



Transition from paediatric care

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Transition between being a teenager and adulthood can present some very difficult challenges. Young adults with cystinosis have some unique challenges in addition to the usual challenges that teenagers have to deal with.

This information aims to briefly explain transition and what you should expect when transferring to adult services.

What's different about adult services?

The main difference is that the environment may appear more formal and clinic will be run on a lot larger scale. Initially it may seem overwhelming but try not to let this deter you and ensure you voice any concerns.

You will have more responsibility for your health and the care you receive; therefore decisions will likely be made between you and the doctor.

How do I make transition easier?

Transition is best when it is personalised to you and your family. The healthcare professional will work with you and your family as a team to ensure a healthy independence is achieved. The following tips may be useful to you but remember that everyone is individual so do not feel under pressure to achieve everything straight away.

- Ask your doctor if your hospital has a transition programme in place
- Arrange a visit to the Adult hospital to familiarise yourself with the surroundings. This will also give you the opportunity to meet the staff that will take over your care
- Try to get involved in any healthcare related discussions about your care and treatment choices.
- Take an interest in monitoring your condition. Try checking your blood results on [Renal Patient View](#)

- Try taking some responsibility over your medications. Start learning what each one does and the side effects. Speak to your doctor about any problems you're having with your medication
- Keep a record of your clinic appointments
- Find out how to make your way to clinic on your own
- Make sure you know who to contact in an emergency
- Don't be afraid to talk to your friends and family about how you are feeling. This may seem hard at first but sharing your problems may make them easier to cope with
- Try making contact with other patients with cystinosis to discuss how they felt during transition. If you don't know anyone try asking your healthcare professional to put you in contact with another patient

Transition is not restricted to issues you have with cystinosis. Try and take the opportunity to discuss sex and sexually transmitted diseases, birth control, alcohol, and drugs.

Knowledge is power!

Being knowledgeable about cystinosis and learning to take control of your condition can aid you in a successful transition. It is well documented that being knowledgeable about your condition results in better outcomes and an increased quality of life.

Speak to your healthcare professional if you would like to learn more about cystinosis. They may be able to arrange some informal teaching or point you in the right direction of reliable information.

If you want you can use the following tool to check your progression through transition.

Questions	✓	Comments
I can briefly explain what cystinosis is and what affect it has on my health.		
I am knowledgeable about my medical history.		
I have been to the adult hospital and met the staff.		
I can access Renal Patient View and monitor my blood results.		
I know what medications I take, what they are for and the implications of not taking them.		
I ask questions in clinic.		
I take part in discussions about my treatment.		
I have had the opportunity to discuss and ask questions about alcohol and drugs.		
I have had the opportunity to discuss and ask questions about sex, sexuality, sexually transmitted diseases and birth control.		
I know who to contact in an emergency.		
I am aware of relevant support groups and local supportive services.		
I know how to get to and from clinic on my own.		
I keep a record of future appointments and know who to contact if I can't attend.		
I have discussed my health aims and goals with my healthcare professional.		

Remember that transition is a very personal and gradual process. If you feel like things are moving too fast or you are not coping it is important to discuss this with your healthcare professional and family.

Useful contacts

www.nhs.uk/livewell/sexandyoungpeople

www.talktofrank.com

www.brook.org.uk

www.kidneymatters.co.uk

www.britishkidney-pa.co.uk

www.kidneypatientguide.org.uk

www.cystinosis.org.uk

www.cystinosis.com