

Patients' experience of exercise and cancer



**Informing 'WESFIT' Pilot
Patient Involvement Report
Feedback to participants
May 2017**

1. Background summary

A pilot programme is being developed through funding from the Wessex Cancer Alliance whereby cancer patients will be offered exercise training 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 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.

2. Summary of key themes across all interviews

- All participants reported physiological and psychological benefit from their experiences of exercising and/or having their fitness monitored.
- People and their next of kin are vulnerable, particularly at the time of clinical investigation and diagnosis, many describe 'fear' and 'emotionally locking down' in this period.
- At the point of diagnosis, it can be difficult to absorb all the information about the diagnosis, treatment(s) and what will happen.
- Understanding/communication about what is going to/ might happen was very important to being psychologically prepared for treatment(s).
- The Clinical Nurse Specialist (CNS) plays a central role in supporting people at this time, particularly explanations of what may happen and signposting to support.
- The personal qualities of those delivering exercise programmes are important. They should be encouraging, friendly, genuine, knowledgeable, and have good communication skills.
- Those interviewed were all motivated to do additional exercise prior to surgery / their treatment to support themselves.
- The participants acknowledged observing others who did not have this positive mind-set and struggled to engage with any self-care/physiotherapy etc.
- Participants felt it was important to convey to patients when describing the trial that it could reduce length of stay in hospital, help recovery and next stage of life.
- Any sessions people are signposted to as part of the trial need to feel like part of their treatment plan to ensure highest uptake.
- They felt that exercise needs to be something a person will enjoy and meets individual needs for longer term participation.
- Around half of participants and a few of their partners accessed additional support, usually via Macmillan including 'coffee and chat' sessions, leaflets, and holistic therapies/pampering/make-up days etc.
- All participants were keen to have support to get back to exercise after surgery.

3. Findings - accessing counselling prior to treatment

Below are themes from all the discussions around experiences and attitudes towards accessing counselling before surgery.

- There was a mixed response when discussing whether accessing counselling prior to surgery was/would have been helpful. There was agreement that it would need to be handled sensitively and be voluntary. 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, rather than using the term 'counselling' which was felt to have some negative stigma attached to it.
- The point at which counselling is recommended would be very important. It should not be too early, i.e. not before appointments to discuss treatment plans.
- Where patients felt informed as to what to expect from their treatment 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.

- Many were receptive to services available through Macmillan.
- Interviewees thought carers should also be provided with support.

Here are key points from the counselling discussions from each of the groups:

Interview 1

- The interviewee suggested that it was necessary to do more than signpost to counselling/psychological support, and thought people would be more likely to attend if it was seen as part of their treatment plan.

FG1

- It was clear that participants in the clinical trials gained a lot from their relationships with the staff responsible for monitoring and delivering their exercise programme. Many talked about them being encouraging, 'genuinely' 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.
- There was a mixed response re 'formal' counselling. Some felt this could be detrimental if the patient was already coping well, others felt it could be helpful. General consensus was that counselling should be optional.
- One participant had a very bad experience of telephone-based counselling, suggested by their GP. He felt the counsellor sounded very disinterested.
- Interviewees thought the timing of approach would 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.

"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 [CNS name] was absolutely the key one really and I absolutely wasn't looking for anything else"

FG2

- One interviewee suggested formal counselling post-surgery rather than pre-surgery could be helpful.
- Of the two participants one knew about the Macmillan centre at Southampton Hospital, the other didn't and was unsure what benefits they would get from it.
- One participant would have liked to access the centre but it was not open when they were free (they worked through their treatment).
- Both appreciated the information given during Fit for Surgery School. It helped prepare them for what to expect after surgery, when they would be expected to get out of bed etc. This 'psychological and practical preparation' was highly valued.

4. Experiences of exercising

Below are themes from all the discussions around exercise:

- All participants were motivated to seek out opportunities to increase their chances of recovering well after surgery and ultimately 'surviving cancer'.
- Framing exercise as important for getting as fit as possible for surgery, reducing their stay in hospital and increasing chances of getting 'back to normal' as quickly as possible is a key message.
- Interviewees appreciated the attitudes of staff delivering the programmes where they showed empathy, knowledge, encouragement, friendliness, and were supportive of progression/improvement without pushing too hard.
- Flexibility and convenience of exercise sessions was a key factor– e.g. in hospital at the same time as treatments or them being near to home.
- With the exception of one participant, all exercised alone prior to surgery.
- All reported physical and psychological gains from taking part in exercise or having an involvement in the programmes.
- There is a 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 re positive experiences of exercise and recovery were powerful and would aid recruitment to the study.

Interview 1

- Heard about the community gym through conversation with another patient in their GP waiting room (Their GP did not know of any such facilities/services).
- They had a very positive attitude towards exercise and confidence to take part in activities to help themselves.
- They were complementary about a community programme staff member and her personal style; friendly and encouraging without being pushy. Other instructors 'didn't smile' and tried to push their clients too hard, resulting in clients disengaging.
- That relationship was important for their continued visits to the gym and they also valued their quarterly catch-ups re their progress/training programme etc. *'She's just there – and gives me some gentle advice.'*
- They liked the 'informal', local setting with a variety of exercise machines at a low cost and accessible at times that suit.
- Struggled to return to exercise post-surgery but did so with encouragement from their partner.

FG1

- General consensus that the clinical trial staff were superb; knowledgeable, encouraging, supportive and genuinely pleased when they made progress. All had an excellent rapport with them.

- 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 [partner], 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 fitness monitoring (CPET) scores and were proud to see improvements and recognised that the hospital team were pleased too.
- A participant who was in the control group and therefore did not participate in the structured exercise programme talked about their initial disappointment but benefitted from additional monitoring.
- People liked having appointments arranged upfront, to fit with other treatments in hospital, but also appreciated the flexibility to change them if necessary.
- They were comforted by the medical support on hand, particularly if they did not feel well during a session.
- General consensus and strong suggestion was the need for at least one session/conversation post-surgery 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 and what would be safe. *'I wanted those faces, encouraging me again'.*

FG2

- Participants thought the Fit for Surgery School workshop speech was excellent.
- Both interviewees 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"*.
- They would have liked the result of their fitness monitoring (CPET) test.
- They could not recall whether the workshop covered strategies to increase exercise other than being told to take a 'daily brisk walk' if people are not very active.
- Much of the conversation was about how to get 'back to normal' after surgery and knowing what daily tasks to do safely, i.e. driving. Not given much specific advice 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.

5. Communication

Below are some reflections from interviews about how best to communicate with patients:

- Make sure any written communication stands out from 'the usual NHS letter', so it does not 'get lost' in appointment letters. Clearly state early in the letter what it is about. Invitations to attend health and well-being events, for example, need to feel like they are part of a treatment pathway.
- Provide a timetable of all sessions that will be offered and how long they will last.

- A written summary of the key practical steps to help yourself prior to surgery from Fit for Surgery School would have been valued, and emphasising the importance of 'helping yourself' at this stage.
- Ensure the message is clear that physical fitness prior to and after surgery will have an important impact on length of stay in hospital and possibly longer term outcomes as participants acknowledge more people are surviving cancer.
- Acknowledging increasing exercise can be difficult but that people 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.
- Communications need to reflect diversity (i.e. age, ethnicity, gender etc).
- Participants had mixed experiences in terms of knowing about or being signposted to support services. Many described doing their own research, usually online (which was sometimes scary). Clear, active signposting is important.

6. Other suggested support and practical considerations

Below are suggestions of other support and practicalities for consideration:

- The importance of partners' support was clear, particularly to absorb information at appointments and to act as the patients' recall afterwards. Some partners accessed support themselves, e.g. the Macmillan Centre, and it was felt that they may need access to psychological support through the process. The convenience of the onsite Macmillan centre at Southampton Hospital was important.
- Support groups would have been valued, possibly for similar ages and diagnosis.
- Dietary support pre and post colorectal surgery would have been useful. Some participants emphasised the importance of reducing alcohol 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.
- Parking was a major consideration. For some this was frustrating and caused significant anxiety in terms of the potential to miss appointments. Hospital parking is also expensive over the treatment period. All participants on the clinical studies really valued the free parking tickets.
- Be mindful of those who may be working through their treatment.

7. Considerations for future involvement of people in the pilot trial as part of a steering committee

- It will be important to talk to people who are not self-motivated to exercise or help themselves as all those who took part had positive attitudes towards their own care.
- It will be important to evaluate the pilot in terms of any barriers to taking up counselling and exercise, particularly in relation to working age as well as personal characteristics, such as age, gender, ethnic background or disability.

8. Evaluation of the interviews

- Of the 8 people who completed the evaluation question all of them said that it had been a good use of their time.

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 they 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

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