

Notes of Prostate Cancer Support Group Meeting Held on Thursday 15 March 2018

1. Introduction

Peter Barton, Chairman, welcomed everyone to the meeting noting we had three new members attending. He gave a special welcome to the ladies present whose support is invaluable. Peter highlighted the recent publicity given by t.v. personalities: Stephen Fry and Bill Turnbull who had recently been diagnosed with prostate cancer, following which he introduced the first speaker.

2. Paul Turner Manager of Mid Sussex Well Being Team

Paul explained he manages the 'Well Being' service for Mid Sussex Council dealing with prevention of disease and promoting healthy lifestyle. He explained his background was sports science, and work on PT projects for the council. The service is delivered in two parts:

1 - A Signposting service, e.g. someone could make a phone call re help quitting smoking, or wanting to know about support services and they will be directed to someone who can help. This is a free service. If someone with multiple issues wants a face-to-face meeting, this can be arranged over a period of say 3-4 months, to discuss the issues. Highly qualified advisors can help with introduction to exercise and awareness training and illnesses such as cancer, dementia etc.

2 - Running Services: eg. 12 weeks' weight management groups, Diabetic programmes, Balance programmes (£1 per session). Health assessments can be made (establishing body fat and metabolic rate) and people can be referred to partners who can help. The service is usually free, funded through Public Health and the District Council. Paul explained he can give basic advice but personalised needs can be arranged.

Paul explained there is evidence that exercise during or post cancer is particularly good for you, helping you feel fitter and more relaxed, as well as helping to protect against diseases such as high blood pressure, heart problems, diabetes and depression. However, that has to be based on GPs advice or advice from the professional you are working with at the hospital. Regular walking or running even a short distance can make a difference. When you have a health problem it is a big drain on resilience and exercise can help improve resilience - therefore the better you will be able to deal with things.

Concern was raised by members as to expense of local gyms. Paul quoted £7 per week for full use of the local Leisure Centre facilities with excellent resistance and cardiovascular facilities. He stressed that even a short amount of exercise can uplift the heart rate. Muscle mass is very important as we age as well as nutrition. He advised a once a week visit could be as little as £2.50 per week. Some sessions are held at St Wilfrid's Church, Haywards Heath and Burgess Hill Park View Surgery, incl Thai Chi. These can be arranged by Well Being Team, contact given below. Paul suggested trying not to focus on a condition but more on trying to search out something which will help improve your personal situation. There are also Support Services at Macmillan, East Grinstead Hospital, Olive Tree at Crawley Hospital and Horizon, Brighton - Note access to the Horizon Centre is uphill. There is provision for counselling, coaching, financial advice, Complementary therapies, as well as pre-diabetic groups, diet/weight problems/exercise advice.

For further information or enquiries: web: midsussex.westsussexwellbeing.org.uk
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3. Questionnaire re Living Well With and Beyond Cancer

Terry (Committee Member) discussed the Questionnaire on Living Well with Cancer in Mid-Sussex which had been circulated to members, and thanked those who had responded. He explained that

the Committee has had the feeling that, at least as far as prostate cancer is concerned, within Mid-Sussex, there are gaps in the provision of this element of the national cancer strategy especially in regard to exercise, supervised by appropriately qualified trainers, and drop-in support facilities.

Some of the interesting findings from the limited number of returned questionnaires returned before the meeting were:

- The Macmillan drop-in support centres at East Grinstead and Brighton (Horizon Centre) were used by very few members but those that did spoke highly of them. About 50% of those present at the meeting said they would be more likely to use such facilities if they were closer.
- Few members have changed their diet or exercise patterns since diagnosis, but about half are taking supplements and good numbers do take exercise. Asked, at the meeting whether members took Pomi-T or pomegranate juice, both of which have been subject to trials which showed they can delay disease progression, only a handful said they did.
- The limited awareness, of our members, of the NICE guidance on 12 week supervised exercise, to combat muscle and bone density loss, for those starting on hormone therapy has come from our support group, not from medical professionals. There have been no referrals by health professionals for such a programme unless asked for by members.
- No programme seems to be available locally although the odd member has been referred to local leisure centres, by GPs, for exercise to combat muscle wastage. In one case this has been achieved by modifying his cardiac rehabilitation programme. A good percentage of members, at the meeting said that they would consider attending such a programme if recommended by their doctor.

Terry concluded by saying there is a massive difference between both the guidance and encouragement to take supervised exercise and the availability of suitable courses in Mid-Sussex as compared with rehabilitation following cardiac events. He said that supervision by trainers qualified to run courses for cancer patients was important for PC sufferers because of the impact of drugs on bone density and muscle loss.

When the final analysis has been done the Committee will consider best how to use the results to lobby for better guidance and facilities within Mid-Sussex.

4. Presentation by Genesis Care, Guildford: Mary Kuponiyi (Radiographer) and Dan Manning

It was explained that Genesis Care is an independent company with 10 centres which provides services with leading cancer specialists, private hospitals and the NHS. They have medical centres where diagnostics take place.

The presentation covered Prostate Cancer Signs and Symptoms, Diagnosis method, Treatment, Side Effects and Follow up arrangements.

Signs and Symptoms

Increased frequency of passing urine

Difficulty passing urine

Passing blood

Urinary obstruction

Urgency to urinate

Dysuria (pain when passing urine)

Diagnosis

Rectal examination

Biopsy following Scan - CT, MRI

PSA screening level above 4ng/ml is abnormal

This does not necessarily mean presence of cancer cells. It could be prostatitis or enlarged prostate. PSA level results usually give an indication of whether further investigation is required.

Treatment Modalities

Watch and Wait

Surgery

Prostate brachytherapy

Radical radiotherapy

Hormone Therapy (usually Zoladex)

Radiotherapy

The aim of radiotherapy is to destroy cancer cells. Radiotherapy does not only affect the cancer cells, it can also affect some healthy cells. It is localised and only affects the area that is being treated. It is delivered quite quickly. There is nothing to feel or see with radiotherapy. You can go about normal activity afterwards. It does not make you radioactive!

Different types of Radiotherapy:

IGRT (Image Guided Radiotherapy).

The term IGRT covers a wide range of techniques. Imaging helps with accuracy. Before treatment the patient would be tattooed, 3D image is produced then treatment can begin. It has to be accurate. Without IGRT the risk of part of the tumour being missed is increased.

IMRT (Intensity Modulated Radiotherapy) - shapes the radiation beams to closely fit the area of the cancer. It takes some time to deliver all the beams, and there is a risk of the patient moving out of position or there can be an urgency to pass urine when treatment would need to be stopped and started again. IMRT uses many small beams within a main radiotherapy beam to intersect the tumour from a number of angles. The ability to spread the dose out in this way helps to lower or negate the dose to nearby healthy tissue or organs. The intensity of each smaller beam can be controlled during treatment to deliver precise and varying doses to different parts of a tumour maximising its effectiveness.

Planning for IMRT may take longer than planning conformal radiotherapy. This degree of targeting is impossible with conventional radiotherapy, which delivers the same dose across the whole beam to both tumour and healthy tissue.

For a tumour to be precisely targeted using IMRT its size and position must be accurately measured and the correct dose defined in advance. This is achieved using specialist imaging and computer technology.

VMAT (Volumetric Modulated Arc Therapy) is a type of IMRT. It is very quick and accurate and maximises the radiation dose to the tumour while minimising the overall dose as well as exposure to surrounding healthy tissue. The machine moves round the patient ensuring uniform dose distribution and spares healthy tissue as much as possible.

Side effects of Radiotherapy - Treatment is cumulative. Everyone is different and some notice side effects earlier than others - particularly with pelvic radiotherapy: Frequency/urgency of passing urine: Cystitis, Loose Bowels, Fatigue, Sexual Dysfunction, Skin Reaction (rare these days). Listen to your body and take it easy following treatment.

Follow up is usually 8 weeks after completion of radiotherapy. There will be a blood test for PSA level before the patient sees the consultant. Also, the consultant may request a CT or MRI scan. Patient would then have 6 monthly checkups, and later it would be annual checkups.

Mary referred to **The CHHIP Trial**, which proved higher dose of radiotherapy over shorter time was beneficial to patient.

Peter thanked Mary and Dan for travelling down from Guildford to give us a very informative presentation.

5. **Date of next Meeting - Thursday 26 July**

