

**Prostate Cancer Support Group
Haywards Heath and District
Notes of Meeting held on Thursday 20 July 2017**

1. Introduction by Chairman

Peter, welcomed everyone to the meeting, with a special welcome to new members, saying it was hoped all members would benefit from the support received by the sharing of experiences and information given by our specialist speakers. The committee members are always available for queries or for any other contact information needed. All conversations within the meeting are strictly confidential.

It was outlined how rapidly things are changing in the field of prostate cancer, life expectancy having been improved tremendously. The side effects of treatment are however still a very real issue.

Peter introduced our speaker, Dr Arnon Bentovim, Child and Adolescent Psychiatrist, who has worked for many years at the Great Ormond Street Children's Hospital, and the Tavistock Clinic in London, and since retiring has been involved in writing and training practitioners in Health, Education and Social Care.

2. Presentation by Dr Arnon Bentovim

Arnon shared his story by explaining that his PSA started rising in 2009 when it rose from 1 to 4. It then rose quickly to 9, and he had a Gleason of 4.5 plus metastases in lumbar 1 and 2. He had private healthcare, and it was arranged for him to have CyberKnife treatment on primary and also for the secondaries. Because of stray cells, he was later treated with Zoladex and bicalutamide to maintain a low PSA. It was acknowledged that the PSA test is currently the only way to monitor the situation, and any sudden rise must be investigated.

CyberKnife is an Image-guided stereotactic radio surgery system. The system refers to advanced, patient-friendly machinery equipped with a robotic delivery system, image detectors, linear accelerator, targeting system, manipulator, ex-ray sources and synchrony camera. CyberKnife delivers accuracy levels in sub-millimetres of the targeted area to provide greater efficiency with highly precise outcomes - not necessarily more effectively than standard radiotherapy, but more conveniently. CyberKnife, being a robot controlled advanced system, renders greater flexibility and manoeuvrability.

Advantages of CyberKnife:

The radiation source is mounted on a general purpose industrial robot and this mounting source allows near complete freedom to position the source within a space around the patient. It allows very fast re-positioning which enables the system to deliver radiation from many different directions without the need to move both the patient and source as required by current gantry configurations.

Another advantage is that the CyberKnife system uses an image guidance system allowing instantaneous ex-ray images to be obtained.

It takes as few as 1 - 5 sessions for the CyberKnife process to cure tumours and help patients with fast recovery. It is beginning to be available on NHS. CyberKnife is one solution for all tumour types. It is technically sound, reliable and safe for all age groups. There are few side effects other than nausea for a couple of weeks and some tiredness. Zoladex maintained Arnon's PSA at a low level. Arnon does not regard it as a cure, but hopes the reduction of activity will mean he does not have such a virulent tumour.

Psychological Coping:

Dr Bentovim outlined the fears felt by newly diagnosed men and explained that research has indicated most adults are psychologically resilient and do quite well at coping. Some believe we should always think positively. However, studies show that it is OK to be sad and angry, to have great days when we feel positive, do what we can to achieve our goal, and of course experience days when we feel less positive and aware of the realities of our situation.

A good coping strategy is to find as much information as we can about our specific cancer. It is accepted that we need 2 support teams: First, our family and close friends who are an enormous comfort, and second, a medical-psychosocial team. It was felt a parallel approach may be needed to help people with the situation.

Other 'psychological coping' help can be found in:

- The 'Living Well' programme (Leaders in Oncology Care) where supportive care is provided every step of the way, from coping with diagnosis, side effects to lifestyle advice.
- Fitness and physical activity workshops
- Coping Skills (to cope practically with uncertainty)
- Nutrition (eating healthily),
- Family members' support,
- Managing Work
- Meditation and Releasing Stress.

Principles of Mindfulness

Arnon gave everyone the opportunity to focus on breathing. The main principle was to let go of negative feelings and thoughts, and to become 'mindful' of each breath to stop us thinking about other things and to concentrate on our breathing without distraction in order to let go of any tension.

Research indicates that there are phases when we are most vulnerable to a 'whirlwind of emotions and racing thoughts'. An important factor in coping is how well we have coped with stress in the rest of our lives.

The good news is that we can all learn stress management skills, build on our strengths, and our families can be involved in helping us with those coping strategies.

Fear, distress, discomfort and feelings of loss can play a greater or lesser role in our lives, and we need to think how to manage these and allow 'Hope and Well-being' to take over.

3. Leighton Eves - Sussex EveryDay

Leighton had requested a visit to the support group (with little knowledge of prostate cancer) to see how we work together and support each other. He offered to help promote in any way he could. He explained he produces "Sussex EveryDay" magazine which will feature people's stories - not always about prostate cancer, but hopefully also uplifting items which members may wish to talk about. He looks forward to being able to include such features on an occasional basis.

For anyone who would like to get involved and share an experience or story in the magazine, he is offering a platform to get the message across. Please contact Leighton on Leighton.Eves@gmail.com

4. Lisa Hilder, Prostate Cancer Clinical Nurse Specialist (based at BSUH) Update on Diagnosis and Latest Treatment for PC

Lisa has been in this post now for one year. She has previously worked at Macmillan specialising in Urology, but now concentrates on prostate cancer.

Before her presentation commenced she clarified one or two points which had been mentioned in Arnon's presentation: Radiotherapy is always offered to people of any age. It is more affordable than Proton therapy. If a patient said they wanted CyberKnife they could be referred to the Royal Marsden or Mount Vernon. You can be treated where you want to be treated, but she stressed that all the 'variables' have to be taken into account. Nowadays we have image-guided radiotherapy and shorter radiotherapy in 4 weeks which is a big improvement. It is a personal decision. Travel to and from the destination should also be taken into account.

Lisa explained that a GP will refer all raised PSA/abnormal DRE to BSUH under the 2 week rule (suspected cancer). There is a very heavy fine of £1k per day for this not happening. They now have a nurse-led raised PSA clinic where men have a full assessment and are sent for a Multiparametric 3T prostate MRI which has a positive predictive value of 98% compared to 68% on normal T2 weighted MRI. It was stressed that not every prostate cancer can be detected.

Lisa explained about the PROMIS trial which tested whether a MP-MRI scan before biopsy could identify men who might safely avoid a biopsy. This compared the accuracy of both MP-MRI and TRUS biopsy against another, more accurate but more invasive, type of biopsy called Template Prostate Mapping (TPM) biopsy. 561 men took part in the trials. PROMIS found that a MP-MRI scan before biopsy would allow at

least 1 in 4 men to avoid a biopsy. The scan identified more than 90% of patients who had clinically important cancer compared to TRUS biopsies which only identified 48% of the men who had clinically important cancer. Men whose MRI scan suggests may have PC will still need to have a biopsy.

Previously, men would have a transrectal-ultrasound (TRUS) biopsy to see if they have the disease. TRUS biopsies miss around half of clinically important cancers, meaning men often have to have extra tests if the biopsy does not find signs of cancer.

If a cancer diagnosis is positive, every case is then discussed with the multi-disciplinary team to get different perspectives and consensus from everyone. With a cancer diagnosis, treatment options are discussed - Active Surveillance: Robot Assisted Radical Prostatectomy: External Beam Radiotherapy: Brachytherapy: Unconventional (not NICE approved e.g.. HIFU,CyberKnife,Proton).

Once the treatment is decided, the patient sees a specialist for the treatment. Surgery is done at Eastbourne, Brighton won the bid for Radiotherapy, Guildford does Brachytherapy. Travel can of course be a problem. Once seen, the specialist treatment is arranged and follow up.

What is New?

The Preston Park Radiotherapy Centre has 3 machines. There is a new Radiotherapy machine at Brighton, new RARP technique (Retzius Sparing technique) - approach from below rather than above the bladder - Continence improved - pad free 5 x better.

Lisa explained her new role at BSUH where she is in charge of all prostate cancer patients, pre, during and after diagnosis. The clinics are nurse-led with a named nurse keyworker. It was felt that because Lisa's role is a constant within the medical journey for men with prostate cancer, this has got to be beneficial for the patient.

Lisa very generously offered her help to the group with suggestions for future speakers, possibly helping to arrange 'Living Well' and other events, also circulating our leaflets and posters within BSUH and PRH.

5. Terry Oliver - Feedback from Surrey and Sussex Cancer Alliance Stakeholder Engagement Meeting

Attendees at the Stakeholder Meeting included primary and secondary care and public health representatives, cancer support charities and representatives of support groups.

Objectives of Alliance:

- Planning and leading the delivery of transformation required to implement the national Cancer Taskforce strategy locally.
- Reducing variation in both outcomes and access to high quality treatment and care for the Alliance's whole population. (Ambition is, over the coming years, to give Alliances more and more levers and control over budgets).

Terry attended two break-out sessions on

- Early Diagnosis (His issue was GPs providing PSA tests for over 50s)
- Living with and Beyond Cancer: - (His issue - The need to a) achieve the same level of service availability as with Cardiac rehab and b) unavailability in our area of drop-in centres adjacent to treatment/consultation centres, provided in Brighton and East Grinstead.

There was no indication of what, if anything, will happen about stakeholder engagement going forward and no indication of how, if at all, stakeholder input from patients and their representatives will be invited.

We will just have to wait and see what, if anything, is forthcoming.

6. Tackle Symposium June 2017 - Peter Barton:

Peter briefly updated on the conference he attended in Birmingham. Some difficult subjects were handled in the most amusing way! 85 people attended. Details on website.

7. Future Topics for Speakers

At our last meeting a questionnaire was completed by members as a result of which the following topics for future speakers were highlighted:

- Side effects of hormone treatment;
- Adjustment of diet,
- Prevention rather than Cure,
- Erectile Dysfunction,
- Insurances
- Living with Cancer and Financial implications.

8. Health Awareness Morning 14 October 2017

It was reported that our group has been approached by Mid Sussex Health Authority asking if we would like to participate in their Health Awareness event. We will definitely attend and will use the event to promote our support group as well as handing out Prostate Cancer information and ensuring someone is available to discuss PC issues. It is understood that there will be stalls with information on other health issues including Parkinson's Disease and Diabetes.

Close of Meeting and Next Date

The meeting was then brought to a close by Peter who thanked our wonderful speakers for their extremely interesting and valued contributions to the meeting. We hope to see you at our Autumn meeting.

Next Meeting - Thursday 23 November 2017

J Lea
24.11.2017