



Living Well with Cancer in Mid-Sussex – Group Survey Report – May 2018

Summary

1. **Background.** At the Stakeholder engagement meeting of the Surrey and Sussex Cancer Alliance held in March 2017, to which our Group had been kindly asked, and was able, to send a representative, **Living well with, and beyond, cancer** was one of the four discussion threads, together with **prevention, early diagnosis** and **treatment**. Following consideration of what was reported back, our committee decided to undertake a survey of our prostate cancer (PC) patient members in order to understand what support and facilities were available, and being used, by them.
2. **Scope.** Our understanding is that **Living well with and beyond Cancer** covers: exercise, non-medical advice and support, diet and other soft issues. The survey covered three main areas:
 - a. The value of drop-in “living with cancer” centres close to clinics was mentioned in the stakeholder engagement meeting so we asked our members about their use of the Macmillan Centre at the Queen Victoria at East Grinstead, the Horizon Centre at the Royal Sussex and the Macmillan room at the Princess Royal Hospital. The extent to which members had **changed** their life style in terms of exercise, diet and the use of supplements as a result of their diagnosis.
 - b. For our members on Antigen Deprivation Therapy, knowledge of the NICE guidance (2014): “Offer men who are starting or having *androgen deprivation therapy* supervised resistance and aerobic *exercise* at least twice a week for 12 weeks to reduce fatigue and improve quality of life” and their experience, if any of being referred for this.
3. **Survey Results.** The survey was completed by nineteen men. This should be compared with a typical attendance at group meetings where twenty-five, out of a total of thirty-six will be PC patients:
 - a. Only three have ever “dropped in” to the centres at the Queen Victoria and Royal Sussex. Those that have rate them highly. Four have used the information room at the Princess Royal Hospital. When asked at the Group meeting, at which preliminary results were presented, whether they would make use of a more local drop-in centre, 50% said they would. (Note: for our Group PC patients, consultations, diagnostics and treatment would not, most of the time, be at the hospitals at which the drop-in centres are located. It would typically mean a special visit.)
 - b. Only three members have **changed** their diet and/or exercise regimes as a result of their cancer diagnosis. Eight take supplements. The answers to an oral question, at the March 2018 Group meeting, indicated there was no predominant supplement.
 - c. Members on Antigen-Deprivation Therapy:

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- i. The limited awareness, of our members, of the NICE guidance on 12 week supervised exercise has come from our support group, not from GP practices or hospitals.
- ii. There have been no referrals by health professionals for such a programme unless asked for by members. **(No nudging!)**
- iii. No programme seems to be available locally although two members have been referred to local leisure centres, by GPs, for exercise to combat muscle wastage. Two have been able use/modify cardiac rehabilitation exercise regimes. *(About ten Cardiac rehabilitation exercise programmes are available locally (Haywards Heath/Burgess Hill), supervised by, appropriately qualified Level 4 Trainers. Except for several weeks of partial subsidy, for some weeks, for patients moving from stage 3 (hospital gym) to outside rehabilitation programmes, attendees pay a commercial fee.)* The two organisations running these courses are not known to have trainers with the Level 4 cancer qualification.
- iv. Many members do exercise even if not on a supervised programme.

4. The Way Forward

- a. The results of the survey indicate that within our local area: mid-Sussex south of Crawley/East Grinstead and north of coastal strip, for our Group prostate cancer patients, “Living well with, and beyond cancer” facilities, support and referral are all largely a “black hole”. This may not be the case with patients of other cancers.
 - b. Clearly it is for Macmillan, and its partners, to determine where it is appropriate to locate their very valuable drop-in centres, our Group can only report on the use made by our members.
 - c. Exercise provision seems to be “a chicken and egg situation”. Nobody gets referred and therefore no facilities are provided, and vice versa. What we have gathered is that:
 - i. All cancer patients are entitled to be referred for exercise assessment and provision by their GP to the Mid-Sussex Well-Being Hub.
 - ii. The appropriately qualified trainers based at Albion in the Community will undertake one-to-one assessments, locally, whether cancer patients have been referred or refer themselves.
 - iii. In one part of the country, where there is no provision for group exercise programmes, qualified trainers will negotiate rates with local leisure centres and provide individual gym programmes for patients at these centres. This does not appear to be being done in our local area.
5. Our conclusion is that, given that cost need not be a serious issue, as shown by the commercial rates paid by those on cardiac rehabilitation exercise programmes, some initiative and co-

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ordination by the relevant parties could make available, and “nudge” prostate cancer patients towards, the exercise facilities and programmes that are recommended for them.

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The Survey Results.

Introduction

Living well with and beyond Cancer covers: exercise, non-medical advice and support, diet and other soft issues. It is one of the main threads of the new cancer strategy and, in addition **to prevention, early diagnosis and treatment**, was one of the four discussion threads at the Stakeholder engagement meeting of the Surrey and Sussex Cancer Alliance meeting last March.

These issues are important to all cancer sufferers and, in part to their family and friends. There is now some clinical evidence on the impact of certain dietary interventions or supplements to slow prostate cancer disease progression making access to advice important. Of special importance for prostate cancer sufferers, including a high proportion of our Group members, is the need to counteract, with exercise, the debilitating effect of some treatments such as Antigen Deprivation Therapy (hormone treatment). NICE 2014 recommendation (1.4.19 in CG175) to “Offer men who are starting or having androgen deprivation therapy supervised resistance and aerobic exercise at least twice a week for 12 weeks to reduce fatigue and improve quality of life.” (We understand the 12 weeks limit is because the benefits of longer periods has not yet been assessed by clinical trials.)

Following consideration of what was reported back, our committee decided to undertake a survey of our prostate cancer (PC) patient members in order to understand what support and facilities were available, and being used, by them. A copy of the questionnaire is included as Appendix A.

Questionnaire Analysis

1. **Response.** Questionnaires were sent out by email or post to all families on mailing list, a total of 84. They could reply by email, post or wait until the Group Meeting on the 15th March. **Nineteen** responses were received, this compares with a typical attendance at our Group Meetings of thirty-six, twenty-five of whom are prostate cancer patients. All answered **Part A** of the questionnaire. **Part B**, for those on Antigen Deprivation Therapy, was responded to by **twelve**.
2. **Part A a) One** responder had used the drop-in centre provided by Macmillan at the Royal Sussex Hospital, Brighton (Horizon Centre) and **two**, the drop-in centre at the Queen Victoria Hospital, East Grinstead. The Macmillan information room at the Princess Royal Hospital Haywards Heath had been used by **four**. In response to a question asked at the March 2018 Group meeting about 50% said they would use a drop-in centre if one was more local. (See Appendix B for information on the facilities available at the two drop-in centres)
3. **Part A b)** Asked about changes to Life Style as a result of prostate cancer diagnosis, **two** had changed their exercise regime, **three** had changed their diet and **eight** took supplements.

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The response to a question asked at the March Group Meeting indicated that there were no predominant supplements.

4. **Part A c)** None of the respondents said they had taken advantage of any of the other non-medical facilities available for cancer sufferers. (Actually we know some members have but perhaps they didn't respond to the survey!)
5. **Part A d)** We asked for general comments about living with cancer – It is clear that many members actually do exercise even if not because they have cancer. Most other comments concerned side effects of treatments
6. **Part B a)** Asked about awareness of the NICE 2014 guidance (1.4.19 in CG175) to “Offer men who are starting or having androgen deprivation therapy supervised resistance and aerobic exercise at least twice a week for 12 weeks to reduce fatigue and improve quality of life” **three** members were aware of the guidance from our Group meetings. **None** had been made aware primary and acute NHS medical staff during consultations or treatment.
7. **Part B b)** and **c)** asked whether anybody had been referred, or referred themselves for this exercise programme and what then happened. **Two** have been referred by their GPs, at their own request, one to the Triangle Leisure Centre (Burgess Hill) and one to the Mid-Sussex Well-being Hub for exercise to counter the muscle wastage side effects of the treatment. In the second case, there being no suitable course available locally, he has amended his cancer rehabilitation exercise programme. (There are plenty of these programmes locally.) Many others undertake various other forms of exercise. The key points are that there appear to be no suitable opportunities for the NICE recommended programme in the Haywards Heath/Burgess Hill area and, in stark contrast to cardiac rehabilitation, absolutely no “nudging” from the medical profession.



Appendix A – The Questionnaire

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LIVING WELL WITH AND BEYOND CANCER

Living well with and beyond Cancer covers: exercise, non-medical advice and support, diet and other soft issues. It is one of the main threads of the new cancer strategy in addition to **prevention, early diagnosis** and **treatment**. It is of special importance for prostate cancer sufferers because of the need to counteract, with exercise, the debilitating effect of some treatments such as Antigen Deprivation Therapy (hormone treatment) and because there is now some evidence on the potential for some dietary interventions and supplements to slow disease progression.

Many of our members are on Antigen Deprivation Therapy and the NICE recommendation, for them, is a programme of twice weekly supervised exercise for twelve weeks. Although it has been made available in some parts of the country we don't know of it being available, locally, in Mid Sussex except for one-to-one assessments from **Albion in the Community** qualified trainers.

The Committee are considering whether the Group should be more active in pushing for the availability of this form of support within Mid-Sussex. As a first step we would like to know about the current experience of our members. We would be very grateful therefore if you could spend a few minutes completing the questionnaire below. Please return it to Terry Oliver either by email (terryoliver459@btinternet.com), post (22 Kleinwort Close, Haywards Heath, RH16 4XG), or bring it to the next Support Group Meeting on 15th March. If replying by email you can either complete the questionnaire and send it back as an attachment or just create an email with the question number and your answers (mostly yes or no). Part A is a few general questions and Part B is specific to those on hormone treatment.

Please do your best to reply even if you answer no in most cases.

Part A: For all those with Prostate Cancer:

a) Have you ever used the information and support services provided by Macmillan:

- | | | | | |
|------|--|--|-----|----|
| i. | At the Horizon Centre at the Royal Sussex Hospital? (or Sussex County Hospital before the Horizon opened) | <table border="1"><tr><td>YES</td><td>NO</td></tr></table> | YES | NO |
| YES | NO | | | |
| ii. | At the Queen Victoria, East Grinstead? | <table border="1"><tr><td>YES</td><td>NO</td></tr></table> | YES | NO |
| YES | NO | | | |
| iii. | At the Princess Royal Hospital, Haywards Heath (Information only) | <table border="1"><tr><td>YES</td><td>NO</td></tr></table> | YES | NO |
| YES | NO | | | |

b) As a result of having been diagnosed with, and treated for prostate cancer have you:

| | |
|-----|----|
| YES | NO |
|-----|----|

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i. Changed your exercise regime?

ii. Changed your diet?

| | |
|-----|----|
| YES | NO |
|-----|----|

iii. Taken supplements?

| | |
|-----|----|
| YES | NO |
|-----|----|

c) Have you taken advantage of any of the other non-medical facilities available for cancer sufferers?

If so, with whom..... and where

d) Are there any general comments you would like to make about your experience of living with cancer?

Part B: For Those on Antigen Deprivation Therapy (ADT) (hormone treatment) e.g. bicalutamide, zoladex, enzalutamide, abiraterone)

a) Are you aware of the NICE guidance on the provision of a supervised exercise programme for patients having ADT treatment?

| | |
|-----|----|
| YES | NO |
|-----|----|

If yes, how did you learn about it?

i. Our Support Group meetings and/or web-site?

| | |
|-----|----|
| YES | NO |
|-----|----|

ii. Your GP surgery (doctor or nurse)

| | |
|-----|----|
| YES | NO |
|-----|----|

iii. Your hospital consultant or nurse specialist

| | |
|-----|----|
| YES | NO |
|-----|----|

b) Have you ever been referred by a medical professional for this exercise programme?

| | |
|-----|----|
| YES | NO |
|-----|----|

or

Referred yourself?

| | |
|-----|----|
| YES | NO |
|-----|----|

c) If YES to Question (b), to whom were you referred:

i. The Mid-Sussex Well Being Hub?

| | |
|-----|----|
| YES | NO |
|-----|----|

ii. The Move-More Sussex Programme at the Emirates Stadium?

| | |
|-----|----|
| YES | NO |
|-----|----|

iii. Anywhere else?

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And what happened:

i. Call back?

| | |
|-----|----|
| YES | NO |
|-----|----|

ii. One-to-One assessment at

iii. Placed on a supervised exercise programme at
.....

d) If no exercise programme was available what have you done instead, if anything?



Appendix B – Cancer Patient Drop-In Centres in East Grinstead and Brighton

1. East Grinstead Macmillan Information and Support Centre

The Macmillan Cancer Information Service has been developed as a joint venture between Macmillan Cancer Support and the Queen Victoria Hospital. It:

- Ensures people affected by cancer have access to good quality comprehensive and appropriate information and support.
- Is staffed by information professionals and supported by trained volunteers.
- Available for cancer patients, carers, or work as a healthcare, including those not patients of Queen Victoria Hospital.

It provides:

- A drop-in centre where people affected by cancer can get information.
- A library, with comprehensive information and internet access.
- Help with completing forms and applying for benefits.
- Complementary therapies for people affected by cancer.

2. Macmillan Horizon Centre – Royal Sussex Hospital Brighton

The Macmillan Horizon Centre is a partnership between Macmillan Cancer Support, the Sussex Cancer Fund and Brighton and Sussex University Hospitals NHS Trust. It offers similar services to the drop-in centre at East Grinstead and in addition:

- Counselling and psychological therapies
- Physical activity
- Body image support
- Practical support
- Café.