

Cystic Fibrosis Related Diabetes

rise above 7 mmols. When this happens, you may experience symptoms such as blurred vision, thirst and tiredness. If your blood sugar levels are consistently high for two or more days (i.e. above 8mmols) please contact your CF team as your insulin may need to be changed.

Who do I contact if there is a problem with my diabetes?

As this is a very specialised type of diabetes, the best person to contact if you have any questions or problems is the CF Nurse Specialists. Many GP and diabetic centres may not be the best point of contact as some of the information given may be for type 1 or type 2 Diabetes and may not be appropriate for Cystic Fibrosis Related Diabetes.

Will I have Cystic Fibrosis Related Diabetes for life?

There is a very good chance that if you develop Cystic Fibrosis Related Diabetes then you will require insulin for the rest of your life. This may seem alarming and very often patients find this difficult to understand and manage. It is important to try and view the diagnosis of Cystic Fibrosis Related Diabetes as positive. Cystic Fibrosis Related Diabetes is something that is treatable and once identified can help to maintain or in some cases improve lung function.

What can I expect from my Cystic Fibrosis Related Diabetic Service?

The CF team at The Liverpool Heart and Chest Hospital will deliver expert specialist individualised care which includes education, training, advice and support, as well as an annual screen. In unusual cases, we may need to refer you to a local diabetic service for more specialist help.

Can I drink alcohol?

You should discuss your alcohol intake with a member of the CF team. Alcohol can initially increase blood glucose levels however it is likely that your blood glucose levels may fall and result in a "hypo". You should never drink alcohol on an empty stomach. You should eat a meal or snack when you drink alcohol to avoid "hypos".

Driving

If you are required to take insulin injections for more than 3 months you need to inform the DVLA (DVLA - 0870600030). You also need to inform your insurance company that you have Cystic Fibrosis Related Diabetes as failure to do so may invalidate your insurance.

If you have any problems or concerns relating to any aspect of your Cystic Fibrosis Related Diabetes please contact the Cystic Fibrosis Nurse Specialists Monday – Friday 8am-4pm on: 0151 600 1374 or via switchboard 0151 228 1616 bleep 2144.

Further information can also be obtained from:

CF Trust - www.cftrust.org.uk

DVLA – <http://www.dft.gov.uk/dvla/medical.aspx>

CF helpline – 0300 373 1000

If you require a copy of this leaflet in any other format or language please contact us quoting the leaflet code and the language or format you require.

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This leaflet has been written to provide information about diabetes for patients with Cystic Fibrosis. We hope it answers some of the questions or concerns you may have. It is not intended to replace talking with medical or nursing staff and is to be used in conjunction with a discussion with the Cystic Fibrosis Nurse Specialists.

What is Cystic Fibrosis Related Diabetes (CFRD)?

Cystic Fibrosis Related Diabetes is a complication of Cystic Fibrosis and is different from type 1 and type 2 diabetes although it has features of both. The average age of diagnosis is around 18-21 years of age and becomes more likely as you get older.

Why do patients develop Cystic Fibrosis Related Diabetes?

Thick sticky mucus surrounds the pancreas causing the ducts to become blocked and scarred leading to fibrosis. The ducts release insulin which regulates your blood glucose levels when you have a meal. This may mean that you will not have enough insulin coming out of the pancreas and your blood glucose rises. When you are unwell and have an infection blood glucose levels may rise and certain drugs required to treat your Cystic Fibrosis can influence levels also.

How is this diagnosed?

Cystic Fibrosis Related Diabetes is diagnosed by monitoring blood glucose levels before breakfast (a "fasting sample") and 2 hours after meals. If glucose levels are high we may start you on insulin. In some cases, we may need to continue to monitor sugars either in hospital or as an outpatient before deciding whether or not treatment is required. In addition to this we now have a continuous glucose monitor which is worn for up to 5 days giving a more in depth view of your blood glucose levels. This would be discussed with you if there was a suspicion of high sugars and can be carried out in the home or hospital setting.

How is Cystic Fibrosis Related Diabetes treated?

Cystic Fibrosis Related Diabetes is usually treated with insulin injections. Depending on your blood glucose levels this may be treated once a day or up to five times a day if blood glucose levels are high throughout the day.

Advantages of treatment

Good glucose control may contribute to less infection resulting in long term benefits for your chest.
Current version amended March 2011
Possible reduction in admissions and antibiotic usage.
Possibility of Increased life expectancy.

Disadvantages of treatment

Extra treatment burden.
Risk of Hypoglycaemia.

What are the differences between CF diabetes and general diabetes?

Although CF Related Diabetes is managed differently from general diabetes however some aspects of the therapy are the same, for example, treatment of hypoglycaemic attacks (glucose levels less than 4) and insulin administration. What makes CFRD different from other types is that sometimes when well, CF patients will not need as much insulin or may not need any at all. In addition to this some of the medication used to treat CF may make managing CF Related Diabetes more difficult.

Managing your diet

In CF more calories are needed in the diet to help maintain weight. Because fatty foods are twice as rich in calories as sugar, a high fat diet is encouraged and you may need to take more crisps nuts and milk rather than sugary snacks. Your dietitian will assess the amount of sugar you currently have in your diet and may advise taking small amounts spread evenly throughout the day. Some foods however, are very concentrated sources of sugar and are best avoided altogether, e.g. lucozade. It is important to mention that you should not change your diet unless you are advised to by a member of the Cystic Fibrosis team.

Why is it important to treat Cystic Fibrosis Related Diabetes?

It may be hard to understand why we need to treat high blood

glucose levels as you may feel no different with or without treatment. It is however a very important part of your Cystic Fibrosis care and research has shown that lung function may go down quicker if Cystic Fibrosis Related Diabetes is not treated and may even be associated with reduced survival. In addition to this, if Cystic Fibrosis Related Diabetes is not treated, you may develop long term complications affecting your eyes, kidneys and circulation, all can be avoided by good blood sugar control.

What is a normal blood sugar level?

A normal blood glucose level is around 4-7 mmols. Occasionally in Cystic Fibrosis, we allow higher levels of up to 9 mmols as one off recording as long as these are not frequent.

What is hypoglycaemia and how do I manage this?

Hypoglycaemia (or a "hypo" as it is more commonly known) is a term used when your blood glucose level drops below 4 mmols. When this happens, you may experience symptoms such as sweating, dizziness, feeling hungry, loss of co-ordination, feeling faint, blurred vision, headache, and palpitations. If you experience any of these symptoms check your blood glucose. If you do not have a monitor at hand to check, treat the symptoms as a "hypo".

To treat a hypoglycaemic attack you must take something sugary that will act quickly to bring your blood glucose up. In the hospital setting this will be a "gluco juice" drink but $\frac{3}{4}$ of a glass of lucozade or non diet/zero drink will be just as effective and should be taken straight away. This is the best and quickest way of raising your blood glucose but after a short period of time your level will drop again if you do not eat some form of carbohydrate as well. Carbohydrate foods such toast, a bowl of cereal, pasta, milk, and potatoes will all help to keep blood your blood glucose level up and should be taken straight after a fast acting glucose drink.

What is hyperglycaemia and how do I manage this?

Hyperglycaemia is a term used when your blood glucose levels