



Newsletter

February 2012

Well the start of the year has been very busy for us as always and it's good to see everyone working through the post New Year Slump. 2012 is shaping up very nicely and we have a lot of exciting stuff in the pipeline.

Membership of our online groups is growing exponentially and the New year has also seen a surge in new volunteers which is great.

National Eating Disorders Awareness Week is just kicking off as we go to publication and I have included the political campaign pack in this issue just in case you missed it!! Please support us in trying to push our agenda by getting in touch with your MP and make some noise!

Our shop is now open on etsy where you can buy some of our subversive cross stitches (Parental Guidance Advised) We will be adding more merchandise as the year goes on so keep an eye out for that on <http://www.etsy.com/shop/dwed>

Helpline

We are going to be reopening the helpline in April following training provided by the Samaritans. This training is particularly focused on dealing in Suicidal Callers and People who Self Harm. DWED is excited to reopen this service but it isn't cheap. If you would like to help us maintain the helpline please donate.

Web and Social Media Update:

We are now on Google+ just log in and search for Diabetics with Eating Disorders. Perhaps the most exciting facility of G+ is the 'Hangout' function which means that at anyone time multiple people can have a video get together

Volunteer Profile: Lucy O'Meara

Hi there everyone, You may know me from the social networking pages, and some of you may have read my blog from January on the DWED site.

I had Diabulimia throughout my teenage years, and I have been in recovery a couple of years. When people ask me how I got to recovery, it's a tough question, because to be totally honest, I'm not sure. I got told I have retinopathy, and had a lot of fresh haemorrhages. The thought of blood + eyes = hysterical Lucy wanting to run away and hide. But, what I didn't know was that little sum also = attitude "I need to do something about this". Anyway the main point is, I got to a point where I slowly managed to reintroduce insulin in to my life. There have been big blips along the way, but they're becoming fewer and further in between. During my worst bit, I wasn't really aware of the support boards, or DWED. In fact I didn't actually know about diabulimia/ed-dmt1. I just thought I was the world's worst diabetic, ever. When I did discover the boards, I used to read the posts from people and wish I could say something. The people that were commenting seemed to know exactly what to say, and I presumed they were DWED staff, so never really joined in, for fear of saying something wrong or something daft.

I saw a post by Jacq, asking for volunteers. Instantly I was just like "yes, go for it!" I worried that Jacq might say I wasn't suitable to help. I'm so so pleased that I sent that message to Jacq. Getting involved with DWED has let me speak to some truly inspirational people, reading the messages on the boards, and being able to offer advice has been such a good experience. I hate seeing people struggling, but I love that DWED is there to give support, advice and to advocate for people going through this, and I'm thrilled that I can be a part of that.

I'm doing a degree in Social Work and I am specialising in Mental Health, which has always been my passion. I'm taking an extra year at uni, as my health has hindered this year's study's. I may not be around as much as I want to be for people on the boards etc, but something I got told on placement has resounded with me really, and it's that "if you want to help others, you need to look after yourself all the more" and I think that's important to remember when volunteering, that you need to look after yourself too. So yeah, I'm thrilled to be volunteering,

Neuropathy:
when good nerves go bad

www.dwed.org.uk

www.diabeticswitheatingdisorders.org.uk

Director: Jacqueline Allan

Email: jacq@dwed.org.uk

Phone: 07869 116832

What's in a name?

Labelling and diagnosis

by Claire Kearns

I've never been keen on labels. Doctors all too often seem eager to place you into one box or another. The fact that you can go from a diagnosis of anorexia nervosa to bulimia nervosa in literally a pound on the weight-chart seems ridiculous. It is my opinion that assessment should always be individual, tailored and psychologically based, rather than how many boxes they may be able to tick off a list of 'warning signs'. Labelling can also cause someone to identify themselves as merely an illness and so lose a sense of themselves, especially in the case of personality disorders.

However with Diabulimia/ED-DMT1, we do desperately need it to become a recognisable, diagnosable condition. Otherwise those suffering will continue to be ignored, pushed aside, asked "what is that exactly?" on a regular basis. Trying to explain what Diabulimia is and that ED-DMT1 is a devastating and real illness despite it having no entry in the Diagnostic Statistical Manual (DSM) can be utterly frustrating.

Additionally, the Portmanteau 'Diabulimia' which seems readily used by the media in scare stories seems clumsy at best. This is why although DWED does use both terms for familiarity, we do recommend ED-DMT1 as the more appropriate. 'Diabulimia' tends to remind me of the unofficial Mickey-Mouse 'conditions' coined by trashy magazines and newspapers; 'Brideorexia', 'Manorexia', 'Pregorexia' and such, phrases flung together in an almost comedic fashion. What 'Diabulimia' stands for is deadly serious, and ED-DMT1 does a far better job of representing that.

ED-DMT1 can cover a vast range of symptoms that any one individual suffering with diabetes and an eating disorder may be struggling with. Some may omit insulin, some may restrict or purge by other means, some may be underweight and some may be normal or over weight, some may have problems with binging. ED-DMT1 manages to group all aspects that may arise from a combination of disordered eating and diabetes, under one umbrella term.

Action is needed and has been for some time now. The fact that ED-DMT1 is not a legitimately diagnosis makes no sense. Although awareness is improving, it is still so evident that treatment and understanding of the illness is falling down hugely because of this. Professionals seem reluctant to address a problem that in true medical terms does not exist. DWED is continuously fighting for a change, a validity and rightful recognition, and we will not give up until ED-DMT1 has a DSM classification code of its own.



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Fundraising

My name is Alan Eastwood and I'm a 53 year old diagnosed with Type 1 Diabetes aged 49. I'm currently the Admin of www.diabetessupport.co.uk and have been a runner of marathons and half marathons for nearly 30 years.

On March 11th 2012 I'll be running in the Bath Half Marathon on behalf of DWED, hoping to raise lots of cash and quite possibly with a bit of an impact (a tightly-guarded secret until I reach my target!).

I met Jacq at the Brighton Forum Meet and we were discussing ways of raising money for very underfunded but desperately needed charities, and I decided that I must do something to try and help such a wonderful organisation which can save and transform young lives. Everyone I have spoken to thinks this is a superb cause to run for and people have been extremely generous from the word go!

I can be sponsored by going to my Justgiving page at

<http://www.justgiving.com/DoingItForDWED>

by credit or debit card, or PayPal, or you can donate by text by

texting **DTLY90** and the amount (in £s) to **70070**.

I am also writing a blog about my training and fundraising experiences at <http://doingit4dwed.blogspot.com/>

Alan

(Admin www.diabetessupport.co.uk)



Just Giving



Thinking of fundraising or DWED?
Not sure what to do?

We all know how massively important fundraising is to our little family and how much we all want to see it grow. Maybe you've been thinking that you would like to help but your not sure how. The answer is simple - fundraising!

So now you've decided you want to raise some money the next step is how? We've put together a little list of inspiration to get you started. So first things first what do you want to do? High adrenalin? Long haul but low key? Or something in between? These are a few of our favourites and hopefully there is something for everyone to enjoy.

Abseiling - individually or with your mates abseiling is a great way to earn money and have a great time. You can either get people to sponsor you or if a lot of people are involved you could do a 'pay to participate' event - or both!

Birthday Parties - got a birthday coming up? How about making it a themed party and ask your friends and family for donations rather than presents? Spread the DWED word and eat cake - perfection! Maybe have a fundraising activity too, like a cake sale or a tea party?

Madhatters Tea Party - this has to be my favourite idea so far! Everyone has to wear a crazy hat and bring a funky tea pot - You can ask for donations or charge an entrance fee. If you're holding it in a village hall etc you could sell tables so people can hold their own tea party! I think I'm going to do this one!

Make a change and donate the difference - maybe you're looking for a reason to **quit smoking** or **give up take aways**? Why not do it for DWED? Every penny you save you can donate to DWED and with lent upon on us what a great time to start!

Sponsored events - you don't have to do something crazy or original though - a sponsored walk or fun run work just as well and can be great fun if you want to get big numbers involved! A midnight pyjama walk or a fancy dress fun run are my favourites!

And finally...**Record Breakers** - how about checking out the Guinness book of Records and find a record to break in the name of DWED?

Hopefully something here will inspire you to get your fundraising cap out and remember whatever you decide to do and however much you raise it will go along way to helping DWED!

For more information and ideas visit www.how2fundraise.org GOOD LUCK!

'Just Doing It' for DWED

Hi Everyone!

I started training properly on January 1st and I have managed to do 3 runs every week. Confession time though -- the vast majority of these have been treadmill runs due to my immense (and annoying) sensitivity to the arctic conditions that we have been blessed with so far this year.

My longest run so far has been 10km, which feels like an achievement on the one hand, but on the other a marathon is 42km and so it seems very insignificant. I am also doing a weight training class and a combination of yoga/thai chi/pilates class three times a week, to try and improve the overall strength, fitness, and flexibility of my body. It must be working because I've kept myself free from injury (yey!) so fingers crossed that continues.

I have looked up some marathon training plans online, however they are all 12-18 week plans which means once I pick the right one for me, I won't actually start 'following' it until early June (as the Chicago Marathon is on October 7th). So in the meantime I have booked myself into a couple of half marathons to help keep me motivated and make sure I keep my weekly mileage up.

First up, the Liverpool half marathon is on Sunday March 18th, and then on May 13th I am doing the Chester half marathon. It would be so lovely to see any of you at these events for a bit of moral support, it always cheers me up and inspires me to speed up a bit when I hear someone screaming my name from the side of the road!! So please feel free to get in touch (email is below).

I am going to launch my justgiving page in April, exactly six months before the marathon, so watch out for my shameless self promoting of the page over all the DWED social networking sites!!

I am also still looking for anyone who knows anyone who might print me a DWED themed running vest to compete in on the big day.

Kathryn
kathryn@dwed.org.uk



Recovery corner: Janine Chivers

It's been just over 8 months that I've been in what I call a solid recovery now! By that I mean taking all the insulin my body needs and covering all the carbs I eat. I check my sugar now roughly 6 times a day and feel like I'm high when reaching numbers of 9+. I still can't believe it, 9 was a hypo for me before and now it makes me brake into a sweat!!

I think a major incentive for me has been my promise of the pump!! I had an insulin pump years before when I was pregnant with my second child. I loved it and I found it so much easier to control my sugars. However I also found it so much easier to manipulate and withhold more insulin! Eventually my pct where not prepared to fund it for me anymore. I was deverstated! The hope of getting one back was highly motivating, my consultant gave me a 3 month trail. I got to have a pump again on the condition I got my hba1c down and used it well. So I did! That was it 3 months to get better!! Now that was pressure.

The good thing was I was already half way down the road to recovery and I wanted it so badly, I needed to stop the already developing complications making me feel even worse than ketones ever did, my memory had become

so bad that I could hardly finish sentences. I worried one day my heart was just going to give in an that would be it, I would end up in my house with my family a dribbling mess in the corner!! Of course there was also my children who to made me want to be well, basically it was do or die. So after 3 months my hba1c was down 2.5 percent and I got the funding for my pump back! There was some of me that wanted to give up again, now I had the pump I could just go back to omitting, but I felt no! To lose something once is bad but to lose it twice would be just god damn stupid!

I would say practically everyday is still a struggle but it's getting so much easier. My weight is stable and did not continue to increase through the roof despite my earlier beliefs. My energy with my children is so much improved and apart from issues with my eyes so have my complications :) I can not imagine now ever going back. My hba1c has now come down 4% in the 8 months and I love my pump...still lots to work on and food is sometimes still my greatest battle but the thought of cutting back my insulin is just not an option, the only thing I want for my body to be now is strong.

What is... Gastroparesis?

Clare Allison

Gastroparesis is a condition in which the stomach takes too long to empty its contents. Normally contractions of stomach muscles propel food through the digestive tract, this movement is controlled by the vagus nerve. Gastroparesis occurs when the vagus nerve is damaged and the stomach muscles do not work normally.

SYMPTOMS: Symptoms of gastroparesis include, vomiting, nausea, feeling of fullness after eating very little, bloating, heartburn, lack of appetite, weight loss, vitamin and mineral deficiencies and fluctuations in blood sugar levels. Symptoms of gastroparesis vary from person to person, some are affected only mildly whilst other people are affected severely.

CAUSES: The most common cause of gastroparesis is uncontrolled diabetes. High blood sugar levels can result in damage to nerves including the vagus nerve which is needed to control the emptying of the stomach. Gastroparesis can also be caused by eating disorders such as bulimia and anorexia plus a number of other things such as stomach surgery, some medications and some metabolic disorders. Many people however have idiopathic gastroparesis, this means that the cause is unknown and medical tests have failed to be conclusive.

TREATMENT: The way in which gastroparesis is treated depends on the severity of the symptoms. Treatment does not usually cure the condition but helps a person to manage the condition.

MEDICATION: There are several medications used to help stimulate contractions of the stomach muscles to aid stomach emptying, these include Metoclopramide, Erythromycin and Domperidone.

DIET: A change in diet can help to control symptoms, changes such as eating six small meals rather than three larger ones can help as less food is entering the stomach each time, a diet low in fat and low in fibre can also help as fat slows digestion and fibre is difficult to digest. In more severe cases a liquid or pureed diet may be prescribed.

If a liquid/pureed diet does not help, surgery may be required to insert a feeding tube directly into the small intestine to bypass the stomach and enable nutrient dense feeds and medication to go directly to the intestine enable them to be digested and delivered into the blood stream rapidly. An alternative to this is a surgical procedure to put a thin catheter tube directly into a vein in the chest so that liquid nutrients can be fed directly into the bloodstream.

GASTRIC ELECTRICAL STIMULATION: This is a surgical procedure which places a stomach pacemaker on the outer edge of the stomach. The pacemaker uses an electric current to produce stomach contractions and have been shown to improve stomach emptying and reduce nausea and vomiting for some people with gastroparesis.

COMPLICATIONS: Gastroparesis can cause a number of complications. If food remains in the stomach for too long it can cause overgrowth of bacteria in the stomach also the undigested food can harden in the stomach which can be life threatening if these solid masses prevent food from passing into the small intestine. Gastroparesis can worsen the complications of diabetes by making blood sugar levels harder to control which in turn can make gastroparesis worse.

What is... Domperidone?

Domperidone is a medication used for gastroparesis. Rather than affecting the cause (damage to the nerves),

it targets the symptoms.

Symptoms of nausea, vomiting, bloating and fullness can be effectively treated using domperidone.

Domperidone works in 2 main ways, firstly on the stomach muscles. It tightens the muscles at the top of the stomach and relaxes the muscles at the bottom so the food more easily passes down into the intestines. This action causes the food to move more quickly through the gastro intestinal tract and bloating, fullness and vomiting is reduced. It's second action is to block the vomiting centre in the brain so that messages from the brain do not trigger the vomiting reflex.

Although this medication is available over the counter it needs to be used with caution in anyone with any kidney or liver problems so I would recommend always getting it prescribed. Domperidone is available in tablet form. There is also a sugar free syrup available which I would recommend in more severe flare ups as the liquid is more easily digestible. If vomiting is occurring then suppositories can also be used. But to be aware dosing is slightly different.



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.

Living with... **Gastroparesis**

Ish Donaldson

A couple of weeks ago, I was walking home with a friend of mine, who doesn't know about my ED, she was talking about her acid reflux. After saying she knew how daft it was to complain because "people don't really understand how bad it is, if they don't suffer it themselves." I felt as though she was literally speaking my thoughts on Gastroparesis. You don't think it's a huge deal, or its as bad as it seems, until you personally have it. Certainly, it doesn't seem as bad as kidney failure, or leg amputation, or blindness. Definitely not as extreme. But, most people don't realise the everyday, excuse my language, pain in the arse (sometimes literally!) living with Gastroparesis is.

A day with Gastroparesis begins like this: on waking, you generally don't feel hungry at all. As a person who has always been brought up to eat breakfast, and always has, I now find it a huge struggle to eat a proper, well-balanced breakfast. However, skipping breakfast sometimes means a hypo mid-morning. A bad hypo, when you've got Gastroparesis, is more than bad, because I am pretty much physically unable to tolerate any form of sugary liquid. The minute I take Coke or Lucozade or any other liquid to remedy the low blood sugar, I just automatically throw it straight back up.

So, if it's just impossible to have breakfast, by the time mid-morning comes, I'm always ravenous, and munch my way through whatever snacky things are lying about. At lunch, because I'll have been snacking all through the morning, I won't be able to eat. Some people would suggest to just have a small thing mid-morning, and have a full proper meal at lunch. I'd love to have a full proper meal. But the thing is, because Gastroparesis is basically the nerve at the bottom of your stomach not working properly, and delaying gastric emptying, it makes it impossible to have a large meal, or even a medium sized meal, at the one time without ending up in a considerable amount of pain afterwards. Even something low carb, like an omelette, can end up making you sick.

Lunch passes, and it's now into early afternoon.

Without fail, this is when the eggy burps always begin for me. Literally every day, without fail.

And its not just wind- like the kind you are able to swallow back down. It's huge, gassy, repugnant smelling emissions- the kind that make your eyes water! After spending the afternoon burping away, with your stomach getting more and more bloated, and feeling increasingly more nauseous, by the time 6pm comes, dinner is the last thing you'd want. In fact, despite being fairly hungry, there's the ever-present nausea. Because the that I eat doesn't leave my stomach for ages after I've eaten it, sometimes the nutrition from food I've eaten from days previously, starts being absorbed, and despite not having actually eaten anything much that day, my blood sugars soar- in turn making the Gastroparesis that much worse.

Usually by 8pm, I'll be starving again, and in order to be able to eat, I'll knock back some units of insulin. But a late dinner means that stomach issues kick in again. Usually, after eating snacky things instead of a large meal makes it slightly less bad- a large meal any time in the evening means haing to run to the bathroom immediately after eating in order to be sick, because the food just can't be digested. But on (rare) occasions, I can just about keep an evening meal down.

Keeping a meal down in the evening, means more stomach gurgles, eggy burps, and general unpleasantness for the rest of the evening, until about 10pm. Then I usually start getting shooting pains in my stomach and feeling like something is trapped in my throat. This is normally coupled with hot and cold sweats, bloating...basically anything that could make someone feel appallingly ill. This goes on until about 11-ish, for me anyway, until it's basically exorcist Linda-Blair projectile vomit time. Most of the time, when my gastro paresis starts making me sick, I'm not going anywhere, or doing anything until I've gotten all food out of my body. And, not to be too graphic, but it's not just the mouth that undigested food is expelled from with extreme force. But I'll leave that to your imagination folks!

Gastroparesis is a physically exhausting, mentally exhausting, depressing and plain embarrassing condition to have. Imagine having to tell a junior doctor at clinic, maybe only fie or so years older than yourself, that you can't stay over at your friends because you need to be essentially locked in the toilet from 11pm-4am with constant omitting and diarrhea, or imagine throwing up, and seeing, to your utter horror, that the Chinese takeaway you had four nights previously, is now lying, still undigested, in the toilet bowl. I started omitting my blood sugars to lose weight, which I did, but ended up putting all that weight back on, and not only that, but giving myself a medical condition that makes day-to-day living sheer hell. Insulin manipulation to lose weight? SO NOT WORTH IT.



Trustee Profile:

Kym Hackett

My first encounter with DWED was at time when time appeared to be running out for my daughter. She found support through the charity and I began to notice a change. Her questions had answers, her illness had a name, and the path she walked began to feel less lonely as others walked beside her. She began to feel more confident, gain control, no longer afraid or judged and so the process of recovery began. When she fell, she was picked up and carried for a while until she felt strong enough to begin to carry others during the times they may fall. My daughter lost 95% of her sight due to the severe complications of the illness but thankfully through life changing surgery, her sight has been practically restored. Without DWED I am in no doubt my daughter would have become another fatality and yet another life lost. For that, I will be eternally grateful.

Some time ago I was asked to become a Trustee for the Charity, which has been a privilege. A decade of living with the illness has taught me a great deal about living with diabetes whilst coping with an eating disorder. My first hand experience of understanding the immense pressures placed on sufferers and the impact on loved ones, allows me the insight of seeing life from both sides of the fence, which is why I find my role within DWED so rewarding. My own academic and professional life helped in not only coping with my own child's illness, but hopefully in the input I am able to contribute to DWED, members, and their families in fighting for adequate care. Unfortunately, little has changed in the way in which services cope with Diabetics with Eating Disorders. I am still amazed at the lack of knowledge, provision and awareness of the illness from Professionals and Government, but DWED are 'doing their bit' in highlighting the URGENT need for change.

In the meantime, this eclectic, passionate team of wonderful people continue to fight and support to help others. DWED offers unconditional support, and light the way for those searching for answers.

Q: I'VE SEEN AT MY HOSPITAL THEY DO PRE CONCEPTION CLINICS.. HOW LONG BEFORE TRYING TO CONCEIVE DO YOU RECOMMEND PEOPLE GO TO THESE? THIS IS LIKE MAYBE 2 YEARS AT LEAST DOWN THE LINE FOR ME. ALSO, T1 GUYS, IS THERE ANYTHING THEY NEED TO DO? WOULD SOMEONE IN APPROX 3 YEARS RECOVERY (WITH BLIPS) NEED MORE PRECONCEPTION CARE?

**Ask
A DSN**

A: Pre-conception care is really important and most Diabetic Clinics will offer extra pre-conception clinics. It is important to get as tight control as possible prior to trying to conceive. high glucose levels prior to and during pregnancy can increase the risk of complications for both mother and baby. If you are not trying to conceive then contraception is important.

Ideally getting HbA1c to below 7.0% (53 mmol/mol), and the lower the better. This will reduce the risk of complications. If control is already optimal for pregnancy then, 3-6 months before trying to conceive discuss this with your diabetes team. Diabetes UK recommend taking folic acid 5mg for three months before conception for women with Type 1 Diabetes. If control is much higher than 7.5% then 6-12 months of working with your DSN is important to get as good control as possible. this might mean attending a course like DAFNE, using a pump and/or continuous glucose monitoring.

The effect of Type 1 Diabetes on male fertility has not been well researched. There may be some evidence that the sperm has increased DNA damage compared to those without Diabetes. However the impact of this on fertility was not determined. There is no specific advice for men with Type 1 Diabetes. However getting good glucose levels is going to be beneficial regardless.

CREATIVE CORNER

Patience Elixabeth Hollinden

- I** -improving my quality of life.
- N** -never giving up on fighting for my health, happiness and life.
- S** -survive physically so I have the strength to attack the bad things mentally.
- U** -use all my strengths to help myself and others.
- L** -let my voice be heard, and help let others voices be heard.
- I** -inspire others to take their insulin by sharing my ups and downs.
- N** -notice when I need to reach out for help

Food For Thought,

*what it is and why it's
good for you*



This recipe is taken from Diabetes UK website.

Black eyed bean, feta and herb burgers (serves 6)

When pre-prepared, these are super easy and quick to make, as well as delicious. Serve as a standard burger in a burger bun with salad.

Ingredients

2 teaspoons olive oil
3 spring onions, finely sliced
400g can black-eyed beans, drained and rinsed
75g granary breadcrumbs
100g feta, crumbled
2 tablespoons mixed fresh herbs, chopped (eg parsley, coriander and chives)
1 egg, beaten

Heat half the oil in a non-stick frying pan and fry the spring onions for 1–2 minutes, until softened.

Place the black-eyed beans in a large bowl and roughly mash. Stir in the remaining ingredients and combine well.

Divide the mixture into 6 and form each into burgers shapes.

Place on a baking sheet, brush each side with the remaining oil and chill for at least 30 minutes. Cook for 2–3 minutes on each side under the grill.

Energy: 150kcal; Protein: 10g;
Carbohydrate: 16g; Fat: 6g

Spilling the beans on beans... by Chloe Bean

Not only are beans the best because they star in my name, but beans are rich sources of low-fat protein, inexpensive, easy to cook and very tasty! Although beans are considered to be loaded with carbohydrates they actually have a low glycaemic index and so are more slowly digested which allows a more gradual rise in blood glucose levels. Beans also have a high-soluble fibre content that can help to prevent constipation and lower cholesterol levels by grabbing on to cholesterol and removing it from the body before it can be absorbed. Additionally, the soluble fibre in beans helps to slow down the rate at which digestion occurs, making us feel fuller for longer. For these reasons, it's no wonder why beans are claimed to be 'the magical fruit'. However, after eating them they can also make us 'toot', which is often why people avoid eating them. Depending on how digestible a certain type of bean is, determines how much gas they will embarrassingly produce. Lima beans (also known as butter beans), chickpeas, kidney beans and black-eyed peas are relatively easy to digest whereas soy, black and pinto beans are not and therefore are more gaseous. Soaking beans in water overnight, before cooking, helps loosen up the skins so that that gas smelling culprit in beans can be released. If limited on time, you can speed up this soaking time by bringing the beans and water to a boil, skimming the foam, and then taking them off the heat to carry on soaking. When using canned beans, always drain and rinse them before eating because they are more likely to cause gas than those you cook yourself. Also, canned beans can have a lot of added sugar and salt so opt for organic tins of beans where possible or simply just ones that have no added salt and sugar.

For those who suffer with gastroparesis, high-fibre foods such as beans, should be avoided as they can lead to bezoar formation (an indigestible mass of food). Instead, low-fibre foods that are easier to digest are recommended for those with gastroparesis. Substituting beans in recipes with vegetables such as carrots, mushrooms, potatoes (no skin), spinach and tomatoes (no skin), where possible, is a good idea. Alternatively, protein rich foods that digest well with gastroparesis are lean meats such as skinless chicken and turkey, non-breaded fish and eggs whites.

The following recipe is from *The Ultimate Book of Diabetic Cooking*

Butter beans with tomatoes This bean dish is really great for this time of year as it is warming and packed with lots of vitamins and minerals. This is a great side dish to go with some type of meat (sausages would be nice) or fish. Alternatively this can be a meal in itself and any leftovers would make a yummy lunch for the next day.

Ingredients 400g butter beans, 2 tablespoons olive oil, 3 onions, chopped, 1 celery stick, chopped, 2 carrots, chopped, 3 garlic cloves, thinly sliced 400g can chopped tomatoes, 2 tablespoons of tomatoe puree diluted in 300ml hot water

Soak the butter beans overnight in cold water, rinse and drain.

Cook beans in a pan of boiling water until tender and drain.

In a clean pan, heat olive oil and add in onions until golden brown then add the carrots, celery and garlic.

Once garlic becomes aromatic, stir in the can of tomatoes and diluted tomatoe puree and add in the beans.

Add parsley and seasoning (optional).

Tip the mixture into a baking dish and bake for 30 mins at 180oC/350oF/Gas 4.

Energy: 205 kcal; Protein: 16.2g; Carbohydrate: 37.4g; Fat: 5.1g; Cholesterol: 0mg; Fibre: 12.7g

Being a "good enough diabulimic"

Claire Kearns

It's a concept people without diabetes and an eating disorder can't comprehend. If you dare to say it out loud you are bound to be met with wide staring 'you're crazy' eyes, rightfully so I suppose. Yet the desire someone sick may have to be a "better anorexic" or "better bulimic" seems far easier understood for some reason. I imagine simply because they are more recognised statements, recorded regularly in various sensationalist news articles. But the fact is that all of these irrationalities are grounded in the need to hurt, to punish, to prove you deserve the worst.

The only way to break those twisted thought patterns, that can be ever so persistent when you are in the grip of ED-DMT1, is to push through, bring yourself back to earth. Remember: You will never be a "good enough" diabulimic, until you are dead, and then there is no going back, no second chances, no "wait, stop, I never meant for this to happen!"

Just like someone with anorexia will always be able to find someone thinner, an outline to press against themselves, with ED-DMT1 you can fall into the trap of comparison. The illness created a myriad of

health problems, and there will be those with lists of complications longer than your own. It's completely messed up, the feeling that you need to suffer more than you are already, as much as x person or y, but let's not pretend it doesn't happen. You think "these are good people and they don't deserve it, but I do." Despite being fully aware of all of this, it can become triggering, and sometimes you need to step back. Give yourself time and perspective to realise that any difficulties you may be facing are not the norm.

The fact is that you may feel too lucky, guilty even, if you aren't experiencing gastroparesis, neuropathy, retinopathy or any number of other medical issues yet. But such reflections are futile, and misplaced. Because you can fall unconscious the first time you experience ketoacidosis, or on the twentieth time. Your body can cave just like that, and with a domino effect it can all come crashing down. Nobody can know what is going on inside you, and no one can chart their illness on a scale of sick to not sick, it is not measurable.

When you are going blind, in organ failure, on dialysis, unable to get around, then will you feel a "good enough diabulimic?" No?

RESEARCH PARTICIPANTS WANTED

Type 1 Diabetes and Eating Disorders - an Exploratory Study

Would you be willing to take part in a study which aims to explore peoples' experience of this condition?

We are looking for people with Type 1 Diabetes, who may have also experienced eating disorders, and who are willing to share their stories. Through getting an insight into the patient's perspective of this condition we want to increase awareness amongst healthcare professionals working in clinical areas where they may have to provide complex care to you, such as A+E, medical admission units or eating disorder services.

Taking part in the study will involve an interview where you will be asked to talk about your diabetic and eating experiences. The interview should last around one hour and will be held at a time and place convenient to you.

For a copy of the Participant Information Sheet or any other information please contact Kathryn Fry

k.l.fry@liverpool.ac.uk or 07928049859

Mokey's make and do

Hearty Garland



WHAT YOU NEED IS:

Natural string or Thick cotton
Glue stick/glue on a roll/sticky dots
Scissors

Ok get your book/magazine and get cutting,,
(if you aren't confident cutting out
freestyle draw your heart shapes and then
cut around them)

Try to cut out the shapes using 2 pages
at a time so you have pairs of identical
hearts.

Each pair can be different from the next
though, different shapes, sizes, colours,
some could just be type etc

Once you have about 10 pairs have a
break and position them in a vertical line,
rearrange them til you're happy with
the way they look and with the spacing
between them, it's all down to personal
choice.

when you're happy, take the top heart
and put it right side down, next to it's
partner,. (like when you turn a page in a
book)

Apply your glue liberally, and run the
string/cotton down the middle of the
heart, now turn the top heart back over,
line it up and fix in place (over the top of
the string)

Carry on til all you 10 pairs are stuck.
Repeat from the beginning until you have
a chain of hearts that is long enough to
drape wherever you want.

This is just the basic idea, you could add
buttons, beads or sequins, try layering
more paper hearts in contrasting colours
or ones cut with pinking shears, how
about trying it with felt and sewing a
loose running stitch through the hearts?

This is just the cutest tip here if you
want a stylish accent on a wall or you
want to make a present really personal
with a hand stamped card and wrapping it
couldn't be easier,

WHAT YOU NEED IS:

A loo roll

Poster Paint/ emulsion

3 x lengths of sticky tape, (easier if
it's pre cut to about 2 inches and
stuck somewhere accessible)

Right squash the loo roll flat, make
sure the edges are creased well
Now push one crease inwards and
as it becomes heart shaped tape the
middle of the loo roll,

If you're happy with it stick the
other tape a couple of centimetres
from each end and presto instant
stamp, mothers day wrapping paper
anyone?



Can you write? You can help us
Could you volunteer and commit a few hours of your
time? Then you can help us too
Could you become a trustee? Guess what you can
help too.
Even if you're not sure, contact us, you'd be surprised
at what you CAN do!

A Carer's Perspective:

"Diabulima, what's that?" asked the GP.

When I told her, she shook her head saying, "In patient treatment – that's really expensive!" I replied furiously, "Well, you've got children, how would you feel if someone said that to you when the consequences of not providing treatment may mean horrendous, early health complications?" She just shifted uncomfortably in her chair and did not reply.

This exchange came at the end of five, long years of trying to find the right support for my daughter. It left me feeling completely crushed. All the soul destroying experiences that we had gone through came in to my mind. I thought firstly of the counsellors who would not read the information that I had given them on Diabetes and the research on diabetics suffering with an eating disorder in order to try to help them to develop their understanding of this dangerous problem. In their professional smugness they felt sure that her issues and problems were nothing to do with Diabetes; it had to be down to poor parenting or bad family dynamics. There was the diabetic specialist who told my daughter that he "didn't do mental health" when she was desperately trying to find someone who could help her with her diabetes and the eating disorder which was completely spiralling out of her control.

I remembered the social worker who decided after five minutes that my daughter was "attention seeking" and had formulated this diagnosis without reading the notes or liaising with the school nurse who had also been valiantly trying to find her the help that she so badly needed. However, worse was to come. When my daughter was referred for inpatient treatment on an adolescent psychiatric ward, the lead psychiatrist almost proved to be my nemesis. He could not have a conversation without yawning within five minutes and the idea of multidisciplinary working in conjunction with the diabetic team was immediately rejected out of hand. I panicked, trying to explain as succinctly as I could (better not talk for longer than five minutes, the man may be comatose by then) how the research indicated that for a diabetic with an eating disorder the most effective way of helping them is for the psychiatric team to work hand in hand with the diabetes specialists. His response - "Your mother talks an awful lot, doesn't she?" he said as an aside to my daughter. So being concerned about the health of your child when it is so obviously in danger is "unhelpful" and trying to fight hard for the right treatment is being "over anxious". The blackest day was when one of the doctors told my daughter that she could not be referred to an eating disorder unit as she was "not thin enough". What an absolutely appalling, inflammatory thing to say to someone struggling with these issues!

I was stuck in a cul de sac with no way forward. That these "professionals" actually seem to prefer neglectful or "head in the sand" parents was the conclusion I came to. However, I remembered the rather ignoble attitude

that certain of the psychiatric profession has displayed historically towards mothers; the mothers of autistic children who have been labelled "refrigerator mothers" and the mothers of children with schizophrenia who have been labelled as "emotionally ambivalent". That certainly put my experience into context.

And then came Jacq! She was fantastic with my daughter; visiting her and immediately establishing a rapport with her and making her feel that there was a way forward and that her issues and problems were ones that DWED could support her with. For me, she restored my confidence and belief that I was completely right in trying to fight for the right help for my daughter. She said that I could call her anytime. I could not believe this and this offer of support reduced me to tears because crises do not happen in office hours, they happen in the evening and at weekends when no one who really knows your child is on duty and you feel so alone. When I felt intimidated by ward professionals, she was the most fantastic advocate; coming on to the ward to support me and so clear and knowledgeable in what she said. However, she never takes over, she never makes you feel like you have done or said the wrong thing and she never blinds you with science. What she does is, she enables you. She made me feel like I was a good mum, that I was completely rational in being worried and that we really would be able to access the right support in the end. She helped us to find where the right treatment was to be found and supported us through the process of approaching the Mental Health Commissioner in our area, in order to fight for this treatment. From initially feeling that you can not challenge the opinion of a psychiatrist, she showed me that this was possible and that there are good, effective mental health professionals out there who really can help people struggling with Type 1 Diabetes and an eating disorder.

And so my daughter is finally an inpatient on an eating disorder ward, where the staff have experience of dealing with patients with diabulimia. She is getting the help that she needs from a wonderful psychiatrist, insightful psychologists and incredible nurses. They also provide much needed support for carers. It is not easy and there are steps forward and also steps backwards but I now have the peace of mind that my daughter has finally got the support that she so desperately needed. Jacq and DWED are still there for us. I love the fact that the Facebook page is available day or night because it is often in the evenings and at weekends when you most need support. What DWED does is so special and unique and the support it gives to Type 1 diabetics with an eating disorder and their carers is way beyond what the NHS in many areas either has the inclination or ability to provide. So thank you Jacq and DWED for everything you have done for us and for all the support and encouragement that I know that you will continue to provide to my daughter. Your support really does change lives!



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



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