Cystic Fibrosis all about nutrition

Staying hydrated and cystic fibrosis

The Cystic Fibrosis Trust is grateful to the dietitians from the Cystic Fibrosis Dietitian Group UK (CFDGUK) who prepared the information in this leaflet.

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Contents

Introduction

This information on hydration is for people with cystic fibrosis (CF) aged 10 years and older. If you need advice on fluid intake for younger children, please discuss it with your child's dietitian, as a younger child may have more individual requirements.

Why is good hydration important when you have cystic fibrosis?

Every cell in the body needs water to work properly. Your body therefore needs new supplies of water daily to allow it to function effectively. Keeping well hydrated can help to keep the mucus in the lungs thinner and make your airway clearance easier, as well as help keep food moving through your gut.

There is some evidence that people with CF do not always feel thirsty when their bodies need more fluid. This may be due to the high salt loss in sweat, which leads to not feeling thirsty even after losing a lot of body fluid. Relying on your sense of thirst is not a good indicator of how much you need to drink as you may already be dehydrated by the time you feel thirsty.

The signs and symptoms of dehydration

Signs and symptoms of dehydration will vary in severity and you may not experience them all at the same time. Common signs may include:

- increased thirst
- dry, sticky mouth
- headache
- feeling tired or irritable
- poor concentration
- dizziness
- not passing urine regularly

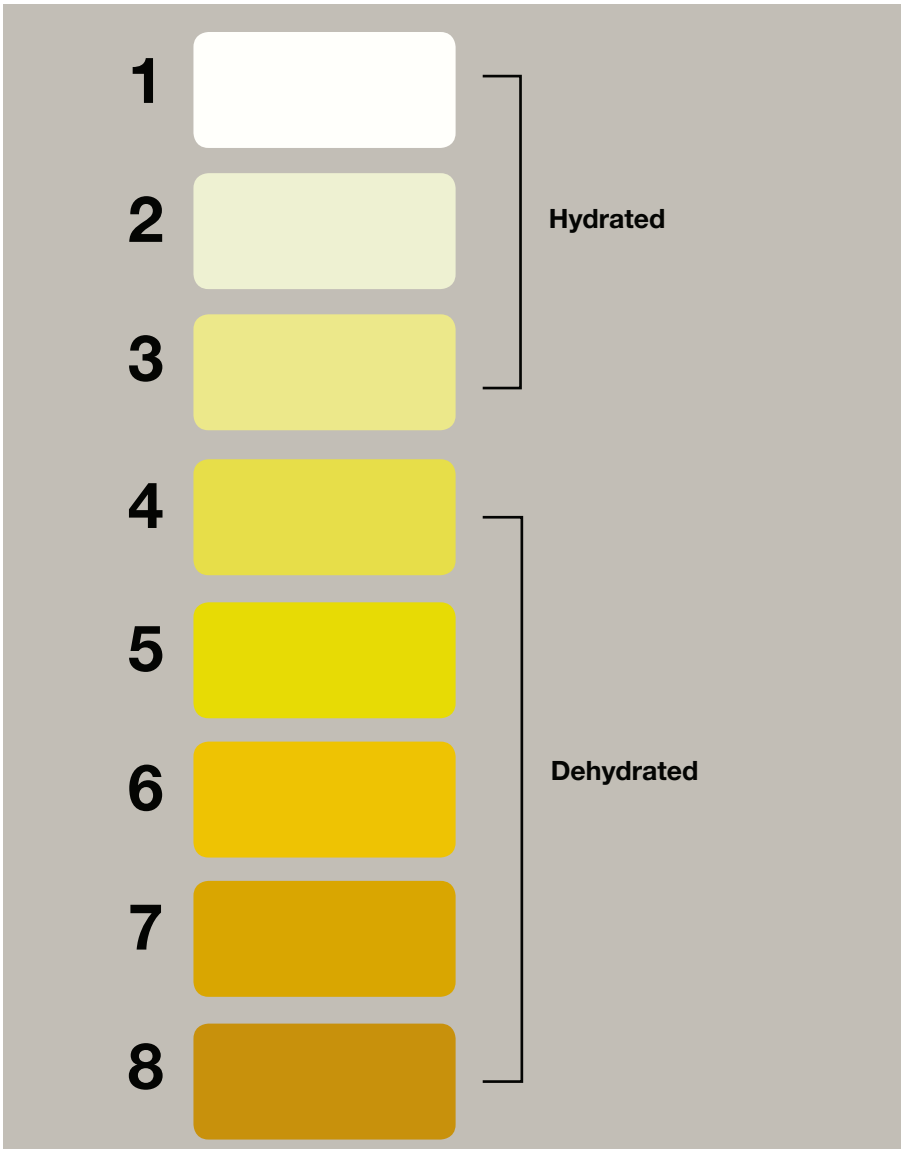
Specific symptoms in people with cystic fibrosis may include:

- thick sputum that may be more difficult to clear from your airways
- increased risk of gastrointestinal problems such as constipation or Distal Intestinal Obstruction Syndrome (DIOS)

How can I tell if I am well hydrated?

A good marker of hydration is to look at the colour of your urine. If you are well hydrated, your urine will be a pale straw-yellow colour. If it is darker yellow or brown it means you are likely to be dehydrated.

Remember that some vitamins and medications can alter the colour of your urine. If you are unsure, please check with your CF team.



Use this urine colour chart to check for signs of dehydration

What are my fluid requirements?

Fluid requirements vary depending on age, gender and medical conditions. You should ask your CF team to help you decide how much fluid you will need during the day.

A rough guide for adults and children with cystic fibrosis over 14 years of age is to try and have 2,000–3,000 ml/day. Younger children will need less than this, around 1,000–1,700 ml each day.

A suggested schedule to drink 2,000ml a day

8am
200ml glass of water with medication

9am
200ml glass of fruit juice with breakfast

11am
250ml cup of coffee

1pm
200ml glass of diluted squash with lunch

3pm
250ml mug of tea

6pm
200ml glass of water with evening meal

8pm
200ml glass of milk

500ml bottle of water (throughout the day)

When might I need more fluid than normal?

- **Illness and chest infections** – if you are unwell then you may require increased fluid to cover losses caused by sweating and having a raised body temperature.
- **Hot weather and hot rooms** – you are more likely to become dehydrated in hot weather, both in the UK and when on holiday abroad. Air-conditioned rooms and hot rooms may also cause you to feel more dehydrated.
- **Exercise** – if you sweat during exercise then you are more likely to become dehydrated, even if the exercise is low intensity.
- **Raised blood glucose levels** – if you have CF-related diabetes and it is not well controlled, you may lose fluid when your blood glucose level is high.

Can I have too much fluid?

Drinking excessive amounts of fluid can be dangerous. However, people with CF will need to drink more fluid than the general population. If you are unsure about how much fluid is excessive, please consult your CF team.

What are good sources of fluid?

All drinks will provide a source of hydration, but they will vary in the nutrients and additives (such as caffeine) that they contain.

- **Water** – healthy and free, a good choice to keep you hydrated. Chilling the water may help you to drink more.
- **Tea and Coffee** – if you choose caffeinated varieties then they are unlikely to make you dehydrated, unless you drink large amounts and/or don't drink any other type of drink. Decaffeinated or herbal teas are another way of varying your hot drink choice.
- **Milk** – this is a good source of fluid, calcium and protein.
- **Diluted sugar-free squash** – this is a useful option if you don't like plain water.

- **Soft drinks including fizzy drinks** – these often contain a lot of sugar and can cause tooth decay (unless you choose diet varieties). If you are trying to lose weight it may be better to avoid drinks high in sugar. You may also find that if you have CF-related diabetes, sugary drinks lead to raised blood sugar levels. Use them in moderation and discuss with your CF team.
- **Energy drinks (eg Red Bull®, Monster Energy® and Relentless®** – contain large amounts of caffeine and sugar, which may limit the hydration effect of the drinks if consumed regularly.
- **Sports drinks/isotonic drinks (eg Powerade® and Lucozade Sport®)** – can be useful to rehydrate you more quickly than water, especially if you are doing lots of exercise or in hot weather, although you should also try to drink water alongside them.
- **Fruit juice and smoothies** – these are more nutritious than squash and count towards your five-a-day, but they do contain concentrated natural sugars and can be acidic, which can damage your teeth if consumed regularly throughout the day. Limit to one a day especially if you need to lose weight.
- **Alcoholic drinks** – these do contain water, however drinking alcohol will also increase the amount of water you lose in your urine. It is important to check with your CF team if it is safe for you to drink alcohol and to keep within the recommended limits of no more than 14 units of alcohol a week for men and women.

Practical tips for staying hydrated

- If you don't like the taste of water in hospital, take in your own bottled water or squash so that you are able to stay hydrated.
- Use a bigger glass (such as a pint glass) at home so you will automatically drink more.
- Add fresh or frozen fruit slices such as lemon, lime or orange to water to add flavour.
- Try adding sparkling water or soda water to squash or cordial for an alternative fizzy drink.
- If you are unwell and struggling to meet your fluid targets, try having foods with high fluid content such as ice lollies, jelly, custard or soup.
- Buy a reusable, spill-proof water bottle that can be easily cleaned, so that you always have access to fresh water when you are out and about.
- Consider buying an insulated cup to keep your hot drinks in when you are working or in hospital, so that your cup of tea or coffee doesn't go cold if you get interrupted.
- Try to drink after each meal and snack, if you have a poor appetite, filling up on fluid before or during a meal may reduce how much you can eat.
- If you feel tired or have a headache then try having a drink to see if these symptoms are partly due to dehydration.
- If you restrict your fluid intake because you suffer from bladder problems, discuss this with your physio team as they may be able to help you improve this. Additionally, the Cystic Fibrosis Trust has a series of leaflets on physiotherapy that includes a leaflet on Pelvic Floor Exercises cysticfibrosis.org.uk/physioleaflets

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The information in this leaflet is general, please discuss it with your dietitian for a more personalised look at the topic.

This leaflet is part of a broad series on nutrition. Leaflets are available as online downloads and printed copies and can be found here: cysticfibrosis.org.uk/nutritionleaflets. You can also order the leaflets and our other publications from our helpline or download them here: cysticfibrosis.org.uk/publications.

Our helpline is open Monday to Friday, 9am–5pm, and can be contacted on 0300 373 1000 or by emailing helpline@cysticfibrosis.org.uk. Trained staff can provide a listening ear, practical advice, welfare/benefits information or direct you to other sources of support.

The information in this leaflet is based on clinical best practice, a consensus of opinion by dietitians within the CFDGUK and a consensus document on nutrition management of cystic fibrosis, which you can read here: cysticfibrosis.org.uk/publications.