

Get back on track

Project report



**PROSTATE
CANCER UK**

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Leading change: helping men with prostate cancer deal with fatigue.

'Fatigue can make you feel very lonely, but Get back on track is a journey you go through together with the nurse. I looked forward to her calls and to discussing things with someone who understood.' John, trial participant

When you think of debilitating side-effects of prostate cancer, tiredness and fatigue probably aren't the first that spring to mind. But for many men like John who are affected by prostate cancer, fatigue is just another burden they would rather do without.

In collaboration with King's College London (KCL), Prostate Cancer UK launched Get back on track, a project to develop and test a new telephone intervention service to help men with prostate cancer related fatigue. Working with leading experts from KCL, we trained our existing helpline nurses to lead an intervention designed to help men manage their symptoms and develop strategies to cope with their tiredness. The results of the six month trial were impressive: men who received this innovative service reported an overall improvement in fatigue levels and severity.

The service also helped men get back in touch with their interests and hobbies. This may seem like a minor point, but symptoms of fatigue can leave men feeling very removed from society. Being able to complete a round of golf for the first time in years or simply having the energy for a quick kick-about in the garden with their children are big battles won.

Following on from the success of this trial, I am pleased to announce that from February 2013, Prostate Cancer UK will be launching a fulltime nationwide service dedicated to helping men with prostate cancer combat their fatigue. Nobody else is currently offering this service and we are proud to be leading change for men in the UK.

A handwritten signature in black ink, appearing to read 'Owen Sharp'.

Owen Sharp

Chief Executive
Prostate Cancer UK

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I. Summary of findings

Introduction

The Get back on track project aimed to develop a new telephone intervention for men experiencing prostate cancer related fatigue. A trial of this intervention was undertaken in 2012 to assess both its effectiveness and the feasibility of integrating it into the current support services offered by Prostate Cancer UK.

Working in collaboration with Florence Nightingale School of Nursing and Midwifery, King's College London (KCL), Prostate Cancer UK was awarded a Knowledge Transfer Partnership (KTP) from the Department of Trade and Industry (DTI). KTP projects are designed to help businesses/charities benefit from the expertise in UK universities, colleges and research organisations by helping them to develop new products, services or processes.

Prostate Cancer UK already operated a successful helpline service but lacked the expertise in delivering tailored interventions to help men with prostate cancer manage fatigue. The KTP award allowed us to work in collaboration with Professor Ream and her team at KCL, who are the acknowledged leaders in cancer related fatigue.

Background

For healthy individuals, fatigue is a normal response to physical or psychological stress, and is usually overcome with rest and relaxation. For people with cancer however, fatigue can be severe and unrelenting, limiting daily routines and activities, and impacting on friendships, families and relationships.

Fatigue in prostate cancer is quite poorly understood compared to other cancers. The Get back on track project was an opportunity to redress this lack of

knowledge through carrying out a review of current evidence and conducting further research into the prevalence and severity of fatigue experienced by men with prostate cancer. This research also provided information on the demand and need for a service to help men understand and manage their tiredness and fatigue.

Research

Research through a review of evidence and a questionnaire was undertaken to find out:

- the prevalence of fatigue in men with prostate cancer
- investigate whether fatigue severity varies according to disease stage, treatment option, exercise frequency or age
- understand the current advice and clinical support in terms of care provision offered to men experiencing fatigue.

The results indicated that up to two-thirds of men with prostate cancer experience fatigue of some form (up to 74%). Men undergoing hormone therapy and radiotherapy recorded the most severe levels of fatigue and hormone therapy patients experienced fatigue for the length of their treatment.

Very few men were offered advice or support for their fatigue. Evidence from the questionnaire and literature review suggest there is an issue with doctors and healthcare professionals failing to recognise fatigue as a serious and far reaching symptom.

Focus groups were carried out to further explore fatigue in men with prostate cancer and establish their thoughts on how a telephone intervention would work successfully. Fatigue was noted as being a symptom that limited a number of daily activities and was associated with a high level of frustration. Fatigue impacted negatively on family life, social contact and general wellbeing. Men wanted help for fatigue and wanted to talk about it in a direct way.

Trial results

Following on from the research a randomised control trial was developed to test the effectiveness of a telephone intervention to manage fatigue in prostate cancer. The intervention was based around psychological support, self-care education and help with behaviour change.

76 men agreed to take part in the trial and were split into two groups of 38; one group received the telephone intervention, one group did not (the control group). The 38 men in the intervention group received four nurse-led telephone calls over a period of 10 weeks, based on a counselling technique called Motivational Interviewing. The control group were offered the opportunity to receive the intervention after the trial had finished but did not receive anything during it. Both groups completed a series of questionnaires on fatigue before and after the trial.

Men who received the intervention reported an overall improvement in fatigue levels, severity and the ability to deal with fatigue. Improvements in fatigue symptoms and social functioning were also reported.

Discussions with 14 men in the intervention group suggested that using the telephone was a good way of delivering the service.

Recommendations

1. Get back on track successfully improved fatigue and should be integrated into Prostate Cancer UK's services to support men.
2. Get back on track should aim to be more accessible to men in the future. To do this the support materials (daily diary and weekly planner) should be made available to be completed electronically. This could be done through providing men with a PDF file which they can record and save information on, or through the development of a smart phone app. During the focus groups, some men were keen for this style of service interaction. Doing this may also improve our ability to report on data more easily and

also track usage of other services, such as publications and website traffic which could be prompted through these uses of media.

3. Talking to men in the trial revealed that many were largely unaware of the different types of support already offered by the Prostate Cancer UK helpline service. Each of these types of support should be offered as separate services in their own right and be marketed more effectively. Increasing awareness of the various services would be likely to increase the number of calls to the service and help reach more men with prostate cancer.
4. Engaging health care professionals to ensure they are able to effectively and actively identify men with fatigue, providing appropriate care or signposting.
5. Men in the focus groups told us they prefer more direct ways of advertising our services, which is in line with our current strategy.
6. Get back on track is innovative and an example of how Prostate Cancer UK is leading change. There should be a concerted effort to share best practice with other organisations so they can use our experience from Get back on track and apply it to different areas of care.
7. Further academic involvement should be encouraged, particularly in the development of pilot and full-time services. Working with these institutions gives access to valuable expertise which can only help develop successful, innovative services.

2. Introduction: prostate cancer and fatigue

Prostate cancer is the most common cancer among men. 40,000 men are diagnosed with prostate cancer each year and it's estimated that 250,000 are living with the disease. Treatment options vary depending on disease stage and patient choice and commonly include active surveillance, surgery, radiotherapy, hormone therapy and chemotherapy.

Prostate cancer and its treatments can result in distressing side-effects such as urinary and bowel problems, sexual dysfunction, skin irritation, hair loss and fatigue. Fatigue is often acknowledged little in a man's prostate cancer journey. For healthy individuals fatigue is a normal response to physical or psychological stress and is typically overcome easily with rest and relaxation. However, Ream & Richardson state that in people with cancer, fatigue is, "a subjective, unpleasant symptom which incorporates total body feelings ranging from tiredness to exhaustion creating an unrelenting overall condition which interferes with individuals' ability to function to their normal capacity".

Not surprisingly, fatigue can severely limit daily routines and activities, while impacting on social roles. Because of these factors, fatigue can also disrupt the lives of partners and other family members, (Harden, Northouse, Mood, 2006). The symptom can also lead to men encountering other problems such as depression and anxiety, (Stone et al., 2000).

Research has aimed to reduce the negative effects of fatigue for cancer patients. High levels of fatigue have been reported in breast cancer, and a number of interventions to improve and reduce fatigue have been developed and tested. Research into prostate cancer and fatigue indicated that exercise is beneficial in reducing fatigue as is using psychosocial approaches and educational self-management techniques.

3. Working with King's College London

Prostate Cancer UK and King's College London (KCL) were awarded the Knowledge Transfer Partnership (KTP) grant from the Department of Trade and Industry. The grant allowed Prostate Cancer UK to work in partnership with KCL, sharing knowledge and expertise, to develop a new service to help men experiencing fatigue in prostate cancer.

Prostate Cancer UK already operates a successful helpline service, but lacked the expertise in delivering tailored interventions to help men manage cancer fatigue. The charity was also unfamiliar with the techniques of motivational interviewing (MI), which would be vital in underpinning an intervention to help men effectively manage fatigue symptoms.

Professor Ream's team at KCL are the acknowledged leaders in this type of intervention and have over 20 years of experience. Being able to access this expertise was a major driver in Prostate Cancer UK seeking the KTP grant. The partnership also allowed Prostate Cancer UK to:

- develop new skills in Helpline staff trained in delivering the fatigue service
- ensure a new and innovative service was embedded into the charity's information and support portfolio
- share new methodology with other cancer charities as best practice.

The KTP enabled Professor Ream and KCL to better understand:

- the impact of fatigue on men with prostate cancer
- the role of helplines' in facilitating men's adaptation to living with prostate cancer
- charity helplines' capacity to deliver interventions for specific cancer symptoms.

Professor Ream and KCL originally developed a telephone-delivered intervention for fatigue in other cancer groups. KCL have benefited from Prostate Cancer UK adapting this intervention for men experiencing fatigue in prostate cancer. Prostate Cancer UK's position and ability to put research and theory into practice was a motivating factor for KCL to be involved in the KTP project.

As well as transferring expertise to Prostate Cancer UK, the KTP also enabled Professor Ream to contribute to KCL's strategic plan of enhancing the transfer of knowledge to businesses and community.

4. What do men with fatigue experience and how can Prostate Cancer UK help?

We carried out a systematic review of literature on fatigue and prostate cancer to answer the following questions:

- What is the prevalence and severity of fatigue in prostate cancer?
- What differences are there in the prevalence and severity of fatigue according to treatment received?

Gathering this information allowed us to understand the likely demands, such as how many men may need help with their fatigue, and how running such a service might impact on Prostate Cancer UK's other services such as our helpline.

Fatigue in prostate cancer is poorly understood when compared to other cancers and this review has added to our overall understanding of fatigue in prostate cancer, which has implications which will be highlighted in this document.

Findings

Fatigue prevalence

- The prevalence of any type of fatigue was as high as 74%.
- Doctors estimated that just 21% of men would be experiencing any type of fatigue.
- Chronic fatigue prevalence was lower and varied according to treatment type.
- Chronic fatigue affected 39% of men undergoing radiotherapy with hormone therapy.

Fatigue Severity

- Severity of fatigue increased following the start of radiotherapy and hormone therapy and continued to rise over the period of these treatments.
- Hormone therapy caused fatigue severity to rise up to 12 months after treatment was started.
- Severity subsided after radiotherapy was completed.
- There were also differences in the severity of fatigue depending on the types of hormone therapy administered:
 - I. leuprolide resulted in more severe fatigue than bicalutamide
 - II. a combination of leuprolide and flutamide had a greater negative effect than leuprolide alone.

Implications of findings

Fatigue is a prevalent symptom in men with prostate cancer and men receiving combined treatments of radiotherapy and hormone therapy are at greater risk of experiencing chronic levels of fatigue. However, all treatment types were seen to cause fatigue in men at differing prevalence levels.

The discrepancy in doctor estimates of fatigue prevalence and patient self-reports may mean that men have to cope with the debilitating effects of fatigue in isolation and may not receive advice and support for reducing the negative impacts of fatigue. Doctors and health care professionals (HCPs) should thoroughly screen men at greater risk of experiencing fatigue and identify those who require support.

The findings relating to fatigue severity highlight how long a man may experience fatigue for, and times within a treatment cycle where they may require more support: during radiotherapy and hormone therapy and after radical prostatectomy. Some hormone therapy treatments cause greater fatigue than others.

As there are alternative hormone treatments available to leuprolide, research should be undertaken to investigate which if any, causes less severe fatigue. This line of investigation may have implications for hormone therapy prescribing decisions.

Conclusion

Fatigue is a common and severe symptom for many men living with prostate cancer, particularly those prescribed hormone therapy. Through better management of fatigue, men with prostate cancer would be in a better position to lead active lives and engage in hobbies, activities and pastimes. With this in mind, the aims of the KTP project were well placed to help achieve these outcomes for men.

Questionnaire exploring the prevalence and severity of fatigue

It was vital for Prostate Cancer UK to carry out its own primary research so we were in a position to confirm what was found in the systematic review. The results, combined with the findings of the systematic review allowed for informed planning and decision making in the development of the randomised control trial.

The questionnaire study aimed to research the following areas:

- explore the prevalence of fatigue in men with prostate cancer
- investigate whether fatigue severity varies according to disease stage, treatment option, exercise frequency or age
- understand the current advice and clinical support in terms of care provision offered to men experiencing fatigue.

Methods

A cross-sectional survey design was used. Potential participants were eligible to take part in the research if they had a current diagnosis of prostate cancer.

Participants were recruited from prostate cancer support groups around the United Kingdom. Additionally, Specialist Nurses working on Prostate Cancer UK's Helpline recruited eligible participants by asking callers if they would be interested in taking part in the research. An online version of the questionnaire was made available via the charity website in order to recruit eligible men from website traffic.

The Brief Fatigue Inventory was used to collect data relating to fatigue in prostate cancer. It consists of ten items. We also included demographic questions on age, ethnicity, year of diagnosis and stage of disease. Two additional questions were included asking about regular exercise habits and whether they had received past advice or support for fatigue.

Findings

A total of 324 participants were recruited from prostate cancer support groups around the UK, and from men who called Prostate Cancer UK's Helpline service. A total of 633 questionnaires were distributed, with a completion rate of 51%.

Prevalence of any fatigue

Of 324 participants, 222 (69%) reported experiencing any type of fatigue.

Fatigue severity

All 324 participants provided a fatigue severity score. A total of 118 (36%) participants were in the mild fatigue group, 129 (40%) in the moderate fatigue group and 77 (24%) in the severe fatigue group.

Analysis was carried out with the fatigue severity groups in order to identify any differences that existed between the groups by disease stage, exercise frequency, treatment and age group. We looked to see if any of the factors (exercise frequency, treatment and age group) also predicted fatigue severity using statistical analysis.

Findings suggested that doing less exercise and undergoing hormone therapy were linked to experiencing greater fatigue severity.

Support offered

11% of men with mild, 16% of men with moderate and 23% of men with severe fatigue were offered advice and support to help them with their symptoms. Below are examples of the type of support received by men from health care professionals.



Macmillan nurses, advised just to rest

Prostate cancer support group in Sidmouth. Sharing experience – splendid support

Macmillan self-Management course with the book, Self-Management of Long-Term Health Conditions.

Fatigue management course at the Neil Cliffe Cancer Care Centre, (1 day/week for 8 weeks).

I am 79 years old. When I had a word with my doctor he said I will get tired because of my age. I have always been very active, so I find it hard to adjust.

Support from my partner by accepting the fact and helping me.

From the practice nurse, advised to try and carry on with all normal activities and take gentle exercise, i.e. swimming, walking etc.

Implications of findings

The results of the questionnaire confirmed that fatigue is very common in men with prostate cancer, affecting over two-thirds of men. Moderate fatigue was most common (40%), followed by mild (36%) and severe (24%).

Hormone therapy was linked to more severe fatigue. Men prescribed hormone therapy

should be identified as being at a higher risk of developing severe fatigue and therefore require support to reduce the impact of the symptom on daily life.

Very few men were offered advice or support for their fatigue. This confirms the evidence from the literature review that there is an issue with doctors and healthcare professionals not recognising fatigue as a serious and far reaching symptom which should be addressed.

Conclusion

The results from the questionnaire helped highlight the real need for a service to improve fatigue for men with prostate cancer. The evidence base also ensured that we could effectively plan to deliver a randomised control trial of a fatigue intervention and test its effectiveness.

Looking at the results, it became clear that any service provided by Prostate Cancer UK would attract a high level of demand. To be able to deliver a good level of fulltime service after the trial period had ended, Prostate Cancer UK would need to provide adequate training for nurses, improve the current support infrastructure and increase the level of administrative support available.

Focus groups exploring fatigue in men with prostate cancer

Focus groups aimed to explore the experiences of fatigue in men with prostate cancer and their requirements for a nurse-led telephone delivered fatigue intervention.

The objectives of the focus groups were to:

- gain an understanding of the experience of fatigue
- establish how a fatigue service should be structured and marketed to engage men's interest
- understand the feasibility and acceptability of a telephone-delivered service for fatigue

- establish what men would expect from such a service in terms of support materials (amount, detail, length), and what this should look like (e.g. pocket sized fatigue diaries & information)
- input on the development of an operating protocol for a telephone based fatigue intervention.

Methods

Participants were approached via an advert sent out in regular communications to Prostate Cancer UK's volunteers. Interested participants were sent an information sheet and consent form. English-speaking men with a present or past diagnosis of prostate cancer who had experienced fatigue were recruited to the study.

There were three separate focus groups, two with 7 participants and one with 6 participants. Two of the focus groups were held in the charity's London office, while the third was held in the charity's Glasgow office.

Findings

Experience of fatigue

Fatigue was seen as a symptom with far reaching consequences that impact upon daily activities, such as work, hobbies or social events. Many men expressed having lost a sense of self, and the frustration that this brought because they could not do what they could do before they experienced fatigue. This also affected relationships and brought with it a sense of guilt. Some men did however describe that the symptoms did also strengthen relationships.



It's frustrating (fatigue), that's what I find, it's so frustrating.

I had to make excuses to my golf buddies, say I'd done my back-in, rather than admit I was just too tired to carry on playing.

It's a mental fatigue rather than physical fatigue.

I just felt like I couldn't be bothered to get involved with everything at work (because of fatigue), and I found that really, really hard.

I want to get back to normal.

Views on a fatigue service

There was an agreement that delivering a service over the phone would be an effective approach to managing fatigue. It was seen as a convenient and direct approach for both the men and the nurses delivering the service. It was generally thought that the telephone would not be a barrier to building a good relationship with the nurse but there were concerns that telephone delivery would mean that subtle information would be lost, such as facial expressions and body language.



It's quicker isn't it? (A telephone delivered service) You know, you don't have to sort of wait for an appointment, or whatever.

Simple means of contact, a good structure, build a relationship with the nurse, less embarrassment, supporting and assisting by producing help to somebody

Not seeing the person and being able to pick up on their body language, and then again, talking on the phone could be impersonal.

There was no preference on whether a male or female nurse should be delivering the service. Continuity with the same nurse over the duration of the service was seen as being vital.



It doesn't really matter whether you speak to a man or a woman because most female nurses are just as sympathetic. All right, they don't... they can't empathise totally with everything, but I don't think it really matters whether it's male or female.

Yes, for the sake of continuity, it's vital (same nurse).

If you're building the relationship, that's exactly right, you open up more with them (same nurse).

There was a feeling among the men that the support materials (daily diary and weekly planner) should be simple and not laborious to fill in, as this could be repetitive and demotivating. It was thought that if the support materials could easily demonstrate their benefit then men would be happier to fill them out. Direct advertising of the service was thought to be the best way of promoting the service and attracting men to use it.



I think it's a really important issue that we don't want to demotivate people by loading them with tasks.

If I felt that this was going to do something to help me get over the fatigue then I'd be really motivated to do it as well.

I couldn't be bothered with all of that, you know it becomes a little bit repetitious, you know, almost like, ditto what I did yesterday, and what have you.

If you put it to them (men) and say, imagine you're not going to have any sex now for a couple of weeks, and they'll go "all right". Now multiply that by a couple of years, yes, and more... And, also, because blokes don't want to talk about it, that's the next taboo isn't it? I mean, you talk about prostate cancer; they don't want to talk about cancer because they want to suffer in silence, don't want to talk about incontinence, don't want to talk about ED, and it's all these taboos that men have to break to get there.

5. Developing a trial intervention for men with fatigue

Prostate Cancer UK adapted an intervention developed and tested by KCL which aimed to reduce fatigue in cancer patients during chemotherapy. The development of a trial to test the effectiveness of the intervention was heavily influenced by the findings of the research carried out during the systematic review, questionnaire and focus groups.

Underpinning the trial intervention was a counselling technique called Motivational Interviewing (MI), which uses behaviour change to improve health and wellbeing. A central concept of MI is the identification, examination, and resolution of ambivalence (feeling two ways about something, both positive and negative) about changing behaviour. Ambivalence is seen as a natural part of the change process. MI is a conversation you have together and is not a one way lecture. It's designed to strengthen your motivation and commitment to changing a behaviour.

The trial aimed to use nurse-led telephone calls to support and encourage men to make positive changes to their behaviour and lifestyle which may lead to less symptoms of fatigue. Examples of such changes could include increasing exercise levels slowly and gradually, increasing social activities, getting back into hobbies, or changing diet.

Training

Training in Motivational Interviewing was given to the nurses who would be delivering the intervention in the trial. The training took place at KCL.

Protocol development

This was an essential element in the development of the trial. This document detailed the overall structure of the intervention and trial process.

It covered areas such as recruitment, the process of taking part (what happens step-by-step), the structure and content of calls made by the nurses, outcome measures to establish the effectiveness of the intervention and how data analysis would be carried out.

6. Trial results

A randomised control trial of the 'Get back on track' fatigue intervention started on January 30th 2012 and ended on June 28th 2012. The trial aimed to reduce fatigue symptoms and improve fatigue management strategies to ensure it impacted less on the daily life of men with prostate cancer. The trial also aimed to prove the intervention was effective enough to make providing a full-time service worthwhile.

Methods

Procedure

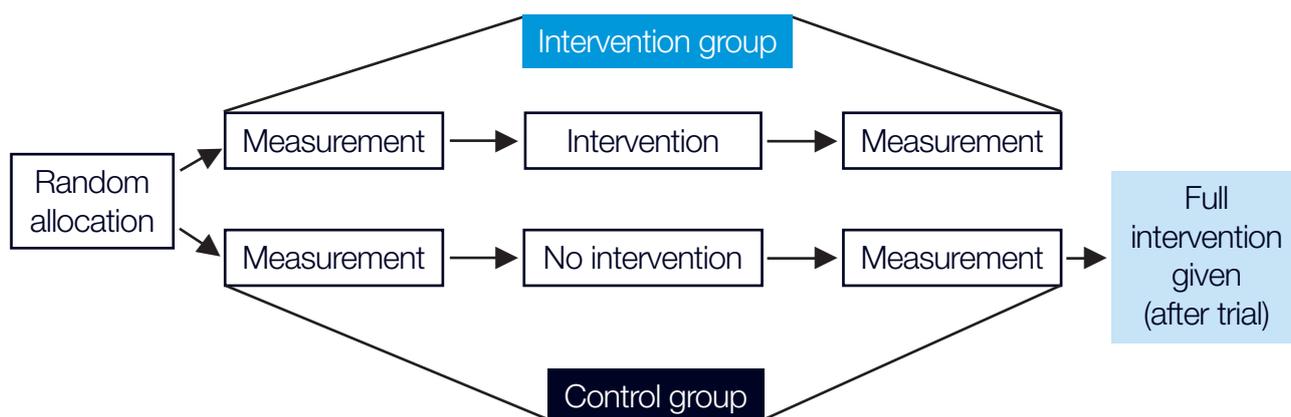
Men were recruited for the trial from:

- participants in the questionnaire study
- focus groups participants

- men who had called the Prostate Cancer UK helpline who mentioned symptoms of fatigue
- an advert on the Prostate Cancer UK website.

Men were eligible to take part in the trial if they had a diagnosis of prostate cancer and were currently (at the time of recruitment) experiencing fatigue. All men who expressed an interest in taking part were asked to rate their worst level of fatigue over the last week between 0 (no fatigue) and 10 (as bad as you can imagine). Men who rated their fatigue level between 4 and 10 were considered to be currently experiencing fatigue and were invited to take part.

All the men who agreed to take part in the trial were randomly allocated to one of two groups. One group was the 'intervention group' and the other was the 'control group'. The intervention group received the Get back on track fatigue intervention, while the control group received no advice or support for their fatigue (but were offered the opportunity to receive the intervention after the trial had ended).



All men involved were required to complete a booklet of questionnaires at both the start and end of the trial, which measured their fatigue levels, fatigue severity, emotional wellbeing, ability to function and readiness to change. Doing this meant it was possible to compare the results before and after the intervention to see if it had helped. Having the control group (who received no intervention) do the same made it possible to see whether it was the intervention that had helped or not. If, for example the intervention group recorded an improvement and the control group didn't, it would be fair to suggest (as this was the only difference between the two groups) that it was the intervention that made the difference. If after the trial, both the intervention and control had similar levels of improvement, it would suggest the intervention was not linked to the change and so hadn't helped.

Those who were in the intervention group had a series of four calls over a ten week period. Each call typically lasted for 20-45 minutes:

Call 1 – Introductory phone call lasting no more than 20 minutes. The Specialist Nurse introduced themselves and the background to the service. The Nurse aimed to gain background knowledge of the man's health and circumstances and further explain the purpose of the subsequent calls.

Call 2 – Took place 3-5 days after Call 1, lasting between 30-45 minutes. Call 2 revisited fatigue levels, reviewed any previous attempts to manage fatigue and explored goal setting for the 10 week period of the service. The daily diary and weekly planner were also introduced during call 2.

Call 3 – Took place 3-4 weeks after Call 2, lasting between 30-45 minutes. Call 3 reviewed progress, use of the weekly diary to identify impact of fatigue and consider other methods that could be implemented to help reduce fatigue.

Call 4 – Took place 3-4 weeks after Call 3, lasting between 20-30 minutes. Call 4 reviewed progress, considered future goal setting and planned for managing fatigue going forward.

Results in numbers

76 men (from the 96 eligible) agreed to take part, which represented a 73% uptake rate. During the trial period 152 calls were made to the 38 men in the intervention group. These calls were made by the three nurses trained in Motivational Interviewing.

When pre-trial questionnaire scores were compared between the two groups, there were found to be no significant differences in scores.

When post-trial questionnaire scores were compared between the two groups, overall (or global) fatigue levels were found to have reduced by the end of the trial in the intervention group. Fatigue severity levels were also reduced by the end of the trial, while fatigue management, social role functioning and fatigue symptoms were found to have improved too. For men in the control group, no reduction or improvements were seen. However, for these men physical functioning got worse by the end of the trial.

Results in words

In-depth interviews were carried out with 14 men who took part in the trial and were in the intervention group. These were done to get a richer understanding of how men experienced receiving the intervention and how taking part impacted upon their fatigue. This backed-up the results in numbers and helped us in aiming to improve the experience of men receiving the service in the future.

A number of themes emerged from these interviews and are detailed below. All quotes are from men in the intervention group who took part in the trial.

Impact of fatigue – before taking part in the trial

This theme takes into account the broad range of impacts that fatigue had on daily life, such as social activities, relationships and sense of purpose.



I might have tried before the intervention to do both my car and my wife's car and then feel disappointed in myself if either I didn't achieve it or I was so wasted at the end of it that I wasn't worth talking to or not worth being in the same room as.

I don't have any problem with mental activities, but I do physically get tired much more quickly than before I started on the hormone therapy.

It's like my family don't, I don't think they understand what it's like to be constantly tired. It probably wouldn't be so bad if I had a partner, you know, but when you're stuck by yourself it makes things a hundred times worse.

Normalising fatigue –after the trial

Taking part was seen as an educational process. The nurse delivering the intervention and the support materials were able to show that fatigue is a normal side-effect of treatments for prostate cancer. This allowed men to understand they were not alone in experiencing this symptom, which gave them a greater awareness and sense of comfort that there was nothing abnormal in what they were experiencing.



It was a relief to find out that this was normal and it is expected that you won't be able to complete things that you could have done before.

I was doing as she told me and by doing what she told me, it did help my fatigue. It most certainly did. I mean, there's absolutely no doubt whatsoever about that.

It's obviously helped to find that other people have got what you've got, is not necessarily just consigned to you really.

Understood and supported to build motivation

This theme shows how taking part in the trial and receiving the telephone calls from the Specialist Nurse helped men taking part become motivated to make changes in their behaviour to try and improve their fatigue symptoms. Having someone on the end of the telephone who understood their fatigue and supported them to make changes was seen as a beneficial aspect of taking part in the trial. This meant that men no longer felt that they were suffering from this symptom in isolation.



She helped me to realise that it was okay to classify things and it was okay to write down things both in terms of feelings, hopes, and ambitions. So, in that respect the intervention was brilliant.

Talking to the lady made me feel rather more positive about things and also the realisation, after a bit, that if I didn't sit down I wouldn't go to sleep.

She'd had a very calming effect on me. And the fatigue... the things that I was able to ask her about that were worrying me at the time, she'd all the answers. It was really excellent and yes, it did help and I've been getting stronger.

Planning around & managing fatigue to increase activity

By taking part in the trial men were able to plan activities around their fatigue more effectively and better manage the symptoms so they impacted less on daily life. Keeping a diary or talking through typical days/weeks with the nurse and setting goals for achievement helped participants see or understand that their fatigue followed daily/weekly patterns. There was a sense of the participants controlling fatigue, rather than the fatigue controlling them as a result of taking part in the trial.



It benefitted me because I was prompted to identify those parts of the day when I felt particularly fatigued and it successfully did that and I was able to come up with a response for that.

I think it's that I've got more control over it than I thought I might have really, and it's more to do with sort of mental attitude than actually anything else.

I sort of reorganize things now, sort of plan ahead so I can the most out of things. So if I have a few busy days I sort of plan days where I'm not doing very much. And I find out from filling in that book I discovered the sort of best times of the days and the best days of the weeks to be doing things, you know the scores I had. So I think that's helped.

Ensuring long-term change

This theme relates to how men would try to ensure that the positive changes they had made to their behaviour in terms of fatigue would remain as long-term changes. While it was seen as something which may have been difficult in some cases, it was usually acknowledged as something which was possible to achieve because the positive benefits were clear.



After ten weeks of filling in the diary quite religiously, actually, I think it's ingrained in me now. Whatever you're going to do in any particular day, make sure it's a realistic ambition. It's achievable no matter how big or how small it is.

It's mostly sort of keeping in mind that I can actually make some changes rather than just giving in to things and, you know, keeping that in mind rather than getting sucked into being tired about things.

I just intend to sort of keep on going, you know, and I know that now, irrespective... as long as you don't do too much, it is doing me a bit of good.

General impressions of the trial intervention

This theme shows us what men thought generally about the trial intervention. While it was seen as positive by many and also beneficial, there were also feelings that the intervention simply backed up what some men were already doing to manage their fatigue. However, even if this was the case, it was seen as a positive thing to have come out of participating.



I think it's been absolutely brilliant for me.

The main positives for me was actually talking to somebody. That's a personal sort of thing, you know, but it certainly didn't do me any harm, put it that way.

The benefit I got from your project is more than just fatigue. It's a greater awareness of the services Prostate Cancer UK offers.

Convenience

The convenience of how the intervention was delivered by the charity was seen as positive aspect of taking part. It was an approach which was flexible enough to fit around daily life and not adversely impact on time and necessary activities.



It was convenient. We were able to set it up at mutually convenient times. I think she was quite busy, but that was fine. She was able to spend... She was always prompt. She spent the appropriate amount of time with me.

Well, the positive side is that it can happen at any time and there's not travelling involved. I don't need to come and see you.

It was just convenient, really. You know, you fixed a date and that was it, you know.

The future of a fatigue service

While no major changes were highlighted with the structure and delivery of the intervention, participants thought there was a need for it to be properly advertised to encourage men to take part.

The same was true of other services currently offered by the charity which men said would have been of benefit to them if they had known of their existence. There was also a sense that further support may be required for some men taking part in the fatigue service in the future outside of the current 10 week, four telephone call design.



Perhaps it might be an idea to say to somebody after the first time; you ring up, how did you get on with the person you spoke to. Do you want to stay with that one or try another one?

Emotional support would be the most useful because most of the sort of technical things you can find out from the internet now, you know, what the drugs do and what... and so on and so forth but it is always... it's... quite often it is actually better to talk to someone about those things if they know about them but they're different.

Maybe after six months you'd have a sort of follow-up because that will sort of get you started and it would... so I suppose I'm sort of suggesting that a follow-up call after maybe six months would be... well, I think it would help me anyway.

The interview findings support the results in numbers, and illustrate how the intervention was a positive experience for men. Men seemed to benefit greatly from gaining an understanding from the nurses that their fatigue was a normal experience for men in their position and did not represent a worsening in their condition. It was seen that by taking part in the intervention men were able to build a better structure and approach to planning activities around their fatigue levels, which in turn allowed them to change behaviours, set goals and make long-term changes to improve their fatigue. The findings are a powerful demonstration of how effective an innovative intervention of this type can be in improving fatigue. Those involved in the trial were older men (average age 68) and many were diagnosed with other illnesses in addition to prostate cancer. However, even with these factors, fatigue was still improved.

By delivering an intervention of this type as a full-time service, Prostate Cancer UK has a great opportunity to improve the lives of the 69% of men experiencing fatigue in prostate cancer and ensure they can lead full and active lives where fatigue has less impact on daily life.

7. Conclusion

The results in numbers demonstrate that the intervention was effective in improving fatigue in men with prostate cancer. The intervention not only reduced overall levels of fatigue, it also reduced the severity of fatigue and improved fatigue symptoms. This suggests fatigue should have less of an impact on daily life for men who receive this intervention, as demonstrated with the improvements men saw in their social functioning as well as their improved ability to manage and cope with fatigue.

8. Acknowledgements

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9. References

- Ream E, Richardson A. Fatigue: a concept analysis. *International Journal of Nursing Studies*. 1996;33(5):519-29.
- Harden, J., Northouse, L.L., Mood, D. (2006). Qualitative analysis of couples' experience with prostate cancer by age cohort. *Cancer Nursing*, 29(5), 367-377.
- Stone P, Hardy J, Huddart R, A'Hern R, Richards M. Fatigue in patients with prostate cancer receiving hormone therapy. *European Journal of Cancer*. 2000 Jun;36(9):1134-41.



**Speak to our
Specialist Nurses**

0800 074 8383*

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The helpline is open Mon - Fri 9am - 5pm, plus Wed 7pm - 9pm

* Calls are recorded for training purposes only.

Confidentiality is maintained between callers and Prostate Cancer UK.

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