

ADVICES FOR A SUCCESSFUL TRANSITION

« Transitioning between being a teenager and adulthood can present some very difficult challenges. Young adults with cystinosis have some additional unique challenges to deal with.

Being knowledgeable about your condition and learning how to take control of your condition can aid you in a successful transition. Try to get involved in healthcare related discussions about your care and treatment choices.

Transitioning is a very personal and gradual process. It's not abnormal to feel like you're not coping or things are moving to fast. Try speaking to friends, family or a health care professional if you are not coping »

Mr Steven Wise,
CNS Renal Metabolic Disease,
Queen Elizabeth Hospital Birmingham, UK



TRANSITION = TAKING RESPONSIBILITY

“During your childhood and young adulthood, many people took care of you: your parents, doctors and nurses. Now that you have almost grown up, it is not that they will stop caring for you, but they will pass you over some of the responsibility to care for your disease.

- Try to keep an accurate schedule of your visits*
- Keep a note of the names and contact details of your old and new doctors*
- Keep a diary of all your treatments and events which seem important*
- Do not hesitate to ask for help*
- Advice from older patients may also be helpful, but don't forget to also discuss it with your doctor”*

Dr. Alexey Tsygin
Chair, Pediatric Nephrology
Institute of Pediatrics NCZD, Moscow, Russia



THE IMPORTANCE OF EARLY TRANSITION

« It is very important that transition is commenced early and that dedicated professionals are identified to lead this process. Transfer should not take place until the necessary skills to function in an adult unit have been developed and preferably not until major educational and social milestones have been completed. Times of social or medical crisis should be avoided. Once transfer has occurred, the option to participate in a young adult clinic is distinctly advantageous. »

Dr Nicholas Webb,
Consultant Pediatric Nephrologist,
Royal Manchester Children's hospital, UK



TRANSITION AND THE IMPORTANCE OF EXERCISING

“Transitioning from adolescence to adult life can be complicated by muscle weakness. It is important to maintain a consistent exercise program to keep the muscles strong.”

Doris Trauner M.D.
Professor, Departments of Neurosciences and Pediatrics
University of California, San Diego School of Medicine
La Jolla California, USA



NEXT

TRANSITION = LEARNING

« Adolescents living with Cystinosis should take their time to adjust to this exciting stage of their lives. They are encouraged to communicate and speak up for themselves. A lot of focus should be placed on empowering adolescents to smoothly take control of their management. Learning more about medications side effects, the multisystem nature of cystinosis, and relevant transplantation issues (in a culture appropriate way) is crucial and would ultimately improve adherence to treatment and health outcomes. Being a treatable condition is a blessing, try to hold on tight to your treatment. »

Neveen A Soliman
Professor of Pediatrics
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