



## **Down's Syndrome Association Medical Series**

### **5. DIABETES AND DOWN'S SYNDROME**

#### **Notes for parents & carers**

#### **DIABETES AND DOWN'S SYNDROME**

There is a lot of mystique surrounding diabetes and its management, although, in most cases, for the majority of the time, it is a relatively straightforward condition to deal with. This leaflet aims to clarify the relationship between diabetes and Down's syndrome and to answer some of the common questions asked by parents and carers of people who have both conditions. It also aims to give up-to-date information on the day to day management of diabetes.

#### **WHAT IS DIABETES?**

In order to work the body needs to use energy. This is taken into the body as food which is used by the various tissues much as a car might use fuel. The most important fuels in food are carbohydrates (sugars and starches) and fats. In order to make sure that the correct amount of energy arrives at the tissues the body controls the level of these fuels in the blood. It does this by using a variety of different hormones for each of the fuels. If there is anything wrong with these hormones then the level of the relevant fuel becomes too high or too low. The major hormones controlling the level of sugar (or more properly, glucose) in the blood is insulin. This is produced from the pancreas, which is a gland situated at the back of the stomach. Increased levels of insulin cause glucose to be taken up into the body tissues and also stop the body releasing glucose from its stores. If there is not enough insulin then the levels of glucose in the blood build up. This is diabetes.

In the early stages of diabetes it is likely that nothing will be noticed. As the level of glucose in the blood gets higher, a point will be reached when it begins to spill out into the urine. When this happens, the excess glucose in the urine will drag more fluid into the urine. This leads to the typical diabetic symptoms of passing excess urine and, in order to replace the

fluid lost, thirst and excess drinking. In addition, the sugar in the urine makes people with diabetes much more likely to develop urine infections or thrush.

If the body is unable to use glucose as a fuel it turns to other sources of energy. Thus people with uncontrolled diabetes will burn more fat and protein than normal. If there is a total lack of insulin, as occurs in most people with insulin dependent diabetes, the use of fat can lead to a build up of the breakdown products known as ketones. In high concentrations these are dangerous and this situation, called ketoacidosis, is very serious and potentially fatal.

## **DIFFERENT TYPES OF DIABETES**

There are two ways in which diabetes can come about. Either the body can stop making insulin altogether or it can still make some insulin, but not enough to supply its needs. These two different processes lead to different clinical pictures which need different treatments.

Although there are some rare causes of diabetes, the vast bulk of patients with diabetes will fall into one of two different categories.

### **INSULIN DEPENDENT DIABETES**

If the body stops making insulin completely it is unable to use glucose and so breaks down protein from muscles and fat. This leads to weight loss and eventually ketoacidosis. This is usually accompanied by severe diabetic symptoms and happens over a relatively short period of time. The only way to treat this is to give back the insulin that is missing and so it is called insulin dependent diabetes (it is also known as type 1 diabetes). This usually occurs in children and young adults and is a result of the body reacting against and destroying the cells in the pancreas that produce insulin. The reasons why this happens are not known.

### **NON-INSULIN DEPENDENT DIABETES**

In older people it is much more common for the body not to be able to make quite enough insulin for its needs rather than to stop making it altogether. This still leads to diabetes but the picture is much more insidious and quite often patients with this type of diabetes are diagnosed by chance such as when they attend for a routine medical check up. Because such patients are still producing some insulin they are not at risk of ketoacidosis. Because of this they do not need insulin to keep them alive and so this type of diabetes is referred to as non-insulin dependent diabetes (or type 2 diabetes). Despite this, we do sometimes choose to use insulin as the best means of treating such patients, although for most such patients, the treatment will comprise of diet, perhaps with tablets.

Unlike insulin dependent diabetes where there is often considerable weight loss, non-insulin dependent diabetes occurs much more commonly in people who are overweight and it is not usually associated with significant weight loss.

This type of diabetes is much more common than insulin dependent and it has been estimated that three quarters of all people with diabetes will be non-insulin dependent. In people with Down's syndrome we see a different picture and it has been estimated that three quarters of people with Down's syndrome who have diabetes are insulin dependent. Most of these will present with diabetes in childhood.

### **RELATIONSHIP TO DOWN'S SYNDROME**

There has been little recent work looking at the relationship between diabetes and Down's syndrome. However, for at least 25 years it has been well recognised that diabetes is more common in children with Down's syndrome than in their ordinary peers. In Down's syndrome, diabetes might be present in as many as 2% of children up to 14 years whereas in ordinary children of the same age it is present in about 0.1%. In many cases diabetes exists alongside hypothyroidism in people with Down's syndrome. The reason for this is that both processes are caused by the body producing antibodies which destroy vital tissues, the thyroid gland in one case and the insulin producing cells of the pancreas in the other. It appears that this process is much more likely to occur in people with Down's syndrome, although the reasons for this are not known.

As indicated above, most of the diabetes in people with Down's syndrome is insulin dependent. Less is known about the occurrence of non-insulin dependent diabetes in older people with Down's syndrome. It might be expected that the tendency to obesity might make this a relatively common problem but that remains to be proved.

### **WHAT ARE THE EFFECTS OF DIABETES?**

In addition to the problems caused by high blood glucose levels as described above, diabetes can have a variety of harmful effects in other areas of the body. These include problems with the eyes, the kidneys and the feet. In addition, people with diabetes are more prone to develop strokes and heart attacks. We have known for many years that early diagnosis of these problems can lead to treatment which stops them from getting worse. So it is important that people with diabetes have regular checks to find early signs of these complications, which can

lead to treatment to stop them going blind, losing a leg or developing kidney failure. More recently, several studies have suggested that good control of blood sugar levels reduces the risk of these complications occurring in the first place.

If someone happens to have Down's syndrome as well as diabetes, the situation is no different. Indeed, it should probably be argued that in view of their other problems, such people require particularly careful diabetic management to minimise their risk of developing still further medical disorders.

### **HOW DO WE TREAT DIABETES?**

The way we treat diabetes in any individual can vary quite a lot, but there are some basic principles that apply. Firstly, we want to get the sugar level low enough so that it is not spilling into the urine and causing diabetic symptoms. This should be the minimum treatment goal for all patients with diabetes. In most patients, we would want to improve on this and do something to try and stop long-term complications of diabetes from developing or, if they are in the early stages, to arrange for treatment to prevent them getting worse. In 3 very few special circumstances, we try to get almost perfect diabetic control. The most common situation for this is during pregnancy. However, the fact that very good diabetic control might delay long-term problems has meant that increasingly we are seeking to achieve normal blood glucose levels for most of the time in most people. The drawback of this approach is that it requires a lot of effort by the person with diabetes themselves and also that there is an increased risk of low blood sugar levels which can be troublesome in their own right (see below).

### **HOW CAN WE DO THIS?**

#### **DIET**

Some patients with non-insulin dependent diabetes can be treated with diet alone. For all other people with diabetes, even if they are taking insulin or tablets, diet is still a very important part of their treatment. In the past, diabetic diets used to be very rigid with fixed amounts of carbohydrate and many patients weighing their food. Thankfully, we have realised that such rigidity is not at all necessary, even if you are on insulin. Nowadays, the dietary advice we give to most people with diabetes is little different from that given to us all as healthy eating guidelines. This involves trying to reduce the amount of sugary food and replace it with starch. In addition, we now consider it just as important to control the fat in the

diet as much as the carbohydrate. In addition to trying to reduce the fat intake, it is also important to try and get a proper balance between saturated fats (largely animal fats) and mono-unsaturated fats (such as olive oil) and polyunsaturated fats (most vegetable oils).

In people with Down's syndrome who have a tendency to be overweight, these guidelines are particularly important. They may also be quite difficult for people with Down's syndrome to stick to!

## INSULIN

Most people with Down's syndrome who have diabetes will need to take insulin.

Unfortunately, if this is given by mouth, it is digested and broken down before it can be absorbed, so it needs to be given by injection. Usually, insulin needs to be taken at least twice a day and sometimes we may ask people to give themselves four daily injections to get really good control of blood sugar levels. Although this is obviously inconvenient and is associated with some discomfort, most people have no major problems undertaking insulin injections. Modern needles mean that there is usually little more than minor discomfort with the injections. In many cases now people do not use ordinary syringes, but a variety of different 'pen' injectors. These contain a cartridge containing insulin and it is just a question of dialling up the appropriate dose and giving the injection. In most cases when the insulin cartridge runs out it is a relatively simple matter to replace it with another one but some of the newer pen injectors are fully disposable and can be thrown away when the insulin is used up.

Most people need to take a combination of both long- and short-acting insulins in order to get stable blood glucose levels throughout the day. It is possible to obtain both of these in pen injectors. There are also pens available which contain mixtures of both long- and short-acting insulin in varying proportions. In many cases it is possible to use these to avoid the need to give multiple injections. It is usually possible to find a means of giving insulin which is suitable for most people.

Many ordinary children with diabetes are quite capable of administering their own insulin, particularly if they use a pen injector. There is no reason why this should not be the case for children with Down's syndrome and diabetes. Obviously, this will take some more effort to learn and may initially require extra supervision, but the essence of insulin administration is that it should become a routine procedure and should be fitted into anybody's daily routine.

One of the problems with injecting insulin is that it is always possible to give more than the body requires at that time. This can happen if too big a dose of insulin is given. It can also occur if the needs for insulin are reduced such as by taking too little food or extra exercise. When this happens the blood sugar levels go too low, a condition known as hypoglycaemia or, more usually a 'hypo'. When this happens most people with diabetes will experience feelings that warn them and the situation usually settles down with some extra food. If this is not taken early enough, then often friends or family are able to recognise the signs, give food and remedy the situation. Only very rarely does a hypo result in unconsciousness, even if this does happen the patient is usually able to be brought round very quickly by injection treatment, which the carers can be taught to give themselves. Although there are many scare stories about people who have been severely damaged or even died as a result of hypoglycaemia, these are very much overstated and such incidents are extremely rare indeed. There is no reason why someone with Down's syndrome need be at any higher risk of hypoglycaemia. Equally, they should not have any more problems being able to deal with their symptoms. Even if this is the case for any individual, their carers could be taught to give them glucagon injections when necessary to reverse the low blood glucose levels and so they need not feel out of control in that situation.

## TABLETS

Although most people with Down's syndrome and diabetes will need insulin therapy, some older people will use tablets to control their diabetes. These come in three types. The most common belong to a group of drugs called sulphonylureas. This includes such drugs as glibenclamide, tolbutamide, gliclazide and glipizide (the names of drugs of this class end in "ide"). They work by stimulating the pancreas to make more insulin. As such they can lead to development of hypoglycaemia but this is much less common than with insulin itself.

Another form of tablet which is sometimes used is called metformin. Its action is less well understood but it probably increases the efficiency with which insulin acts, it may also delay the absorption of carbohydrate. The most modern drug is called acarbose and it acts by delaying the absorption of carbohydrate from the diet. Both these drugs are of most use in overweight patients and so may be particularly useful in people with Down's syndrome and non-insulin dependent diabetes.

Since all these tablets act in slightly different ways it is very common for us to use them in combination to achieve the desired level of blood glucose control. In addition, it is

particularly important to control the blood pressure and cholesterol levels in people with diabetes and so many people with diabetes are given treatment to deal with these problems as well as the diabetes itself.

## OTHER TREATMENTS

Various treatments have been tried to get around the problems of giving insulin by injection. At present none of them is particularly successful and they are all still in their experimental stages. These include procedures such as transplantation of the pancreas and the isolation of the insulin producing cells and implantation of these directly. Since evaluation of new treatments would usually be done in people with as few additional problems as possible it is unlikely that any such procedures will be undertaken in people with Down's syndrome in the near future.

Although different people with diabetes will have different treatment goals, it is important that we are able to check whether we are achieving these. Some means of monitoring the response to treatment is therefore necessary. With a few patients it may just be sufficient to make sure that there are no symptoms of diabetes. In such cases, the diabetes clinic can measure the overall sugar control with a blood test such as glycated haemoglobin (sometimes called HbA1) which gives an indication of what the average glucose concentration has been over the preceding couple of months.

Most people will want more information and control over their diabetes than this. That is why the majority of diabetic patients will test their own blood glucose levels. Exactly how often this is done will depend on the patient's individual circumstances, but a person on insulin might expect to average one test a day, and someone on tablets, two or three tests a week. Not only do these tests give an indication of how well the sugar level is controlled but they also help people who are on insulin treatment adjust their insulin dose to avoid excessively high or low sugar levels.

The test is performed on a small drop of blood obtained from the side of the finger with a pin prick. There are special little gadgets available which make this both easy and relatively painless. From the finger, this is then transferred onto a special strip which is impregnated with the chemicals needed to determine the level of glucose. In the past, the level of glucose was measured by comparing the colour of the strip after a set time with a reference chart. This was sometimes quite tricky to do and now there are a large number of meters

available which take the guesswork out of this process. These meters are now very simple to use and, in most cases, will do all the timing for you. All you have to do is put the blood on the strip, place the strip into the machine and read out the answer when it is displayed.

Using such a meter is well within the capabilities of most people with Down's syndrome and, since many of the meters have memories which record the results, there is no need for the user even to write down the result. Thus, there is no reason why the majority of people with Down's syndrome and diabetes should not be able to benefit from the improved control and flexibility which monitoring of blood glucose levels allows.

### **WHERE TO GET FURTHER INFORMATION OR HELP**

If you have any questions relating to diabetes, the first place to ask is your own GP or diabetes clinic or centre. In many cases, you will not even need to speak to the doctor - the nurses there will often be able to answer your questions. Obviously, you should ask to see a dietician if you have specific problems regarding diet. Similarly, a chiropodist would probably be the best first contact for problems with the feet.

Diabetes UK, formerly known as the British Diabetic Association, (10 Queen Anne Street, London W1M 0BD, Telephone: 0207 323 1531) looks after the interests of people with diabetes in the same way that the DSA does for people with Down's syndrome. They have recently published very helpful checklists of what sort of care people with diabetes should expect to receive. Just because someone also happens to have Down's syndrome, there is no reason why their care should in any way fall short of these guidelines. If you feel that your or your child's diabetes care has been compromised because of Down's syndrome, then either Diabetes UK or the DSA could try and help you get the service you deserve, if you have not been able to solve matter locally. Diabetes UK is also able to give answers to more specific questions relating to diabetes, to which you may not be able to get satisfactory answers locally. Diabetes UK has been and still is a very important force for the good of people with diabetes; if you or anyone in your family has diabetes, then I would strongly urge you to join.

Diabetes UK have produced two booklets for people with learning disabilities called "*What to do when you have Type 1 diabetes*" and "*What to do when you have Type 2 diabetes*".

## CONCLUSIONS

Although diabetes is relatively common in people with Down's syndrome, it is still present in only 1 in 50. The extra burdens associated with the treatment of diabetes have been minimised over recent years. Obviously, the learning difficulties associated with Down's syndrome can make diabetes more difficult to cope with and, in the initial stages, a lot of effort may be needed to learn new routines. Once these have been established, most people with Down's syndrome should be able to cope with the day-to-day management of their diabetes with little or no extra supervision than they need for their other daily activities.

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