

Minutes of Meeting Thursday 2nd August 2012, 2-4pm
Venue – Mackenzie Medical Centre, Burnley General Hospital

23 people attended, including Deborah Dobson from Blackburn Hospital and our guest speaker Steven Edwards.

Our Chairman Martin opened the meeting by informing us that a range of books had now been purchased with the grant money received from Macmillan Cancer Support and all were on display as our own 'library books', **please sign out a book for anyone wishing to take them away!** He then introduced the new attendees and (gently) invited them to share with the meeting their Prostate Cancer journey's to date.

Graham who had recently been diagnosed said that his initial treatment had been Radiotherapy but he had been on Hormone treatment since, however he had decided to come off it due to it causing side effects, (hot flushes and crying when watching anything emotional.) Graham had been recommended to come to the group by Deborah so that he could find out more about other treatments and to speak with other men who had had to make decisions about treatments, he had found it very helpful.

George, who is very quiet and reserved didn't speak too much, and he did say that he had had 37 Radiotherapy treatment sessions!

Glyn said that he had been diagnosed 5 years ago after seeing his GP for a routine 'MOT', he received a call 5 days later asking him to go back immediately. Following further tests and a Biopsy he was advised that he would require a Prostatectomy. Following his Prostatectomy he was fitted with a leg bag due to incontinence, he later had an Artificial Sphincter fitted which had caused him difficulty although he now says that it has settled down and that he does not have much difficulty at present.

One of our members informed the meeting that the Rosemere Foundation for North Lancashire now has a new unit where patients can receive Radiotherapy treatment and that a Prostate Cancer patient has just been treated there.

We have received a letter from the NHS regarding the funding which has been offered to help the start up and finance Support Groups. As we know Donna Sheridan has had the responsibility for organising this and she has done it very successfully, now the funding for her position is due to cease. Four area meetings have been arranged for anyone who have any concerns or want to comment on this, the meeting for our area is on **Thursday 6th September at Pendleside Hospice, Colne road, Reedley, Burnley at 11-00 am**

Following a 15 minute break the meeting reconvened with Martin introducing guest speaker Steven Edwards, Steven is Head of Patient Experience at Lancashire Care NHS Foundation Trust. He explained that he started his career as a Journalist (Communications) and one of his jobs was working for a Hospital radio station, he then moved to a large Pharmaceuticals company in the roll of main Communications, Product and Patient Communications, he then moved to Canada.

It was whilst working in Canada that part of his work was to look at how Support Groups operate in other countries with the emphasis on Cancer screening. He said that when patients are diagnosed they should have access to all the opportunities and facilities which are available to them e.g. Specialist staff and Clinics and where they are to be found. Too often patients are sent away with little or no information, we as patients should ask for anything that we need to know and insist that we are given as much information as possible. It is only by doing this that our Doctors and Nurses will know what we need! Deborah said that patients have a right to complain but they can also speak out without actually complaining.

Martin asked Steven what in his opinion makes a good Support Group? He said that a group like ours is a good example, where people are 'face to face' and the meetings are light hearted as much as possible. He said that in

his experience women's meetings are different to men's, women seem to prefer chatting together in groups whilst having tea or coffee whereas men like to talk more privately with friends or professional people. - This gives 'food for thought' with regards to our meetings, as we have both men and ladies in attendance at our meetings it might be a good idea if the men and the ladies have about half an hour separately to discuss any personal or sensitive matters, some other groups already do this.

Steven said that it is also worth forging links with industrial organisations in order to get our message across. He then gave us some very interesting information about how the Toronto group operates; it can be viewed on www.pccntoronto.ca – well worth a look!

Colin from the Bolton group who visits us regularly told us about the next meeting and A.G.M. of the Prostate Cancer Support Federation N.W. at the Christie Hospital, ward 7, 15th September 1-30pm. (There are no parking problems on a Saturday). A leading Neurologist from Stepping Hill will give a lecture about the side effects of treatments and surgery and Erectile Dysfunction.

Many thanks to Dave Howard who gave us a £10 donation.

The raffle raised £24

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