CYSTIC FIBROSIS RELATED DIABETES

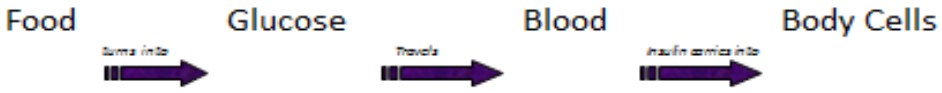
P DYCE MAY 2017

What is Insulin?

Insulin is a hormone produced in the pancreas.
The pancreas is a small organ that sits behind the stomach.

How Does the Body Use Food?

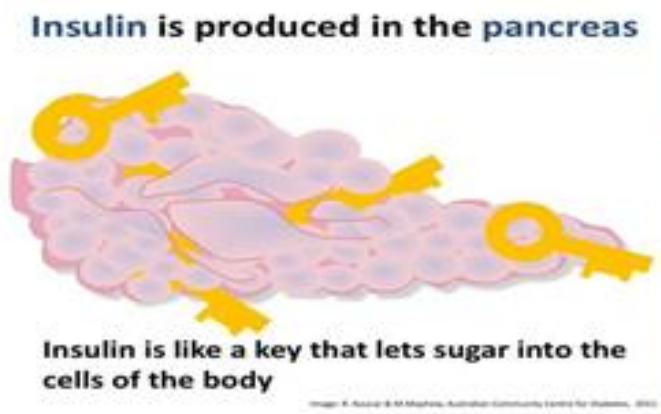
When you eat, the food is digested into *glucose (sugar)*. A hormone called *insulin* helps your body use the glucose for energy. Insulin acts as a key that opens the door of each cell in the body to let the glucose inside.

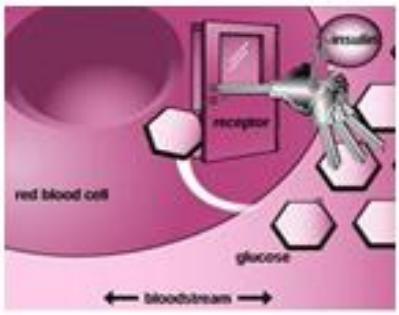


What happens without insulin?

- Body cannot turn carbohydrates into energy
- Extra glucose builds up in the blood and spills over into the urine
- Losing glucose in the urine causes frequent urination and thirst
- Protein breaks down and muscle is lost
- Loss of muscle affects breathing because lung function depends on good muscle strength
- Body's fat stores are depleted and weight loss occurs

- In CFRD extra glucose without sufficient insulin can lead to more infections.
- Infections feed off sugar and so more frequent infections, extra treatments may happen and it may have an effect on your lung function in the future.





In CFRD, the key is still there (you still have your own insulin working in your body) but there are a couple of things that can affect sugar levels.

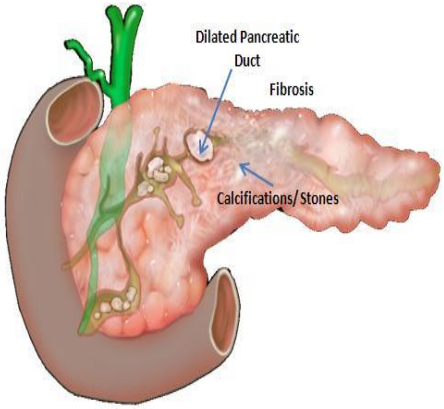
- There has proven to be a delay when insulin is released into the body when you eat which can make sugar levels rise within an hour after eating.

- The insulin struggles to unlock the door properly and so there isn't enough to control sugar levels that go up. This is usually because thick sticky mucous that surrounds the pancreas makes it more difficult for the insulin to get out and do its job.

WHAT IS CYSTIC FIBROSIS RELATED DIABETES?

Cystic fibrosis related Diabetes (CFRD) is different to type 1 and type 2 Diabetes.

CFRD can be caused by thick sticky mucous surrounding the pancreas makes it difficult for insulin to get out.



This can lead to fibrosis and damage around the cells of the pancreas so the insulin doesn't work properly.

Patients with CFRD have a delayed insulin release when they start to eat which makes sugars go high 30-60 minutes after eating. Insulin in the body still works but it is slow, not enough and struggles to get out.

It's important to realise that as you approach adulthood you are more likely to develop CFRD with 90% of adults having some degree of difficulty in controlling sugar levels by time they are 40 years of age.

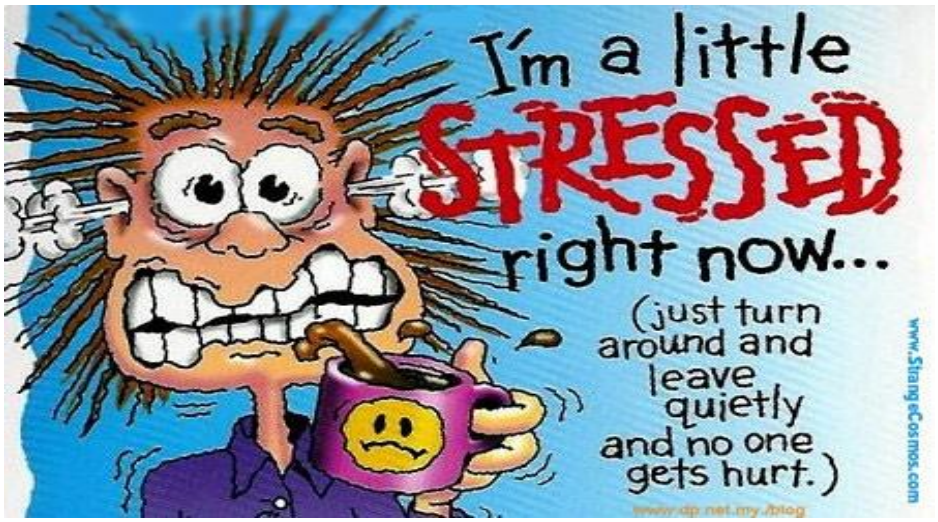
DIFFERENCES BETWEEN CFRD AND OTHER TYPES OF DIABETES

TYPE 1	TYPE 2	CFRD
Insulin deficient no insulin production	Insulin resistant with some insulin production	Variable Insulin resistance which can lead to insulin deficiency
Some insulin resistance	Variable insulin deficiency	Has a reduced amount of insulin production with a delayed response
Treated with insulin injections	Oral medication, diet and +/- insulin.	Treated with insulin injections
Can cause ketosis (very high prolonged sugars) as no insulin production	No ketosis requiring hospitalisation as some insulin produced	No ketosis requiring hospitalisation as some insulin produced
Symptoms – weight loss, thirst, and frequency in going to toilet.	Symptoms – sometimes none, lethargy, overweight	Symptoms- sometimes none, weight loss, lethargy, poor lung function, more infections

- You still have your own insulin working; it's just not effective enough. Patients who have CFRD do not develop extremely high sugars for very long periods of time (ketosis or ketoacidosis) that will not come down by themselves and require hospitalisation. Patients with CFRD do not produce ketones in their urine and do not need to test for this.

- The best way of managing high sugars is by insulin injections.
  Previous research studies have found that tablet medication doesn't work in CFRD

HOW DO YOU FEEL ABOUT YOUR CFRD?



Many people struggle with CFRD. It is a challenge to control sugar levels and balance medication, infections and steroids.
No two days will ever be the same which makes the diagnosis difficult for some people.
In addition to this, we may need you to adjust your diet slightly to help with sugar control which may include information which seems opposite to what you and your family have been told previously.

Try to view your CFRD in a positive light as without diagnosis and treatment, your lung function may decline and you may become sicker including requiring more treatment and /or hospital admissions.

You are not alone, there is a specialised team to help and support you.

Please note down your feelings. These comments with not be discussed with you unless you would like to discuss them with the Advanced Nurse Practitioner for CFRD, CF Nurse Specialists or clinical psychologist**.**

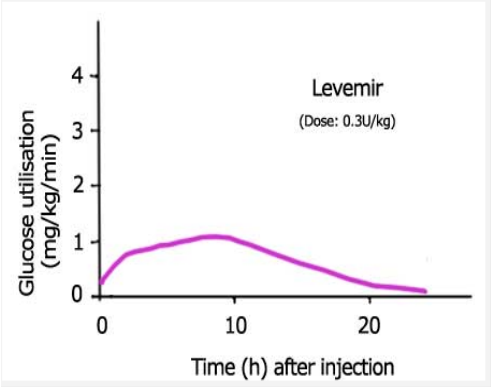
DIFFERENT INSULINS

There are many different types of insulin that can be used to help your sugar levels.

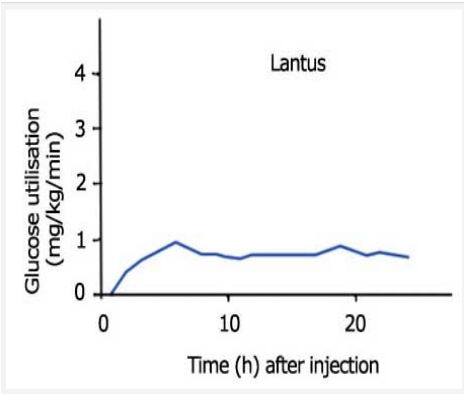
The three mains types are ;
Basal
Bolus
Basal and Bolus together

Your CFRD team will discuss and choose the type of insulin they think will be best suited to your glucose/sugar readings although this may change at a later date.

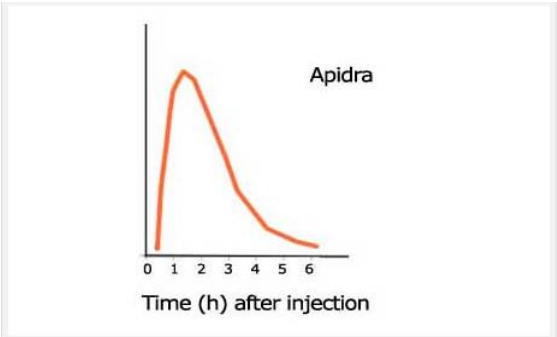
Here are some of the more commonly used insulin's and the time that they work. Find your own insulin and read the notes at the side of the picture.



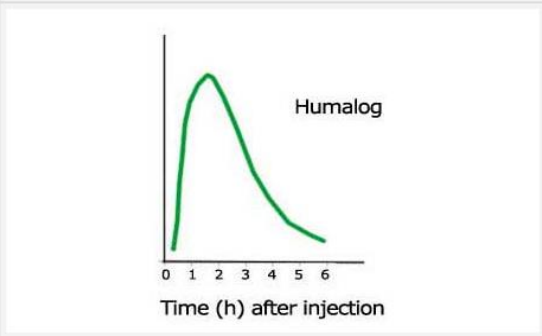
Levemir is long acting (basal) insulin which provides a mild background insulin for up to 24 hours a day. It typically lasts for around 18 hours and has a slight peak after 2-3 hours.
It is usually taken either once or twice a day at the same time.



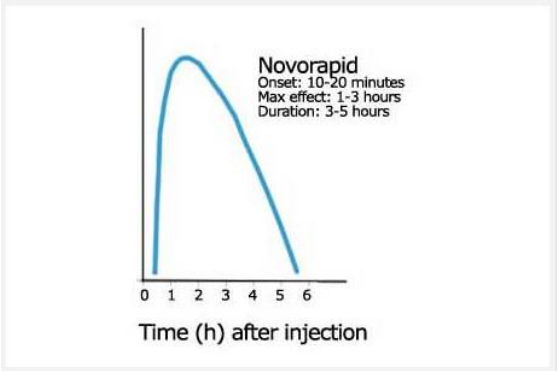
Lantus is long acting (basal) insulin which provides a mild background insulin for around 24 hours and is usually taken once a day at the same time.



Apidra is a rapid acting type of insulin which is taken just before, during or just after a meal. It acts within10-20 minutes has a peak at 1.5-2 hours and is out of your system 3-4 hours later.

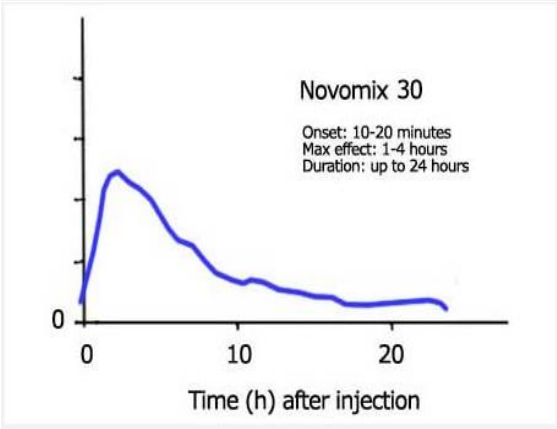


Humalog is fast acting insulin which is taking before a meal.
It acts from around 10 minutes and last around 4 hours.



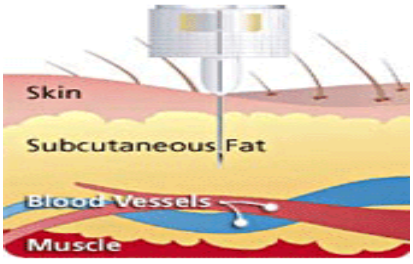
Novorapid is fast acting insulin taken with meals.

It acts 10-20 minutes after taking has a maximum effect at 1-3 hours and last 3-5 hours



Novomix 30 is a mixture of fast and slow insulin with an onset of 10-20 minutes and last up to 24 hours. Can be taken once, twice or three times a day.

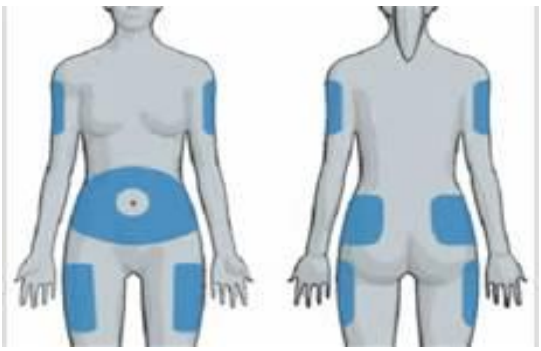
Lypohypertrophy

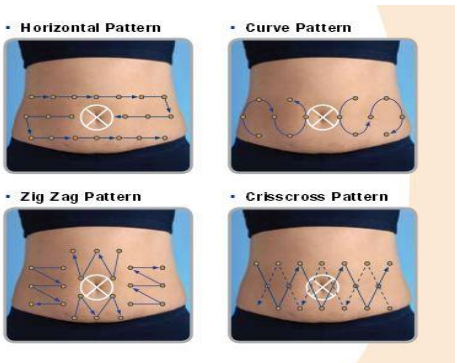


In order for insulin to be absorbed properly, it should be injected into the subcutaneous fat, which is the layer of fat just below the skin. Healthcare professionals recommend this method because research has shown it is the best way for insulin to be utilized by the body.

It is important that you change the area where you inject every time to avoid something called lipohypertrophy.

This happens when the fatty tissue underneath the skin gets damaged and the insulin may not be going in correctly causing your blood sugar levels to become erratic.





These are the areas where you can inject. Try and ensure that where you inject is a different place each time to avoid lipohyperthrophy. Rotate injection sites around. The bottom diagram shows how you can use different patterns to help you do this.

HYPOGLYCEMIA

One of the risks of insulin is that your blood sugar goes too low. If your blood sugar level is less than 4, this is called Hypoglycaemia.

Some of the symptoms of this include;
Sweating
Dizziness
Trembling
Tingling of hands, feet, lips, tongue
Hunger
Anxiety
Irritability
Headache
Poor concentration
Poor co-ordination
Double vision
Confusion
Odd behaviour
Slurred speech

If any of these symptoms happen or even if you just don't feel like yourself, you need to test your blood glucose straight away.

HYPOGLYCEMIA

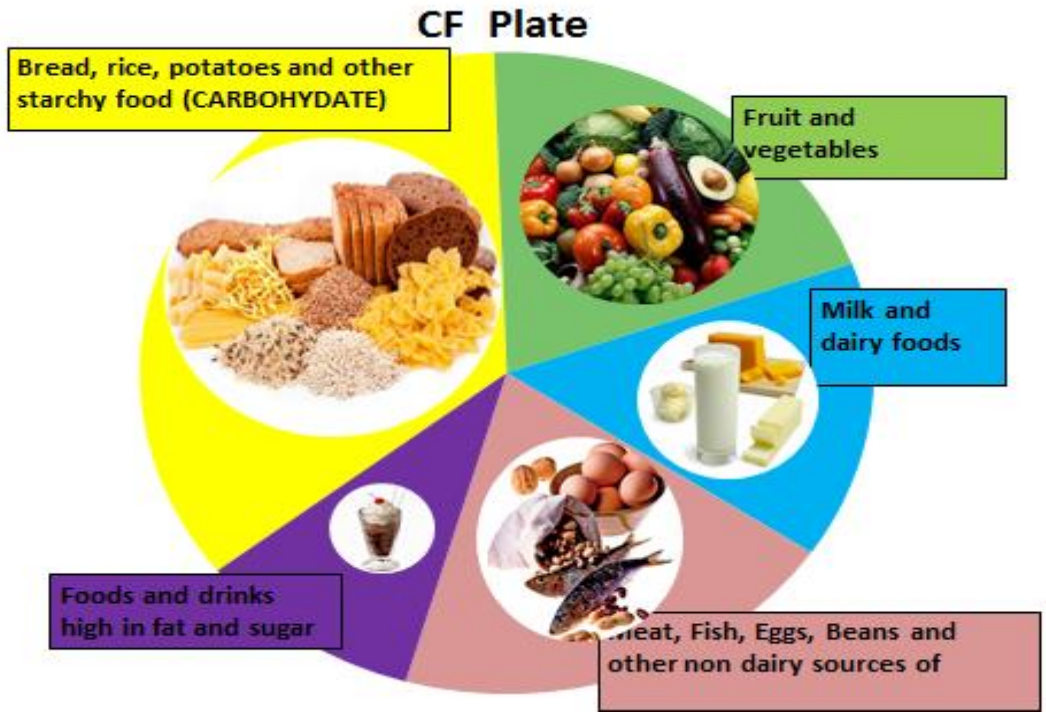
If you blood sugar is less than 4 you need to;
1. Have something sweet to bring your sugar levels up quickly. (i.e. 4 Gluco TABS/ 6 jelly babies)

2. Immediately after something sweet, you need some slow acting foods called carbohydrates in order to keep your sugar levels where they should be. Without this you may become hypoglycaemic again as the sweet fast acting sugar will not last long enough.

Recheck your sugar after 15-20 minutes and if it is still below 4, repeat steps 1 and 2 and check your blood sugar again until it is above 4.

DIETARY ADVICE

- Advice for CFRD is not the same as type 1 or type 2 Diabetes.
- Please take advice from your CFRD team and not friends, relatives or other sources of information. You need more calories that an average person.
- We would ask you to switch to no added sugar drinks, avoid Lucozade and Haribo.
- We will try our best to adjust your insulin according to your food intake.
- Patients with type 2 diabetes require a healthy diet which may not always be appropriate for a patient with CFRD.
- Patients with type 1 diabetes count carbohydrate and avoid lots of high calorie food sources however these patients do not produce any insulin and you do and need high protein, high calorific diets so please do not dramatically adjust your diet until you speak to your own CFRD dietician.



CARBOHYDRATE

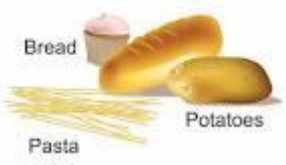
Foods containing carbohydrate affect your blood glucose level most.

Simple sugars

- This is digested very quickly And can cause a rapid rise in Blood sugar levels
- It is therefore important that You restrict the main source Of sugar if told to do so.

Complex sugars

- Starchy foods take longer to digest, releasing glucose more slowly into the blood, therefore helping to control your blood glucose levels.
- It is important to eat starchy foods at each meal.



PROTEIN

- Foods that contain protein are, meat, poultry, fish, milk, cheese, yoghurts, eggs, beans and pulses
- Protein will not affect your blood glucose levels.

FATS

- Fat is found in oil, margarine, butter, mayonnaise, cream, crisps, nuts.
- Fat does not affect blood sugar levels
- If any of these or other fatty foods are eaten in combination with carbohydrate-containing foods; can slow down can slow down the absorption of sugar

ALCOHOL

- Alcohol can initially increase your blood sugar but it will drop and cause you to have a hypo/low blood sugar level.
- Never drink on an empty stomach.
- Always have a starchy carbohydrate snack after drinking to prevent hypos.
- Check your blood sugar after drinking to see how alcohol affects you.
- Remember your awareness of hypos may be less due to the effect of alcohol.
- Signs and symptoms of hypoglycaemia may be mistaken for being drunk.
- Always carry something with you that states you have CFRD.

EXERCISE

- When we exercise, glucose is used by the muscles to provide energy
- This leads to a decrease in blood glucose levels
- To help prevent your blood glucose going too low (below 4) when you exercise, you may need to increase the amount of carbohydrate you eat before and after and may need to reduce your insulin.
- It is important that CF patients exercise and individual advice will be given by your CFRD team.
- Please be mindful that the effects of exercise do not stop as soon as you finish. It can last for the rest of the day/night.

DRIVING

- You need to monitor your blood glucose levels before you drive. Make sure that they are 5 or above before you set off and if they are not at this level, have something to eat before you set off on your journey.

- If you are required to take insulin injection for more than 3 months you need to inform the DVLA (DVLA 0870600030).

- You also need to inform your insurance company as failure to do so may invalidate your insurance and you may be prosecuted if you are in an accident.

ANNUAL SCREENING FOR COMPLICATIONS

Any patient that is taking insulin needs a Diabetic annual screen. Your GP will probably call you to attend but you don't need to as we will provide all the screening that you need here and send a copy of the results to both you and your GP.

Annual screen for CFRD consists of the following;

- **Blood pressure**
- **Usual blood taken at CF annual screen**
- **Urine sample to check kidney function**
- **Foot check**
- **Review of monitor**
- **Review of glucose control**
- **Checking injection sites**
- **Asking how you are coping with your CFRD.**

This only takes around 10-15 longer and will be done at the same time as your CF annual screen.

The only test we cannot do is a retinopathy eye screen. We will contact your GP to make sure you are referred to your local screening centre. It is important that we do these tests each year.

MEDICATION PAYMENTS

As you have been diagnosed with CFRD, you are entitled to free prescriptions.

You can apply for an exemption certificate as you have been diagnosed and require insulin injections.
Either the Advanced Nurse Practitioner or CF Nurse Specialist can sign the medical exemption form for you and send it off.

Your exemption card will then be sent to your home address 2-3 weeks later.

Paula Dyce Advanced Nurse Practitioner CF diabetes

0151 600 1199 or 0151 600 1616 bleep 2148

Victoria Jackson CFRD/CF Nurse Specialist

0151 600 1199

Sejal Pandya Specialist Dietician

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CF Nurse Specialists

0151 600 1374 or 0151 600 1616 bleep 2144