

**Notes of Prostate Cancer Support Group Meeting  
Haywards Heath and District  
Thursday 26 July 2018**

## **1. INTRODUCTION**

It was explained that in the absence of Peter Barton, our Chairman, Mike Streeter, Committee Member, would chair the meeting. Mike then, as part of his introduction, outlined his personal journey with PC and how he was diagnosed as part of an MOT test about 6 years ago. He invited the new members to stand up, introduce themselves and give a brief outline of their pc situation. Confidentiality was stressed regarding contents of the meeting.

Mike outlined the timetable for the afternoon advising that there would be an update by Committee Member, Terry Oliver, on 'Living Well with and beyond Cancer' (LWBC), following which refreshments would be available and then from 4pm GP Tina George (Clinical Commissioning Group NHS Horsham and Mid Sussex - Lead for Cancer) would be joining the meeting for an informal discussion with members on PC topics eg, Early diagnosis and GP role in PSA testing, Treatment referral, Recovery packages - exercise referrals/availability.

## **2. TERRY OLIVER (Committee) - Living Well With and Beyond Cancer**

**Background:** Terry explained that LWBC is a main thread of the new national cancer strategy along with prevention, early diagnosis and treatment. This covers exercise, non-medical advice, therapies and various forms of support, diet plus other soft issues.

Our support group has undertaken a survey of our PC patient members to understand what support and facilities were available and being used by them in Mid Sussex (which is defined as being between Crawley/East Grinstead and the coastal strip). A preliminary report was given at our last meeting. The final report, which largely confirmed the preliminary conclusions, is on our website.

### **Update: - What have we done since?**

We have emailed Brighton and Sussex University Trust lead Oncologist, (Dr Fiona McKinna); Urological Nurse Specialist (Sharon Clayton); the Clinical Leads for the Horsham and Mid Sussex and High Weald and Havens GP Clinical Commissioning Groups; and Clinical Commissioning Lead for Cancer of Horsham and Mid Sussex CCG (Dr Tina George - who attended the meeting today). Other recipients included Macmillan contacts, the local Well Being Hub and contacts within the local Leisure Centres, also Exercise programme providers. (Full email is on website)

It was explained in our email that LWBC services locally are largely a 'black hole' in so far as our members are concerned. The valuable Macmillan Drop-in centres at East Grinstead and Brighton are not necessarily locations where our members go for many clinical consultations and treatments, and very few have used the centres.

NICE has issued specific guidance on exercise for PC patients on hormone treatment to mitigate muscle and bone loss, but virtually no-one gets referred and therefore no facilities are provided - and vice versa!

Our conclusion was that a co-ordinated approach could make available the NICE recommended exercise facilities and programmes, and 'nudge' patients towards them.

We suggested that:

- For example, patients being given their first Zoladex injection, should be invited to be referred for exercise assessment.
- If no supervised cancer exercise programme were available, patients could be given individual gym programmes with occasional monitoring, which happens elsewhere, or be included in the supervised Cardiac Rehabilitation programmes.

- LWBC support and therapies, rather than just information, might be provided in future at the PRH Macmillan Room during cancer clinics.
- We also suggested ways in which our Group could help including, maybe, facilitating a local conference, provision of information and literature, and possibly helping out at a PRH Drop-in Centre - if this is provided in the future.

### **Finally, What Progress?**

We are still awaiting a response from the Primary Care sector, but where we have had comments they have been very positive and supportive. As one respondent said “Thank you for the feedback from your members....I am so pleased that men in the area can benefit from their peers, from such an established and well organised group”.

Fiona McKinna, who is also Clinical Co-Chair of the Surrey and Sussex Cancer Alliance, mentioned at a recent event how timely our survey was and it will help inform ongoing work in Surrey and Sussex on LWBC improvements. This work has now received funding.

Both Sharon Clayton , Urology Nurse Specialist (BSUH NHS Trust) and Macmillan are keen to talk to us and co-operate on moving forward locally.

Macmillan is funding a Cancer Rehab course at the Dolphin Leisure Centre to accredit trainers to do supervised cancer exercise assessments and programmes. (We have found a volunteer to assist with the case studies needed to obtain accreditation.) Accredited trainers will enable exercise programmes for cancer patients to be available locally.

It was explained that if you are on hormone treatment, muscle loss and bone density loss could be countered by an exercise programme. Programmes at the gym are also beneficial and some of the circuit training programmes are useful but can be quite expensive to set up. Activities such as walking, swimming and gardening are also helpful.

Once again, Terry thanked those members who contributed to the survey and explained that the Committee is now considering how we should move things on. He also advised we can expect opportunities through Surrey and Sussex Cancer Alliance, to be able to contribute as a patient support group, to other threads such as Early Diagnosis and Treatment. His humorous warning was - *Be prepared therefore for more surveys!*

### **3. DR TINA GEORGE - DISCUSSION WITH MEMBERS**

General discussion about appropriate exercises and the likelihood of these being made available/ accessible for PC patients in our area.

Members outlined examples of muscle wastage as result of treatment. It was confirmed weight bearing exercise would be very beneficial.

It was acknowledged that referral for exercise post cancer treatment seems to be non-existent in our area. However, when it comes to exercise itself, this is really important, not just for PC patients, but for those with a vast number of cancers. Whilst it makes sense to exercise, it is only now that medics realise just how important it is. GPs are aware of NICE guidance re exercise and pathways for referrals for exercise. Whose responsibility is it? It is a little bit on both sides - patients should feel empowered to talk this through with their GP, and it is important for GPs to find the appropriate services. There is good clinical evidence that exercise is good for you. Patients who are active have higher energy levels, and are more positive about life than those who do not undertake exercise. It helps with weight control and having a good BMI, helps body produce antioxidants, improved digestive system. There are a whole range of reasons to exercise, although it has not, physiologically, been pinpointed why - it is multi-factorial.

It was stressed that the exercise should not be prescriptive; it should be something that is enjoyed; maybe a daily brisk walk, or even a short game of football with grandchildren. Swimming is of course the best all round exercise. When you feel fitter, you're more able to cope.

In terms of support during recovery, when patients are coming to the end of their treatment, GPs should make patients aware of the importance of exercise. Men should be encouraged to self-refer or get GP to refer them for exercise therapy. GPs are a good source of information and support and should tell patients about recovery packages. A patient needs to be told what is advisable and available. A good opportunity could even be when in discussion with a Nurse.

Locally there are various ways to get involved in exercise: via Dolphin Leisure Centre, "Move More" package, Macmillan Horizon Centre.

Terry advised that when our members were asked if they were aware of NICE guidance on exercise, no-one had heard about it from Primary or Secondary care. They did however recall being advised about it at Support Group meetings.

On the question of whether Dr George looks at cancer treatment as 'Palliative' or 'Recovery', she said she would look at it as 'Recovery'. With her experience of cancer and looking at the trends, compared to 40-50 years ago, there are very positive messages now for recovery. We ought to be treating cancer as any other long term condition. Many patients now live well beyond diagnosis and need to be supported. It was stressed the earlier you get diagnosed, the better survival rate.

It was clarified that Prostatitis is a separate entity to PC. It is inflammation within the prostate gland and is usually associated with urinary tract infection. One does not necessarily lead to the other. It can inflate PSA level but when treated it should come right down.

Discussion took place on some GPs reluctance to do PSA tests. Should we have blanket testing or testing when a man has a problem? It was acknowledged that men do not always recognise the symptoms of PC and sometimes turn a blind eye. Regular testing will pick up problems and should be discussed with GP. Dr George confirmed the test is not unreliable. It is an indicator that something is wrong.

When asked about the CCG's view on regular PSA testing for men over 50 years of age, Dr George felt it would not be offered routinely. A large US study was referred to where the decision was made that men should not be screened for PC as it does not improve survival rates. If men are in a high risk category (eg PC within family) with no symptoms, they should get a test and should get advised of the pros and cons. Patients need to be given time to make an informed choice having had explanation of pros and cons. A digital examination should be done as well as blood test. mpMRIs are now being done earlier and results are much more precise.

The Lions' PSA testing regime in Burgess Hill was highlighted, where more than 280 men turned up in 2016 and again in 2017 to be tested with about 9% being found to have a raised PSA level and recommended for further GP tests. Dr George confirmed she preferred the route of having a conversation with the patient and giving them an informed choice.

For members who need further advice re their treatment, it was suggested a list of questions be prepared beforehand to be discussed at follow up meeting with specialist, along with how medication makes you feel, psychological effects, coping, exercise regime, or any other information that helps a patient. Different patients have different needs. Side effects can be different for different people.

A member outlined his experience of consultant's refusal to operate as he is over 75 years of age. It was clarified that an assessment has to be made as to whether operating could cause more damage. Forms of treatment vary. Advice from the Doctor has got to be taken into account. For those who need it, PCUK Helpline will give advice on patient experience, post treatment monitoring etc.

Mike thanked Dr Tina George for participating in what was a very helpful and informative discussion.

Before the meeting concluded, a member expressed his personal thanks for the all help he had received from the Support Group. He explained that as hormone treatment was no longer working for him, and the cancer has now spread to his hip and bones, he has begun a course of Radium 223 which it is hoped will give him an improved quality of life, and he took great pleasure in informing his consultant that he had already learned about the treatment at a meeting of his PC support group.

**4. Next Meeting** - Thursday 29 November 2018. Dolphin Surgery Meeting Room 3-5pm.

JLea  
30.7.2018