



Cys'Teen Transition Guide

Moving to adult care



**RECORDATI
RARE DISEASES**

GROUP

Focused on the Few™

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Adolescence can be a hard time for everyone. It's the period when you move from childhood into the adult world and that comes with important psychological and social challenges. It's even more complicated when you have a rare disease.

What is a care transition?

Your paediatric nephrologist may have spoken about your “care transition”. This is the period when you switch from a paediatric to an adult care unit. This should be a progressive and seamless process, and it only starts when you are ready to make the transition to adult care. Having new contacts in your medical environment will help you to progress into adulthood and to be truly involved in your medical care, without having to depend on your parents at every step. To do that, you will need to be independent and to accept more responsibility during this period of your life.

What is this booklet for?

The aim of this booklet is to support you during your care transition, and inform the nephrologist who will look after you in the adult care unit. In addition to your medical history, which is of course essential, this booklet records the emotional side of your experiences. It will help you share what you believe are the most important details about your life and your care with the clinicians who will manage your care in the future.

This booklet is organised into 4 sections:

PSYCHOSOCIAL & EMOTIONAL EFFECTS

TREATMENT & SIDE EFFECTS

YOUR DISEASE & YOU

FUTURE PROJECTS

By answering all the questions as completely as you can, you will help your future nephrologist and any other doctors involved in your care to understand more about you, your life, your expectations and your plans for the future. This will help everyone involved in your care to know what is best for you.

So, grab a pen and let's go!

NEPHROLOGIST SECTION

Your patient has been receiving care in a paediatric unit for cystinosis. This booklet has been completed by him or her to help facilitate a seamless transition from a paediatric to an adult care unit. It is intended to improve your understanding of his or her experiences, expectations and hopes for the future.

For more information about cystinosis, please visit the dedicated Recordati Rare Diseases website:

<http://medialibrary.recordatirarediseases.com>





PSYCHOSOCIAL & EMOTIONAL EFFECTS



How do you feel about taking medication every day?



Do you have friends who also have cystinosis?

YES NO

How do you feel if you forget to take your medication?

From 1 (not at all) to 10 (completely), how well do you feel your doctors understand you?

1 2 3 4 5 6 7 8 9 10

From 1 (not at all) to 10 (completely), how well do you feel your family understands you?

1 2 3 4 5 6 7 8 9 10



How might your experiences of living with cystinosis be better understood?

By medical professionals:

By your family:



From 1 (completely) to 10 (not at all), how afraid are you of the complications of the disease?

1 2 3 4 5
6 7 8 9 10



Have you had any traumatic experiences with your medical treatment?

YES NO

YES

What happened?

How might these kind of incidents be avoided?

NO

Could you say that during some periods of your life living with cystinosis was particularly difficult? (For example: going to school, changing school, traveling, etc.)



From 1 (completely) to 10 (not at all), do you feel inconvenienced as a result of your illness?

1 2 3 4 5
6 7 8 9 10

Have you experienced any difficulties at school because of your illness?

YES

What

NO



From 1 (not at all) to 10 (completely), are you happy to switch to adult care?

1 2 3 4 5
6 7 8 9 10





TREATMENT & SIDE EFFECTS



Do you think your treatment is useful?

YES NO

Were the side effects sufficiently troublesome to make you want to stop taking your medicine?

YES NO



Do you know about your medication and what it does?

Have you ever wanted to stop taking your medicine?

YES NO



If yes: Why?



Are the side effects a problem for you?

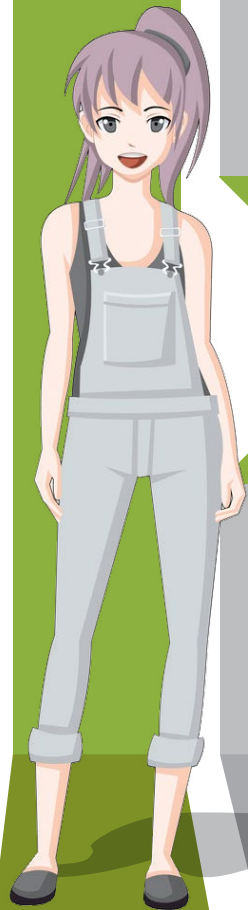
YES NO

If yes: Why?

From 1 (completely) to 10 (not at all), would you say that side effects have a big impact on your life?



- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10



YOUR DISEASE & YOU

Would you prefer if your treatment centre was closer to where you live?



YES NO

Do you want the switch to adult care to be progressive?

YES NO



Do you want to be more involved in the management of your disease?

YES NO



Do you want a team:

With different specialists managing your disease?
Explain why:

Or would you prefer your treatment to be supervised by a single specialist?
Explain why:



FUTURE PROJECTS

How might you expect the management of your condition to change, as you become an adult?



Are you in any patient associations?

YES NO



If not, would you like to join any patient associations?

YES NO

If yes, do you know which one you would like to join?



What do you want to become in the future?

What course of study do you want to follow? (science, literature, economy, history, etc.)



What skills would you like to develop in the future? (sport, music instrument, etc.)



Where would you like to live?

Do you want to travel around the world? Which countries do you want to visit?

Do you have the recommended vaccinations?

YES NO

Do you have travel insurance?

YES NO

For your information:

Foundations:

<http://www.cystinosisfoundation.org/>

<https://www.cystinosisresearch.org/>

<https://cystinosis.org/>

<https://rarediseases.org/>

Associations:

<http://www.vml-asso.org/>



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