

Insulin Pumps: a new lease for life



Insulin Pumps: A new lease for life could not have been produced without the help of those whose lives have been transformed by using an insulin pump. We hope that by reading their real life experiences you will be able lend your voice to theirs in calling for fair and equal provision of pumps across Scotland.



Developing an insulin pump service.

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Insulin pump therapy should be offered as a treatment for diabetes to children, young persons and adults with Type 1 diabetes as part of a cohesive and comprehensive diabetes service. Appropriateness should be determined by clinical need, personal choice and suitability - not on the basis of where a person lives or ability to pay.**

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Diabetes UK Insulin Pump Position Statement

Pump therapy is an alternative insulin delivery option and awareness should be raised amongst healthcare professionals and people with Type 1 diabetes alike.

Insulin pumps can change people's lives. The stories from people living with diabetes in this report are a powerful reflection of this.

As yet, there is no cure for diabetes but insulin pumps are one of the most significant advances in medical technology, freeing people from the daily challenges of multiple injections, helping to reduce the risks of complications, raising quality of life and freeing up NHS time and resources. This is why access to pumps is such an important issue for Diabetes UK Scotland and, more importantly, for those living with or supporting others with diabetes. Our aim is to ensure that wherever anyone lives in Scotland they should have access to pumps.

Across Scotland healthcare professionals are actively supporting insulin pumps as an alternative to other more established insulin therapies. In an often challenging environment NHS staff are working with people with diabetes to deliver access to a therapy which, in Scotland, is still relatively rare.

The National Institute for Clinical Excellence (NICE) estimates that between 2 and 15 per cent of the Type 1 population could benefit from insulin pump therapy¹. In Scotland, this means that over 4,000 people with

Type 1 diabetes could benefit. Currently we are looking at around a quarter of that number and even then the distribution across Health Boards is patchy and uneven². With 2 per cent of the Type 1 population in Scotland on insulin pumps, the challenge of developing new services to European levels of between 10 and 30 per cent will require immense effort and commitment. We have that commitment and through reading these stories hope you will too.

The Scottish Government is supportive of increased access to pumps services and some Health Boards are making good progress. For example, Fife, Tayside, Borders and Lothian Health Boards account for 60 per cent of pump use in Scotland. The new Diabetes Action Plan for Scotland will, we hope, stimulate and support increased provision and access.

Patients have also become organised around the issue. In 2009 a new campaigning and support group, the Insulin Pump Awareness Group (IPAG), was formed to support and campaign for people to be able to access pumps. IPAG and others, including Diabetes UK Scotland, have worked tirelessly to help people learn about pumps and to support greater access. Optimum care and equal access remain at the core of our work.

Finally, we would like to thank the groups and people who helped to put this publication together: Marc Hillis for his artwork, The Insulin Pump Awareness Group, Professor Steve Greene, Dr Vicki Alexander, Dr John McKnight and, of course, the staff of Diabetes UK Scotland.

Jane-Claire Judson

Director, Diabetes UK Scotland

Insulin Pumps and the health service

According to SIGN Guideline 116₃: Management of Diabetes, which reviewed the literature information about insulin pump therapy,:

- Continuous subcutaneous insulin infusion (CSII) therapy is associated with modest improvements in glycaemic control and should be considered for patients unable to achieve their glycaemic targets. ^[i]
- CSII therapy should be considered in patients who experience recurring episodes of severe hypoglycaemia. ^[ii]
- An insulin pump is recommended for those with very low basal insulin requirements

(such as infants and very young children), for whom even small doses of basal insulin analogue may result in hypoglycaemia. ^[iii]

- Pump therapy should be available from a local multidisciplinary pump clinic for patients who have undertaken structured education. ^[iv]
- Targets for improvement of HbA1c and/or reduction in hypoglycaemia should be agreed by patients using CSII therapy and their multidisciplinary diabetes care team. Progress against these targets should be monitored and, if appropriate, alternative treatment strategies should be offered. ^[v]

Together with the NICE guidelines SIGN 116 should be a stimulus to diabetes services in Scotland to support suitable patients who wish to go on pump therapy and there is a clear pressure to accelerate these developments. The possible barriers to this include the cost of pumps and consumables, plus the required commitment, time and developing expertise of the diabetes teams.

As described in the patient stories presented in this document, there is no doubt that insulin pump therapy can make a big difference to some people with type 1 diabetes but a major commitment is needed

to enable this to work well. This therapy requires more finger prick tests and frequent insulin dose adjustments. It is very hard work initially to calculate and programme the correct basal doses of insulin and then adjust these optimally. If the pump stops, or is disconnected, there is no background long acting insulin to prevent diabetic keto-acidosis, which may therefore happen more quickly in pump users. Some individuals also dislike being continually attached to a pump.

However, there is clearly a group of people with diabetes who gain great benefit from this form of treatment. Pump use is likely to increase in Scotland, perhaps with continuous glucose monitoring systems. On reviewing the history of type 1 diabetes in the UK, from the discovery and first use of insulin to the present, one sees many very positive changes to treatment, particularly during the last thirty years. We need to continue to use developments such as CSII appropriately for those who would benefit from them.

John A McKnight

Consultant Physician. Western General Hospital
Edinburgh

Notes

- i level A (strong evidence)
- ii level B (quite strong evidence)
- iii A good practice point (based on the clinical experience of the guideline development group)
- iv A good practice point (based on the clinical experience of the guideline development group)
- v A good practice point (based on the clinical experience of the guideline development group)

Insulin pumps and children

Insulin pump therapy - continuous subcutaneous insulin infusion (CSII) – was developed in the UK in the 1970's. Rapid technological developments changed the initial pumps from the size of a house brick, charged by mains electricity, to an acceptable dimension and battery driven. Whilst countries across the world, notably the USA, continued with pump development, the UK appeared to move away from CSII, following initial concerns about efficacy and safety and the potential financial burden on the NHS. In the past decade technology has advanced and modern pumps are now small in size (matchbox), reliable, very safe, available and relatively affordable. Many countries throughout the world use pumps as part of the modern management and treatment of Type 1 diabetes in children and young people and large pump centres can be found in Germany, Holland, Belgium and Scandinavia, as well the USA.

Since 2002 we have used insulin pumps in young people in Tayside and our experience has been very positive. As with any therapy there are a number of advantages and disadvantages. Not all children will be capable of using an insulin pump, nor would they choose to use one. The advantages of the therapy can be that it offers a more

flexible lifestyle and eating pattern, while at the same time delivering insulin in a more physiological way and improving glucose control. Multiple daily injections are replaced by one injection every 2-4 days. Severe hypoglycaemia does not appear to be a major concern with education of the patient and there are very positive effects of pump therapy on the quality of life in young people with this devastating progressive disease. There are of course practical disadvantages to CSII, the most common being risk of infection at the cannula site. Some patients have psychological problems being attached to a device 24 hours a day, enforcing their negative image of diabetes and serve as a reminder of the disease on a daily basis. There is a small risk of Diabetic Ketoacidosis, but the literature would suggest that this improves with experience of using the pump, and is more common in the early days of pump use. Perhaps the major perceived disadvantage of pump therapy in this country today are the financial implications for its use.

Insulin pump therapy for children with Type 1 diabetes must be increasingly used as a mode of treatment in the UK. However, using the technology alone will not necessarily improve overall glycaemic control and long-

term prognosis for long-term diabetes related complications. In order to optimize health outcomes, the adoption of more intensive insulin strategies needs to be accompanied by ongoing education and support for children and their families. Whilst relatively expensive, when compared to conventional insulin therapy, there are considerable financial benefits in the longer term if diabetes related complications are reduced by improved glycaemic control. The considerable benefits to an individual – both in terms of improved glycaemia and improved quality of life must also be taken into account.

Professor Steve Greene and Dr Vicki Alexander
Tayside Children's Diabetes Team

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Young children

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As parents of a toddler using an insulin pump we have a united opinion to its effectiveness. **For us it worked.** It really did help to stabilise Daisy's blood sugar levels and was noticeable within hours of the pump first being fitted.

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Transparent, consistent and equitable protocols should be in place in all localities covering: assessment, referral, follow-up, ongoing support, education, support during initiation, supply of consumables, discontinuation, staff training and competencies.



Young children and insulin pumps

Parents are naturally concerned for their children's health. However, being told that your child has diabetes has an immediate impact on the whole family's life. A new routine of regular hospital appointments, a future of insulin injections, glucose monitoring, managing carbohydrates and activity levels: the prospect of learning to manage diabetes can seem overwhelming. Some will do well; however for children in particular, pumps can dramatically improve quality of life.

Daisy

It's been quite a rollercoaster 18 months for our family. Daisy was diagnosed with Type 1 diabetes in November 2007. She was just 18 months old and we immediately embarked on a strict regime of hourly blood testing, diet control, four insulin jags a day, followed by a program of constant learning that would never end for our family of five.

Despite all our efforts Daisy's blood sugar levels were still very erratic. It was obvious that such small amounts of carbohydrate or insulin could swing such a tiny frame in any direction.

After 11 months of blood sugar highs and lows, and jags coming from all directions (she never flinches or resists), we finally embarked on insulin pump therapy on 29 September 2008 and the learning began all over again. As parents of a toddler using an insulin pump we have a united opinion to its effectiveness. For us it worked. It really did help to stabilise Daisy's blood sugar levels and was noticeable within hours of the pump first being fitted.

The pump carries the responsibility of constantly drip feeding tiny amounts of insulin throughout the day which acts as a basal (or background) treatment. The pump uses this information and increases the background levels to suit.

Using the pump for the first time we realised that diabetes must be one of the most complex diseases known to mankind. It's amazing that such tiny malfunctioning islet cells in the pancreas have such a giant responsibility to the whole body.

We had excellent support and help from our diabetic team in Ayr. It involved three two hour learning sessions and trials using a pump where the insulin was replaced with saline solution. My wife and I were both hooked up to pumps for three days and had to use them assuming we were diabetic too. It was a great insight for us to be able to really understand how they work and to be able to sympathise with Daisy having to wear it forever. For us the reward was very much worth it. Daisy's sugar levels were under far better control and she was noticeably happier

although she still pains a little bit when we have to change her infusion set every three days. We were so delighted that she could now eat whatever she wanted, snack whenever and treats weren't a problem, so long as we knew how many carbs she was consuming.

We consider ourselves blessed to have three happy, healthy children and the past 18 months has served as a great bonding experience as we have tried to live within Daisy's body understanding how it reacts to all concerned. At two years old she can now say "diabetes" as clear as day but the hard job will come in teaching her all that comes with it.

So if you feel that a better blood sugar balance might be achieved using a pump then we believe that it should be fully funded and available to all children because it will make a difference to their wellbeing.

Daisy seems to keep smiling through whatever nature throws at her.

Peter

Diabetes entered our lives in May 2006. My son had just celebrated his fifth birthday and was looking forward to starting school as a healthy 'normal' young boy. At that point in time I knew very little about diabetes, and had no idea of the impact it would have on the whole family for the rest of our lives. We are very lucky to be living in Angus, which comes under the care of NHS Tayside, one of

the leading areas for the care of paediatric diabetes in Scotland.

Every time we had a clinic appointment I spoke to the consultant about the problems we had, then one day she asked me what I knew about insulin pumps. She said that Peter would be an ideal candidate for a pump and she wanted to put him on the waiting list. I went away and did my homework. I read all the literature I could find. It seemed too good to be true. Peter was nervous, but was reassured that if he didn't like it he could give it back.

1st July 2008 is a date I will never forget, the day we started pumping and the beginning of a new life for us all. Peter's blood glucose levels improved from day 1. We have occasional high readings, but we can act on them. We have more control over exercise and far fewer hypos post-exercise. His highest HbA1c since pumping has been 7.9% - I know we are improving his long-term prospects and he is now as near to being a normal healthy child as he will be until they find a cure.

At his first clinic after he started on his pump, the nurse asked him "Can I buy your pump back for £1 million?" He replied "I will have the £1million and keep the pump!" He never wants to go back to injections.

The consultants and nurses have been wonderful and this should be standard care across the whole country – we are lucky, but this shouldn't be the case. Every child with Type 1 diabetes should be entitled to a pump.

Young adults

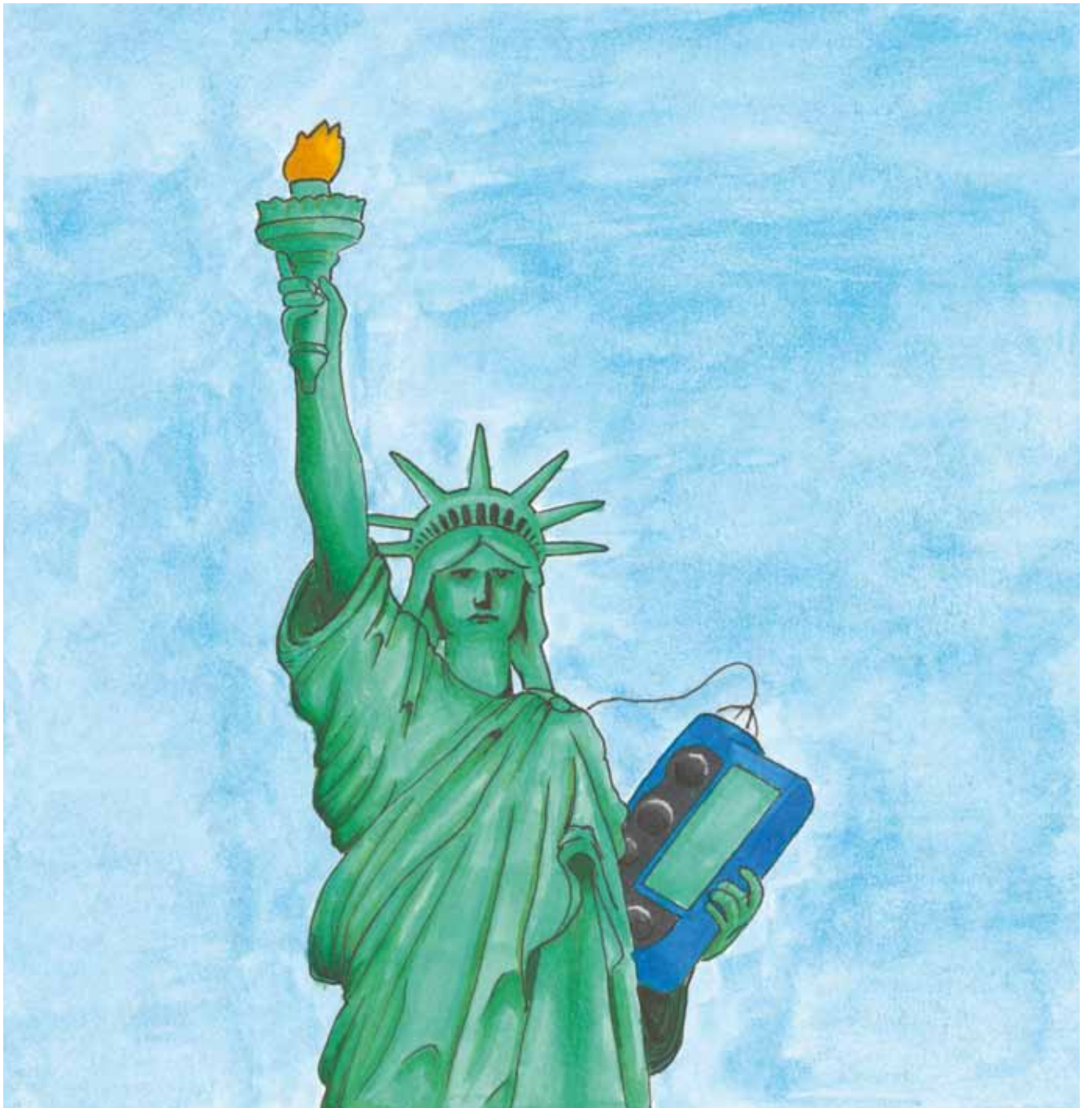
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Insulin pumps! We got hundreds of information and thought this is for us, the insulin pump is for us.

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Funding for pumps and consumables should be accessible when criteria are met.



Young adults

Young adults with diabetes often use the internet to find out about diabetes care and advice from healthcare systems all over the world. Social media and websites such as Reality Check in Australia have allowed young people to share their experiences and as a result they are highly informed and are increasingly aware that there are treatment choices available other than their current regimen.

Martyn

I first found out about the insulin pump when I went to a diabetes conference in Florida. I was just flicking through the internet and found a diabetes conference while myself and my family were on holiday. My mum, dad and I went to where it was being held and walked in and we were amazed at the entire event. From the people at the conference to the sheer volume of people with diabetes all under one roof. We were welcomed with open arms. We also saw all these kids running about with a thing attached to them. INSULIN PUMP! We got hundreds of information and thought this is for us, the insulin pump is for us.

When we got home, I read up on insulin pump therapy and how all it works, went

to see my diabetes team and said: "can I have this please," thinking it would just be as easy as that. I was wrong! It took me and my family two years to convince my diabetes team this was the way forward. We had to go to the extent of contacting my local MP, the Health Minister. Every time I went with my mum and dad to my diabetes meeting we were spending most of the time pleading to get this pump, which is a life changing piece of equipment. If it was not good then why do insurance companies pay for people to use it in the USA? They would not do that unless it was cost effective.

I cannot describe how much my insulin pump has changed my life, but I will try. I feel I have got such a better quality of life now I have got my insulin pump. I feel more like a 'normal' person. I think everyone should be able to get an insulin pump.

Marc

I was diagnosed with Type 1 diabetes just after my thirteenth birthday (I'm now 17). It was a massive shock for me when I was told the only treatment was injections. I have had a fear of injections all my life. I was told I had to get to grips with injections quick or I would die, and I was taken round the kidney dialysis ward to see what would happen to me. This didn't make injections any easier, it just made me so much more depressed to have diabetes. The last four years have gone from bad to much much worse.

I first asked about a pump over a year ago at my clinic, as I had been feeling really unwell for a long time and while looking for ways to help me feel better I met other young people on the internet who had pumps. They had had similar symptoms to me and a pump had really helped them. It made a massive difference to their lives. I met my Diabetes Specialist Nurse,

she was really encouraging and I was totally over the moon and felt so happy that day. But soon after, I was told the answer was no. At that point the fight for a pump was on.

A year later, and after being bounced between hospitals and thinking I was going to have to go private, the struggle seems to be over.

For me, it's about life before the pump and life after:

Before the pump:	With the pump
<p>Needle phobic all my life. 2,000 injections and another 2,000 self blood tests ever year. I dread every injection.</p> <p>Fear of hypos after frightening experiences means I am scared to be alone and sleep at night in case I don't waken in the morning.</p> <p>Lost all my independence.</p> <p>Was doing great at school and should have sailed through my Standard Grades and Highers; instead it's a daily struggle to keep up with work. School have told me I can't take all the Highers I was doing this year. I am totally devastated how diabetes is affecting my life in every way and I can no longer do the course I wanted to do at Uni.</p> <p>Advised to see psychologist, waited over 5 months to be told she can't help as problems all diabetes related.</p>	<p>I feel like a different person already, I feel less tired, I have more energy.</p> <p>My lifestyle is more flexible already, I have a sense of freedom now that I haven't had for 4 years.</p> <p>Managing my levels for rugby is much easier and I am avoiding hypos now which I couldn't do before.</p> <p>In 3 weeks my levels didn't go over 14mmol, but most readings are under 10 mmols.</p> <p>First Hb1Ac 24 days after starting the pump down from 8.9 to 7.1.</p> <p>I actually feel like I have a chance now to re-build my life!</p>

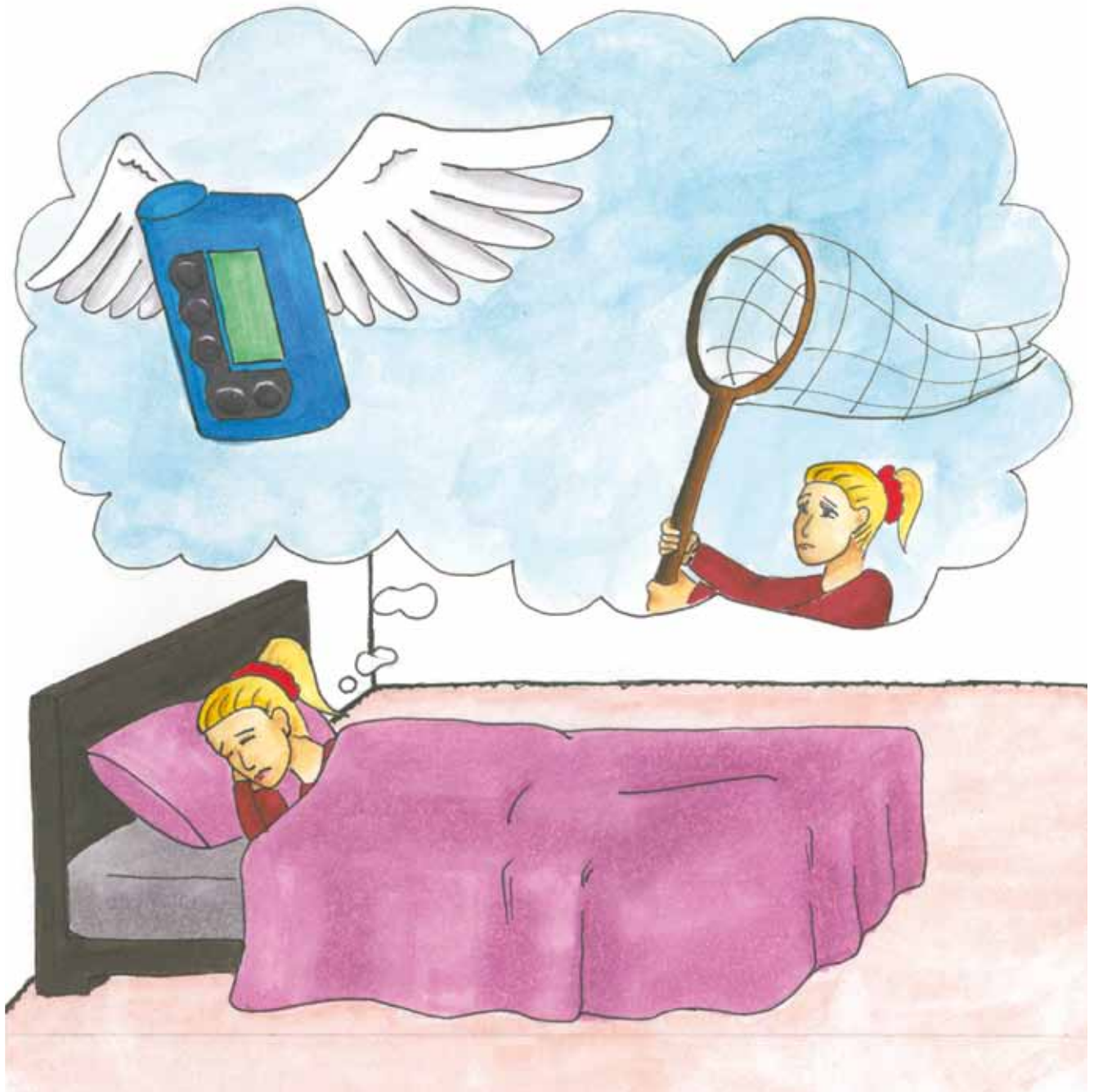
Adults

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I've been with my pump for four and a half years and it's now a **trusted friend.**

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The development of local pump centres, with appropriate infrastructure, staff, education and training, should be encouraged. Local arrangements need to be put in place to support this.



Adults

Diabetes is a complex condition and, for individuals, it can be a difficult condition to control. For adults with long experience of trying to manage their diabetes, insulin pumps provide a possibility of a solution to, sometimes, years of struggle.

Maggie

I've had diabetes since the age of seven, back in the days when we boiled pyrex syringes and terrifyingly long needles. The idea of controlling one's own insulin dosage was unthinkable. My diabetes belonged to some team of doctors and nurses on a general children's ward. My first big revelation was disposable syringes, next human insulin, then insulin pens and much later on, at the age of 50, an insulin pump! Well, it took a while for sure and my local MSP, Kenny McAskill, helped me lobby for one, but Lothian Health Board was fantastic and really enthusiastic because I'd developed, over the years, a weird tendency to go to bed on a 7 and get up on a 20-something.

The pump has taught me a lot about the way I use insulin and I seem to go through vast numbers of test strips. Now I know I need more insulin in the mornings; less as the day goes on. My HbA1c is currently a bit on the

low side at around 6.4 and since I have no sensitivity at all to hypos after 47 years, I'm still inclined to have too many of them.

I love having a pump. It has literally changed my life, teaching me to think in carbs and small amounts of insulin. I've never been concerned about doing injections so not doing them isn't a big deal. What matters is having the control in my own hands and, on the whole, knowing what my diabetes is going to do - though there will always be those unexpected highs and lows.

Gail

Having struggled with my blood sugars due to diabetic complications, I felt that I was getting nowhere with multiple injections – my body was not giving me the test results my efforts should have shown.

While exercise is always recommended for a healthy lifestyle, pre-pump it was always a lot more effort than it seemed to be worth. Hypos, early morning hypos, high sugars the next day...somehow exercise did not seem like an easy option.

Having only been on an insulin pump since February this year, I can quite honestly say that, even in a short period of time, my quality of life has improved greatly.

The pump has enabled me to go back to exercise without the worry of the after-

effects and allows me the freedom and flexibility to tackle new challenges including a 95 mile hike over six days...something I would have never considered on injections.

I used to feel like I was literally being dragged out of bed every day, the fatigue of roller-coaster blood sugars left me with absolutely no energy. Starting on the insulin pump has given me a new lease for life, much more energy and people have commented on the change in me, both physically and mentally. While my HbA1c results have improved, the ultimate benefit is how much better I feel and how much more control I have of my diabetes.

Fiona D

I've been with my pump for four and a half years and it's now a trusted friend. The thing about having a pump is that life becomes much more 'normal', so much so that it's possible to forget that I'm diabetic. I still have the highs and lows that many of us with Type 1 diabetes experience but with a pump they are so much easier to rectify. Before I had my pump too much time was wasted feeling very below par. Now I work, exercise, socialise and look after my family without having to take time out to deal with my diabetes. Having a pump has hugely improved my quality of life and has given me the freedom I could only dream about five years ago.

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Dorothy

I've had Type 1 diabetes for 38 years. For many years I had considered myself to be a healthy person who happened to have diabetes. In October 2002 my blood sugar went totally out of control.

During this time I had terrible sleep problems, felt ill all the time, had terrible gastric problems and struggled to live my life. I was diagnosed with gallstones but my Blood Glucose (BG) was too high for the surgeon to operate but the gallstones were causing my BG to be too high! Catch 22. This situation lasted for almost three years until I was given an insulin pump in June 2005. Within four weeks of starting the pump, my HbA1c came down to 7.5. I suddenly had my life back. My appetite returned and at last I could see the light at the end of the tunnel.

Despite feeling 100% better, I still have problems with my BG control which I believe is directly related to earlier nerve damage caused by poor diabetes control. For this reason and many others, I strongly believe that insulin pump therapy should be available to everyone who would benefit from it and especially to young people who have their whole life in front of them.

In my opinion, pump therapy changes lives. It enables people with diabetes to avoid complications and remain physically and economically independent. So why then is Scotland, with the third highest incidence of Type 1 diabetes in the world, lagging behind?

Having diabetes is not just a medical condition. For some people managing insulin levels with their lifestyle is a never ending task. Living with diabetes can be emotionally challenging and even going onto a pump can mean patients feeling they have to prove the investment made in their health.

Fiona C

My pump journey has been far from easy, and I still do not have the funding for my own pump. I am currently on a pump trial and using a loan pump which I have refused to give back until I receive my own pump. I was told I was unsuitable for a pump because I have an irregular lifestyle, follow no set routine each day, have a stressful life and was on a relatively high dose of insulin – these tend to be factors that suggest an insulin pump would help me understand and control my diabetes.

Clinicians said that I did not “have the intelligence to manage a pump” and as I had not followed rules for 26 years, how could I be “trusted to follow the rules of pump therapy.” One quote I have proved wrong - I was told that pump therapy would be a lethal option

for me, now they are saying it would be detrimental to remove the pump. I hope I have proved this particular person wrong – but still live in fear of them taking the pump back.

I think the NHS has well and truly recouped money that would have been spent in the last three months with my usual hospital admissions and multiple appointments. I have been told that there is no available funding for new pumps in my area and there will not be until at least April next year. On checking I am not one of those on the waiting list for my clinic, I am a lost statistic somewhere in a pile of papers. I am not going to give up. I am going to keep on fighting. No one will take this pump from me!

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Politicians

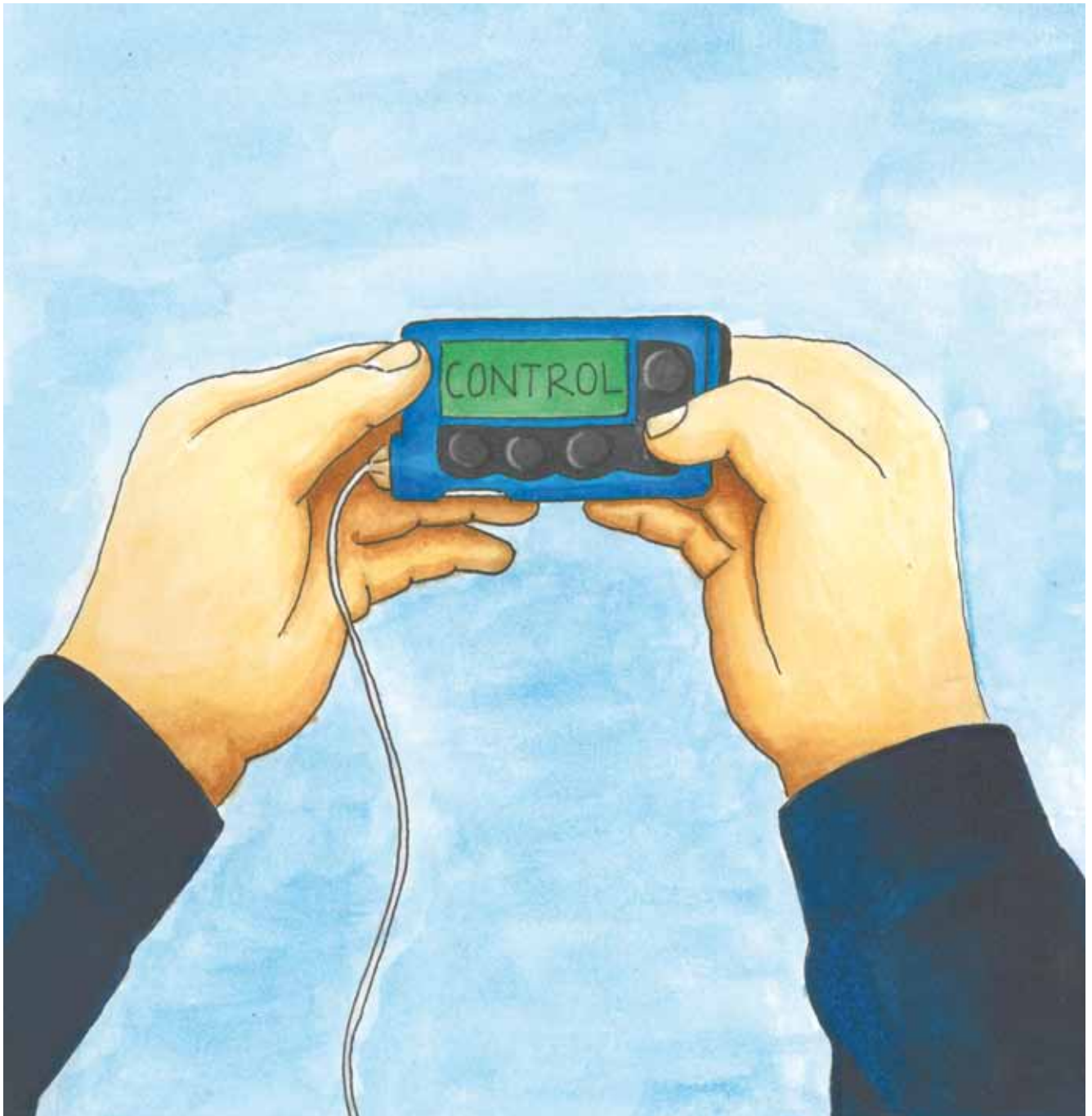
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“It's only a few injections,” as if a child having six injections a day has no right to seek better alternatives.

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Kenneth Gibson MSP, Official Report of the Scottish Parliament
3 September, 2009

Teams delivering pump therapy services should establish databases to support quality assurance and adverse events reporting and national audit.



Involving politicians

Ministers of the Scottish Government and Members of the Scottish Parliament (MSPs) are on public record supporting the development of pump services and increased access for patients. MSPs also pick up the issue in their constituency work and have been lobbied by pump campaigners looking for real improvement in access and delivery.

On 3 September, 2009 the Scottish Parliament debated a motion from David Stewart MSP on the provision of insulin pumps across Scotland. With so many MSPs wanting to make contributions, a rare procedural motion was passed to allow for extra debating time. The following speeches are extracts from the debate.

Kenneth Gibson MSP

Jenny, aged 11, lives in my constituency. She is insulin-dependent Type 1 and has been since the age of three. Jenny has been on a basal-bolus regime since she was seven, which involves an average of six injections a day. As members will appreciate, a child who lives with 2,000 injections a year would absolutely love to have an insulin pump, which requires only a set change every three or four days.

While she was living in England, Jenny's parents asked her consultant whether she could have a pump. He said no. Because she co-operated with respect to her care and kept excellent control, she did not meet the criteria. That is equal to someone being told that it is only if they do not give a damn about their care and let the disease spiral out of control that they will be considered for the best type of treatment.

Thankfully, Jenny has continued to co-operate on her care. She asked again this year about the possibility of a pump. Again she was denied. She did not meet the criteria. That insult was compounded with the closing comment, "It's only a few injections," as if a child having six injections a day has no right to seek better alternatives.

Official Report of the Scottish Parliament
3 September 2009

Cathie Craigie MSP

One of my constituents raised with me the experience and difficulties that his young relative has had in that regard. That young man, who is now 16, was diagnosed with Type 1 diabetes four years ago. The diagnosis was a nightmare for him. He was and is needle phobic, so members will understand the other difficulties that he has to live with daily. Last summer, he became unwell and, while looking for ways to feel better, started chatting to other young people via the internet.

Sadly, he had never met anyone of his age with Type 1 diabetes because he was, on diagnosis, referred straight to adult services. I am sure that people will agree that that is a sad situation for a young person. Many of the young people whom he sought out and spoke to told him that they used insulin pump therapy, and that it had brought great benefits to them, to the quality of their lives and to that of other family members.

Over the past year, that young man and his mother have had a long and stressful battle with the NHS to get a pump. He is sure that his symptoms, his swings in blood glucose levels and the negative impact that they have on his quality of life and ability to enjoy everyday things would be greatly improved if he had pump therapy. His family are still hopeful that he will get a pump, because they believe that he meets the criteria that have been set. However, he needs the pump now; at a time in his life when he has so much to do to complete his school education and get qualifications

that will open doors on the quality of his life and his aspirations for the future. However, he still does not have the pump.

Official Report of the Scottish Parliament
3 September 2009

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Karen Whitefield MSP

Despite the existing guidance and policies and despite the apparent commitment at national and health board level, the majority of people who could benefit from insulin pumps simply do not have access to that valuable therapy. Too many diabetics continue to fight against a health service that is reluctant to grant them access to such treatment.

Although there is no doubt that substantial costs are associated with the treatment, considerable savings to the NHS can accrue when people use insulin pumps. Diabetes UK Scotland estimates that the reduction in the need for on-going clinical intervention for problems such as recurrent hypoglycaemic episodes and hyperglycaemia could result in savings of up to £23,500 per patient over just two years. Those savings could be offset against the cost of maintaining a patient on insulin pump therapy.

A recent survey by Diabetes UK Scotland found that pumps are within the top five priorities for local service development, especially for parents of children with diabetes. However, although NICE has recommended that between 15 and 50 per cent of under-12s with diabetes would be suitable for pump therapy, the latest statistics show that we have only 57 under-15-year-olds in Scotland on pumps.

Official Report of the Scottish Parliament
3 September, 2009

A letter to MSPs from Linda Park

I am contacting you regarding insulin pump therapy. My daughter Nicola Park is coming up to 13 years of age and as you may or may not know being a diabetic and reaching puberty is not a smooth passage. Nicola has been looking into ways to tighten up her control of her diabetes and has found out about insulin pump therapy. We have been told that no funding has been made to set this treatment up although it has been proven that within two years the NHS would make savings on diabetics who are on the pump as they have tighter control over their condition but more so it opens up a whole new life of freedom to them. As far as I am aware we have two kids on insulin pump therapy in our district but they have since moved onto adult clinics. This is not good enough.

I believe that there was a debate in Scottish Parliament in September of 2009 raised by David Stewart where there was a lot of good information in this debate and points for and points against. The amount of children who have insulin pumps in Scotland is totally unacceptable. I would love to hear from you on this subject as I do not intend to let this just slip away quietly. I want to know why my child isn't receiving treatment that could give her a better quality of life. Nicola's dad and myself both work and pay our duties but we just need a little help to help our daughter and we are asking the government for that.

Conclusion

At the end of 2009, Health Boards were asked by the Scottish Government to detail their planned investment in pump services iv. As Dr John McKnight says elsewhere in this report, “there is a clear pressure to accelerate these developments”.

This report is filled with the voices of those people for whom pumps have been a success. Many have been fortunate to either live in an area with a well established insulin pump service or in some cases have forcefully argued their case to the NHS with the support of politicians and groups like IPAG. There is however an immense sense of injustice felt by some people who see insulin pump services available in health board areas other than their own or, even where there is provision, it is limited and involves long waiting times. Health boards such as Fife, Lothian, Tayside and Borders have well developed insulin pump services in place with around 4 per cent of people with Type 1 diabetes on pumps and with ongoing plans to develop services even further. If the rest of Scotland had pump services at 4 per cent perhaps another 540 people would be on pumps doubling current numbers. In other words, 540 people could perhaps look forward to a more positive future.

We recognise the difficulties and challenges of developing insulin pump services and we support and recognise the work many

healthcare professionals are carrying out to create better insulin pump provision across Scotland.

Insulin Pumps: A new lease for life shows how pumps can bring a real improvement to the quality of life of people for whom multiple daily insulin injections are unsuitable. Throughout this publication, people have enthusiastically spoken about their new life on pumps. Before being assigned a pump, they talk about their struggle with independence, and about a life blighted by depression, missed opportunities and complications with their diabetes. The difference in the language used after starting pump therapy is quite startling. People begin to look forward to life, they say their diabetes feels more balanced and for once they have a feeling of being in control.

Diabetes care should be on the basis of clinical need taking into account patient experience of living with diabetes. In the new language of patient rights, people with diabetes should experience optimum care which is fully patient focussed. The story of insulin pumps described in this report is a very close match to that ambition.

Insulin Pump Usage – Scottish Diabetes Survey 2009

NHS Board	Type1 Population	Number of patients	%
Ayrshire & Arran	2,234	9	0.4%
Borders	596	23	3.9%
Dumfries & Galloway	871	12	1.4%
Fife	1,896	83	4.4%
Forth Valley	1,526	24	1.6%
Grampian	2,976	59	2.0%
Greater Glasgow & Clyde	5,923	56	0.9%
Highland	1,688	19	1.1%
Lanarkshire	3,454	38	1.1%
Lothian	4,019	142	3.5%
Orkney	118	3	2.5%
Shetland	114	2	1.8%
Tayside	1,771	82	4.6%
Western Isles	181	1	0.6%
Scotland	27,367	553	2.0%

References

- i NICE technology appraisal guidance 151. Continuous subcutaneous insulin infusion for the treatment of diabetes mellitus (review of technology appraisal guidance 57). National Institute for Health and Clinical Excellence. July 2008.
- ii Scottish Diabetes Survey 2009. Scottish Diabetes Survey Monitoring Group. NHS Scotland 2010.
- iii SIGN Guideline 116, Management of diabetes: A national clinical guideline NHS Quality Improvement Scotland. March 2010
- iv Scottish Parliament Written Answer, S3W-30155, 22 January, 2010

Resources

Scottish Diabetes Group

www.diabetesinscotland.org.uk/

Diabetes UK Scotland

www.diabetes.org.uk/scotland

Insulin Pump Awareness Group

www.ipagscotland.co.uk

Diabetes UK Insulin Pump position Statement

www.diabetes.org.uk/About_us/Our_Views/Position_statements/Insulin_pump_therapy/

NICE Guidance

ww.nice.nhs.uk

INPUT (national support group for pump users)

www.input.me.uk

Insulin Pumpers UK (internet based discussion group)

www.insulin-pumpers.org.uk

Pump management for professionals (PUMP)

www.insulin-pump.info

SIGN Guidance 116 on Diabetes

www.sign.ac.uk/guidelines/fulltext/116/index.html



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