



InDependent Diabetes Trust

For Parents of Children with Diabetes

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Contents

- Introduction
- Diagnosis
- A personal experience
- Diabetes, beware of climbing that mountain
- Life in school with a chronic condition
- Testing and injecting at school – all options need to be considered
- Relationships within the family
- Babysitting
- Hypoglycaemia
- Growing up with diabetes
- Discovering alcohol
- Eating disorders
- IDDT Publications

Introduction

Parents of children and teenagers who have diabetes are very special sorts of carers. They are suddenly faced with the diagnosis of their child and at the same time, the loss of their healthy child. They are bombarded with information about insulin, diet, blood tests, blood glucose control, hyper and hypoglycaemia and the future health of their child. It is a difficult time for the whole family and there are many worries, fears and concerns. We hope that this leaflet will help to provide information, help and support. Knowing that you are not alone with the experiences of living with diabetes in your child can be of help and a comfort.

One message that we all need to remember

Whatever the cause of your child's diabetes and however you may feel, it is not your fault that it has happened and there is nothing you could have done to prevent it.

Diagnosis

The role of parents and their involvement in day to day living with diabetes is very different according to the age of their child when diagnosed. If your child is diagnosed when young, then clearly, as a parent, you are taking full responsibility for your child's diabetes 24 hours a day, everyday. If your child is a teenager when diagnosed then very often the teenager takes immediate responsibility for injections, blood testing, diet etc and the parents role is one of watching over with less direct involvement. This may sound easier but in many ways it isn't, especially if your involvement in the diabetes clinic educational programme has been minimal.

However, whatever the age of your child when diabetes is diagnosed, it is a difficult and often traumatic time and most parents go through similar feelings. We care deeply for our children and it would not be natural if we did not go through a period of grief.

These feelings are:

Shock – that this can happen to our child

Denial – 'This can't be happening to my child'. 'I'll wake up in the morning and it will have been a bad dream.'

Anger – 'Why my child?' 'Why not someone else's child?'

Sadness and grief – a sense of loss for the healthy child you had and for the expectations you had for your once healthy child.

Guilt – 'Is it something that I have done?' 'Could I have prevented it?' Guilt is not a rational feeling because it is certainly not anyone's fault when a child has diabetes. But Mums especially seem to feel guilt when their child is diagnosed and probably for a long time afterwards. But there is a very important message for ALL parents:

Whatever you may feel or think and whatever the cause of diabetes, it is NEVER your fault that your child has diabetes and there is nothing that you could have done to prevent it.

The need to know – many parents go through the stage of wanting to know why their child has diabetes and where it came from. This seems to be part of the process - a need to blame someone or something,

perhaps this helps to ease the burden of 'guilt'.

Responsibility – it seems that the whole future health of your child rests on your shoulders and this is a huge weight to carry around.

A personal experience of diagnosis

My daughter was diagnosed soon after her fifth birthday, one Friday evening, a Friday evening that I shall never forget! She was admitted to hospital - this was the first time either of my children had been away from me, so that alone was difficult. During her stay we were given masses of information about diabetes by innumerable different people – hypers, hypos, diet, exercise and shown how to inject. No one seemed to understand that I could not take all this in, the shock of diagnosis and accepting this was all my mind could deal with. So when we left hospital, along with all the other feelings of shock and grief, I felt alone, frightened and very ignorant about diabetes.

We were also given some of the hard facts of diabetes:

- it was here forever and that my little girl would have insulin injections for the rest of her life. We needed to keep 'good control' of her diabetes to avoid the complications in later life.
- it was a simple matter of injecting the right amount of insulin to balance with the food. I soon learnt that this was rubbish, there is nothing simple about achieving 'good' control!
- she could live a perfectly normal life with diabetes.
- I think that these last two statements were most confusing and unrealistic. They also had a long lasting and damaging effect. No doubt they were said to cheer me up! But actually they had just the opposite effect.

Initially diabetes seemed to take over our whole lives – injections, tests, snacks, meals. It was just like having a new baby in the house. On top of all these practical things there was still the worry of my

daughter's reaction to her diabetes; how she would cope; my son's reactions to the changes and would he feel left out and finally the turmoil of my own emotions.

I waited for the normal life I had been promised to appear. It didn't seem to arrive and I felt that this was my fault – I must be doing something wrong and I felt as if it was my inability to manage that was preventing us from having this 'normal life' the doctor had promised. I felt a failure. That one statement led me to expect that life would go back to how it had been before diabetes – normal. Had this not been said to me, my expectations would have been different and I would not have felt such a failure or so much guilt for not achieving this 'normal' life we had been promised.

Life has been normal now for many years – diabetes just became part of our lives, a part that does affect the whole family and a part that cannot be ignored. We all have feelings about diabetes, especially the child with it. We found that it was important to talk about these feelings within the family or within a support group because this way they seem normal and actually are normal when living with diabetes. Once I realised that our experiences were similar to those of many other people in the same position, that I was not the only one who could not always achieve the standards set by the clinic and that I was not a failure, life became much better for us all. Looking back now over the 37 years that my daughter has had diabetes I know that some of my feelings that I had at diagnosis are still there – the guilt and the sadness. They only really loom if there are problems, which do occur from time to time, but I also now know that I have always done my personal best. This 'best' may not seem as good as someone else's best but none of us can be expected to do anymore than our best.

A quote from my daughter when she was 25 and had diabetes for 20 years.

"Nobody wants diabetes but if I had to have it, I'm glad I got it when I was young and can't remember life without it. Being diabetic is just part of me and not something that suddenly hit me. I didn't have to get

used to any great changes in my life or adjustments in my lifestyle or self image."

Diagnosis - Hospitalisation or home?

If your child suddenly becomes very ill and this is an emergency, then hospitalisation at the time of diagnosis has to take place. If you notice over a matter of weeks or days that your child is unwell, going thin and drinking a lot, you usually see your GP who then diagnoses diabetes. Whether hospitalisation takes place in this case very often is dependent on the local policy and thinking. Diagnosis and treatment maybe started at home without a hospital stay or it maybe that a couple of days are spent in hospital. In the past children used to always stay in hospital for at least a week at diagnosis.

There are advantages and disadvantages to both policies.

- Going into hospital can be quite traumatic for your child, although visiting in children's wards has few restrictions nowadays and parents staying overnight is often available. It also means that your child will be away from school longer.
- It has the advantage of giving you, the parents, time to adjust to the diagnosis, time to be sad and angry etc, away from your child. It gives you a break where you do not have to keep up the 'brave face' all the time for your child.
- A hospital in stay also has the advantage of making everyone concerned realise that diabetes is a serious condition which needs care, attention and cannot be treated lightly – this includes the parents, other family members, friends and teachers. Diagnosis at home and back to school in a couple of days has the disadvantage of appearing to reduce the importance and effects of diabetes, especially in the eyes of outsiders such as teachers. It may seem to them like any other minor illness for which a child is absent for a few days. This could affect how your child is treated in the future by the school, friends and family. It could also affect how you are treated – you could be seen as a fussing parent if people underestimate the significance of diabetes. [The neurotic mother syndrome that many of us know so well!]

- Diagnosis at home means that life is less disrupted for everyone and diabetes does not seem to be such a huge infringement on normal life. It also enables you to have the help, advice and support in your own home where you feel more comfortable and are less intimidated by all the white coats of hospital.

Whatever the circumstances this is not an easy time for anyone and it is important that the seriousness and subsequent changes in lifestyle that diabetes brings, are not underestimated or influenced by whether or not your child is hospitalised at diagnosis.

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Diabetes, beware of climbing that mountain

All too often we read about children, teenagers and adults with diabetes climbing mountains, sailing the seas and doing all sorts of fantastic things. I'm sure these articles are written with the best of intentions – to make us all feel better and let us know that our children can do anything, even with diabetes. Well they probably can, providing they take all the necessary precautions.

Does this actually make us feel better? Do these articles, in fact, make us feel worse, more inadequate and perhaps even a bit of a failure because we, or our children, don't achieve these things?

It is important to remember that the vast majority of people with or without diabetes don't want to climb a mountain or sail across the Atlantic - they simply want to lead a normal everyday life just like their friends. This is just as great an achievement as climbing a mountain! Your child with diabetes attending its first party on its own, your teenager going to its first disco without going hypo or having blood sugars out of the roof – these are achievements that are just as important as climbing any mountain. These are the things that enable our children with diabetes to be like their friends and this is something that matters greatly to them, especially as they get into the teenage

years. We can be justifiably proud of them for this.

Are we over enthusiastic about their achievements?

I think that sometimes we, as parents, are in danger of this. Quite naturally we want our children with diabetes to achieve their full potential and we don't want diabetes to interfere with their schoolwork or their hobbies. But we have to be very wary of falling into the trap of encouraging our children to do things just to prove that they can do them and to prove they are just as good, if not better, than their non-diabetic friends. We also have to be wary of our own desires to prove that our children can achieve even though they have diabetes.

We have to ask ourselves about the people in the articles – did they climb the mountain because they wanted to or did they do it to prove that they could as someone with diabetes? Would they have wanted to climb the mountain if they had not had diabetes? Are they going to go through life trying to prove that diabetes does not interfere with their lives? If the answer to this last question is yes, then I think this is sad and I do not believe that any of us, as parents, want that for our children. If they want to climb mountains because that is their hobby, then that's fine.

The balancing act

Just like the rest of living with diabetes, getting this aspect right is a balancing act. We do not want to pressurise our children with diabetes into being high achievers but at the same time we do not want to 'spoil' them simply because they have diabetes. Finding this balance is not easy – it is probably just as difficult as getting good blood glucose results!

One thing that most of us discover fairly early after diagnosis is that the world does not make allowances for someone with diabetes, whether a child, teenager or an adult and having this in mind when bringing up a child with diabetes, helps to find a balance. The one thing we all want for our children is that they are able to cope in the adult world, that they grow up to be independent, healthy and above all, happy.

The role model

Having said all of this there is a place for role models and Gary Mabbutt who was captain of Spurs and the first person with diabetes to play football for England, is a good example. 'If Gary Mabbutt can play football for England, then diabetes doesn't have to stop me doing anything.'

Gary and his family were in a TV programme about his life and his diabetes kept cropping up. His parents were justifiably proud of him. Without in any way detracting from Gary's success, the programme showed that he came from a footballing family and he was well on the way to a football career when he was diagnosed in his teens. Gary's real achievement was that he did not let diabetes interfere with his ambitions to be a professional footballer. This is the role model that children with diabetes need. He was not trying to prove that he could be a footballer and have diabetes but he was not letting diabetes stop him from doing what he wanted to do. There is a subtle difference. His parents were rightly very proud of him and we can be equally proud of our children when they do what they want to do, while at the same time managing their diabetes.

Life in school with a chronic condition

The NHS Research and Development Programme funded a two-year study to investigate the support needs of young people with special health needs attending mainstream schools. They consulted young people, their parents and teachers and found the following:

- Young people were making active efforts to manage their own condition in school.
- They felt they needed support from health and education professionals in dealing with absence from school, including keeping up with school work.
- They also felt they needed support for joining in school activities,

relationships with other pupils and having someone to talk to about health-related worries.

- Young people and parents said that support from teachers was variable, depending on the teacher's awareness and understanding of the child's condition.
- Teachers felt their need for health information was largely unmet and they did not want to rely solely on parents or school doctors for advice and information.
- Teachers urged the child's health professional to make contact on a regular basis.
- All participants in the study expressed concern about systems in the education services for passing information between and within schools.

These are issues that can apply to children and young people with diabetes and to some extent always have. IDDT can provide an Information Pack for Teachers which is an excellent way of giving information to schools about diabetes and a free Parents Passport for Schools.

The passport has been designed to enable parents to inform schools about how to manage their child's diabetes and in turn support schools to comply with Special Education Needs (SEN) regulations. It also provides teachers with vital information about the condition. The passport contains a wide range of information on how a child's diabetes is managed, including:

- Dealing with high and low blood sugar levels.
- Food and mealtimes.
- Insulin administration and blood testing.

If you would like to order copies please call IDDT on 01604 622837 or email martin@iddtinternational.org

Each child or young person should have a care plan and this should be discussed with the school, ideally by a diabetes specialist nurse. The care plan and the Parents Passport need to be regularly updated.

Receiving an informed choice of treatment

IDDT recently had conversations with several parents:

Parent 1: has a son whose last two HbA1cs were 6.4 and 6.2 on twice daily injections – really good, yet the hospital want him to change insulins and go on to 4 injections a day. He doesn't want to and his mum does not want to upset him when he is achieving good results without having to inject at school. So she's putting her son's wishes first and he is not changing to 4 injections a day.

Parent 2: her 5 year old daughter was on 4 injections a day before starting school and now she has started, the school is refusing to take responsibility for doing the lunchtime injections and blood tests. There is an ongoing letter-writing battle...

Parent 3: her 9 year old daughter is using insulin analogues and a pump. She has chosen this option for her daughter because she believes that it will provide better control and will be less likely to cause future complications.

Parent 4: has a son who is really unhappy about injecting at school on his 4 injections a day regime and after looking on the internet, she found that there are alternatives eg twice daily injections of longer-acting insulin. She is quite angry that this choice has never been offered to her or her son.

Four different experiences and views but they all raise one question – have the parents and the children been given an informed choice of all treatment options?

In considering the options, as parents, we need to ask some pretty pertinent questions:

- Does injecting and testing at lunchtime, make your child feel different from the rest of the class? Is this causing your child extra stress [which can raise blood sugars]?
- Which is the best regime for your child and is there evidence that it produces the best HbA1c results?
- Is 'going into battle' with the school going to solve the problem

and could it hinder your child's overall needs? Will it single your child out with the teachers as being 'different' and is this what you want?

- What will give your child the best quality of life?

Confessions of an old parent!

My daughter was diagnosed at the age of 5, 37 years ago and the advice from our paediatrician was to make life as normal as possible for her so that she didn't feel different from the rest of the class. Her diabetes control was as vital to us then as it is to parents now but her paediatrician encouraged us to look at aspects of her overall needs as a little person, as well as a little girl with diabetes. So fitting in at school and not making a big issue about her diabetes influenced the choices we made and as she got older, she was involved in those choices. My daughter went through her school career without having to inject at lunchtime. Occasionally she went low before lunch or before her morning snack but then children on multiple injections can do this as well!

How did we achieve this? By using short and intermediate-acting insulin before breakfast and before the evening meal. We did not use pre-mix insulin so that we could adjust the short-acting insulin independently of the intermediate acting insulin. Short-acting insulin before breakfast lasts longer than rapid-acting analogue and took her over lunchtime when the longer-acting insulin kicked in and took her through to her evening meal. She then had another mixture of short and intermediate-acting insulin to cover her through the night. Interestingly, she keeps her carbohydrates down and still only needs the occasional lunchtime injection of short-acting insulin if she has a high carb lunch.

So lunchtime injections can be avoided with free-mix as we did or with premix insulins. But don't take my word, look at the available evidence so that your choices are informed ones.

The evidence...

The study [DCCT, 1990s] showed intensified insulin regimes [4

injections a day] improve control and at the same time increase the risk of severe hypos threefold. But this study was only carried out in adults with Type 1 diabetes, not children, so it should not be assumed that this also applies to children. But there are now two recently published studies that provide evidence to help:

First study: Intensive therapy and pump therapy over 10 years has not improved HbA1cs but has increased insulin dose

The researchers classified the information about 26,687 children, treated from 1995 to 2005 in 152 paediatric clinics. Their average age was 13.6 years and average duration of diabetes 5.4 years. 73% were treated with 4 or more daily injections [intensive therapy], 14% with continuous subcutaneous insulin infusion [CSII] and 13% with 1-3 injections per day [conventional therapy].

The researchers concluded that:

- 87% of the children were treated with intensive or pump therapy but while this percentage increased over the period of the study, the average HbA1c [approx 8.0%] was almost constant – in other words, it did not improve.
- Those using insulin analogues received up to 11% higher insulin doses per day compared with those treated with human insulin. [Diabetic Medicine, October 2007]

Second study: Twice-daily free mix insulin regimes gave the best HbA1cs

Continuing stability of centre differences in pediatric diabetes care: do advances in diabetes treatment improve outcome?

This international study in 21 paediatric diabetes centres investigated the influence of changes in insulin regimes, and other factors, on HbA1cs, hypoglycaemia and ketoacidosis. The 2,269 participants were aged between 11-18 and had diabetes at least a year. Fourteen of the centres had participated in previous studies so allowing a direct comparison of glycaemic control between 1998 and 2005.

The average HbA1c result for the whole group was 8.2 with girls having higher results than boys [8.3 vs 8.1] and those who had a

longer duration of diabetes had modestly higher HbA1cs. 85.3% of the children/adolescents were on one of 5 insulin regimes - the remaining 309 were on regimes that could not be classified.

The HbA1c results for the different regimes were as follows:

Regime	HbA1c 8.2	Insulin dose [by body weight]
Miscellaneous	8.2	0.66
Twice daily premix	8.6	1.01
Twice daily free mix	7.9	1.00
Thrice daily	8.2	1.24
Basal bolus	8.2	1.03
Pumps	8.1	0.92

BMI [weight] was not significantly associated with HbA1cs. Insulin dosage was unrelated to hypoglycaemia but was significantly correlated with diabetic ketoacidosis [DKA], with higher insulin dose associated with poorer metabolic control and more frequent DKA.

Comparison of the 1998 and 2005 studies

- Participants in the 2005 study had a higher BMI and were on more intensive regimes than in the 1998 study.
- There has been no significant improvement in HbA1cs and no difference in the frequency of hypoglycaemia.
- Only two centres significantly improved glycaemic control compared with 1998 but this was not explained by intensification of insulin regimes.

So what did the researchers conclude?

Despite many changes over the past 10 years including increased use of insulin analogues, basal bolus regimes [4 injections + a day] and pumps:

- those using twice daily free mix of soluble/regular plus NPH [intermediate-acting] had lower HbA1cs than all other groups.

“This suggests that the so-called conventional regimes may be superior to modern intensive regimes.”

- HbA1cs on pump therapy were not significantly different from the total group even in centres where considerable numbers of patients were using them.

So the researchers concluded that despite major and continuing changes in insulin and insulin regimes, glycaemic control has not improved over a decade in 21 international centres.

So back to injecting at school...

Glycaemic control and a happy childhood are paramount for our children with diabetes. The above evidence gives choices that you and your clinic may not have considered. If injecting at school is a problem or your child does not want to have so many injections, the alternative of twice daily injecting is an option, especially as there is evidence that it can give the best HbA1cs, needs a lower daily insulin dose which in turn reduces the risk of diabetic ketoacidosis and weight gain!

Insulin Pumps

General Pump Enquiries

For general or detailed pump information or other people’s experiences, I usually advise callers to contact an organisation called INPUT
<http://www.input.me.uk/>
Contact Email: input.diabetes@gmail.com
Telephone: 0800 228 9977

Animal Insulin

Contrary to the myths, animal insulin can be used in a pump. While this may be unusual, it is by no means impossible. If this is something you are contemplating, IDDT can put you in touch with an experienced person with Type 1 diabetes who has used pork insulin in a pump. Just call IDDT on 01604 622837 or email enquiries@iddtinternational.com.

org and this can be arranged

Relationships within the family

As an organisation whose members have the practical experience of living with diabetes, one thing that we are all very aware of is that diabetes affects everyone in the family. This is probably especially so when it is your child and being aware of this may help to prevent some of the pitfalls which make life more difficult. Everyone in the family has their own way of coping with diagnosis and the subsequent changes in the life of the family. We all react differently so it is impossible to cover all the various dynamics in all families. Here are just a few examples that may help you to realise that your family is not alone with your experiences and concerns.

Mums and Dads

However strong a marriage or relationship is, it is important to recognise that diabetes, like any other chronic condition will put a strain on that relationship and diabetes in the child that you both care so much about, is no exception. It can, and often does, bring couples closer together at time of diagnosis:

Quote from a friend of a family where one of the children had been diagnosed 12 months earlier. *“You seemed a very close family. It was as if you had all closed ranks and didn’t want to let anyone else in.”*

But is that the case when living with diabetes 24 hours a day, 365 days a year every year? Sometimes the day to day stress can affect the parent’s relationship with each other and cause conflicts.

Responsibility

It is best if the responsibility for your child’s diabetes can be shared but very often, because of circumstances, one parent takes most of the responsibility. This is usually for very practical reasons – work. So,

by force of circumstances, it is the often Mum who shoulders most of the responsibility, although the following can apply just as much to Dads who shoulder most of the responsibility. Here are just some of the possible effects, citing Mum as been the main 'carer':

- Dad feels excluded and Mum feels he doesn't do enough or is not interested. Resentment builds up
- Mum feels that their child's diabetes has become her sole responsibility and then resents Dad having an opinion on decisions about control or approaches to diabetes within the family.
- The worry and energy spent on 'getting everything right' makes Mum tired and irritable and arguments easily develop.

Visiting the diabetic clinic

This should be seen as helpful but it often feels like the third degree and a test of the competence of the parents. You have been set blood glucose targets for your child and these may well have not have been achieved. [I say this as an old hand at parenthood because I concluded that all too often the targets are unachievable if you want any sort of life that is not totally ruled by diabetes!] However, the fact that you are questioned about these and why the results are not what the health professionals at the clinic would like to see, makes you feel guilty, ashamed, a failure. Worst of all, you feel you are letting your child down and at risk of affecting their future health. You may also feel angry with the health professionals for making you feel this way when you have been trying really hard 'to get it all right'. This is something the parent who does not attend the clinic does not have to go through and they probably cannot understand the effects this can have. It is easy for resentment to grow against the parent who escapes this ritual.

Fear of hypoglycaemia

This is very common and understandably so. It is a time when we have to make decisions and take action and we feel a great weight of responsibility for the outcome. Severe hypos at night are frightening, especially if accompanied by seizures and, whether the fear is rational or not, we sometimes fear that our child will die. All of this can

result in:

- Conflicts from one parent wanting to raise blood sugar levels in future to avoid future night hypos and the other parent not agreeing because of their fears of the long-term complications.
- Both parents not sleeping well and being tired etc. The parent who has to go to work the next day assuming that their sleep should be less disturbed and the other seeing this as a 'cop out'!
- Because of fears of night hypos, one parent sleeping in the child's bedroom – not good for the relationship between the parents.
- Not feeling able to go out for an evening together because of the fear that the babysitter not being able to handle a hypo which gives parents no break and freedom, not even for a few hours. If both parents are not happy with this, it can lead to fewer activities together as a couple and doing more things separately. Even worse, it can mean that one partner is always the one to go out.

Quote from one Mum. *"We didn't used to argue very much and then only about one thing – money! Now we argue a lot more and about two things – diabetes and money!"*

Quote from a Mum. *"It seemed at one point every time we had sex Gabby knew and walked into our bedroom in a hypo. I found it difficult to have sex and my husband could not understand why – he thought I was being irrational and that I no longer cared for him."*

Siblings and their rivalry

It is unavoidable that sometimes your child with diabetes comes first:

- At diagnosis everything centres around the child with diabetes.
- Hypos have to be dealt with instantly, even if you are helping his brother or sister with homework.
- Mealtimes often are influenced by diabetes and so is the food the family eat.
- Clinic visits have to fit into the family routine.
- At times of illness or emergency the needs of your child with diabetes do come first.
- Depending on their ages, it is easy to ask the brother or sister to

'keep an eye out' without realising that this is a responsibility that they don't need or want. If the children go to the same school, it is not uncommon for the teachers to ask the brother or sister to help with a hypo.

The list is almost endless and it is obvious that diabetes in the family is going to affect the brothers and sisters in many different ways. It can and often does bring them closer and they show a protective approach if anyone criticises their sibling with diabetes. But at the same time it is natural that there may be some resentment and jealousy. Families have to work their way around these problems but being aware of the possible problems and attempting to meet them before they develop into permanent sources of conflict and sibling rivalry is half the battle. Talking about the problems within the family is important and it is not unreasonable to apologise to the brother or sister for perhaps not spending as much time with them as you would like. They need an explanation, albeit, within the limits of their age and level of understanding. They need to know that you love them just as much as you always have and that because diabetes is serious it sometimes has to come before everything else.

But let us not forget that sibling rivalry works both ways!

Just as we can see that the child without diabetes feels jealous and envious, the child with diabetes can feel jealous and envious of their sibling because they don't have diabetes. They may even feel that you love their brother or sister more, because they don't have diabetes – perhaps a difficult concept because so much more time, energy and worry seems to go into the child with diabetes!

Here is a point worth remembering at times of conflict. What is the first thing we do in the mornings with our child with diabetes – blood test, injection and then breakfast. Essential but not the nicest way to start the morning! If injections and blood tests are difficult and a struggle to achieve [in young children and teenagers, for example] then there may also be a battle! So it is hardly surprising that they feel that you don't care about them compared to their sibling. The role of a Mum is expected to be loving and caring - the person who protects, supplies

comfort and does all the nice things. This image falls down when your child has diabetes - Mum has to do or instigate all the nasty things, starting straight away in the morning! No wonder they can feel unloved and resentful.

Quote from a sibling. “Often one of the first signs that my sister was hypo was that she would get bad tempered and argumentative – this often happened before Mum realised that she was hypo and so we would both get into trouble. Then the penny would drop and my sister was given sugary foods. She came around feeling happy again, totally unaware that we had been very angry with each other, but I remember being left still feeling angry with her. Even though I knew she'd been hypo she had still made me angry and a biscuit for me didn't sort out how I felt!”

Tip from a Mum. “I found that blaming diabetes rather than my daughter [with diabetes] was the best way around problems – we could all hate it together then. It helped to make my son realise that when things were difficult, it was not his sister's fault but the fault of diabetes.”

Grandparents

As parents going through our own grief at the time of diagnosis and having to learn so much, we are perhaps unaware of the effect it can have on our parents [our children's grandparents].

One mother's experience: “My daughter was diagnosed when she was 5 and her brother was 6 – they had two grandmothers but no grandfathers. My mother had difficulty believing that my daughter had diabetes and she was upset and emotional for a very long time. Perhaps only now that I am a grandmother myself do I truly understand what she felt like. Grandchildren are very special – we can enjoy them, we can spoil them and we are free from the responsibilities we had with our own children. So I can now understand why my mother felt so upset at diagnosis – it also seems so unfair that we are older, that it is someone so young that should have lifelong condition like diabetes.

I'm quite sure that she sometimes felt I was being hard but I was lucky, she never interfered or criticised. But I know of other families where this has not been the case, probably because of the difficulty the grandparents have in accepting diabetes in the family. The grandparents have interfered, have paid more attention to the child with diabetes, so leaving the other grandchildren feeling left out and ignored. However unintentional, they leave emotional chaos behind them after a visit.

I have to say that my mother-in-law reacted in a very different way. There were similarities in that it was as if she had difficulty accepting it too, but her way of handling this was to ignore it. I don't think that she ever understood the seriousness of diabetes or the effects it had on our family life. This was her way of coping and we are all different. It later became a family joke because it was tradition that she made the first cup of tea on Christmas morning and she always asked if my daughter took sugar, every single year up to adulthood!"

Babysitting

One of the most useful roles that grandparents play is as babysitters, especially in nowadays when both parents need to work. But this is often difficult for parents and grandparents.

We, as parents, naturally find it difficult to leave our child with diabetes even with our own parents and they may feel that they cannot baby sit because the weight of responsibility is too great or they do not feel to know enough about diabetes. These reactions are both understandable but it does limit what the parents can do and it denies the grandparents the pleasure of looking after their grandchildren.

Quote from a parent. "My mother learnt about hypos, testing and food and I learned to leave my daughter with her for a couple of hours during the day to start with. Of course, I was always at the

end of a phone. I could not leave her for overnight stays because she sometimes had severe night hypos and this would not have been fair on my mother and nor could I have slept!

Hypoglycaemia in children

"Good diabetic control is as much about avoidance of hypoglycaemia as it is about avoidance of high blood glucose levels," a quote from Professor Stephanie Amiel.

Hypoglycaemia, the fear and avoidance of it, are probably the most frequent worries for adults and children with diabetes and their families. These concerns have increased with the present recommendations that blood glucose levels should be as near normal as possible because it has been shown that with this 'tight control' there is a threefold increase in the risk of severe hypoglycaemia. For this reason we are treating the issue of hypoglycaemia as a separate item. IDDT has a leaflet about hypoglycaemia in children and if you would like a copy call IDDT on 01604 622837 or e-mail enquiries@iddtinternational.org

Growing up with diabetes

Growing up is not easy and growing up with diabetes or any chronic condition makes life that much more difficult for your child. This is something that we can recognise and try to understand, but unless we have actually had the experience ourselves we don't know how it really feels. This is perhaps something that our teenagers with diabetes will remind us of on many occasions!

Here are just some of the experiences that our children may have as

they grow up:

- Feeling different from other children.
- Being treated differently from other children at home, at school and socially.
- Not feeling as good as their friends or the other children at school – having a low self-esteem or being aggressively determined to be as good, if not better, than everyone else.
- Being frightened of looking foolish if they have a hypo at school or when out socially and being called names.
- Feeling pressurised to achieve and do everything, by messages of being ‘normal’ when they don’t feel normal.
- Being excluded from school activities or parties because they have diabetes.

The feelings and experiences of our children with diabetes will vary with the age of diagnosis and there will be different effects for them and for the family. It is difficult to grow up with diabetes from a young age and perhaps never know what it is like to not have diabetes and be treated normally. But it is equally difficult to be diagnosed in the teenage years – perhaps more difficult. Suddenly being faced with diabetes and all the changes that this means in both lifestyle and self-image during the teenage years are all happening at one of the most difficult stages of growing up.

One mother’s experiences of the teenage years!

When my daughter was quite young I remember her going through a phase of believing that no one would want to marry her because she had diabetes. When I was young I believed that no one would want to marry me because I had straight hair and wore glasses. The answer to that is relatively easy – you can wear contact lenses! Not so easy to hide diabetes or to give reassurances to a 10 year old.

So when boyfriends started to appear on the scene at 14 or 15 years old there was always the worry of “when do I tell him about diabetes?” At this age she was very reluctant to tell anyone about it – she just wanted to be like her friends. The good text book standard advice of

always tell your friends that you have diabetes, just in case..... really was totally ignored and understandably so. Teenagers are teenagers and with or without diabetes, they do not want to be different from their friends.

So what do a parents do in this situation? Perhaps this question should be “ what CAN you, as a parent, do in this situation?”

I think perhaps the answer has to be – nothing. Sit back, keep your fingers crossed, hope and have a bit of faith.

- Hope that in the long run common sense and self-preservation will prevail. Hope that in the short term if she does have a hypo while she is on the date that it won’t be that bad that she can’t handle it before he notices. Hope that if the worst comes to the worst and he discovers that she has diabetes before she has told him, he’s a nice lad and is not put off.
- Faith is very important and sometimes very difficult when we see our teenager at home breaking all the rules, being stroppy and from time to time being fairly objectionable! But having faith is very important to give your teenager the confidence they badly need and to show that even though you would prefer it if they told their new boy or girlfriend about their diabetes, you do understand how they feel.

This all sounds a bit like women’s magazine stuff, but my years of experience as a parent has taught me that the one thing young people do not like is looking foolish in front of their friends. So, they make damn sure that they do not go hypo by eating plenty or by drinking normal [not diet] coke. It is called **self-preservation** - so have a bit of faith in that, if nothing else!

What are the alternatives?

There is only one and that is **conflict**, probably a word that can never be over used when discussing teenagers, parents and diabetes. You can insist that they do the right thing, but you cannot make them. You can keep them cosseted at home longer because of their diabetes. But what are you achieving? Conflict, resentment and a breaking down of

family relationships probably at a time when your teenager needs you the most, even though they would not admit it. You are not needed in the way you were – to manage their diabetes for them, but to just be there, to boost their confidence by showing that you trust them [even if you don't always!] and to pick up the pieces when necessary.

I wasn't a wonderful parent.

If I sound as if I was a wonderful parent who got it right, make no mistake, I wasn't. I learnt the hard way and we struggled through. We had conflicts, battles and tears, both hers and mine. Things improved but the change came from me, rather than her. I attended a course on listening skills and it slowly dawned on me that I **wasn't really listening to my daughter**, that my own feelings, my emotions and my worries were preventing me from listening to her, to her fears and to her concerns. She had them despite the bravado she often displayed. So I tried to put all my emotions out of the way and truly listen to her. My emotions were largely ones of caring for her but nevertheless, came over to her as being over protective and not letting go of the apron strings. By putting aside my feelings, many of the conflicts disappeared. It enabled us to develop a good relationship, albeit that there have been some ups and downs along the way!

Looking back over those years

Why should parents always get it right, even worse, why should we think that we ARE right! If we have not grown up with diabetes then we do not know how it feels – the difficulties, the conflicts and the worries that our children have. Diabetes in the family is a new experience for all of us, we have no previous experience to guide us through it and it is a continual learning curve. We can only do our best but of one thing I am sure, we have to let go of our children. If they make mistakes in the process, then we have to hope that they are not too serious or damaging, but we have to be there for them when they need us. That is a parent's role, made more difficult by diabetes but even more essential.

Discovering alcohol

Like it or not our teenagers discover alcohol. It is all part of growing up and having diabetes does not alter that nor does it dull their desire to experiment! It is a worrying time for parents of children with diabetes – we cannot just be slightly amused by the first bout of getting a bit drunk because alcohol affects blood sugars. So it is important that our teenagers learn how and what to drink and what precautions they should take.

The effects of alcohol

- It lowers the blood glucose levels and can lead to hypoglycaemia, especially during the night.
- It can affect the blood glucose levels for up to 24 – 48 hours afterwards causing unexpected hypos during that time.
- Drinking can mask the warning signs of an impending hypo and lead to a severe attack.
- Friends around can assume that the person with diabetes is drunk when in fact, they are hypo.
- The carbohydrate content of alcoholic drinks does not counteract the effects of the alcohol in lowering the blood sugar levels and should not be counted as part of the total daily carbohydrate intake.
- The effects of alcohol will vary in different people and it is necessary for each person to discover how to drink alcohol and avoid hypoglycaemia.
- Alcohol should be taken in moderation.
- Low carbohydrate beers are often very high in alcohol and so should be avoided.

Precautions

It is important to remember that alcohol affects people differently and you have to discover the precautions that are necessary for you, to avoid severe hypoglycaemia. This process of discovery has to be approached with care to avoid “learning the hard way”!

Here are some pointers:

- Where possible eat a meal with your alcohol.

- If it is a drink in the pub with friends, then nibble crisps or other carbohydrate during the evening.
- Have a good meal before going out and monitor your blood glucose. It may be necessary to give a lower dose of insulin to counteract the effect of alcohol.
- Measure blood sugars before going to bed.
- Drink in moderation.
- Always have a good snack, preferably with both fast acting and slower acting carbohydrate, before going to bed.
- Monitor blood sugars more frequently for the next couple of days, especially if there is going to be physical exercise.

Eating disorders

The following story by Michelle Tichy will be of interest to many parents of children and young people with diabetes and to those affected by one of the eating disorders that we hear so much about. We are grateful to Michelle for sharing her story with us to not only help others in similar positions but to help give all of us a better understanding of these problems. The views are those of Michelle and are not necessarily those of IDDT, but we welcome this first-hand experience. Eating disorders are bad news for anyone but an eating disorder with diabetes is particularly serious. Before reading Michelle's story we need to know what an eating disorder actually is.

Basically eating disorders are serious preoccupations with food, weight and/or body image.

Clinically there are 3 types:

- **Anorexia** – self starvation triggered by an extreme fear of gaining weight
- **Bulimia** - a binge/purge cycle stemming from a fear of gaining weight.

- **Compulsive eating** – bingeing thought to be caused by a need to numb negative emotions and negative self-image.

However there is a range of eating disorders that happen to people with diabetes that do not fit into the 'clinical' definitions but need recognition.

My Story

by Michelle Tichy

I was diagnosed with Type 1 diabetes in February 1982 - I was 7 years old. The first couple of years were OK aside from adjustments to the new routine and my parents increased fighting. I guess I blamed myself for their fights, I was always putting myself in the midst of these fights and often I tried to deflect their anger at each other on to myself. By the time I was 11 it was clear that they were headed to separation and divorce.

My response to the pain that this caused me was self-inflicted pain and a warped perfectionism. I developed an eating disorder that can best be classified as 'borderline anorexia' in that my symptoms were: rigid food rituals, strict rules about the amount of food eaten, purging, excessive exercising and extreme fear of gaining any weight. At the same time I developed a fanatical fear of ever getting high blood sugar, so I ran normal to low. My eating disorder continued for the next 7 or 8 years, made worse by puberty and I actually delayed menses until 6 months after I turned 15 and this can be considered a symptom of anorexia. Since my weight never went below normal the only clinical diagnosis I ever received was 'borderline anorexia' and this was inaccurate because of the purging bulimia. This is one reason that I choose not to use clinical definitions for eating disorders that do not take into account the realities of all sorts of eating and body image problems.

My eating disorder was never caught by any of my doctors, in fact I was their star diabetic patient because I kept my blood sugars so close to normal! Even the dietitians missed the fact that I was barely

eating enough to continue functioning. I never lied to any of them but I never offered any information to them about my Eating Disorder.

I cannot pin point the cause of my eating disorder to one thing specifically, the following are the main causes I see:

- Indoctrination by doctors on the importance of diabetics being thin.
- Society's standards of beauty.
- Stress/ perfectionism.
- My family falling apart.

I have been in recovery now for 3 years – it is rough at times.

My view of the connections between diabetes and eating disorders

People with Type 1 diabetes have eating restrictions placed upon them by doctors generally from diagnosis. They are told to follow a specific diet and to reduce their sugar intake to next to nothing. From my experience as a 7year old, it felt like I had been locked into a cage and was only allowed to eat certain things, none of which was 'fun stuff'. Some of my diabetic friends that were diagnosed in adolescence felt direct pressure to be fanatical about food and their weight. It seems to me that direct pressure from doctors to be thin and constantly concerned about food is a clear way to create the groundwork for eating disorders. My assertion is validated by research on diabetics and other young people with chronic conditions which has shown that young diabetics have a higher probability of developing eating disorders than those in the same age group who have no chronic illness.

More common eating disorders related to diabetes:

- Running high blood sugars [hyperglycaemia] so that your body produces ketones and in doing so there is weight loss.
- Reduction of insulin dosage so that you run high blood sugars and so that you don't have to eat very much.

My views on being healthy with diabetes and avoiding or

overcoming body image problems and eating disorders

- Know yourself and what it feels like to be high or low.
- Respect yourself, neither an eating disorder nor ignoring diabetes is healthy.
- Doctors are resources to keep you healthy. If you don't trust yours enough to be able to talk to them, maybe you need a different one.
- Try to be the best you can – not some societal ideal.
- Remember to try to get something from each food group at each meal.
- Do everything in moderation from food to exercise. Find activities you enjoy to both 'de-stress' and be active [walking tennis etc]. Try meditation or yoga for stress relief and getting to know your body.
- Find people to talk with about your insecurities. Join a support group.

Diabetes and coeliac disease

Both diabetes and coeliac disease are autoimmune diseases and there are increasing amounts of research to show that there is a link between the two both in adults, children and adolescents. There are views that more attention should be given to this link.

Further information is available in IDDT Leaflet, 'Coeliac Disease and Diabetes', contact IDDT on 01604 622837

IDDT Publications for families living with diabetes

Parent Information Pack - to help and support parents

Diagnosis in your child.
Teenagers living with Diabetes.

Parents' experience.
Growing up.

Teacher Information Pack - to help teachers understand the needs of children with diabetes at school

Introducing teachers to children with diabetes.
Having a child with diabetes in your class
Hypoglycaemia at school

IDDT Quarterly Newsletter

Update information about diabetes.
Latest research news.
Campaign progress reports.

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