

Minutes of meeting Thursday 7th June 2012, 2-4pm
Venue – Mackenzie Medical Centre Burnley General Hospital

18 people were in attendance at this meeting including new attendee Richard, presumably the number was lower due to the good weather and holidays.

It was decided that we would have a more informal meeting and general discussions from the floor. Martin commenced by saying that he had seen an article about the organisation N.I.C.E, he asked if anyone in the room knew exactly what they do other than control the availability and financing of drugs etc. for the N.H.S. Fortunately our regular visiting nurse Deborah Dobson was present again and she was able to provide some more information about N.I.C.E. She explained that they issue guidelines for G.P.s to work to, for example, to establish the best ways for G.P.s. to diagnose and talk to patients. Moira, who has previously worked for the N.H.S. said that it is important to have an organisation such as N.I.C.E. otherwise all sorts of drugs at all sorts of prices would flood the market place. The guidelines, for all types of Cancer and other illnesses are based on worldwide experiences and are to ensure that Doctors, Specialists and Clinicians work within them.

A discussion took place as to how people can acquire more information from the 'health system' as many patients often feel as they have not been given information or been told enough by the Medical people. Deborah said that the Professionals and Medical people have to be discretionary and careful because some patients don't like too much information, particularly if it is not good news. She said that is also very difficult because every patient's illness or cancer is different and she continued by saying that patients and Support Groups can have a big impact by lobbying organisations such as N.I.C.E.

New attendee, Richard, gave us a brief insight into his situation and how he had decided to attend our meeting after seeing the information published in the Burnley Herald. He commenced by telling us that he is 79 years of age and has been suffering from Liver Cancer, it was whilst having treatment for his Liver Cancer that a blood test showed a PSA reading of 13, he also had an enlarged Prostate (BPH) and following a Prostate Biopsy it was discovered that Cancer cells were present. However, he said that his Prostate issue had to be put on the 'back burner' whilst having treatment for his Liver Cancer.

Richard said that he was only told that his Prostate Cancer is 'normal' for a man of his age and had no idea what is supposed to be 'normal'. After reading about our group he decided that he needed to attend our meeting to find out more about Prostate problems. His main concern was to find out what treatments are available and to learn more about them in order to help him make decisions. He explained that he had not been given too much information by the medical people. Steve explained that he had Hormone treatment prior to having Radiotherapy and it has been successful for him to date. He said that he has a very positive attitude and that the Prostate Cancer does not control him, he controls it! Steve said that when he was diagnosed he also had not been informed as well as he thought he should have been about potential side effects from having treatments.

Deborah said that following diagnoses Doctors and Clinical staff get together to discuss patients' conditions and treatment options. (one thing that is always apparent at our meetings is that information does not seem to be getting back to the patients from the medical people)! Richard said that he had learnt a lot from our meeting and he is looking forward to attending our next meeting in July.

Martin informed everyone that six of us had visited the Sanctuary of Healing and had a very nice lunch in the café, we were then taken on a tour of the venue, which was extremely impressive! The Sanctuary of Healing offers many types of therapies for wellbeing and each room for Therapies is a sight to behold. He explained that they take group bookings and would be able to accommodate us as a group in September and it is anticipated that each person who attends would receive a £20 voucher to spend on or towards a treatment of their choice.

Don suggested that we might have different events by taking advantage and utilising other peoples hobby's or interests David suggested having a 'Buddy' system whereby people at the meetings can have the opportunity of pairing up with others who have the same problems or interests.

The raffle raised£22

Next meeting: Thursday 5th July, 2-4pm at the Mackenzie Medical Centre, Burnley General Hospital