

Notes of Haywards Heath and District Prostate Cancer Support Group held on 28 March 2019

1. Introduction

Mike Streeter, Chair, welcomed everyone to the meeting, and asked new members to introduce themselves, giving a short profile of their prostate cancer journey.

The group was informed that Arthur Millard, who had been Secretary and Treasurer on the committee for about 4.5 years, has had to resign because of serious health issues. His input into the meetings will be greatly missed, and our very best wishes are with him.

As a result of losing Arthur's support, Mike explained that the committee would appreciate any offers of help from our members. Anyone who is interested, please get in touch with him, or indeed contact any of the committee. Contact numbers are on website, and of course, you can use Jenny's email address. - jennyleauk@aol.com

2. Exercise Referral for Cancer Patients

Mike Alcock and Lorraine Elsdon from the Dolphin Leisure Centre introduced themselves. Mike leads the Exercise Referral Team. Referrals range from people with depression, anxiety, alcohol issues, arthritis, fibromyalgia, cancer, and their aim is to help get everyone on the right path to maintaining their health. Mike has managed the department for almost 2 years and has been undertaking training. He hopes to qualify very soon.

Lorraine has been with the centre for about a year, although involved in the exercise industry for 35 years. She specialises in GP referrals, cardiac rehab and now cancer rehab. She has undertaken training and is now a qualified trainer.

Classes are for 45 minutes, every Thursday - one class a week - and these take place in a small studio, with hydraulic machines and weights. There is no pressure, and it was stressed you work to your own individual limits. Instruction is given on all machinery for upper and lower body and/or cardiovascular. The weekly class is £4.70. Once they get a GP referral, consultation takes place. Particularly for those on hormone therapy, exercise is recommended ideally for 12 weeks. One member outlined his positive (and fun) experience of attending the gym classes. There are various pricing structures. If you sign up for 10 classes it's £2.60 per class, with access to the gym, private pool, steam room and sauna. Classes will soon be available at the Triangle, Burgess Hill, and Hassocks Leisure Centre with further plans for East Grinstead a little later.

Firstly you need to get a referral from your GP, or Nurse Specialist at the hospital.

Members were encouraged to 'give it a go' as the measured benefits can be as much as 30% for cancer patients. They stressed YOU ARE NEVER TOO OLD.

3. Hermione Davidson, Carers Support, West Sussex

Hermione explained her background and work with Carers Support which is part-funded by West Sussex CC. She is already undertaking work with Macmillan in a partnership role to

ascertain how carers of people with cancer are supported, and also to see what care is available eg, from unpaid family and friends. Macmillan fund 2 positions, North and South of the County. They offer practical guidance and emotional support where needed. She explained that a lot of carers do not see themselves as carers. If a person is independent and dealing with their illness, that is fine, but the person looking after them might be finding it difficult to cope and will probably encounter questions they cannot answer. Carers Support are there to help. Leaflets can be found in Doctors' surgeries giving information on help in the community.

Cards requesting 'Access to toilets' was discussed briefly and thought a great idea. These cards can be obtained from Macmillan, Ring 0808 808 0000

Contact

For Carers Support - for family and friend carers, Ring 0300 028 8888
Offices in Crawley, Littlehampton and Worthing
www.carerssupport.org.uk.

4. Professor Robert Huddart, Cancer Research and Royal Marsden

Prof Huddart commenced his talk by explaining that over the past 5 years there has been a lot of change and development in the treatment of Prostate Cancer.

- **Imaging** – the increased sensitivity of PET scans with Choline and, now, PSMA(Prostate Specific Membrane Antigen) radio-active dyes, are providing far more options for treatment of individual tumour areas. Full body MRI, more valuable than CT, gives a better understanding of metastatic spread and the impact of treatment. PSMA is only available on two machines in London (one at RMH Chelsea) and not available yet for NHS patients. (*Note – A recent invitation to participate in clinical trials , which was received by the Group and passed on to members, included PSMA scans in the trial process*)

- **Diagnosis** – the expanding use of mpMRI prior to biopsy makes the whole diagnosis process less taxing. Increased use of image guided biopsy ensures a much more accurate appreciation of the staging of the tumours. Fewer biopsies mean fewer medical problems from the process, and with treatments being brought forward to earlier stages of the cancer journey, PSA or newer testing programmes may become more valuable with fewer medical problems to balance against, potentially, the increased benefits of early detection.

- **Radio-therapy** – the newer treatments such as IGRT are able to deliver radio-therapy much more accurately enabling the clinical benefits of higher doses over a shorter period of time. (Now reduced from 37 days to 20 days). Spacers, such as Hydrogel (not currently available on NHS) provides good protection for the rectum from radiotherapy damage, although very few problems are noticed with IGRT. MR guided radiotherapy means that the location can be accurately determined to cater for any movements in the prostate due to bodily changes during the process. This is more accurate than the current process of planning prior to treatment and reduces the area that otherwise needs to be treated in order to allow for movement. Two MR Linux machines, made at Crawley, are now being trialled. Currently each treatment needs about an hour of clinical input and this will need to be massively reduced before equipment use. Presently, 2 patients per day, can be rolled out more widely. Further clinical trials are looking at reducing the number of

sessions to 5 over a period of a week. In the long term, it may be possible to have a one-stop shop, over a day, for both diagnostics and radiotherapy treatment. Stereotactic RT, such as Cyber knife, move the radiotherapy source around the body to target the path to the treatment site more accurately.

· **Adjuvant Therapy** is used to increase the cure rate of traditional therapies. For advanced prostate cancer, standard treatment is hormone treatment (eg Zoladex). Recent trials have shown that adding other treatments can extend time to relapse and survival, specifically chemotherapy (Docetaxel), new secondary hormone treatments such as Abiraterone, and the use of radiotherapy on both the main tumour, and metastasis.

Other therapies being tested include:

- other hormone combinations although combining Abiraterone with Radium 223 (used to reduce bone pain) has not been found to be effective;
- Metformin, a type 2 diabetes drug;
- use of Stereotactic Radiotherapy on metastatic tumour, and
- possibly Isotopes.

· **Relapsing Cancer Treatments.** These are treatments which are used once the PSA level starts to increase after treatment with, for example, Zoladex. It now seems that bringing drugs into use earlier in the cancer journey is more effective. The problem is that it takes longer to get the results of those clinical trials than with trials at later stages of the cancer journey. Drugs such as Apalutamide and Enzalutamide, previously licensed for metastatic cancer, are now being licensed for use whilst the cancer is still non-metastatic as they extend the period before the primary tumour metastasises.

For metastatic cancer, potential new treatments include: Lu-PSMA a highly targeted form of nuclear medicine that has been shown to reduce pain, improve the quality of life and, in some cases, significantly extend survival of men who have exhausted all other therapies, and PARP inhibitors such as Olaparib, originally developed for ovarian cancer, which repairs damaged DNA in cancer cells.

Anyone who is interested in getting involved in a trial, please speak to your GP or hospital contact regarding this. Most hospitals are looking for volunteers for trials - eg Brighton, Guildford.

5. Chairman's Thanks

Mike thanked Professor Huddart for what everyone felt was an extremely informative presentation.

6. Next Support Group Meeting

Thursday **25 July 2019** Meeting Room, Dolphin Surgery, Haywards Heath 3pm-5pm.

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NB: These notes are an aide memoire for members who attended the meeting and an indication of what was covered for those members who couldn't attend. No questions/answers are included, and the notes have not been checked by speaker.

