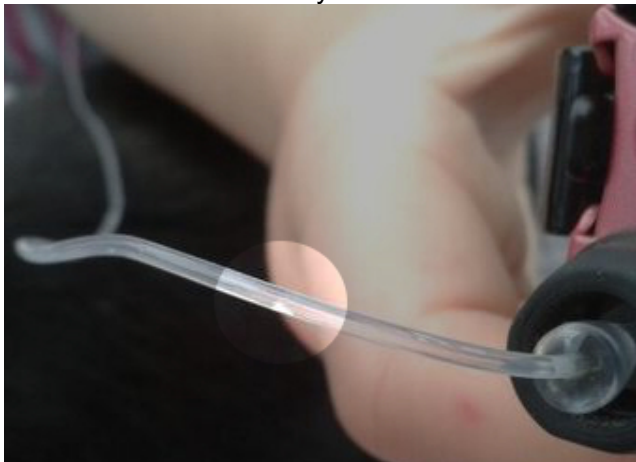


Getting answers quickly – the tube bubble

Picture the scene, Amy had only just got her insulin pump, we were used to injections but this pump was new – and a little scary.

We knew the tube could get bubbles in it and we knew what to do if that happened.

But what did one actually look like? This?



I asked a question on Twitter:

 **Oceantragic / KevW**
@OceanTragic

#DOC question about pump tubes. What is this? Pretty sure it's not an air bubble, or is it [twitpic.com/cyrb6e](https://twitter.com/cyrb6e) cc @annieastle

I got many replies in minutes; here's a couple:

 **Emma S** @bigpurpleduck 23 Jun
@OceanTragic Just a little mark/dent on the tube, nothing to worry about. If its an air bubble you'll see it all the way round the diameter.
Details

 **Oceantragic / KevW** @OceanTragic 23 Jun
@bigpurpleduck Thanks. We looked at it from different angles and guessed it couldn't have been an air bubble but don't remember seeing it b4
Details

 **understudy pancreas** @annieastle 23 Jun
@OceanTragic that looks like a mark on the tube. Best test is to prime & if it doesn't move it ain't a bubble!! We get those marks sometimes
Details

Getting answers quickly – the pink tube

At 9pm one night Amy changed her pump's infusion set and hit a blood vessel...

 **Oceantragic / KevW**
@OceanTragic

Amy's loving her new limited edition pink tubing...oh no hold on...that's not the tube

Within minutes I had quite a few messages of support plus a few which suggested that once insulin had been primed everything should be ok.

If not we'd just have to do another set change.

Thankfully priming worked fine so I let everyone know, thereby helping others.

 **Oceantragic / KevW**
@OceanTragic

Thanks for everyone's concern but the bleed didn't hurt whatsoever, just one of those things I guess. Primed through it and all ok

How Social Media Helps Us with Type 1 Diabetes

I believe that our daughter's care and future has improved through our use of Social Media.

I'm Kev, parent to Amy who was diagnosed with Type 1 Diabetes at the end of 2010; she had just turned 10. In the year that followed both my wife Jane and I coped with the daily tasks but very much felt overwhelmed and alone. We didn't exactly feel beaten by diabetes and did some fairly courageous (for us) things, such as going backpacking in India for a month only 7 months after diagnosis.

The support from our hospital was great but we didn't call them much – that's good right?

We'd met with a couple of local parents who have children with diabetes (CWD) but the kids had nothing else in common so it fizzled out.

So that was it, we were pretty much alone.

In mid-2012 a work colleague asked if I'd heard about this local girl named Laura who'd set up a social media service using Twitter and Facebook; she and it went by the name of Ninjabetic.

Being an IT geek I couldn't help but take a look at what she was doing. So began my involvement with using Social Media, including Twitter and Facebook to become proactive with Amy's diabetes care.

For the rest of this article I am going to refer to the diabetes online community as #DOC, who generally use Twitter to communicate. There are also lots of Facebook groups/forums available if you prefer.



There's a **What to use and where to start** bit on page 4.



If this leaflet is not folded already fold the pages like this

From here on in you're not alone

The first thing you'll notice when you start joining in with the #DOC is that you are not alone. We never really had anyone we could talk to that understood our fears, stress and frustration. Sure friends were great listeners but who could advise or help emotionally? We had no one.

Now with the #DOC I can ask a question on pretty much anything diabetes related and get an answer pretty quickly.

Learn from others' experiences

There are people in the #DOC from all walks of life, of all ages, from different areas (and countries) and they all attend different clinics. Clinics do things differently, some better than others and through the #DOC we can learn about the good (and the not so good). If we think we should be receiving a certain level of care we can find out what others are receiving.

Whether you're worried about gluten intolerance or retinopathy or neuropathy there's someone around who will be willing to talk to you about it, or point you in the direction of someone or somewhere that can help.

A worry for me – a parent of a diabetic girl approaching her teens – is diabulimia and through using Twitter and finding people and their blogs I've learned a lot more than I knew before. Importantly this is not from a book but from real people that I can ask.

“Becoming proactive helps our hospital help us”

Learn about new technologies

Our hospital is great but if things are going reasonably well they don't seek to, or need to, change things. Becoming proactive helps our hospital help us, which ultimately helps reduce Amy's potential future complications.

New technology – getting a bolus advisor meter

Many in the #DOC were using an Aviva Expert meter to help them calculate the bolus amount and with a ratio of 1u:13g it's something we were struggling with.

At the first clinic after I learned about this I asked for an Expert meter and Amy got one within two weeks. Life became instantly easier.

And on to an insulin pump

Six months later after #DOC conversations and research Amy requested an insulin pump. The clinic had no issues and it seemed like they were waiting for us to ask.

Initially we were offered either an Accu-chek Combo or a Medtronic Veo, both were equally fine pumps but not the only options available in the UK.

“Amy's pump has made such a difference already”

And on to the right pump for us

I'd learned from the #DOC that the Animas Vibe was waterproof and had a built-in Continuous Glucose Monitoring (CGM) display for Dexcom's G4 sensors. CGM was something I was interested in for the future. It seemed like the right one for us.

People in the #DOC suggested that my hospital might be flexible and we should ask to get the Animas Vibe. With this confidence we asked for one and Amy became the first Animas Vibe recipient in paediatrics at our hospital.

Amy's pump has made such a difference already.

Chatting online in a Twitter group chat

A “tweet chat” is where people ask/answer questions at a given time of day/week. They log in using their Twitter user to tweetchat.com (etc.) and use a particular hashtag. Questions are asked surrounding a particular topic, answers given and everyone learns from and helps each other.

See ‘Twitter group chats’ on next page for times.

What to use and where to start

Twitter

Register at twitter.com and search for #DOC, #GBDOC or #ourD. Start by following the following charities/groups @diabetesuk @jdrfuk @hedgiepdiabetes @DRWFDiabetes @ninjabetic1 @INPUTDiabetes @theGBDoc @OurDiabetes I'm @OceanTragic and I'll happily introduce you to others in the #DOC if you wish.

Note on privacy: you can protect your account so only those who follow you can see your tweets

Twitter group chats

#GBDOC: Wednesday nights at 9pm.
#ourD: Tuesday nights at 8pm

Facebook

Register at facebook.com and search for diabetes groups, of which there are many, my favourites being: *Ninjabetics, The Insulin Gang, Parents of children with type 1 diabetes in the UK, Dads battling diabetes – D-dads (mainly USA), Diabetes Family and The D Team.*

There are some private groups just for kids/teens too – such as *Type One Teens.*

Note on privacy: many groups are closed/private so the general public cannot see your posts.

Google+

DiabetesUK are currently trialling a weekly group chat using Hangouts, Tuesdays at 7pm.

Blogs

There are so many of these around, you'll find them as you connect with others via social media, but for now the best one (*ahem*) is <http://circles-of-blue.winchcombe.org> (mine!)

Any questions?

Feel free to contact me on Twitter (@OceanTragic), or via email on kev@winchcombe.org