹ In the lungs, this manifests as airway obstruction and inflammation as well as mucous plugging.¹ The chronic inflammation and infection experienced by children with cystic fibrosis often results in permanent lung damage and the eventual need for a lung transplant.¹ This patient population often requires direct medical intervention during acute exacerbations.² However, during chronic stages, there is a significant amount of required maintenance to be performed. Physical therapy intervention has been found to be effective during acute exacerbations as well as chronic stages of cystic fibrosis in pediatric patients.³ During the chronic, or maintenance stage of cystic fibrosis, patients may benefit from physical therapy interventions such as postural drainage and percussion, forced expiratory technique, and exercise.³ A combination of these interventions serves to reduce secretions, improve lung function, and maintain cardiovascular health.³ Exercise specifically improves aerobic fitness for children with cystic fibrosis, which has been associated with decreased risk of hospitalization.^{2,4} Perez et al reports that in the US and Canada alone, “27% of patients aged 6-12 years and 41% of patients aged 13-17 years suffered one or more episodes of acute respiratory exacerbations requiring hospitalization for an average of 10 and 11 days...”² These frequent hospitalizations have an impact on quality of life, which is already typically rated lower for these patients compared with their healthy peers.² For these reasons, exercise, with its positive impact on aerobic fitness, is a critical component for maintenance of pediatric cystic fibrosis. While exercise interventions as well as other interventions discussed previously may not require weekly or monthly monitoring by a physical therapist, as the child ages, his or her maintenance plan may require periodic re-evaluation in order to stay current with individual needs and interests. Lannefors et al actually defines modern [physical therapy] for pediatric cystic fibrosis as involving “the whole individual in a long-term perspective” and suggests that a maintenance program must take into account individual factors such as “culture, tradition, and geographical influence.”¹ Further, physical therapists are able to perform tests and measures that indicate the health status and prognosis of a child with cystic fibrosis.^{5,6} Lannefors et al states that the role of modern physical therapy in regard to this population is to <i>prevent</i> complications associated with cystic fibrosis, slow the progression of lung disease, and to sustain lung function as well as physical fitness.¹ An annual exam with a physical therapist would support the</p>

<p>system of health and wellness discussed in earlier weeks of this course; by contributing to the maintenance of this chronic condition through interventions and testing summarized above, physical therapists can serve to improve the health and quality of life of these patients.²</p>

Annual exam: subjective/objective

Question/test	What testing	Positive finding	Clinical reasoning (Evidence if indicated)
<p>“How are your airway clearance techniques going?”</p>	<p>Effectiveness of and adherence to airway clearance regimen</p>	<p>Child and/or parent reports poor adherence, or simply has questions or concerns related to current techniques</p>	<p>Physical therapy plays a role in several airway clearance techniques, including postural drainage and percussion.¹ Lannefors et al reports that when strategies such as directed coughing or huffing are performed without these techniques, lung function declines.¹ Postural drainage and percussion can be taught to patients and caregivers in order to be performed at home. However, as the child ages and physically grows, aspects of the techniques, such as hand placement, will change.¹ This warrants intermittent review of airway clearance techniques to ensure effectiveness. If the child and/or parent is dissatisfied with their current regimen, other options are available for incorporation, such as assisted autogenic drainage, oscillating positive expiratory pressure, or simply adjusting positioning during postural drainage, which are within the physical therapist’s scope of practice to suggest.¹ Lannefors et al states that no single airway clearance regimen exists; each patient requires an individualized plan.¹</p>
<p>“What things are you currently doing to remain physically active?”</p>	<p>Gauging how active the child is as well as types of exercise in which he or she is participating</p>	<p>Child and/or parent reports little to no regular physical activity</p>	<p>Children with cystic fibrosis typically participate in less physical activity compared to their healthy peers, even if their lung function is high.¹ This leads to other complications later in life such as osteopenia and fractures.¹ Lannefors et al emphasizes the need for identifying the cause of reduced physical activity for the individual.¹ Some frequently reported reasons include time constraints due to other maintenance</p>

			requirements, protective parents, or the condition itself. ¹ Lannefors et al also state that these patients need more than just education when it comes to physical activity: “they probably need more active guidance and continuing encouragement to become and remain physically active.” ¹
“What do your meals typically look like? Are you taking any dietary supplements?”	Assessing general nutritional status of the child	Unbalanced or infrequent meals or dietary habits	Children with cystic fibrosis are at risk for nutrition-related issues. ^{5,6} For some individuals, these issues present as malnutrition; for others, they present as overweight or obesity. ⁵ This can lead to other issues, such as decreased bone mineral density or even shortened lifespan. ⁵ Additionally, depending on whether other organ systems are involved, patients may experience fat, vitamin, and protein absorbance issues. ⁷ Thus, nutritional habits must be included in regular assessment of this population.
Postural observation	Looking for characteristic poor posture associated with this population	Hyperinflation of the chest, exaggerated thoracic kyphosis, forward head and rounded shoulders	As airway obstruction and collapse occurs, the body attempts to maintain tidal volume by way of hyperinflation of the lungs and chest. ¹ To achieve this, the muscles of inspiration expand the chest wall concentrically, followed by eccentric unloading to accomplish exhalation. ¹ This acts as a feed forward mechanism; as the chest becomes more hyperinflated, lung function worsens, and inspiratory muscles are put into a state of active insufficiency. ¹ This causes accessory muscles to play an increasing role in respiration, leading to their shortening and impact on poor posture. ¹
Palpation	Mobility of intervertebral and costovertebral joints, tension of accessory respiratory muscles	Hypomobility of intervertebral and costovertebral joints, increased resting tension of accessory respiratory	Due to hyperinflation of the chest and associated impacts on posture, stiffness of intervertebral and costovertebral joints often occurs. ¹ Additional resting tension of accessory muscles may also be present due to the mechanics of hyperinflation discussed previously. ¹

		muscles	
“Have you experienced or are you currently experiencing any back pain?”	Assessing whether back pain is present	Presence of back pain	Long-term implications of poor posture and exaggerated thoracic kyphosis include back pain associated with wedging and compression of vertebral bodies. ¹ Because wedging cannot be changed by physical therapy interventions, it is important to detect and manage back pain associated with poor posture before it becomes irreversible. ¹
Auscultation of lungs and breath sounds	Assessing for abnormal lung or breath sounds	Abnormal breath sounds, presence of excessive mucous	Lung and breath sounds can give insight into the health of the respiratory system. ¹ Monitoring and comparing these sounds as the child ages can help track disease progression of cystic fibrosis.
Spirometry	Measuring and listening to lung “volumes and flows,” mucous movement, and assessing “ability to handle breathlessness” in order to evaluate effectiveness of airway clearance intervention ¹	Abnormal lung sounds or mucous flow, unable to cope well with breathlessness	Similar to the rationale for auscultating lung and breath sounds, assessing response to spirometry can give information regarding overall lung function and respiratory health. This can also serve as an opportunity to review the technique being used by the patient for home-based spirometry, if applicable.
Six-Minute Walk Test	Six minute walk distance, functional capacity, and risk of hospitalization due to pulmonary	Distance walked during test is <577.7m (indicating 4x greater risk of hospitalization) ⁸	Donadio et al found that the greater the distance walked during a six-minute walk test, the lower the risk of hospitalization for children with cystic fibrosis. ⁸ The authors also found that for children who were hospitalized, a greater distance walked correlated with decreased length of hospitalization. ⁸ This suggests that increased functional

	exacerbation. ^{7,8,10}		capacity may play a role in avoiding hospitalization for this population. ⁸ The six-minute walk test can also be used for tracking prognosis throughout the disease course, as well as estimating submaximal exercise capacity. ^{8,10}
Cystic Fibrosis Questionnaire (Appendix A)	Health-related quality of life for patients with cystic fibrosis (separate version available for children under age 14) ¹¹		This disease-specific questionnaire has been proven reliable and valid for assessing quality of life in patients with cystic fibrosis. ¹¹ The version attached in the appendix is for patients aged 14 and older. However, revised versions are also available for use with patients ages 6-13 years old, for preschool aged children, and for parent assessment. ¹¹ Because quality of life is generally rated poorer by children with cystic fibrosis compared to their healthy peers, this would be a good tool to use during an annual assessment to ensure all aspects of health and wellness are being addressed. ²

Resources/referrals:

Test item	Resource/referral	Reasoning
Child and/or parent reports little to no regular physical activity	Day-to-Day Exercise Handout - Cystic Fibrosis Foundation (Appendix B)	Exercise is a critical component of cystic fibrosis management and preservation of lung function. ^{2,4} If this question raised a concern during an annual exam, the physical therapist would first need to assist the patient and caregiver with developing an agreed-upon exercise plan. The handout from the Cystic Fibrosis Foundation would be a helpful supplement to this conversation. The handout does a good job of balancing addressing the audience as children as well as addressing the audience as a population with a chronic condition. ¹² It also gives exercise advice for different ages, which adds to the emphasis of the importance of lifelong exercise for this population. ¹² Finally, the handout includes a chart for tracking exercise. ¹² This may be helpful for children who are motivated by a visual reward system, or teenagers wanting to gain independence with their own disease management.

<p>Child and/or parent reports unbalanced or infrequent meals or dietary habits</p>	<p>Referral to registered dietitian</p>	<p>As stated previously, children with cystic fibrosis are at risk of nutrition-related issues in the forms of either malnutrition or overweight and obesity.^{5,6} Depending on the extent of disease involvement, nutritional counseling may be warranted. This is important from a physical therapy perspective especially if the child's nutrition is having impacts on factors such as bone mineral density. The physical therapist would need to work closely with the registered dietitian in order to safely increase weight-bearing activities as nutritional status improves. Additionally, if malnutrition is present, the physical therapist would need to consider the dietitian's goals for caloric intake and expenditure when prescribing a home exercise program.¹³ Finally, if overweight or obesity is at play, the physical therapist would need to work with the dietitian for the same reasons in order to ensure effectiveness of both disciplines' interventions.⁵</p>
<p>Poor postural mechanics are observed</p>	<p>Referral for regular physical therapy intervention</p>	<p>Poor postural mechanics seen in children with cystic fibrosis have long-term implications discussed previously.¹ If the mechanics are not addressed by physical therapy intervention, soft tissues will continue to shorten, and breathing mechanics will continue to be negatively impacted.¹ If the child is not yet having pain due to poor posture, he or she will likely experience it in the future due to associated vertebral wedging and compression discussed above.¹ Physical therapy interventions can improve soft tissue length, strengthen posterior postural muscles, and provide intervention for breathing mechanics in order to prevent future postural issues.</p>

Bibliography:

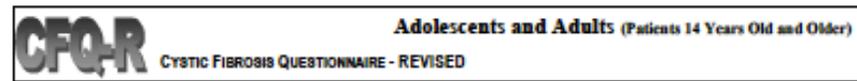
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Appendix (if indicated):

A. Cystic Fibrosis Questionnaire - Revised

Accessed from the University of Miami. http://www.psy.miami.edu/cfq_QLab/. Last accessed September 14, 2018.



Understanding the impact of your illness and treatments on your everyday life can help your healthcare team keep track of your health and adjust your treatments. For this reason, this questionnaire was specifically developed for people who have cystic fibrosis. Thank you for your willingness to complete this form.

Instructions: The following questions are about the current state of your health, as you perceive it. This information will allow us to better understand how you feel in your everyday life.

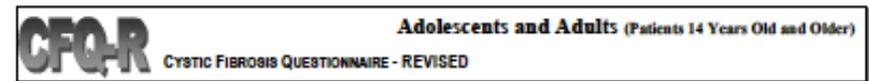
Please answer all the questions. There are **no right or wrong answers!** If you are not sure how to answer, choose the response that seems closest to your situation.

Section I. Demographics

Please fill-in the information or check the box indicating your answer.

- A. What is your date of birth?
Date

Mo	Day	Year							
- B. What is your gender?
 Male Female
- C. During the past two weeks, have you been on vacation or out of school or work for reasons NOT related to your health?
 Yes No
- D. What is your current marital status?
 Single/never married
 Married
 Widowed
 Divorced
 Separated
 Remarried
 With a partner
- E. Which of the following best describes your racial background?
 Caucasian
 African American
 Hispanic
 Asian/Oriental or Pacific Islander
 Native American or Native Alaskan
 Other (please describe) _____
 Prefer not to answer this question
- F. What is the highest grade of school you have completed?
 Some high school or less
 High school diploma/GED
 Vocational school
 Some college
 College degree
 Professional or graduate degree
- G. Which of the following best describes your current work or school status?
 Attending school outside the home
 Taking educational courses at home
 Seeking work
 Working full or part time (either outside the home or at a home-based business)
 Full time homemaker
 Not attending school or working due to my health
 Not working for other reasons



Section II. Quality of Life

Please check the box indicating your answer.

During the past two weeks, to what extent have you had difficulty:

	A lot of difficulty	Some difficulty	A little difficulty	No difficulty
1. Performing vigorous activities such as running or playing sports.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Walking as fast as others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Carrying or lifting heavy things such as books, groceries, or school bags.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Climbing one flight of stairs.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Climbing stairs as fast as others.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

During the past two weeks, indicate how often:

	Always	Often	Sometimes	Never
6. You felt well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. You felt worried.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. You felt useless.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. You felt tired.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. You felt energetic.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. You felt exhausted.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. You felt sad.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please circle the number indicating your answer. Please choose only one answer for each question.

Thinking about the state of your health over the last two weeks:

- 13. To what extent do you have difficulty walking?
 - 1. You can walk a long time without getting tired
 - 2. You can walk a long time but you get tired
 - 3. You cannot walk a long time because you get tired quickly
 - 4. You avoid walking whenever possible because it's too tiring for you
- 14. How do you feel about eating?
 - 1. Just thinking about food makes you feel sick
 - 2. You never enjoy eating
 - 3. You are sometimes able to enjoy eating
 - 4. You are always able to enjoy eating
- 15. To what extent do your treatments make your daily life more difficult?
 - 1. Not at all
 - 2. A little
 - 3. Moderately
 - 4. A lot

CFQ-R Adolescents and Adults (Patients 14 Years Old and Older)
CYSTIC FIBROSIS QUESTIONNAIRE - REVISED

16. How much time do you currently spend each day on your treatments?
 1. A lot
 2. Some
 3. A little
 4. Not very much
17. How difficult is it for you to do your treatments (including medications) each day?
 1. Not at all
 2. A little
 3. Moderately
 4. Very
18. How do you think your health is now?
 1. Excellent
 2. Good
 3. Fair
 4. Poor

Please select a box indicating your answer.

Thinking about your health during the past two weeks, indicate the extent to which each sentence is true or false for you.

	Very true	Somewhat true	Somewhat false	Very false
19. I have trouble recovering after physical effort.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I have to limit vigorous activities such as running or playing sports.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I have to force myself to eat.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. I have to stay at home more than I want to.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I feel comfortable discussing my illness with others.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I think I am too thin.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. I think I look different from others my age.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. I feel bad about my physical appearance.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. People are afraid that I may be contagious.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. I get together with my friends a lot.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. I think my coughing bothers others.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. I feel comfortable going out at night.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. I often feel lonely.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. I feel healthy.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. It is difficult to make plans for the future (for example, going to college, getting married, advancing in a job, etc.).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. I lead a normal life.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

CFQ-R Adolescents and Adults (Patients 14 Years Old and Older)
CYSTIC FIBROSIS QUESTIONNAIRE - REVISED

Section III. School, Work, or Daily Activities

Questions 35 through 38 are about school, work, or other daily tasks.

35. To what extent did you have trouble keeping up with your schoolwork, professional work, or other daily activities during the past two weeks?
 1. You have had no trouble keeping up
 2. You have managed to keep up but it's been difficult
 3. You have been behind
 4. You have not been able to do these activities at all
36. How often were you absent from school, work, or unable to complete daily activities during the last two weeks because of your illness or treatments?
 Always Often Sometimes Never
37. How often does CF get in the way of meeting your school, work, or personal goals?
 Always Often Sometimes Never
38. How often does CF interfere with getting out of the house to run errands such as shopping or going to the bank?
 Always Often Sometimes Never

Section IV. Symptom Difficulties

Please select a box indicating your answer.

Indicate how you have been feeling during the past two weeks.

	A great deal	Somewhat	A little	Not at all
39. Have you had trouble gaining weight?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Have you been congested?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Have you been coughing during the day?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Have you had to cough up mucus?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Has your mucus been mostly: <input type="checkbox"/> Clear <input type="checkbox"/> Clear to yellow <input type="checkbox"/> Yellowish-green <input type="checkbox"/> Green with traces of blood <input type="checkbox"/> Don't know				
How often during the past two weeks:	Always	Often	Sometimes	Never
44. Have you been wheezing?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. Have you had trouble breathing?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Have you woken up during the night because you were coughing?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. Have you had problems with gas?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. Have you had diarrhea?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. Have you had abdominal pain?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. Have you had eating problems?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Go to Question 44

Please be sure you have answered all the questions.

THANK YOU FOR YOUR COOPERATION!

B.

Day-to-Day

Exercise and Cystic Fibrosis (CF)



This guide explains the role of exercise in treating CF. When you think of “exercise,” think of “activity,” more than gyms or health clubs. “Exercise” includes many activities.



It’s hard to know if those with CF do better because they are active or if they are active because their CF is milder. Either way, exercise helps!

Exercise helps you be less limited in what you do with friends and family. The limits that CF may put on you will be worse if you are not active. Regular exercise can help you do the things that increase self-esteem and give confidence to face each day.

Before you get more active or start exercising, team up with your CF Care Center for advice and support.

Why Exercise?

Because it helps you feel better! Children, teens and adults with CF who exercise do better than those who don’t. Their rate of lung function decline slows. They enjoy a more normal lifestyle. Regular exercise helps the heart so it is stronger during stress. Regular exercise also helps the lung function so there are more reserves to use during **exacerbations*, or lung infections.

Who Should Exercise?

Almost everyone can be helped by being more active. It is not a good idea to exercise if you have *cor pulmonale*, *pulmonary hypertension*, an exacerbation or respiratory infection.

What Kind of Exercise?

For all ages, there are three things to look at when choosing activities. The first is the activity itself. Do you *like* the activity?

*Words that appear in bold italic are defined on page 5 of this pamphlet.

Does it fit into your schedule? If not, you won’t stick with it.

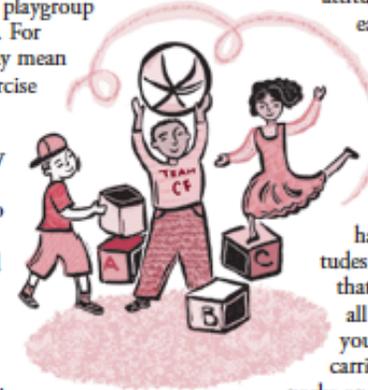
Second, do the activities connect you to friends or family? For children or teens, this may mean playing with a playgroup or sports team. For adults, this may mean finding an exercise partner.

Third, are they *cardiovascular exercises* or do they exercise your heart and lungs? Can you do them for more than 20 minutes at a time? Activities that make your heart beat faster and harder over time make your heart and lungs stronger. They also help lower the risk of cancer, heart disease, circulation problems, diabetes, and high blood pressure. Activities that involve weights or *resistance* are good for helping you get stronger muscles and bones. Any exercise, even short easy bursts spread through the day, is better than no exercise. Harder and longer exercise (to a point) is best.

Advice for Children, Teens and Adults

Children

It is vital for all children to develop good exercise habits and attitudes. This starts early and with the family. When families commit to regular activity, children learn good habits and attitudes. Find activities that are easy for all to do. Very young children carried in backpacks on family hikes learn the joy of hiking and soon join in walking.



Tips for Children

- Involve them in many types of activities
- Reward them when they join group events
- Plan active playtime on most days of the week
- Keep TV and video game time to a minimum

Expose children to many types of activities. Too often we push one kind or just a few, not knowing what the child will like and stick with. Children are more likely to find an activity they like and will do it if exposed to many varied activities early on. When children join in family or group activities, reward them. The best rewards are those that grow good positive attitudes

about joining in again, for example a canoe rental or a special active trip. Be creative!

Planning active playtime on most days helps grow good attitudes toward activity in children less than 4 years old. Five- and 6-year olds can do more “adult,” “life-long” activities, like biking or hiking.

Watching TV and playing video games keep kids from being active. The more time children spend doing these things, the more likely they are to become unhealthy.



Teens

Teens need activities that help them feel good around their peers. This is truer for teens whose activities are limited by lung disease.

Teens are more likely to stick with a regular activity program that increases their self-esteem. This is true with sports teams and leagues. Teens: put the sports teams and leagues to this test first and ask yourself:

- “Are they run so that I will feel good about my growing skills?”

- “Are those in charge trained to give me a good experience and do they care about my CF needs?”

- “Is winning ‘number one?’” Having fun should be most important in order for teens to want to stay involved.
- “Are players matched by age, skill *and* size, or am I sometimes overwhelmed by the other players?”

If you feel uneasy (fear of exposing CF, poor skill levels, etc.) or unable (due to CF) to play on a sports team or league, think about a formal exercise

program. If you are well enough, point systems (see page 6-7) can support you in meeting your goals through varied activities. Formal exercise programs can include treadmills, stationary bikes, etc. Before starting, you should have an **exercise test** ordered by your doctor. This test will show if your heart and lungs can handle the exercise. Rarely, exercise makes the hearts of some people with CF beat abnormally. If this happens during the

test, your **heart rate** should be watched during exercise and your exercise kept at a lower level. Exercise should also be kept at a lower level if it causes low **blood oxygen levels**. You should be monitored until you learn how to keep your exercise at a safe level.

Adults

If adults haven't made regular activity part of their lives, they *must* talk with their CF Care Center *first*. Some activities can make heart and lung disease and bone and joint problems worse. As with teens, an exercise test may be needed to find safe levels.

When planning an exercise program...

- Pick comfortable activities to do that you *like*. This will help you stick with them.
- Choose activities that keep your heart and lungs exercising the whole time.
- Find an exercise partner. This will also help you stick with it.
- Do a variety of activities. This will reduce boredom and bone/joint injuries.
- Choose activities that fit your life. You may like to snow ski,

but you can't do it regularly if you live in Florida! Also, find an exercise time that fits your schedule.



- Pick lifetime activities like running and biking. Tackle football is fun but isn't something people do for too many years.
- Find some activities that aren't extremely competitive (against others or yourself). Exercising “just for fun” lowers tension.

Set fair yet challenging goals. Most of us won't become paid athletes, but we can all improve our health.

How's the Weather?

With exercise, people with CF should be careful when it's hot and humid. They don't handle heat stress well. More sodium (Na⁺) and chloride (Cl⁻) or salt is lost in CF sweat, so drinking fluids is vital. Drink more fluids and choose fluids that maintain or replace Na⁺ and Cl⁻ (**electrolytes**). Many sports drinks have a certain level of electrolytes to best absorb **ions** and fluid from the stomach into the blood. For those with CF, the level should be slightly higher.

Safety

It is important to participate safely in whatever activities you choose. While one might say that the problem with common sense is that it isn't common enough, that's basically what it comes down to.

To reduce the risk of *musculoskeletal* injuries be sure to participate in any activity in mod-

eration until you have built up enough *stamina* to exercise at a higher intensity.

Pay attention to proper clothing, footwear and other gear required for your activities; wear a reflective vest in poor light conditions if you are exercising on the road; wear a bicycle helmet whenever you ride your bike, etc.

GLOSSARY

Blood oxygen levels: How much oxygen is in the blood. It is measured by a small monitor (oximeter) put on the finger.

Cor pulmonale: When the right lower part of the heart grows larger. This makes the heart less able to pump blood through the lungs.

Electrolytes: Chemical salts that help cells work. Electrolytes include sodium, chloride, potassium and bicarbonate.

Exacerbation: When there is an infection in the lungs.

Exercise test: An exercise is often done on a treadmill or stationary bike. The person will likely exercise for 10 to 15 minutes. The workout gets harder until they have to stop. During the test, the heart and lungs are watched for problems.

Cardiovascular exercises: Activities that use lots of muscles and last at least 20 minutes.

Heart rate: How many times the heart beats in a minute. During exercise, a small heart monitor (electrocardiogram) can be used to watch heart rate.

Ion: a charged atomic particle, such as sodium (Na⁺) or chloride (Cl⁻).

Musculoskeletal: The muscles and bones of the body.

Pulmonary hypertension: High blood pressure in the lungs.

Resistance activities: These activities make muscles work harder than normal, and strengthen muscles.

Stamina: Staying power, ability to do something for a while.

Track Your Success to Exercise Your Lungs

The object of "Exercise Your Lungs" on the next page is to help you track your exercise program. To complete the chart, fill in a box with the appropriate symbol that represents the type of the activity you completed. The duration of your exercise activity will determine how many boxes to fill in with the symbol. For instance, if you ride your bike for 15 minutes, you fill in

Suggestion
Make several copies of the chart on next page before using so you can keep your exercise reward program going!

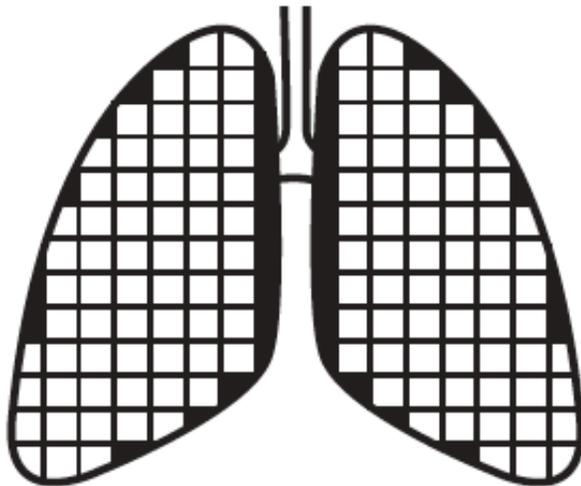
one box with a B and if you ride for 30 minutes, fill in two boxes. If you hike for 1 hour you get to fill in two boxes with H. And so on.

Activities that are 15 to 30 minutes are best. Choose activities that you like and try to find a partner to join you. Start your program slowly and work your way up, for example try to fill in 10 to 12 boxes in week one and increase to 15 to 18 boxes by week four. Listen to your body; if it hurts too much, slow down.

When you complete one sheet, give yourself a reward such as a special family activity or a movie night!

Exercise Your Lungs

A point system to support your activity program



Minutes	Activity	Symbol	Minutes	Activity	Symbol
5	Running/jogging	R	30	Ping pong	P
	Cross-country skiing	CS		Horse riding	HR
10	Swimming	S		Dancing	D
15	Riding bikes	B		Bowling	BO
	Gymnastics	G		Hiking	H
	Downhill skiing	DS	60	Walking	W
	Team sports (soccer, volleyball, basketball, etc.)	T		Golf	GO
	Ice skating	I		Gardening	GA
	Rowing, canoeing	C			
	Weight training	WT			
	In-line skating	IL			

NAME _____

DATE BEGUN _____

DATE COMPLETED _____

Resources

Exercise: "Just Do It" for Improved Health and Longevity. CF Services Newsletter, HomeLine Guest Author Series, May 2002, www.cfservicespharmacy.com

Exercise - The Facts. CF Services Newsletter, HomeLine Guest Author Series, March 1997, www.cfservicespharmacy.com

These Web sites have more information about exercise:

The CDC: how much exercise do you need?
www.cdc.gov/physicalactivity/everyone/guidelines/index.html

CF Foundation: Virtual CF Education Day Web cast:
Exercise and CF
www.cff.org/LivingWithCF/Webcasts/ArchivedWebcasts/#Exercise_and_CF

MedlinePlus: Exercise and Physical Fitness
www.nlm.nih.gov/medlineplus/exerciseandphysicalfitness.html

Tips for increasing physical activity:
www.mypyramid.gov/ - go "Inside the Pyramid" and click on the person climbing the pyramid

Gauge your fitness level:
www.healthierus.gov/exercise.html

An interactive tool for kids: Body and Mind - www.bam.gov

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