

The Varied Challenges of Cystinosis for Young Adults and Adults

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With improved knowledge for both health care providers and patients as well as access to a wider range of treatments there are many young adults and adults who live with cystinosis. The unique challenges of diagnosis and early years of treatment change in the second and third decades (and beyond) of life. New challenges are added (while some are lessened) and reflect the transition in usual life stages with less extensive parental involvement to the relative independence of adulthood. Persisting "childhood" challenges may need to be dealt with differently as an adult. Additionally there are new issues, both psychosocial and medical, to be faced in adulthood for those living with cystinosis.

Some of the varied challenges are:

- Transition to "adult" health care providers; the problem of change with new and multiple clinics.
- The young adult wish to be independent.
- Deteriorating native kidney function and kidney transplantation.
- Adherence to treatment balanced with the issues of "adolescence".
- Challenges of (more or less) independent living.
- Work/career, relationships and considering starting a family.
- Longer-term medical issues such as myopathy, hypothyroidism, diabetes mellitus, lung function, corneal and retinal disease may become an issue in addition to post kidney transplant concerns of cardiovascular disease and malignancy.

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