

# The Patients' Views

The experiences of the North Gloucestershire ICD Group  
(June 2007-June 2008)


Affiliated to the Arrhythmia Alliance – the Heart Rhythm Charity



The ***N. Gloucestershire ICD Information and Support Group*** was formed a year ago. We have 46 members (29 with ICDs) and about 60% are men.

We meet quarterly and exchange our experiences in a relaxed, friendly atmosphere. We have a telephone 'Helpline'.

**We are never short of views!**




“ I didn’t realise there were  
so many people in the same  
boat as me...”




**The Problems:** Shock; Isolation;  
Bewilderment; Who to talk to?

**The Solution:** Find a credible focus for  
the Recipient and the Carer



“Well, I talked to my GP and he said ‘how interesting’ - he had heard of these things but never seen one.....”


“The practice nurse asked me what an ICD was.....”



**The Problem:** In many instances there exists a substantial disconnect between the Pacing Clinic/Consultant and the local GP/Practice Nurse. Will this be exacerbated/alleviated by Remote Monitoring?


**The Solution:** I dunno!

Thanks to the AA and its Arrhythmia Awareness Week for the Information Packs we have distributed to GPs



“I have to speak quietly,  
because if he hears me talking  
about him, he will get really  
upset...”


“He will never come to the  
meetings as he does not want  
to talk about ICDS...”



“Do you have frightening dreams....?”

“Do you sleep OK since your ICD...?”

“Does Colin have mood swings like Charlie does...?”



**The Problem:** The multifaceted  
'psychological baggage' that comes  
with ICD – for Recipients and Carers;  
The lack of any available therapy on the  
NHS


**The Solutions:** I dunno!

- Availability of, say, CBT on the NHS?
- Create a forum for Group/Self help?
- Do we have to do it ourselves?



“What can I do about my frozen shoulder?.....”

“I used to be so active, but since the operation I have not done much.....”



**The Problem:** No salient Physiotherapy input after Implantation; **no Rehab.** and no consistent messages across the country. For some, acquiring an ICD is the first step to becoming an invalid

**The Solution:** A national, structured REHAB programme, to get people back on their feet, and moving again. Generate the momentum and capability as seen for Heart Attack victims; serving as a prime focus for mutual support



“That amiodarone is the  
Devil’s own medicine....!”

“I was OK till they put me on  
warfarin....”



“Do you ever feel dizzy...?”

“I’ve got no energy...”


“It used to be 2 pills a day,  
now it’s 7.....”



“What will I do if I need an MRI scan...”


“They said that if I get Alzheimer’s, like my mother did, I can’t have any treatment...”

“My gout is terrible and the medicine does not work anymore...”




**The Problems:** Understanding modern pharmacology (drug-drug,- environment, diet-interactions); adverse reactions; ‘complex’ cocktails; the GP/Consultant relationship; subsequent changes in health (Alzheimer’s; cancer; surgery)

**The Solution:** I cannot think of one. Maybe expert speakers at meetings; ‘Better’ hand-outs at discharge; ‘healthy heart’ clinics giving salient information



“I’d love to come, but I can’t get a lift – my wife does not drive....”

“The trouble is Oxford (Bristol) is just too far away and there are no buses.....”



**The Problem:** For the older, more infirm ICD recipients, transport/driving to their (usually distal) Centre of Expertise is a serious problem (complicated by DVLA Rulings)

**Solutions:** Local down-loading; remote down-loading; more local 'Information and Support Groups' (promoted by the Centres of Expertise and co-ordinated by the AA/BHF)



“I don’t have a computer....”

“I don’t understand this  
Internet...”

“I feel so alone...”



**The Problem:** Communication, particularly to the ‘no-computer’ generation/the elderly

**Solution:** Keep working together, airing problems and evaluating approaches; identify ‘Buddies’


**Special acknowledgement:**

To the cardiac staff at the several hospitals we have come into contact with


To the Arrhythmia Alliance, for their continuing help and encouragement



**Is it worth it?**



“Oh thank you, thank you for  
setting up the Group....”



“How am I? Well, I am still a bit sore after having the box fitted, but I have nearly finished installing my new kitchen.....I have only got to fit the granite work-surfaces – do you have any advice on that.....?”

# North Gloucestershire ICD Group

Colin Prottey  
Robin Harvey

[www.icd-gloucestershire.org.uk](http://www.icd-gloucestershire.org.uk)