

# Cystic fibrosis related diabetes (CFRD)

Information for families

Great Ormond Street Hospital  
for Children NHS Foundation Trust

**This information sheet from Great Ormond Street Hospital (GOSH) explains the causes, symptoms and treatment of cystic fibrosis related diabetes (CFRD) and where to get help.**

## **What is cystic fibrosis related diabetes?**

Cystic fibrosis related diabetes (CFRD) is different to other types of diabetes.

CFRD is caused by the build-up of thick secretions in the pancreas. These secretions damage the cells that produce a hormone called insulin. Insulin normally helps take glucose from the blood to the cells of the body.

When the insulin does not work as it normally should, it can cause blood glucose levels to go too high and this can sometimes be followed by low blood glucose levels. This is called rebound hypoglycaemia. Symptoms of hypoglycaemia include dizziness, feeling shaky, sweaty or hungry or looking pale.

A lack of insulin causes the blood glucose levels to rise. High blood glucose levels can lead to symptoms such as poor weight gain, tiredness and reduced lung function. These high levels can also increase the risk of infection.

## **How is it diagnosed?**

CFRD is diagnosed by an oral glucose tolerance test (OGTT). This test tells us how well the body can cope with a high glucose intake.

If your child's OGTT is abnormal, they may need to wear a continuous blood glucose monitoring system (CGMS). This device is worn under the skin and measures blood glucose levels every five minutes for seven days.

## Treatment

CFRD is treated with insulin alongside some changes to your food and drink intake.

Treatment aims to keep blood glucose levels between 4 and 10mmol/l.

## Insulin

Insulin is used to achieve stable blood glucose levels by helping glucose leave the blood and enter the cells where it can be used for energy.

The dose of insulin given can be adjusted according to the amount of carbohydrate eaten.

## CFRD and food

There are three main food groups: Carbohydrate, Protein and Fat.

Carbohydrate is a term for both starch and sugar (glucose) and it is the only food group that directly affects blood glucose levels.

Fat and protein have very little effect on blood glucose levels.

Carbohydrate foods are digested and absorbed into the blood at different rates.

Sugary foods will be broken down into glucose and absorbed quickly and so cause blood glucose levels to rise quickly.

Examples of sugary foods:

- jelly sweets                      ■ honey
- non-diet fizzy                  ■ syrup drinks

Starchy carbohydrates are absorbed much more slowly and so do not have an immediate effect on blood glucose levels. Examples of starchy foods:

- rice                                      ■ potato
- pasta                                    ■ bread
- chapatti                                ■ breakfast cereals

Carbohydrate is also found in fruit and in milk and milk products like yoghurt.

## Recommendations

It is important to eat regular meals and snacks, including starchy carbohydrates, protein and fat. This will ensure you get enough energy and nutrients to maintain a healthy body weight.

You should avoid any drinks that contain sugar such as fizzy drinks and squashes. You should also avoid sugary sweets.

Fruit juice contains a lot of fruit sugar so should only be taken in small quantities with a meal.

Milk and milkshakes are a good source of energy (calories) and calcium. It is OK to continue to include these as part of your diet.

All sugar-free drinks are suitable.

It is important that you continue to eat plenty of starchy carbohydrate foods as part of your meals. These foods are a good energy source and provide important nutrients. Try to include them at each meal.

## Snacks

If you currently have food or drink in between your meals then you should continue to do so.

## Hypoglycaemia (Hypo)

Hypoglycaemia is a blood glucose level of less than 4.0mmol/L.

Symptoms of hypoglycaemia include dizziness, feeling shaky, sweaty or hungry or looking pale.

You need to treat a hypo with 15g fast acting carbohydrate. Some examples are in the table below:

Fast-acting carbohydrate	Quantity	
Lucozade Energy	100ml	½ cup
Glucose tablets	5	1 tablet = 3g carbohydrate
Non-diet fizzy drink	150ml	1 mini-can
Fruit juice	150-200ml	1 small carton
Glucogel®	1-2 tubes	Each tube has 10g

Once treated wait 15 minutes and then re-check your blood glucose level.

If it is still less than 4.0mmol/l then re-treat.



If your blood glucose has increased have 15-20g of slow-acting carbohydrate to prevent your level from dropping again.

Slow-acting carbohydrate	Quantity	Carbohydrate content
Digestive biscuits	2	20g
Cereal bar	1	20g
Bread/toast	1 medium slice	15g
Banana	1 medium	15-20g
Cereal with milk	1 small bowl	25-30g





## Frequently asked questions

*Can I still drink my high calorie supplements?*

Yes. If you take high calorie supplement drinks you should continue to do so as these provide the extra calories you need. They do contain some carbohydrate but are suitable for those with CFRD. You should discuss this with your specialist dietitian.

*I have a continuous overnight feed; will this affect my blood glucose?*

Usually overnight feeds are given over several hours so the carbohydrate is broken down gradually and the glucose is absorbed slowly. There is a long acting insulin that is also absorbed slowly that can help control blood glucose overnight. Your specialist diabetes team can advise you how to manage your regimen.

*Which foods should I avoid?*

There are very few foods that you need to avoid completely. You should however avoid sugary sweets and sugar-containing drinks unless you are treating a hypo. These drinks contain pure sugar which requires very little digestion so is absorbed very quickly and can cause blood glucose to rise rapidly

*Do I need to buy diabetic products?*

Diabetic products are available but are not recommended. They contain sugar alcohols which, if eaten in large quantities, can have a laxative effect. They are also expensive.

*Do I still need to take my enzymes?*

Yes, you will need to continue to take your enzymes as advised. If you are eating extra fatty foods you may need to increase your enzyme dose to prevent malabsorption.

## Further information and support

Call our **Clinical Nurse Specialist for Diabetes** on 020 7405 9200 ext. 1597 or **Diabetes Specialist Dietitian** on 020 7405 9200 ext. 5941

**The Juvenile Diabetes Research Foundation (JDRF)** provides support and advice to families of children with diabetes. Call them on 020 7713 2030 or visit their website at [www.jdrf.org.uk](http://www.jdrf.org.uk)

**Diabetes UK** is the main support organisation in the UK for anyone affected by diabetes.

Call their Careline on 0845 120 2960 or visit their website at [www.diabetes.org.uk](http://www.diabetes.org.uk)

## Notes

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Compiled by the Diabetes Specialist Dietitian and Clinical Nurse Specialist for Diabetes in collaboration with the Child and Family Information Group

Great Ormond Street Hospital for Children NHS Foundation Trust  
Great Ormond Street  
London WC1N 3JH

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