

Managing diabetes burnout through social media and the Diabetes Online Community

Laura Cleverly

Diabetes burnout is a major factor in influencing how people manage their diabetes; however, it is often difficult to understand and can be equally difficult to manage. Many patients self-manage burnout as well as they can, but it can prove to be too much of a burden for some, resulting in their diabetes management being neglected. In this commentary, social media and the Diabetes Online Community will be discussed as a source of peer-to-peer support for those experiencing diabetes burnout. Social media provides information and communication outside of the clinical setting, bridging the gaps between appointments and helping people with diabetes to feel less isolated. The online community, which consists of patients, carers, friends and professionals, acts as a voluntary network with a shared purpose of supporting one another through social media sites such as Twitter and Facebook. This less traditional means of support provides effective encouragement, motivation and creative thinking in order to assist people with self-managing their diabetes and, in turn, the feeling of being burnt out.

Diabetes, as we know, does not allow for patients to have a day off. As much as people with diabetes would like to be able to forget about their condition and set it aside from time to time, that option simply does not exist. It requires constant attention to detail and, although many people take this in their stride, it can weigh some down until they reach breaking point.

Burnout

A few years ago, I heard a few people discussing taking a “diabetes holiday” and I wondered what that entailed. Upon exploring the phrase further, I realised that many people were feeling so emotionally burnt out from the management of their condition that they sometimes just put it down and walked away from it for a short period

of time. It was their way of letting go of the day-to-day management – the calculating, counting, weighing, planning, pricking, injecting and the rest. It was their way of offloading the emotional weight that had been piling on top of them, gradually wearing them down until they felt they did not have a choice but to say “no more”.

I have lived with type 1 diabetes for almost 14 years now. My diagnosis at the age of 16 was traumatic and, sadly, was followed by a 9-year period of denial in which I neglected my condition and everything that came with it. I was burnt out in ways that I cannot even begin to describe and, as a result, I made mistakes with my diabetes management that I deeply regret. I stopped injecting, testing my blood glucose levels and attending appointments. I was admitted to hospital with diabetic ketoacidosis on a regular

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Article points

1. Diabetes is a demanding condition that can cause people living with it to experience burnout which, in turn, can affect their diabetes management.
2. Social media and the Diabetes Online Community are consistently being used to address burnout through peer-to-peer support, shared experience and flexible learning.

Key words

- Diabetes burnout
- Diabetes Online Community
- Self-management
- Social media

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Page points

1. The feeling of “diabetes burnout” affects people differently; for some it can be tuned out and has little impact, while for others it can have extremely disruptive symptoms, both physical and emotional.
2. Discussion with other people who experience burnout has revealed that many people are forced to manage it on their own, without support from healthcare professionals.
3. In these cases, people can turn to social media, which provides much-needed peer support and information.

6-monthly basis and I soon became known to the staff in my local emergency department. However, at the time, I did not know that life with diabetes could be any different; I thought the feeling of being burnt out was normal. I had accepted that “lows” were not restricted to blood glucose levels and that I would continue to feel emotionally down as well. I thought that what I was experiencing was just another piece of the jigsaw puzzle that comes with diabetes life.

It is incredibly difficult to explain the experience of diabetes burnout to someone who does not live with the condition, especially as it affects people so differently. For some, it could be a slight nagging voice at the back of their mind that is easily tuned out and does not impact them greatly. For others, though, their every thought could be drowned out by this mighty voice shouting them down. In my experience, it was as if I was slowly shrinking while my diabetes grew more powerful, until it finally took over. The physical symptoms included loss of appetite, disturbed sleeping patterns and feelings of anger, frustration, resentment and sadness, to name but a few. Emotionally, it felt like my mind was on overdrive, constantly trying to process far too many thoughts and never allowing a moment to switch off. All the while there was a numbing feeling of loneliness and of being misunderstood by my healthcare professionals.

How is burnout managed?

Experiencing diabetes burnout is not a decision that people make. As hard as they try to avoid it, it can creep up and overwhelm them, causing the condition to become much harder to manage. If that time comes, what resources do people have to enable them to manage it? There is a known shortage of psychological support. Not all diabetes services are flexible enough to provide patients with additional time outside of their 6-monthly or annual appointments. Even if they are, the signs need to be spotted in advance in order to be tackled before burnout hits. Are healthcare professionals even able to spot those signs?

From discussing this topic many times with people over the years, I have discovered that many self-manage burnout as best they can, but they

often do so in isolation. This raises the question: are people are merely coping with it rather than dealing with it? And are there perhaps less traditional but more effective means to manage diabetes burnout?

Social media and self-management

For many people, diabetes is an ever-changing challenge, requiring different approaches that often cannot wait until an appointment becomes available. This can leave them feeling alone and vulnerable, knowing that they face a long wait until they can address their issues with a healthcare professional. One method that thousands of people with diabetes have turned to in order to bridge the gap and access further support between appointments is social media.

In today’s world of technology and ease of access to information and communication, it is no wonder that people with diabetes are taking to social media to interact with one another and share their stories. Patients are increasingly encouraged by healthcare professionals to take on more responsibility when it comes to self-management and, in turn, this has led to a revolution, with people seeking advice and support from peers to manage the highs and lows of diabetes.

One of the greatest facets of using social media as a self-management tool is that 24/7 support can be accessed anywhere, at the touch of a button. By using social media sites such as Facebook and Twitter, people are able to access a digital world of support and information, at a time that suits them. Social media is flexible, fast and convenient. It is able to keep up with the pace that diabetes demands and, when used well, it can be a very effective tool in the self-management of diabetes burnout.

One of the most effective methods of self-managing burnout that I have used is blogging. Creating my blog, “Ninjabetic – The Highs and Lows of a Ninjabetic Life” (available at: <http://ninjabetic1.blogspot.co.uk>), opened up a world of possibility for me to address the issues that I was experiencing, and blogging continues to be a hugely popular platform amongst people with diabetes to release the burden that the condition can bring. The blank canvas that a

blog provides enables people to map out their thoughts, feelings and experiences, and to make sense of them through reflective thinking and problem-solving.

In terms of gaining peer support through blogging, this happens through sharing my blog on social media platforms like Facebook and Twitter. I often receive feedback from patients and carers telling me that they feel the same way that I do, which in turn helps them to feel more supported with their condition. Quite often, people will tell me they have lived with an issue for such a long time, without discussing it, that they haven't been able to see a way out. However, by reading about someone else's experience, they feel confident in starting to address those issues. Living with diabetes can be rather lonely, and patients often say that healthcare providers cannot relate to how they are feeling, but knowing that another person is experiencing similar struggles is incredibly liberating and is a turning point for many. When it comes to burnout, people often find it difficult to understand their thoughts, pushing them to the back of their mind in the hope that they will remain there; however, by seeing and discussing thoughts through blogging, they are able to make sense of them and move on.

Social media may not be everyone's cup of tea, but for many it has been a real eye opener, alerting them to different resources and tools that can be used to self-manage different aspects of their diabetes. Personally, I view social media as an important part of my diabetes treatment, and the changes to my wellbeing and overall health are what encourage me to recommend it to other people. If nothing else, it is always worth trying.

The Diabetes Online Community

In the last four years, since joining the diabetes online community (#doc), I have found I can manage diabetes burnout far more effectively than before. The reason for this? The people within the community. A group of thousands of patients, carers, friends and professionals from across the globe come together with one shared purpose: support. Whether that support comes in the form of storytelling, sharing educational information, campaigning or simply being there

for one another to say "me too", that support is invaluable. Personally, I cannot think of a better place to be when the walls start closing in.

When I joined the online community, I was close to saying "no more" myself – not taking a diabetes holiday, but walking away from it altogether. I was exhausted, overwhelmed and desperate. It seemed to take all of my strength to go online and talk about my condition (something I had never done outside of an appointment before), and for me that was a risk. However, it turned out to be one of the best risks I have ever taken. I had not realised the power the community would have in enabling me to feel happy again almost instantly. Reflecting upon those rocky nine years, I cannot remember a time before joining the online community that I actually felt happy about diabetes. In the past, I had only ever felt bitter resentment towards it.

The community soon opened my eyes to a world of possibility and opportunity that I had no idea even existed alongside diabetes. For years, all I had felt was loneliness, fear and anger about my condition, but I was soon being guided by others into a world of achievement, courage and companionship. Burnout soon became a small voice at the back of my mind that I could easily block out by talking to others who knew exactly what I was experiencing. One day that voice itself burned out, and was extinguished, if you like, as I had become stronger than the condition that had worn me down for so long. The community motivated me and enabled me to find ways out of the dark hole that burnout had put me in. That feeling of knowing I was not the only person experiencing this exhaustion was incredibly powerful and continues to be a strong force against diabetes burnout.

This isn't to say that burnout does not occasionally return; diabetes still proves to be difficult at times and that voice does slowly start whispering again, but it is now far easier to manage. Unfortunately, social media and the Diabetes Online Community cannot give patients the holiday they need; however, they can help to relieve us some of the strain that we experience. If it can prevent people from saying "no more", then even better.

Page points

1. Many people with diabetes can find it liberating to read that other people are experiencing similar struggles to them, and airing their thoughts can be a useful way to make sense of them and move on.
2. The Diabetes Online Community comprises thousands of patients, carers, friends and professionals from across the globe who have come together with one shared purpose: support.
3. The community has been a real motivational force for the author and has helped her deal with the feelings of loneliness, fear and anger that her condition sometimes causes.
4. The author encourages healthcare professionals to become more involved in social media in order to gain insight into the ways in which people view and manage their diabetes on a daily basis.

“There is concern about patients taking bad advice from others or reading misleading information; however, this is why I recommend that professionals try social media for themselves in order to make safe recommendations to their patients.”

Should healthcare professionals join social media?

I would encourage healthcare professionals to consider becoming involved in social media and the Diabetes Online Community themselves, in order to gain insight into the ways in which people view and manage their diabetes on a daily basis. There are many platforms that can be used; however, I think the most effective are Twitter and Facebook. An example of a diabetes-focused group to watch and interact with is OurDiabetes (@ourdiabetes on Twitter). This community-led group provides “tweet chats” for one hour a few times a month, in which patients, carers, professionals and charities will ask a large audience of peers to answer their diabetes-related questions. If you would prefer to sit back and watch, that is absolutely fine, but if you want to be actively involved you are more than welcome. It is a friendly learning environment for both patients and professionals, which can be used to answer questions, develop services and, importantly, is an effective network for peer support.

For those looking for professional connections and idea sharing, I can recommend following the “We Communities” (@wenurses on Twitter) for organised discussions run by healthcare professionals.

Should professionals recommend social media to their patients?

Of course, recommending social media to patients can be daunting for healthcare professionals. There is concern about patients taking bad advice from others or reading misleading information; however, this is why I recommend that professionals try social media for themselves in order to make safe recommendations to their patients. The majority of patients will have access to the internet, and Dr Google is the first port of call for many when a question arises, which can open up a wealth of information – some helpful and some not. However, it is an opportunity to guide patients to safe and credible resources which will complement their needs and can be hugely beneficial in the self-management of diabetes. ■

Links to social media

Ninjabetic blog – <http://ninjabetic1.blogspot.co.uk>
Ninjabetic Twitter – @ninjabetic1
Ninjabetic Facebook – Ninjabetics
OurDiabetes Twitter – @ourdiabetes
OurDiabetes Facebook – Our Diabetes
We Nurses Twitter – @wenurses
We Communities – <http://www.wecomunities.org>