

The Good, the Bad, and the Ugly: Of Facebook and Forums



THE GOOD

The internet contains a wealth of medical information. You can google just about anything and find what you are looking for. It is also a place to meet others with the same medical condition and get advice. You don't feel so lost and alone when you join support groups and Facebook pages.

THE BAD

On the flip side, the internet can be a huge source of misinformation and a place to encounter the bullies were they reside.

For example, no blogger or organization can post something related to research and new treatments for diabetes without a flood of the following type of comments:

"That's not good enough"

"WE WANT A CURE!!!!!!"

"Who cares, we won't be able to afford it anyways"

"It's just a big conspiracy to make money off their drugs and devices"

"This stuff can kill you!"

The ironic thing is, when a cure comes to pass – it might be a drug, or it might be a vaccine. Will the same people then be ranting about the cost of the drug, that it's a conspiracy, or that vaccines will kill you. From the nature of a lot of comments, you can tell that people commented, often negatively so, without even have read the article/news report. The comment had no bearing to what the information was even about. Then there is the ugly.

THE UGLY



One of the most egregious example of “the ugly” I have seen in the internet on support group forums was in the comment sections of the facebook page of a popular blog on Hypothyroidism. A women had come on to say that she was “run off” by bullies just because she had commented that she liked her physician and was happy with her therapy by the conventional medicine way. She was told to go away, that this was a place where people go to to complain about their doctors and complain about their mistreatments.

Negativity was the rule here, no room for someone who had a good experience to report. I am sure most people with something positive to say were already run off and those still there were so in secret, being afraid to make a comment that was deemed to not be negative enough. This woman had left her positive experience, not to criticize or devaluate those who were unhappy, but to let others especially newly diagnosed people to know that most likely things were going to be ok.

What Can You Do?

The problem with this is that the vocal minority rules. People searching out information are unduly frightened as all there is to read are hyperbolic horror stories. By human nature, there will be less upbeat comments from the happy campers. Happy campers are out there in the world being happy and not taking the time to comment on a blog, forum, or Facebook post. However, their presence is very much needed. Time for the silent majority to not be so silent and help those who are in need of information be able to obtain it in a more balanced and useful manner.

Double Diabetes – An Increasing Epidemic



From the NY Daily News

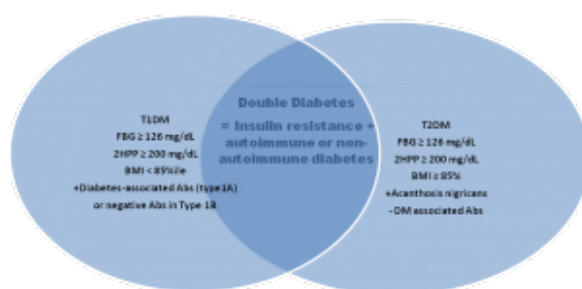
As reported on ABC News, there has been a recent brouhaha over an inappropriate tweet made by the CEO of CrossFit and the ensuing Twitter exchange between him and singer/Type 1 diabetes advocate, Nick Jonas, regarding consumption of sugary beverages and developing diabetes. Some people misinterpreted the ensuing exchange as if CrossFit was claiming that sugar *causes* **Type 1 diabetes**. (It doesn't. Type 1 diabetes is an

autoimmune disease where the pancreas gets attacked by antibodies and can no longer produce insulin.) CrossFit then put up a Facebook post clarifying what they meant, saying their intention was to warn people that drinking sugary beverages *can lead to* **Type 2 diabetes** and wanted to help prevent people with Type 1 Diabetes from *also developing* Type 2 Diabetes.

Once again, CrossFit got pounced on by people misreading what they said and interpreting it as “Type 1 diabetes can ‘turn into’ Type 2 diabetes.” Hold on! “Can lead to” and “can turn into” are **not** the same thing.

Can a person with Type 1 diabetes **also develop** Type 2 diabetes? YES. It is becoming an increasing epidemic and is referred to as “Double Diabetes”.

From the Medscape article listed below: “It is quite possible to have a patient who develops DM1 due to autoimmune destruction of beta cells who also has the genetic predisposition for insulin resistance. Therefore, if this patient gains weight and becomes more sedentary, insulin resistance and features of the dysmetabolic syndrome could occur.”



From NY Daily News

Everyday Health has an article on Double Diabetes – published in 2009. This is not something new. You can read it here:
The Double Diabetes Epidemic

While CrossFit's tweet was uncalled for, and their lack of apology unfortunate – as well as doing a poor job explaining what they meant – the whole exchange did lead to more awareness of this important topic. Once the brouhaha is over, and the flurry of rants is over on social media, more thoughtful discussion can occur. The diabetes epidemic is real, and the double diabetes epidemic is real.

Scholarly articles:

- Metabolic Syndrome in Type 1 Diabetes from Diabetes Care
- Adult Patients with Type 1 Diabetes on the Metabolic Syndrome on Medscape
- Metabolic Syndrome and Type 1 Diabetes: Prevalence and Risk Factors
- Double Diabetes: The Search for Treatment Paradigm in Children and Adolescents from “Hot Topics in Endocrine and Endocrine-Related Diseases”

False Hopes and Unwarrented Fears: Ethics in Medical News Reporting



False Hopes and Unwarranted Fears: Don't let this get you down.

On a daily basis we are surrounded by sensationalized headlines in the media. Unfortunately this includes medical and health news. Journalists and bloggers need to get your attention in this age of mass media where information is rapidly distributed and then just as rapidly forgotten. A small study that is done on animals, or even just on the cellular level in a petri dish, gets reported as "Hope for a Cure: Insert Disease De Jour." This spreads like wild fire on the internet causing false hope for many as only a small fraction of early research ends up leading to an actual treatment for human beings.

On the other side, another small study or a poorly designed one, might give an indication that a medical treatment or medicine currently in wide use may have a negative side effect. This also gets reported in a sensational way: "This might kill you..." with very little investigation being given to the story, no real world context, no discussion on the pros and cons of treatment or the risks of the alternatives. People stop taking their medicine based on a sound bite and that might cause more harm.

An example this past year in what we would call "premature hope" was the various reporting on a study regarding a

potential vaccine for **Type 1 Diabetes**. This was a small study done on just 80 people. The research is in the very early stages of the process and even if it pans out to prove to work and be safe it will be years and years, maybe decades before it would be available. Also, the study was just done on people very early on in the disease process. Yet there were headlines such as "A vaccine so you won't have to take shots!". In the comment sections of the articles with this type of headline were people asking how soon this will be available and people who had long term diabetes (who from the initial study detail would not qualify most likely for this treatment) stating they were anxiously awaiting the arrival of this vaccine. This same story has been bounced around all over the internet for the past year and a half! If this same study had occurred 10 years ago, few other than those in that field of research would have even heard about it. A more realistic headline was "Type 1 Diabetes Vaccine Shows Promise In Small Trial."

Take time to study further what you saw in a tweet, read in a news media report, or heard in a TV news lead in. What was their source? What is the medical expertise of the reporter? Does this even relate to me right now? Is this information clinically relevant at this time? And remember, always talk to your medical provider before making any changes with your medications.