

# **Cystic** **Fibrosis** *our focus*

**Cystic fibrosis-related diabetes**

Factsheet – March 2013

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# **Cystic fibrosis-related diabetes**

## **Introduction**

**Cystic fibrosis-related diabetes (CFRD) is common in adults and adolescents with cystic fibrosis (CF). It occurs in approximately 20% of adolescents and 40 to 50% of adults with cystic fibrosis. It is less common in children. This factsheet explains what diabetes is and why it can be associated with CF, what the symptoms are and how it is diagnosed, why screening is carried out and the care and treatment someone with CFRD should expect.**

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## What is diabetes?

Diabetes is a condition where the amount of glucose (sugar) in the blood is too high. Normally a hormone called insulin controls the amount of glucose (sugar) in our blood. Insulin is needed to move glucose from the bloodstream into the cells. In diabetes the pancreas does not produce enough insulin and the insulin produced does not work properly. When people talk about blood glucose or blood sugars they mean the same thing and often use the terms interchangeably.

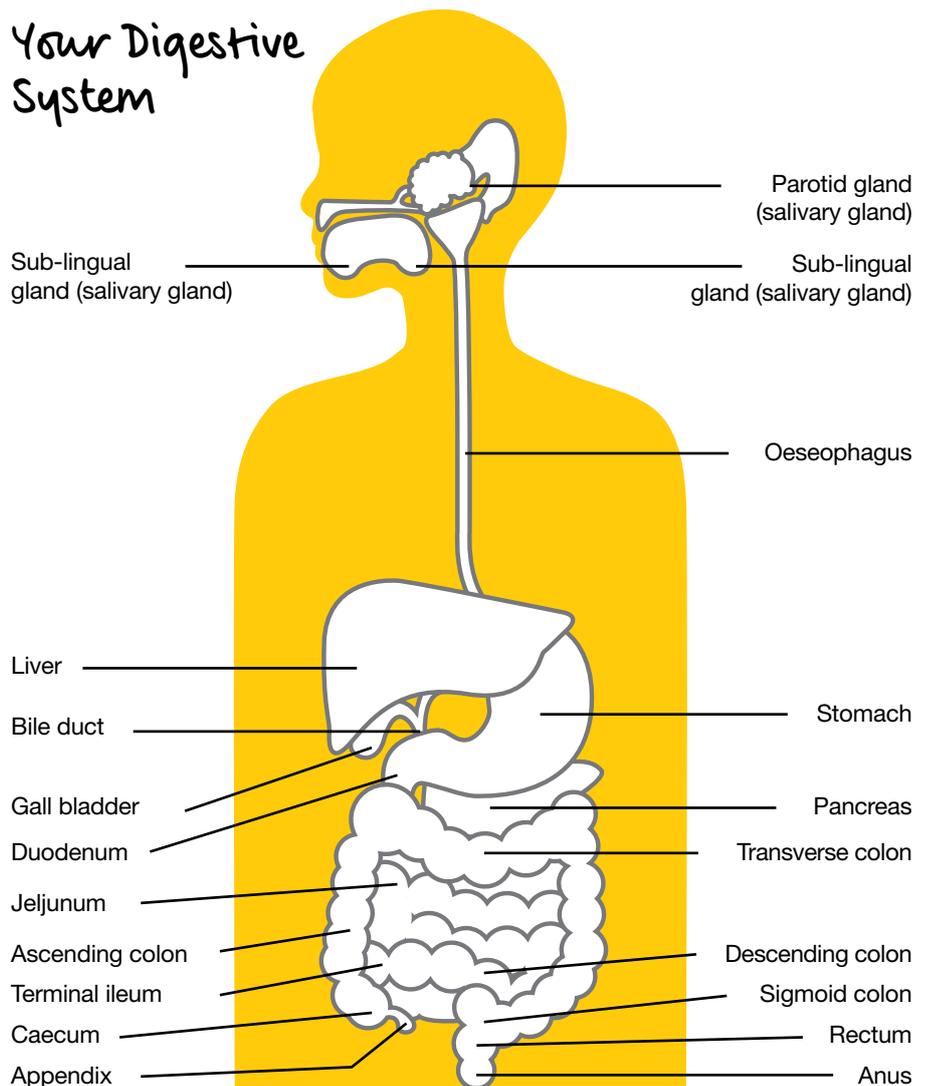
## Why is cystic fibrosis associated with diabetes?

It is well known that in most individuals with cystic fibrosis the pancreas does not work properly. This results in two important medical problems.

Firstly, the pancreas is unable to produce enough digestive enzymes, which break down foods such as carbohydrate, proteins and fats so that they can be absorbed in the gut. This is why most people with CF have to take additional pancreatic enzyme replacement therapy with food and snacks containing fat.

Secondly, the pancreas can stop producing enough insulin and this can result in CF-related diabetes.

## Your Digestive System



Organs expanded to show detail  
Liver rotated upwards to show gallbladder

## **Is cystic fibrosis-related diabetes different from diabetes in people who do not have cystic fibrosis?**

Cystic fibrosis-related diabetes is different from the two main types of diabetes. These are:

- Type 1 diabetes, which generally affects younger people and develops when the insulin-producing cells in the pancreas have been destroyed. It is not clear why this happens but it is most likely caused by an abnormal reaction of the body to the cells.
- Type 2 diabetes, which usually occurs in middle-aged or elderly people. The main causes are that the body no longer responds normally to its own insulin and/or the body does not produce enough insulin.

Cystic fibrosis-related diabetes is distinct from type 1 and type 2 diabetes but also has features of both. In addition, people with CF may be more at risk of episodes of CFRD or high blood glucose levels due to infection or drugs such as oral steroids or immunosuppressants. In some cases this may be temporary and may resolve when the acute infection is treated or the steroids reduced or stopped.

It should be remembered that some people may actually have type 1 diabetes and with improved nutrition, the diagnosis of patients with milder mutations and pancreatic sufficiency and increasing age some people may develop type 2 diabetes.

## **What are the symptoms of cystic fibrosis-related diabetes?**

With routine diabetic screening, most cases of CFRD are picked up before any symptoms occur. If untreated, the symptoms of diabetes are weight loss, increased thirst and the need to pass urine more frequently. CFRD may present as more frequent or more severe respiratory infections. Unlike type 1 diabetes, coma is virtually unknown and the onset of symptoms is generally more gradual.

## **Why screen for cystic fibrosis-related diabetes?**

It is important to screen for diabetes as early treatment can protect against weight loss, deterioration in lung function and long-term complications.

## **Making the diagnosis**

The oral glucose tolerance test (OGTT) is the most effective way of screening for CF-related diabetes. The OGTT is a simple test. After an overnight fast, blood samples are taken to measure blood glucose levels for up to two hours after drinking a prescribed amount of glucose solution. The OGTT is usually carried out annually in children with CF over 12 years of age and in adults. The OGTT may be carried out in younger children, or more frequently than annually in adults, where there is unexplained deterioration in weight or lung function.

Diabetes may also be suspected if a random or fasting glucose level is abnormally high. These measurements are less accurate for the early diagnosis of CFRD particularly as infection, food intake and some medication can all affect blood glucose (sugar) levels.

## **Abnormal or impaired glucose tolerance**

Impaired glucose tolerance (where the blood glucose levels following an oral glucose tolerance test are only moderately raised) is common and may progress to full diabetes or revert to normal. An abnormal OGTT or high random/fasting blood glucose levels are usually followed by a period of blood glucose monitoring, before and after meals, to determine the pattern of your blood sugar levels in everyday life.

A more complete picture of blood glucose levels over a period of days can be obtained by using a continuous glucose monitor and some CF centres may choose to perform this on some patients. This involves placing a small sensor under the skin and attaching a small recording device. The sensor measures glucose between the cells and gives a complete trace of what is happening 24 hours a day over a number of days. Regular finger prick tests are also needed with most forms of continuous glucose monitoring.

The results obtained from either form of blood glucose monitoring will indicate what treatment, if any, is needed. (A diabetic OGTT with normal random blood glucose levels before and after meals can occur. Your CF consultant or CF team will discuss blood glucose monitoring with you and will often arrange for a repeat OGTT if this happens.)

## **Complications of diabetes**

Early and prompt treatment of diabetes is important to avoid potential complications relating to the eyes, kidneys, nerves and blood vessels.

## **Treatment**

Although diabetes cannot be cured, it can be treated very successfully. While some people can control their blood sugar levels by taking tablets, in CFRD most people are best treated with injections of insulin. Insulin cannot be taken by mouth because it is destroyed in the stomach. It is usually given as an injection two to four times a day.

Many people with CFRD should have a high-energy diet with the insulin dose tailored to their individual requirements. They should not decrease their carbohydrate intake but should be encouraged to eat regular meals and snacks with similar carbohydrate content each day. People can be taught to count carbohydrate and to adjust their insulin dose to their dietary intake. As nutritional and clinical status can vary significantly between people, individualised dietary advice from a specialist dietitian experienced in the management of CFRD is essential. A more traditional diabetic diet may be appropriate for those people with a high body mass index or elevated blood lipids (fats).

## How will I feel?

It is very common for people with cystic fibrosis to feel completely overwhelmed when told they have an additional diagnosis of CF-related diabetes. Being given any medical diagnosis has an emotional impact and when it is on top of an existing chronic condition the effects can feel enormous. You may have many questions and concerns, such as:

- How much more treatment will I need?
- How will I fit it all in?
- What does this mean for my long-term prognosis?

Many people in these circumstances feel very low and over-burdened by the extra health responsibilities. If you feel like this, you are not on your own. Members of your CF team will have come across this before. Ask to speak to someone in your CF team who can offer you the support you need.

## Diabetic care

Specialist CF centres may have different arrangements for patients diagnosed with cystic fibrosis-related diabetes. However, close liaison between the CF team and the diabetes team is essential. Routine diabetic follow-up is important. It allows your doctor to identify any problems so that they can be treated as early as possible.

Ideally the CF doctor and the diabetes doctor (diabetologist) should also carry out a combined general and CFRD Annual Review. In practice it is usually more convenient for the CFRD Annual Review to be carried out separately.

The CFRD Annual Review usually includes:

- A review of your recent history
- A review by the CF dietitian
- A review of your insulin and injection sites/techniques
- A routine examination
- A urine test
- An eye examination
- Blood pressure reading
- Blood tests including HbA1c (a test indicating your blood sugars over the previous weeks)
- An examination of your feet
- An opportunity for you to ask questions and to learn more about your CFRD
- An opportunity for adults to update their Insulin Passport (a patient-held record which contains details of their current diabetic treatment)

## When should I check my blood sugar levels?

It is generally recommended that initially you check blood sugar levels several times each day to help determine how much insulin you need. One important difference between cystic fibrosis-related diabetes and other types of diabetes is that your blood sugar levels may be higher only after meals but your fasting and blood sugar levels before meals may be normal.

You should check your blood sugars as directed by your CF team or diabetic team but the following are general guidelines:

- *Vary the times when you check your blood sugars so that over a week you get the full picture.*
- *Blood sugar levels are best taken before meals, 1½-2 hours after meals and before, after and once during overnight tube feeds (vary the time).*
- *Check your blood sugars more often if you are unwell.*
- *Check your blood sugars if you feel strange or hypoglycaemic (hypo) (See **What is hypoglycaemia?** below.)*
- *Check your blood sugars before and after strenuous exercise.*
- *Check your blood sugars before bed if you have had alcohol.*
- *Remember to record your result in a diary and to take your diary to all clinic appointments.*

## Why should my blood sugars be well-controlled?

Keeping your blood sugar levels within an acceptable range is very important because:

- Allowing your blood sugars to run too high may mean that it takes longer to get over an infection.
- Poor diabetic control can lead to weight loss.
- High blood sugars may cause your sputum to be more viscous (thicker) than usual.
- Keeping your blood sugars within the normal range (4-7 mmol/l) helps to prevent the symptoms of diabetes.
- You may not have symptoms when your blood sugar levels are high so monitoring is essential.
- Having poor diabetic control over a period of time can lead to complications, which may affect your eyes, kidneys, feet and circulatory system.

## What is hypoglycaemia?

Everyone with diabetes should be aware of the symptoms of hypoglycaemia (low blood sugar levels of less than 4mmol/l).

Hypoglycaemia (a *hypo*) is when your blood glucose (sugar) levels are **too low**. *Hypos* can happen when you are treated with insulin and some diabetic tablets. Good diabetic control occurs when you achieve a balance between the food you eat, exercise and your tablets or insulin injections. If this balance is disturbed your blood sugar may be too high (hyperglycaemia) or too low (hypoglycaemia).

*Hypos* can occur very quickly and may be caused by:

- too little carbohydrate
- missed, delayed or late meals or snacks
- too much insulin/tablets
- more exercise than usual
- more rapid absorption of insulin after an injection
- alcohol
- hot weather

It is important to be able to recognise when your sugar is too low. Different people get different symptoms. The most common symptoms of hypoglycaemia (low blood sugar) are:

- Trembling or shaking
- Excessive sweating
- Tingling of the mouth/fingers
- Hunger

And/or:

- Headache
- Difficulty in concentration
- Confusion
- Faintness
- Blurred vision
- Irritability and bad temper
- Palpitations
- Paleness

You will usually experience one or more of these symptoms each time your blood sugar becomes too low. Everyone has different symptoms. Other people may notice that you are pale or glazed, unable to speak properly, uncoordinated or showing mood changes. If you do not treat a *hypo* you can go into a coma.

## How do I treat a *hypo*?

When you feel a *hypo* coming on, you should:

- Stop what you are doing.
- Immediately take a form of pure quick acting sugar. The amount of sugar needed depends on your size, the type of insulin and how recently you have taken insulin but 15 to 20g is usually sufficient. This can be provided by:
  - 90 to 120 (a small glass) of Lucozade
  - 100 to 200ml full sugar Cola or lemonade
  - 3 to 4 teaspoons of sugar dissolved in water
  - 4 to 5 GlucoTabs®
  - 5 to 7 Lucozade Energy® tablets
  - 5 to 7 Dextro Energy® tablets
  - 1 ½ to 2 tubes GlucoGel® or DextroGel®
- Sit down and relax for a few minutes. The symptoms should disappear.
- Take some more quick acting sugar if you do not feel better after a few minutes.
- It is important that you take a form of quick acting sugar. Chocolate is NOT recommended as an effective treatment for hypos as the body takes longer to digest lactose which is the sugar present in chocolate.
- Try not to over treat your hypo as you will then have high blood sugars

If you are not sure whether you feel *hypo*, check your blood sugar.

Once the symptoms of a *hypo* have gone, it is important to make sure your blood sugar does not fall too low again. If you are due to have a meal, eat it as soon as possible. If you are not due to have a meal, it is wise to have a small carbohydrate containing snack e.g. two digestive biscuits or a small sandwich followed by your meal at the normal time.

## Remember

- Always carry some form of sugar with you that can be easily swallowed, e.g. Glucose tablets, GlucoGel® or DextroGel® or sweets.
- Hypos occur quickly so if you feel any symptoms of hypoglycaemia (*hypo*) you should take the sweet food quickly.
- Always carry some identification with you that says you have diabetes and which insulin or diabetic tablets you take (this may be your Insulin Passport). Others will then know you are diabetic and give you the correct assistance should you have a hypo or become unwell.
- Ensure the “Emergency Information” section of your Insulin Passport is complete and up to date with your usual hypo treatment and carry it with you.
- Tell friends and relatives about your diabetes and make sure they know what to do if you are hypo.

- Aim to take your meals at regular times and do not delay or miss a meal or snack.
- Make sure you eat starchy food at each meal and snack.
- Take an extra snack before exercise or strenuous work.
- Hypos should not be a regular occurrence. When you have a hypo you should look back and identify a reason so you can prevent it happening again.
- If you do have a lot of hypos and are unable to find a reason or are having difficulty treating them, contact your CF centre or clinic doctor, dietitian or diabetic nurse specialist.
- Never drive if you feel hypo or are at risk of becoming hypo (see the Driving section on page 10).

## **What is hyperglycaemia?**

Hyperglycaemia or high blood sugar levels may be caused by:

- Not taking enough insulin or tablets
- Having the wrong type of insulin for your lifestyle
- Taking less exercise than usual
- Steroid treatment (oral or intravenous not inhaled or nebulised)
- Eating or drinking more sugary or carbohydrate food than usual
- Infection or fever
- Your insulin being damaged by extremes of temperature

Some people with cystic fibrosis-related diabetes will experience symptoms of high blood sugar levels which include:

- thirst
- passing a lot of urine
- pins and needles
- hot sweats
- blurred vision
- tiredness
- weight loss

Other people do not experience symptoms even if their blood sugar levels are very high.

Some of the symptoms of hyperglycaemia are similar to some of the symptoms of hypoglycaemia so checking your blood sugar levels is important.

## What type of diet should I have?

Maintaining a healthy body weight is one of the most important steps you can take to ensure good health. People with diabetes who do not have cystic fibrosis are normally advised to eat a high fibre, low fat, low sugar and often a low calorie diet to help control blood sugar levels and prevent too much weight gain.

In cystic fibrosis-related diabetes many people still need to eat their usual high calorie, high protein and high fat diet to help achieve and maintain a healthy body weight. This is the opposite of the usual advice for people with diabetes and it can become confusing. Keeping your blood sugars at a near normal level will help to maintain or improve your weight. However, as nutritional and clinical status can vary significantly between people individualised dietary advice from a specialist dietitian experienced in the management of CFRD is essential. A more traditional diabetic diet may be appropriate for those people with a high body mass index or elevated blood lipids (fats).

### Fatty foods

Fat does not have a direct effect on your blood sugar but it slows down the absorption of glucose (sugar) from a mixed meal. It therefore has an indirect effect on your blood sugar levels.

- Fats are found in oil, ghee, margarine, butter, mayonnaise, cream, and cheese and in high fat snacks such as nuts and crisps.
- Fatty foods are twice as high in calories as sugar. If you develop CFRD you should continue to eat a diet rich in fatty foods to help you achieve a good body weight.
- The fact that you have CF and are unable to absorb fat properly means you are less likely to develop heart disease and other illnesses associated with a high fat diet.
- It may be beneficial to your health to use monounsaturated cooking oil or spread instead of lard or butter e.g. olive oil, rapeseed oil, olive oil spread.
- Remember to adjust your enzymes if you are increasing the fat in your diet (ask your CF consultant or dietitian at your specialist CF centre or clinic).

### Carbohydrate

Carbohydrates have the most effect on your blood sugar levels. The two main types of carbohydrate are:

**Sugary carbohydrates** e.g. sugar, sweets, soft drinks, squashes, cakes, biscuits, honey, jam, marmalade.

**Starchy carbohydrates** e.g. bread, rice, pasta, potatoes, cereals, chapatti, naan, crackers, crispbread, crisps, snacks.

Both types of carbohydrate are allowed and encouraged in your diet. Sugary foods are absorbed very quickly into the bloodstream and can cause your blood glucose (sugar) to rise quickly. The amount of sugary food allowed in your diet will be assessed and advised by the dietitian. The following general rules apply:

- Sugary foods should be taken in small amounts spread throughout the day.
- Sugary foods are best taken with or after meals.
- Some foods contain very concentrated sources of sugar e.g. Lucozade, glucose drinks, and you may be advised by your dietitian to avoid these (except for treating low blood sugars).

Starchy foods take longer to digest. During digestion they are broken down to sugars and therefore starchy foods will cause your blood glucose (sugar) to rise. However, because these foods can take longer to digest they may cause a slower rise in your blood glucose (sugar). Starchy foods will give you longer lasting energy and should form part of every meal and snack.

- Balancing your dietary carbohydrate, exercise and your insulin is the key to good diabetic control.
- Eat starchy carbohydrate at every meal and snack. Spread your carbohydrate throughout the day.
- Too much carbohydrate at any one time will cause high blood sugars (hyperglycaemia) and may need adjustment of your insulin.
- Too little carbohydrate at any time, especially if you have injected your insulin, may cause low blood sugars (hypoglycaemia).
- Some people may benefit from learning to count the carbohydrate in their diet to enable them to adjust their insulin according to the amount of carbohydrate they eat at a meal or snack giving them greater flexibility and possibly improved control.

## **Protein**

Foods rich in protein do not usually have much effect on your blood sugar level. Protein is found in meat, poultry, fish, eggs and cheese. Milk, nuts, beans and pulses also contain protein but these also contain carbohydrate so will have an effect on your blood sugar level.

- Protein is used by the body to build, repair and maintain muscle and other body tissues.
- Protein-rich foods should be eaten regularly in the diet.
- Milk is a good source of protein, calories and calcium.

## Can I drink alcohol?

If you have liver problems or if you are taking certain CF medications that interact with alcohol it may be better not to drink alcohol or at least to limit your alcohol intake. You should always check with your CF consultant whether drinking alcohol is safe for you.

It is important that you understand the effects of alcohol on your blood glucose (sugar) levels. Alcohol can initially make your blood glucose rise. This may be related to the type of alcohol you drink, e.g. a spirit with a mixer or an alcopop. However, more commonly, alcohol causes your blood glucose to fall and this can lead to a *hypo*. This is because when you drink alcohol your liver breaks down the alcohol and therefore releases less sugar into your bloodstream.

- Always check with your CF consultant whether it is safe for you to drink alcohol.
- Never drink alcohol on an empty stomach. Try to have a snack (crisps, nuts) while you are drinking.
- Always have a bedtime snack to help prevent nighttime hypos, especially after drinking alcohol.
- Have no more than two to three units of alcohol at any time.

A unit is:    half pint of ordinary beer, lager or cider or  
                  one pub measure of spirits or  
                  one small (100 ml) glass of wine or  
                  half a bottle of alcopop or  
                  a small (50 ml) glass of sherry

- Check your blood sugar after drinking so that you know how alcohol affects you.
- Remember the signs/symptoms of a hypo may be mistaken for being drunk. Make sure you carry some identification that clearly states that you have diabetes. Make sure the “Emergency Information” section of your Insulin Passport is complete and up to date with your usual hypo treatment and carry it with you.
- Never forget, your awareness of hypos may be impaired due to the effects of alcohol.
- Never drink and drive.

## What about nutritional supplements?

Some people with cystic fibrosis take high-energy nutritional supplements which provide a valuable source of calories. Nutritional supplements help people to achieve energy requirements and help to prevent weight loss especially during times of infection or illness.

You should discuss with your dietitian which are the most appropriate supplements for you now that you have cystic fibrosis-related diabetes.

## What about tube feeding?

Some people require overnight tube feeding (nasogastric or gastrostomy feeding) to help them to gain and maintain their weight.

In some people with CF their diabetes will already be known when they commence tube feeding. However in others, CFRD may be discovered when they start tube feeding.

- If you are on overnight feeds you should check your blood glucose (sugar) levels before, during and after your feed.
- It may be helpful to check your blood glucose (sugar) profile throughout your feed if you are a hospital inpatient.
- You may require a different insulin or more insulin in the evening to cover your feed.
- If your blood sugar is not well controlled whilst you are feeding you will not get the full benefit of your feed.

## What about exercise?

Regular exercise is good for you for many reasons. It can help to improve your circulation, keep your lungs healthy and make you feel healthier. Exercise can also help to improve your diabetic control. These are just a few of the benefits of regular exercise.

Your CF physiotherapist will be able to advise you on the most appropriate exercise regimen.

It is, however, important that you understand the effects of exercise on your blood sugar levels.

During exercise you will use up more carbohydrate than usual. This is because the sugar (carbohydrate) gets used for energy by the exercising muscle and so lowers your blood sugar levels. This could lead to an increased risk of hypoglycaemia or a *hypo*. In addition, exercise can make your body use the insulin more efficiently and this can also increase the risk of *hypos*.

The following points are to help you plan for your exercise:

- Check your blood glucose (sugar) before starting exercise.
- Try to avoid injecting insulin into the areas of the body you will be exercising.
- To prevent your blood sugar levels from falling too low (*hypo*); you may need to take a carbohydrate-containing snack before exercising.
- If you are planning to exercise after a meal, take extra carbohydrate with that meal e.g. potato, rice, bread, pasta, chapattis.
- Fast, intense and strenuous exercise such as swimming, rugby, squash, tennis and running will need a faster supply of energy and therefore a mix of quick acting carbohydrate e.g. sugary fizzy drink, DextroEnergy Dextrosol, Glucotabs or Lucozade tablets, should be taken. This form of carbohydrate is absorbed quickly into the bloodstream. Slower acting carbohydrates e.g. bread, biscuit or fruit should also be taken to help prevent a delayed *hypo*.
- Prolonged exercise e.g. walking, golf or football will need slow acting carbohydrate e.g. a sandwich or extra carbohydrate at the meal before. You might need to take additional carbohydrate at intervals throughout or “top up” halfway through.

- Whatever the exercise, carry fast-acting sources of carbohydrate with you in case you have a hypo.
- Check your blood sugar after exercise. If you have been doing fast or hard exercise, you should check your blood sugar regularly as exercise makes your body use insulin more efficiently and the lowering effect on your blood sugar levels could last for 12 to 24 hours after exercise.

Talk to your CF team if you plan to exercise regularly or are havin problems.

Remember it's not only sport that counts as exercise. Physical work such as gardening, digging and heavy housework is included, especially if it is not part of your usual routine.

## **Will diabetes affect my holiday?**

Planning your holiday is always exciting. If you have CFRD it is important that you plan your holidays carefully.

When travelling, remember:

- Talk to your CF doctor, dietitian or diabetic nurse if you are unsure about diet or different time zones whilst you are on holiday.
- Check with your CF consultant whether you need to take salt tablets.
- Take out appropriate medical insurance that covers both your cystic fibrosis and your CF-related diabetes.
- Check you have enough insulin or tablets and equipment for the duration of the trip. Always take spares in case of breakage.
- Carry all equipment in your hand luggage. This will include insulin syringes, insulin pens, blood glucose monitoring equipment, glucose tablets, Insulin Passport or identification, insulin or tablets.
- Insulate your insulin in a cool bag whilst travelling and keep it away from direct light.
- Carry extra snacks and drinks for the journey.
- Store insulin in a cool place when you arrive.
- Make sure you drink plenty of low sugar fluids e.g. water, diet drinks, especially in hot countries.
- Enjoy yourself!

## **Drug prescriptions**

As a person with diabetes treated with insulin or tablets you are entitled to free prescriptions for all your medication (including your medications for cystic fibrosis). You can apply for a prescription exemption certificate (which lasts for five years) by completing forms available from your GP or from the Post Office. People with diabetes in the UK are also exempt from VAT on items such as blood glucose monitors and test strips.

## Illness

It is important to understand the effects of illness on your diabetes and to know what you should do if you become unwell and/or are unable to tolerate food and fluids.

- The first sign of a chest infection or illness may be that your blood sugars are higher than normal. This is quite normal and you may temporarily need more insulin or tablets. Discuss this with your CF team at your specialist CF centre or clinic.
- In some people, especially if they are unable to eat regularly, blood sugar levels may be lower than normal.
- It is important when you are ill to check your blood sugars very regularly (every four to six hours) and to record them in your monitoring diary.
- Continue your usual dose of insulin or tablets unless advised to change it by your doctor or unless your blood sugars are very low.
- If you are unable to tolerate solid food it is important to take an alternative e.g. a drink or snack every two to three hours. Suitable alternatives would be: Lucozade, milk, fruit juice, fizzy drink (not diet), ice cream, soup or a supplement drink.
- To prevent dehydration it is also important to take some fluids that do not contain carbohydrate e.g. water, sugar free drinks.
- If you are vomiting, have diarrhoea, or your blood sugars are poorly controlled (too high or too low) or if you are worried, you should contact your specialist CF centre or clinic.

## Driving

Having diabetes does not mean that you need to give up driving. However if you have diabetes that is treated with insulin or tablets, you must, by law, inform the Driver and Vehicle Licensing Agency (DVLA) on 0300 790 6806 or in Northern Ireland the Driver and Vehicle Licensing Northern Ireland (DVLNI) on 0845 402 4000.

If an insurance company asks about your diabetes you must tell them that you have the condition. Failure to do so can invalidate your insurance cover in the event of a claim. If you have just been diagnosed as having cystic fibrosis-related diabetes you should notify your insurance company.

- You must inform the DVLA if any diabetic complications develop that may affect your ability to drive safely.
- If you fail to inform the DVLA or your insurance company then your driving insurance will be invalid.
- If you already have CF-related diabetes and you are applying for a driving licence for the first time, the application form will ask whether you have a number of medical conditions, including diabetes. You should answer yes to this question.
- If you take any diabetic medication you will be sent a form (Diabetic 1) to complete prior to your application being processed.
- If you take insulin you will be issued with a restricted licence, which is a licence for one, two or three years. Renewal of restricted licences is free of charge.

- If you have a motorbike the same rules apply.
- Further information on LGV and PCV licences can be obtained from the DVLA on 0300 790 6806 or 0300 330 3000 or DVLNI (in Northern Ireland) on 0845 402 4000.
- You can also view additional information on [www.direct.gov.uk/DrivingAndMedicalConditions](http://www.direct.gov.uk/DrivingAndMedicalConditions) or [www.direct.gov.uk/driverhealth](http://www.direct.gov.uk/driverhealth).

## Remember

### Do not drive:

- If you have just started insulin and your diabetes is not yet properly controlled.
- If you have difficulty recognising the signs of a hypo.
- If you have problems with your eyesight that can't be corrected by glasses.

### If you drive you should:

- Check your blood sugar levels before you drive, regularly on long journeys and whenever you take a break. You should make sure your blood sugar is above 5mmol/L before driving.
- Avoid long, stressful journeys if you are tired.
- Always carry identification (such as your Insulin Passport) of your diabetes and some sugary carbohydrate e.g. Lucozade, Dextrose tablets, GlucGel® in the car.
- If you notice any signs of a hypo stop driving as soon as it is safe to do so, remove the ignition key and leave the driver's seat if safe to do so. This is to show that you are not in charge of a car whilst under the influence of any drugs including insulin.
- Do not attempt to start your journey again until the symptoms have disappeared. (The DVLA advises that you wait 45 minutes after the blood sugar (glucose) returns to normal).

## Pregnancy

Women with CF and/or CF-related diabetes who wish to become pregnant should discuss this with the CF multidisciplinary team/diabetes team at their specialist CF centre or clinic. Diabetes may occur in pregnancy as insulin requirements are increased at this time. People who do not have CF-related diabetes should be screened for diabetes prior to conception and in the first two trimesters. Women who have diabetes should optimise their diabetic control in the pre-conception period. They are usually referred to a Diabetic Pre-Conception Clinic to optimise their diabetes prior to conception. Individuals who are on diabetic tablets should be switched to insulin therapy before pregnancy. Good control is important as it prevents potential complications for both the mother and baby.

## Useful contacts

### Diabetes UK

10 Parkway, Camden, London NW1 7AA  
www.diabetes.org.uk  
Tel 020 7424 1000  
Email info@diabetes.org.

### Diabetes UK Careline

A support helpline for anyone with diabetes, their friends, family and carers.

Call 0845 120 2960 Monday–Friday, 9am–5pm.  
Email careline@diabetes.org.uk  
Or if you are in Scotland carelinescotland@diabetes.org.uk

### Additional reading

*Management of Cystic Fibrosis Related Diabetes Mellitus: Report of the UK Cystic Fibrosis Diabetes Working Group 2004.*

Published by the Cystic Fibrosis Trust, this publication was produced by an expert group of doctors and allied health professionals. It describes the clinical management for all health professionals working with people with cystic fibrosis-related diabetes and includes issues of education, support and advice available to patients and their carers.

The publication is a heavily referenced technical document intended for staff responsible for treating people with cystic fibrosis. However, it has always been a policy of the CF Trust to ensure such documents are made available to people with CF and their families.

### Further information

The Cystic Fibrosis Trust provides information about cystic fibrosis through our factsheets, leaflets and other publications.

Most of our publications can be downloaded from our website ordered using our online publications order form.

Visit [www.cysticfibrosis.org.uk/publications](http://www.cysticfibrosis.org.uk/publications).

Alternatively, to order hard copies of our publications you can telephone the CF Trust on 020 8464 7211.

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We would welcome your feedback on this or any other of our publications. Please email [publications@cysticfibrosis.org.uk](mailto:publications@cysticfibrosis.org.uk).



More factsheets available at:  
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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.

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