

<h2>Checklist before transition</h2>

- ✓ I understand my condition and can describe it to others
- ✓ I can make decisions for myself about my treatment
- ✓ I know my medications and what they are for
- ✓ I know what the adult clinic arrangements are and who will be my responsible consultant
- ✓ I know how to make my appointments
- ✓ I can make my own transport arrangements to get to hospital appointments
- ✓ I am able to talk about my worries concerning blood tests and other treatments
- ✓ I know who to call in a medical emergency
- ✓ I know the restrictions that I have to follow, including diet advice and activity
- ✓ I have sufficient knowledge about sexual health matters
- ✓ I have discussed alcohol, smoking and drug issues

Transition: what to do and when ?

Task	Age expected
Name and describe cystinosis	14
Name symptoms for cystinosis, transplant rejection, or other condition(s)	14
Have a basic understanding of genetics related to cystinosis	14
Discuss how cystinosis may affect the future	14
Take medications as prescribed	14
Carry a back-up supply of medicines and an updated list of medications	15
Explain consequences of not taking medications	15
List medications, dosage, and timing	15
Describe medication side effects	15
Go to all scheduled clinic visits and arrive on time, perhaps even traveling independently and meeting parent(s) there	16
Have a primary care doctor and know how to reach him/her	16
Know why it is important to avoid tobacco, alcohol, and illegal drugs	16
Know about sexuality, safe-sex practices, and the use of condoms to prevent sexually transmitted diseases – and be able to talk with parents, providers, and/or potential partners about these issues	16
Know about reproductive health issues related to cystinosis	17
Have a medical team that addresses all questions directly to the patient	17
See medical team independently – the team can provide parents and patients with goals to be accomplished prior to visits to allow for independent interviewing	17
Get labs as scheduled and know what is needed when, and why.	17
Have awareness of insurance information (i.e. provider, changes in insurance at what ages, etc.)	17
Have a plan for school or work after high school graduation	17-18
Graduate from high school or receive a GED	17-18
Contact clinic to schedule appointments	18
Call for medicine refills independently	18