

Transition to Adulthood for patients with CF

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What is transition?

- ▶ According to Webster's
 - “the passage from one state, stage, or place to another:
- ▶ Our goal for all patients with CF:
 - To learn about and manage their CF
 - To successfully transition from the pediatric center to the adult center
 - To lead a happy, healthy successful adult life

Stages of Transition

- ▶ Stage I: ages 8–10
- ▶ Stage II: ages 10–12
- ▶ Stage III: age 13
- ▶ Stage IV: ages 14–15
- ▶ Stage V: ages 16–17
- ▶ Stage VI: ages 18–21

Stage I

ages 8–10

- ▶ Learn what it means to have CF
 - Learn how your lungs work
 - Understand why airway clearance is necessary
 - Learn how your body uses food
 - Understand why salts and fluids are important
 - Learn names and basic understanding of reasons for medications
 - Start taking responsibility for taking own enzymes
- ▶ Understand why some people have CF and some do not
- ▶ By age 9: know all medication names, doses, frequencies
- ▶ By age 10: know why each medicine is necessary

Stage II

ages 10–12

- ▶ Know all from Stage I
- ▶ Describe how your lungs work
- ▶ Remember (most of time) to do own AWC
- ▶ Describe how your body uses food
- ▶ Take enzymes on your own
- ▶ Remember to take more salt/fluids
- ▶ By 11: learn about CF and smoking
- ▶ By 12: learn about CF and reproduction

Stage III

age 13

- ▶ Meet w/team alone
 - Answer questions independently in clinic
 - Independent clinic visits
 - Understand why you need to come to clinic quarterly
- ▶ Understand respiratory baseline & changes
- ▶ Pass performance check on AWC and meds
- ▶ Need fewer reminders to do therapies
- ▶ Understand digestive baseline & changes
- ▶ Remain independent with enzymes
- ▶ Learn to use well plan and sick plan
- ▶ Understand what testing is done and why

Stage IV

ages 14–15

- ▶ Be independent with AWC
- ▶ Be independent with enzymes
- ▶ Describe annual testing and its rationale
- ▶ Make healthy lifestyle choices:
 - Friends
 - Alcohol/drugs
 - smoking

Stage V

ages 16–17

- ▶ Plan your annual testing
- ▶ Describe healthy lifestyle choices
- ▶ Begin to monitor medications and supplies
- ▶ Begin to call CF Center directly for advice
- ▶ By 16: talk with parents about your basic health plan, cost of meds, insurance options
- ▶ By 17: develop own list of important qualities in an adult CF center

Stage VI

ages 18–21

- ▶ Independent with AWC and all meds
- ▶ Know meds, reasons, doses and frequencies for sick and well plan
- ▶ Independent clinic visits, plan annual testing
- ▶ Continue healthy lifestyle choices
- ▶ Monitor meds/supplies, call for own refills
- ▶ Call CF Center directly when sick
- ▶ Secure financial coverage or insurance
- ▶ By 18: complete advance directive

College Readiness

- ▶ Locate adult CF care options in area
- ▶ Determine insurance coverage for school
- ▶ Meet with student health center re needs
- ▶ Talk w/disability office re provisions for illnesses/admits
- ▶ Talk w/CF team to see if you need a “tune-up” just before leaving for school

College Readiness cont'd

- ▶ Plan w/parents how to get meds at school
 - Have a back up plan in case you run out of meds
- ▶ Living situation
 - Power needs: surge protectors, 3 hole grounded outlets
 - Infection control: disinfect room before unpacking, check for mold, use germacidal wipes for all surfaces/drawers, vacuum regularly
 - Determine if bathroom facilities meet your needs
- ▶ Prevention
 - Immunizations must be up to date: flu shot, HPV, meningitis
 - Avoid people with obvious viral illnesses
 - Make healthy lifestyle choices

Wellbeing

- ▶ Course Load
 - Consider CF a 4 unit course
 - Plan on finishing school in 5 years not 4
 - Plan one fun, low stress class per semester/quarter
- ▶ Exercise regularly
- ▶ Eat healthy
 - Plan to get your calories daily
 - Consider a small refrigerator &/or microwave
 - Weigh self weekly–buy a scale for your room.

Preparing for Transition

▶ Parents/adult family members

- Start at age 8 and follow transition guidelines
- Work with child to take on more responsibilities
- At age 13, support child seeing team alone at first, then jointly
- Determine age limits/terms of coverage with your insurance and start talking with the 16 year old about this
- Determine how insurance handles referrals to adult center
- Ask to connect with other parents who have successfully transitioned their children
- Rely on CF Center team for support

Preparing for Transition cont'd

▶ Adolescent/Young Adult

- Gradually assume all aspects of care
- Keep records organized
- Work w/RD to obtain/maintain appropriate weight and nutrition
- Ask to connect w/another young person with CF who has successfully completed transition
- Work w/parent to understand how insurance coverage works
- List questions for adult health care practitioner
- Work thru the Transition workbook
- Rely of parents and CF Center team for support and encouragement

Preparing for Transition con'd

▶ CF Center Care Team

- Follow the transition guidelines
- Encourage patient to interview adult care team members and choose the best fit
- Encourage patient to come to clinic visits prepared to talk about health, medications, therapies
- Remind patient/parent of CF Center Care Team support
- Contact Adult Center with records to assure smooth transition

Knowing you are ready!

- ▶ Takes responsibility for own care
 - Able to get healthy meals
 - Able to make own appointments, get refills and supplies
 - Able to identify a change in health and call CF team
- ▶ Able to discuss health history and make a plan with input from the team
- ▶ Met all goals in Transition workbook
- ▶ Has a plan for the future

Conclusion

- ▶ Transition binder given at age 8
- ▶ Tasks reviewed at every visit
- ▶ Individualized plans
- ▶ “Partnership” with CPMC, Stanford, UCSF
- ▶ Team approach: MD, RN, MSW, RD, RT
- ▶ Private Insurance, GHPP
- ▶ No “medically fragile”

Greatest Success

- ▶ Pt calls to say how well the new center is doing in caring for them
- ▶ New center calls to say how well the pt is doing

Nagging Failure

- ▶ None so far!