



How to let adolescents with cystinosis grow up into adults with cystinosis

The importance of a transition program

Femke Glaap-Roeven, Nurse Specialist Pediatric Nephrology

Amalia Children's Hospital
Radboudumc

To grow up with a chronic condition is a challenge

- Most adolescents experience a lower quality of life:
 - Conflict with disease and treatment in growing up
 - More worries about the future
- Slower in independence and self-management
- Are more vulnerable in life

So, it's important to support these adolescents in growing up with a chronic illness!



Transition programme

Transition is not a moment but a process from 12 to 25 years

- Pediatric nephrology:
 - Structured preparation for transition to adult care.
 - Improve adolescents to take ownership of their health needs and be fully informed about their disease
- Nephrology:
 - Continuing the transition process



Improve independence

- Know what cystinosis is, the treatment and what's important for your health,
- Know your medication,
- Make agreements and comply to them
- Learn to make choices about your healthcare,
- Learn to speak independently with doctor and nurse,
- Learn to ask questions.



Attention for psychosocial aspects

- Friends
- Hobbies/ sports
- Lifestyle
- Learn to deal with your illness in daily life
- School
- Career choice
- Sexuality



Ready for transition to adult care

- Start with a **transition program** at the age of 12 years
- Inform about **difference between child and adult care**
- Use annual a **transition questionnaire**
- Make a **transition plan**
- Inform about **rights and obligations of adolescents** (12+ and 16+)
- Encouraged to **speak up for themselves** and spend a few minutes of the **consultation without their parents** being present.
- More **coaching role of parents**
- **Meet the new doctor** before transition



Adult care

- Ultimate goal: a seamless transfer from child to adult care
- Recommend continuing to use the transition questionnaires in the first years after transition
- Attention for psychosocial aspects, besides cystinosis
- Keep the same doctor the first few years after transition
- More consultation time the first year(s)



What kind of transition program do you use?



Sponsors



3rd CNE International Cystinosis Conference

Paramedical Meeting July 7, 2022

Pharmaceutical Companies

Patient Organisations



Mdeon visa number: 22/V2/13900/008177

