



My healthcare

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'My Clinic'

When you attend your clinic appointment it is important that you make the most of your time with your consultant.

Before clinic

Write down any questions you may have because it can be easy to forget when you enter the busy clinic environment.

Write down any symptoms you may have experienced since your last clinic appointment. Make sure you include when the symptoms started and what makes them worse or better.

Take your Cystagon 5-6 hours before your clinic appointment so that an accurate white cell cystine level can be taken.

If you require any assistance with communication, for example an interpreter, then contact the hospital.

During your appointment

Never be afraid to double check and ask for things to be explained if you don't understand

Ask for any words you don't understand to be written down and explained.

Write down a summary of any plans that have been made or any tests that have been booked.

Don't forget to ask the questions you have written down!

Before you leave!

Write down when your next clinic appointment is.

Ask about any support groups and if there are any events/conferences coming up.

Ask who to contact if you have any problems.

Ask how you can get hold of your blood results.

You can use the following tool to assist you:

'My Clinic'

Clinic date:

My questions:

.....
.....
.....
.....

*Any new side effects/symptoms? When did it start?
What makes it better/worse?*

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.....
.....

My medication (include any tablets you have bought over the counter).

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.....

My clinic summary:

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.....
.....



Who do I contact with any problems/queries?

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.....

Are there any upcoming support group meetings or events?

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How will I receive the results of my blood test?

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The date of my next clinic appointment is:

.....

.....

Access to my records

Renal patient view (www.renalpatientview.org) allows you to access information about diagnosis, treatment and your latest blood results. Speak to your renal consultant if you are interested in signing up to renal patient view.

My care

It is important for you to have a plan of care for your condition. The following pages can be used to help plan your care over the coming months or years and provides a brief framework of what care/input you should expect to receive. You should complete your plan of care in association with a healthcare professional.

My clinic dates:

1.
2.
3.
4.
5.

My medication:

Medication name	Dose and frequency	What's it for?	Date started	Date stopped

My investigations

There are certain investigations that patients with cystinosis should have routinely to ensure they are receiving the most appropriate care. The following investigation/appointments are necessary and attendance should be discussed with your consultant.

Ultrasound scan (USS)

Date of last test

I should have this test every.....years/months*

Lung function test

Date of last test

I should have this test every.....years/months*

Echocardiogram

Date of last test

I should have this test every.....years/months*

Speech and language therapist

Date of last appointment

I should see a speech and language therapist every.....years/months*

Neurologist

Date of last appointment

I should see a neurologist every.....years/months*

Ophthalmologist

Date of last appointment

I should see an ophthalmologist every.....years/months*

*Delete as applicable

The next section is entirely up to you! If there is anything you would like to achieve, regarding cystinosis, that we can help with you can write your aims down and discuss objectives with your healthcare professional.

Aims (What you want to do)	Objectives (How it can be done)
<i>1. Example: I would like to learn more about cystinosis.</i>	<i>2. Example: Provide educational materials about cystinosis and attend conferences/events.</i>

Signature (healthcare professional)

Date

Signature (patient)

Date