

The background is a solid orange color with several large, overlapping, curved lines in a lighter shade of orange, creating a sense of movement and depth. The lines are smooth and flow from the top left towards the bottom right.

Young people with cystinosis

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Living with a chronic condition

Transition from childhood to adulthood can be a particularly tough time and having a chronic condition, such as cystinosis, doesn't make this transition any easier.

It's not abnormal to feel like you are not coping. Try to talk about how you feel with your family and friends. It's a good idea to be aware of the signs of depression as this is entirely treatable. The signs of depression include:

- Feeling sad
- Getting angry easily
- Not eating at all or eating too much
- Feeling tired
- Feeling anxious
- Sleeping too much or too little
- Thinking about self harm

You should not feel embarrassed or scared to discuss this with people close to you. Informing your healthcare team to seek help is essential.

The smell of Cystagon

Cystagon is currently the only treatment for cystinosis and the only way to minimise damage to your organs. Taking your Cystagon decreases and delays the onset of complications and improves life expectancy.

Unfortunately Cystagon can lead to some unpleasant side effects. Gastrointestinal, unpleasant body and breath odour in particular are difficult for young people to cope with. At an age where you are looking to build new relationships and undertake social activities it is understandable that it may be tempting to skip doses or stop all together. However this is not advisable as skipping doses can be

detrimental to your health and can damage your organs without you realising.

You should discuss any issues you are having with side effects with your healthcare team. There are often ways to deal with the odour of Cystagon such as Vitamin B, body sprays and breath sprays.

Getting to know your cystinosis

It's important for you to be able to answer questions about your health. In an emergency situation it would be useful to know:

- When you received your transplant or when you started renal replacement therapy
- What medication you take? When you take them? And why do you take them?
- Are you allergic to anything?
- Recent illness, infection or admission to hospital
- Your history of surgery and any other medical problems you may have
- Who your main doctors are and how to get hold of them

Knowing this information will help the doctors make an accurate diagnosis in an emergency.

Networking

Ask your healthcare team if they can put you in touch with another patient who has cystinosis. Some people find it useful to discuss their problems and difficulties with people in a similar situation.

Make contact with The Cystinosis Foundation UK. They will be able to provide you with information, support and keep you updated on any future events.

Moving out

The law does not allow people under the age of 18 to have a mortgage or hold a tenancy on a rented property.

However a tenancy on a rented property can be granted if you have a joint tenant who is 18 or over.

To apply for council housing you should apply through your local council. You usually need to be 18 to apply for council housing. However some councils will let you join the waiting list at 16. Council housing is usually offered to those who need it most. For further information you should visit:

- Your local council website
- **www.gov.uk**

Employment

Throughout your working life you may experience concerns and issues that are unique to an individual with cystinosis. However living with cystinosis should not limit your choice of employment. Your choice of career should be entirely based on your intellect, ability, interests and life goals.

You should never be treated less favourably because you have cystinosis. An employer has a duty to make 'reasonable adjustments' to avoid you being disadvantaged compared to other employees. 'Reasonable adjustments' can include providing you with adapted equipment or adjusting your working hours.

If you feel like you are being discriminated against it is advised you discuss this with your employer and inform them of your rights and their responsibilities under the Equality Act 2010. If you are not satisfied you can make a complaint to the employment tribunal. All complaints must be made within three months of the alleged discrimination.

Further information about the Equality Act 2010 and your rights is available at: **www.gov.uk/discrimination-your-rights**

Equality and Human rights Commission: www.equalityhumanrights.com

Citizens Advice Bureau: www.adviceguide.org.uk

Employment Tribunal (general enquiry line): 0845 795 9775