ROLE OF PATIENT ADVOCACY

FROM ONE PATIENT TO A NATIONAL ALLIANCE

HOW DO PEOPLE GET INVOLVED?

I founded a charity in 1993 after my own daughter was, after more than three years, diagnosed with reflex anoxic seizures. We had made many, many visits to GP, paediatricians and neurologists. We had been through many tests and four different hospitals. We started with my local hospital, were referred onto a teaching hospital, and then went privately to London. It was as a result of one of the numerous letters to 'The Paediatric Neurologist, The Children's Hospital, Any Town, Anywhere' that led to a professor in Scotland. We travelled with my young daughter, still suffering up to eight blackouts/T-LOC per day, to see him. Finally after further, and in some cases repeated, tests a diagnosis of reflex asystolic syncope (RAS), as it is now known. I was told my daughters' heart was asystolic; it had completely stopped during one of the tests for 28 seconds! Unbelievably I was informed there were no treatment options.

- Would there be long-term damage?
- Would she die?
- How could she survive if her heart was stopping and she wasn't breathing?
- Would there be brain damage if her brain was being starved of oxygen albeit for brief periods, but nonetheless it was occurring up to eight times a day and that wasn't normal?
- What should I do to help her and to help my other daughter who frequently witnessed her younger sister collapse and 'die' several times per day?

I had so many questions and yet there were so few answers. The paediatric neurologist who originally named this condition in 1978, and who diagnosed my daughter, asked if I would be prepared to speak to others. Well if medicine could not be prescribed to make her better then maybe if I spoke to others they would be able to give me advice!

Key learning points:

- Patient groups are often started by patients, families, carers and spouses who have had a terrible experience and may have formed adverse opinions about the health professions and the healthcare system
- Patient advocacy groups have tremendous power by virtue of their experience and the view that their motives are of the highest order
- Professional groups should be aware of adverse experiences in patients' advocates, but harness their energy and effect to improve care for all patients

Trudie Lobban, Arrhythmia Alliance

AFTER MY EXPERIENCE, WHAT DO I THINK OF DOCTORS?

I have always tried to work with the medical professionals. I never see it as a battle, there is no point, and there would be no winners. The important thing is to learn from experiences and try to improve. My reasons for forming a charity?

- If there were no treatment options for my daughter then maybe by speaking to others I could learn how to cope.

- Perhaps by sharing my experiences and raising awareness, others would not go through the anguish and stress, we as a family experienced for over three years by not knowing what was wrong with our daughter. Now 12 years later I can still learn and share these experiences as each milestone is reached and overcome or circumnavigated.

- Gathering experiences, sharing them with each other and with the professionals may lead to research, treatment options and maybe even a cure.

Last month our charity received over 35,000 hits to the web site, 7,000 of those were unique hits. The Freephone Helpline has seen a 91% increase in the last 12 months. An average of 1,750 e-mails per week are dealt with. I think these figures prove the need for patient groups.

As I joined forces with other parents and individuals living with syncope and reflex anoxic seizures, so I came to realise that although our charity has taken huge strides into raising awareness, we could make even larger steps by joining forces with similar organisations with the same aims and objectives.

WIDER AIMS AND OBJECTIVES

I realised that in spite of the workload, the smaller “arrhythmia” charities would struggle to get their particular voice heard amongst many. A larger campaign would have a greater impact; all the voices could combine together and be heard as one. Hence the formation of ArrhythmiA Awareness Week, (www.aaaw.org.uk).

CMA, SADS UK and STARS and BCPA formed a partnership to raise awareness of arrhythmias and to seek the inclusion of a new chapter on arrhythmia into the NSF. This campaign, together with others, was without doubt a success. However, one campaign does not complete the task, hence the formation of the Arrhythmia Alliance (www.arrhythmiaalliance.org.uk) – to bring together patients, patient groups, medical professionals and allied groups, and industry, all working under the umbrella of the Arrhythmia Alliance to raise awareness of all arrhythmias, to improve diagnosis and treatment options thus leading to a better quality of life.

These groups remain independent, serving their own particular community, but can join forces as the Arrhythmia Alliance to make a real difference. The Arrhythmia Alliance can facilitate for and on behalf of these groups thus enabling them to reach a wider audience and have a greater impact.

Key learning points:

- Patient groups can help to galvanise action and cut through traditional barriers between agencies such as government and the professionals

- Patient groups easily outstrip supply-lines and need recognition and public and charitable funding to be effective in the longer term. Mechanisms need to be explored to find the best method of channelling public funding to the best effect

- Partner groups such as the professions and industry have much to gain by effective alliances with patient advocacy groups

EFFECTIVE USE OF COMMUNICATION TOOLS

When ArrhythmiA Awareness Week commenced there were just three key people. However by channelling our energies back to the members, who are all volunteers, we suddenly had an army of 6,000+. Tapping into the skills of these volunteers and recognising their worth made the campaign a success. The use of volunteers is under valued. It should be recognised that volunteers are employees, bringing with them particular skills, the only difference is – they are unpaid.

6000+ volunteers based around the country is a very large corporation. Much can be achieved with a workforce of this size!

Key learning points:

- New technologies, such as the internet, are replacing older forms of communication such as posters and leaflets, and are empowering patients many of whom come armed with information from health websites.
- Government and professional groups could make better use of Patient Advocacy Sites as portals for accessing better arrhythmia care, and accessing information for healthier living.

HOW TO PUT PATIENT ADVOCACY IN PLACE FOR ALL PATIENTS

Charities are the central contact point between patients and public knowledge. Patient Advocacy groups learn what the patients want and can disseminate it to those who can do something about it. Patient groups build up a huge database of knowledge about how treatment and diagnosis have affected them. This information can be shared and used to improve future diagnosis, treatments and therefore lead to improved quality of life. It is an important part of any charity not only to give information and support but to also gather information and inform the medical professionals and government to help bring about change.

This document would not have come about if it were not for the hard work of all the charities involved in highlighting the arrhythmia issue.

Trudie Lobban, Arrhythmia Alliance

KEY STEPS FORWARD:

- Patient advocacy groups must have local and national partnerships with professional groups
- The Arrhythmia Alliance must help with implementation of the NSF for Arrhythmias by working with Regional and National representative groups and local cardiac networks to identify areas of low access, and provide patients with the information they need to get the care they deserve
- The Arrhythmia Alliance must help with implementation of the NSF for Arrhythmias by working with Regional and National representative groups and local cardiac networks to establish workforce initiatives, foster clinical audit and help professionals establish and grow resources for arrhythmia care
- The Arrhythmia Alliance must help with implementation of the NSF for Arrhythmias by working with Regional and National representative groups and local cardiac networks to raise funding for capital projects and make applications for funding from Regional and National sources, such as the National Lottery

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