



**Healthy living for people with  
cystinosis**

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# Healthy living for people with cystinosis

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## Introduction

Living with a life long condition, such as cystinosis puts you at a higher risk of contracting an illness or getting an infection. Therefore it is important that you lead the healthiest possible lifestyle so that you give yourself the best chance of fighting off an illness.

## General advice

There are a number of lifestyle choices everybody should try and make, whether they have a condition or not. These are:

- Not smoking
- Having a healthy balanced diet
- Exercise
- Try to avoid stress
- Drink alcohol in moderation
- Stay warm in the winter
- Use protection against the sun (sun creams etc.)

Ask for advice from a healthcare professional if you would like advice on modifying your lifestyle.

## Cystinosis specific advice

- There are some tips specific to cystinosis that you should try and follow, particularly if your kidneys are damaged, if you want to lead a healthy life and protect your kidneys and other organs. These are:
- Take your medication as prescribed and inform a healthcare professional if you are taking any over the counter medication
- Attend your clinic appointments to ensure you're receiving the best and appropriate care

- Follow advice from the healthcare team about diet and fluid intake
- Involve yourself in your care through regular discussions with your healthcare team. Agree on a 'care plan' to ensure all your needs are met
- Keep up to date with the relevant vaccinations
- Seek medical advice if you feel unwell
- Consider taking steps to ensure people are aware of your condition and who to contact in an emergency such as medical alert jewellery

## Where can I find more information?

See the below websites for specific information on the kidneys and cystinosis:

- The National Kidney Federation website – [www.kidney.org.uk](http://www.kidney.org.uk)
- Kidney Research UK website – [www.kidneyresearchuk.org](http://www.kidneyresearchuk.org)
- British Kidney Patient Association – [www.britishkidney-pa.co.uk](http://www.britishkidney-pa.co.uk)
- Cystinosis Foundation UK – [www.cystinosis.org.uk](http://www.cystinosis.org.uk)
- Rare Renal Diseases – [www.rarerenal.org](http://www.rarerenal.org)
- Cystinosis Research Network – [www.cystinosis.org](http://www.cystinosis.org)

The following NHS websites can provide you with a wealth of information about various health topics and point you in the right direction of local services:

- NHS Stop Smoking Services website – [www.smokefree.nhs.uk](http://www.smokefree.nhs.uk)
- NHS Immunisation Information website – [www.immunisation.nhs.uk](http://www.immunisation.nhs.uk)
- NHS Choices – [www.nhs.uk](http://www.nhs.uk)
- NHS Live well – [www.nhs.uk/livewell](http://www.nhs.uk/livewell)
- Change 4 Life – [www.nhs.uk/change4life](http://www.nhs.uk/change4life)