Venom Immunotherapy – the Patient Perspective

There are events which, when they occur, can change the course of your life. For the majority of adults and children who have suffered from anaphylactic shock, this is one of those events.

I have suffered two life threatening anaphylactic reactions to wasp venom and since 2002 have run a website on the problems of stinging insects and the potential reactions which can occur, from the very mild sting to life threatening anaphylaxis. The website now has approximately 200,000 visitors per annum and over the last nine years I have personally supported approximately 300 individuals via email undertaking a course of venom immunotherapy, the majority here in the UK, and the remainder from the United States and Europe. I therefore consider I can speak with some authority on the patient's perspective of venom allergy and venom immunotherapy.

I would claim to be an emotionally stable, rational and very pragmatic individual with a successful academic and business career. I have been the Chief Executive of a public limited company, Chairman of a number of bodies in the voluntary sector, and currently have a number of business interests, including, since 1995, a directorship of the three Michelin stars restaurant The Waterside Inn, Bray.

I would never have imagined that the sting from a small wasp could have had such a huge impact on my life and those around me.

The Impact of Anaphylaxis

There are many possible symptoms of a severe anaphylactic shock suffered by the victim and these are well publicised and documented. Without minimising the importance and severity of the physical effects of anaphylaxis, only modest consideration and academic research has been undertaken on the psychological impact of anaphylaxis on the patient and their families and the quality of life issues that ensue. Perhaps we, the patients, are in any event the best placed to provide that perspective,

The physical symptoms of anaphylaxis are of course well researched and may present themselves in different degrees to the patient: these include flushing, hives, throat swelling, difficulty swallowing and speaking, heart arrhythmias, abdominal pain and reduction in blood pressure.

The one symptom, acknowledged by patients and doctors alike, that does not disappear quite so quickly is the "impending sense of doom" as described on The Anaphylaxis Campaign website and many others.

For many patients and their families, this sense transforms after the event into a level of anxiety that rationally is not appropriate to the threat. We know that provided we carry our adrenaline and administer it correctly then we should probably overcome the shock and survive. It was following years of self-reflection and discussing these anxieties with patients that it became apparent that this anxiety did not arise simply from the statistically unlikely threat of death, but also from the experience of anaphylaxis itself and its possible reoccurrence in the future.

It's Also About the Shock

Anaphylaxis is the most horrendous trauma to experience – one minute you are absolutely fine and within a few minutes you are literally fighting for your life. I can only compare it to being forcefully drowned in water – if you could imagine some malevolent entity forcing your head under water, the pain and terror of drowning, a chest bursting to breathe, breathing in fluid, noise, bubbles, sheer terror. And there is nothing that you can do about it. That is like anaphylaxis.

Anaphylaxis literally takes over the body and whatever you try to do does not change the terrifying, painful, overwhelming slippery path of the condition towards a seemingly inevitable end.

I can personally confirm that at the time of my second shock I both welcomed and chose to give up the fight for life and slip away, as the fight was simply too painful, exhausting, overwhelming and horrendous to continue. I was fortunate in that the emergency treatment, once I had lost the fight and consciousness, got me through the event to live and tell the tale.

It may be that for many professionals it is difficult to understand why the threat of shock can be just as terrifying as the threat of death.

But it can be, and for many patients I think it is more so.

Why Adrenalin Injectors are not the answer

For most venom allergic patients an adrenaline injector is far from ideal because it does not prevent anaphylactic shock but instead treats it.

After venom anaphylaxis the simple pleasures of life take on a sinister edge to them: the family picnic, the children's sports day, watching cricket, a day on the beach, mowing the lawn, sitting in the sun, shopping, and gardening. Do you avoid these simple activities altogether as too high risk? Do you participate in them and enjoy them like you used to do before your venom allergy reared its head? Can you imagine how it must feel for the family who may well have witnessed the horrendous shock (and emergency treatment) before participating in these activities with you, fully aware of the possible outcome following another sting?

The provision of an adrenalin injector is like offering an individual with a weak heart the opportunity to carry around a defibrillator – it might save my life but the quality of life whilst waiting for the event is poor. A heart patient would always choose a valued course of preventative medical support like advice on diet, an exercise programme, blood thinners, stents or a by-pass so that he or she could live a sensible normal life. Similarly, as a venom allergic patient I would far rather have a proven preventative treatment – venom immunotherapy – than suffer the considerable anxiety and inevitable reduction in the quality of life for my family and I.

The adrenaline injector, whilst offering important potentially life-saving medication, surprisingly offers little psychological support and does little to alleviate the very poor quality of life experienced by people with venom allergy. The reality is that people with severe allergy never, ever want to suffer anaphylaxis again just like someone with a weak heart would never, ever want to suffer a heart attack again. Where possible, the focus for the patient must always be on the treatment of

the condition and not the life-saving emergency medication which may be required for the effects of the condition.

Venom Allergy is Different

Anaphylaxis affects all severely allergic patients and venom allergic patients are no exception to this rule. There are however a number of special features of venom allergy.

The first feature is that allergen avoidance is particularly difficult – in the UK bees, wasps and hornets may be found outdoors for up to 10 months of the year whilst indoors they may be found in lofts, airing cupboards, under beds throughout the year. In truth you are never, ever "safe" and professional advice not to wear bright clothing, perfume, or flap around in panic is in our experience pretty ineffective against an aggressive wasp or a fast moving honey bee.

Secondly, many venom shocks occur outside in locations more remote from medical assistance than say food shocks – these precious minutes count in the event that the adrenaline is not available or is not administered properly. The sting victim is also more often alone in contrast to, for example, food, latex or pharmaceutical anaphylaxis which typically takes place in an environment populated with other people.

Thirdly, in my experience venom allergic patients are "outdoor" individuals, typically adults, whose employment is outdoors (eg builders, farmers, road engineers) or their passions, hobbies and interests are outdoors (eg gardeners, bee keepers, sportsmen and sportswomen). Venom allergy is not just an inconvenience for these individuals but typically dramatically changes their lives.

Finally, research indicates that venom anaphylaxis is, after medications, the fastest to occur after exposure to the antigen. There is so little time to get things sorted out before the shock hits and this makes the allergy especially worrisome.

In short if there is a way of desensitising our response to venom then it is no surprise that venom allergic patients are especially interested.

The Patients Perspective

In my experience, the great majority of patients undergoing venom immunotherapy hugely value the treatment offered. The people that contact me through my website are often those who have gone through the treatment but are having difficulties coping with the physical and psychological challenges. However, to a person they all continued the treatment as much as they possibly could and the vast majority, including the writer, have nothing but praise for the improvement in the quality of our lives from what was a very difficult place to live. Its value for us as a group can be seen from the evidence:

1) We agree to be injected with venom

Undergoing venom immunotherapy takes considerable courage. For the venom allergic patient, who may have suffered a very terrifying shock, it is extremely brave to volunteer to take the risk of

having another shock. We would not take that risk and the burdensome treatment schedule unless the alternatives of living with the risk of anaphylaxis and an adrenaline injector were preferred.

2) We rarely miss appointments or stop the treatment

The NHS has indicated that across the board 1 in 10 outpatient appointments are missed by patients with no warning or reasons given. In a random sample of 6 weeks in my own allergy clinic there were 134 venom immunotherapy appointments and 6 non attendances – most of whom advised the clinic of their non-attendance in advance, and all of whom returned to the clinic the following week. Given the length of the course of treatment, my own allergy clinic has very few drop outs and those that do occur are typically for medical reasons and not because the treatment is considered of little value by the patient.

3) We know it works

We know it works during the course of treatment because we are routinely injected with venom and have no anaphylactic shock. Once we leave the clinic and have finished the course of treatment, unlike most patients we have nothing physical to show for the treatment such as a scar, mended bones, or shrunken tumour. We do have however an extraordinary peace of mind and improvement in confidence, perhaps unique in medicine, which arises from desensitisation. This intangible benefit has a value beyond any obvious physical benefit and we don't need to get stung to prove that the treatment works – for the great majority it works because we have our psychological lives back and not just because of the change in characteristics of our immune system.

4) We readily sacrifice time and money for the treatment

A typical course of venom immunotherapy consists of perhaps 12 treatments in the build of phase and then 36 maintenance treatments over a three year period – a total of 48 treatments all of which are held during the working week. Many patients, particularly outside of the south-east of England, have journeys to the specialist allergy clinic of more than an hour. The cost of time, travel and lost income on patients and their families is significant and once again indicates the genuine commitment and value that is placed on this course of treatment.

Conclusion

For many patients venom immunotherapy is a curious treatment. It is hard for us to understand why it works, why its administration and protocol vary from clinic to clinic, quite how long the benefits last, and for many patients there is apparently little follow up after the treatment has been undertaken.

Despite its unusual features, venom immunotherapy is a course of treatment that allows its patients to return to a quality of life that for a period of time between the shock and the treatment seemed completely unattainable.

It value and importance to us, the patients, is considerable.