

Staying hydrated and cystic fibrosis

Cystic Fibrosis Trust is grateful to the dietitians from the British Dietetic Association Cystic Fibrosis Specialist Group who prepared the information in this leaflet.

November 2025



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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 needs water every day 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 mucus that may be more difficult to clear from your airways
- increased risk of gastrointestinal problems such as constipation or Distal Intestinal Obstruction Syndrome (DIOS)

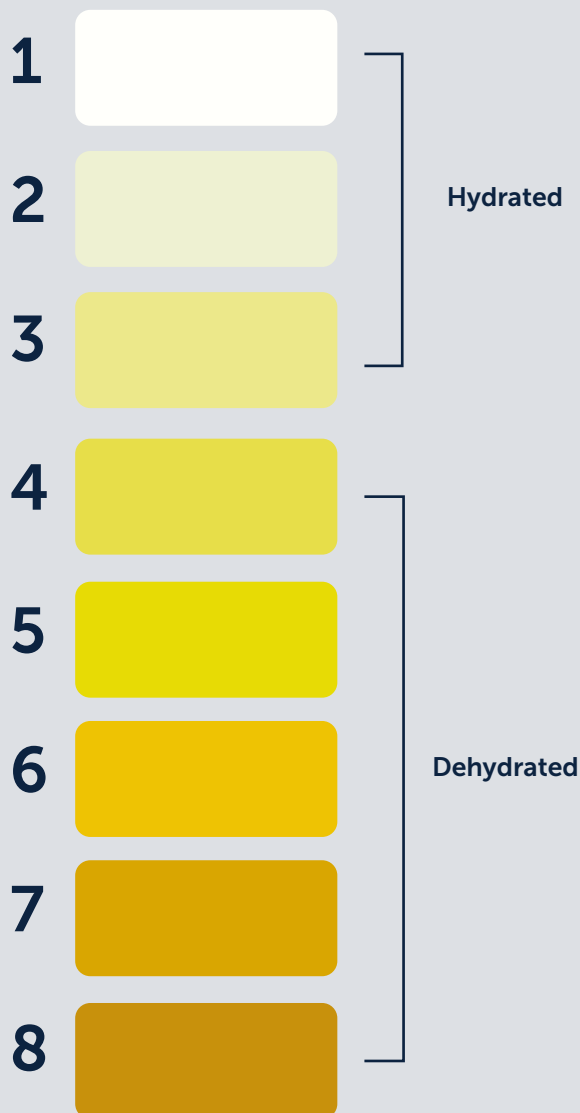
How can I tell if I am well hydrated?

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®)**
Sports drinks/isotonic drinks (eg Powerade® and Lucozade Sport®) contain a little salt and carbohydrate (5–8g/100ml). They are absorbed as fast as, or faster than, plain water. Therefore, these drinks can help to replace sodium losses and fuel for the muscles. This means they can be especially useful if exercising for more than one hour (ie when energy and sweat losses are greater) or when it's hot weather and you are sweating a lot. Drinking a flavoured sports drink has been shown to encourage drinking and therefore reduce the effects of dehydration. A homemade isotonic sports drink is 200ml squash (not low calorie or no added sugar), 800ml water and a large pinch of salt.
- **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, Cystic Fibrosis Trust has a series of leaflets on physiotherapy that includes a leaflet on Pelvic Floor exercises
cysticfibrosis.org.uk/physioleaflets

Further information

Find more information resources about living with cystic fibrosis at cysticfibrosis.org.uk/information.

Our Helpline is open 10am – 4pm Monday to Friday. It's available to anyone looking for information or support with any part of cystic fibrosis, a listening ear, or just to talk things through.

How to reach us:

- Call **0300 373 1000** or **020 3795 2184**
- Email helpline@cysticfibrosis.org.uk
- Chat with us on **Facebook, Twitter** or **Instagram**
- Message us on WhatsApp on **07361 582053**

Visit cysticfibrosis.org.uk/helpline for more information.

We welcome your feedback on our resources.

You can also ask for this resource in large print or as a text file.
Email infoteam@cysticfibrosis.org.uk.

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This leaflet has been designed to be given out by a CF dietitian, along with their advice. If you downloaded or requested it directly from Cystic Fibrosis Trust we would advise you to discuss this information with your CF dietitian.

The information in this leaflet is based on clinical best practice and a consensus of opinion by dietitians within the British Dietetic Association Cystic Fibrosis Specialist Group. For detailed guidance on CF nutrition, please see the **Consensus document on nutritional management of cystic fibrosis**. Our consensus documents as well as other publications about cystic fibrosis can be found at cysticfibrosis.org.uk/publications or they can be ordered through our Helpline.

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

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Next review due: September 2027

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The information in this resource does not replace any advice from your doctor or CF team. It is important that you seek your team's advice whenever you want to change your treatment.

Cystic Fibrosis Trust

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

cysticfibrosis.org.uk

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