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Prostate patient directed open access workshop handbook

General information

A guide for patients and carers

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Welcome

Welcome to the Patient Directed Open Access (PDOA) Workshop and the team that will support you on this journey. We offer the opportunity to learn more about prostate cancer signs and symptoms; additional ways of managing your physical and emotional wellbeing and how the online health record My Medical Record (MMR) can support you in your follow up pathway.

Working Together

1. Feel free to bring your experiences and ideas to the group so you can help each other.
2. Try to participate with any activities as best you can.
3. Give space for everyone in the group to speak.
4. Respecting other people's privacy. You may want to talk about this workshop with your family and friends, which is great, but we ask that you do not give any personal details of the other men in your group.

Workshop Aims

1. To introduce PDOA and MMR and develop an understanding of how you will be supported by your healthcare team.
2. To provide help with monitoring signs and symptoms, tracking PSA test results and contacting your clinical team when you need to.
3. To increase understanding and awareness of the physical and emotional impact of prostate cancer and how best to manage this.
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.

Introducing Patient Directed Open Access (PDOA)

Your specialist cancer team have referred you to PDOA and you no longer need to travel to the hospital for routine follow-up appointments. Instead you can contact your team at The Clatterbridge Cancer Centre directly to arrange a follow-up appointment if you have any concerns.

Your team will continue to review any blood results and your health and wellbeing.. You will be contacted if they have any concerns.



Introducing My Medical Record (MMR) Your Online Personal Health Record

As part of your follow-up care you will be provided with secure and confidential access to an online resource called MMR Online. www.mymedicalrecord.uhs.nhs.uk

This resource can be accessed via the internet, and you can use it to:

1. View your prostate specific antigen (PSA) test results.
2. Message your specialist cancer team.
3. Access information on living with or after prostate cancer.
4. Take assessments to monitor issues related to prostate cancer and its treatment.

We understand that not everyone feels comfortable with technology or has access to a computer on a daily basis. To help support you, the team will offer you information on how to obtain free-of-charge guidance on access to internet skills training, if needed. If you choose not to register to use MMR online, you can continue to take assessments and receive information in paper format.

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

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 Nano grams (a billionth of a gram) per milliliter of blood (ng/ml).

You will be sent a PSA form in the post and can go to your GP or local hospital for the test.



Health MOT Checklist

You will be asked to complete regular assessments in the form of a "Health MOT Checklist". This can be found on your online personal health record or will be in paper format with your PSA letter sent to you in the mail. The checklist is there to help you identify any concerns or problems that you may have and would like to discuss further with your Prostate Cancer Support Worker who will be introduced to you.

Important Signs and Symptoms

It is important to report to the clinical team any of the symptoms below.

This **DOES NOT** necessarily mean that the prostate cancer is more active or has returned.

Bone pain lasting for more than 6 weeks: this may be general wear and tear on the joints/bones or it may be related to 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.

Bowel problems: constipation or diarrhoea – this may be a late effect of treatment but may also be related to your diet, fluid intake, and level of Physical activity or medication that you may be taking.

Blood in urine: this could be caused by a urine infection or be related to a bladder or kidney problem which needs further investigation

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 this could be due to a urine infection.

New or worsening incontinence: this can 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, 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.

Emotional Impact

Concerns that the prostate cancer is going to come back or get worse.

After treatment, some men will put their cancer experience in the past, think about it on limited occasions and have little concern for uncertainties. Others think about cancer often and find thoughts overwhelming. Some live in fear 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 had brought; such as a new purpose and strength in life. They may more easily



accept and adapt to change and challenges. Any one of these reactions is normal. Some degree of worry is quite usual. It would be strange not to be worried about these issues at some point.

When to Ask For Help

Please do not feel embarrassed or anxious to ask for help, whether this is from clinical staff, your Cancer Support Worker, a family member or friend.

Here are some suggestions of when to ask for help:

- Any minor aches, coughs or headaches make you think that your prostate cancer has come back/got worse
- You are finding it difficult to rebuild your life because of uncertainty about prostate cancer and is it going to come back or spread/get worse
- You are having problems sleeping that have lasted for a few weeks; this could be worry about your cancer before you go to bed
- 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 are finding it difficult to concentrate like you did before

Emotional Impact Management

Ways to manage worry and uncertainty about prostate cancer.

- Join a support group (see your Cancer Support Worker)
- Write a diary about your fears and feelings
- Get involved with an interesting hobby or other things you enjoy doing
- Learn to focus on the ways prostate cancer has made you a stronger person
- Talk to family or friends about your concerns
- If depression, anxiety or any of the cancer journeys becomes overwhelming, seek advice from your clinical team, GP or Cancer Support Worker

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

If that is the case, it is 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 have 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.



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 will not disappear, you will probably feel more able to deal with it once you have released the tension in your body and cleared your thoughts.

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

Do not worry if you find it difficult to relax at first. It is a skill that needs to be learned and it will come with practice.

Relaxed Breathing

Practice deep breathing at a regular time and in a quiet place where you will not 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 are lying down, stretch out your legs, keeping them hip-width apart or slightly wider. If you are sitting in a chair, do not 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 are 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 (do not worry if you cannot 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

Practice 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 require 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 is 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, and 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 are 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.



- Plenty of fruit and vegetables.
- 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.
- Some milk and dairy foods
- Some meat, fish, eggs, beans and other non-dairy sources of protein.
- 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
- Can also help to prevent:
 - High blood pressure
 - Heart disease
 - Kidney disease
 - Diabetes
 - Stroke
 - A new cancer

Exercise Tips

- **Keep in mind the benefits** of becoming more active and what that is going to do for you
- **Throw away** the old tracksuit / jogging bottoms... and the memory too. It is 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 do not have the time, so write it down like an appointment every day. You would not cancel an appointment would you? Why would you cancel on yourself? Are not you important too?
- **Start slowly.** Do much less than what you are capable of. Take a 20-minute walk if you are returning to exercise. You might feel like it is not enough, but it is 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
- **Do not beat yourself up if you do not manage to exercise as planned.** Think about why you did not get round to it and what you could do differently next time to change that



Further Information and Contacts

National contacts

Prostate Cancer UK

Telephone: 0800 0748383 | www.prostatecancer.org

Cancer Research UK

Cancer Research UK's patient information resources

Helpline: 0808 800 4040 | www.cancerresearchuk.org

Macmillan Cancer Support

Free information, practical and emotional support.

Telephone: 0808 808 00 00 (7 days a week, 8am-8pm)

Email: via the online support line through Macmillan cancer support or online chat open 8am-8pm seven days a week

NHS Choices

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

Citizens Advice Bureau

www.citizensadvice.org.uk

Local Contacts

The Clatterbridge Cancer Centre Prostate Cancer Support Worker

Contact: 0151 556 5769

ccf-tr.cccpatientdirectedopenaccess.prostate@nhs.net

Maggie's Merseyside - Maggie's Centre

Contact: 0151 334 4301

clatterbridge@maggiescentres.org



How we produce our information

All of our leaflets are produced by staff at The Clatterbridge Cancer Centre and this information is not sponsored or influenced in any way. Every effort is made to ensure that the information included in this leaflet is accurate and complete and we hope that it will add to any professional advice you have had. All our leaflets are evidence based where appropriate and they are regularly reviewed and updated. If you are concerned about your health in any way, you should consult your healthcare team.

We rely on a number of sources to gather evidence for our information. All of our information is in line with accepted national or international guidelines where possible. Where no guidelines exist, we rely on other reliable sources such as systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals and government publications.

References for this leaflet can be obtained by telephoning 0151 556 5570.

If you need this leaflet in large print, Braille, audio or different language, please call 0151 556 5570.

If you have a comment, concern, compliment or complaint, please call 0151 556 5203.

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