

## Patients' experience of exercise and cancer



### Informing 'WESFIT' Pilot Patient Involvement Report May 2017

## 1. Background summary

A pilot programme is being developed through funding from the Wessex Cancer Alliance whereby cancer patients will be offered exercising and/or counselling prior to treatment. Organisations working with the Wessex Clinical Alliance held three sets of interviews with patients who have been encouraged to exercise prior to their treatment.

The groups of people we spoke to were:

- An individual who had experience of exercising in a community setting with support from a training instructor qualified to work with people affected by cancer (Interview 1).
- A focus group (FG) of people who had taken part in a clinical trial where their fitness levels were monitored and/or they had undertaken exercise training in a hospital setting (FG1).
- Two people who attended Southampton Hospital's 'Fit for Surgery' School (F4S) and were encouraged to increase their activity levels prior to surgery (FG2).

We asked interviewees about:

- Where they got support when they were first diagnosed with cancer.
- Whether they had accessed counselling and how helpful this was/might this have been.
- How they felt about exercising at this time and whether or not it worked for them.

The findings from those discussions are set out below under the following headings:

- A summary of key themes
- Accessing counselling prior to treatment
- Experiences of exercising
- Communications
- Other suggested support and practical considerations

This brief report also sets out other considerations for future involvement of people in the pilot, and the feedback from participants about their involvement in the interviews.

The findings below have informed the design of the pilot study; details are provided at the end of this document.

## Key themes across the 3 groups

- All participants reported physiological and psychological benefit from participation in community based exercise, clinical trials of exercise prehabilitation or F4S.
- People and their next of kin are vulnerable, particularly around the time of investigation and diagnosis, many describe 'fear' and 'emotionally locking down'.
- It can be difficult to absorb the information and what is going to happen early in the treatment pathway.
- Understanding/communication about what is going to happen and might happen was very important to being psychologically prepared for treatment/s and surgery.
- Clinical Nurse Specialists (CNS) are central to support people at this time – communication was key. Or could be: The Clinical Nurse Specialist (CNS) is central in supporting people at this time – communication was key
- The importance of personal qualities of those delivering exercise programmes – encouraging, friendly, genuine, knowledgeable and good communication skills.
- The people we spoke to were all motivated to do additional exercise prior to surgery to support themselves
- The participants also acknowledged observing others who did not have this positive mind-set and really struggled to engage with any self-care/physio etc.
- Convey when describing the trial that it could reduce length of stay in hospital and help with recovery and the next stage of life.
- Around half of participants and a few of their partners accessed additional support, usually via Macmillan including 'coffee and chat' sessions, and holistic therapies/pampering/make-up days etc.
- Exercise needs to be something the person will enjoy and meets individual needs for longer term participation.
- All were keen to have support to get back to exercise after surgery.
- The sessions people are signposted to as part of the trial need to feel like part of their treatment plan to ensure highest uptake.

## Counselling

### Counselling summary

- Mixed response re 'formal' counselling – agreement that it would need to be handled sensitively and be voluntary, but that appointments would need to be provided to increase chance of attendance, i.e. seen as part of treatment plan. This could be described as becoming 'mentally fit' for surgery.
- Timing of approach will be very important – ensuring it's not too early, i.e. before appointments to discuss treatment plans.
- Many were receptive to services available through Macmillan (i.e. holistic therapies, additional info leaflets and 'coffee & conversations').

- Be mindful about possible options for support for carers.
- Where patients felt informed as to what to expect from their treatment/surgery they felt psychologically supported, especially when they had a good relationship with their CNS. These patients were less likely to feel the need for additional psychological support.

### Interview 1

- Suggested that it was necessary to do more than signpost to counselling/psychological support. More likely to have uptake if seen as part of treatment plan.

### FG1

- It was clear that participants in the exercise prehabilitation studies gained a lot from their relationships with the individuals delivering the programme. Many talked about them being encouraging, proud of their progress and keeping them motivated. This gave them a more holistic sense of support and positive attitude towards their illness and impending surgery. As such, they felt less in need of additional emotional support.
- Mixed response re 'formal' counselling, some felt this could be detrimental if already coping well, others felt it could be helpful. General consensus was it should be optional.
- One participant had a very bad experience of telephone-based counselling, suggested by his GP. He felt the counsellor sounded very disinterested.
- Timing of approach will be key. A number of patients talked about withdrawal from friends and family in the week or two before definitive diagnosis and treatment plan given. Suggest we ensure patients aren't approached re the study until they've had their appointment with consultant and conversation with CNS re treatment options.

*"it's a tricky time when you're hanging on in there' waiting for diagnostics, treatment plan etc 'not saying much as a couple, we found, you're kind of locked down, you haven't told your family, you're just waiting for that news, so Donna was absolutely the key one really and I absolutely wasn't looking for anything else"*

### FG2

- More receptive to formal counselling post-surgery than pre-surgery.
- Of the two participants one knew about the Macmillan centre at SGH, the other didn't and was unsure what benefits he would get from it.
- One participant would have liked to access the centre but it was not open when she was free (she worked through her treatment).
- Appreciated that the information given during F4S prepared them for what to expect after surgery, when they would be expected to get out of bed etc. This 'psychological and practical preparation' was valued.

### Exercise

## Exercise summary

- All were motivated to seek out opportunities to increase their chances of recovering well and surviving their diagnosis.
- Framing the programme as a means of getting the patients as fit as possible for surgery, reducing their stay in hospital and increasing their chances of getting 'back to normal' as quickly as possible.
- Importance of staff delivering the programme (exercise or F4S) – attributes such as empathy, knowledge, encouragement, friendly, supporting progression/improvement without pushing too hard.
- Flexibility and convenience of sessions – i.e. in hospital at same time as treatments.
- With the exception of one participant, all others exercised alone prior to surgery.
- All reported physical and psychological gains from taking part in exercise/involvement in the programmes
- Need for post-op support for returning to exercise (safely).
- For longer term participation, finding activities that are enjoyable/give variety rather than only stationary cycling
- It was felt stories from patients describing positive experiences of exercise and recovery were powerful. They could relate to this. Pricilla would be an excellent candidate as a 'role model' for the benefits of the prehabilitation exercise studies.

## Interview 1

- Heard about Wildern gym through conversation with another patient in GP waiting room (he had asked his GP who didn't know of any facilities).
- Ex forces PT so very positive attitude towards exercise and confidence to take part in activities to help himself
- Very complementary of Stephanie (healthworks), and her personal approach; friendly and encouraging without being pushy. He observed other instructors who 'didn't smile' and tried to push their clients too hard and the client disengaged.
- That relationship was important for his continued visits to the gym on the day he thought Stephanie would be there. He also valued their quarterly catch-ups re his progress/training programme etc. *'she's just there – and gives me some gentle advice'*
- Liked informal and local setting with a variety of exercise machines, low cost and accessible at times that suit.
- Struggled to return to exercise post-surgery but did so with encouragement from wife.

## FG1

- General consensus that Lisa/Sam/Rosie were superb; knowledgeable, encouraging, supportive and genuinely pleased when they made progress. All had an excellent rapport.
- All felt they were being proactive about giving themselves the best chance of a positive outcome from surgery/treatment. Quote from participant,

conversation on the morning of surgery - *'I said, 'well [husband], we have done absolutely everything we could to help the outcome of this'. And that was very comforting, to feel that, I couldn't have done anything more'. And I got a good result, out within 10 days. And that was really good for me, emotionally.*

- All liked to have CPET scores and proud to see improvements and could see the team were pleased also
- Participant who was in the control group talked about initial disappointment but benefiting from the additional monitoring.
- Liked having appointments in advance, to fit with other treatments in hospital, but appreciated the flexibility to change them if necessary
- Were comforted by the medical support on hand (examples of dropping heart rates and not feeling well before sessions and needing to see a doctor)
- General consensus that at least one session/conversation post-surgery would be helpful to 'get back on track' with exercise. And at this stage to introduce a variety of activities. Some had tried to get back to exercise but had struggled and would have liked to discuss problems/symptom management/what's safe.  
*'I wanted those faces, encouraging me again'*

## FG2

- Participants thought Imogen was an excellent speaker at F4S, and both were motivated to do more exercise prior to surgery.
- They would have liked the result of their CPET test.
- No mention of strategies to increase exercise other than told to take a 'daily brisk walk' if not very active.
- Much of the conversation was about how to get 'back to normal' after surgery and knowing what to do safely. Not given much advice on how on this, other than 'don't lift anything heavier than a kettle for 4 weeks', then use 'common sense' and 'listen to your body'. They would have liked more support post-surgery.
- Both were motivated to get themselves in as good a physical state as possible before surgery *"I knew my body would take a massive kicking, so it was to put it in the best position I could beforehand"*.

## Other suggested support

- The importance of spouse support was clear, particularly to absorb information at appointments and to act as the patients' recall afterwards. Some spouses accessed support themselves, e.g. via the Macmillan Centre, and it was felt that they too may need access to psychological support through the process. Convenience of the Macmillan centre located on site at SGH was also important.
- Support groups would have been valued (similar age and disease)
- Dietary support pre and post colorectal surgery would be valued
- Participants emphasised recalling the importance of reducing alcohol (particularly pre-surgery).

- Advocacy was consistently mentioned, with concern for others who didn't have support during treatment/appointments.
- Support at the first chemotherapy session would be helpful
- Support for managing stomas would also have been valued; one participant accessed a stoma charity

### Practicalities

- Parking was a key consideration. This caused significant anxiety re missing appointments etc. if a parking space couldn't be found, and the expense. All participants on the exercise prehabilitation studies really valued the free parking tickets.
- Flexibility in when to attend exercise sessions was highly valued.
- Having exercise sessions/support services closer to home was valued unless already traveling to hospital for other appointments.
- Letters – ensuring any communication stands out from 'the usual NHS letter', so it's not lost. Importance of clearly stating early in the letter what it is about. The invitation to attend Health & Wellbeing events/F4S etc. need to feel like part of their treatment pathway.
- Clearly state all sessions they will be offered through the trial, what they are for and how long they will last.
- A written summary of the key practical steps to help yourself prior to surgery from F4S would have been valued, and emphasising the importance of 'helping yourself' at this stage.
- Be mindful of those who may be working through their treatment

### Communication

- Ensuring that the message is clear that your physical fitness prior to surgery will have an important impact on your outcomes/length of stay etc.
- Include messages about the importance of fitness post-surgery to optimise health outcomes as more people are surviving cancer.
- Acknowledging increasing exercise can be difficult but that they will be supported to do so, and it doesn't matter if they weren't 'sporty' before. This is where patient's stories could help i.e. Pricilla/David.
- Very mixed in terms of who had heard about various supportive services – clear, active signposting very important, and many described doing their own research, particularly online (which was often scary).
- Communications to reflex diversity (i.e. age, ethnicity, gender).

### Limitations of our sample

- All participants were self-motivated to take part in activities to support themselves through their treatments/recovery.
- Majority were >60 and white British and retired, mostly male

- All had positive attitudes towards being physical active.

## 9. Changes to study design and services as a result of interviews

- The counselling element of the study will be reframed and referred to as 'psychological support'. Participants will also be offered sessions termed 'healthy conversations' as well or instead of psychological support. This approach involves a focus on the client to identify a behaviour they would like to change (i.e. increase physical activity) and they are supported to do so.
- Those undertaking CPET exercising testing will now be given feedback on their scores
- At the 12 week post-surgery appointment as part of the pilot trial, participants will have the opportunity to discuss how to safely resume exercising with their exercise trainer.
- The team are investigating how to support participants at the end of the trial to maintain exercise participation, e.g. signposting to community services
- The first two exercise sessions will be conducted in a hospital setting to ensure patients feel reassured that it is safe to exercise outside of the hospital setting with supervision from qualified physical trainers.
- Any letters for appointments as part of the trial will include a distinctive logo so that can be easily identified amongst other NHS correspondents.
- Nutritional assessment will now be included in the study. We are also working with the Cancer and Nutrition National Institute of Health Research Infrastructure Collaboration (comprising experts in the field of nutrition and cancer) to produce guidelines to support patients with diet post-treatment.
- The Wessex Cancer Trust are changing practice to increase the uptake of men to their counselling services, promoting men's 'support groups' and not using the term 'counselling'.
- Quotes from participants will be used (with their permission) within recruitment materials to facilitate uptake and patient confidence in taking part in such a study.