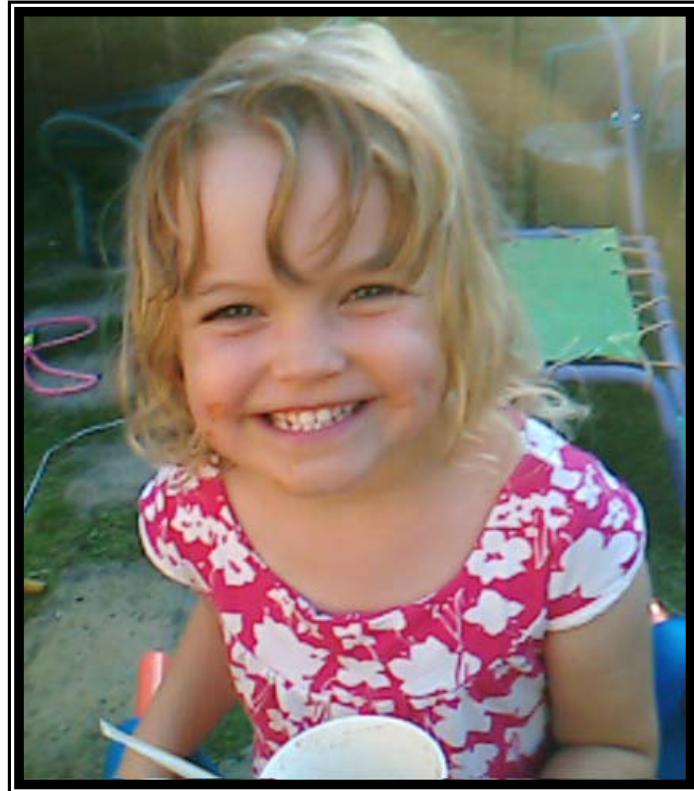


"I am Rose"



"I have Type 1 Diabetes and I wear an insulin pump"

By Rebecca and Simon Gumble.

Contents

What is type 1 diabetes?	3
This is me	4
Why have I got diabetes?	5
What is an insulin pump?	6
Why I like my insulin pump	7
This is how I have a set change	8
This is how I have a set change	9
Why do I have to have insulin?	10
Why do I have finger pricks?	11
What is a hypo?	12
What is a hyper?	13
What is Glucogel?	14
What is the glucagon injection?	14
What can I eat?	15
Can I exercise?	15
What happens if I'm poorly?	16
True or false?	17
Answers	18
Answers	19

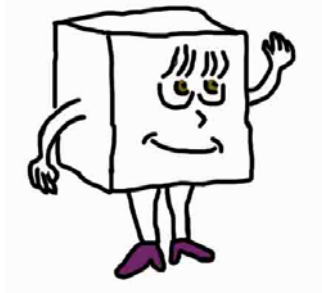
What is type 1 diabetes?

Type 1 diabetes is a chronic and life threatening disease. It is an invisible disability. Type 1 Diabetes never takes a break; it is there day and night, 24 hours a day, 7 days a week, 365 days a year.

Type 1 diabetes is the most common type of diabetes in childhood. It is where the pancreas does not produce insulin, a hormone necessary to sustain life. Without insulin the glucose in the blood cannot enter the cells of the body to provide fuel. It just keeps building up and up in the bloodstream. Rose must have insulin delivered via the pump to survive.

All staff that comes into contact with her need to be aware of her condition and know where her emergency boxes are.

Throughout this book
Rose's words are
written in black ink**



Throughout the
book our words
are in blue**

**Except pages 16 and 17

This is me



“This is me, Rose. I am 6 years old. I have a little brother Finnan who is 3. I love going on the computer; swimming; playing with my friends and I like sausages and chocolate. I do not like people being nasty to me; rain; broccoli and pasta.

I am and look like all my friends. Except I am different because I have type 1 diabetes.

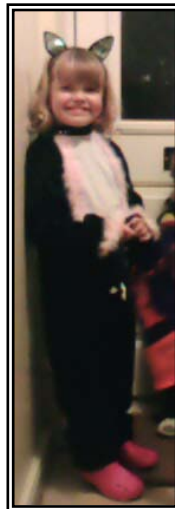
I wear an insulin pump because my pancreas doesn't work. I have no insulin in me so my pump gives me the insulin. I would get very sick if I didn't have insulin.

I don't like having type 1 diabetes because I'm different and I don't want to be at all but I have to be. I don't like the needles (finger pricks) because it hurts sometimes but I have to see what my levels are.

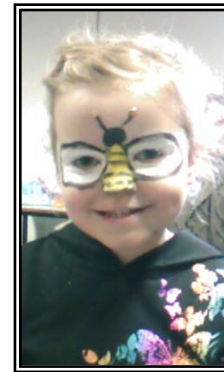
BUT having type 1 diabetes doesn't stop me from:



being a superhero



trick or treating



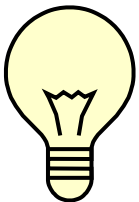
going to parties

Having type 1 diabetes makes me special. My mummy and daddy say I'm very brave and they are proud of me.”

Why have I got diabetes?



“I got Type 1 diabetes in January 2006. My mummy and daddy have said I was very poorly. I was drinking so many glasses of water and I was always going to the toilet. I was losing weight but I was so hungry! I didn’t want to go to pre-school and play with my friends but I didn’t want to play at home either. I was just so tired. All I wanted to do was just sit on the sofa and sleep. I started pumping insulin in February 2008, before that I was on 4-5 injections a day.”



The cause of type 1 diabetes is unknown. However, it is believed that people inherit a tendency to develop it and that some outside trigger may be involved.

In Rose’s case she had a cough and cold for about eight weeks. It is believed, as she has a disposition to an auto immune disease through genetics, her immune system was trying to fight her continuous cold and failed to recognise the cells producing insulin and started to attack them and eventually eradicated them.

What is an insulin pump?

Rose's insulin pump is a small, battery-operated device (about the size of a pager) it replaces her need for insulin injections. The pump is delivering insulin into Rose all the time and this is her background insulin (basal rate.) It slowly drips through the cannula at different rates which we have pre-programmed. The aim is to try and get the pump to act more like a healthy pancreas would, by accommodating different needs at different times of the day which we could not achieve on injections.

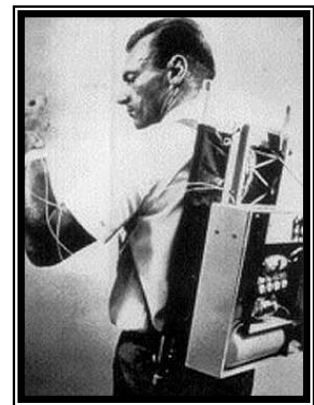


Rose is connected to the pump, 24 hours a day, and 7 days a week. It is only disconnected for strenuous exercise or for a severe hypo.

Food time insulin (bolus) is given whenever Rose eats anything. All food with carbohydrates need to be entered into the pump and by using the Bolus Wizard the pump will work out the amount to give from the pre-programmed ratios that we have set up. It also takes into account insulin that she might have on board from previous boluses and will deduct this from the amount. Clever stuff!

Rose will still need finger pricks at school: - before morning snack; before lunch; mid afternoon; before PE and after. At home, when not at school, she is tested when she wakes, at 10am, noon, 2pm, 5pm, before bed, 10pm, midnight and sometimes 3am. It gives us a clearer picture of what her levels are like and if we need to do anything.

“This was the first insulin pump in 1963. It’s heavy and I wouldn’t like it as it’s even bigger than my pump.”



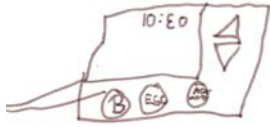
“This is my pump, it’s so tiny.”



Did you know...? A healthy pancreas delivers insulin every 10 to 14 minutes. A pump closely mimics the pancreas by continually delivering insulin around the clock.

Why I like my insulin pump

"I can do my pump"



"I can have different food"

"I can still go swimming and do PE"

"I like the pump instead of the needles (injections)"

"I go to the toilet less"

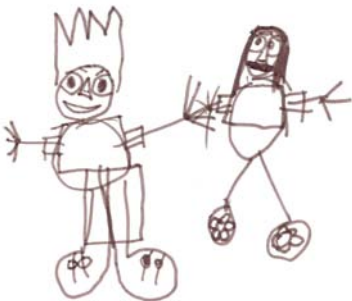
"I feel better"



"I can eat whenever I like at home"

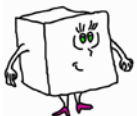
"I can eat the same snack as my friends at school now."

"Had another injections if high, but now put a basal on"



"I can run around more with my friends"

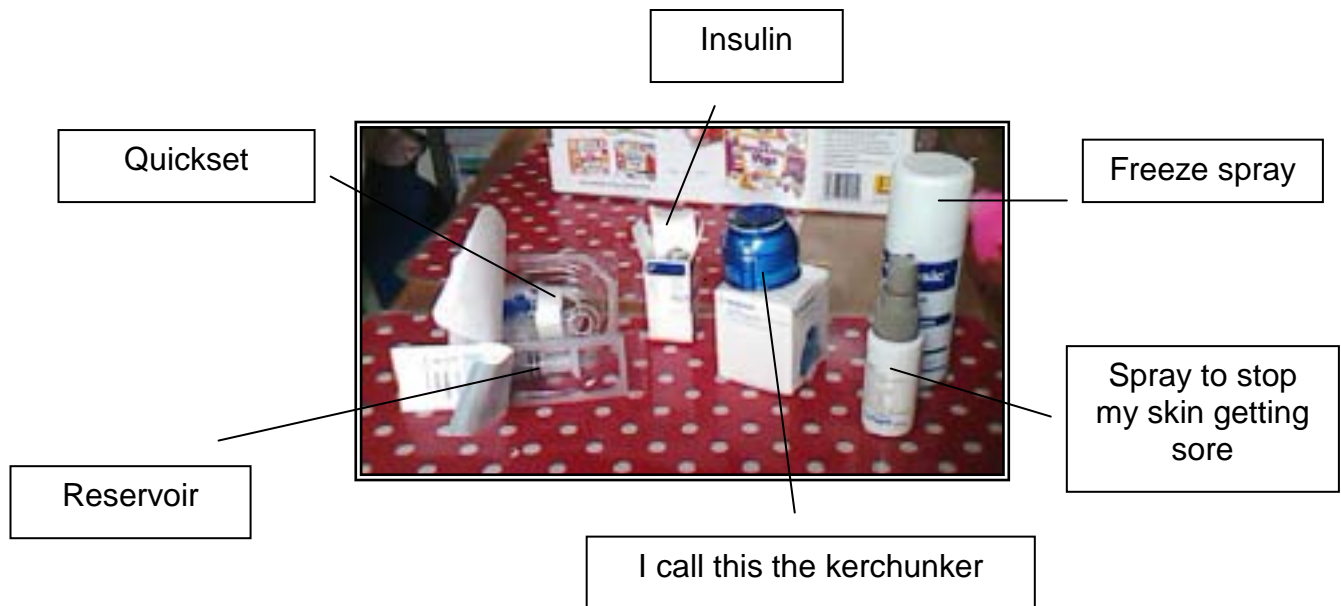
The pump has changed our lives. Although, it is still not a cure and it is not always easy, we have seen such a difference in Rose. She has more energy; is less high than she was; there is less restriction on when we eat as a family; it gives Rose more freedom to eat what she wants and when she wants; there is more spontaneity; she can be more like other children and friends and we feel more in control.



This is how I have a set change

"I can wear my cannula for 3 days and then I have to change it. It hurts sometimes but I wouldn't go back to injections every day!"

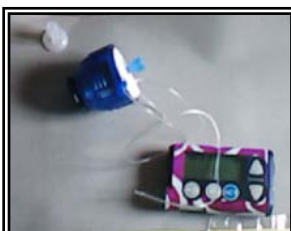
"All the things I need for a set change."



1) "Mummy or daddy puts insulin into that bit."



2) "Put a quickset onto the reservoir. Mummy or daddy takes the old quickset out of my pump and then rewinds the pump."



3) "The reservoir goes into the pump; the quickset goes on the kerchunker."



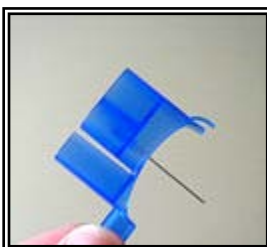
- 4) "Pull back the tape – careful, very, very sticky!!!"



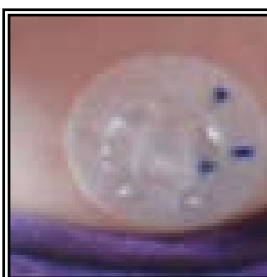
- 5) "Pull back on the kerchunker and take blue cap off. Mummy or daddy then sprays my skin with the one to stop it getting sore and then the freeze spray. COLD, COLD, COLD brrrrrr!!!!"



- 6) "Put on body, I take a BIG breath and let it out and mummy or daddy presses the buttons. They take away the kerchunker – it does hurt a bit."



- 7) "Take out the needle – don't worry, the needle may look long and scary but only a little bit goes in me."

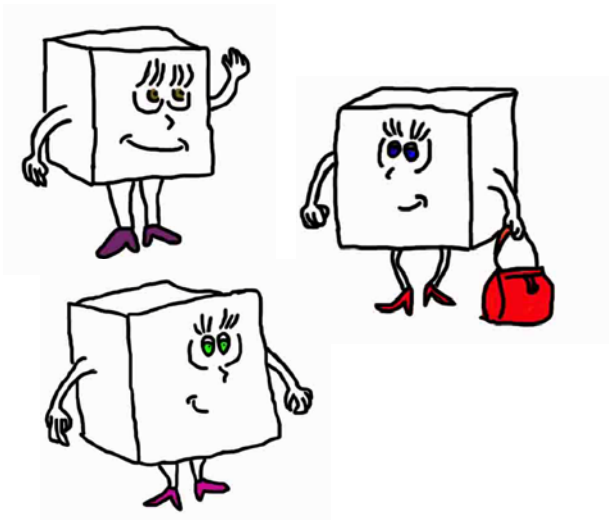


- 8) "And I'm left with my cannula which is connected to my pump."



- *** "When I go swimming or do PE, I disconnect the pump from the cannula until I have finished and then I reconnect. I do this because my pump is not waterproof and I could also get all tangled up!"

Why do I have to have insulin?



"If I don't get enough insulin the glucose in my blood just keeps building up with nowhere to go. I end up going to the toilet lots to get rid of the glucose and this is why I get so thirsty!"

"Luckily I have an insulin pump which gives me the insulin that goes into my body that helps the glucose get into the cells to give me lots of energy."



"Mummy and daddy tell me I am very brave. I have to have a "set change" every 3 days where a new cannula is put in and the old one is taken out and the insulin is changed."

Why do I have finger pricks?

“Mummy or Daddy check my blood glucose levels eight – twelve times a day. I feel well and happy if my levels are not too high and not too low. My target range is between 4.5 and 8.0mmol/L. The BMs are put into my pump and it works out how much insulin to give me if I’m too high.”



“I have a special blood monitoring kit.”



“My finger gets pricked”



“Wait for the blood – you only need a tiny bit”



“And blood goes into the strip. It’s all very quick.”



“Then the numbers come up and that’s my reading. They are then entered into the pump and written in my communication book.”



Food makes the glucose levels rise. Exercise and insulin makes the glucose levels fall. It is a constant balancing act of food, exercise and insulin.

What is a hypo?

“When my blood glucose levels drop below 4mmol/L I start to have a hypo. It is not a nice feeling at all. Most times I can tell you when I am going low, but sometimes I cannot say that I feel funny and so I need watching carefully.”



“I get hungry
I have tummy pains
I feel shaky
I feel very tired
I find it hard to listen
I get sweaty.”



“YOU NEED TO DO A FINGER PRICK!!!!!!!”

“Follow my care plan and it will tell you what action to take.

I will need some glucose tablets.

Lots of things can make me low – too much insulin; hot weather; swimming and PE.

After a hypo I get very tired and it takes me a long while to recover.”



If I have a hypo I need sugar – not insulin

What is a hyper?

Toilets



“When my blood glucose levels go above 10mmol/L I start to become hyper. This is also not a nice feeling at all.”

“I am so thirsty!!!
I need the toilet lots
I get very tired
I can be aggressive.”



“YOU NEED TO DO A FINGER PRICK!!!!!!!”

“Follow my care plan and it will tell you what action to take.



I will need to keep on drinking lots and lots of water. Please let me go to the toilet if I need to go. I may need some more insulin, test me and put a correction bolus into the pump. Mummy or Daddy will need to test my blood for ketones if I am continuously high.



Lots of things can make me high – too little insulin; I am poorly or a virus could be on its way; I’ve eaten too many carbohydrates; I haven’t been exercising much; stress or I am excited!!!

If I start being sick you have to call mummy or daddy and give me sips of my Ribena. I can get very poorly quickly with sickness and diarrhoea and may have to go to hospital.”

If I have a hyper I need insulin or exercise – not food

What is Glucogel?

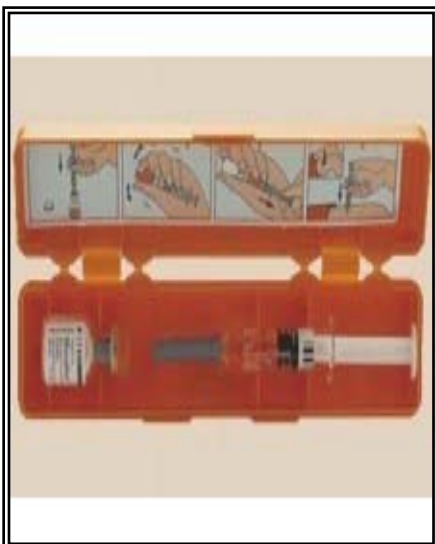


“When I go low (have a hypo) I may not feel like eating my glucose tablets because it’s just too difficult. As stated in my care plan you can rub this into my gums and it works the same as glucose. You need to disconnect me from my pump.”



NOT TO BE USED IF ROSE IS UNCONSCIOUS

What is the Glucagon Injection?



“If a hypo goes untreated I will probably become unconscious.

Dial 999

Follow my care plan and take appropriate action.

Someone can give me my glucagon injection. It will save my life.

Glucagon is a hormone which can be given as an injection which allows my body to produce glucose.

It takes about 15 mins. You cannot overdose me. I might feel sick and have a headache afterwards.”

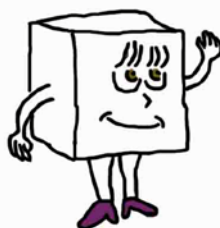
What can I eat?



“Even though I have type 1 diabetes I can still eat sweets and chocolate. I just need to eat the same healthy foods as my friends.

Mummy and daddy makes sure my insulin matches the carbohydrates in my food. Please can you make sure I eat all my snacks and lunch.

I get all my energy from the food I eat. The food breaks down into glucose which the insulin lets into the cells which gives me energy.”



Can I exercise?

“Having type 1 diabetes doesn't mean I cannot exercise. I need to make sure my blood levels are ok before I take part in anything physical though. This is to make sure I do not go too low whilst running around. I may need to have a snack before taking part or even when I finish. See my care plan for what needs to be done.”



“Please make sure you take my emergency box with me wherever I am exercising. I may need glucose.”

What happens if i'm poorly?

“When I am unwell my sugar levels are likely to rise – even when I just have a cold! Having type 1 diabetes doesn’t mean I’ll get more illnesses than my friends; but it’s just harder for mummy and daddy to manage my levels and insulin needs as my body is fighting the illness and so is working harder.”



“When I’m poorly I may produce ketones in my blood. When this happens mummy and daddy need to keep checking it to make sure they don’t get bigger. I need to drink lots to get rid of them and I may need more insulin.

Ketones are not good for me. Ketones are made when my body breaks down fat to get energy. They are poisonous.”

“Because I have type 1 diabetes, if I’m sick I need to be carefully looked after and it can be very dangerous if I cannot eat or drink.”



If Rose continuously vomits she will probably need to go to hospital.

Children with diabetes can become dehydrated very quickly so please give her sips of Ribena.

IF SHE BECOMES DROWSY WITH LABOURED BREATHING – DIAL 999

"All people with diabetes are chubby"

"Can't she have a day off from the injections?"

"She shouldn't be eating that biscuit if she's got diabetes"

True or false?

These statements in speech bubbles have actually been said to families with children who have type 1 diabetes. There are lots of myths and confusion concerning type 1 diabetes. Can you answer the questions below? They are either true or false.

- 1) Type 1 diabetes is contagious...
- 2) Type 1 diabetes can be prevented...
- 3) Children with type 1 diabetes can take tablets to control their blood levels and not need insulin injections...
- 4) You get type 1 diabetes by eating sweets and sugary foods...
- 5) You can outgrow type 1 diabetes...
- 6) There is mild or bad diabetes...
- 7) Children with type 1 diabetes cannot eat sweets or chocolates...
- 8) You get type 1 diabetes if you are overweight...
- 9) Children with type 1 diabetes can always feel whether they are high or low...
- 10) If a type 1 diabetic is hypo they need insulin...
- 11) Type 1 diabetics are more likely to get colds and other illnesses...
- 12) It's easy to control blood glucose levels for children with type 1 diabetes...
- 13) Insulin cures type 1 diabetes...
- 14) Healthy foods do not raise blood glucose levels...
- 15) Having to take more insulin means the diabetes is getting worse...

"Did she get it by eating too many sweets?"

"Will he grow out of it?"

"Does she have the 'real' diabetes?"

"Can my child catch it?"

"Have you tried homeopathy?"

"Why haven't you got some control yet?"

"So, if he starts to have a hypo, I have to put insulin into his mouth."

"Your kids have got diabetes really badly haven't they? They are always doing blood tests and stuff?"

Answers - true or false?

All the answers are FALSE. Surprised? How did you do? Here are the answers with the explanations.

- 1) [Type 1 diabetes is **NOT** contagious...](#) You cannot 'catch' any form of diabetes, we may not know why some people get it but it is certainly not contagious.
- 2) [Type 1 diabetes **CANNOT** be prevented...](#) There was absolutely nothing we could do to prevent Rose getting type 1 diabetes. This confusion stems from the differences between type 1 and type 2 diabetes.
- 3) [Type 1 diabetics **CANNOT** take tablets to control their blood levels and **DO** need insulin injections...](#) Rose could not take tablets to control her diabetes as the acid in her stomach would destroy the tablet before it could be absorbed. Rose will never make insulin again as the cells in her pancreas have been destroyed. It has to be given in another form.
- 4) [You **DO NOT** get type 1 diabetes by eating sweets and sugary foods...](#) It is very upsetting when people assume Rose has diabetes because we fed her the 'wrong things.' However, it has nothing to do with this. The insulin producing cells in her body were destroyed and this is why she has type 1 diabetes.
- 5) [You **CANNOT** outgrow type 1 diabetes...](#) But oh how we wish this could happen! This is a common question asked. Rose will need insulin given by some form for the rest of her life. Without the insulin it would become fatal.
- 6) [There is **NOT** mild or bad diabetes...](#) Another myth which causes a lot of confusion. There is no borderline, mild or bad diabetes. There is type 1 and type 2 diabetes. They both have different needs but all diabetes needs looking after, as if it is not properly controlled it will lead to serious complications.
- 7) [Type 1 diabetics **CAN** eat sweets or chocolates...](#) As long as it is in moderation, like any other of Rose's friends, then it is perfectly ok. We have to carbohydrate count the sweets or chocolate and then we can cover it with the appropriate amount of insulin.
- 8) [You **CANNOT** get type 1 diabetes if you are overweight...](#) Another personal pet hate. Because of the stigma attached to type 2 diabetes and obesity, type 1 diabetes often gets 'lumped' into the same category. However, it is certainly not true. The disease is down to insulin producing cells in the pancreas being destroyed and absolutely nothing to do with weight – Rose, upon diagnosis, had lost a lot of weight and was very very skinny.
- 9) [Children with type 1 diabetes **CANNOT** always feel whether they are high or low...](#) Children can feel the physical symptoms - extreme thirst, shakiness, weakness, or

tiredness – but often find it hard to tell the difference between being high or low. A BM is needed to determine what level they are.

- 10) If a type 1 diabetic is hypo they DO NOT need insulin... Hypo = glucose urgently. A hypo can occur if too much insulin is given so giving more could be fatal! Sugar is needed to raise the blood glucose levels to combat the insulin onboard.
- 11) Type 1 diabetics are NOT more likely to get colds and other illnesses... It is no more likely that Rose would get more illnesses than her friends. However, when she is ill she needs more monitoring as her blood glucose levels are likely to rise. We also need to check for ketones regularly so that she does not end up in hospital. Unfortunately, even with all the testing and extra insulin, she still might not avoid going in.
- 12) It's NOT easy to control blood glucose levels for children with type 1 diabetes... If there is an easier way to control blood glucose levels then we would love to hear it. So many things can affect a child's blood glucose levels. The basics are food, insulin and exercise. Then throw in the weather; environment; stress; illness; growth hormones and excitement and it can become very tricky and frustrating indeed. Rarely one day is the same as the next even with the same conditions.
- 13) Insulin DOES NOT cure type 1 diabetes... Insulin is not a cure for diabetes, it is a life support. Without insulin it would be fatal. We are hoping and praying that one day there will be a cure.
- 14) Healthy foods DO raise blood glucose levels... Most foods provide carbohydrates. If Rose was to eat grapes; oranges; bananas or sweetcorn for example we would have to count the carbohydrates in the portions size and put this into the pump so that insulin can be given to match the food. Without the insulin her blood glucose levels would rise regardless of it being healthy foods. We know with Rose that a bowl of cereal can raise her blood glucose levels tremendously but a chocolate bar would not cause as much a problem!
- 15) Having to take more insulin DOES NOT mean the diabetes is getting worse... It will not matter how many injections a child is on a day or how many units. This works for them. Insulin doses are adjusted to suit the child's day – how much they eat; how active they will be; if they are growing; if they are going through puberty; if they are having exams, what the weather is like etc. will all play a role in how much insulin is needed.

