

The Joys and Toils of Setting up a Patient Support Group



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As a cardiology ward sister, from 2003, who very much enjoyed working ‘on the front line’ so to speak, it soon became very clear to me that there was a huge gap in the advancing service we provide in Sheffield for patients with heart rhythm disturbance.

Whilst medical and surgical therapies and procedures are very much backed and supported by research and finance, in my opinion, no one seemed particularly concerned that these patients suffer a great deal from anxiety and depression with no resource for help other than the ward staff who are often too busy to do basic tasks such as talking to patients.

In Sheffield, we have psychologists assigned to some speciality areas but cardiology is not one of them, therefore it has until recently been left purely to GP’s to refer patients requiring support to psychotherapists based in the community. The problem here is that the waiting times can often run into 12 months or longer.

It is evident from several studies looking at psychological impact of issues such as acute diagnosis of heart disease, new onset heart rhythm disturbance, inherited heart conditions and the need for implantation of heart devices, that the earlier support is provided, the less chance of them developing depression and other disturbances such as panic attacks and inability to sleep. Along with this, we must never forget that the whole concept of cardiac illness does not only provide trauma for the patient, but for the family as well.

Just over two years ago, I became an Arrhythmia Nurse Specialist based at Sheffield Teaching Hospitals Trust. This role has provided me with the opportunity to address my concerns and a large proportion of my time is spent talking, listening and educating patients and families in how best to deal with changes in medical and psychological changes.

Whilst I consider myself lucky to have the ability to empathise, I never underestimate the fact that the only people who fully understand what a situation can possibly be like, is another person who has experienced the same or similar circumstances.

From this, I recognised the need to link patients up with each other. The aim being to share experience, make friends who have a common interest, allow families to gain support and most importantly to allow patients to realise that there are many other people who are suffering as much as they are.

I have developed and now successfully run support groups in Sheffield for patients with Internal Cardioverter Defibrillator’s, and patients with Atrial Fibrillation. These were the two main areas that I felt needed the most support. Both groups started off with a small amount of attendance but have very quickly increased in numbers.

We usually begin the meetings with a formal topical presentation then have an open forum for questions with the opportunity for patients to then speak with various members of staff from all areas within cardiology on a one to one basis if they so wish.

The ICD groups are held twice yearly, and the AF groups are held quarterly.

I have received some very positive feedback from patients who feel that the support group provides them with a voice and a comfortable opportunity to open up their feelings. Many have said that knowing that other people have the same anxieties and fears about their illness is very reassuring.

My personal view is that if only one person, leaves the meeting feeling better than when they walked in, then my motivation and desire to carry on in my plight to ensure that psychological support can and should be available for our patients will have been worth it.