

**Notes of Prostate Cancer Support Group Meeting
Haywards Heath and District
held on 28 November 2019**

Mike Streeter, Chairman, welcomed everyone to the meeting and explained that, sadly, Andrew Symes, our main speaker, had to cancel his talk with us as he had an urgent operation to perform that afternoon. We hope to engage him next year.

Mike then informed everyone that, sadly, Roger Wotton, Chair of TACKLE, had recently died which was a big loss to the organisation. He also advised that Terry, who had been on the Support Group Committee since the group's inception, has had to resign as his cancer has become terminal. Terry was a very proactive member of the group and his input will be very much missed. A request was made for members to consider if they could find a little time to help out on the committee as we have lost 2 members this year.

First time members were asked to introduce themselves and give a brief outline of their prostate cancer journey so far. We had two new members: Gordon who was diagnosed in March, started hormone treatment and is waiting to see the oncologist in January with a view to having radiotherapy. The second new member was Ian from Brighton who has had hormone treatment since April and radiotherapy.

Jenny outlined a telephone call she had received from a member who was unable to attend the meeting, but he had hoped someone would be able to speak to Mr Symes (Urologist) on his behalf. The problem he asked about was regarding his PSA level which would rise and fall quite dramatically even though he had not been diagnosed with prostate cancer. Jenny was later advised that we did have a member who had experienced this same situation and suggested I pass on his telephone number to the gentleman concerned.

SPEAKER 1: Graham Dale

In the absence of Andrew Symes, Graham, a member of the group since summer 2019, had very kindly agreed to talk about his treatment for prostate cancer. Graham asked members to give a show of hands, firstly, those who were recently diagnosed having had no treatment, then those currently undergoing treatment, and those post treatment. One member was on second treatment for secondary in lymph nodes.

Graham explained his father had died 27 years ago of untreated prostate cancer, age 68. He sadly wouldn't go to the doctor! Since his death Graham had done a study on prostate cancer and the various treatments. He explained he was not medically qualified but felt he did know a lot about the disease which he wanted to share with the members.

Graham's brother and he were tested 11/12 years ago and at that time both were found to have a single figure PSA. His brother's PSA was slightly higher and he decided to undergo robotic surgery on the tumour privately in London with the Davinci machine which was found to be a very good method. Graham explained the basics of the procedure. This treatment is less invasive than radical surgery. The downside is the operative can't physically see in 3D, all around or behind the tumour, and therefore any further problem may go undiscovered. Following Graham's diagnosis about 10 years ago he decided to have a prostatectomy, which he felt was the best treatment for him, even though it was the most onerous at the time. After his prostate was removed, it was found that he had a satellite tumour fixed to his spinal chord which couldn't be dealt with because of the potential of serious spinal injury. He had post operative radiotherapy - 33 doses which was not easy! Graham confirmed he was 56 years old when he had his operation. Graham welcomed any questions.

He confirmed that, to the best of his knowledge, a prostatectomy will be carried out on men over the age of 65 as long as their physical health is good. Opinions of oncologists can vary.

A support group member (age 78) explained that he had HIFU (High Intensity Focused Ultrasound) in August for a quite aggressive tumour. His Oncologist kept postponing radiotherapy because his prostate was so large. However, he heard from someone who had HIFU 5 years ago and because of this positive experience, he decided to undergo the treatment himself. The Ultrasound kills cancer cells by heat which is believed to be very accurate. It may now be available under certain circumstances on NHS. This treatment has not been carried out for many years, due to it not being endorsed by NICE, therefore the data on success is limited.

Graham continued by giving percentages of men surviving prostate cancer in different countries, ie. Great Britain 84% survive more than 5 years, in Bulgaria only 50% - because they rarely go to the doctors, whereas Austrians have a 91% survival rate because they are more cancer aware.

Difficulties experienced in getting a PSA test and digital examination were discussed. It was agreed that if men don't have the PSA test done they'll never know what the situation is as they need a benchmark - a starting point.

Graham's opinion is that the advantage of having a prostatectomy as against other treatment, is there is chance of a 'mop up' if something goes wrong. Currently if you have radiotherapy treatment there's little to mop up if things fail. However, post surgery and post radiotherapy there can still be problems. It was noted that when you've had radiotherapy treatment, you can't have it again. Other more recent treatments are now coming on line. MRI scan prior to treatment will confirm whether or not there are satellite tumours. Men will usually get a choice of treatments.

Graham advised that since developing PC and having treatment, he has stopped smoking, cut down on alcohol and lost weight which he feels has helped him cope with the treatment.

SPEAKER 2:

Mark Witcomb, Engagement Lead for Macmillan, Sussex and Surrey

Richard Longrigg, Partnership Manager for Macmillan

Marc explained that about a year ago Macmillan issued a Research Questionnaire to Hospital Trusts and Macmillan staff to try to identify the information and support needs of cancer patients who were going through the cancer journey. GPs were also consulted as well as Haywards Heath & District Prostate Cancer Support Group, and members completed the questionnaire which also asked about diet, exercise and emotional well being and peer support. They got as many people as possible to complete the questionnaire including those who attended cancer clinics. This enabled gaps in service to be identified which Macmillan and others in NHS could help with in the community.

Richard Longrigg has since been working with Healthcare coordinating the results of the questionnaire. As well as feedback from the support group they received similar feedback from patients and professionals at Princess Royal Hospital and Royal Sussex University Trust Macmillan needed to ascertain how they could help but not just working on their own but working with the NHS and Partners in the community. They asked questions of patients and members of the public to identify any gaps in services. It was accepted that sometimes what patients would like is not always within Macmillan remit. Macmillan staff and volunteers helped and a couple of discussion groups with healthcare staff were involved, plus clinical specialist nurses and their insight supporting patients, the idea being to help support them to help you. The results were collected.

Patient feedback: they have 68 completed surveys. A lot of the surveys were completed during conversations and the level of detail gleaned was really valuable. The majority of people who responded were going through treatment. This included urology and prostate cancer, kidney, and bladder cancer patients.

Comments re Information Needs: There wasn't a huge amount of differentiation between Needs highlighted in the survey and what people told us were their priorities within those Needs. It showed main areas of concern were Information Support and Side Effects of treatment.

- Returning to Work - people do want to return to work in some capacity after treatment.

- Spirituality was brought up, sitting alongside Emotional and Psychological support needs which could be improved in the area. Specific information needed about cancer sites, Financial support, Benefits, Exercise and Physical Activity,
- Understanding how exercise can help and support with outcomes.

How would people prefer to receive the information and when is it most useful to get the information?

Patients would like to receive this information in various ways. Some said leaflets; others conversation or Online access.

Our Conclusion is that we need to be providing information and making it accessible in different formats.

In terms of when this information should be offered, people felt the most useful time to receive the information is when being diagnosed or when undergoing treatment. It was acknowledged that needs can change as patients go through the experience/treatment. Checking on what people's needs are as they go through their treatment was felt to be very important. This aligns with Macmillan's understanding of what patients nationally have advised in that point of diagnosis is very important and when they want their relationship with Macmillan to begin. It is about what information is available, and how to access it throughout treatment.

Where do People currently access information?

According to the majority of people, it seems information is usually accessed in a healthcare setting at PRH or Brighton and this is the most appropriate time. Also people like to access information in their home and in the GP surgery. Macmillan realise they cannot meet everyone's needs with one solution, but at least they now know where the gaps are.

Re Current Services:

People were asked what service would be important to them that they do not access at the moment. Top services were identified as Counselling, Emotional and Psychological support, Financial support and advice, Complementary therapy particularly in connection with challenges of treatment eg. Acupuncture, reflexology, massage for relaxation, yoga. It was confirmed that a patient would speak to the clinical nurse specialist or consultant to see which treatment(s) could be beneficial.

In answer to a member's question, Richard clarified that Macmillan Nurses based in hospitals are funded by Macmillan for 2 or 3 years, following which, once established, the Hospital Trust continue the funding for that nurse. They will however continue to be Macmillan Nurses. Acknowledged there are currently not enough Macmillan Nurses or NHS Nurses. Macmillan are continuing to invest nationally in the nurse specialist role, and more volunteers are being trained. There is an established Macmillan team at PRH but more volunteers are being trained on site to help with access to support.

Members voiced their good and not-so-good experiences when trying to contact Macmillan specialist nurses particularly at Brighton. Richard said that they are already taking steps to improve lines of communication but communication problems as mentioned will be fed back. It was acknowledged that the specialist nurses are 'stretched'.

To enable Macmillan staff to be more easily recognisable, it was suggested by a member that a badge or logo on uniform could be used.

Richard explained that what Professionals, Nurse Specialists and Dieticians say they need is more training and information on is what's available in the local area and where to direct patients to. This will be included in Macmillan's action plan.

Re appointments at the hospital, it was suggested we should all perhaps be more proactive and make contact with the hospital prior to an appointment to ensure it is still happening - and not changed or being cancelled, or of course, if there is a lengthy delay waiting for an appointment,

you may be lucky if when you telephone they have just received cancellation which can be offered to you.

Macmillan currently have an established team at PRH but don't have a huge presence of volunteers on site to help patients access information in absence of specialist nurses. Macmillan are currently developing volunteer roles, trained by Macmillan and hospital, to be on site particularly in chemotherapy, urology and main reception.

The Cedar Room (manned by volunteers) is a valuable resource - but is not always accessible as is used by others for counselling.

Directions to Cedar Room: Situated on Ground floor - into Reception past the Cafe, turn left and left again into Main Outpatients Dept. Just past reception on the right is the door to the Cedar Room. There is an information stand outside the door. Directions and information points are to be placed in Urology, Chemotherapy etc. If the Cedar Room isn't in use the door should be open.

It was confirmed that Macmillan are committed to running and funding the Brighton Horizon Centre themselves.

Richard explained he is very conscious that the survey is more focused on PRH at moment. The wider community will be looked at and they would welcome returning to the prostate support group to get further feedback. **This was Agreed.**

Mike thanked Mark and Richard for their excellent presentation which was enjoyed by everyone.

Date of Next Meeting

Next Meeting Thursday 26 March 2020

JL
3.12.19