Cystic Fibrosis Trust

Cystic fibrosis diabetes

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Patient Information Forum

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Contents

What is cystic fibrosis diabetes (CFD)?

Cystic fibrosis diabetes (CFD) is a common complication of cystic fibrosis (CF). **UK CF Registry** data from 2022 shows that almost a third of people living with CF over the age of 10 will develop CFD. The chance of developing CFD increases with age.

CFD is a condition linked to a small organ called the pancreas. Most people with CF are pancreatic insufficient, which means the pancreas doesn't work properly. The pancreas is an organ which has two important functions:

- Making enzymes to help digest your food
- Making a hormone called insulin, which is important for keeping your blood glucose (sugar) levels under control.

Your body converts the food you eat into energy. You need this energy for exercise, everyday activities, and thinking. Most of this energy comes from carbohydrates, which are broken down into glucose. Insulin has the job of moving this glucose from your bloodstream into your cells where it can be used for energy.

There are several different types of diabetes, but the most common types in people who don't have CF are type 1 and type 2. Although people with CF can develop these types of diabetes, CFD is a different condition to both. Type 1 diabetes occurs when the body does not produce any insulin. Type 2 diabetes occurs when the body is not using insulin in the right way, known as 'insulin resistance'.

CFD can have features of both type 1 and type 2 diabetes. In CFD, the pancreas makes some insulin, but not enough. This can lead to high blood glucose levels. Other aspects of CF can make people less able to respond to insulin, such as when nutrition is poor or when chest infection leads to inflammation. Drugs such as steroids, which some people with CF need, can also reduce the body's sensitivity to insulin.

If you or your child are diagnosed with CFD it might come as a shock. You may have new treatments to learn. Your CF team understands this may be a time of uncertainty and adjustment. They are there to assist you and provide any support you may need.

Screening for CFD

Many people don't have any signs or symptoms of CFD. This is why yearly screening for CFD is important, which usually starts from the age of 10 years. There are different ways to screen for CFD and your CF centre will let you know which test they use. The different types of screening tests are described in Cystic Fibrosis Trust's **Management of Cystic Fibrosis Diabetes** guideline.

Some children may be screened before the age of 10 years if the CF team feel there is reason to check for high blood glucose levels.

These reasons could include the following in your child:

- passing a lot of urine, feeling thirsty and drinking a lot
- poor weight gain or slowed height growth
- unexplained weight loss
- a decline in lung function or more frequent infections without an obvious explanation.

How is CFD treated?

Your CF team will give you advice about treatment that is specific to you and your dietary and clinical needs. The aim of treatment is to reduce high blood glucose levels and keep these levels within the normal range as much as possible. The main treatments for CFD are dietary changes and insulin therapy.

Diet

Dietary changes aim to improve blood glucose control whilst making sure your nutritional and health needs are met. Your CF dietitian will give you specific dietary advice to meet your current needs. This means that some people with CFD may receive different dietary advice to other people with CFD, and to people with diabetes who don't have CF.

Carbohydrates are your body's main source of energy and everyone needs carbohydrates in their diet. If you have CFD, you will need to pay attention to when and how many carbohydrates you are eating. This is because carbohydrates are broken down into glucose, so have the biggest effect on your blood glucose levels. Balancing your dietary carbohydrate, exercise, and your medical treatment are key to keeping your blood glucose levels under control.

Carbohydrates can include foods such as pasta, rice and bread

Read more about carbohydrates and diabetes:
Carbs and diabetes – Diabetes UK

Insulin

If you need insulin, your CF team will advise you on an insulin regimen to meet your needs. They will teach you how to take insulin and give you the support you need.

Oral medications

Some people will be able to manage their CFD with dietary changes and oral medication. Your CF team will assess if this is the case for you.

If you are diagnosed with CFD and start treatment for this, you are eligible for free prescriptions and you should complete a prescription charge exemption application. Speak to your doctor about how to apply.

> **"My first question at the point of diagnosis was 'what am I going to eat?' but I soon learnt that even with CFD I can eat the things I want, as long as I manage the glucose/sugar in my diet."**
>
> Martin, person with CF

Monitoring blood glucose levels

Your CF team will advise you how often and when you should be checking your blood glucose levels. Blood glucose levels can be monitored by pricking your finger and using a blood glucose meter or by wearing a continuous glucose monitor (CGM) such as FreeStyle Libre® or Dexcom®. A CGM device can reduce the need for regular finger prick tests. Normal blood glucose levels are generally between 4–10mmol/l, but this may vary and your CF team will recommend blood glucose targets for you.

Hypoglycaemia

Hypoglycaemia, also known as a 'hypo', happens when blood glucose levels drop below 4mmol/l. Low blood sugar can feel different for different people.

Symptoms might include:

- trembling or shaking
- sweating
- a fast pulse or heart palpitations
- mouth or fingers feeling tingly
- hunger
- headache
- faintness
- difficulty concentrating and confusion
- blurred vision
- turning pale
- feeling anxious, irritable, or tearful

It is important to be able to recognise when your blood sugar is too low so you can treat it quickly. A hypo can be treated by eating or drinking 15–20g of fast-acting carbohydrates, such as four jelly babies, five glucose or dextrose tablets, a small glass of a sugary drink (not diet), or two tubes of a glucose gel such as GlucoGel®.

Read more about managing hypos:
Having a hypo, Guide to diabetes – Diabetes UK

Annual review for complications

Having high blood glucose levels over a long period of time is usually linked to complications. This is because it can damage blood vessels and nerves in the body. You can avoid complications by diagnosing CFD early, getting high glucose levels under control, and having regular checks for signs of complications. If you have CFD, you will have a yearly diabetes review for signs of complications. This may be with your GP, local CFD specialists, or CF team.

The diabetes annual review will usually include:

- review of your recent clinical history, such as respiratory and gastrointestinal health
- weight
- dietary review
- lung function
- blood pressure measurement
- blood tests for fat in the blood, chemicals that affect heart rhythm, kidney function, liver function, and blood glucose levels
- urine test for kidney function
- review of blood glucose levels
- review of diabetes treatment, such as your insulin doses, injection sites and techniques
- referral to local retinopathy service for eye screening
- foot examination
- review of wellbeing

Driving

If you have diabetes that is treated with insulin or some oral medications, you need to tell the Driver and Vehicle Licensing Agency (DVLA) and your motor insurance provider. If you live in Northern Ireland, it's the Driver & Vehicle Agency (DVA).

Read more about driving when you have diabetes
Diabetes: Safe Driving and the DVLA – Trend Diabetes

Driving when you have diabetes – Diabetes UK

Diabetes and driving – GOV.UK

Exercise

Exercise is important for your health and wellbeing. During exercise, your body uses up glucose for energy. How exercise affects your blood glucose levels will depend on the type of exercise you're doing and how long you're doing it for. You should discuss your exercise plans with your CF team.

Read more about diabetes and exercise:
Diabetes and exercise – Type 1 and type 2 – Diabetes UK
Exercise nutrition in CF – Cystic Fibrosis Trust
Staying active – Cystic Fibrosis Trust

Alcohol

Alcohol can affect your blood glucose levels. You should check with your CF team whether drinking alcohol is safe for you.

Read more about drinking alcohol with CF and diabetes:
Drinking alcohol and CF – Cystic Fibrosis Trust
Alcohol and diabetes – Managing your diabetes – Diabetes UK

Pregnancy

Planning for pregnancy is very important when you have diabetes to reduce the risk of complications. Please talk to your CF team if you are thinking about getting pregnant.

If you are pregnant and have CF, it is recommended that you monitor your blood glucose levels during each trimester or continuously if you already have confirmed diabetes. Please discuss this more with your CF and obstetric teams who will be able to arrange this with you. The following blood glucose targets are recommended for pregnant women with any form diabetes:

- Fasting: below 5.3 mmol/l
- 1 hour after meals: below 7.8 mmol/l

Pregnant women with diabetes are also advised to take folic acid (5 mg/day) until 12 weeks of gestation.

Read more about pregnancy and diabetes
Pregnancy and diabetes – Diabetes UK

Psychological impact

Many people can find aspects of managing CFD emotionally challenging. Reach out to your CF team, including your CF psychologist if available, if you are struggling.

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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Next review due: October 2026

The information included in this publication is not intended to replace any advice you may receive from your doctor or CF multidisciplinary team and it is important that you seek medical advice whenever considering a change of treatment.

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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