



# IN OUR OWN WORDS

Eating Disorders in Type 1 Diabetes

Diabetics with Eating Disorders: Published October 2016

## Beets 26\*

I don't want to start with spontaneity. I wouldn't know how to word it. I wonder what it means to me to be spontaneous. Impulsive, I get. Self-indulgent, I get. Spontaneity, I don't get. You know what I mean? It seems like a sort of freedom, and to me, freedom is "normalcy". I didn't start omitting insulin so that I could lose weight. I didn't know that weight loss was a side effect of insulin omission and I had no prior history of disordered eating. I started omitting because I refused to accept that I would never be able to feel freedom, and, at that age, I wanted more than anything, to be the 'same' as everybody else. I was rebelling from my personal truth and have been doing such for the past 13 years. For a long time, I did not even come close to correlating my insulin omission with any form of eating disorder. The added bonus of weight loss was just that, an added bonus [although it took over in short order]. Diabulimia wasn't a word, and as far as my experiences could tell me, it wasn't even a concept. It didn't happen. At the age of 26, 13 years after I began omitting insulin, I was sent to an eating disorders unit at the University Hospital. It had been 5 years since the unit had seen a diabetic patient, and at the time of my admittance, there were 4 other women on the unit with "Diabulimia". It was a slap to the face! There are other people in the world with this problem!? We're coming out of the woodwork all of a sudden!? This is becoming a serious issue!? I don't think that Diabulimia is new or emerging; rather that it is becoming recognized by the medical community as an actual illness, not just laziness or non-compliance by patients, but a bonafide illness separate from Diabetes. People do not willfully destroy themselves because of "laziness" and "non-compliance".

This is all well and good, but it does not solve my issue. That of a dream of normalcy. Naturally, I've a delightful slew of complications due to prolonged hyperglycemia. It's surprising the way we can just change how we live day to day to work around things that are debilitating. Just re-arrange your entire way of life and be accommodating. Sheesh, that's not so bad, is it?? Every new issue is band aided just enough to make it bearable. Denial is my sword and shield. Now consider all of this, really: would you say that developing a full system of actions and behaviors to account for the ways things are going wrong, both physically and mentally, is, in any way, normal? There is both a physiological and social breakdown. Things more than the nervous system are destroyed by living in this way, and I find that instead of turning to insulin omission for freedom, I am forced to adhere to taking insulin to feel the closest thing in my experience to freedom. I will probably die before I feel a cure for Diabetes, and my death is (if I can be fully honest with myself) likely to be full of painful delights, but I do have the chance to be my own free, in my own way. I can feel the freedom of choices that just happen to be facilitated by medicine. But I have to get this fully into my head before I can recover from this eating disorder. Diabetes is food-centric, insulin is weight-centric I will always need insulin and food if I want to live any kind of life in this world. I need to accept that I can't have both food and emaciation - normal is that fact. I need to feel free from the shackles of a lie. And Diabulimia is a lie.

The first time I omitted my insulin was when I was 18 soon after starting university. I can even put a date on it... Weds 21st Jan 2004. Why did I start omitting insulin?...I was beyond the point of caring. I was so depressed and so sick of my eating disorder, so trapped in a never ending cycle and I knew that skipping my insulin would give me the weight loss I so desperately desired. I had never heard of "Diabulimia" but I knew all the science behind insulin and blood glucose control. I knew all about DKA and how my body would be unable to convert the food I ate into energy and would instead start digesting its own tissues and organs. And although misusing insulin was one thing I had promised myself I would never do I had sunk so low and fallen so far into the Eating Disorder trap that I just didn't care about the consequences and the possibility of death. All I cared about was the fact that I knew for a certainty that no insulin would mean drastic weight loss. In retrospect I can see that misusing my insulin just wasn't worth it. It made my life hell, it wasn't living at all, it was barely survival. There is nothing glamorous about it, I lost weight quickly but I also lost so much of my life. I always promised myself that no matter how bad my eating disorder got I would NEVER EVER let it result in uncontrolled Diabetes.

I've been Diabetic since I was tiny (just 2yrs old) and have grown up knowing the importance of good control and knowing all the dangers and complications of uncontrolled Diabetes. And it worked for a long while...from the age of 12 (when I first developed disordered eating habits) until 18 I had good control of my Diabetes. But then something changed and one day I skipped all my insulin...the next day I felt such a sense of elation when my weight was down, despite feeling ill from high blood sugar levels the desire to lose weight over rode all my instincts to control my Diabetes. And it progressed from there. It was absolute hell and not worth it at all. So why did I keep doing it? It was stupid I know but it's like the bulimia, once I started it, it just kind of got out of control and began controlling me rather than me controlling it. It seems so pathetic...all I needed to do was pick up that insulin pen and inject myself...not difficult huh? But the internal battle that goes on, took everything out of me. My mum was terrified that she would find me dead in my bed one day. My family was constantly treading on eggshells around me. My friends didn't know how to deal with it. My consultant told me that I was walking on the edge and anything could tip me over, with my blood sugars and HbA1c being so high he was really surprised that I hadn't already been admitted to hospital in DKA. I'd avoided admission by knowing exactly how far I could push myself. I would withhold my insulin until I was at the point where I couldn't walk or talk, I was vomiting uncontrollably and struggling to breathe. At that point I would give myself just enough insulin to bring me out of such severe ketosis, enough to last another couple of days without insulin before I was at that point again.

In June 2004 I hit a really low point. One day I cried down the phone to my mum for 45 mins, she sent my dad to uni to bring me home and when I got home she was on the phone to my Diabetes nurse telling him that I needed help because I had bulimia. From there I was referred onto a psychiatrist and then onto specialist eating disorder services. At first I was having twice weekly therapy which was helpful in getting me to understand some of my ED behaviours but rather than my health improving it got worse as I was trading off one behaviour for another. For example I was eating more regularly but taking less insulin because I was terrified of the effects that regular eating would have on my body. The

professionals treating me at this point were treating the ED as something completely separate from the Diabetes which wasn't helpful because for me they were totally linked into each other. However none of the therapists had ever worked with a 'Diabulimic' before and had no idea how best to help me. After it became clear that this programme wasn't working I was referred to the ED unit and onto an intensive day patient programme. At first I felt like none of the therapists or nurses understood and that they thought I was just being stubborn and attention seeking by not taking my insulin. I knew far more than they did about Diabetes and this created problems because at they expected me to be responsible for controlling my blood sugars and taking my insulin, which pretty much amounted to the equivalent of asking the anorexics in the unit to make sure they ate their meals without supervision. After a while I was admitted as an inpatient and the nurses became responsible for my blood testing and injections. At first I really rebelled against this because I didn't want them to have that kind of control, but I eventually accepted that in order to get better I had to comply fully with the professionals. It was extremely difficult once I started to get regular insulin again because I was constantly having hypo symptoms when my sugars first started coming back down. I had spent so long with readings above 30 that it had almost become normal for me. Also my blood sugars fluctuated widely and did actually go low a lot partly I think because the psychiatric nurses didn't really understand about carb counting and altering my insulin so had me on pre-set doses and didn't trust me when I said I needed less or more insulin. I spent a lot of time feeling very frustrated because although the professionals were able to support me from an ED perspective for some of them it was the first time they had to deal with a diabetic and the unit had never had a diabetic patient before...so that didn't fill me confidence or hope that they knew what they were doing. No one understood my fear about insulin and weight gain, they all tried to fob me off and tell me I was imagining it and that it was all part of the my eating disordered mind lying to me. Even when I quoted the scientific facts at them they still tried to make me believe that taking insulin would in no way affect my weight. A lot of the time I felt that that they thought of me as a 'naughty child' refusing to take my medicine because I didn't like it. Before I was admitted to IP it was agreed that it would be a 6 week stay. As the six weeks drew to a close I finally started to feel that I was making some progress and begged to be allowed to stay longer as I didn't feel ready to go. Yes I was taking my insulin and testing my blood sugar levels but that was only because I had to as the nurses supervised me doing it, I didn't have to take responsibility myself and there was no way I would be compliant if left to my own devices. However my request and reasoning was ignored. After being discharged from inpatient treatment I was still very much eating disordered and had the mindset of a person with an ED but I managed to keep myself in some sort of recovery and was well enough to hold down a full time job for approximately 3 months. However it proved too much and I began omitting my insulin again until I was barely taking any at all and became too unwell to continue working.

I ended up taking about 4 months out of work during which time I worked really hard to get myself back on track. I got engaged in March 2007 and that gave me added motivation to continue my recovery as I wanted to be well and healthy for my wedding. From then on I have been in what I call a 'solid state of recovery'. I still struggle at times to take my insulin but for me omitting is no longer an option especially now that I have a gorgeous baby boy to look after. Throughout my recovery the one thing that always spurred me on was that I knew I wanted to have children and every day that I continued to omit insulin and engage in eating disorder behaviours I was putting that dream in jeopardy. Becoming pregnant after 2 and a

half years of trying for a baby was the most amazing yet frightening experience. Suddenly I was responsible for this tiny person growing inside of me and everything that I did in terms of my Diabetes control had the potential to harm or nurture him. I had to be incredibly strict with my blood glucose control and maintain blood sugars as stable as possible between 3.5 and 6mmol. Throughout my pregnancy I grappled with hatred for my changing body and intense feelings of guilt whenever my blood sugars did something unexpected. However despite that I managed to stave off the eating disorder thoughts and produced a healthy little boy in September 2010. For me recovery has been and continues to this day to be the hardest battle of my life but it has meant restoration of my health and fulfilment of my desire to be a mummy. I am incredibly blessed that my years of mistreating myself have not damaged me more severely, as at one point I never believed that I would hold my own baby in my arms. My journey isn't over yet but for the most part my days of insulin omission, obsessive food rituals and desire to die are over and I can hold my my head up high and proudly say that I beat Diabulimia.

### Daisy 30\*

I Know I Cannot Be Alone? Last Week: I am on the tube and I am disgusting. Sweat is pouring down my face, I am bright red and shaking. My heart is racing and I swear for a second that it stops...and starts...and stops. My head is screaming and I can't see my hand in front of my face. My jaw is still aching from the tooth that I had extracted this morning and my kidneys ache. My mouth feels like I've been licking sand paper even though I'm considering getting off at the next station because I'm bursting for the toilet. I rumage through my bag for a bottle of water but all that's there is empty chocolate bar wrappers....and my diabetes monitor.... I feel that familiar pang of guilt and wonder if this time I really have gone too far, is this the time I'm going to die? I have been hospitalised 3 times in the last year because of this thing that no one wants to talk about. This eating disorder without a name. I hang onto to this feeling and and promise myself to never forget it because it will be the last time I put myself through this. The Americans call it Diabulimia. I am in acute diabetic ketoacidosis, I know that this is fatal in 15% of all cases and I put myself in this state on purpose. Why would I do this to myself you might ask? I'll give you the same answer that I gave my therapist a year ago. Because I'd rather die than be fat. Then it used to be about the weight. To be honest now I just don't know.

I get off the tube and onto the bus. I am so exhausted that I don't feel like I'll make it to the front door. With every step I can feel my heart rate increase and I remember what my doctor said about the imbalance of electrolytes causing a heart attack not in a years time, not in a months time but maybe tommorow and that was last week. I struggle to open my front door I am so weak. Its 7.30pm I throw myself on the bed and drift off to sleep wondering if I'll wake up. 9pm: I wake up and have to bolt to the toilet and urinate for an abnormally long time as usual. My genitals itch with the thrush that dogs me constantly . I have stomach cramps but they're not from any menstruation issues as I've not had a period for well over a year now. I look in the mirror and see dead eyes, flaky skin and as I run my hands through my hair a big clump comes out in my hand. I go back to bed in the knowledge that I will not have a good nights sleep but rather one that is broken with frequent toilet breaks and if I'm having

a really bad night, trips to the fridge, more sugar. 6:30am I have to set my alarm for this time even though I do not have to get out of bed till 8. It takes me this long to summon the will to get up. When I do its back to the toilet again and then straight on the scales. I am a lot lighter than I was yesterday. My BMI is below that needed for an anorxia diagnosis. I am severely underweight yet I look in the mirror and all I see is fat. I know that I am also Body Dismorphic.

I call in sick to work... again... I know that soon I won't have a job anymore .... just like I don't see my friends anymore.... just like I don't play in my band anymore... just like I don't have a boyfriend anymore. I realise I have lost everything to the monster in my head. I wonder how much of me is left up there. I can't do it anymore. It's get better or throw my arms out to death and welcome it.... I sit my room crying and rocking for what seems a lifetime....I choose life..... I cry some more and I promise myself that today will be different, today will be the day that this stops and I mean it so I do something I've not done for too long. I inject. I cry, I cry a lot and and I vow to look for new ways to beat this. I am going to talk about it, scream about it, get mad, cry even more and probably screw up but I am at least going to try.

This Week: I am angry. I have tried to reach out, to speak to other sufferers. Apparently noone wants to talk about this eating disorder. I have emailed all the big forums to see if they would set up a Diabetic ED board and all of them have said no, 'We can not provide that due to the medical nature of your ED' apart from one that wasn't accepting new members. I have been berated by sufferers of other EDs. . It reminds me off the last time I was hospitalised and begged my doctor not to discharge me because I couldn't be trusted, his response, 'I'm sorry but we just don't have anywhere to put you.'Well, I see this as an illness , just like any other ED and I think that I and others like me deserve a community where we can support each other in a bid to try an overcome this most serious combination of diseases

## JP 26

Well where do I start, never been easy for me from an early age. I was about 4 years old and caught an infection that affected my brain; couldn't walk, couldn't write and was un-coordinated it then happened again about 6 months later so there was me a happy, go lucky child having to relearn how to walk and write. Unknown to me, this was the start. I had a pretty normal childhood; loving parents and close family so no-one ever expected me to have an eating disorder let alone diabetes. I thrived in primary school and gained the skills to be like a normal child and really enjoyed PE and other activities. Was popular, had loads of friends then the transition of becoming an adolescence and leaving my friends took a toll on me. Whilst at secondary school, my mood slipped, started to comfort eat at school, this then led to bulimia. My weight would go up and down, even to the point that I was getting dizzy from malnutrition. During my SATs in Year 9 I then started to self harm. I hated school and used pro-mia sites and information to get the best out of my habit. My parents and doctors just assumed it was puberty. I was very withdrawn at school and was referred to the psychologist – all he had to say was that my parents would need to keep an eye on me as it was stress. My parents never knew any of the habits I had formed.

I was diagnosed with diabetes in 2002 after my weight kept falling and was always drinking loads, going to the toilet and a very curious smell to me. The GP assumed I was Type 2 as I was not classed as underweight or at risk of T1 so put on tablets however after 4 weeks I was put onto insulin. This led to substantial weight gain and a dislike for what I saw in the mirror. I found out about "diabulimia" after an article on the web and then investigated the omission of insulin to lose weight. It took time to realize how I could use this and I used this method for many times over the past years. My turning point was whilst at nursing college after a long shift and had assignments due - I broke down in my diabetic review and admitted all to my consultant. I explained everything to him, and he was so good and referred me to the Psychiatric Liaison Team and it's not been an easy ride, and have relapsed twice since then. My initial control was very poor, now it's the best it's ever been. But I am now 2 years into recovery, not easy and the thoughts are still there. I have complications from it too; retinopathy, maculopathy and even some neuropathy. I just think that diabetes definitely doesn't have me, I am now in control. I may not be comfortable with the mirror still, but I will be in time.

## LC 42

I got diagnosed with type one diabetes at age 10 with the usual symptoms thirst, and weight loss. At age 16 I developed an eating disorder. I lost some weight by reducing my intake and running track. Then, out of nowhere, I started bingeing. I would buy numerous candy bars and eat them all. Somewhere around that time, I learned that if I did not "cover" those binges with insulin, I would not gain weight. People told me all about complications, but it felt so remote. So I kept going. It became habit.

Now I am 42 years old. I have lost two toes on my left foot, and had a below the knee amputation on my right side last August. I had a wound so big the doctors didn't think it could be saved. I have been in a wheelchair for about 7 years because I could no longer feel my feet. My legs got weak and my balance was terrible. I have also had about 20 laser surgeries on my eyes. Thankfully, I have not had any extensive kidney damage, though it has been a while since I got that checked. When I was fifteen, I set the school record for the two-mile run. Now I cannot walk. It's all because of diabulimia. If I can get one girl to seek treatment earlier, to try harder, to take that shot, then writing this will have been worth it. You can have diabetes, be active and maintain a healthy body weight.

## Kayleigh

I look back now and ask myself "was it worth it?" ...I scream "No!" with every inch of my being...yet this terrible illness consumes and controls me still. I've had a binge eating disorder for as long as I can remember, I recall my parents locking the kitchen door and finding myself compelled to climb through a tiny serving hatch in a desperate attempt to numb my anxiety and thoughts of self loathing. At the age of 6 I was diagnosed as a type 1 Diabetic, prior to the diagnosis along with all the classic symptoms I lost a considerable amount of weight, at first

my parents were concerned I was being bullied but it soon became clear something more sinister was to blame. I had difficult relationship with my diabetes and over the years would be admitted to hospital many times. At the age of 17, overweight and very depressed I spent a brief period in Foster care during which I lost some weight. When I went back to school I was greeted with much praise and decided I wanted to lose more, having a binge eating disorder and not being a great fan of exercise it was clear in my mind there was only one feasible option. Initially I would skip the odd injection, particularly when I had overindulged. During the next year my obsession with losing weight continued, the weight literally fell off overnight and so a week prior to my 18th Birthday I woke up severely acidotic, my blood sugar unrecordable. I had chest pain and was having great difficulty breathing, my head pounded, my mouth drier than the Sahara, my body so weak I could barely lift my head from the pillow. I felt a huge wave of Nausea wash over me, my throat burning as I vomited violently, sweat pouring down my face yet my body shivering uncontrollably. An hour later I arrive at the hospital in DKA where I collapse onto the bed This is the last thing I remember..... 3 days later I wake in Intensive care, I have lines and machines monitoring every part of my anatomy. I can see the relief on my mums face and suddenly I realize the Hell I've just put her through, I feel immense guilt however my next thought is that of panic and disgust when I realize just how much Insulin and Dextrose is being pumped through my veins. I start to wonder how much weight I've gained...How many days will I have to skip my insulin to lose it? The consultant reviews me and tells me that had I arrived 30 mins later I would be dead... This is the beginning of hundreds of admissions to hospital in DKA and the first of 22 admissions to Intensive Care. Between the ages of 17-22 I lost a dangerous amount of weight, last year with my body weak and riddled with complications including autonomic Neuropathy and chronic pain I found myself Incontinent and on large doses of morphine. After several attempts previously to section me I was finally detained in a medical hospital to be re-fed. Unfortunately during this time although I managed to gain the weight I received no psychological support and as such was unable to make any changes regarding my Diabetes management or relationship with food. A year on I've maintained my weight however really struggle with severe depression, administering my Insulin, monitoring my blood sugars and managing my binging. Every day is an uphill battle and as a result of complications, especially gastric, I am rarely able to leave the house and do normal day to day activities. It's my hope that in the future ED-DMT1 is recognized as both a life threatening and complex mental health condition and as such criteria for both the diagnosis and treatment becomes readily available. I believe that nobody should suffer the ignorance or dismissal or be labeled an "uncooperative" diabetic that I have been confronted with along my journey.

## Lucy 21

August '05: I was 15, had a wonderful group of friends, a boyfriend, lead roles in plays and was doing really well inschool. The year leading up to my illness was the happiest of my life. But with all the wonderful things I also carried a great deal of insecurity. That summer, whilst away with family at a cousin's wedding, one day I just didn't take my Lantus. I'm not completely sure why I didn't, but I recall I'd read about having higher blood sugars lead to weight loss. For the past year, in particular the last 7-8 months I'd been cutting down a lot on food and weight-loss was certainly at the forefront of my mind. The way I felt empty after



having to drink a lot, then use the toilet, I liked. Being young and naive I wasn't thinking about the future, or the potential consequences of my actions.

September '05: I had been restricting my insulin considerably for the last month, teachers were concerned of my weight loss and my energy was nothing compared to what I'd had. During the night I was up multiple times, sometimes every hour, needing to use the toilet and drink yet more water. However, I did not start taking my insulin again. Being in such a bad state of mind due to being so tired meant that I got consumed by the illness, and trapped in the downwards spiral that took over my life.

25th September '05: Admitted to hospital with DKA. I almost died. If I could write the pain I saw in my Dad's face when he told me this, I would. I'll never forget it. I stayed in intensive care for a few days and then transferred to a normal ward for a week. Once I got home, I thought things would be ok. But I wasn't in the habit of looking after my diabetes alone. I was weak and quickly slipped back into restricting my insulin. My time spent living with 'diabulimia' was a haze of exhaustion, endless doctor and hospital appointments and misunderstanding from those around me. Those in the mental health profession told me I was everything but what I was telling them. Parents didn't understand that I wasn't strong enough to make myself well, that my moods and irrationality were due to dizzying blood sugar levels. My hair was falling out, I was getting one infection after another and was in constant amazement at how others, such as my friends in sixth form, managed to keep it all so together. People knew what the problem was - I knew what the problem was - but none of us knew how to solve it. Inside I was still me, dying to get out. But my failing body and shattered mind couldn't bring things together. Most of the time I just wanted to be hugged and told that I would have someone there to fight this demon with me. Be told that someone understood.

Easter '06: Another spell in hospital for yet another complication due to my illness. After this one something in me changed. I knew for certain I didn't want this life anymore, I truly wanted to recover. But, still, I was shunted from one health 'professional' to another. They frustrated me, not listening to me and diagnosing me from a textbook. Low weight? Anorexic. Getting rid of food by excessive means? Bulimic. But consistently high sugars? No, they didn't deal with that. Their books said nothing of that. So there was a constant battle going on inside my head, trying to get back on track but still being too weak to do it alone.

January '07: After struggling through the previous year and deciding to re-take my first year of a-levels I was still fighting my illness. I was managing to take more insulin than I had been, but it still wasn't enough. However, I was noticing some cloudiness around the edges of my sight, but since it wasn't immediate I wasn't sure if I was imagining things. However, I was having to wear my glasses in all of my lessons to be able to read the board properly, which I had never had to before. A visit to the opticians resulted in a referral to the eye clinic at the hospital, just to see what was going on as he'd noticed something - he said it was most likely just an infection which would clear up with tablets. Actually, it was cataracts. I was told it was unlikely I would get an operation for months. In the meantime I was ready, really ready and beyond tired of not living my life, of relying on the doctors to help. So I made an appointment with my diabetic doctor. Throughout my illness she had been very understanding, but she, also, did not know what action to take. I told her I wanted inpatient care, in an eating

disorder clinic. It was the only way I saw of getting the routine and stability I so desperately needed. She listened and did her best for me. The work my diabetic doctor did for me, particularly with this, I will always be grateful for. Meetings were set up and I was lucky enough to be told a place would be available for me by June of that year. Hope.

Easter '07: I woke up and could not see. The cataracts had slowly been metabolising over the past few months, but drastically overnight, they had become much worse. I could no longer read. This meant I could no longer attend sixth form. Devastated. Time passed slowly, but I had a lot of time to think, and build hope for the future I was going to make for myself. Without being able to see well, I could not analyse myself in the mirror. I did injections, although still not enough insulin, but still more than I had been. I was looking forward to getting my life back and one day, being able to see. Although I knew it could be months. Not long afterwards my mother informed me that she'd been rung by the hospital and that my eye doctor was able to perform my eye operation early May, in just a couple of weeks. This was amazing news, it meant that I wouldn't have to go into in-patient care without being able to see.

May '07: I had to be admitted to hospital a week before the operation was to be done, to regulate my sugars so it was safe. My time in hospital, that week, gave me so much strength. I was no longer in control of my insulin, but the people who knew what they were doing were. I was given a routine and some structure. I was surrounded by old ladies who were so ill and thought to myself 'I've got my whole life ahead of me yet'. I was able to sleep through the night. My operation was a success and I felt so strong. I felt I had been given exactly what I needed to beat the illness. After much thought I made the decision not to go into the eating disorder clinic. It took a lot of persuading (and for once I am grateful of this) but I wanted to live and finally get on with my life. I felt that being surrounded by others with issues with food wouldn't be beneficial to me, however I don't think it would have done me any harm in the long run by no means. I had such hope and determination. I overheard one phone conversation in particular, where I heard 'she'll just end up dead'. I proved him wrong. It was a struggle at times but I knew I was going to make it. Finally I was able to think with a clear mind, think about what I wanted to do and actually be able to do it. I have now been in recovery for 3 and a half years, currently in my second year at university studying maths. Oh, and I got discharged from the eye clinic last Thursday :D I want to be able to give the hope I have to others who are in a similar situation to the one I was in, because it really is there

Rita 23\*

Those 3 little words, I needed to hear. YOU WILL DIE never had much of an effect on me. I didn't care, death was some kind of random concept that if anything meant an end to suffering, I wasn't scared of death enough to inject I was far more scared of being fat. Similarly threats of being hooked up to a dialysis machine or liver failure or even a heart attack didn't phase me either, these were just other random sh\*!ty bits of me that didn't work properly, big whoop my body is a sh!t heap, tell me something I didn't f@\*&ing know.

Being ed I was so detached from my crappy body, my ultimate enemy, that damaging it never scared me. I have never been able to consolidate my mind with my body and I think that's why I was able to shock my doctors by doing things like laughing all the way through another speech about what I was doing to 'myself'. I'll tell you something though, I sure as f\*ck wasn't laughing yesterday

You have retinopathy

The only part of my physical being I have ever truly been happy with are my eyes. Sitting in that chair yesterday, looking at the back of my beautiful blue eyes and seeing those broken blood vessels I have never felt so ashamed in my entire life. I did this. I did this. I did this. The damage is permanent and irreparable. I did this. Every time I did not inject I did this. Suddenly I don't care about the weight I don't care about my clothes size I don't care about not being able to eat crap because I did all of this TOO ME. There is no incongruity between my mind and my body, I need both to be healthy and in sync otherwise I WILL GO BLIND.

You have retinopathy

I think about all the times I have used social networking to laugh at the people who called me fat in high school, I felt so f@\*&ing superior being thin, like I had the power, I was BETTER as a person. I relished in my ED I fed it and it made me STRONG, look at me look at me look at me I am better than you and now it is I who looks at you like you are dogsh!t because I am thinner than you. Ha ha look at how I have matured into a thin and beautiful woman as you look like a beached whale. Well, I WON'T BE ABLE TO POINT AND LAUGH IF I CAN'T F@\*&ING SEE. And I'm sure as [f@ck](#) not laughing now. Since when did having an eating disorder make you superhuman? I wish I'd realised that it doesn't, it makes you weaker and weaker and weaker.

you have retinopathy

my 'recovery' of late hasn't been going to well. I have not skipped an injection for 12 weeks now but on several occasions I have found myself with my head back down the bog. Swapping one Ed for another - well, bulimia's not that bad is it? Emm looking at those broken blood vessels at the back of my eye I can put my hand on my heart and swear that I will NEVER EVER DO THAT TO MYSELF AGAIN. You know I read other people's stories about going blind and thought, my god that's awful, but it won't happen to me. I've only been diabetic for three and a half years and I've not been doing this for that long surely? You have retinopathy EHHH EHHH WRONG!!!!!!!!!!!!!!!!!!!!!! If this can happen to me in that space of time then it can happen to any of you at any time. I am begging all of you now, RIGHT NOW. INJECT INJECT INJECT. Please please please. if you don't THIS WILL HAPPEN TO YOU. IT IS NOT A POSSIBILITY IT IS AN ABSOLUTE INEVITABILITY. PLEASE DON'T END UP LIKE ME. You have retinopathy You have retinopathy YOU HAVE RETINOPATHY

## Melany 26\*

I've had an unhealthy relationship with food for as long as I remember. Years of over-analysing leads me back to when I was diagnosed with type 1 diabetes (insulin-dependent). At a pivotal time in my life - starting secondary school - my life was turned upside down and suddenly everything in my world revolved around food. As part of my new eating regime, I had to eat SIX times a day...breakfast, mid-morning, lunch, mid-afternoon, dinner and supper! Everything I did had some connection with food...would I need to eat more to do P.E? Was I high and needed to eat less? Am I carrying around enough food with me in case I can't get sugar if I need it?

My weight increased from diagnosis throughout school. I was teased about my weight for most of the time I was there. I also discovered 'food-freedom' from my parents' understandable strict eating regime, and suddenly all I wanted to eat was everything I shouldn't - sweets, cakes, crisps - and more than I should of the things I could eat (essentially I suppose I was rebelling as my eating was controlled with what I could eat, as well as portion size.). This habit, I still fight with everyday. The older and more self-sufficient I got, the more my money went on food it shouldn't. I'd find myself looking at people eating, and want whatever they had. Problem was, I wouldn't just look at one person for a day...so if I saw 3 people eating cakes, I'd think 'well I'm normal, I'm no different to them, I can eat that too' and did. Several life experiences later, I now couldn't even guess how many times I think about food during a day...pretty much constantly would be the best guess I could give. If I'm not eating, I'm thinking about what I want to eat, or feeling guilty for what I have eaten. Everyday I wake up telling myself I'm only going to eat 3 small meals a day, I'm not going to eat anything bad, I'm not going to overeat - how easy is that to do??? millions of people do it everyday...so why when the cravings and urges come, can I not resist it? and once I've broken my aim, it's downhill from there...the disappointment in myself sets in, and gets comforted by binge after binge, and the more I eat, the guiltier I feel. And with bingeing comes the secret eating - the lengths I go to sometimes still shock me....going to different shops to get more food so people don't judge the amount I'm eating and thinking people will just 'know'. I've even made up I'm having a kids birthday party, or 'it's not for me' statements, or 'it's our week's shopping'. I make excuses to go to the shops in the evenings, and/or at the weekends just so I have some time on my own where I can binge with nobody knowing. I actually start to feel excited when I know I'm going to be home alone as I can binge whilst I'm totally alone. I'm at the stage now where I am so conscious of over-eating in front of people, that I barely eat in front of people at all.

A few years ago I gave up smoking and my weight increased. The feelings I experienced during this period left me desperate and depressed. The panic of not having any control over my weight increases, and then knowing I was making it worse by bingeing gave me such a huge amount of guilt, I would end up in a very emotional, depressive state. My bingeing got worse, much worse. To combat this I went into exercise overdrive, doing 2 workouts a day. Unfortunately this didn't combat the amount I was eating. The disappointment I feel about myself is overwhelming, I just don't understand why I find it so difficult to control what I eat. I am also amazingly ashamed. The feelings I experience are all-consuming and the most overpowering feelings I have ever felt...I couldn't even begin to explain how powerful they are. I am so worried about people judging me, but my ultimate fear? People thinking I'm just fat

and greedy. But I suppose I know really, that secretly eating, endless thoughts about food and how it affects everything I do, can't just be normal. To me, it's no surprise that some people with Diabetes have ED's, and there is a link...I'm just shocked that the link is not recognised by more professionals. I know I'm not alone. And if I know that, why don't others?

Sarah 31\*

It all started at High school. I was a curvy girl - not chubby, just grew lady-lumps at a young age. Didn't really know what I wanted to do, but just knew it would be creative. I became aware that I seemed to eat a lot more than my peers, and my rigid lifestyle of 2 injections a day, 3 set meals, 2 snacks and nothing else in the middle was proving to be a bit difficult to handle through my teens and I wanted to live a "freer" lifestyle the same as everyone else. I spoke to my diabetes nurse who suggested I go on a new insulin regime to help me cope with my "non rigid" teenage lifestyle. Once I'd changed my insulin from slow-acting to fast-acting, which allowed me to eat a more flexible diet, I realised quite quickly that by reducing the amount of insulin I could reduce the amount I ate. This led to me losing weight just by healthy eating, eating a bit less and exercising. Unfortunately though my control started to slip, my sugars started to go all over the place and I couldn't concentrate on my school work, all of which led to low self esteem, added to which my dieting started to turn into an obsession.

People were showing me a lot of attention and I got a lot of compliments about my "new figure" which egged me on to lose even more weight. I remember having my first binge after a hypo which I suppose was inevitable after half starving myself, and so the cycle began: starve, binge, lots of exercise, sugars all over the place. Eventually, I discovered that by missing my injection after bingeing I'd be less bloated the next day. I discovered this was an even better tool for losing weight than exercise and went on to miss the next morning's jab, then eventually lunch, then tea, and so on and so on.

I lost lots of weight but felt so ill at times that I felt I couldn't function properly or concentrate on anything. My sugars ran so high sometimes that they'd be off the scale. I'd decided that I wanted to go to drama school after leaving school but wanted to work for a few years first. I managed to get a few very good jobs and work my way up the ladder but the diabulimia became worse, and by the age of 18 I was smoking and drinking like all my other friends but without being careful of the kind of alcohol I was drinking. I'd drink really sugary drinks, and, a few times I got myself into such a state that friends had to inject me as I was incapable myself. My sugar was off the scale when the diabulimia reached its worst. I was at work one day and went to the toilet and sat down and looked at the floor and thought that if I just lie on the floor now, I'm not going to wake up. I felt so poorly, I couldn't concentrate on my work, I just wanted to sleep and never wake up again. At one point I felt so low that I contemplated suicide as I couldn't see a way out of the mess I'd got myself into. The only thing stopping me was my mum and family and I couldn't do that to them. So I went to the doctor's and confessed everything. She immediately referred me to hospital where I saw (over a period of time) 2 different psychiatrists. I didn't feel as if I was making much progress, but persisted with my diabetes clinic (even though one doctor told me I'd die if I didn't start

injecting myself and give up smoking). It was very difficult as the condition was hardly recognised within the medical profession at the time. Eventually my GP referred me to a lovely psychologist who specialised in eating disorders and who made the effort to do some research on diabetes and food. Together we unravelled the mess I'd got myself into. She left and a lovely man took her place. He worked with me until I felt I was ready to go alone. I had to learn how to be a diabetic again and learn how to have a good relationship with food. I decided to take a less stressful job and pursue my arts in my spare time.

Unfortunately, a few years after I felt free of the diabulimia, I lost my sight due to diabetic retinopathy. I was 23. There were 2 things I could do, I thought - sink or swim. I'd felt I'd been through so much that I couldn't possibly let this beat me. I had a succession of laser treatment and operations over a couple of years and now I'm left with a bit of vision in my left eye. A year or so after losing my sight, I was offered a lead role in a musical and haven't looked back. Since that role, I've chosen to do all the things diabulimia stopped me from doing - I see that as the disability. I feel I've been given a second chance and feel lucky to be here and be able to look after my body which enables me to carry on as a professional performer and live a full and happy life. Going blind at the age of 23 has been very difficult as you have to start from scratch and have to learn to be independent in a different way from someone who has sight, and it takes a long time, - but I can honestly say it's not as difficult as getting through an eating disorder with type 1 diabetes. It's just a matter of taking things one step at a time, one day at a time and never losing hope. It's been a tough road, but I've learned to respect my body and work in harmony with my diabetes. I do everything I want to do now as I don't ever see anything as a barrier - I just try and work out a sensible strategy for tackling a certain challenge. Alongside my music and acting work, I've just set up a company to customize white canes for the partially sighted and blind to give them the facility to have a unique cane that nobody else has! And these days, I manage to keep my HBA1C below 7.0, and at this moment in time, - I love my lady-lumps and am extremely grateful for them!

## Scarlett 26

I've had diabetes since I was 14, and an eating disorder since age 16. I'm now 26. Although I've never completely been free of eating disorder symptoms, for a period I kept things in relatively good control. Over the past couple years, however, I started omitting insulin much more drastically. I'd go for weeks without a single shot. My A1C is double what it was. I've been through intensive treatment but this is a persistent, cruel disease. Last month I got an infection that destroyed all the bone in my bottom front teeth. Those four teeth had to be pulled. The dentist remarked, "Twenty-five is a hell of an age to lose your front teeth." Younger women have suffered much worse complications from this disorder, and a few teeth are nothing compared to what I could lose if I continue on this track. I believe that one of the reasons many with diabulimia resist treatment, or refrain from being fully honest with their treatment team, is that we are plain tired of trying to explain this disorder. It's not a matter of lack of education-- I know how to carb count, thank you very much. I know the frightening complications for which I'm putting myself at risk. I even know that I'd look fine -- maybe

even better -- if I gained some weight. None of that knowledge stops me. I do not need a nutrition lesson or a pep talk

## Sian 23

It all started while I was at school It all started while I was at school. I was 15, had my first boyfriend, and essentially I was happy. That will probably leave you wondering how on earth this illness got its grips on me. I fell ill with some bug and the high sugar levels over a couple of weeks lead to the weight loss. I wasn't in any way shape or form over weight before hand but when I lost the weight everyone commented on it. And so it began... from then on, I mistreated my body for years. What seemed at the age of 15 to be so simple, easy and harmless almost killed me in the end.

December 2005 It's Christmas in two days. I have a ton of uni work to do and I haven't finished my Christmas shopping, but I can't get out of bed. My chest hurts every time I breathe, my head hurts like hell, my eyes are blurred, my kidneys r in agony, the stomach cramps are unbelievable and, despite drinking pint after pint of water, my mouth feels like it has a rock inside of it instead of a tongue as it is so dry. My mum keeps asking if I have tested my blood sugar and I lie and tell her it was 'a little bit high.' In reality, I know if I test it will be un-recordable (above 30 – the highest the machine can record). I sleep until Christmas day when I briefly get up to watch my 5 year old nephew open his presents. I feel so guilty that I can't share the day with him, he looks so concerned and constantly comes to check on me throughout the day. Why should a five year old be put in a position where he should feel the need to spend half of his Christmas day sitting on my bed talking to a half dead, selfish, idiot. The next day, close to death, I am rushed to A&E, where it takes six doctors to stop me from dying, and spend days unconscious in intensive care. My mum is told if I had got there an hour later I would have been dead. When I come round and see my mum asleep in a chair next to me I feel a huge sense of guilt, a feeling I am now used to and growing very tired of. I can barely move but am very aware of the many drips and wires keeping me alive in my neck, arms and groin. I survived this time. Was it all worth it? No. Despite this not being the first or last time that this happened I was never treated for any kind of eating disorder. Doctors were aware that I had fallen into DKA numerous times but never questioned why, just putting it down to something that I would 'grow out of'. I became a compulsive liar, always having an excuse for the persistently ridiculously high HbA1c results. No, doctors never helped me with my eating disorder and at the time I didn't realise that it was even an eating disorder as I still loved to eat. I felt like I was the only person doing this and I couldn't understand why I couldn't take my insulin. All I knew was that the mere thought of injecting insulin terrified me. In my distorted view, I might as well of been injecting fat. I became somebody I hated and deceived everybody I loved.

Despite everything I was going through, against all the odds, I managed to get a teaching degree. However, due to complications of my high blood sugars, I had to give up my first teaching job almost as soon as I started. I developed autonomic neuropathy and with this I was vomiting up to ten times a day and felt completely drained of any energy. My stomach was so swollen people often assumed I was pregnant and on my skinny body this looked



ridiculous. The pain of having to give up a job I loved, along with the unwavering encouragement and support from my boyfriend led me on a determined road to recovery. It was hard, at times extremely frustrating, and I needed constant will power, but I got there. I am one of the lucky ones who came out the other end, although I bear the scars of what I went through in the form of painful, life changing complications including neuropathy and kidney damage. Others aren't so lucky and I now more frequently hear horror stories of people too young to die, losing their battle to this horrible illness. I now want to make sure that if others are suffering as I did, there are people who can help, that professionals can recognise the signs of this often life threatening illness, and that there is an easier way out. This is something I feel passionate about and will fight for until the system is better, works and understands the patients and their needs.

### Tasha 20\*

I suppose I have always had run - ins with death, right from the very start. At just a few months old I managed to survive meningitis; some of the other babies in hospital with me lost limbs, lost lives. I got away without a scratch; or so we thought. Less than 12 years later, I was diagnosed with type 1 diabetes. I vividly remember sitting in the diabetes clinic being told when to inject, when to test, what not to eat and basically how to live. I injected myself for the first time within hours of my Mum taking me to the doctor. And so, off home I was sent. Within months it was going wrong. I hated it, I'd flinch and pull my hand away when testing, I'd tense up when injecting and feel sick. I began to 'forget' my insulin, only taking it when the thirst began to annoy me or I couldn't stay awake. I remember the exact moment it all clicked in my head. I was standing in my Dad's kitchen, making some food, and I ran my hand along my stomach, feeling ribs. That was the moment... when I forgot my insulin, my ribs stuck out. I had never had a problem with my body image but after gaining all the weight I'd lost before diagnosis and the kids at school making it very clear they had noticed, I was glad to feel my ribs again. The next few years are a blur, bound together with countless hospital visits and hyperglycemia-fueled rows and outbursts... I became a problem child, bad mouthing my parents, my teachers, sent out of classes and a known nuisance. I never really thought not taking my insulin was a problem. I just thought it was what my life had become, and so I accepted it. Looking back I know that I had countless people telling me what would happen, but I just knew in my heart something like that would never happen to me. My eyes would be fine. My feet would be alright. It wouldn't kill me. I tried to fix it... I became withdrawn, depressed and isolated. I began to steal and hide sugary food, eating in secrecy away from the people that would tell me off. Huge amounts of food would go missing from the cupboards and I'd lie my way out of it. At the age of 13, I decided to take my life in to my own hands and put myself on a strict no-carb diet. The weight fell off, my blood sugars were perfect. Everybody breathed a sigh of relief... she's okay after all. But I wanted more, there was something in my head that pushed further, and eventually every single morsel of food that entered my mouth was too much. I still have the diary I kept; complete turmoil over an extra tomato or something that was banned from the diet such as an apple. One day I couldn't take it anymore. I ate sugar, and so bulimia well and truly came to stay. I would starve myself at school then come home and eat until I couldn't move. Eventually I missed so much school due to constant ketoacidosis, I was moved to a pupil referral unit, a place I could do my exams



in a safer environment where my health problems and emotional difficulties would be better understood. I managed to get 7 GCSEs, and even one A\* and two A's. I still kick myself now, even nearly 5 years on, about how well I could have done if I had been even half alive.

However, a new, fresh start was underway - I started sixth form with all my friends from my old school, and it felt like things were going right. Even so, the pressure mounted - skinny, beautiful girls around me constantly, all making way too much effort to impress, as well as pressure from my teachers telling me I was capable of getting straight A's for my a-levels. I caved - it seemed at this point, neglecting to take insulin was my coping mechanism. I told myself that this time it would be 'hardcore' - I worked out weight goals to get down to using my insulin and every one I hit I made a new one. I met a boy - an older boy - and fell head over heels, but was too scared of myself to get close. I pushed him away and tried to move on. Eventually my Dad made me leave and get a full time job. By this point I was so fed up with life, I just got worse. The binging was unbearable. I was spending a good quarter of my income on visits to the supermarket, yet anything I ate would just get flushed out from the ketoacidosis I constantly lived in. Eventually it hit the lowest point, at the age of 17, that we finally looked in to an inpatient eating disorder unit. It lasted a month, and the insurance ran out. I relapsed within days of being home, and as I had by now turned eighteen, I was sectioned and sent to somewhere else against my will. It felt like the lowest point of my life so far, but eventually I began to co-operate and do what they said to get out. I would lie and scheme to get home leave so that I could find ways to secretly withdraw my insulin, just to lose a few extra pounds. A few months in to my treatment I realised how much I enjoyed being even semi-well, and how the weight gain was starting to settle down. I couldn't get my mind off the boy I'd fell for the year before, and so I wrote to him.

The next few months flew by in a blur of happiness and excitement. He breathed life in to my bones again, all I had to do was let him in. I was discharged in the March of 2009, but within a few months I was relapsing again. I still can't pinpoint why this happened even after 8 months of inpatient treatment. The levels of support I was getting from my community care team wasn't great, I felt like I was just meant to forget about the eating disorder and move on. My boyfriend watched in despair as I got more and more sick. The pressure mounted on our relationship, I was asleep all the time or grumpy and emotional. I moved to Bristol to be with him in the August and to re-start my a-levels, but by the September I was back in A&E. I pushed him and pushed him and he broke. My Mum drove the 5 hours to Bristol one night to pick me up and I had to say goodbye to the city I fell in love with, as well as the man.

2010 was the worst year of my life to date. If I went in to detail I would be here all day. It was full of trying to find ways to cope, trying to win back the only man I ever loved, making bad friends... I experienced a drug addiction, got a job, lost it, got kicked out of my flat, got sectioned and put in to a general psychiatric ward twice, had to move away where I didn't know a soul, got pregnant, had a miscarriage. But I will always remember 2010 for one thing. My light bulb moment. I can't pin point when it happened exactly, but for a while I had been feeling sicker and sicker of coping with the turmoil. My days were made up of the same cycle; wake up, binge, smoke, sleep, wake up, binge, smoke, sleep. I'd been diagnosed with borderline personality disorder at the start of the year, and I wanted to feel some normality. I started taking small doses of insulin, maybe once a day. I built it up and built it up. It took me months but eventually I started to take full doses. I felt tired and emotional most of the time,

and then all of a sudden I felt calm, clear. Happy. My hair started to grow rapidly, my periods came back. My skin glowed, my eyes sparkled. I felt like the girl I was when I moved away to Bristol, when I had the world at my feet. I got back in contact with the healthy friendships I used to have, started applying for college courses, and now I'm planning to move out with friends and have decided to go to university to become a psychologist or eating disorder consultant. I feel so much sadness for what my clouded outlook made me do to my body for so many years - I have severe neuropathy in my feet and hands, that keeps me up most nights, and very little feeling in my feet especially. I have the early stages of retinopathy which means I struggle to see if my blood sugars are high. I never grew properly, I am 5ft 3 and should have been about 5ft 8. Compared to many of the people I have spoken to, I am very, very lucky. I really am one of the exceptionally lucky ones, to have been hospitalised over 90 times and have very few complications is a miracle. Saying this, I lost everything. I lost friends, I lost my teenage years, I lost my education, I lost money, I lost memories, I lost the man I loved. But I look to the future, because the past has been and gone, and I live in the present, and I live for the future. I have been in recovery for 2 months, 2 weeks, and 2 days. Don't ask me why, but I know in my heart, I will never go to that place again. Diabulimia is not living. It is surviving. Every day that you wake up is a miracle, but every day that you wake up is just functioning. As long as you live in the grips of this illness, you will never be 100% happy, even if it feels like it. You won't be living your life. Your life will begin the day you break free. I am 2 months, 2 weeks and 2 days old.