



March 2011

Welcome to the March edition of the Diabetics with Eating Disorders Newsletter.

This Month has been a busy one with much attention focused on National Eating Disorders Awareness Week.

We also held our first fundraiser which managed to raise £300 !!! We have more events coming up so please come along if you're in the area.

In this issue we will be publishing our aims and objectives and we are hoping that you will feedback to us with your thoughts and also any offers of assistance.

Please also find provided our Awareness poster, take it to anyone who will listen!

We hope that you enjoy the newsletter ! Love Jacq



## SUGAR RUSH Fashion show

The Fashion show in February was a great success and raised £300 for DWED.

Many thanks to everyone who helped, participated and attended.

## National Eating Disorder Awareness Week

We had a great National Eating Disorders Awareness week. We managed to officially release many of our publications including an awareness poster which we are incorporating into this news letter, please feel free to download and distribute. We also formalised the running of our helpline so there is someone available between 7 - 11 every night of the week. Our Facebook group got over 21,000 views and our website readership has increased 51% from last month.

## Coroner returns verdict of Death by Natural Causes

DWED has been working with Jane Sanders who tragically lost her son, Rhys, in July 2009. DWED has been involved as there were many issues surrounding Rhys' care including a suspected eating disorder that was not investigated. Despite Jane stating 'I believe better management of his two conditions and receipt of the help which I tried to get for him would have prevented his tragic, premature death' and Diabetic Consultant Dr Paul Underwood admitting 'he knew he wasn't doing what he should be doing to control his blood sugar levels and his test results were at the top end of the scale for poor management', the coroner returned a verdict of death by natural causes. DWED is disappointed with this verdict and our sincerest sympathies go to Jane, her son and husband (who also both have Type 1 Diabetes). We are currently investigating how death within our demographic is recorded and will be fighting to ensure that verdicts possible are reflective of our condition.

## Helpline Volunteer Profile

### Sarah Calteiri

On Monday Sarah Calteiri is on the Helpline: Sarah has had Type 1 Diabetes for 24 years. She developed an eating disorder in her early teens, overcame that by her late teens and in her early twenties was registered blind. Today, Sarah has been in recovery for 12 years, lives alone, runs her own business and has been a professional actor / musician for 7 years. She's happy to talk about any aspect of living and coping with an eating disorder and Diabetes



Skype: [dwed.org.uk](http://dwed.org.uk)  
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# Brothers in Arms

This month we would like to bring your attention to some really worthy organisations that we have come across.

**MGEDT (Men Get Eating Disorders Too):** MGEDT are doing fantastic work raising awareness surrounding Eating Disorders in Men of all ages. MGEDT and DWED face many similar challenges, particularly under representation, misdiagnosis and misunderstanding. Having attended a workshop with Sam and Nick DWED is reviewing its policies to ensure that going forward we are more gender inclusive. We look forward to a prosperous and long term friendship. **Please see <http://www.mengetedstoo.co.uk/> for further information and resources.**

**Diabetes Power:** We are always inspired by organisations that have been founded via personal experience. Angela Allison, Diabetes Power founder has a 9 year old daughter who has Type 1 Diabetes and Coeliacs. DWED Director Jacqueline meet Angela at a Diabetes UK meeting and it was obvious that her passion and commitment to the cause would make her a natural DWED ally. On the website Angela states:  
*The aim of the group is to raise awareness of Type 1 Diabetes.*

Diabetes Power is a not for profit organisation working towards charitable status.

It is only through raising awareness of Type 1 Diabetes, that we will educate and gain the understanding of the wider public & the health professionals, through this hopefully we will help people identify the condition at it's early stage.

The group will always be honest, true and very real, as we live this life every single day! We will not be restricted by NHS rules or regulations, we will be driven by our passion and love for all people who have Type 1 Diabetes.

I would also like to raise the profile of Coeliacs Disease as this is closely linked.'

Email: [angela@diabetespower.org.uk](mailto:angela@diabetespower.org.uk)  
Website: [www.diabetespower.org](http://www.diabetespower.org)

## Aims and Objectives

### 1) Support for people with Type 1 Diabetes and Eating Disorders and their Carers

- Extend capacity to offer support to members via email, visits, Skype and the hotline
- Provide more volunteers who have recovered to be involved in Helpline services
- Provide self help groups consisting purely of ED-DMT1 sufferers
- Carers and family support network
- Provide self help materials
- Continue to provide outreach services to sufferers and their
- Organise a retreat for sufferers over the age of 18

### 2) Advocacy

- Pressure for ED-DMT1 to be diagnosable
- Service User network to be set up in order to feedback into the NHS
- Promotion of the rights of sufferers under current clinical guidelines (i.e. NICE) and intervention when these rights are not being upheld.

### 3) Awareness

- Official launch of DWED to involve various awareness activity
- Sensible media campaign raising awareness but not alerting vulnerable Type 1s to the practice of Insulin Manipulation/ Omission
- Conference on Diabetic Eating Disorders
- Information packs to be sent out to all of those involved in Type 1 Diabetes care from GPs to Eating Disorder Specialists to Youth Workers
- Representation of DWED at conferences, meetings and relevant events

### 4) Training

- Training courses for those involved in ED-DMT1 care including DWED volunteers
- Lecture Tour aimed at undergraduate Doctors and Nurses
- Collaboration with other organisations

### 5) NHS Protocol

- Emergency Protocols
- Screening and Detection of ED-DMT1
- Referral Pathway
- Multidisciplinary Approach
- Treatment Options
- Specialist Inpatient Treatment
- Structured Outpatient Treatment
- Long Term Support for Recovery

### 6) Research

- Effective treatment for ED-DMT1
- Research into prevention of ED-DMT1
- Research into the effectiveness of DWED as an organisation

### 7) [www.dwed.org.uk](http://www.dwed.org.uk)

- Website to become the focal point for all things related to ED-DMT1 in the UK
- Website to provide downloadable materials for volunteers, professionals, sufferers and carers
- Website to have a greater presence. Search Engine Optimisation to be utilized

# Diabetes and Me: Claire Kearns

I don't quite know where to begin...

So many people think it's no big deal, or that it's purely medical. You just test your blood and can't eat as much cake as you'd like sometimes, right? Of course, they'd hate to be you because they're so scared of needles ("Wow, 5 times a day?! Does it hurt?") but guess you just must be used to it by now.

Not at all. I don't know if you ever get used to it so much as tolerate it. Diabetes is complex, rooted, and emotional, a demanding child that needs constant attention and consideration. I hate it and I resent it. I've asked myself so much 'why me?' It's all too easy to dwell on that question, and feeds self-hatred like water on sunflowers. Surely, I must have done something wrong? Regardless of the irrationality of that thought, it's another piece of ammunition to use against yourself. An eating disorder seemed like an obvious continuation of my Diabetes, the enemy within me had already been created in a space littered with ketostix, lancets and Diet Coke.

I was always very good at denial. On over-hearing my Mum discussing with someone the worry that I could have Diabetes I stormed into the room shouting "No I am not, there's nothing wrong with me!" Ironically, that attitude continued far past the point of diagnosis. I remember within the first few weeks on insulin, aged 9, I was locking myself in the bathroom and squirting my Mixtard 30 (remember that one?) dose down the toilet. Not because of any desire to lose weight at that point but because I thought I didn't need it. I didn't want to need it. I was like everyone else, see. I sat through many lessons at school with low blood sugars, bolting for a Lucozade on the bell so I didn't have to leave the classroom early and make what I deemed a fuss. A fear made even worse when a teacher humiliated me when I was trying to eat a snack discreetly by asking me a question when I had my mouth full, then questioning me as to why I was eating. I felt ashamed. The widespread ignorance hurts, too, because no, none of us are this way because we eat too many sweets. All my friends thought I was lucky because I got to eat a mini chocolate bar before sport, and I wanted to scream at them that they could have the stupid Milky-Way if they wanted, if they took the Diabetes too. At moments like those, I never felt more alone.

The problem is it never will leave you alone. It's such a constant, demanding condition. You can't forget, ever, no matter how much you try. Like the snacks and emergency glucose you should carry around with you (I still struggle with this now), it's always there, persisting, getting in the way, and as hard as it is, you have to actively care for yourself. With an eating disorder the desire to ignore and push it back is so strong but I've learnt from experience that ultimately, all that does is allow it intrude more into your life, complete with cramping legs and dry, ketone ripe breath - symptoms that persist. The crucial realisation is that trying to work with Diabetes, instead of against it, is the only way you can diminish its presence. Ultimately, to accept it, you have to acknowledge it. I think slowly I'm getting there.

This month's poem was composed by Erin M Akers, CEO of [www.diabulimiahelpline.org](http://www.diabulimiahelpline.org). Diabulimia Helpline is based in the states and we have been working with Erin for a long time. We are proud to call her our sister organisation. Erin has done some fantastic work stateside and we would urge you all to visit her online and offer her your support.

## In Case

Incase nobody's told you, and  
incase you haven't heard.  
I'm trapped inside this limbo,  
teetering on the verge.  
Incase I get too scared, and  
incase I lose all nerve.  
Incase I lose myself trying to erase  
all of my curves.

Incase one day I vanish,  
disappear into the air.  
In case the day arrives as if I was  
never there.  
Incase one day this plan works,  
and no longer can you see.  
Incase one day I finish in erasing  
all of me.

Incase I cannot beat this, and this  
letter's all you find.  
Incase one day ED wins in taking  
hold of heart and mind.  
Incase one day I cannot fight, for  
the war is far too great.  
Incase I can no longer hide from  
this, my hopeless fate

And when the day "incases" come  
and I am ash upon the wind.  
The eulogy they speak for me  
won't talk of fat or thin.  
Now the rhythmic words in which I  
write may read like fairy tales.  
But know I gave both life and limb  
for the numbers on a scale

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## Study Results Highlight Danger of Pre-Diagnosis

### Complications

by Claire Kearns

A recent study published in the British Medical Journal reports that 1 in 4 children with Diabetes experience Diabetic ketoacidosis (DKA) prior to official diagnosis. The research, which was led by Dr Julie Edge, Consultant Paediatric Diabetologist at Oxford Children's Hospital, also reveals that one in three of newly diagnosed children have at least one related medical visit before being correctly diagnosed, suggesting the condition is all too often being missed by doctors. With regards to eating disorders, DKA can also bring with it a whole host of other problems.

Diabetic Ketoacidosis is a highly dangerous state that occurs when blood sugar levels are dangerously high and the body is starved of insulin. Symptoms include nausea, vomiting, heavy breathing, exhaustion and weight loss. Prolonged DKA can lead to coma and eventually death. It is therefore paramount that healthcare professionals, and parents, have sufficient knowledge of the signs of undiagnosed Diabetes in order to begin prompt treatment via insulin, and prevent DKA.

It has been reported within the past by both professionals and sufferers of Diabetes and eating disorders, that subsequent weight-loss resulting from such cases of DKA may cause further emotional difficulties. Any decrease in weight of this kind may unfortunately be welcome by a young girl or teenager with Type 1 Diabetes, and in turn, they may be resentful of any weight-gain that may occur alongside a prescribed insulin regime. Of course, if a someone with Type 1 Diabetes then experiences image and body issues at a later date, they may well revert to cutting back on that vital medicine. In light of this connection, it is clear that the resulting trauma of late diagnosis may be much more prolonged than any immediate medical danger.

Simon O'Neill, Director of Care, Information and Advocacy at Diabetes UK said: "With around 2,000 children diagnosed with Type 1 Diabetes every year, it's worrying that a quarter of children will have only been diagnosed through DKA. DKA must be treated in hospital and for children and their parents, a diagnosis of Type 1 Diabetes is frightening enough, let alone the manner in which the diagnosis happened. This research highlights the need for more awareness of Diabetes symptoms if we want to reduce the numbers of children being rushed to hospital."



## Take a Look

Just a quick reminder about our two major events this year, Type 1 Diabetes and Eating Disorders DWED conference (1 day TBC 27th Aug - Sep 02) and our First Annual Retreat, the 13th - 21st June. You can register your interest for both of these events at [www.dwed.org.uk](http://www.dwed.org.uk)



## Acoustic Night

DWED director Jacqueline is doing something she said she never would and heading back to the stage in order to raise some much needed funds. Jacqueline says, 'I'm nervous and excited about it actually, it is going to be a very random night as I am intending to playing songs you wouldn't expect on instruments you wouldn't expect to hear them on. My piano, ukulele and accordion will all be making an appearance, I'm trying to bribe people to come with the promise of sandwiches (and alternatives for people who have coeliacs of course!)'. Also on the bill is Catherine Westmacott <http://www.myspace.com/catwestmacott> and some other long time friends. The idea is that the gig will be completely unplugged with our favourite artists covering their favourite songs. Please come along to Dirty Dicks Pub opposite Liverpool street Station, 202 Bishopsgate, London EC2M 4NR. 5 pounds on the door all proceeds to DWED.



# Health Bill Changes Threaten Continuity in Diabetes and Eating Disorder Care

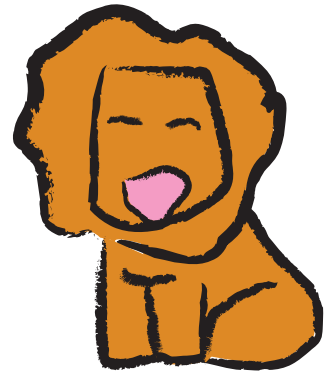
by Claire Kearns

DWED supports Diabetes UK in their proposal to the government over damaging changes being made to the health and social care bill. In a letter published in the Guardian last week, Barbara Young, Chief Executive of Diabetes UK voiced the charities concerns over new arrangements that will mean people with Diabetes do not have one integral health provider to turn to. Different bodies will instead compete in providing various sources of care which will undermine values of partnership and familiarity. She said "Under the new proposed arrangements, different aspects of Diabetes care could be commissioned by different bodies and services could fail to be joined up round the patient... The continuity of care which is vital to people with Diabetes risks being damaged by fragmented commissioning arrangements."

Over three million people in the UK currently have Diabetes and that number is rising every year. Many sufferers rely heavily on NHS care, management of feet, eyes and dietetic needs are just a few aspects of the illness that need to be monitored on a regular basis. Under the new bill decisions concerning these vital life-lines of care may fall on a host of varying sources such as a patients local authority, health and well-being boards, GP consortiums and the NHS commissioning board. Young insists that "The bill needs to require Monitor, the economic regulator, to have regard to the integration of services – not just the need to promote a competitive market."

Individuals requiring support for not just Diabetes, but the complex illness of Diabetes with an eating disorder, are particularly in need of specialist care through the NHS. It is difficult enough to get healthcare providers to understand both sides of the condition, with all too often eating disorder clinics offering one kind of help, and Diabetes practitioners the other. With these changes to the health care bill, it is of little doubt that the vital communication that is required between such professionals treating people with Type 1 Diabetes and an eating disorder, may become even harder. This is something that we must refuse to allow happen, especially since there are clearly still great strides to be made in tightening that structure of available care. Gaps that need tightening, not widening to make way for more casualties and more lives lost.

For the benefit of people with Type 1 Diabetes, representatives from Diabetes UK will be meeting with the Bill committee members in the near future to discuss their concerns over the bill, while strongly encouraging that vital amendments be made.



*Courage doesn't always roar. Sometimes courage is the quiet voice at the end of the day saying, "I will try again tomorrow."* -

*Mary Anne Radmacher*

## BloodSugar Sex Magic fundraiser in Liverpool

On the 20th of April the first DWED BloodSugar Sex Magic fundraiser will be held at Mellomello's Jazz Café on Slater Street in Liverpool. This musical bonanza will be hosted by Sarah Leahey and Jack Howarth in order to raise funds for DWED. There will be live music from a selection of artists, including the up and coming PictureBook (who's beautiful front lady Greta Svabo-Bech has recently collaborated with Deadmou5 on his new single Raise Your Weapon), The Sky Pirates, David Jaggs (front man of The Ragamuffins and Venus In Faux) and introducing Yellow House (including front man Phil Walsh of The Entire Population Of China). Tickets are priced at £5 in advance (available through the facebook group BloodSugar Sex Magic) or £6 on the

door. Doors will open at 7.30pm and the show will go on 'til late, so prepare yourself for a night to remember, and it's all for a fantastic cause.



[www.dwed.org.uk](http://www.dwed.org.uk)  
[www.diabeticswithheatingdisorders.org.uk](http://www.diabeticswithheatingdisorders.org.uk)

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**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**

