



Information prescription for patients with cystinosis

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Information prescription for patients with cystinosis

What is an information prescription?

Information prescriptions contain information about the condition, treatments, care services, benefits advice, and support groups.

Information prescriptions let people know where to get advice, where to find support, and how to make contact with others with the same condition. They include helpful addresses, telephone numbers, and websites.

The aim is to provide you with information that is specific, comprehensible and timely. It is hoped that this will reduce unnecessary stress, anxiety or confusion about your condition.

The information will allow you to make informed choices about what decisions to take in relation to your health and well-being. The information prescription may make you better informed about your condition which will enable you to voice your needs to healthcare professionals, understanding your condition can also lead to better health outcomes.

How does it work?

You can have as much or as little information as you would like. The information will be given to you in an ongoing basis tailored to your individual needs. You will have the chance to discuss any of the information that has been given to you with a doctor or nurse specialist.

Contents

This information prescription is for patients with cystinosis. The following areas are available for your information prescription:

- Cystinosis: An introduction to cystinosis for patients and families
- Cystinosis: Management and treatment
- Cystinosis and your eyes
- Genetics: Information for patients and families
- Transition
- Young people: Health and personal
- Sexual health and fertility
- Diet, exercise and lifestyle
- Supportive services
- Welfare and financial information
- Helpful contacts
- Travelling with cystinosis
- 'My Care'
- 'My Clinic'

This list is not exclusive. Further information will be developed on an ongoing basis to meet the needs of the patient. Please feel free to add in any other information that you have found that you think is useful.

If you would like to provide feedback or have any suggestions please email renal.metabolic@uhb.nhs.uk.