

Life isn't always fair. It's a lesson we all have to learn eventually. It's how we deal with those bouts of unfairness that help define us as individuals. Sometimes, dealing with adversity can actually have positive outcomes. When I was diagnosed with Multiple Sclerosis (MS) in 1993, it felt like my world had come to an end.

Well it didn't. My MS diagnosis proved to be something of a turning point. I write this not because I'm inviting you to a pity party, but because my experience has helped shape my view of how the pharmaceutical company/patient relationship is changing, and how it should continue to change and develop, moving forward.

The pharmaceutical company/patient relationship has traditionally been: patient gets ill; patient visits doctor; doctor talks to patient; doctor prescribes medication for patient; patient receives medication from pharmacist, and patient hopefully reads patient information leaflet. In essence, there has not been any kind of real relationship or genuine connection.

Some of you will read this and say that there is a reason for this: the law. The pharmaceutical industry is highly regulated and direct-to-patient advertising is not allowed in many parts of the world, so there are only certain types of advertising and communication that advertising and PR agencies are allowed to contemplate on your behalf.

Yes, I know the law and appreciate its implications for global companies and the different territories in which they operate. But the laws regulating the pharmaceutical industry, while prohibitive in many circumstances, should not mean abandoning all attempts to consider the pharmaceutical company/patient relationship in a more real world context.

My first suggestion is that pharmaceutical companies need to listen to patients in order to focus more on what matters to the patient population. Many pharmaceutical companies are doing this already. Those that are not should at least be cognisant of what is being said about them, specifically online. This isn't another argument for the immediate adoption of a comprehensive digital strategy, which is in danger of becoming this season's must-have item, but it is a plea for more pharmaceutical companies to connect with the patient communities they serve.

I think if pharmaceutical companies spend a little more time contemplating what patients really want and need when they get ill, they will find that they have an opportunity to become more successful, and improve their reputation within the patient community at the same time.

So, let me describe some of what patients want and need. This isn't just my own view, by the way. Over the last ten years, we have worked with thousands of people living with a variety of chronic medical conditions like MS, epilepsy, cancer and rheumatoid arthritis. Of course we're all individuals, and we all react differently to devastating news, but here are some common themes that have emerged.

# make contact

**Taking time to listen to sufferers' stories helps patients, doctors and industry relate and benefit**



Our ability to cope depends on a relatively small number of factors. Some people fall apart, others find new reserves of extraordinary determination that even they or their loved ones did not know they possessed. The factors contributing to how people cope with the news of a chronic illness include their prior emotional state, their age, the amount of accessible support, the types of people around them, their own communication skills, and those of the people around them, as well as the knowledge and communication skills of the medical team treating them.

## COPING STRATEGY

How quickly a coping strategy is developed often depends on the skills of the support team around the ill individual. That support team could consist of a direct family member, a friend, someone from the medical team, or a third party like a voluntary group support worker. People who develop a coping strategy have the best chance of living well with their chronic illness. A study among AIDS patients at Massachusetts General Hospital in the US concluded that patients with adequate social support and good coping skills were least likely to report depression, poor quality of life, and low self-esteem. On a broader scale, academics at the US Rochester Institute of Technology have studied the link between health and social support in detail. The Institute's Corey Clark defines six criteria for social support:

- Support from a lover/spouse
- Support from a group of people/friends
- Assurance of worth from others
- Reliable support
- Guidance and support from a higher figure
- Opportunity of nurture.

Information is key. We hear more and more about the empowered patient. I think some doctors regard this with some trepidation. The most enlightened healthcare professionals do not, however. They know that a partnership approach to treatment is vital. Encouraging people to learn about their condition, and the treatment options available to them, is essential. It encourages treatment compliance too.

Access to information varies, according to where sufferers live, and the condition they have. Information in the UK is superb for the most part, not least because of the presence of a hugely evolved voluntary sector. Increasingly, our first port of call for information is online. In 2009, 85 per cent of online Europeans in the UK, Germany, France, Italy, and Spain turned to the internet and other technologies for health and prescription drug information, according to the latest *Cybercitizen Health Europe v9.0* study from Manhattan Research.

Access to specialist consultants might be harder though, again depending on where people reside. Indeed, it's easy to forget that in some parts of Europe there

are still areas where both information and access to specialists is a challenge, and stigma remains barely unchallenged.

I have already mentioned the importance of the immediate support team, but there is another angle to this. When you, or someone who is dependent on you for care, receives a diagnosis of a chronic medical condition, there is a tendency to feel that the world is against you, that however eminent your doctor may be, he or she doesn't really know 'what it's like'.

Connecting people with others who have trodden a similar path is enormously important. Their experiences are the most authentic. They don't pretend it's all straightforward. They don't guarantee success. By helping to make these patient connections happen, pharmaceutical companies have the opportunity to bridge some of the trust gap that exists between the pharmaceutical industry and the consumer, in order to build greater connections with patients. They have a chance to be seen as thought leaders in the disease areas in which they operate, thus gaining respect from all stakeholders.

Returning to my own personal journey with MS, I saw, met and heard some great people. I received some good advice, and some appalling advice too. After hearing of people who had received terrible care, I was determined to use my experiences positively to help others have the best opportunity of managing their MS. I also saw that there was a chance for the pharmaceutical company/patient relationship to become more relevant. Thus, I developed the proprietary Patient Ambassador programme to bring strategic, regulatory-compliant, real-life patient stories to direct-to-patient marketing and communications initiatives. I founded Snow & Associates in 2001, a full service boutique agency providing customisable direct-to-patient and word-of-mouth solutions. Our Patient Ambassador programme is at the heart of what we do and, nearly ten years on, these programmes are up and running all over the world, effectively changing the face of word-of-mouth marketing.

## AUTHENTIC STORY

The Patient Ambassadors are real people committed to raising awareness about their diseases and sharing their experiences to help empower others to be active participants in their own healthcare choices. So what makes a good Patient Ambassador? As stated at the start, this isn't about inviting pity. It is about presenting an authentic, balanced, and realistic story, based on an individual's personal experience with an illness and what worked well for that person. We stress the importance of background and total honesty. These stories simply would not be credible if they made everything seem easy. The fight to receive the best possible care, and the best possible treatment, is often a long, demanding journey over rough terrain. But patient experience is the single most powerful communication tool



→ available. It is totally authentic, and totally relevant. In my opinion, it is the most effective way of influencing long-term behaviour and actions.

Many people have a compelling story of their journey with a chronic illness, of course, but not all of them have the confidence or experience to deliver that story well to an audience. Telling one's story can be a hugely emotional experience, and it would be cruel and unprofessional to ask a Patient Ambassador to present to a group of people before he or she is ready. It's also important that people know how to answer sensitive questions. How, for example, to deal with direct questions regarding medication strategy is key to our training process.

We also work with clients, Ambassadors and numerous patient advocacy groups to identify appropriate forums for the Ambassadors to share their stories. These could take the form of a meeting of patients, a healthcare professionals' meeting, or a webcast. One of our Ambassadors was telling me about a meeting he presented at recently. He had spoken to a group of 150 doctors from across Europe, and was struck by how many of them waited to talk to him at the end of his story, simply to thank him for reminding them why they became doctors in the first place, and for describing what it was really like to be in the other seat in the consulting room. That is the power of genuine patient stories.

"57 per cent... would not take their medication unless they completely understood why they needed it"

Patient Ambassador programmes can also help with compliance. A 2008 AstraZeneca survey revealed that 57 per cent of respondents would not take their medication unless they completely understood why they needed it. At least one third of hospital admissions for heart failure result from non-compliance with therapeutic regimen. A recent study in the US concluded that, unless they have a trusted confidant, limited-literacy patients might be reluctant to ask others for help to take their medicines correctly. Patient Ambassadors can help provide that support.

We know that many people stay with a treatment even when it is proving ineffective, or producing very unpleasant side effects. Epilepsy is a good case in point here. It is a condition which is often misunderstood, and rarely hits the headlines. Many people have tolerated a lifetime of treatment on older medications, despite the fact that numerous newer anti-epileptic drugs have been launched over the last two decades.

There can be many reasons for this, some of which are related to the patient needs I wrote

about earlier. Patient Ambassador programmes are a highly effective means of raising awareness of a condition, thus giving patients the knowledge and confidence to visit their doctor to seek a diagnosis for symptoms they are experiencing, or a second opinion. Ambassadors can play a critical role in helping other patients understand the signs and symptoms of their illness, know what questions to ask their doctor and empower people to be proactive about their health.

We have also started to see more pharmaceutical companies consider Patient Ambassador programmes long before a product launch. It is the exception rather than the rule, but the logic is compelling. Most pharmaceutical companies talk about their commitment to the patients for the disease areas in which they have key products, but the long-term support of patient programmes like these speaks louder than words. Those companies that take this commitment to heart and act upon it will be those that redefine the pharmaceutical company/patient relationship.

## PROGRAMME SUCCESS

Measuring programme effectiveness is, of course, a much talked about discipline within marketing communications. Dare I suggest that it is talked about more than it is actually delivered? Refreshingly, measuring the success of Patient Ambassador programmes is relatively straightforward. The key is to ensure that programme objectives are clear from the outset. That might sound obvious, but many people struggle to compose a succinct answer when the question is posed. We spend a significant amount of time clearly defining measurable objectives with clients. Typically, the three primary components include execution effectiveness, directional impact and return on investment, which are measured by tactical success, impact (patients' reactions) and response.

While Patient Ambassador programmes may not suit everyone, or every brand, they have been effective across the globe. We have worked with some extraordinary people suffering from a broad spectrum of illnesses across Europe and the US. We have had success in the Far East, too.

I am sure that Patient Ambassador programmes do help to address many of the issues raised in this publication over the last few years. Specifically, they answer the question of how pharmaceutical companies connect more effectively with their customers, both existing and potential. We all share the common goal of helping people to live well with their illness. Often, it feels like the relationship between pharmaceutical company, healthcare professional and patient has overlooked this goal, because there is too much suspicion at all levels. Patient Ambassador programmes are changing that dynamic the world over.

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