

[http://www.connecticutchildrens.org/body\\_dept.cfm?id=688#steps](http://www.connecticutchildrens.org/body_dept.cfm?id=688#steps)

## **Office Locations:**

### **Pediatric CF Clinic**

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Hartford, CT 06106

Appointments and Questions: 860.545.9440

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Contact Person

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860.545.9440

## **Transition**

### **What is "Transition"?**

When we describe transition, we define it as a process, a series of steps involved in ending care with your pediatric healthcare providers and beginning treatment with a team of providers who specialize in the care of adults with CF. The key aspect of our Center's philosophy of transition is that we do NOT view it as simply a "transfer" of your medical records to an adult physician. No one expects you to see your Pediatric CF Team one day and then the Adult CF Team the next without preparation. We believe we have a responsibility to help you get ready to take charge of your health as one part of your overall transition to adulthood. The most important thing about transition, then, is that it is gradual, not something that happens overnight.

You will be taking charge of many areas of your life such as deciding where you want to live, go to college or what kind of work you want to do. This is the exciting part of transition: making more of your own decisions as you take on more responsibility. But as a person with an illness that requires daily attention, there are some additional tasks involved in planning for your future. Therefore, it's important to know that you, your family and your healthcare team all share the responsibility for making your transition as smooth as possible, that we will work together to get you ready one step at a time. This way, completing your move to the Adult CF Program will be a goal you look forward to reaching just like any of the important goals in your life.

### **The Steps of Transition**

The following is a description of the actual steps involved in moving from the Pediatric to the Adult CF Program. It is our policy that all patients 18 years old and older are seen in the Adult Program; also if hospitalization is needed, patients in this age group are admitted to Hartford Hospital. However, the other time frames described below are approximate as no two patients are alike in their readiness to move from one step to the next. For instance, one patient may be fully independent with taking their medications at age 13, but another may not. (We have created "Transition Checklists" to use as self-assessment tools to help you review your knowledge and skills. Then you, your family and your healthcare team will all know what needs to be accomplished to get you ready for the transition. Please review the Checklists and instructions for completing them for more details.)

Another important aspect of the transition process is that we are sensitive to each family's need to attend appointments together, separately or in some combination of the two. Again, patients are not all alike and families will have different approaches to their involvement in a patient's care. We do, however, strongly encourage patients to begin learning how to take full responsibility for their health as early as possible, and part of that learning includes spending time alone with healthcare providers to practice self-advocacy. You should feel free to discuss any questions you may have about this process with any of the CF Team members.

1. At about age 12, the Pediatric CF Team will begin discussing with you and your parents in increasing detail what you need to know about your CF and daily self-care. The Social Worker will introduce the first Transition Checklist in order to assess what you know and what you need to learn more about. (These will be completed once per year in order to review your progress.)
2. Around 15 years old you may meet one or more of the Adult CF Program team members during a Pediatric Clinic visit. You and your parents will complete the next Transition Checklist which is geared toward young adults. (It is also possible to tour the Adult CF Clinic prior to your first appointment there. Inquire with your CF Social Worker about how to arrange this.)
3. Then, once you turn 17 you will begin alternating your Clinic visits between the Pediatric and Adult clinics until you are 18. Again, the Social Worker will give you and your parents the last Transition Checklists to complete.
4. By age 18 you will begin attending the Adult CF Clinic only. During the previous year you will have already met with the Adult Team and determined what areas of your CF care you still need assistance with.
5. We recognize that just because you turn 18 DOES NOT necessarily mean you or your family feel you are ready to take on all the responsibility for your healthcare. Therefore, the Adult Team will continue to work with you and your parents on any areas you believe need more practice, information or skill.
6. As stated previously, it is our policy that if hospitalization is needed, those patients 18 and older will be admitted to Hartford Hospital. However, you and your parents will be given an Admission Brochure before you turn 18, and as with the Adult Clinic you may even arrange a tour of the unit well in advance of a hospital stay.

### **Instructions for Transition Checklists**

The purpose of the Transition Checklist is to encourage you and your family to think about what specific steps are involved in you taking more charge of your health care and in your overall "transition" to adulthood. First, by completing the Checklist, we will see what you and your parents think you already know and do by yourself. Next, we will figure out what you need to practice and which topics you need more information about. Then we can list specific things you, your family and your health care team can all do to help you feel confident in your ability to take on more responsibility. We will regularly review how well you are learning and practicing what you need to know. The "Tips for Transition" sheets include some helpful hints on the kinds of things both you and your parents can practice or think about along the way.

1. During a Clinic visit, the Social Worker will provide you and your parents each with Transition Checklists. Both you and your parents should complete the Checklists separately during the visit if time allows. (If not, you may complete them at home and mail/ bring them to Clinic.) That way we can see if you and your parents have similar or different ideas about what areas we need to focus on.
2. Follow the instructions at the top of the Checklist.
3. On the last page, the more detailed you can be in your answers the better.
4. Review them with the Social Worker.
5. Together, we can decide what needs work and what you already do well enough on your own.
6. Then, we will all have some "homework" to do. For example, you may want to practice making your own Clinic appointments, so the Social Worker can provide you with instructions as to who to call and the phone number, then your parents can follow up by asking you if you made the call.
7. The Checklist can be completed yearly or more often if it would be useful to do so.

8. Finally, keep completed Checklists in your Education Notebook or create a separate one just for transition if that's easier. Keeping them will allow you to see just how far you've come in your knowledge and skills!

It is important to remember that we can be as creative as we want to be in how the Checklists are used, how to go about "practicing" new skills or how to test your knowledge about CF. We can involve other members of the team, include other family members, just focus on what you will be doing or any other ways you can think of that you will learn best. The point is that as you get better at doing things on your own, you will be better prepared to move on in all aspects of your life and plan for a great future!

### **TRANSITION CHECKLIST: Ages 12-15**

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_

Today's Date: \_\_\_\_\_ Name of person completing form: \_\_\_\_\_

Relationship to Patient: self \_\_\_\_ parent(s) \_\_\_\_ CF Clinic staff \_\_\_\_

Please use the following scale to rate the **FREQUENCY** of each item. (For parents completing this form, use the scale as it applies to your **observations** of your child):

**1= Does Not Apply    2= Never    3= Sometimes    4=Often    5= Always**

<b>CF HEALTH KNOWLEDGE:</b>	
I can accurately describe my diagnosis.	1   2   3   4   5
I can accurately describe the symptoms of my illness.	1   2   3   4   5
I can describe my daily care routine.	1   2   3   4   5
I know my medications, the amounts and times I take them.	1   2   3   4   5
I know what each medication is for.	1   2   3   4   5
I know emergency medical phone numbers.	1   2   3   4   5
I know the "warning signs" that mean I should call the doctor.	1   2   3   4   5
<b>INDEPENDENT HEALTHCARE ACTIONS:</b>	
I answer at least one of my health care provider's questions myself.	1   2   3   4   5
I ask my health care providers at least one of my own questions.	1   2   3   4   5
I meet with my health care providers during clinic visits by myself at least part of the time.	1   2   3   4   5
I take charge of my daily health care routine without reminders.	1   2   3   4   5
I schedule my own clinic/ doctor's appointments.	1   2   3   4   5
I tell my parents when I need to have them order more medications.	1   2   3   4   5
I tell my parents or other adults about any unusual changes in my health.	1   2   3   4   5
I help my parents remember my daily care routine.	1   2   3   4   5
<b>LIFESTYLE ISSUES:</b>	
I know why smoking, alcohol and drug use are not good for me.	1   2   3   4   5
I engage in regular physical activity.	1   2   3   4   5
I get enough rest and sleep.	1   2   3   4   5
I know what and how much to eat and drink to be healthy.	1   2   3   4   5
<b>SOCIAL RELATIONSHIPS AND WELL-BEING:</b>	
I have friends and get together with them at least once a week.	1   2   3   4   5
I know when I feel stressed out, nervous, angry or down.	1   2   3   4   5
I talk with friends, family or other trusted people about problems when I need to.	1   2   3   4   5
I know when and how to ask for a counselor's help with different problems.	1   2   3   4   5
I am realistic about my health.	1   2   3   4   5
I have thought about the risks and benefits of discussing my health with different people.	1   2   3   4   5
I have thought about how to discuss my health with different people.	1   2   3   4   5
I enjoy my life and generally have a positive outlook.	1   2   3   4   5

Name:

Date of Birth:

<b>SEXUAL HEALTH:</b>	
I understand how reproduction works.	1 2 3 4 5
I know where and how to seek more information on reproduction.	1 2 3 4 5
I understand how to prevent pregnancy.	1 2 3 4 5
I understand how to prevent sexually transmitted diseases.	1 2 3 4 5
<b>EDUCATIONAL AND VOCATIONAL PLANNING:</b>	
I have ideas about what I'd like to do after High School.	1 2 3 4 5
I have talked with my parents/ school counselor/ teacher/ doctor or nurse about plans for college and/ or employment.	1 2 3 4 5
I have talked with my parents/ school counselor/ teacher/ doctor or nurse about volunteer work I might like to do.	1 2 3 4 5
I understand the importance of a healthy work environment.	1 2 3 4 5
I have attended a school 504 meeting.	1 2 3 4 5
I know my rights under the ADA and Sect. 504.	1 2 3 4 5
<b>FINANCIAL AND PRACTICAL NEEDS:</b>	
I know the name of my health insurance.	1 2 3 4 5
I know how health insurance works.	1 2 3 4 5
I know how to find my health insurance identification number.	1 2 3 4 5
I manage my own money. (I have a bank account, I stick to a budget, etc.)	1 2 3 4 5

What are your **top 3 concerns** about any area of your (your child's) life? :

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

How would you like to handle these concerns? : \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

What are your strengths? : \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

What would you like to do better? : \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

**Information You Would Like to Have:**

- |   |  |
|---|--|
| <input type="checkbox"/> Medical information            | <input type="checkbox"/> Advanced Directives         |
| <input type="checkbox"/> Financial assistance resources | <input type="checkbox"/> Fertility                   |
| <input type="checkbox"/> Insurance                      | <input type="checkbox"/> Genetic counseling/ testing |
| <input type="checkbox"/> Disclosing CF                  | <input type="checkbox"/> CF websites                 |
| <input type="checkbox"/> Disability rights              | <input type="checkbox"/> Sexuality                   |
| <input type="checkbox"/> Employment                     | <input type="checkbox"/> Adult CF Clinic             |
| <input type="checkbox"/> Education                      | <input type="checkbox"/> Nutrition                   |
| <input type="checkbox"/> Financial aid for college      | <input type="checkbox"/> Infection prevention        |
| <input type="checkbox"/> Lung Transplantation           | <input type="checkbox"/> Vocational counseling       |
| <input type="checkbox"/> Other                          |  |

For the above, please describe specifics: \_\_\_\_\_

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**PLAN:**


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This Checklist completed: \_\_\_\_/\_\_\_\_/\_\_\_\_

Next Checklist to be completed: \_\_\_\_/\_\_\_\_/\_\_\_\_

Patient/ Guardian Signature: \_\_\_\_\_

Social Worker Signature: \_\_\_\_\_

### **TRANSITION CHECKLIST: Ages 15-16**

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_

Today's Date: \_\_\_\_\_ Name of person completing form: \_\_\_\_\_

Relationship to Patient: self \_\_\_\_ parent(s) \_\_\_\_ CF Clinic staff \_\_\_\_

Please use the following scale to rate the **FREQUENCY** of each item. (For parents completing this form, use the scale as it applies to your **observations** of your child):

**1= Does Not Apply    2= Never    3= Sometimes    4=Often    5= Always**

<b>CF HEALTH KNOWLEDGE:</b>	
I can accurately describe my diagnosis.	1   2   3   4   5
I can accurately describe the symptoms of my illness.	1   2   3   4   5
I can describe my daily care routine.	1   2   3   4   5
I know my medications, dosages and times I take them.	1   2   3   4   5
I know what each medication is for.	1   2   3   4   5
I know emergency medical phone numbers.	1   2   3   4   5
I know the "warning signs" that mean I should call the doctor.	1   2   3   4   5
<b>INDEPENDENT HEALTHCARE ACTIONS:</b>	
I answer my health care provider's questions myself.	1   2   3   4   5
I ask my health care providers my own questions.	1   2   3   4   5
I meet with my health care providers during clinic visits by myself at least part of the time.	1   2   3   4   5
I take charge of my daily health care routine without reminders.	1   2   3   4   5
I schedule my own clinic/ doctor's appointments.	1   2   3   4   5
I call to report symptoms and/ or changes in my health.	1   2   3   4   5
I get my own prescriptions filled.	1   2   3   4   5
I help my parents remember my daily care routine.	1   2   3   4   5
<b>LIFESTYLE ISSUES:</b>	
I understand the negative effects of smoking, alcohol and drug use.	1   2   3   4   5
I engage in regular physical activity.	1   2   3   4   5
I get enough rest and sleep.	1   2   3   4   5
I know what and how much to eat and drink to be healthy.	1   2   3   4   5
<b>SOCIAL RELATIONSHIPS AND WELL-BEING:</b>	
I have friends and get together with them at least once a week.	1   2   3   4   5
I know when I feel stressed out, nervous, angry or down.	1   2   3   4   5
I talk with friends, family or other trusted people about problems when I need to.	1   2   3   4   5
I know when and how to ask for a counselor's help with different problems.	1   2   3   4   5
I am realistic about my health.	1   2   3   4   5
I have thought about the risks and benefits of discussing my health with different people.	1   2   3   4   5
I have thought about how to discuss my health with different people.	1   2   3   4   5
I enjoy my life and generally have a positive outlook.	1   2   3   4   5

Name:

Date of Birth:

<b>SEXUAL HEALTH:</b>	
I understand how reproduction works.	1 2 3 4 5
I know where and how to seek more information on reproduction.	1 2 3 4 5
I understand how my diagnosis impacts on sexual development and reproduction.	1 2 3 4 5
I understand how to prevent pregnancy.	1 2 3 4 5
I understand how to prevent sexually transmitted diseases.	1 2 3 4 5
<b>EDUCATIONAL AND VOCATIONAL PLANNING:</b>	
I have ideas about what I'd like to do after High School.	1 2 3 4 5
I have plans for higher education and/ or employment.	1 2 3 4 5
I have plans for doing volunteer work during High School.	1 2 3 4 5
I understand the importance of a healthy work environment.	1 2 3 4 5
I know how to look and apply for a job.	1 2 3 4 5
I know how to look and apply for college.	1 2 3 4 5
I know how to apply for financial aid.	1 2 3 4 5
I know my rights under the ADA and Sect. 504.	1 2 3 4 5
<b>FINANCIAL AND PRACTICAL NEEDS:</b>	
I understand my current insurance coverage.	1 2 3 4 5
I know the length of my insurance coverage under my family's plan.	1 2 3 4 5
I am aware of COBRA and how to maintain continuous coverage.	1 2 3 4 5
I know how to drive and/ or arrange adequate transportation.	1 2 3 4 5
I have thought about where I am going to live.	1 2 3 4 5
I know where/ how to access entitlement programs for financial/ medical assistance.	1 2 3 4 5
I manage my own money. (I have a bank account, I stick to a budget, etc.)	1 2 3 4 5

What are your **top 3 concerns** about any area of your (your child's) life? :

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

How would you like to handle these concerns? : \_\_\_\_\_

\_\_\_\_\_

What are your strengths? : \_\_\_\_\_

\_\_\_\_\_



What would you like to do better? : \_\_\_\_\_

Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

**Information You Would Like to Have:**

- |   |  |
|---|--|
| <input type="checkbox"/> Medical information            | <input type="checkbox"/> Advanced Directives         |
| <input type="checkbox"/> Financial assistance resources | <input type="checkbox"/> Fertility                   |
| <input type="checkbox"/> Insurance                      | <input type="checkbox"/> Genetic counseling/ testing |
| <input type="checkbox"/> Disclosing CF                  | <input type="checkbox"/> CF websites                 |
| <input type="checkbox"/> Disability rights              | <input type="checkbox"/> Sexuality                   |
| <input type="checkbox"/> Employment                     | <input type="checkbox"/> Adult CF Clinic             |
| <input type="checkbox"/> Education                      | <input type="checkbox"/> Nutrition                   |
| <input type="checkbox"/> Financial aid for college      | <input type="checkbox"/> Infection prevention        |
| <input type="checkbox"/> Lung Transplantation           | <input type="checkbox"/> Vocational counseling       |
| <input type="checkbox"/> Other                          |  |

For the above, please describe specifics: \_\_\_\_\_

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**PLAN:**

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This Checklist completed: \_\_\_\_/\_\_\_\_/\_\_\_\_

Next Checklist to be completed: \_\_\_\_/\_\_\_\_/\_\_\_\_

Patient/ Guardian Signature: \_\_\_\_\_

Social Worker Signature: \_\_\_\_\_

### **TRANSITION CHECKLIST: Ages 16-18**

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_  
 Date: \_\_\_\_/\_\_\_\_/\_\_\_\_ Name of person completing form: \_\_\_\_\_  
 Relationship to Patient: self \_\_\_\_ parent(s) \_\_\_\_ CF Clinic staff \_\_\_\_

Please use the following scale to rate the **FREQUENCY** of each item. (For parents completing this form, use the scale as it applies to your **observations** of your child):

**1= Does Not Apply    2= Never    3= Sometimes    4=Often    5= Always**

<b>CF HEALTH KNOWLEDGE:</b>	
I can accurately describe my diagnosis.	1   2   3   4   5
I can accurately describe the symptoms of my illness.	1   2   3   4   5
I can describe my daily care routine.	1   2   3   4   5
I know my medications, dosages and times I take them.	1   2   3   4   5
I know what each medication is for.	1   2   3   4   5
I know emergency medical phone numbers.	1   2   3   4   5
I know the “warning signs” that indicate I should call the doctor.	1   2   3   4   5
<b>INDEPENDENT HEALTHCARE ACTIONS:</b>	
I answer my health care provider’s questions myself.	1   2   3   4   5
I ask my health care providers my own questions.	1   2   3   4   5
I meet with my health care providers during clinic visits by myself most of the time.	1   2   3   4   5
I take charge of my daily health care without reminders.	1   2   3   4   5
I schedule my own clinic/ doctor’s appointments.	1   2   3   4   5
I call to report symptoms and/ or changes in my health.	1   2   3   4   5
I get my own prescriptions filled.	1   2   3   4   5
I help my parents remember my daily care routine.	1   2   3   4   5
<b>KNOWLEDGE OF ADULT CF CLINIC:</b>	
I have met with at least one member of the Adult CF Clinic staff.	1   2   3   4   5
I know where the Adult CF Clinic is located.	1   2   3   4   5
I know the phone number of the Adult CF Clinic.	1   2   3   4   5
I know how to schedule an appointment with the Adult CF Clinic.	1   2   3   4   5
I know where adult CF patients are hospitalized.	1   2   3   4   5
I have had at least one Adult CF Clinic appointment.	1   2   3   4   5
<b>RELATED HEALTH KNOWLEDGE:</b>	
I understand what genetic counseling is.	1   2   3   4   5
I know how to arrange to have genetic counseling.	1   2   3   4   5
I know some basic facts about lung transplantation.	1   2   3   4   5
I know where to seek more information about lung transplantation.	1   2   3   4   5
I know how to try to prevent lung infections.	1   2   3   4   5
I know how enzymes work.	1   2   3   4   5
I have a basic understanding of CF Related Diabetes.	1   2   3   4   5
I understand the relationship between BMI and FEV1.	1   2   3   4   5
I know what and how much to eat and drink to be healthy.	1   2   3   4   5

Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

<b>LIFESTYLE ISSUES:</b>	
I understand the negative effects of smoking, alcohol and drug use.	1 2 3 4 5
I engage in regular physical activity.	1 2 3 4 5
I maintain an adequate sleep schedule.	1 2 3 4 5
<b>PSYCHOSOCIAL WELL-BEING:</b>	
I have friends and get together with them at least once a week.	1 2 3 4 5
I know when I feel stressed out, nervous, angry or down.	1 2 3 4 5
I talk with friends, family or other trusted people about problems when needed.	1 2 3 4 5
I know when and how to ask for professional help with different problems.	1 2 3 4 5
I am realistic about my health.	1 2 3 4 5
I have considered the risks and benefits of discussing my health with different people.	1 2 3 4 5
I have thought about how to discuss my health with different people.	1 2 3 4 5
I enjoy my life and generally have a positive outlook.	1 2 3 4 5
<b>SEXUAL HEALTH:</b>	
I understand how reproduction works.	1 2 3 4 5
I know where and how to seek more information on reproduction.	1 2 3 4 5
I understand how my diagnosis impacts on fertility.	1 2 3 4 5
I understand how to prevent pregnancy.	1 2 3 4 5
I understand how to prevent sexually transmitted diseases.	1 2 3 4 5
<b>EDUCATIONAL AND VOCATIONAL PLANNING:</b>	
I have ideas about what I'd like to do after High School.	1 2 3 4 5
I have plans for higher education and/ or employment.	1 2 3 4 5
I understand the importance of a healthy work environment.	1 2 3 4 5
I know how to look for a job.	1 2 3 4 5
I know how to apply for a job.	1 2 3 4 5
I know how to apply for college.	1 2 3 4 5
I know how to apply for financial aid.	1 2 3 4 5
I know my rights under the ADA and Sect. 504.	1 2 3 4 5
<b>FINANCIAL AND PRACTICAL NEEDS:</b>	
I understand my current insurance coverage.	1 2 3 4 5
I know the length of my insurance coverage under my family's plan.	1 2 3 4 5
I am aware of COBRA and how to maintain continuous coverage.	1 2 3 4 5
I know how to drive and/ or arrange adequate transportation.	1 2 3 4 5
I have plans for where I am going to live.	1 2 3 4 5
I know where/ how to access entitlement programs for financial/ medical assistance.	1 2 3 4 5
I manage my own money. (I have a bank account, I stick to a budget, etc.)	1 2 3 4 5

Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

What are your **top 3 concerns** about any area of your (your child's) life? :

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

How would you like to handle these concerns? : \_\_\_\_\_

What are your strengths? : \_\_\_\_\_

What would you like to do better? : \_\_\_\_\_

**Information You Would Like to Have:**

- |   |  |
|---|--|
| <input type="checkbox"/> Medical information            | <input type="checkbox"/> Fertility                   |
| <input type="checkbox"/> Financial assistance resources | <input type="checkbox"/> Genetic counseling/ testing |
| <input type="checkbox"/> Insurance                      | <input type="checkbox"/> CF websites                 |
| <input type="checkbox"/> Disclosing CF                  | <input type="checkbox"/> Sexuality                   |
| <input type="checkbox"/> Disability rights              | <input type="checkbox"/> Adult CF Clinic             |
| <input type="checkbox"/> Employment                     | <input type="checkbox"/> Nutrition                   |
| <input type="checkbox"/> Education                      | <input type="checkbox"/> Infection prevention        |
| <input type="checkbox"/> Financial aid for college      | <input type="checkbox"/> Vocational counseling       |
| <input type="checkbox"/> Lung Transplantation           | <input type="checkbox"/> Other                       |
| <input type="checkbox"/> Advanced Directives            |  |

For the above, please describe specifics: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**PLAN:** \_\_\_\_\_

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\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

This Checklist completed: \_\_\_\_/\_\_\_\_/\_\_\_\_

Next Checklist to be completed: \_\_\_\_/\_\_\_\_/\_\_\_\_

Patient/ Guardian Signature: \_\_\_\_\_

Social Worker Signature: \_\_\_\_\_

### **Transition Tips: For Parents**

1. Take good care of yourself first! Be a positive role-model by enjoying your own interests, friendships, work, etc.
2. Be educated about the many aspects of transition BEFORE you and your child are actually going through the process. Ask to meet with any member of the CF Team to discuss this complicated topic and break it down into manageable bits.
3. Get involved with our Center's Patient Family Advisory Board to have direct input about the transition process and how to improve this; attend the monthly meetings or just stay informed of the PFAB's work via email. (Inquire with the Social Worker for more details.)
4. Give lots of positive praise for ANYTHING your child does to take charge of their own health.
5. Teach your child how to call the doctor's office about any changes in their health in addition to first telling you.
6. Help your child understand their respiratory and GI "baseline" (how their systems typically function), and be able to describe any changes directly to the doctor.
7. Teach your child about the connection between good nutrition and lung function.
8. Avoid discussing weight in terms of favorable appearance. (e.g. Instead of commenting, "You look great now that you've put on some weight", say, "Your weight gain is so healthy and great for your lungs.")
9. Teach your child to take their own medicine and to be able to tell you the names and doses of each medicine.
10. Ask your child to remind you of their schedule of daily care.
11. Teach your child how to ask the doctor, nurse, etc. questions during an appointment, perhaps by writing them down ahead of time.
12. Either you or your child should ask the doctor, nurse or social worker for written materials about reproduction; this may be a good starting point for talking about this subject.
13. Attend some appointments with your child and some only at the end of the appointment.
14. Give your child typical, age-appropriate responsibilities around the house.
15. Start teaching independent living skills such as time management, handling his/her own money, how/ where to access information and resources on a variety of topics, food preparation, and how to drive.
16. Continue to assess your child's interests and encourage these. Help him/ her weigh the pro's and con's of different vocations/ careers as people with CF need to think about a healthy work environment.
17. Encourage your child to do volunteer work or even get a part-time job.
18. Teach your child basic information about health insurance, e.g. that their medical appointments are not completely paid for by insurance and that there are "co-pays" for each visit, or that when you work for someone/ a company they pay for part of the insurance plan and you pay for some of it, etc. Stress how important it is for them to have insurance AT ALL TIMES.

19. Ask your child how they have talked about CF to friends, teachers, etc., and support them in their decisions about how and with whom to discuss it. Offer suggestions if they seem to be having difficulty with this.
20. Ask your child questions about any aspect of their lives and LISTEN when they actually respond! Rather than offering words of wisdom, just continue to ask more questions and listen some more. (This helps them learn to explore and analyze situations/ problems which is the first step in figuring out solutions to problems, a crucial skill needed in ALL areas of life as an independent adult.)
21. Have difficult conversations with your child when you are both feeling your best, and maybe do so while engaged in an activity you both enjoy so that it is more casual, less intense.
22. Pay attention to signs of depression, anxiety, drug/ alcohol use, and disordered eating.
23. Talk with other parents of a child with CF or other chronic illness to get ideas.
24. Use your child's school's resources for educational/ vocational information. Also, obtain information on vocational planning from the Bureau of Rehabilitation Services or visit the Connecticut Department of Labor website: [www.ctdol.gov](http://www.ctdol.gov).
25. Explore both State and Federal assistance programs at least one to two years in advance of your child's 18<sup>th</sup> birthday. (See previous sections of this Notebook on income and insurance assistance.)

Finally, there are many resources on-line to explore, parent advocacy groups, and our own Center's Patient Family Advisory Board members to contact so you can be continually involved in your child's care even as he/ she begins to do more on their own. Ask the Social Worker for assistance with any of the above.

### **RESOURCES:**

Healthy and Ready to Work.....[http://www.hrtw.org/tools/check\\_assessment.html](http://www.hrtw.org/tools/check_assessment.html)  
Health Care Transitions.....[http://hctransitions.ichp.ufl.edu/training\\_materials.html](http://hctransitions.ichp.ufl.edu/training_materials.html)  
Tips for parents on a wide variety of adolescent issues.....[www.kidshealth.org](http://www.kidshealth.org)  
Connecticut Parent Advocacy Center.....<http://www.cpacinc.org/>  
PACER Center, Inc. .... [www.pacer.org](http://www.pacer.org)