



July 2011

Hello All

So today I went to look at some possible offices for DWED, it was very exciting I have to admit, and even more exciting that we are actually at that point. This month has been another great one for our members and we are taking on more clients than ever before. Unfortunately we are not taking on any more resources or money so I am renewing our call for help. You can now donate to DWED via just text giving. All you need to do is text 70070 with DWED01£1, DWED01£3 or DWED01£10. Please help us help others. It really is needed.



85% at risk

Diabetes UK today reported that more than 85% of children and young people with Diabetes in the UK and Wales are not achieving good blood glucose results. In a move supported by DWED, they have issued a crucial research call for interventions aimed at improving Diabetes care and management.

The National Diabetes Paediatric Audit, by the NHS Information Centre, which was largest audit of its kind to date also revealed that the largest proportion of people with high blood glucose levels were those aged 12 to 24. Alarmingly, only 4% of this age group received all the eight basic annual health checks including blood glucose, foot and eyes. This could mean that as many as 20,000 sufferers have a high risk of diabetic complications in later life.

Barbara Young, Chief Executive at Diabetes UK, said, "The results of this audit cannot leave us in any doubt that urgent action is needed to improve Diabetes care and management for children and young people. Of all people with Diabetes, teenagers have the worst control. This can partly be explained by the high rate of not attending clinic and poor transitional care from paediatric to adult services, where many are 'lost' in the system."

It has been shown that individuals with Diabetes and eating disorders are often resistant to care for a number of reasons. For someone with ED-DMT1/ Diabulimia, it can be all too easy to fly under the radar when continuity between professional bodies and a level of compassion and understanding of the condition is not maintained. Perhaps you skip one appointment because you are scared what the response may be to your meter readings, then you skip another, and another, till they stop sending appointments at all. Encouraging patients to get back into the system and access the help they need is a crucial part of the management of ED-DMT1, especially since the condition requires closer attention and monitoring than would be the case for a non-eating disordered person with Type 1 Diabetes.

Diabetes UK's call for more of a focus in engaging patients and keeping them actively seeking support is certainly a step forward, and something DWED hopes will improve the quality of services available to those with ED-DMT1/ Diabulimia. Young described the process that will ask "healthcare professionals and researchers to submit innovative research proposals that will specifically look into overcoming barriers to patient engagement, such as teenage non-attendance or projects to help patients achieve good blood glucose control." "Our investment in research has the potential to help health services develop care which caters for the very complex and specific needs of younger people. Giving them the start they need to manage their Diabetes for the rest of their lives means a generation of children do not have to face a future of devastating health complications."

Mokey's make and do

Coming soon ...

more on page 3

DWED SCOTLAND EVENT

DWED will be holding a get together on the 12th of August in Perth, Scotland. This is a great opportunity for us to meet for a wee natter. Some friends of DWED will also be there from the medical/psychological services to listen to our issues, see where they can help and ascertain how they can improve the services they provide. If you would like to attend please email jacq@dwed.org.uk so we can get solid numbers. If you would like a 1-1 visit DWED director Jacqueline will be in Scotland between the 5th and 14th of August, would love to meet you and will happily travel..



'Have Diabetes and an Eating Disorder: WILL TRAVEL'

I think it is necessary to state right from the off that DWED (or I for that matter) probably wouldn't exist without Facebook. I had published my own (rather ugly) website and forum in a far flung corner of the internet under 'sugar rush' (I know, I know, not only embarrassing but strangely pro sounding now!! In fact it actually had a skull and cross bones on it Oh the shame!!!!) People would intermittently drop in, I would cling to them in a desperate attempt to create some kind of space for people like me only to be disappointed when they didn't come back. Maybe I was too full on, maybe it was the 'please don't leave me I'm mental too' desperation in my posts, maybe it was the TMI-ness of yet another comment asking if anyone had ever wet themselves in DKA or maybe it was that back then I really wasn't in the best place to be advising anyone ...on anything Anyway I felt like I was doomed to be a lone crusader with only my own (fairly crazy) experience and research from Dr Goebel Fabbri for company. And then I joined facebook..... I was amazed there were so many of us on 'Diabulimia Awareness' (even though there were only about 30!) and Erin's picture in hospital, I remember thinking ' Oh my god, you get it, you know what its like, I KNEW it wasn't just me' it was a total revelation and the beginning of the end of my lifelong struggle with self esteem and eating disorders. I could moan about Diabetes on my page and people actually got it, I could scream about my Eating Disorder on the group wall, and not be judged. I have to say at this point that it's not like my 'offline first' friends wouldn't sympathise it's just that unless you've got it, well, you just don't 'get it'

I hear so many people moaning about what people post online on their social networking sites, 'oh such and such just posted about making a cup of tea'. Guaranteed the poster is only an acquaintance, someone you barely knew in high school, or had a fleeting encounter with. Someone inconsequential. Why is no one asking why people would post so inanely? I think it's because as sociable, pack animals we have a desperate need to communicate, to network, to feel like what we have to say matters to someone. Granted tea might not be the most interesting of topics but perhaps that person has no one to say, 'you know what that's a great cup of tea' to. Imagine that being the only thing you felt needed said and not having anyone to say it to. The internet provides shelter for us all when we're lonely and if, like me, you're really lucky, it provides a whole new support network 'offline'. At the moment we are looking at setting up physical support groups, we know that it's a great idea because at least half of the volunteers at DWED have come from facebook and now we see each other as much as possible. It really really helps. My life has improved immeasurably because of social networking. And it started improving from the comfort of my own sofa (which is just as well as I didn't go out for 2 years into recovery). I didn't need to travel far to meet people who are now some of my best friends. So the next time you are about to complain about your boring friend posting about tea again can I suggest that you send them to the 'Tea Appreciation Society' instead.



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Facebook*



*Join us on
tumblr.*



*follow us on
Twitter*



*watch us on
YouTube*



ask us anything on
formspring



Life Story Joanna Penn



*Seeds
sown in
sorrow often
blossom in
joy*

Well where do I start, never been easy for me from an early age. I was about 4 years old and caught an infection that affected my brain; couldn't walk, couldn't write and was un-coordinated it then happened again about 6 months later so there was me a happy, go lucky child having to relearn how to walk and write. Unknown to me, this was the start.

I had a pretty normal childhood; loving parents and close family so no-one ever expected me to have an eating disorder let alone Diabetes.

I thrived in primary school and gained the skills to be like a normal child and really enjoyed PE and other activities. Was popular, had loads of friends then the transition of becoming an adolescence and leaving my friends took a toll on me. Whilst at secondary school, my mood slipped, started to comfort eat at school, this then led to bulimia. My weight would go up and down, even to the point that I was getting dizzy from malnutrition. During my SATs in Year 9 I then started to self harm. I hated school and used pro-mia sites and information to get the best out of my habit. My parents and doctors just assumed it was puberty. I was very withdrawn at school and was referred to the psychologist – all he had to say was that my parents would need to keep an eye on me as it was stress. My parents never knew any of the habits I had formed.

I was diagnosed with Diabetes in 2002 after my weight kept falling and was always drinking loads, going to the toilet and a very curious smell to me. The GP assumed I was Type 2 as I was not classed as underweight or at risk of Type 1 so put on tablets however after 4 weeks I was put onto insulin. This led to substantial weight gain and a dislike for what I saw in the mirror. I found out about "diabulimia" after an article on the web and then investigated the omission of insulin to lose weight. It took time to realize how I could use this and I used this method for many times over the past years.

My turning point was whilst at nursing college after a long shift and had assignments due - I broke down in my diabetic review and admitted all to my consultant. I explained everything to him, and he was so good and referred me to the Psychiatric Liaison Team and it's not been an easy ride, and have relapsed twice since then.

My initial control was very poor, now it's the best it's ever been.

But I am now 2 years into recovery, not easy and the thoughts are still there. I have complications from it too; retinopathy, maculopathy and even some neuropathy.

I just think that Diabetes definitely doesn't have me, I am now in control. I may not be comfortable with the mirror still, but I will be in time.

What is it?...

Well it's a column dedicated to distraction. It's therapy through creativity. You don't have to be Rembrandt or Banksy, you don't even have to know how to do it, as there'll be instructions. I found that making stuff was and still is really helpful as a positive distraction. Something good to come from from bad, so tune in next issue for the first of many ideas and instructions in the art of distraction, maybe you'll learn something, maybe it'll just give you a springboard to other ideas. Next Issue we'll be starting to knit, I'm warning you, it's hard to think about anything else once you've started...

Mokey's make and do



In an embarrassing blunder Lloydspharmacy were forced to revise a major advertising campaign last month after a determined back-lash from the public.

"Diabetes - are you at risk?" was aimed at promoting Lloyds' new Diabetes screening service and consisted of print based media and television adverts featuring Nadia Sawalha. However, the campaign failed to highlight that the service was aimed towards people at risk of developing Type 2 Diabetes. Instead viewers watching the TV ads were simply told "We can help you avoid Diabetes", without any acknowledgement that this can never be the case with Type 1 Diabetes.

Members of the Diabetes community, as well as representatives from a number of charities including DWED and Children With Diabetes Advocacy Group immediately sought answers from Lloyds regarding the advertising. Complaints were made through e-mails, telephone calls and a bombardment of messages to the pharmacy's official Facebook page.

Lloydspharmacy were applauded for their prompt and efficient response to these concerns. They issued a statement of apology which read: *"We understand your concerns about making the distinction between Type 1 and Type 2 Diabetes in our advertising, and apologise for any distress caused. We have taken on board your feedback, and we're changing our TV and press advertising to make it clearer that we are talking about Type 2 Diabetes."*

Jacqueline Jacombs, Co-ordinator of UK Children with Diabetes Advocacy Group said: *"90% of children with Diabetes have Type 1 (autoimmune Diabetes). Type 1 Diabetes is not preventable and there is nothing that a child, or their parents could have done to prevent Type 1 Diabetes from developing. Type 2 Diabetes, a different form of the condition, requires totally different management. Type 1 Diabetes is growing at an alarming rate of 5% among pre-school children and 3% in children and adolescents each year."*

"Because Type 1 Diabetes is so often confused by the media with Type 2 Diabetes, this leads to children at school being bullied by other children and adults and being told they were fat or lazy or that they ate too many sweets. The confusion also causes problems with donations to charities researching the causes of Type 1 Diabetes if the general public believe that all types of Diabetes are avoidable by changing one's lifestyle or diet."

Adding fuel to Lloydspharmacy's advertising controversy was their misguided decision to place a sculpture depicting a pile of amputated limbs in Trafalgar Square to reflect National Diabetes Week. This was a move that seemed at best baffling and at worst vulgar and distasteful.

A member of diabetes.co.uk forum wrote of her personal distaste of the statue: *"shock tactics might be appropriate for people in denial, but for a child with Type 1 like my 9 year old daughter, who is not in denial and works hard every single minute of every single day of her life to manage the condition...it's an insult to show her something like this...Those who put so much effort into managing their condition do not need to be reminded of the risks associate...frightening them offers absolutely nothing constructive or supportive in any way shape or form."*

When asked for an explanation regarding the sculpture, Lloyds stated that: *"In a move to attract the attention of those unaware or complacent about Diabetes we commissioned an artist to create a temporary sculpture to represent the 5,000 limbs amputated each year because of Diabetes. We consulted with diabetics before constructing the sculpture which was created from shop mannequin limbs and was in no way designed to be disrespectful. We apologise to those who felt it was too shocking."*

"The sculpture was only intended to provide a short-term impact and while we have received feedback from people who do not agree with this approach, we have also heard from Diabetics, including those who have had a limb amputation, who have been supportive and shared the view that the strength of the message needs to match the seriousness of the condition."

As a result of recent events Lloydspharmacy have also pledged to undertake an awareness campaign specific to Type 1 Diabetes. The project will involve those directly affected by Diabetes and is currently in its early stages but progress will be available via their Facebook page.

A representative for Lloyds said: *"We are grateful to those who've shared their opinions and pleased we've been able to address some of their concerns quickly. We have learnt from this experience and going forward we will consider more broadly those living with the conditions we're campaigning about."*

By Claire Kearns

Lloyds Pharmacy Gaff



Diabetes, Mental Health and Common Sense.

by Lucy Traver

Studies linking Diabetes, depression and other mental illness are nothing new. Through researching various articles and studies online, I found a strong correlation between Diabetes and suffering from some form of mental illness.

Case studies show a higher incidence of poor mental health and well-being in adults with Diabetes than in those without – with one study suggesting that Diabetes doubles the risk of depression.

This leads to the question – if there have been so many studies and there appears to be much awareness of a strong link between Diabetes and mental illness, then why are medical professionals so unprepared to diagnose ED-DMT1/Diabulimia?

Diabetes is a condition which focuses on food, control and unfortunately an attitude where too many are deemed 'good' or 'bad' depending on their blood sugar results. Why is it so surprising that, in this age where people are sadly judged on the size of their clothes, that many people are falling into insulin omission? Health professionals are forever telling us the dangers of running high, the risks involved and why it's so important to

manage our Diabetes well. Why is it then, when people are struggling to control their sugars, that so little help and understanding is available?

Why is this illness, which is scarily easily to predict, approached with next to no common sense in regards to treating it? Why do doctors struggle to see the obvious links between social pressures and insulin omission? If they supposedly know so much about the dangers high sugars can bring – why is the illness dealt with so impersonally? Too often, we hear about sufferers being shunted from one specialist to another, with no one person capable of providing adequate care. Sufferers are often criticized for poor Diabetes management, not listened to about depression or just met with a blank face.

ED-DMT1 is such a complex, delicate situation and I can only hope that through the work DWED is doing, GP's, Diabetes specialists, Psychologists and the rest will open their eyes. I hope that they will be able to finally understand that this is not something their textbooks can give an answer to – that they will have to use a bit of humility and emotional understanding as well as physical knowledge, to help beat this illness.



Recovery corner: Lou

My disordered eating began in my early teens, it progressed gradually, sneakily to omission. Initially I omitted, because I could! MY illness, MY control! A non-bloody self harm. I just wanted to be 'normal' like my friends, I stopped testing, lied in my result books, which was apparent from my HbA1c. I didn't realise that my weight loss and omission were linked. I loved the compliments on the way I looked, when I was being 'normal', they stopped when I was being 'good'. I didn't realise how unhappy I truly was.

I was very ill with Flu at the end of 1995 (ironically I had been striving to get to grips with it all). My Gp ignored/didn't notice that I was ketotic, despite me not being able to even drink water without an anti-emetic, my bedroom smelled of vomit and pear drops. By the time I was admitted to Hospital after a 999 call from my parents, I was treading a fine line between life and death. I lost a third of my body weight in under 2 weeks and I developed Pneumonia. I was afraid, confused and sick for a very long time.

I felt truly worthless, I became isolated from my friends and family and more unhappy. I tried to get better but every time someone wagged their finger at me or told me I should do better, it reinforced the already low opinion I had of myself.

Why should I even bother, noone believes in me anyway? I am useless, flawed, unfixable.

As I moved on to adult clinics I got lost in the system, it was easy to stay lost, nobody cared. It all looked so bleak, I was swimming up stream in a tsunami for a long time. Then I met my partner. He encouraged me to get healthy, my mum encouraged me to move clinics, two of the 3 best decisions of my life I owe to the encouragement they gave me.

But I decided I had to own this, not just survive it! For the family I already had but mostly for the family I wanted to begin, for the children I wanted to have. There was a lightening moment of resolve but it wasn't fixed over night it was hard, slow and frustrating, step by tiny step, but I am here, I am well, and now I am in control of this beast.

Type 1 & Type 2

by Sian Howarth



*Volunteers Trustees/
Writers:*

This is our usual call for more volunteers. We are still looking for trustees. If you feel you could lend your expertise whatever that maybe then we desperately want to hear from you. We are also looking for writers who are willing to contribute news and blog articles to the website as well as writing for our monthly newsletter. Please email info@dwed.org.uk.

When people talk about Diabetes, do they really understand it? People often generalise without knowing the differences between Type 1 and Type 2 Diabetes. When people ask, 'do you have Diabetes because you ate too much sugar?' Or when people say, 'can you wean yourself off insulin like Halle Berry did?' it can be very frustrating to people with Type 1 Diabetes. People with Type 1 Diabetes have a genetically pre-disposed condition which has absolutely no links to the food they ate before diagnosis or their weight, it can not be 'cured,' and people with Type 1 Diabetes can not live without insulin injections or an insulin pump. The main difference between Type 1 and Type 2 Diabetes is that a person with Type 1 Diabetes' pancreas does not make any insulin,

Insulin is the hormone produced by the pancreas that allows glucose to enter the body's cells, where it is used as fuel for energy so we can work, play and generally live our lives. It is vital for life. (Diabetes UK) Without multiple daily injections and regular blood testing people with Type 1 Diabetes would not survive longer than a couple of weeks and would suffer with Diabetic Ketoacidosis (DKA). Type 1 Diabetes is often diagnosed in childhood or young adulthood and usually in patients under the age of 40.

People with Type 2 Diabetes' are insulin resistant and/or the pancreas can not produce enough insulin for their needs. Type 2 Diabetes accounts for between 85 to 95 percent off all people with Diabetes. It can be quite distressing for children or young adults to be teased or victimised for having the condition, as people assume that they have the condition because of choices that they have made (i.e. eating sugary foods) as Diabetes is often portrayed as an avoidable condition.

Advertising rarely distinguishes between Type 1 and Type 2 Diabetes, giving the impression that it can be avoided or managed by just by eating healthily.

However, the two conditions are very different; they are not only different in their symptoms and causes but also in the way that they are treated.

In Type 2 Diabetes, changing to a healthier diet and lifestyle can often control the condition without the need for further treatment. (NHS choices)

It is because of this that I believe the two conditions should have individual names and not both be called 'Diabetes.' NHS funding for Diabetes is vastly reduced for sufferers of Type 1 Diabetes as the majority of funding goes to avoiding Type 2 Diabetes. However, if more funding was available to educate people with Type 1 Diabetes about how to manage their condition and avoid complications then the NHS would avoid having to fund life saving admittances in the future for people suffering with life threatening complications of Type 1 Diabetes. I do not discriminate against people suffering with Type 2 Diabetes, I am aware that it is not always avoidable and can be very difficult to control. However, I do feel that this is a different condition and therefore the two should have different names so that people can distinguish between the two more easily and so that funding can be distributed evenly and fairly.

www.dwed.org.uk

www.diabeticwithheatingdisorders.org.uk

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www.dwed.org.uk

Type 1 Diabetes and ED-DMT1

Deliberate insulin omission/manipulation and disordered eating

Small words... BIG PROBLEM

Signs and Symptoms

- High HbA1c
- Frequent hospitalisations for DKA/Hyperglycaemia/Hypoglycaemia
- Lack of BS testing/Reluctance to test
- Assigning moral qualities to food (good for sugars/bad for sugars)
- Loss of appetite/Eating More and Losing Weight
- Severe Fluctuations in weight
- Injecting in private/Insisting on injecting out of view
- Fear of injecting/Extreme distress at injecting
- Avoidance of Diabetes Related Health Appointments
- Anxiety/distress over being weighed at appointments
- A fundamental belief that insulin makes you fat
- Frequent Requests to switch meal plans
- Frequent trips to the Toilet
- Frequent episodes of thrush/urine infections
- Nausea and Stomach Cramps
- Drinking an abnormal amount of fluids
- Dental Problems
- Early onset Diabetic complications
- Delay in puberty or sexual maturation
- Irregular menses/amenorrhea
- Co-occurrence of depression/anxiety/Borderline Personality Disorder

