

K: Useful Information

K1: Diapedia

Artificial Pancreas (closed loop). This is not yet available unless taking part in a research study with your diabetes team. This involves wearing an insulin pump and sensor and the child/young person also carries a device (like a smart phone). The sensor then tells this device the glucose levels, the device then tells the insulin pump how much insulin to give dependent on levels. This is instead of the usual basal rate running in your pump. All meals/snacks need to be calculated for carbohydrate content and a bolus given in the usual way.

Autoimmunity: The process by which the body develops 'antibodies' (like when fighting infection) but these are directed against some part of the body's own tissues. In diabetes it is against the 'islet cells' which make insulin, resulting over time to the failure to make insulin and type 1 diabetes.

Bolus insulin: This refers to the insulin given as a single dose usually to cover carbohydrate containing food/drink (food bolus) or to correct if one is running high (correction bolus).

Basal insulin: Those without diabetes, even if they starve, will have a background level of insulin in their blood - this is required to deal with glucose released by the liver. This has to be mimicked and is either long acting insulin such as Glargine or Levemir or the 'basal' level of fast acting insulin delivered by an insulin pump over 24 hours. Your basal level changes over the 24 hours and in teenagers in particular are highest at 0400-0600 and 16.00-18.00 (Circadian rhythm), due to increasing levels of growth hormone in the body.

Basal bolus regimen: This refers to combining bolus insulin (with food) with a long acting of insulin in those who inject and continuous insulin in those on a pump.

Blood pressure/Hypertension: Each time you come to clinic your blood pressure should be checked. This can rise in association with poor control and may need treatment with tablets. It is rare to occur in childhood. You can minimise the risk of this by maintaining good control, keeping your weight under control and reducing the amount of salt in your diet. (Discuss this with your team's dietician). It is bad news to start smoking as this will contribute to hypertension.

Carbohydrates (CHO): These are food substances which are also called 'saccharides' which is Greek for sugar. They come in different forms (monosaccharide (e.g. glucose), disaccharide (e.g. sucrose, table sugar) and polysaccharide (e.g. starch). The rate at which they are absorbed from the gut varies

but as a general principle the simple ones are absorbed quickly and the complex ones slowly.

Carbohydrate counting: This requires practice but if you get it right it improves your diabetes control. It can only be used to its best effect with basal bolus regimens (see *basal bolus*). In most cases, particularly those on pumps, it is the amount of carbohydrate which requires 1 unit of insulin. It is in part dependent on age and how long you have had diabetes. A 5 year old may start on 1 unit of insulin for 20 grams of carbohydrate whereas a teenager who has had diabetes for many years may require 1 unit for 5 grams of carbohydrate.

Circadian rhythm: Most hormones in the body are released in different amounts at different times over 24 hours. This is controlled by the natural day/night pattern and it in part explains 'jet lag' when you are flying across time zones and your circadian rhythms are disrupted. Due to the 'circadian rhythm' of two of the body's hormones (cortisol and growth hormone) you need to make more insulin in the early morning and late afternoon.

CGMs or Continuous Glucose Monitors: These are devices which are able to measure your glucose levels in the tissue by using a small probe inserted under the skin. As it is not measuring glucose in the blood, there is a lag period so may not always measure rapid hypos. There are two sorts - one where the results are stored but cannot be viewed until downloaded and another where the result can be seen all the time; each have their own advantage. They are particularly useful to see what is happening at night or when you are trying to tighten control.

Dawn phenomenon: This occurs particularly in teenagers who are growing fast. It refers to the natural 'circadian' rise in blood glucose towards early morning. This is why on insulin pumps the basal rate of insulin often has to be higher at this time.

Diasend: This is a commercial system made in Sweden and allows the download of the majority of meters and some insulin pumps (Roche, Animas and Omnipod). This should be available in all clinics and you should be asked to bring all meters for download. The Diasend system can display up to 4 meters on one chart in a simple tabular and graphical display. Discuss this with your Diabetes Team if you do not download meters or pumps in clinic. You may also be able to download your meter/pump at home using Diasend. Please ask your Diabetes Team for further advice.

DKA or diabetic ketoacidosis: This very unpleasant problem is associated with becoming very dehydrated, fast breathing and vomiting. It is usually associated with high blood glucose levels, but not always. Some people with diabetes will not have experienced it if diagnosed early and they are well controlled. The 'ketoacidosis' refers to the build-up of ketones in the blood due to the breakdown of fats (see

ketones). This occurs if you have not had enough insulin (in sufficient dose or missed doses). Ketoacidosis requires urgent admission to hospital.

Fats: These are an important source of energy; oils are a form of liquid fat (e.g. olive oil, sunflower oil). They are an important part of the diet but as they are so energy rich, they must be eaten sensibly to avoid putting on weight. Fatty foods which include certain chocolates can slow down the absorption of carbohydrates.

Glucose: a simple sugar (monosaccharide) which is absorbed through the gut very quickly and easily. The term sugar tends to refer to glucose but can consist of a load of different forms of sugars (*see sugars*). It is the main food source for the brain but is an essential energy source for the body as a whole. It is stored in the liver and muscles of the body. In the normal situation the blood glucose level is controlled very accurately to between about 4mmol/l and 8mmol/l. If the levels go too high, the glucose spills over into the urine and pulls water with it. This results in passing large quantities of urine in 24 hours and making you thirsty. Low glucose levels results in glucagon (*see glucagon*) being released which pushes your blood glucose up again but in diabetes it often goes up too far so a low sugar 'hypo' is often associated with a swinging blood glucose level, or rebound high following a hypoglycaemic episode.

Glucagon: This is a natural hormone secreted by the pancreas which is released when your blood glucose level is too low. It mobilises glucose from the liver and muscles in the body to stop your blood glucose levels falling too far. If you have Type 1 diabetes this may be associated with a raised blood glucose level, rebound high, following a hypo.

Glucogen; This is the trade name for artificially made glucagon (*see glucagon*) and comes in an orange box. This is used to treat hypos if the person is unable to swallow or take glucose by mouth.

Glycogen: Glucose is stored in the liver as a complex substance called glycogen. This acts as a source of glucose particularly when extra energy is required. It is converted back into glucose naturally when stimulated by glucagon released by the islet cells in the pancreas if your glucose level falls too low and similarly if you injected glucogen in severe hypo situations. Your glycogen stores only last about 12 hours if you do not eat and you start breaking down fats, a good reason for eating sensibly.

Glycation: You may hear your diabetes team talk about glycation. The HbA1c test is for 'glycated' haemoglobin and refers to the binding of glucose to proteins such as haemoglobin around the body. This can occur in all tissues of the body and if glucose levels stay high can lead to irreversible changes to these proteins similar to the 'ageing processes'. It is the mechanism by which microvascular disease probably occurs (*see microvascular*).

Glycaemic index: This may range from low to high and refers to how quickly glucose in the food is absorbed from the gut into your blood. Low glycaemic food is in general better and allows the food to be slowly absorbed and examples include wholegrain bread, pasta. High glycaemic foods are best for treating hypos and tend to contain pure sugars. This is a complex area and you need to discuss with your dietician particularly if you are on an insulin pump.

HbA1c: This term is often misunderstood; it is not a blood glucose level. It reflects the blood glucose level but is a measure of the number of red cells in the blood, which have glucose stuck to them. Recently the way of measuring this has changed; in old units the ideal level was less than 7.5% or 58mmol/mol in the new units. Poor control is greater than 9.0% or 75mmol/mol. As red cells last about 3 months before they are replaced by the body, it reflects the blood glucose level over 2-3 months.

Hormone: This is a chemical which is made and stored in a particular part of the body (e.g. insulin in the islet cells of the pancreas or thyroid hormone in the thyroid gland) but when released under specific situations travels around the body acting on all the tissues in a predefined way (e.g. insulin transfers glucose from the blood into the cells throughout the body)

Hypo or hypoglycaemia: This is a low blood glucose level usually defined as less than 3.9 mmol/l. If it is associated with symptoms (sweating, moody and temperamental, etc) it is classed as a 'symptomatic hypo' and needs urgent treatment. Common triggers for hypos are too much insulin for a given amount of food, increased exercise and alcohol.

Hypoglycaemic unawareness: This can occur over time and refers to the inability to detect when you are starting to have a hypo. If you feel this is happening you need to discuss with the diabetes team.

Insulin: This is a 'hormone' which is produced by very specific cells (see *Islet cells*) in your pancreas (see *pancreas*). Insulin is very important in that it is released when your glucose levels starts to rise in your blood (e.g. after a meal or drink containing carbohydrate). Insulin allows glucose to move from the blood into your muscles and tissues and to be stored around the body.

Islet cell: The islets cells lie in the pancreas and are natural human glucose sensors which release insulin when the blood glucose level starts rising making the glucose move from the blood into the tissues. It is these islet cells which get destroyed in the autoimmune process and stop your body making insulin.

Insulin pen: A simple device which allows you to dial the dose of insulin and inject it with ease. Some pens have 3 ml cartridges and some are disposable. For young children half unit pens are often better for accurate insulin doses.

Insulin Pump: This is another way of given insulin. There are several different makes available and they all deliver only fast acting insulin via a small tube placed under the skin. When used properly they can help you to get very good control of your diabetes and allows you to fit your diabetes management around your lifestyle. There are now pumps that don't have the long tubing. Please ask when the next 'show and tell' session is to enable you to look at the pumps available.

Insulin resistance: This is seen in type 2 diabetes (see *type 2*) but is also important in type 1. It means that for a given amount of carbohydrate you need more insulin than you would expect. This tends to occur as you get older but is found at its most obvious during the growth spurt of puberty. This is why your carbohydrate ratio may be 1unit:10grms CHO at 7 years and 1:5 at 13 years. It is also found in association with high ketone levels when you are unwell or have not been having sufficient insulin and are poorly controlled with a high HbA1c. It is thought to be the main cause of type 2 diabetes in its early stages in association with being overweight or obese. It can improve on losing weight.

Insulin sensitivity (correction dose): All of you who are on rapid insulin with each meal should know how much insulin to give to correct a high blood glucose reading (one greater than 7 mmol/l). In teenagers who have had diabetes for some years this is usually 1 unit for 2 mmol/l of glucose above 7 mmol/l. In younger children or newly diagnosed it may be as little as 0.5 units for every 5mmols/L above 7 mmol/l. Your diabetes team should advise you about this. Always ask if you are unsure.

Ketones: Everyone makes ketones if they are not eating regularly. In diabetes they are a particular problem and are triggered when your body is unable to utilise glucose, usually because the glucose is in the blood but there is insufficient insulin to make it transfer across into the tissues. It is associated with starvation or intercurrent illness in particular. Ketones can be measured more accurately in the blood. They need to be treated by having adequate carbohydrate intake, sufficient insulin (often more than usual) and careful monitoring to see that they are settling. Ketones should be measured with a meter in the same way you measure blood glucose, anything over 0.6 mmol/ml needs attention.

Medtronic carelink system: As with Diasend this allows download of information from Medtronic pumps and the display in tabular and graphical forms. There is a home version which you might want to try - ask your Diabetes Team about this. If combined with contour link glucose meters this allows display of blood glucose levels as well. When using a continuous glucose sensor this information will be displayed as well.

Microvascular: This refers to the small blood vessels of the body which occur throughout the body. They can actually be seen in the back of the eye and are very common in the kidney. They get damaged by high sugar levels (see *glycation*) and

explain why the eye and kidney are easily affected by poor diabetes control over several years.

Macrovascular: This refers to the larger blood vessels around the body such as those around the heart (coronary vessels). It is thought that they get affected by high glucose levels but in a different way from the small blood vessels.

Nephropathy: This refers to the long term damage which can be done to the kidney with poor diabetes control. It starts with protein from the blood leaking into the urine (the reason why you are asked to give a urine sample each year so we can test for it). If this continues the kidneys' ability to clear normal waste material is impaired and kidney failure occurs. Early signs can also include high blood pressure (see *hypertension*). The risk of this can be minimised by good control and if it occurs can be helped by improving control and specific medication (ACE inhibitors).

Neuropathy: This is less likely to occur in childhood and can be difficult to diagnose. It refers to damage done to the long nerves in the body leading to loss of sensation in your toes and hands. This may result in ulcers and damage to your skin. It can affect specific parts of the body such as the stomach (gastric paresis) associated with vomiting and difficulty eating. Good control minimises the risk of developing these problems.

Proteins: These are very important substances in the body and occur in all plants and animals. Insulin is a protein. They are made of building blocks called 'amino acids' and are crucial to a healthy body.

Premixed insulin: This refers to insulin solutions which contain fast insulin and longer acting insulin all together. It is usually given with breakfast and at tea. The fast insulin deals with the breakfast and main evening meal and the long acting insulin works through the rest of the day or night. It has the problem of having once been injected you must eat during the rest of the day otherwise you will go hypo. You cannot carbohydrate count with premixed insulin. It is now rarely used in the clinic.

Retinopathy: This refers to the abnormalities which can appear at the back of the eye with poor diabetes control. It is graded from 1 to 4 and refers to the macula and retina specifically. The macula of the eye is used for fine vision and it is crucial for this to stay as healthy as possible. The risk of retinopathy can be reduced considerably by maintaining good control from diagnosis and avoiding smoking (both active and passive). The early changes are reversible with improvement in control.

Sensor Augmented Pump Therapy (SAP) This is an insulin pump which works with a sensor . The sensor tells the pump if the glucose levels are falling rapidly and the pump would stop the basal rate. This should then prevent a hypo from occurring.

Somogyi effect: Described by Michael Somogyi and is the falling of blood glucose levels at night and then rebounding high in the morning. The danger is that the high blood glucose level in the morning could be interpreted as needing more long acting insulin but in fact you need **less**.

Sugar: This term is often incorrectly used meaning glucose (*see also carbohydrate*). Glucose is the most simple and refined part of all sugars and is often the breakdown product of complex sugars like fruit sugars. The rate at which sugars cross into the blood from the gut is dependent on how complex it is and what you eat with it (*see glycaemic index*).

Type 1 diabetes: The alternative term is 'insulin dependent diabetes mellitus' (IDDM). This means that your ability to release insulin when your blood glucose levels rise is impaired. Eventually you will make no more insulin of your own and are dependent on the insulin you inject. Type 1 diabetes is caused by the body destroying the cells which measure your blood sugar and release insulin (*see Islet cells*) by a mechanism called 'autoimmunity' (*see autoimmunity*).

Type 2 diabetes: This is also called 'insulin resistant diabetes' as you continue in the early stages of the condition to make a lot of insulin but it does not work very well (*see insulin resistance*). This is commonly associated with being overweight and is more common when there is a strong family history of type 2 diabetes or in families who originally came from Asia and the Afro-Caribbean regions of the world. The keystone of treatment is weight loss, occasionally tablets and, if not successful, you will need to start injecting insulin.

K2: Useful web addresses

General

Diabetes UK www.diabetes.org.uk/

Juvenile Diabetes Research Foundation www.jdrf.org.uk/

Medical alert bracelets

Medi tag alert bracelets www.medi-tag.co.uk

Mediband www.allergysesex.co.uk

Universal medical ID www.identifyyourself.com

Medical tags www.medicaltags.co.uk

The ID band company www.theidbandco.com

Pen users to check last dose of insulin www.insulcheck.com

Food related

Lenny the lion CHO teaching site: www.lenny-diabetes.com/

General

Diabetes Power (family support group) diabetespower.org.uk

Change for life-health advice www.nhs.uk/Change4Life

Pumps

Pump companies

Medtronic www.medtronic-diabetes.co.uk/

Animas www.animascorp.co.uk/

Roche www.accucheck.co.uk/gb/products/insulinpumps/

Omnipod (via my life diabetes care) www.ypsomed.co.uk

Insulin pump accessories

www.diabete-ezy.com

www.pumpwearinc.com

www.angelapumpstuff.com

www.funkypumpers.com

www.insulin-vests.co.uk

www.childrenwithdiabetesuk.org

www.insulin-pumpers.org.uk/support

www.input.me.uk

www.jdrf.org.uk/schools

www.integrateddiabetes.com

www.runsweet.com

Pump support groups

Exercise

K3: Holidays-how to enjoy them and still keep good control

Ideas

Listed below are some factors which may affect your diabetes whilst on holiday. In all cases it is best to discuss with your Diabetes Team before going away particularly if you are into 'extreme sports' or going to somewhere 'isolated'. Remember it is best to plan well in advance and get everything ready a week or two before.

1. Temperature (see also exercise below)

Hot Temperature: insulin needs to be kept out of direct sunlight. This is particularly important with pumps, so put them under a towel or clothing when in the sun. Use a cool bag to carry insulin.



Cold temperature: Insulin does not tolerate being frozen, so keep it somewhere warm. Wear pumps under clothing and protected from freezing temperatures.

2. Exercise

Most holidays involve more exercise, swimming, walking etc. To get this right does require regular blood glucose testing and experimenting to see what is correct for you. Here are some ideas you might want to try, the more intense and prolonged your exercise a greater reduction will be required:

- i. If on a pump put a 10-20% basal reduction and monitor blood glucose levels to see if they are okay.
- ii. If on multiple daily insulin reduce your long acting insulin (glargine, detemir) by 10-20% on the day you leave.
- iii. Bolus insulin: try your usual ratio to start with but this may need reducing. e.g. 1: 10 to 1:15.
- iv. Snacks (ice cream etc). You may be able to have a limited number of these without insulin if you are exercising a lot.

3. Time zones

- Local flights to mainland Europe require no change but America or more than 3-4 hours time change requires careful planning.
 - i. It is important to get into the local time as fast as possible, so that you give your long acting insulin at the 'normal' time e.g. evening. Flying to America means you have a longer day and this delays your long acting insulin so you may need to give extra fast acting insulin. Flying back from America shortens your day so you should be careful not to overdose with long acting insulin and it is better to delay giving it if you have had your previous injection within 20-24 hours, or reduce the dose by 30%.
 - ii. If flying long distances, drink plenty of water and give insulin with food on the plane.
 - iii. If you are on the pump, change the clock to local time as soon as you can.

4. Alcohol

- i. If you want to drink alcohol it is best to combine it with food.
- ii. If you are drinking a lot, you are at risk of hypo. Remember the symptoms of hypo and being drunk can be the same.
- iii. Make sure your friends know what to do and how to treat a hypo.
- iv. Wear an identity bracelet saying you have diabetes.

5. Spare equipment

- i. Remember not to put it in your main luggage as it will be too cold in the luggage hold of the plane and it may get lost.
- ii. Plan in advance to make sure you have enough insulin, hypogel and testing kit. If on a pump you must have emergency pens in case the pump fails. Some manufacturers will have a holiday scheme where they lend you a spare pump. You will need to know your basal rate and bolus ratios in case this happens.
- iii. Split it up into different hand luggage
- iv. Make a check list of what you must take with you.
- v. If on a pump, take the pump manufacturer's emergency contact number in case it breaks.

6. 'Extreme sports'

- i. It is important to enjoy holidays and many teenagers wish to bungee jump, white water raft, tandem sky dive etc. It is good to do these things if you so wish but it is important to be safe.
- ii. Check your blood glucose beforehand to make sure you are not low. If the activity requires a lot of physical activity make sure you have some extra glucose tablets. It is your responsibility to make sure you are safe.

7. Insurance

- i. Make sure you have health insurance covering your diabetes. Admission to hospital can be very expensive.
- ii. Travel to the EEC requires having the appropriate form (European Health Insurance card) for emergency care. Ask at the post office.
- iii. If on a pump make sure it is covered in case it is stolen.

Most importantly have a good holiday!!

K4: Translated Leaflets

Leaflets for children and young people with a new diagnosis of diabetes, and on the management of hypoglycaemia, are available in Somali, Arabic and Urdu.

Please ask a member of the Children and Young People's Diabetes Team if you would like a copy of the translated leaflets