

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.
25. Explore both State and Federal assistance programs at least one to two years in advance of your child's 18th 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
 Health Care Transitions.....http://hctransitions.ichp.ufl.edu/training_materials.html
 Tips for parents on a wide variety of adolescent issues.....www.kidshealth.org
 Connecticut Parent Advocacy Center.....<http://www.cpacinc.org/>
 PACER Center, Inc. www.pacer.org