

May 2011

Another month and more monumental progress.

I am pleased to announce that we are now actually a charity. We are registered in Scotland (SCO42226) which is so exciting but also slightly scary as well. This is why I'm renewing my call for anyone who can help us with the accounts and guide us through Charity Commission (England) Registration. Any support is greatly appreciated.

I am also pleased to announce our first funder, Don't Lose Your Grip! They are kindly helping us to fund physical support groups all over the UK which I'm so so grateful for. I am also a model for the organisation (which is a sentence I thought I'd never say). You can read more about them in main news.

So now that we are a charity there are a few people we'd like to thank, our amazing staff who do such a good job, our designer Louisa Hawken who has been a god send, our software consultant Jon Staley (without him there would be no dwed.org.uk), all of our friends and family for their continued support, our trustees who are so generous with their time and my dad for doing all of our legal work and getting us to charity status.
THANK YOU XXX



Changes to the Helpline

We have previously been operating on a rota basis whereby you can call our volunteers on their mobile phones or through their personal skype handles. We now have one dedicated Skype address and a dedicated phone number. Our Skype User Name is dwed.org.uk and our phone number is 020 8133 7659. This should make things cheaper, easier and provide you with a more streamlined service. Please note that the helpline is open between 7 – 11 every evening. We are looking to extend our hours soon so we will update you when that happens.

Don't Lose Your Grip

From DYLG: Don't Lose Your Grip is an organization founded in February 2011 by Chrisselle Mowatt.

We're here because there's too many people who have lost their voice and need someone to tell the world what beauty really is. We're tired of looking at magazines, websites and TV shows and seeing the same airbrushed images telling us what we should look like and what we should believe in. DYLG is here to remind you that you're beautiful just the way you are and that no matter what someone says to you, it can't take who you are away. We aim to raise funds with a fashion show and charity concert, well two actually. One in Liverpool, UK this summer and one in Edinburgh, Scotland late this year/early next year! With the money raised from these events we will donate to suicide helpines, self harm charities and eating disorder charities.

DYLG is in memory of Lacey Crawford, a close friend who committed suicide in November '10.

From DWED: Please follow DYLG on Twitter @ and see their website. DWED is looking forward to a lasting friendship with DYLG and Director Jacq is also a model for them, as in ROLE model of course!!. You can read her interview on the DYLG website: Here is an extract

What made you want to take part in this project?

I think the lack of Strong Female Role models is so sad given how long and hard we had to fight for equality. I'm normally totally against publicity but I am a real person with a real body (which is a minor miracle given the abuse it's suffered) and for the first time in my life I can say that I'm proud of my achievements. I wanted to be an alternative option an antithesis to the manufactured, I am beautiful in my imperfections because that's what makes me real. I guess I am finally ready to be recognised for the right reasons. I now get my self-worth from what I do and who I am instead of what I (think I) look like.

New Quality Standards For The Treatment Of Adults With Diabetes

The National Institute for Clinical Excellence (NICE) have published new quality standards regarding the treatment of adults with diabetes. The standard consists of 13 parts which will be applied across NHS services in England, and is aimed at professionals that provide specialist care, as well as their patients and those funding the services.

New Quality Standards For The Treatment Of Adults With Diabetes (ctd)

The guidelines relate to areas of information and education relating to diabetes, while providing a framework for treatment, from frequent eye checks to the monitoring of HbA1C results and hypoglycaemic episodes. The quality standard also emphasises the need for individual care plans and integral support, especially during and after hospital admissions.

Thankfully, it seems that many of these standards, if sufficiently adhered to may be particularly useful in the management and understanding provided to individuals with ED-DMT1/Diabulimia. For example, section two advises that: "People with diabetes receive personalised advice on nutrition and physical activity from an appropriately trained healthcare professional or as part of a structured educational programme." While section eleven says: "People with diabetes admitted to hospital (should be) cared for by appropriately trained staff, provided with access to a specialist diabetes team, and given the choice of self-monitoring and managing their own insulin."

Section eleven of the Quality Standards suggest that people admitted to hospital with diabetic ketoacidosis should "receive educational and psychological support prior to discharge" as well as follow a up by a specialist diabetes team. This is of course crucial to someone who has fallen into ketoacidosis by complications of an eating disorder or omission of insulin, whereby they will require intense communication and support in preventing another repeat episode.

Perhaps most useful of all is section nine, which says that people with diabetes should be "assessed for psychological problems, which are then managed appropriately." Here the standards mention eating disorders as an example alongside other psychological problems that could potentially occur, such as depression, difficulty coping with the diagnosis of diabetes and injection related anxieties. They also outline considerations for equality and diversity by stating: "People with psychological problems and diabetes should have the opportunity to make informed decisions, including advance decisions and advance statements, about their care and treatment, in partnership with their practitioners. If patients do not have the capacity to make decisions, practitioners should follow the Department of Health's advice on consent and the code of practice that accompanies the Mental Capacity Act."

Diabetes UK Chief Executive Barbara Young has said that: "We welcome the development of this NICE Quality Standard for diabetes. All the statements cover important aspects of diabetes care. We are particularly pleased with the inclusion of statements that reflect the importance of individually tailored care and the involvement of the person with diabetes both in decision making and their own care; recognising their expertise. Examples of these include the statements on care planning, structured education, and individually tailored HbA1c and psychological wellbeing.

"Of course we would like more, as the standard does not cover all aspects of diabetes care. We understand that children will be covered in a separate standard, and urge that this and other aspects of the diabetes pathway are prioritised for standard development so there is a full suite of quality statements for diabetes available to inform commissioners and service providers, and support the goal of integrated services.

"The Standard challenges and supports commissioners and service providers to deliver on high quality care, and they must be effectively monitored on their achievement. The Standard should contain further measures reflecting quality of life and patient experience. These outcomes must be measured to drive quality service improvement informed by the voice of the patient."

'You must be the change you wish to see in the world.'

Mahatma Gandhi

Take a Look

Remember the major DWED event this year, Type 1 Diabetes and Eating Disorders DWED conference (1 day TBC 27th Aug - Sep 02) You can register your interest for



Anorexia

Resistance is my heroin,
A needles Scratch to freeze the pain.
Strung out, on a half lit energy fuse,
The burnt out nib still yellow,
& clipped together with safety pins,
To hide the holes. You talk to me in
riddles.

In figures, quantities and volumes.
Our own hushed military operation.
You draw me pretty pictures,
And sing to me in raspy tones.

To distract me, from the gnawing.
Clawing, gurgling.
You tempt and promise me,
With lower red blinking numbers.
Flashing like price tickets,
To determine my worth.
Eventually – Zero

You are always Here, stalking me
Creeping around corners,
Your bony scratched knuckles.
Cold against my cheeks.
I cower and I crawl, like a puppet,
dangling.

You are unwelcome by now,
And, yet still, I welcome you back,
With arms clutching, squeezing
Like my grandmother,
On Christmas morning.

Not chains, but bracelets. Bangles,
Lines of links adorned with raindrop
charms.

We move them, up, down
Up, down.
Up, down.

Testing, checking, checking again,
The free space skimming,
Between silver and my skin.
The smallest one is placed on my
dresser.

Now ceasing to fit. It sits at the front,
Teasing, taunting me.

by Claire Kearns

'Revolutionary' Breakthrough In Diabetes Care

An exciting breakthrough in the prevention of night time hypos has been demonstrated through research carried out by Diabetes UK and supported by the Juvenile Diabetes Research Foundation (JDRF). This involves the use of an 'artificial pancreas' or closed-loop insulin delivery system. The device works by continuously monitoring blood glucose and releasing sufficient insulin when levels are found to be high, while with-holding it when they are too low, just as a working pancreas would. Such a device could eventually mean people with diabetes no longer have to rely on injecting themselves with insulin or wearing insulin pumps which are connected to the body by a cannula inserted into the skin.

Dr Roman Hovorka, from the University of Cambridge conducted the study that surveyed evaluate effectiveness of the artificial pancreas in 10 men and 14 women, aged 18 to 65, who used an insulin pump for at least three months. During this time they were monitored overnight on two specific occasions after having consumed varying amounts of food and alcohol. Findings revealed a 22 per cent improvement in the period participants were able to keep their blood glucose levels within a safe range and halved the time they spent in hypoglycaemia, ultimately reducing both short and long term complications. Common signs of hypoglycaemia include shaking, blurred vision, sweating, tingling in the lips or inability to make sense of things. In extreme cases it can lead to coma, brain damage and death. Hovorka commented: "Hypoglycaemia remains a major challenge, especially during the night, so it's encouraging to see such promising results from our trial using commercially available devices."

Although individuals with ED-DMT1 /Diabulimia are more typically partial to high blood glucose (hyperglycaemia), episodes of low blood sugar can also easily become an issue. Often hypoglycaemic episodes are a very real fear of those suffering from both diabetes and eating disorders and they may very well put off taking insulin injections with worry that may lapse into a hypo as sugar levels drop back down. This can also become a problem when someone with ED-DMT1 attempts to re-introduce an insulin regime or enter into recovery. In addition, a restriction in food intake can may cause sugar levels to fall significantly while those that engage in bulimic-type behaviours (self-induced vomiting) are likely to experience sugar levels that regularly rise up and crash down, as control can undoubtedly be extremely chaotic.

David Wade for the Juvenile Diabetes Research Foundation believes that "An artificial pancreas could revolutionise diabetes care and management" while Dr Iain Frame, Director of Research at Diabetes UK said: "Although early days, this exciting area of research is a fantastic example of how existing technologies, in this case, insulin pumps and continuous glucose monitors, can be adapted and developed...We now need to see an extension of this study, one which tests larger numbers of people, and then take it out of the hospital and into the home setting."

Twitter

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Parliamentary Event

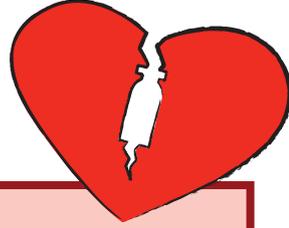
As you may be aware that the new coalition government is trying to induct changes into the Health & Social Care Bill giving GPs full commissioning over healthcare services such as podiatry, ophthalmology and even low intensity mental health care.

Diabetes UK and various other non-profit organisations attended a Parliamentary Event at Portcullis House on 27th April 2011 to discuss the problems and possible solutions to the new suggestions from government.

MP Stephen Dorrell stated that the new changes would mean that there was more choice and competition for our provider services; however this mustn't lead to fragmented care. He made us aware that 89% of care in the NHS is from chronic and long term illness. He made no allowances for mental health service users.

After another two speakers including a care-giver, I feel that these new changes could work out for us but we need to ensure that the new GP consortia need to be made aware of ED-DMT so we can lead a bottom down care approach (where we are in control of the services in our area).

If any of you feel that you would like to discuss this further or would like advice on how to contact your MP regarding these changes; do not hesitate to contact me on jo@dwed.org.uk
MNNNewQualityStandardsForTheTreatmentOfAdultsWithDiabetes



Could you volunteer?

*Make a
difference*

www.dwed.org