

Cystic Fibrosis Diabetes (CFD)

Information for families following diagnosis

What do I need to know about CFD?

What is it?

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 hormone insulin. Everyone needs insulin 24 hours a day. Insulin is made by tiny cells in the pancreas gland (which lies behind your stomach).

CFD (cystic fibrosis diabetes) is a unique form of diabetes. It is very common in people living with CF (cystic fibrosis).

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.

Development of CFD is no-one's fault and you could not have done anything to prevent it.

What does insulin do?

Insulin therapy improves health outcomes in patients with CF.

Insulin is vital in the process of storing the energy we get from food in the form of glucose energy. This glucose energy is stored in our liver, our muscle, and fat. Our bodies need glucose energy day and night.

Insulin deficiency in CF is associated with a '**catabolic state**' which is the term used to describe the breakdown of both fat and muscle. Remember that **insulin is 'anabolic' and helps to 'build up' your body to help keep you healthy.**

How is it diagnosed?

The glucose data from your recent Libre (or finger prick) monitoring indicates that your pancreas is struggling to produce enough insulin to keep your glucose levels in target. For some people, this may only happen after particular mealtimes.

This really means that your body is not getting all the energy it could be getting from the food/drinks you consume. You may also have seen a drop in your lung function levels.

Why do I need treatment when I feel OK?

This is a very normal question to ask.

Symptoms of CFD include weight loss, need to pass urine more frequently, and increased thirst. However, with routine diabetes screening, most cases of CFD are picked up before any symptoms occur, which is a good thing. If untreated, above target glucose levels are linked with poor weight gain, recurrent chest infections, and reduced lung function. Longer term complications can affect eyesight, and can cause kidney and nerve damage.

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How is it treated?

Insulin by injection is the recommended current treatment for CFD. The main aim of insulin therapy in CFD is to preserve and improve lung function and nutrition. It is important that we prescribe the highest amount of insulin that is needed to do both these jobs.

The diabetes team will help you learn how to give your insulin injections daily and to calculate the carbohydrate content of your food. The insulin doses will be tailored to 'match' the amount your body needs for the carbohydrate you eat/drink.

You will learn how to monitor your glucose readings either by using a Libre Flash glucose scanner or by using a finger prick blood glucose test.

Insulin is injected using an insulin 'pen' with a very fine needle. Injections are given just below the skin on your tummy, thighs, or buttocks/ bottom.

We will keep you updated regarding advances in diabetes technology.

Top Tips to manage CFD

- The diabetes and CF teams are here to help you. We realise there is such a lot of information to take on board, but it does become a lot clearer with time and we know you can do it. Keep asking questions so we can best help you.
- Keeping 'on top of' your CFD will help keep you healthy. This means learning to count carbohydrates and 'matching' the food you eat with insulin, alongside regularly measuring your glucose levels.
- Your insulin needs will change over time but please remember that once a diagnosis of CFD is made, (remember- through no fault of your own), that on-going insulin therapy is most likely.
- Some young people report feeling generally a bit better after starting insulin therapy.

