

Prostate Cancer and Living Well

Workshop Handbook



UNIVERSITY OF
Southampton

UNIVERSITY OF
SURREY



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Contact Details for Your Clinical Team

Making the best use of our time

Please chat with your neighbour (3 minutes) about your response to the two questions below...

1. What were your thoughts about coming to the workshop today?
2. Are you happy with the **Purpose** of our workshop, and **Our Ways of Working (below)**? Is there anything you'd like to add? Do you have any questions?

Our Purpose

To make sure you've got everything you need to know about your follow-up care and supported self-management.

1. To give you the skills and confidence to check your symptoms and look for any signs of cancer recurrence
2. To manage lifestyle change and set your own goals for recovery and rehabilitation

Our Suggested Way of Working Today

How can we all make this morning work in the best way possible:

1. All of you can add your experiences and ideas so you can help each other
2. Opinions are allowed. You don't all have to agree and we expect differences of opinion
3. Trying to go along with all of the activities as best you can. There's always a good reason for these.
4. Giving space for everyone in the group to speak
5. Respecting other people's privacy (you may want to talk about this workshop with your family and friends which is great but we'd ask that you don't give any personal details of the other men in your group)
6. We can offer our team's clinical expertise and get answers to any questions we don't have immediate answers to
7. Please feel free to leave the group for the loo

Workshop Aims

1. To provide help with monitoring symptoms, tracking PSA test results and contacting your clinical team when you need to
2. To develop an understanding that self-management means you work with and are supported by your healthcare team
3. To increase understanding and awareness of the physical and emotional
4. To help you return, as best you can, to life as you used to know it
5. To direct you to information and support so that you can live as full and active a life as possible



Good Planning The “Why, What and When Approach”

Turns good intentions into real action!

	Question to ask yourself... Examples
Why?	<p>Why is this plan important to me? I've been feeling really tired and sluggish for the last few months. I'd like to get my energy levels back.</p> <p>It's really important to me to keep an eye on my PSA test results and to get these without having to ring or book an appointment at my GP's.</p>
What?	<p>What do I want to do? Am I clear about it?</p> <p>I'd like to start walking half a mile every other day to the paper shop and back so I get some fresh air, exercise and wake myself up a bit as I've been doing less exercise recently.</p> <p>I don't use my computer much but I'd like to try logging on to the IT portal at home and looking at my PSA test results.</p>
When?	<p>When do I want to do this? I'd like to walk half a mile every other day first thing in the morning at 7:30am. That means I can get a paper, bring it home and read it.</p> <p>I'll try this on Friday afternoon when I know I'll be able to set aside a good half hour or so to log on to the IT portal and work my way round the system.</p>

Your plan may not include all of these steps but using some or all of these can help you to get there

Who am I going to do it with?	
Is anything going to stop me from doing it? How will I get round that?	
How will I reward myself?	

How confident are you about carrying out this plan?

	0=Not at all confident						10=Totally Confident				
Confidence	0	1	2	3	4	5	6	7	8	9	10

If you've rated your confidence level as lower than 7, think about what might stop, or get in the way of meeting this aim. It's better to set something that's realistic, than to set something that's too difficult to do.

These are the kinds of plans other men like you have thought about:

- Read the Handbook, invite my partner to read and discuss the Handbook
- Getting to know the IT Portal – open, navigate, fill in HNA, send trial message, look up information
- Improve quality of life – incontinence issues, sex life, relaxation for any worries
- Become Fitter – for energy, stress management, better health, brain benefits (walking, gardening, swimming, cycling)
- Eat Healthier - better health, reduce weight (less, less fats, more fibre)

PSA Testing

This is a blood test that measures the total amount of prostate specific antigen (PSA) in your blood. PSA is a protein produced by normal cells in the prostate and also by prostate cancer cells. It is normal for all men to have a small amount of PSA in their blood.

Following a diagnosis or treatment for prostate cancer the PSA test is a good way of monitoring your condition. You will need to have regular tests as outlined by your hospital specialists.

You should have the PSA test at your local GP surgery. If for some reason, you do not get your PSA test done, you will receive reminders. You will receive a letter in the post acknowledging your PSA test has been checked by your clinical team. A letter with your PSA test result will be sent to you and your GP.

The level of expected PSA varies with each different type of treatment for prostate cancer and your hospital specialist will be able to guide you as to what is considered normal following your treatment.

The amount of PSA in your blood is measured in nanograms (a billionth of a gram) per millilitre of blood (ng/ml).

Tip:

Try to avoid looking at your PSA results, at the weekend or in the evenings, when you know you won't be able to contact your clinical team as they run a Monday to Friday service.

Important Signs & Symptoms

It is important to report to the clinical team any of the symptoms listed below. These symptoms **do not** necessarily mean the prostate cancer is more active or has returned. They may be due to side effects of treatment or completely unrelated to your condition. By contacting your clinical team they will be able to advise and reassure you. If necessary they can arrange any investigations that might be required.

- **Bone pain lasting for more than 6 weeks:** this may be general wear & tear on the joints/bones or it may be related to the prostate cancer. If your PSA is undetectable or very stable it is very unlikely that it is related to your prostate cancer.
- **Blood in poo:** this can be a late effect of radiotherapy. Most commonly it is related to haemorrhoids or piles, or straining if constipated. Sometimes it is due to an anal tear. Occasionally this could be due to an unrelated bowel disorder or may indicate a bowel cancer so needs to be reported & investigated promptly.
- **Bowel problems:** Constipation or diarrhoea – this may be a late effect of treatment but may also be related to your diet, fluid intake, level of physical activity or medications that you may take.
- **Blood in urine:** this could be caused by a urine infection or be related to a bladder or kidney problem which needs further investigation.
- **New or worsening incontinence:** this may be a late effect of treatment, an enlarged prostate or bladder instability. If you have had surgery to remove your prostate, most likely this is due to reducing the frequency of performing pelvic floor exercises. In the first instance, increasing the frequency of performing these exercises usually improves things. In some instances you may be invited back to the hospital for urinary flow tests and an ultrasound scan.
- **Changes in passing urine (hesitancy or slow flow):** may be due to a urethral stricture (a narrowing of the water pipe) or an enlarged prostate. Again, you may need to attend the hospital for urinary flow tests.
- **Unplanned weight loss:** could be due to stress or related to dietary intake.

Emotional impact: Is the prostate cancer going to come back or will it get worse?

After treatment, some men will put their cancer experience in the past and hardly ever think about it. Uncertainties may not bother them. Others think about cancer often and find those thoughts are overwhelming. They may live with fears about whether their cancer will come back; get worse or how it will affect their future. Some men will focus on the positive changes cancer has brought such as a new purpose and strength in life. They may more easily accept and adapt to changes and challenges. Any one of these reactions is normal. Some degree of worry is quite normal. It would be strange not to be worried about these issues at some point.

When to ask for help

- Any minor aches, coughs or headaches make you think that your prostate cancer has come back / got worse
- You're finding it difficult to rebuild your life because of uncertainty about prostate cancer
- You constantly worry that the prostate cancer is going to come back or is going to spread/get worse
- You worry about prostate cancer before you go to bed at night and the first thing in the morning
- You are having problems sleeping that have lasted for a few weeks
- You have little or no appetite
- You have no desire to spend time with friends
- You have little or no interest in carrying on with your normal routines
- You're finding it difficult to concentrate



Emotional Impact: Ways to manage worry and uncertainty about prostate cancer

- Learn to focus on the ways prostate cancer has made you a stronger person
- Talk to family and friends about your concerns
- Join a support group
- Write a diary about your fears and feelings
- Get involved with an interesting hobby or other things you enjoy doing
- Review your priorities towards interesting and meaningful activities
- Remember that as time goes by, these worries will fade
- If depression, anxiety or any part of the cancer journey becomes overwhelming seek advice from your clinical team, GP or a professional counsellor

Some friends and family members may be uncomfortable talking about cancer.

If that is the case, it is very important to remind yourself:

- You have done nothing wrong by bringing up the subject – the other person may be responding to his or her own experience and fear of cancer
- The other person may not know how to discuss the subject
- Although what they said may not be what you wanted to hear, it may be that this person is doing the best he or she can right now

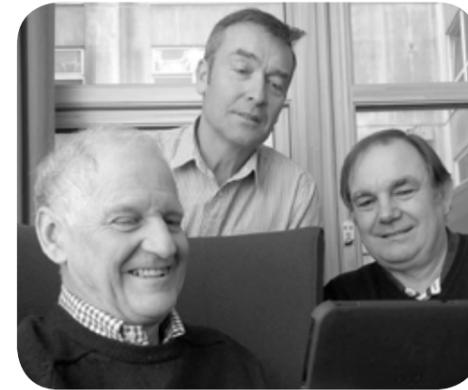
Find a cancer support group.

Support groups can provide a safe environment to share experiences with other people who have gone through similar experiences. You can also learn new ways to handle difficult situations and talk about emotional issues that only other people like you will really understand. These groups can offer an opportunity to learn different ways of coping. Prostate Cancer UK, Macmillan Cancer Support, the Expert Patients Programme and Penny Brohn Cancer Care can give you information about free cancer support workshops.

Talk with a professional therapist if worry or low mood overwhelms you.

Counsellors are trained to listen and can help you to find your own ways to deal with things. Your GP can usually refer you to a counsellor or you can pay for one and arrange it yourself. Contact the British Association for Counselling and Psychotherapy for more information. Telephone: General Enquiries: 01455 883300; Text: 01455 560606; email bacp@bacp.co.uk; website: www.bacp.co.uk

Relaxation Exercises



Relaxation can help to relieve the symptoms of stress and anxiety. It can help you calm down and take a step back from a stressful situation.

Although the cause of the anxiety won't disappear, you will probably feel more able to deal with it once you've released the tension in your body and cleared your thoughts.

All relaxation techniques combine breathing more deeply with relaxing the muscles.

Don't worry if you find it difficult to relax at first. It's a skill that needs to be learned and it will come with practice.

Relaxed breathing

Practise deep breathing at a regular time and in a quiet place where you won't be disturbed. Loosen or remove any tight clothes you have on, such as shoes or jackets. Make yourself feel completely comfortable.

Sit in a comfy chair which supports your head or lie on the floor or a bed. Place your arms on the chair arms, or flat on the floor or bed, a little bit away from the side of your body with the palms up. If you're lying down, stretch out your legs, keeping them hip-width apart or slightly wider. If you're sitting in a chair, don't cross your legs.

Good relaxation always starts with focusing on your breathing. The way to do it is to breathe in and out slowly and in a regular rhythm as this will help you to calm down.

- Fill up the whole of your lungs with air, without forcing. Imagine you're filling up a bottle, so that your lungs fill from the bottom.
- Breathe in through your nose and out through your mouth.
- Breathe in slowly and regularly counting from one to five (don't worry if you can't reach five at first).
- Then let the breath escape slowly, counting from one to five.
- Keep doing this until you feel calm. Breathe without pausing or holding your breath.

Practise this relaxed breathing for three to five minutes, two to three times a day (or whenever you feel stressed).

Progressive muscle relaxation

This technique takes around 20 minutes. It stretches different muscles in turn and then relaxes them, to release tension from the body and relax your mind.

Find a warm, quiet place with no distractions. Get completely comfortable, either sitting or lying down. Close your eyes and begin by focusing on your breathing; breathing slowly and deeply, as described above.

If you have pain in certain muscles, or if there are muscles that you find it difficult to focus on, spend more time on relaxing other parts.

You may want to play some soothing music to help relaxation. As with all relaxation techniques, deep muscle relaxation will need a bit of practice before you start feeling its benefits.

For each exercise, hold the stretch for a few seconds, and then relax. Repeat it a couple of times. It's useful to keep to the same order as you work through the muscle groups:

- **Face:** push the eyebrows together, as though frowning, then release.
- **Neck:** gently tilt the head forwards, pushing chin down towards chest, then slowly lift again.
- **Shoulders:** pull them up towards the ears (shrug), and then relax them down towards the feet.
- **Chest:** breathe slowly and deeply into the diaphragm (below your bottom rib) so that you're using the whole of the lungs. Then breathe slowly out, allowing the belly to deflate as all the air is exhaled.
- **Arms:** stretch the arms away from the body, reach, and then relax.
- **Legs:** push the toes away from the body, then pull them towards body, then relax.
- **Wrists and hands:** stretch the wrist by pulling the hand up towards you, and stretch out the fingers and thumbs, then relax.

Spend some time sitting or lying quietly after your relaxation with your eyes closed. When you feel ready, stretch and get up slowly.

Healthy Lifestyles: Healthy Eating

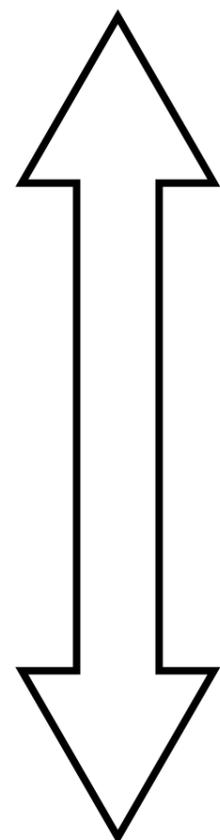


The Eatwell Plate

Use the eatwell plate to help you get the balance right. It shows how much of what you eat should come from each food group.

1. Plenty of **fruit and vegetables**
2. **Starchy foods** should make up about one third of the food you eat. This includes bread, rice, potatoes, pasta and other starchy foods. Choose **wholegrain** varieties whenever you can because they are a good source of fibre.
3. Some **milk and dairy foods**
4. Some **meat, fish, eggs, beans** and other non-dairy **sources of protein**
5. Just a **small amount** of foods and drinks high in **fat and/or sugar**

Healthy Lifestyle: Benefits of Physical Activity



- Reducing cancer-related fatigue
 - Reducing stress and anxiety
 - Improving low mood or depression
 - Improving bone health and helping prevent osteoporosis
 - Improving heart health
 - Building muscle strength
 - Helping maintain a healthy weight
 - Improving your quality of life
-
- High blood pressure
 - Heart disease
 - Kidney disease
 - Diabetes
 - Stroke
 - A new cancer

Jim's Story



I was diagnosed with prostate cancer in November 2012. I had a prostatectomy and then went on to hormone therapy a few months after my surgery. I'd always been fairly active before I was diagnosed; walking, gardening and playing squash once a week with some friends. After my surgery, I was really worried about damaging myself or falling if I did any exercise and I spent a lot more time indoors. I've been retired for four years now. I think if I'm honest, I'd become a bit down and depressed. Anyway, one of my friend's Ted, who I used to play squash with joined a walking club and started going on about it to me. I thought it was a bit of nonsense at first. I mean, walking can't really do you that much good can it? Anyway, to stop him going on at me more than anything, I joined him on one of these walks. By this time, I'd been on the hormone therapy for about six months and I

think that combined with the fact that I'd not been exercising like I used to meant that I'd put on about a stone in weight.

Well, that first walk with the walking club, I was surprised. We did this really nice route along the canal and stopped for a coffee at a nice café. The other people in the group were really friendly and there were quite a few blokes my kind of age. I remember that night, I felt much more rested and less stressed and I slept better than I had done for ages. I started walking with that club regularly and me and Ted quite often go off for walks on our own and have become a bit more adventurous going off on hikes rather than gentle walks. I've started to lose weight and it has given me a lot more confidence. It also gets me off the sofa and out into the open air which can't hurt can it?

Exercise Tips

- **Keep in mind the benefits** of becoming more active and what that's going to do for you
- **Throw away** the old tracksuit / jogging bottoms... and the memory too. It's normal to have a mental image of yourself when you last exercised, like a 20 year old. But if that image is from a long time ago, you could be in big trouble. Remember as little as possible of what you used to look like. Starting today, make new memories.
- **Prepare.** We already know you don't have the time, so write it down like an appointment every day. You wouldn't cancel an appointment would you? Why would you cancel on yourself? Aren't you important too?
- **Start slowly.** Do much less than what you're capable of. Take a 20-minute walk if you're returning to exercise. You might feel like it's not enough, but it's a good start.
- **Get the family or friends involved.** Go walking with friends. Share your plans to exercise with people you know are supportive. Celebrate with a little something special every time you manage to exercise.
- **Ask for advice from your GP or health care team** if you are unsure about any aspect of exercise and your health
- **Don't beat yourself up if you don't manage to exercise as planned.** Think about why you didn't get round to it and what you could do differently next time to change that.



Other Places for Support and Information

National Organisations

UK Movember Foundation (020 7952 2060):
www.uk.movember.com

Prostate cancer support organisation (0845 650 2555):
www.pcaso.org

Macmillan cancer support charity (020 7840 7840):
www.macmillan.org.uk/Home.aspx

Orchid - Fighting male cancer (020 4655 766):
Support service/pioneering research and promoting awareness
www.orchid-cancer.org.uk/home

Prostate cancer support federation (0845 601 0766):
www.tackleprostate.org

Mens Health Forum (020 7922 7908):
www.menshealthforum.org.uk

Penny Brohn Cancer Support (01275 370100):
www.pennybrohncancercare.org

Positive Action on Cancer (01373 455255):
www.positiveactiononcancer.co.uk

Self-management support

A positive approach to self-management (from Coventry University) (024 7688 7459):
www.hopeprogramme.coventry.ac.uk

For the day to day challenges of cancer www.livestrong.org

Bladder and bowel foundation (0845 345 0165):
www.bladderandbowelfoundation.org

BABS (Adult Bowel and Bladder Service) (01225 831766):
www.sirona-cic.org.uk/services/adult-bowel-and-bladder

Sexual Advice Association (020 7486 7262):
www.sda.uk.net

Prostate Cancer UK
www.prostatecanceruk.org
To speak to a specialist nurse
call 0800 074 8383

Health with pride - Online resource which has information on cancer issues and erectile dysfunction for gay men (020 8591 9595): www.healthwithpride.nhs.uk

National Osteoporosis Society (0845 450 0230):
www.nos.org.uk

DEXA scan bone Density Scan patient information:
www.patient.co.uk/health/dexa-Scan

NHS Choices Includes all NHS online services and information, to help you make choices about your health: www.nhs.uk

Alcoholics Anonymous (0845 769 7555):
www.alcoholics-anonymous.org.uk

Quit Now Smokefree NHS:
quitnow.smokefree.nhs.uk

World Health Organisation:
www.who.int/dietphysicalactivity/pa/en/

Diet, physical activity and prostate cancer:
www.prostatecanceruk.org/prostate-information/living-with-prostate-cancer/your-diet-and-physical-activity

MacMillan 'Walking for Health' (020 7339 8541):
www.walkingforhealth.org.uk

NHS Change4life (0300 123 4567):
www.nhs.uk/Change4Life/Pages/change-for-life.aspx

Local sport and leisure parks in the South West:
www.bathnes.gov.uk/services/sport-leisure-and-parks

AgeUK supporting independence and wellbeing (0800 169 6565):
The UK's largest charity working with and for older people
www.ageuk.org.uk

Carers Trust is a major new national charity for, with and about carers helping to improve support, services and recognition for anyone living with the challenges of caring (0844 800 4361): www.carers.org/

Carers UK is a national based organisation to offer advice, information and support for carers (0808 808 7777): www.carersuk.org/

CitizensAdvice - the charity for your community (03444 111 444):
www.citizensadvice.org.uk

Benefits advisory service:
Benefits advice including tax credits, eligibility and appeals
www.gov.uk/browse/benefits

Healthcare travel costs scheme:
www.nhs.uk/NHSEngland/Healthcosts/Pages/Travelcosts.aspx

