

Cystic Fibrosis Diabetes and Impaired Glucose Tolerance

Information for parents and carers

This factsheet explains:

- What diabetes is and why it can be associated with cystic fibrosis (CF)
- What the symptoms are
- Why screening is carried out
- How cystic fibrosis diabetes (CFD) is diagnosed
- Treatment for CFD
- What is impaired glucose tolerance and what important dietary changes are recommended.

What is diabetes?

Diabetes is a condition where the amount of glucose (sugar) in the blood is too high. When people talk about blood glucose or blood sugars, they mean the same thing. Diabetes occurs when the body does not produce enough of the key hormone insulin, which everyone needs 24 hours a day. Insulin is made by tiny cells in the pancreas gland (which lies behind your stomach).

What is CF diabetes?

CFD is a unique form of diabetes. It is very common in adults and adolescents with CF. Up to 50% of adults with CF and 19% of adolescents with CF are likely to develop CFD.

The **insulin deficiency** in CFD is mainly caused by scarring (fibrosis) in the pancreas caused by thick sticky mucus. There can also be some **insulin resistance** when the body is not able to use the insulin it does make in the right way.

CFD is different from type 1 and type 2 diabetes. Very occasionally some people with CF develop type 1 diabetes and we usually carry out blood tests to rule this out.

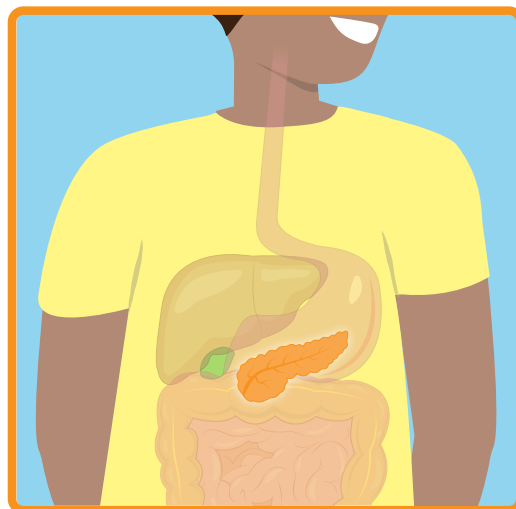
Development of CFD is no-one's fault and there is nothing you can do to prevent it.

What are the symptoms of CFD?

With routine diabetic screening, most cases of CFD are picked up before any symptoms occur. Symptoms of CFD include weight loss, increased thirst and need to pass urine more often. If untreated, high blood glucose levels can cause long term complications such as poor body weight, recurrent chest infections, reduced lung function, kidney damage and nerve damage, and can affect eyesight.

Why screen for CFD?

It is important to screen for diabetes, as often people do not experience symptoms initially. Early treatment can protect against the complications described above. Screening for CFD usually starts from ten years of age.



The pancreas lies behind the stomach

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Making the diagnosis

Libre glucose monitoring

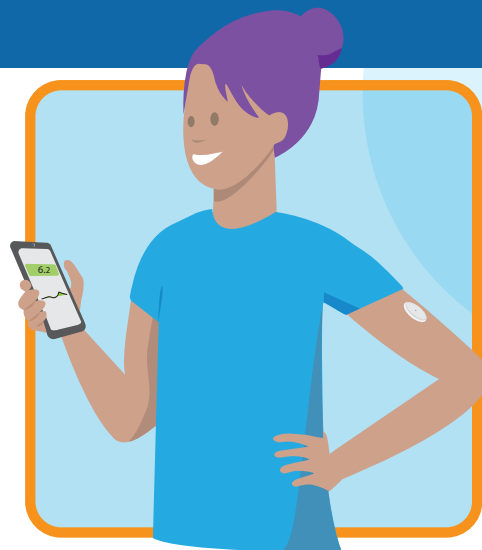
This involves attaching a Libre sensor to the upper arm, (about the size of a two pence coin). The sensor has a thin, glucose detecting filament which measures glucose in the interstitial fluid (a thin layer of fluid that surrounds the cells of the tissue below your skin).

The majority of children do not find it painful at all when the sensor is put in or afterwards.

A smart phone can be used to scan the sensor and it will display your current glucose level (with a trend arrow). With regular scanning, it gives a glucose trend over a few days. Scanning also downloads the glucose trace for the previous 8 hours, allowing 24 hour glucose traces if the sensor is scanned at least every 8 hours. A food diary should be completed alongside the glucose monitoring.

Libre sensor readings are usually carried out for 1-2 weeks to give a more real time indication of what blood glucose levels are doing with normal eating and drinking.

Diabetes may also be suspected if a random or fasting glucose level is abnormally high, although we are aware that infection and some medication can affect blood glucose levels.



Treatment

Although diabetes can't be cured, it can be treated and managed very successfully. Present UK recommendations are to treat CFD with injections of insulin. Insulin can't be taken by mouth because it is destroyed by acid in the stomach. The frequency of insulin injections could be between one and four times a day. Diabetes management is developing and in the future, patients with CFD may be able to use an insulin pump to deliver the insulin. If you have CFD, some high-energy foods may still be needed, and insulin doses can be adjusted to individual needs. It is important to avoid high sugar drinks and eat regular meals.

Impaired glucose tolerance

Impaired glucose tolerance is where glucose levels are raised beyond the normal range but not so high as to be defined as diabetes and needing insulin treatment. Avoiding sugary drinks is very important to help avoid big glucose spikes. It is also important to limit sugary foods such as sweets and chocolate, high sugar puddings and high sugar snacks. As children/young people are individual with their weight status and CF, it is important to have individualised dietary advice from a specialist dietitian experienced in the management of CFD.

