

When your Internet Angel is a "Dog"

My internet support group for rosacea was a dream come true. We had thousands of members and a selfless guru to guide us. This was as good as the internet could get. Sadly the foundations were crumbling; our saviour was proffering blatant lies. Things were looking bleak. How did we miss the warning signs?

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Dogs and the Internet

The New Yorker magazine had it right. A cartoon from 1993 told us "*On the Internet no-one knows that you're a dog*" [1]. Surely the cartoonist was warning someone else. I knew better. Having been on the internet since 1989, and being a pretty good judge of character, I had no idea they were speaking directly to me. But I get ahead of myself; let's go back to the beginning.

Rosacea Beginnings

Back in mid 1998 I was feeling sad and a bit desperate. Having been diagnosed with rosacea, I had seen a couple of GPs and a couple of dermatologists. None of them had anything to offer me beyond metronidazole gel and antibiotics. These run-of-the-mill treatments left me wanting. Surely this wasn't the best that the medical world could offer me. Every night more papules and pustules would grow from no-where. Each morning I would dread looking in the mirror. At that stage, in 1998, I had already had a constant red nose for 10 years.

So it was off to the internet to see what I could learn about rosacea. There was a real dearth of information so I decided to start my own email group. I found a free email hosting web site called *makelist.com*. They would manage the list of email group members for me, and even archive a copy of each message on their server. Furthermore, the price was right as well – it was free. After canvassing a few usenet newsgroups, more and more rosacea sufferers joined the email group that I called *rosacea-support*.

With very little effort on my part I was already learning about treatments that weren't even available in Australia yet. Something else became obvious quickly as well – there was a general dissatisfaction with the current state of rosacea knowledge and treatment.

This Internet thing rocks!

The group continued to grow. One of the people I had invited to join the email group was already active on the internet. Board certified Dermatologist Linda Sy Fang jumped straight in by offering her experience and knowledge freely. Dr. Sy had her own skincare company from her years of dealing with patients. Wow, I thought, this is great. My visits to dermatologists in Perth had left me cold. Now I had access to my own personal cyber-derm. Dr. Sy was even in the process of formulating products like sunscreens, moisturizers and cleansers specifically for rosacea sufferers.

I was lucky enough to be able to meet Dr. Sy in San Francisco in 2000. She is one of the most delightful people that you are likely to meet.

This support group was what the internet was for – letting people from all over the world learn from each other. Emails were fast and convenient. Everyone in the group was on equal terms. Everyone could read what

everyone else had to say. Who needs to visit your doctor when you could get all the advice you need online? The group couldn't get any better. I was quietly chuffed that one guy sitting in the world's most remote city could have created such a great group.

Enter Geoffrey Nase

In early 1999 I received an email from Geoffrey Nase. He had been following the group for a couple of months and had a really intriguing email for all to read. Nase was working on a book about rosacea.

This email had some amazing claims. In his research for his book, Nase had apparently interviewed, now take a big breath; 38 Dermatologists, 10 Vascular Surgeons, 7 Plastic Surgeons, 4 Rheumatologists, 8 Endocrinologists, 2 Immunologists, 10 Ophthalmologists, 3 Allergy Specialists, 3 Gastroenterologists, 6 Neurologists and 2 psychologists¹.

Could that be for real? Straight away I got emails asking me this question. It did seem strange, but I keep wanting to get ahead of myself. All I could think at that stage was that we were about to be rescued by an angel.

Over the next 2 years while we waited for the book to be published, and in the years since, Nase posted a staggering number of emails to the support group. His status in the group grew. We had our own guru, our own saviour – and what's more he was on call ! He would answer questions any time, day or night.

Nase had the unlikely combination of a professional background in physiology and victory over all of the severest forms of rosacea. He had access to the best research minds in the country. He had read all known research papers on rosacea. All of us - his captive audience, lapped it up.

This Guru is starting to scare me

As Nase's status grew, so did our willingness to overlook outbursts of ego and other quirks. Nase was our best possible advocate, a resource we needed to protect. He was always talking about the treatments just round the corner. A cure was tantalizing close. We were encouraged to ignore

¹ In the introduction to Nase's book, - 'Beating Rosacea', (published 2 years later) this astounding list had grown by as much as 500%.

real-life doctors that disagreed with what Nase was telling us. "Dermatologists were the world's laziest medical professionals", we were told. "Doctors have good reason to be scared of internet support groups", we were lead to believe. New information was dispensed at the speed of the internet. Any doctor who couldn't keep up was tardy, and their opinions were to be discarded.

The usual niggles from internet email groups would come and go. As the group owner I eventually gave up my dislike of moderation and put the email group into pre-moderated mode. The group now had many thousands of members, and was becoming a hostile place. A slightly harsh email would have the inevitable acerbic retort. I was determined to not let my little support group turn into a school yard fracas.

Two incidences with Nase were telling. The first was in April 2003 and involved an emergency room MD. The MD was the first to question Nase on a medical level. Marjorie didn't buy into Nase's theories on rosacea. She was unimpressed with the medical proof for Nase's theories, and his subsequent belief in how to approach treating rosacea. A few heated posts went back and forth. Marjorie had been the first to ask Nase tough questions. We had missed a chance to see Nase for who he was.

The second interesting incident was in June 2004, and involved a PhD rosacea sufferer named Rick. Rick too had suffered some of the chronic symptoms of rosacea just like Nase. He had tried many of the treatments Nase recommended in his book. Dissatisfied that his success did not match what we could all read about in Nase's book, Rick called on Nase for an explanation. Why didn't the book give a chronological description of what treatments Nase undertook and when? Nase didn't like such a tough question. Nase was rude and grandiose. More was unraveling

We could still forgive Nase still though. He was still our Angel, working tirelessly as our rosacea advocate.

In any human endeavour it is natural to overlook foibles. If someone in the office is a star performer, but a right royal pain, you would probably just put up with them.

The Good Doctor

Nase just loved to be called Doctor. He was happy to let people confuse his PhD with him being a medical doctor. His email address said **drnase1000**,

his website was drnase.com [2], each email was signed **Dr. Nase PhD**; and indeed we were told by Nase that he had passed his medical school board exams. Dr. Nase was, naturally enough for a `doctor', dispensing medical advice every day.

For those not happy with the recognized treatments Nase would suggest off-label drugs. Almost nothing was too dangerous to contemplate. Strong drugs used for cystic acne, hypertension, depression and pathogenic infections were all on offer. Again, if your doctor wasn't willing to prescribe it for rosacea then that is only because they are years behind Nase.

For some rosacea sufferers to be able to match Nase's miraculous clearance, it seemed they would need to be as medically adventurous as Nase had been.

Getting Chummy with the Guru

Starting from the middle of 2004 Nase started to call me a couple of times a week. The calls would always be mid afternoon Perth time, which meant 2AM or 4AM CST. This was another warning sign, why wasn't he asleep like normal people would be? How could he be holding down a research position at a medical university, and post messages tirelessly to the group, as well as be up all night on the phone ?

I worked from home so his calls were always interruptions, but I didn't mind. I was getting close to the guru of the group; he was interested in my opinions on stuff.

I worked on his web site as a form of encouragement for his volunteer efforts. His web site was very basic, it really needed some work to look professional. My Rosacea Support Group website [3] had been around for a few years by now and was ranking on the front page of Google for those searching for rosacea. My site was simple but Google judged it as a quality site based on how many other sites linked to me. My web site was sending oodles of traffic to Nase's web site. Google was unimpressed with his web site ; so you had to look hard to find it.

A New Research Foundation

Fresh from being generously praised by Nase, I was totally sold on the idea that the world of rosacea research was in a shambles. Other inflammatory skin conditions like psoriasis and eczema had their active research foundations. Rosacea only had the National Rosacea Society. All of the

opinions that we could find about the NRS were discouraging. What if we could make our own foundation? In a short space of time a group formed around Nase. It was agreed that I would become President of the Rosacea Research Foundation [4]. We registered in the state of Alabama, where the Vice President, Chuck Young lived. Now, everything good about an internet support group was coming together. The RRF would have the world's leading rosacea expert at its helm. We were going to '*Change the Face of Rosacea*', as our cute tagline promised. What a ride we were on.

Centimetres from Danger

Little did we know that this ride was about to come off the rails. Just a few weeks into the operation of the RRF some health issues surfaced with Nase. We were told that Nase had been suffering from stomach cancer for an extended period. He told us that he had kept this news from all of his family and the rosacea community. The months of chemotherapy hadn't been able to reduce the "2 pea-sized benign tumours in his upper intestine". So he was off to Chicago where the countries' best would use a new laparoscopic laser to remove the tumours. We were in turmoil. Our rosacea angel was seriously ill.

Things get very strange in this part of the story. Nase was unwilling to tell us which hospital he was going to, so we just had to sit tight to wait for him to return. Nase returned home. Next thing we knew, an email arrived from Nase's Hotmail account, purporting to be from a neighbour. This neighbour had found Nase comatose one morning. He had bled out from his stomach surgery site, had lost a lot of blood and had lapsed into unconsciousness. The neighbour told us that he was being air lifted back to Chicago, 300 km from where he lived. Again we just had to sit tight while we waited for news. Apparently no friend or family member was with him, so we were stuck for updates.

A couple of days later I was out riding my bike mid afternoon. My mobile rang and it was Nase. He told me he was calling from the hospital in Chicago. It was 4:30 AM CST. Nase was slurring his words and was barely audible. He said that he has been unconscious for 4 days after losing a large amount of blood. During the helicopter flight to Chicago his heart stopped 3 times, requiring him to be paddled back to life. By now you are probably asking why did he need to go all the way back to Chicago again? It wasn't like he lived in a small city. We wanted to know as well. During this time other members of the Rosacea Research Foundation also got phone calls from Nase. They were deeply troubled by the fact that Nase's

home number would appear on their cell phones when he rang. We were sure that he wasn't in Chicago being treated for cancer - he was at home in Indianapolis in front of his PC.

From here, the health stories only get more bizarre. Neurological symptoms shortly later lead to 2 brain tumour surgeries. I'll spare you the medically impressive details that we waded through. I'll also spare you the series of incoherent phone calls from his death bed. Those who fake cancer are universally held to be pretty low.

After these cancers and surgeries we were wondering why we were being played for fools. We asked Nase privately if he had been embellishing his health stories - if he had been truthful with us. He took immediate offense and went public with his indignation and resignation. A message thread started by Chuck on rosacea forum became a flashpoint. Nase has been posting about why he had left the RRF, fabricating generously. Chuck challenged him to come clean. The vitriolic response was stunning.

I knew then that nothing could save the RRF, and maybe nothing could save Nase or his rapidly declining reputation.

How would he ever be able to have any kind of reputation again? What more lies would emerge to cover his tracks? More worryingly, what chance did the remainder of the RRF stand, now that Nase was on the attack? Who would believe us against the word of the guru of the group?

On top of all this we were sad because the RRF had held so much hope. Supporters had backed their hope with their donations. \$USD 18,000 had been raised in just 3 months.

How did we end up here?

These questions got us thinking. What exactly do you do when your support group angel goes bad ? We felt cheated and angry that we had wasted so much time building a group around Nase. Furthermore, we knew that the RRF would never be the organisation that we all hoped for.

We started dissecting his behaviour. How had we ignored all the signs that something was amiss? Had we gone too far in allowing unacceptable behaviour because we all selfishly wanted a cure? I fear the answer is yes. Analysing his personality we came across descriptions of Narcissistic

Personality Disorder [5]. Even more exotic were web sites that we found talking about 'Munchausen by Internet' [6][7].

Only a fool would diagnose someone over the net, but boy it was tempting when you find a web site that lists traits common to an illness, and you think you recognise someone.

I had failed the group. I had been one of the many that had allowed Nase to prosper. So by now you the reader probably have a feeling as to why I wrote this paper. I need to put up my hand and say sorry for my part in letting Nase get into a position where he would abuse the power we gave him.

What Did I Learn ?

1. Expect high standards of behaviour from everyone. Don't allow anyone in your group to have special privileges where you let them behave poorly and without respect.
2. Don't rely on information solely from the internet. Google is good; so good that you can be tempted to think that if you can't find it there, it doesn't exist. In academia and indeed in real life, much is not visible on the internet.
3. Critically question everything that happens. Chances are if something looks too good to be true, it probably is.
4. Watch out for experts without peers. I'm sure that if Nase had had a *single* personal or professional peer that we could have talked to, this story would never have needed to be told. No one can exist without accountability in their lives. Make sure that you have some form of accountability for everyone in leadership in your internet group.
5. Your local doctor may just be your best friend. Don't ignore the wise counsel of doctors with real patients. The medical community may be staid and slow moving, but there is good reason for this.

So please take this story as a warning. You just never know when your internet angel might turn out to be – to use the *New Yorker's* analogy - A Dog.

References

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