

Minutes of meeting Thursday 5th July 2012, 2-4pm
Venue - Mackenzie Medical Centre Burnley General Hospital

There were 24 people in attendance at this meeting. Chairman Martin introduced himself and welcomed guest speaker Polly Harris and 3 new attendees. Polly is a specialist nurse for the East Lancs Hospital Trust and works in the Incontinence Service at Accrington Victoria Community Hospital. She commenced her talk by explaining that Post Prostatectomy Incontinence is usually temporary but can vary in severity, the tiniest drop of Urine always seems severe because we are all used to being dry, 6 months is classed as temporary but there is a possibility of an increase on 6 months following Radiotherapy. Incontinence occurs due to damage caused through surgery around the Prostate removal area and Urine leaks when pressure in the Abdomen is raised and the muscles that squeeze the Bladder become over active. Pelvic floor exercises are normally strongly recommended following Prostate surgery in order to aid recovery. Consultants and Doctors will discuss post Prostatectomy treatments and drugs etc. with patients. Stu asked Polly; at what stage would a patient be directed to the Incontinence Clinic? She said that the patient would need to have it investigated further and if still not satisfied ask to be referred to the Clinic. She explained that they have only a small team at the Clinic, but they can treat anyone over the age of 4 within 12 different locations in East Lancs. provided they are registered with a GP. Polly said that in the East Lancs. Hospital Trust most men should be offered advice and supplied with pads from the ward prior to discharge from the hospital. Colin said that he had not been offered this advice when he was discharged from Blackburn Royal Hospital and Polly said that men who had just had Prostate surgery would be automatically 'flagged up' as a priority for the Incontinence Service, Telephone No. is 01254 359129 email: continenceadmin@elht.nhs.uk. Polly was thanked for her excellent advice and information she gave us.

Shaun said he had just recently been diagnosed and was going for his Pre Op next Thursday. He had heard of the possibility of Incontinence problems and was pleased that he had come to the meeting to find out more about it. Shaun had also been interested in having Brachytherapy treatment but had been told that it was not an option for him because he had a Gleason score of 8, he had wondered if the reason was due to funding issues, Debbie said it would be due to the severity of his Cancer and his Histology, he said his PSA is 5.5

Our regular attendee Dave M talked to us about his recent operation to have an artificial sphincter fitted due to his lengthy Incontinence problem, He was diagnosed 6 years ago and he had a Prostatectomy, his PSA was 10 but his Cancer was classed as aggressive. He said that he was told by his Consultant that if he had had Radiotherapy he would not have been able to have a Prostatectomy. Dave had found out about the artificial Sphincter from Colin who attends our meetings from the Bolton group, one of their members had the operation and it was very successful. Dave had his operation at Stepping Hill Hospital as this is the nearest hospital for this particular operation. He went to great lengths to explain to us how it was done and how it works – with the help of a white board and his sketches and a little amusement. The operation gave the appearance of 'human plumbing, a pipe, a valve and a pump', inserted into his lower regions! He goes back to be 'switched on' in 3 weeks once all healing has taken place. Less than 1% of men who have had Prostate surgery will need this type of surgery. Dave said that Incontinence had been such a problem to him that he considered it worth having this latest surgery.

Steve said that when he was diagnosed as positive it was a tremendous shock and he had great anxiety when in consultation with his Doctors and Medical staff, he found it difficult relating with them and felt that he was not in control of being able to have the right conversation at the right time. Some suggestions from the floor were: Let the Doctors and Nurses know what you expect from them. Let them know what you think is going on in your own body. Agree a plan of action with them and ask what you need do if things are troubling you or are not progressing as expected, ask who you should contact.

Colin told us that he had his prostatectomy carried out with keyhole surgery and still has discomfort around his stomach area. When he was younger he had an Appendix operation which had caused Adhesions. It was found that when he had his Prostate surgery his Prostate was attached to the Adhesions and he was interested to know if anyone else has had the same problems. There was not anyone present who had experienced the same problems.

John who was here for the first time had just been diagnosed positive and was concerned about which treatments would be best for him. A general discussion took place on the subject and John said that it had been a big help to him that he was able to listen and talk to other people who had already been through the same experiences.

The raffle raised £32

Next meeting: Thursday 2nd August 2012, 2-4pm. Mackenzie Medical Centre. Burnley General Hospital