



You may have noticed that it's been a while since we put out a newsletter. So much has happened this year that its hard to quantify what is important to our community in a paragraph. I guess for me personally I can sum up this year in 2 words. Sian Died. I'm sure that I'm not the only one who will remember 2011 for this reason. We have a tribute to her in this issue. That would never ever be enough to mark her passing and we will be holding events in the future in her name, Sian's legacy will outlive us all. I promise that. I really hope that everyone reading this knows the sacrifices that Sian made to help them. So often she would be up at 5 am talking to someone with neuropathy or gastro or just feeling blue. She was so special, so unique and although I'm not personally religious, if I was I would believe that Sian is an Angel watching over all of us. There have been a lot of questions surrounding her death but it has been ruled Dead in Bed Syndrome: Natural causes. I know that for many of us that raises even more questions and we will be looking at the history of dead in bed syndrome in a future issue. In the run up to Christmas the boards always experience much heavier traffic and we know that it is a difficult time regardless of eating disorders and diabetes. Personally, this year I am going to try and let go a bit and do Sian proud. Although condolences feel like lip service considering the depth of their loss I really hope that the Howarths know how much I, and the entire community, love and appreciate everything that Sian has done and also that thanks to her continued time, effort and energy there are members of our community who wouldn't be here and many less grieving families this Christmas. Although nothing can ever take away from the loss, Sian has saved so many other families from going through it that I know you are incredibly proud.

As a result if Sian's death things at DWED have been very difficult and so I am renewing my call for help as I do in every issue. We desperately need experienced fundraisers, charity heads, money men, creatives etc. etc. to help with the charity. DWED cannot keep running as it is now and if we can't get the help we need then certainly we will need to look at reducing the services we provide which would be terribly sad for all of us here and within the community. There are new ways that you can donate to DWED including monthly by direct debit via just giving, we have a focus on fundraising in this issue.

Next year is going to be tough for us as we all try to tackle running DWED, the boards, our jobs, school, uni, family life but I know that if we have a strong enough belief and some decent structure then we will come out the other end a force to be reckoned with. I wish you all the best for the festive period. Stay safe, Do Sian Proud.



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ask us anything on
formspring

DUK Conference

Some of you may know that my mouth leaves me prone to getting myself in trouble every now and then and that's exactly what precipitated my appearance as a speaker at this years annual volunteer conference for Diabetes UK. Last year I publicly objected to the lack of young people there and as a result Alex Silverstein asked me to speak at this years conference by way of recompense. A few good things came out of this engagement, firstly I got to meet some lovely new people including Diabetes UK Chairman Richard Lane (OBE) and Alex's wonderful mother who is a real world beater and an amazing advocate for young people with diabetes. Nicola feels very much s I do that NHS Services for Young people with Diabetes are pretty woeful and as such we may well be joining forces for a new project over the coming year in Sian's name of course – Will keep you posted.

Website and Social Media Update

Treatment Finder: We have now updated our treatment finder. Thank you very much to all of the diabetes and eating disorders specialists who responded to our call for information. Please take a look and see if there is somewhere near you who can help, there is information about how you can get a referral and catchment areas. If your catchment area isn't represented please let us know and we will go on the hunt for you.

Youtube: We have now started a series of vlogs around the subject of type 1 diabetes and eating disorders. These can be found at

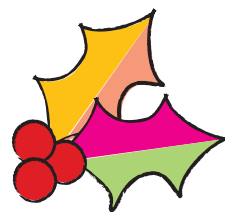
<http://www.youtube.com/DWEDinfo>

we are also gathering relevant videos for playlists for your information focussing on eating disorders and body image. I hope that you will take a look and subscribe to our channel. Of course we need you to do your own vlogs so we can add them. So much content on the internet about our condition is misinformed and distorted that it's really important we create our own space and get the truth about the condition out there. Every fortnight we will be looking at a different topic, if you would like to suggest one or contribute please email me jacq@dwed.org.uk

Diabetics with Eating Disorders: Liverpool Contingent

For all our scousers to get involved you have your own Facebook group page now. If you want to get involved please like the page at

<http://www.facebook.com/DWEDLC>



DWED in Scotland

A big thank you to everyone who came to our event in Perth. It was lovely to see some familiar faces among the new. DWED is particularly enamoured with the use of the DEPS (diabetes eating problem survey) and the research that Dr Michelle Quilter is carrying out. We look forward to the results safe in the knowledge that it will affect real change. Our network in Scotland is rapidly expanding and Director Jacq is planning on spending much more time there in the future.



Fundraising

So many ways to donate!!!!

There are now loads of ways to donate to dwed, you can make a one off payment using Paypal or you can send a cheque (don't forget the gift aid form!!!!) to the address on our shiny new donations page!!

<http://www.dwed.org.uk/Donate/>

JUST GIVING

I am also really excited that we are using **just giving** which gives us loads of ways to raise money. You can now donate monthly via direct debit please follow the link on our website or Facebook page and please remember that even £1 a month means a great deal to us. Should you wish to make a one off donation this can also be done via just giving on either the website or the Facebook group page.



Become a dwed fundraiser?

If you fancy doing something for dwed all you need to do is sign up to just giving and nominate us as a charity that you are raising money for. It is now also possible to raise money in someone's memory, if any of you wish to do so for Sian then you are more than welcome. Just keep us in the loop and let us know if you need anything

<http://www.justgiving.com/diabeteswed/Raisemoney>

Diabetes Power

I would also like to take this opportunity to thank Angela Alison from Diabetes Power for her sterling effort in raising money for us From Angela's Justgiving Profile: <http://www.justgiving.com/DiabetesPowerCycleRide>

Nipro-Europe are supporting **Diabetes Power** to gain Charity Status, plus **10%** of the total raised will be going to **DWED**. This Cycle Ride is in honour and memory of Sian Howarth. The first time I met Sian was at a fashion show raising funds for DWED. She was young beautiful & full of fun. Sian had Type 1 Diabetes. Sian inspired me, I knew that the future was bright for Claudia.

Donate Right Now using Just Text Giving

Christmas Survival tips

Make sure you take time to yourself to relax!

Remember it is just one day...its really easy to get caught up in it all but like any other day we just take it one day at a time...

Use the boards, lets all get through this together

Try not to focus so much on the food if you possibly can.

Treat it like any other day in regards to food and insulin - remember everything's still the same in that respect. Give yourself the chance to really enjoy your day :)

Distract yourself by spending time with family, watching christmas tv, calling friends, opening presents! Think of the Christmas meal as any other meal and take it as it comes. It's a day to enjoy not obsess, everyone deserves that.

It's the season of goodwill to all (that includes yourself), so cut yourself some slack, be less self-critical, give yourself credit for the things you achieve, believe in yourself!

REMEMBER it is just a couple of days really.. try and have control as tight as possible beforehand. Maybe go for a lovely long walk sometime during the day, we all know how a good walk clears the head and helps with blood sugars...

Remember a New Year is just around the corner too bringing a fresh start.





'Just Doing It' for DWED

Hi Everyone!, I'm Kathryn, I knew some of you from the DWED facebook group (I regularly post and comment there) but to those of you I don't know, hello!

I am a lucky winner of the Nike+ Five Year birthday Challenge! The amazing prize is flights, three nights accommodation, and entry into the Chicago Marathon 2012 for myself and a friend. At first I was convinced it was a big hoax designed to part me from all my worldly goods; but it is in fact the real deal, and the lovely people from the Nike Running UK facebook page have sent me lovely new kit to train in (Lunarglide 3's in black with pink soles if you're interested).

I am going to raise sponsorship money for my efforts, all of which will be donated to DWED; and in the run up to the event, which is on October 7th 2012, I am going to have a regular column here in which I discuss the trials and tribulations of training for a marathon whilst managing with ED-DMT1.

My background is that I have had ED-DMT1 in various forms and at various levels of intensity for the last 13 years. I had in-patient treatment in an eating disorders unit in 2006, and I have had over 60 admissions to medical and mental health wards. I had 18 months of CBT and am currently in DBT – dialectical behavioural therapy.

I have been running since I was about 9 years old. Whilst I have done a number of half marathons, this is my first (and to be honest I envisage it being my only) full marathon. Training for this marathon is huge inspiration for me to keep well, as running with high BG's and ketones is exhausting, not to mention dangerous.

There will in due course be a fundraising website, but in the meantime if anyone has connections to a shirt printing company and/or a personal trainer with marathon training experience then please get in touch - as I am after donations of a vest decorated with the DWED info to run in, and a proper training plan.

I hope you all enjoy the festive season, and I will be back in the new year to moan discuss running in the rain and snow! Stay Safe



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.

What Is... Neuropathy?

Clare Allison

Neuropathy is the medical term for nerve damage. It is not fully known how Diabetes causes nerve damage, but hyperglycaemia (high blood sugar levels) is known to damage the ability of nerves to transmit signals and damage blood vessels responsible for transporting oxygen and other nutrients to the nerves.

Nerves carry messages between the brain and every part of the body and therefore have an important role in the function of major organs. The main types of neuropathy to affect people with Diabetes are; sensory, autonomic and motor which all affect the body in differently.

Sensory neuropathy is the most common form of neuropathy affecting nerves carrying signals from the skin, muscles and bones to the brain. It tends to impact the senses, in particular touch, and affects how a person perceives sensations such as pain and temperature. It typically affects the feet and legs but can also affect the hands and arms; it leads to a loss of feeling. The failure to sense things such as pain can lead to damage going undetected (because you cannot feel it) and therefore increases the risk of infection. Symptoms include pain and numbness, tingling of the hands and feet and an extreme sensitivity to touch.

Autonomic neuropathy affects nerves that control involuntary activities such as the action of the stomach, bladder and the heart. It can cause gastroparesis (a condition where the stomach takes too long to empty). Autonomic neuropathy of the stomach may cause intermittent diarrhoea or constipation, nausea, vomiting, bloating and stomach pain. If it affects the bladder it can result in incomplete emptying of the bladder, incontinence and in rare cases a complete inability to pass urine. When autonomic neuropathy affects the heart and blood vessels it can cause irregular heartbeat, abnormal blood pressure and can mask the pain of a heart attack. Autonomic neuropathy can also affect the sweat glands resulting in difficulties regulating body temperature.

Motor neuropathy affects movement by interfering with the signals from the nerves to the muscles. It can cause muscles weakness and wasting and therefore cause problems with walking and hand movements. If it affects the feet it can lead to Charcot's foot which is a condition where loss of sensation and muscles weakness cause bones in the foot to fracture. The shape of the foot can distort due to being unable to feel the fractures which this results in incomplete healing and foot deformities.

It's probably particularly fitting that I'm writing this at 4.30 in the morning. After all, that's the main side-effect of neuropathy - the pain in your feet keeping you up till well into the wee hours of the morning, infact not even the wee hours... Neuropathic pain, especially that present in the feet, can develop to such extreme extents that it becomes impossible to fall asleep till about 10am the following day. Neuropathy turns you into a vampire - awake all night, in tears from the burning, pins-and-needles type pain that plagues your feet, until it's impossible to stay awake any longer - it's not from a reduction of pain that you eventually pass out, but from sheer, bone-tired exhaustion.

It has affected my life a huge amount, more than I could ever explain without getting emotional. Because it gives me unbearable restless legs in addition to the pain, even if my feet weren't agony, I still doubt I'd be able to sleep due to the almost 'itchy' feeling, deep into the very marrow of my legs.

Neuropathy begins as somewhat numb feeling in the feet. Even if this prompts you to start improving blood sugar control, chances are, you'll still suffer some form of neuropathic pain. I know that, regardless of what my sugars are, my feet still ache and throb. It's affected my life so much, when I dropped out of uni earlier this year, I knew it was partly due to the fact my sleep cycle was appalling - almost every night, I don't fall asleep until at least 4am because of the neuropathy, and when I sleep, I won't wake up until at least 2pm. It makes doing normal everyday things like finding a job, and working long shifts pretty much impossible. When I was phenomenally ill with my eating disorder, I still loved going out at night clubbing, that's not really so much of an option now, even the idea of heels for longer than 45 minutes makes me feel the soles of my feet burn.

A huge issue with neuropathy that I personally have, is that pain medication doesn't seem to work for me. I've been on Pregabalin for the past two years, which has a minimal effect, think dropping a pebble into 'an ocean of pain', that's essentially the effect it has. Tramadol, which works at first, very quickly becomes all but completely ineffective. Not to mention how addictive it is. Amitryptiline, while working well for some people, generally doesn't really do much for my neuropathic foot pain, but still has the ability to knock me out for 14hours minimum, once I manage to fall asleep. The one thing that I've heard consistently good reviews about, in regards to affecting pain enough to allow you some sleep, is Morphine. And the negatives of that particular drug could be said to far outweigh the positives.

If I could go back in time to when I started messing with my sugars to lose weight, I absolutely would. Being thin isn't worth such a high level of pain day in, day out. It's not worth being unable to go on nights out because you can't stand for extended periods of time due to the burning agony. Being skinny is useless when you're phenomenally unhappy in day-to-day life because working in a full time job becomes unimaginable- even things like transport become tricky. I know that I always try my hardest to avoid travelling when the bus or train will be busy, as it means I'll be unlikely to get a seat. The only shoes I can wear between the months of December and February, are my uggs, they're the only things that can keep my feet even slightly warm. But god forbid they get too warm, because that starts the pain off again. So if I could take away any diabetes complication for me, it wouldn't be the constant vomiting, or slightly damaged eyesight, the permanently present yeast infections or the recurring kidney infections. It would hand on heart be to get rid of neuropathic foot pain. It is just not, in any way, shape or form, worth it.

Living with...
Neuropathy
Ish Donaldson



The National Institute for clinical excellence (NICE) produce guidelines on the treatment of different conditions in order to standardise care. The guidelines to treat painful Diabetic neuropathy. The first line treatment is an oral medication Duloxetine, (Cymbalta-trade name).

It is an antidepressant medication which inhibits the reuptake of noradrenaline and serotonin, the effect being more of these chemicals are available in the brain which help reduce pain. The usual starting dose is a 60mg tablet taken once a day, the maximum dose is 120mg per day, although limited increased benefit has been found with the higher dose.

The advantages of Duloxetine are that it works quite quickly, for some people within the first week and it does work very well for lots of people. As it is an antidepressant for people with ED-DMT1 depression is common it may have positive effects on mood. If you are taking another antidepressant which works on the same chemical pathway then duloxetine may not be suitable (e.g. fluoxetine or venlafaxine).

The most common side effects are nausea, headache, dry mouth, drowsiness and dizziness. Unlike some of the other medications used for neuropathy weight gain is not a side effect. A disadvantage of this medication is that it cannot be abruptly stopped or withdrawal symptoms will be experienced.

Q: *Why do lumps and masses occur in women with Diabetes, is it through poor care or can it be explained?*

Long term high glucose levels can cause several skin conditions which may account for lumps and bumps. High glucose levels can affect (or is it effect) the skin in many ways. Dehydration can cause the skin to become dry so it becomes less flexible and prone to cracking. Long term high glucose levels can affect (again might be effect) and damage the nerves. If the nerves that control sweating are damaged then then the skin will be unable to maintain the correct moisture level. High glucose levels can damage the blood vessels. Bacteria thrives in warm sugary environments so skin infections are common, signs of infection are heat, swelling, redness, itching. If any wounds or areas of skin show these signs it is important to see a health professional as antibiotics may be needed. High glucose levels in combination with high cholesterol (blood fats) can cause small hard lumps under the skin that can be itchy. The common skin conditions caused by high glucose levels can be improved with improved control. Any concerns regarding lumps and bumps please see your GP and an assessment can be made as to if you need to see a dermatologist.

Q: *If Dr's know Diabetes is a stressful condition, why isn't there access to psychological services?*

Simply there should be. Diabetes is a difficult condition to live with, because Diabetes is 99% self management. I can't think of another condition that carries the same amount of guilt or blame if the outcomes are not ideal. As with many things funding is often an issue. In my area there is no access to therapy or counselling that is specific to Diabetes or chronic conditions, only general services. Ideally psychologists as part of the diabetes team could help people with problems such as accepting diagnosis, needle phobia and the impact of Diabetes on social and working life. My personal opinion is that Diabetic Eating Disorders are mental health conditions and therefore should be cared for under specialist services. I don't think Diabetes teams should solely treat eating disorders. Joint working with ED teams so that shared understanding can form is how things should work.



The most beautiful people we have known are those who have known defeat, known suffering, known struggle, known loss, and have found their way out of the depths. These persons have an appreciation, a sensitivity, and an understanding of life that fills them with compassion, gentleness, and a deep loving concern. Beautiful people do not just happen.
Elizabeth Kubler Ross

Fantastic Food For Thought,

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



I first came across Quinoa when my mum was doing some crazy detox so I was sceptical about it initially but actually it has become a cupboard staple. Unlike rice or pasta, as a seed, Quinoa contains a lot of protein so it's great for filling up and keeping blood sugar stable. As someone who has problems eating rice or pasta it has become a godsend. It is also incredibly easy to cook, just 5-10 mins in boiling water. The other great thing about quinoa is that its very malleable and will take on the taste of whatever you boil it in such as vegetable, chicken stock or herbs so it can be used as a substitute in a variety of dishes from Italian meatballs to stir-fry, I have also seen recipes for quinoa porridge with fruit, honey and yoghurt it really is that versatile. It also has an impressive nutritional count with loads of B-vits which are particularly important for people with Diabetes as they are lost in the urine and lots of minerals which are important for electrolyte balance. You can buy quinoa from most large supermarkets now and from health food shops.

The Following Savoury Recipe is from the **BBC Olive Magazine** August 2010

Ingredients

- * 75g quinoa
- * 1 large courgette
- * 1 tbsp red wine vinegar
- * olive oil
- * 4 spring onions , finely sliced
- * 100g cherry tomatoes , halved
- * 1 red chilli , finely chopped
- * 100g feta cheese , crumbled
- * small bunch parsley , chopped

1. Cook the quinoa following the pack instructions then drain and rinse under cold water. Drain again. Cut the ends off the courgette then cut into ribbons using a potato peeler. Whisk together the vinegar and 2 tbsp oil and season.
2. Put the rest of the ingredients in a large bowl, then pour over the dressing and toss everything together.

Nutritional information Per serving

375 kcalories, protein 15.9g, carbohydrate 25.9g, fat 23.8 g, saturated fat 8g, fibre 2g, salt 1.37 g

And here is a Sweet Recipe for Porridge from www.allrecipes.com

Ingredients

- * 1/2 cup quinoa
- * 1/4 teaspoon ground cinnamon
- * 1 1/2 cups almond milk
- * 1/2 cup water
- * 2 tablespoons brown sugar
- * 1 teaspoon vanilla extract (optional)
- * 1 pinch salt

1. Heat a saucepan over medium heat and measure in the quinoa. Season with cinnamon and cook until toasted, stirring frequently, about 3 minutes. Pour in the almond milk, water and vanilla and stir in the brown sugar and salt. Bring to a boil, then cook over low heat until the porridge is thick and grains are tender, about 25 minutes. Add more water if needed if the liquid has dried up before it finishes cooking. Stir occasionally, especially at the end, to prevent burning.

Nutritional Information Per Serving

Calories: 173 | Total Fat: 3g | Cholesterol: 0mg



Sian's ARMY

in loving memory of Sian Howarth

Everyone thinks that their best friend is the best, right? Well, I think everyone thought my best friend was the best too... Sian lived, slept (not so much this perhaps) and breathed DWED. I swear, we couldn't go anywhere without her telling random people about the charity. A simple trip to the shops to get a pint of milk would result in her chatting the leg off someone about DWED. Even one normal weekday night spent at home developed into her being on Liverpool's local radio station spreading the word about diabulimia and the help that is available. She never stopped.

Sian's role in DWED was no doubt quite tough and difficult for her at times, and I sometimes questioned her if she was up to what she was doing. As we all know though, her passion for helping young girls in need made her the trooper she was and in many cases, a life saver. All I would ever hear was positive comments. The way in which a Mother is so proud of her child at making their first baby steps, was often mirrored in the way in which Sian would express her feelings of all the girls she helped and formed relationships with over the years. No matter how small or big of a step someone had taken in terms of their road to recovery from their eating disorder, she always expressed an overwhelming state of being very proud; that somehow put those around her in a good mood too.

I could continue to write copious amounts of wonderful things about my very wonderful friend and it is probably possible that I could write a whole novel on the memories we shared. However, let me take a little moment to tell you why Sian was the best to me....

...Upon reflection of the week running up to Sian's passing, I can honestly say it was the best. I can't help but think about all of the happy endings we could have shared.

One happy ending that is possible however, is for us to come together and to continue all of Sian's hard work to make DWED get the recognition it deserves, and ultimately help anyone that is in need of support as a result of being affected by diabulimia. I know if we all lean on each other and do this for Sian, those affected will come out of this at the other end fighting too.

Baby steps girls... baby steps.... Xx Chloe Bean

I have been wondering exactly what to write here.

I remember the first time I met her was at the houses of parliament for a debate on Type 1 Diabetes. When George Howarth said the word, 'Diabulimia' I nearly fell off my chair!! I was so desperate to speak to him that I nearly burst through the rail to give him my business card. He took a look at it smiled and told me to meet him outside, heart racing I walked out the room and saw this beautiful, tall blonde bombshell of a girl standing next to him, introducing her as his Daughter, Sian told me she was just saying that someone should be doing something about diabulimia and I told her, I am, and I really need help. And that was that.

Sian was so easy to talk to, I told her things that I've never told anyone and I know I'm not alone in that. Sian could put you at ease, talk you off the ledge, make things better, cheer you up in a heartbeat. She was a rare individual, she really truly cared and she gave everything of herself and asked for nothing in return. You can read her story here She was also, often unwell, something I think I forgot as she really did 'live' with her diabetes. She had a lot of complications, not that she ever moaned or complained about them, like I said she really did her best to get on with living.

In the weeks preceding her death Sian and I had both ended up in the back of ambulances due to hypos. we laughed about it, what else could we do but keep on going, keep on laughing, never let it get you down. As of yet we don't know exactly what contributed to Sian's death but I can tell you that she was taking her insulin. Sian was loved by everyone and she loved all of us in return. DWED will never forget her and I swear her legacy will outlive us all.

- Jacqueline Allan



I've been trying to find the "perfect" words but the truth is there are none, Sian was such a beautiful soul and I could never do her memory justice.

I smile when I remember the first time we met, she was strikingly beautiful and I was surprised when she spoke in her Scouser twang.

Despite fighting her own battles Sian always had time for others. She was there for you night and day and never made you feel you were a hassle, nothing was too much trouble.

She exuded a joy for life which she shared with each and every one of us who was blessed to have known her.

Her memory will continue to inspire us as she did, Sian we love you and miss you always, rest in peace Babycakes x

Kayleigh

Sian Howarth is a Tour de Force!

I can't use the past tense because she is still here, still inspiring so many of the people, friends whose lives she touched. I never got to meet Sian, or even speak on the phone with her, which is something I shall regret forever. My experience was mainly from the background, or in a wee IM chat when I managed to track her down. I was usually chasing her for her newsletter submissions or the like, which she always bore with good natured, self effacing humour.

She struck me as beautiful, inside and out, amazing would be an appropriate word. I marvel at the fact that there are so many people, the length and breadth of the world in fact, who's lives have been touched, mine included by Sian. Lives changed for the better, diverted from crisis or brought back from the brink with her support. Parents and peers alike, it seems she took the time to aid and comfort everyone who needed it. It is a testament how many people miss her and crucially how many are still fighting this condition in her memory. - Lou

This is one of the hardest things I've ever had to write. And I never thought I'd be here. Choosing the words to explain just how much Sian did for me is literally an impossible task, and it's hard to believe that one girl can change (and save) so many lives across the world. But that's what she did.

Sian was one of the most rare women I've ever had the chance to meet. She had the biggest heart - and I know that this is a phrase that tends to get thrown around like it's nothing, but in this case, there's nothing that could be truer. Sian and I spent countless nights chatting back and forth on Facebook, her providing me with endless amounts of support, and me trying to make her laugh about whatever it was she was dealing with at the time. I knew I could always message her at any hour and she'd be there with exactly what I needed, whether it was a laugh, a cry, or a talk back from the edge. (I'm no longer ashamed to admit that I contemplated suicide almost every day, but Sian showed me that life truly is worth living). I couldn't wait to share with her, whatever progress I had made in my own eating disordered life. It was almost as if it wasn't real unless Sian told me how much she was proud of me, and how much she loved me.

...Even when I KNEW she was having a rough time with her diabetes, she would never allow our conversations to steer towards that direction. I'd try and persuade her to moan and complain (after all, don't we all need that sometimes...?) but she'd ALWAYS, without fail, call me silly and tell me not to worry about her....

...I'm proud to say that it's been just over a month that I've been taking care of myself 100% ... and I know that I'd never have made it to this point if it wasn't for Sian. She changed my entire outlook on life. And from this day forward, every single ounce of fight I have left in me - is dedicated to her memory. I love you so much Siannypants. I know we've been continents apart since the first day we started talking, but you were one of my absolute best friends. I hope you're up there partying with the greats... we're still down here, fighting :) Sian's Army forever. xo - Chelsea

I first came to know Sian over Facebook about 3 years ago. I run a social group for 18-30's with diabetes and she was interested in coming along as she had just moved to my area. She came to a meet up and shared her experiences of the complications of diabetes as well as her fab liverpuddlian accent! I liked her straight away. Over the years we would chat over facebook and text every now and then and she attended a couple more young d events. One of which was a day trip to Southend, it was a pretty rainy day but we had loads of fun on the rides and chatting. We bought a group picture of us all on a rollercoaster and you can't see Sian's face because she was hiding with fear!! Haha. She also came to a picnic in summer 2010, it was a boiling hot day and we all sat round eating and drinking. It was lots of fun, especially Sian accidentally spilling Pimms all over herself hehe, think we were all a bit tipsy!

Sian was a warm and generous kind hearted person that will be missed by so many. Circle D (my group) have been moved by her passing and we displayed her picture at our last meet to remember her. It's only in the last year or so since DWED started that I have learnt about the link between diabetes and eating disorders. I'm type one myself but ED is not something I have lived with personally...

...Sian was an amazing source of support to so many and will continue to be. I am so very proud of Jacq for striving forward and being so strong and keeping the group going. I'm sure Sian is very proud of you up in heaven in them big ole heels!!!:

...Whenever I see Pimms or sparkly high heeled shoes I will remember you Sian as well as when I hear a Liverpool accent!!! Party on with the angels gorgeous girl. - Shelley, Circle D <http://www.circledrocks.co.uk>

I wanted to write my memory and thanks to Sian and all of your works at DWED, my, now 27yr old daughter has diabulimia, she has been stricken with this nightmare for 7 yrs. I started searching for help, anywhere, at Drs. mental health providers, hospitals, no one understood it. Her endocrinologist said she was out of his scope of care and then sent her home with me...what was I to do, I didn't have an education, I was not a professional?! How could this be! So I turned to the internet and started searching the word diabulimia, I started taking information with us to the emergency room, the drs. the therapists... I was becoming the educator and I needed help! Then I saw the website DWED and I left a comment, and Sian got a hold of me immediately. OH MY GOD! Someone else knows about this! What a relief! It was at the most desperate time ever, Elizabeth was at her lowest point ever and I was so scared. Sian began IM'ing me, at all hours of the night, giving advice, encouraging me, supporting me, talking me through it. I wondered did she ever sleep, we are in Oregon, USA and the time difference is great, and she'd be there on line everytime I needed her, I was finally able to tell someone how I felt, someone knew how Elizabeth felt, it was so comforting. She tried over and over to reach my daughter, getting up at odd hours to reach her when Elizabeth would be awake. She never stopped. Elizabeth went through hell this past year and without Sian, it would have been so much worse. Elizabeth and I are so grateful for Sian and all of you at DWED for your support and encouragement. Elizabeth hit a rough patch at Sians passing and I think shes pulling through. I don't think Sian realized how many lives she touched. I miss her popping up on my chat bar, I miss her telling me that I'm a great mum, when I feel like a failure, I just miss her. Sian, you were loved by so many people, even if we never met face to face. We love and miss you. - Betty, Elizabeth and Michelle Tomas, Springfield, Oregon USA

I still have the first ever message Sian ever sent me, and the first time I ever properly talked to her. It was Autumn 2010, and I was maybe getting in two or three injections , tops, of lantus every week, and no fast acting. My neuropathy had gotten so much worse from a summer job spent on my feet for 13 hour shifts, and I was completely miserable. I got a friend request from a stunning blonde girl, with whom I'd a few mutuals, alongside a message, telling me she worked with Jacq , not only that, but she had crippling bad neuropathy too, that she understood far too well how painful it was, and how much it could get you down. It was the first time I had properly spoken to anyone at length about how agonising I was finding all the complications, even though I was unable to increase my insulin. It was Sian that I first told about my increasingly bad stomach complications, her advice I asked about what to do for it....and its embarrassing side effects. The fact that Sian made me feel less embarrassed, less worried, and even laugh about it, is just an example of the kind of personality she had- calming, reassuring and above all else, she could make the best out of a truly appalling situation. It was Sian who I could always have a rant and a rave to at half four in the morning, when neither of us could sleep due to neuropathy. I remember the most ridiculous conversations we had... No wonder Sian got so much joy out of teaching- she was still part kid herself! It was Sian who spent over an hour on the phone with me when I was so unhappy at uni at the start of this year, and decided I wasn't going to do any insulin anymore, and "just die." It was Sian that convinced me to take insulin, but also, to phone an ambulance- something that was no mean feat. If she hadn't gotten a degree as a teacher, Sianny would have made an excellent hostage negotiator. Or possibly a salesperson, given the amount of times she persuaded people to do what they thought they wouldn't/ couldn't... i.e insulin

When Jacq told me Sian had died, I thought it was some kind of joke at first, it was so unbelievable someone so hugely important to so many people, someone who had quite literally saved more than a few lives, wasn't going to live out the rest of hers. It's still unbelievable, impossible to grasp, and phenomenally bitter-tasting.

I've been taking every dose of insulin for the past three weeks now. Sure, its not the longest amount of time, but it's a step in the right direction. I owe it to Sian to at least make the effort, when she made that amount of effort (and more!) every day, with the work she did for DWED, the amount she cared for and tried to motivate us all, and the sheer amount of time she spent just listening. Thank you SO MUCH Sianny. I can't actually express how much I owe you. Love you hen. - Ish xxx



Mokey's make and do

Hey there, this is my first crafty column and I thought I'd make it an Xmassy one.

This project is a variation of origami (paper folding) which is recognised by many as a therapeutic tool benefiting all sorts of health issues. There are many virtues some more obvious than others but I won't bore you with the sciencey bits, let's get on with making pretty things!

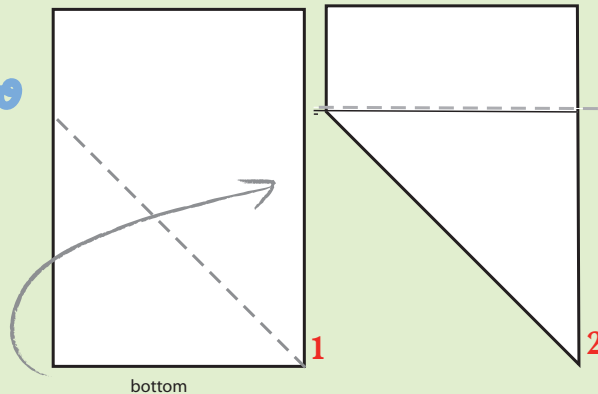
WHAT YOU NEED IS:

A piece of paper (it doesn't really matter what type, could even be a magazine page)
a pair of scissors
glue stick or double sided tape
piece of thread

Lay your paper flat on the table, take the bottom left hand corner and fold it to the right hand side of the paper. Line up the bottom edge with the right hand edge and press down the crease. (pic#1. Take your scissors and trim off the extra paper (above the dotted line pic#2). You should be left with a square of paper folded diagonally from corner to corner.

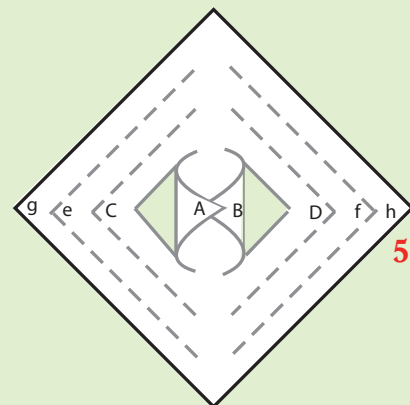
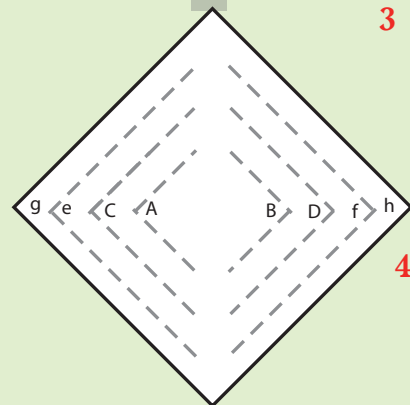
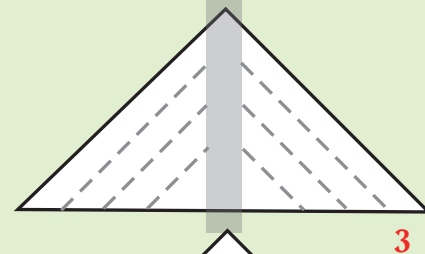
For the next bit you can use a ruler and pencil or if you feel confident just get in there with the scissors.

Lay the triangle of paper out on the table point facing away from you,



Right, see the dotted lines in pic#3? cut a minimum of 3 slots from the folded edge (that's the long edge which should be closest to you) toward the midline (which is inside that grey box and runs from the point to the middle of the folded edge, you can draw it on if you need to) **Stop cutting** about 1/2 a cm from the midline (that grey box on the pic is about how much you need to leave). Repeat on the other side.

So you should have 6 finger width lengths and a triangle of paper. Open it out carefully and lay it flat like pic#4, pick up B and curve it towards the middle dab your sticky on the pointy bit, don't let go of it (otherwise it'll get stuck to the table) and then pick up A, overlap the points a bit and stick them together (Pic#5). Now for the slightly tricky bit, turn the paper over so the loop you just made is face down, but don't press on it. Take D, curve it to the middle, dab it with the sticky like before, bring C over and overlap and stick the points together. keep turning and sticking til all your points are stuck.



On its own this is a pretty cute, clever hanging decoration, which is kind of like an optical illusion as it turns on its thread, but if you make 5 or six and stick them together you can make a christmas star. Finally make a tiny hole for your thread so you can hang up your pretty decoration and admire it.

Trustee Profile

My name is Nikki, some of you may have met me through the social networking sites.

I qualified as a general adult nurse in 2007 and since 2010 I have worked as a Diabetes Specialist Nurse. My interest in working with people with Diabetes goes back to my training and a placement on a Diabetes ward. It was at this time that I knew I wanted eventually to become a DSN. This placement and my own experience of being diagnosed with Diabetes as a teenager led me into this field.

Recovery corner:

I was diagnosed in the late 80's at just 5 years old, I wasn't particularly ill, there was no lightning bolt that caused it, I started to drink a lot and wet the bed and then the neighbour said to my Mum 'hasn't Vikki lost weight?' Mum thought I had a kidney infection and took me to the doctors he took one look at me and said I'm 99% sure she is a diabetic and that was that. In some ways I was very lucky mum caught it early and I didn't even have to stay in hospital that first night.

Other than the occasional bad hypo I was very well controlled during my childhood years, I was active and pretty much did anything I wanted to Mum looked after my food intake and in general my diabetes was fantastically controlled.

At 18 I went off to University...at the time I had been living in Holland for my Dad's job so I came back to England alone and I loved every minute of my time at university but my diabetes slipped, I put on more and more weight and was more often than not poorly in some way or other, I never let myself think this was related to my diabetes (although looking back now I guess it played a big part) I just made the best of it and continued to have a good time.

I am a DAFNE educator and Insulin pump trained DSN, so I have a particular interest in Type1. My personal experience of recovering from an eating disorder has influenced my approach and the way I work with my patients.

I first met Jacq and Sian at the beginning of 2011, I had seen a short piece about DWED in the Balance magazine produced by DiabetesUK. After contact with Jacq, we met at my place of work to discuss issues around ED-DMT1. Having been in contact with DWED and jointly working to support my patients with Diabetes and an eating disorder, I was asked to become a trustee of the charity. I was honoured to be asked and I am extremely proud of the work DWED does.

As a DSN I feel that identifying those at risk of, or suffering from a Diabetes related eating disorder is something, in general, I am good at. The biggest challenge is not having the resources or knowing what to do or where to go next. I would like to see a care pathway and referral process so that once people are identified as having an eating disorder, the appropriate help can be obtained quickly. DSN's are always going to be the first line and best placed to initially identify problems. An improved working relationship and better communication between eating disorder and diabetes services is essential. I have found that joint reviews are mutually beneficial, so that each service is aware of their responsibilities to the patient.

My ultimate vision for DWED's future is an inpatient unit solely for ED-DMT1 patients. A unit staffed by Psychiatrists, Diabetologists, mental health nurses and general trained nurses, so that people would not be bounced between the two specialities. The care provided can be specific to diabetic eating disorders, including a degree of ketosis and dehydration could be managed.

Recovery corner: ViKKi etd

Once graduated my life pretty much stayed the same as it did at university, I met a boy and was having the time of my life for about a year I was the happiest I had ever been. But in 2006 the bottom dropped out of my world, my boyfriend dumped me and a week later my parents separated, I continued to not look after myself and got bigger and bigger, my relationship with my ex boyfriend was on and off and completely messed with my head, although my parents got back together, I put everything down to the fact that I hated the reaction I had when I looked in the mirror.

I decided to make a positive change and joined weight watchers, I was going to get healthy and slim and sort my diabetes out and everything in the world would be perfect! After 7 weeks of not losing a single pound and actually gaining weight my depression deepened... I'd heard about insulin omission helping to lose weight and decided I'd just give myself a little kick start and lost a stone in the first week but by then I was hooked.

I loved the compliments I was getting, everyone told me how amazing I looked and asked how I did it. I lied and manipulated my way through the questions and somehow just survived by doing the usual tricks, thinking I was clever and never truly admitting that what I was doing was wrong.

As time went on I started to lose sleep, waking up with horrific cramps in my legs and stomach, constantly needing the toilet because I was drinking so much, the list went on. I was getting more and more terrified by what was going on in the inside but more and more in love with the person staring back at me. I ignored the dark circles under my eyes and constantly ate mints and chewing gum to stop smelling my despair but the terror grew.

In the background I had started talking to my first proper boyfriend again on the internet, he was living in Australia at the time but was planning a trip to the UK and I desperately wanted to see him, it was June and I knew if I wanted to make it to August I had to change. I went to the doctors for a separate issue and literally broke down and blurted the whole thing out. The doctor told me he couldn't talk to me about it today but not to worry just make another appointment and come back the following week. I left feeling confused but positive, maybe I wasn't doing anything too bad? Everything was fine the doctor said he hadn't even tested my blood I must have been fine! I went back the following week with a spring in my step I saw a different doctor this time she tested my blood straight away, it was off the chart, the story she painted was a much different one and she rang the hospital straight away and got me a bed, however I had to find my own way there! I left that room devastated, sobbing uncontrollably, I didn't know what to do, I tried all my friends but nobody picked up and I didn't want to tell my mum.

Eventually I called my sister and she came to get me, closely followed by my Mum, my sister had called her. I was petrified of what she would say, but I needn't have worried, she was her normal amazing herself and although petrified she stood by me 100%, she didn't judge me or tell me off, she was the most amazing support I could have hoped for and at that moment I realised how lucky I was.

My hospital experience wasn't exactly a positive one... they got me stabilised (I had the highest HbA1c they had ever had) but that was it...they told me off and offered no support, nobody understood and they didn't once send a diabetes specialist to talk to me...I knew at that point if I was going to beat it then they weren't the ones to help me do it.

2 weeks later my Chris came home from Australia and I had the drive to carry on he literally saved my life, I suddenly had a reason to live and for the first time in a long time I wanted to do it. I suddenly saw a future with marriage and babies and I wanted to grab it with both hands.

3 and a bit years later and I've been married for 3 months I'm looking to the future and loving the present. I still don't like what I see in the mirror and having my picture taken is the biggest trigger for me but the positives outweigh the negatives now and I know how lucky I am.



NEEDS

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

