

MK ICD Group Newsletter



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MK ICD Group Newsletter

Introduction

Hi everyone. The newsletter has taken on a simpler format this month. Rosie was kind enough to share the template that Sam had produced but unfortunately we had software problems and in the end had to revert to this Word document. Still, hopefully it will not detract from the content!

Thank you for attending the November meeting and we hope you all found it informative and useful. We welcomed 3 new members, enjoyed 2 guest speakers, caught up on some relevant medical news and grilled Debbie during an impromptu question & answer session! We thought the general meeting agenda ran well and hope to include similar sessions in future meetings.

New members – Lingerie & pushing cars...

We welcomed 3 new members; Lynda Temple and Tom & Ella Bullen. Lynda had her subcutaneous ICD fitted in August and is still getting used to it. In particular the device is rather in the way of ladies underwear. So Lynda is considering patenting a device friendly range of lingerie for the growing band of women having SICDs fitted! Tom learnt he had Brugada's syndrome following a cardiac event when pushing a friend's car. He has had a subcutaneous ICD fitted and made a full trouble free recovery from his implant. Learning to live with the device is taking a while and he does find himself knocking it about a bit. He is clearly very active with 3 young children and his work/hobbies include arc welding so it was useful to have Floyd Brown from Boston scientific there to answer questions on welding with an ICD.

Floyd Brown – Boston Scientific. Devices & useful reminders

Floyd Brown from Boston scientific took the floor and spoke to us about the range of different devices currently available including the relatively new Subcutaneous ICDs. SICDs are implanted in the left side, under the arm with a lead running across the abdomen and up the side of the sternum. SICDs cannot pace or synchronise the heart, they only monitor the heart and deliver a defibrillation shock if necessary. The size and positioning of SICDs is fairly fixed due to the way they deliver their shock so there is not much expectation of them getting significantly smaller. They are quite substantial in size compared to CRTDs & ICDs.

Floyd explained that transvenous devices such as pace makers and CRTDs have leads which run inside veins and inside the heart chambers. This creates inherent difficulties in terms of lead longevity and complications which may be solved in the next few years with wireless devices. Such devices are already in the testing phase and involve small "items" placed inside the heart chambers as necessary according to required treatment. These will talk wirelessly to the "mothership" ICD unit implanted elsewhere in the chest that will monitor the signals and talk back to deliver therapy as required. These could be available for patients in as little as 2-3

years. (A question was raised as to whether the "mothership" boxes had to be implanted but the risk of leaving it on the bus or in another pair of jeans at home made implantation somewhat vital!)

A few other reminders came up in terms of safety. Certain environments involving magnetic fields can switch off devices. Once the magnetic field is no longer present the device will simply switch back on with all previous settings retained.

Reminders:

Stay at a distance when electric buses are charging (in MK you may not board a charging bus).

Don't loiter in between security thingies in shop doorways or at airports.

Don't lean over conduction cooking hobs, ok to cook at normal arm's length.

Beware when doing high voltage arc welding. Short bursts should avoid the device becoming confused and thereby remove the potential for delivery of inappropriate therapy.

Debbie – pacing & local MK cardiac Q & As

Debbie let us know that a replacement for Dr. Khiani is looking likely as a locum in December, potentially going permanent early next year. The current hot candidate is a doctor from Leicester, the biggest ICD implant centre in the country.

People had various other pacing related questions that Debbie ably answered but I didn't make a note of them – sorry!

Current news & medical technology developments

St Jude have developed microchip monitoring for heart failure. The chip is implanted in the pulmonary artery and monitors fluid level in order to help patients and doctors control heart failure before symptoms show. The idea is it will keep people out of hospital. There was no clear news on when or whether this is readily available yet.

Energy drinks can unmask heart faults and induce electrical events in people with heart problems. Reported instances varied from palpitations right through to ventricular fibrillation and most relate to over consumption, i.e. more than 1 can at a time.

MRI compatible ICDs are now available for patients but people do not receive an "upgrade" for this or any other reason if their current device is still delivering appropriate therapy. This was a combination of news, confirmation by Floyd and the upgrade warning by Debbie!

EBR are developing a wireless pace maker which is already in trials but it's not a CRTD or ICD. Those will come next as Floyd explained because pace makers are much simpler.

Kerrie Brindle – diet & fitness

Next up was Kerrie Brindle from Benefit Health and Fitness who provides health advice to small businesses. She got us thinking about the problems & health implications of growing obesity. The main reasons we all know are sedentary lifestyles and convenience foods. Kerrie then had

us playing our cards right. We had to guess the calorie comparison of different foods and some came as a shocking surprise. A few calorie examples that got either a laugh or a gasp:

- ❖ A pint of Beer only 3 higher than 4 fish fingers.
- ❖ Soup 844 per tin veg soup, same as in a KFC meal!
- ❖ Pizza 2768 (medium domino pizza).

Slow to digest food is better healthier option as people feel fuller for longer rather than the quick hit from rapidly digested food which leads to craving. Hidden sugars seem to be everywhere. A can of coke contains 35g of sugar in coke which is approx. 9 teaspoons of sugar but that is less than a bottle of milk shake coming in with 46g of sugar. Even that healthy choice smoothie you enjoyed weighs in with 24g. The message? Cut out sugar and up water intake.

Looking at our waistline can tell us something about our risk for diabetes, heart disease and other "lifestyle" disease. We're in the high risk category if our waist measurements exceeds 88cm (36 inches) for women or 102cm (41.5 inches) for men.

Exercise and getting active gives many benefits including improved immune system, better sleep and being better mentally focused. Muscle work also helps maintain bone strength, even something as simple as regular baked bean tin lifts in the kitchen.

- ❖ So to round up some simple steps to better health.....
- ❖ Eat your 5 a day with preference for veg over fruit
- ❖ Cut back on sugar and snacks
- ❖ Stop eating refined and make wholegrain choices
- ❖ Eat fresh home prepared whole foods whenever possible
- ❖ Do 150 mins of appropriate exercise a week such as 5 x 30 min walks.

Topics & dates for 2016

The meeting wrapped up with helpful suggestions of topics for future meetings. We are looking for speakers on these topics. If you have more ideas please let us know. We already have a local cardiac focused GP, a member of the genetics team from JRH & Gill from MKCCG booked with others getting back to us shortly so should be an interesting year.

- ❖ Other device manufactures
- ❖ Our new MK consultant once they've settled in!
- ❖ Remote monitoring
- ❖ Medications
- ❖ Cardiac nurse
- ❖ GP their role in helping us manage our medications and heart conditions
- ❖ Various different cardiac conditions specialists
- ❖ End of life issues
- ❖ Genetics in relation to cardiac conditions
- ❖ MK Community Cardiac Group
- ❖ Medical statistician
- ❖ Cardiomyopathy Association

- ❖ CPR & external defibrillators – keeping people alive until help arrives

Next year's meeting dates in case you missed the fridge magnets! All 10 am to 12 noon.

At Age UK, Peartree, Milton Keynes:

- ❖ Feb 2nd
- ❖ June 7th
- ❖ Sept 6th

At Peartree Bridge Inn, Peartree, Milton Keynes:

- ❖ November 23rd

Would you like to get involved?

Martin and I would like to ask if anyone would please take on the newsletter. This is written in Word so as it is easy for anyone to use but if you prefer to use a different piece of software that's fine! It just means taking a few notes during the meeting and then writing it up to email out. Please give us a ring or drop us an email and we can send you the file to use. Thank you.

Accounts

These are being sorted out so we'll bring you up to date on donations and expenses next time.

Spread the word about MK ICD support group.

Please pass on details of the group and our contact information to anyone you think could benefit or who would like to talk about living with a device. We can also arrange to talk to patients in hospital or prior to making a decision if they would like to hear the patient perspective.

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