Prostate cancer news and views

Prostate cancer news and views Issue 1 | February 2013

RAY CLEMENCE J Prostate cancer and me



Funding the future

New grants to keep research talent in prostate cancer

Owen Sharp

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Adrian Mole:

The Prostrate

Years

THE TREAT IN

Sue Townsend

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INBOX

Tell us what you think about the magazine. All feedback is welcome: the good, the bad and the constructive.



Dear Prostate Cancer UK

I was recently diagnosed with prostate cancer and after a friend told me about you, I rang your Specialist Nurses. I just want to say the service I got was amazing, absolutely fantastic. When my wife was standing there with me, the nurse even said to her:

Anytime you want to ask something, ring me up and I'll be there

I then ordered some booklets, which I showed to my oncologist and she

Hello Prostate Cancer UK

I want to personally thank whoever placed the toilet adverts in spring last year. It was very effective. I stopped at Donnington Services on

Like us on Facebook: Prostate Cancer UK

thought they were amazing too. They're so helpful.

I'm a very positive person and believe that I don't have to live with cancer - cancer's got to live with me. And while positive energy can't cure you, it can help. My PSA has gone down from 27 to 0.6 so I'm very fortunate. Because of the fantastic response I'm signing up to be a volunteer. I want to help in any way I can. I'd recommend calling the nurses to anyone. It was so informative and completely satisfied my mind. Thank you for taking the time to talk to me and my wife.

Mick, Harlow

*** † †** *

the M1, rushed in to the toilet and your poster was right in my face. It got the message home in one and it got me to see my GP only to find out I had PSA over 41, Gleeson 8, and T3 cancer so any later and my prostate cancer could have gone to my bones.

I can only tell you it was a highly effective campaign.

Follow us on Twitter: @prostateUK

You can also tweet us with your comments about Progress. Please include #ProgressMag so we know you're talking to us.

For each issue of Progress, we ask our volunteers and support groups to share their views and experiences, for example in Hot Topic (page 5). If you have been affected by prostate cancer and would like to join our email list and recieve these requests,

please get in touch.



I am living proof it works! Thank you, and all the good folks at Prostate Cancer UK. I use your site and your forum a lot, and they are very informative.

I cannot say how grateful I and my family are. The advert has certainly extended my life.

Peter, West Oxfordshire

Editor's note

Dear Readers,

A very warm welcome to the first issue of Progress.

In these pages, we bring you news about the future of prostate cancer research, an expert Q&A on sex and prostate cancer; goalkeeping legend Ray Clemence on his experience of the disease; and an extract from Sue Townsend's brilliant Adrian Mole: The Prostrate Years.

Ben, Nick, Penny and I work together to provide you a useful, interesting and enjoyable read. We really hope we achieve this, so please do let us know what you think: Did we get it right? Could we could do better? Do you have any suggestions?

Finally, huge thanks to the volunteers and support groups who have helped us by sharing their views and experiences so openly. They are at the very heart of this magazine. We hope you will join them.

Very best wishes,

Cothanne

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PROSTATE CANCER NEWS

New blood test could detect aggressive prostate cancer

Research part-funded by Prostate Cancer UK has identified a blood test that could be used to distinguish between aggressive and non-aggressive prostate cancer. The test looks at the pattern of gene activity, meaning which genes are active and which are not. Genes are the building blocks of who we are, deciding what we look like and whether we are more likely to develop certain diseases.

Researchers scanned all the genes in blood samples from 100 men with prostate These results were

cancer, 69 of whom had advanced prostate cancer and 31 of whom had lowrisk early stage disease. These 100 patients were then split into four groups according to their gene activity. Two and a half years later the researchers followed up with the groups. It was immediately clear that the men in one of the four groups had not lived as long as the others. Further investigation identified nine active genes that were shared by all the men in that group.

confirmed in a further 70 American men with advanced cancer, where the presence of these nine active genes could accurately identify which men survived for a shorter time.

Linking particular genes to cancer has been done before, but usually involves taking samples from the tumour. What makes the new research stand out is that for the first time this information can be detected through a simple blood test, paving the way for a potentially accurate and

non-invasive test to assess how aggressive a man's prostate cancer will be.

"For years it has been extremely difficult to try to predict which men have very aggressive tumours and which do not." said Dr Kate Holmes, Head of Research at Prostate Cancer UK. "If these findings can be confirmed by much larger studies over time this method could empower men and their clinicians to make much more informed decisions about which treatments are best for them."

BEHIND THE HEADLINES Dispelling myths about prostate cancer **Daily Express:** Proof that greens slash cancer risk

"Eating broccoli, cauliflower and cabbage at least once a week can cut the risk of developing a range of cancers... Sulforaphane, which is found at high levels particularly in broccoli, has been shown to destroy prostate tumours while leaving normal cells healthy."

Digging deeper into this, we have been unable to find any solid proof that broccoli can destroy prostate tumours. However, that's not to say there is no evidence that broccoli can be beneficial.

Broccoli is just one vegetable in the cruciferous family, along with cauliflower, cabbage and Brussels sprouts. There are numerous studies in humans about cruciferous veg and prostate cancer; some show a benefit, some don't. There is some limited evidence for cruciferous veg having a protective effect against prostate cancer when eaten several times a week, but more work is needed to confirm this.

Studies on cells and on animals have shown that a nutrient called sulforaphane, present in cruciferous veg, may have a role in reducing the risk of prostate cancer. But, and this is a big but, these types of studies cannot be used to prove the same effect in humans. What they can do however, is suggest why a finding in humans may be possible by showing us how it might work in our cells.

Broccoli might not be the miracle veg you read about in the headlines, but it's still a good addition to your plate. A healthy diet with plenty of fruit and veg is important for overall health, so there's no need to turn your back on the humble broccoli just vet.



Prostate Cancer UK demands fairness in new drug pricing system

From 2014 the price of all new drugs for use on the NHS will be assessed under a new system called value-based pricing. Valuebased pricing aims to make sure prices charged by drug companies for new drugs reflect the value they provide to patients and the NHS with less emphasis on the drugs' actual cost.

However, we were concerned that people affected by cancer had not been properly consulted on the proposed changes, and commissioned research to gather their views. In November 2012, we published a report in partnership with fourteen other leading cancer charities based on this research. The report, Value-

based pricing: Getting it right for people with cancer. has five recommendations:

- Reform of the current system must lead to significant improvements in access to effective drugs
- People affected by cancer must have an equal role in designing the new system
- A new method for involving people affected by cancer in the process of appraising individual drugs should be introduced
- Drugs that improve people's quality of life should be given the greatest value
- The 'wider societal benefits' of drugs should be carefully considered

Memory metal could ease flow for men

Men with benign prostatic hyperplasia (BPH) may soon be thanking a littleknown metal called nitinol for relieving their symptoms. One of the most common symptoms men with BPH face is difficulties urinating as the enlarged prostate presses on the urethra (the tube you pee through) and restricts the flow of urine. To combat this problem, researchers are testing a new surgical technique that involves inserting a small metal tube up the urethra to relieve the pressure on it.

The tube, which is made of nitinol and moulded at low temperature to a width of 5mm, is inserted into the urethra. Nitinol is a metal alloy of nickel and titanium and is a type of memory metal - it can be moulded into different shapes but always returns to its original shape when heated. As the body temperature warms the nitinol tube, it starts to return to its original size, opening up the urethra and releasing the restriction in flow of urine. Similar treatments have been used previously,

If you'd like to comment on this or other news stories, go to prostatecanceruk.org/newsanddebate and join the conversation.

Following our report, The Association of the British Pharmaceutical Industry (ABPI) said it supports the idea of creating a more meaningful method for involving patients and that better access to drugs should be the main objective of the new pricing system.

Our Chief Executive Owen Sharp has already met key members of the Government to press for greater involvement of patients in defining value-based pricing.

You can read the report and catch up on new developments at prostatecanceruk.org/ valuebasedpricing

but what makes this different is that the nitinol tube only needs to be in place for five days before it is removed.

Early results of trials in Israel and Italy suggest that the device is effective, with patients still symptom free after six months. The new treatment could offer a less invasive but effective treatment option for men with BPH and we look forward to the publication of these results and further trials.

HOT Topic

We asked men to share their views on our news story (below left) about a potential new treatment for benign prostate hyperplasia (BPH).

As a man are vou comfortable with the idea of this procedure?



"I am comfortable with this having read that it has been tried successfully, albeit with small populations."

If you had BPH, would you choose this procedure?

91% Yes 9% No

"As my BPH symptoms are mild, I don't think I'd run the risk of surgery."

If you could take part in a trial of this or another new treatment, would the potential benefits outweigh the risks of testing something that hasn't yet been trialled on a large scale?

"I'd be willing to take part in a trial but I'd need more detail about the procedure."

"I have taken part in a clinical trial and think it is important to do so to contribute to advances in medical knowledge.'

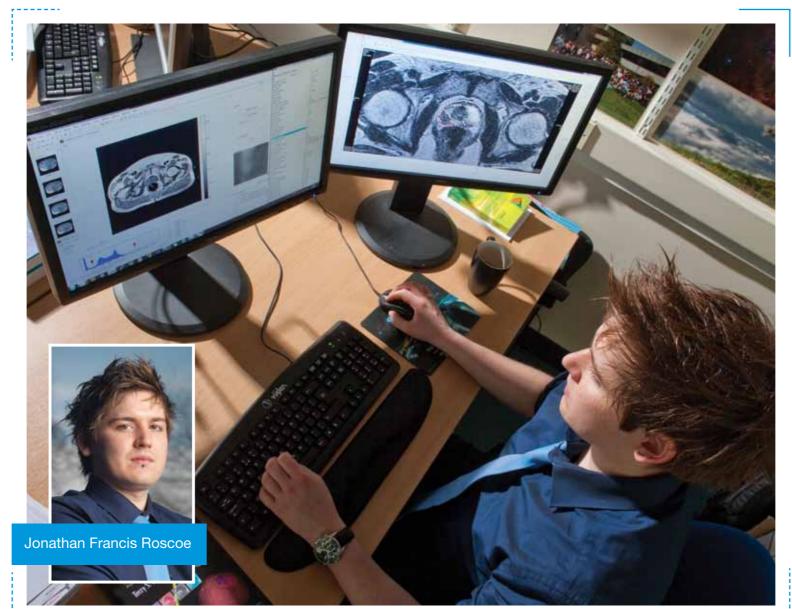
Funding the future

New grants launched to find and keep the best researchers

Tough economic times are driving promising and experienced researchers away from the lab and threatening the future of prostate cancer research. Prostate Cancer UK is responding to this by spending over £2 million on Training and fellowship grants to increase the number of researchers working to defeat prostate cancer. From funding PhD students to supporting surgeons with an interest in research, we're going to increase the field of excellence across the board.

It is thanks to the overwhelming generosity of our supporters and The Movember Foundation that we are in a position to lead the fight back. Our Research strategy 2012-2020 is our battle plan. The strategy sets out three priorities we will focus on: to better predict risk, to detect aggressive disease more effectively and to treat advanced prostate cancer more successfully. Our guiding principle throughout is to support the best research carried out by the best people in the best places. However, finding the best people and keeping them working in prostate cancer research is one of our biggest challenges.

We all know we're living in a time of financial constraint and this is having an impact on researchers from PhD students all the way up to lead investigators. Funding is getting harder to come by and research positions in laboratories up and down the country are fought over as the money dries up. This is deterring promising young researchers from embarking on careers in medical research. And it means men and women with years of experience in the lab are being forced to find



We need to make sure researchers starting their careers are encouraged to study prostate cancer

other means of employment, wasting their talents and diminishing our impact on prostate cancer.

Our Training and fellowship grants are a direct response to this. We will be funding PhD studentships, career development fellowships, clinical research fellowships and a scheme to help talented researchers get back into the lab after career breaks.

The grants will allow us to fund more promising research projects and researchers like Jonathan Francis Roscoe, a PhD student studying at the University of Wales, Aberystwyth. We have been supporting Jonathan's work since 2011. "Prospective PhD students always struggle to gain funding," said Jonathan. "I'm very glad Prostate Cancer UK was able to fund my project. I'm proud to be working in such an important field and I look forward to continuing to work in prostate cancer research."

"In the 2012-13 grant round, we will be funding at least four PhD studentships," said Dr lain Frame, Director of Research at Prostate Cancer UK. "We need to make sure men and women starting their research careers are encouraged to study prostate cancer. We aim to support them throughout their development as they continue to focus their growing expertise on fighting this disease.

"Through our Career development fellowships, we will also be supporting high calibre researchers for five years, enabling them to establish their independence and become leading prostate cancer researchers."

Find out more about the work we fund at prostatecanceruk.org/research

Following a successful collaboration with the Medical Research Council, we are offering Clinical research training fellowships with the Royal College of Surgeons and College of Radiographers. These fellowships are designed to encourage surgeons and radiographers to focus their study on prostate cancer. We are also working with the Academy of Medical Sciences to fund up to two Starter grants for clinical lecturers so they can pursue their research work in prostate cancer.

And we're keen to support researchers who are struggling to get back into work. Just a few years away from the lab, on maternity leave for example, can be a career killer and this is a real waste of talent. The Daphne Jackson Trust offer flexible, part-time fellowships to scientists who have taken a career break of two or more years for family, caring or health reasons. This year, we are delighted to be collaborating with them to fund up to two fellowships.

To be considered for the Training and fellowship grants, every application must be based in the UK and in some way target one of the three priorities in our Research strategy. This grant round began in December 2012 and we will be making awards from April this year.

We believe the amount we plan to invest in this area more than £2 million - is vital to secure the future of prostate cancer research. We want to support the individuals who will carry out the research that will lead to the advances in diagnosis and treatment that men deserve.

Improved initial diagnosis and localisation of prostate cancer University of Wales, Aberystwyth

Overview

Jonathan is studying under Principle Investigator Professor Reyer Zwiggelar to find a more accurate way to identify where a man's prostate cancer is (initial diagnosis) and how far it has spread (localisation). The project involves merging ultrasound and Magnetic Resonance Imaging (MRI) images to form a more detailed image. This image would allow doctors to be more This will allow the two accurate in stating whether the cancer has progressed out of the prostate (staging) and _____

its exact location. This could make biopsies more accurate and make it easier to tailor effective treatment.

Progress so far

The team have identified the best techniques to enhance the image quality of both ultrasound and MRI images. They are now looking at mapping both types of image to identify the outer boundary of the prostate. images to be accurately placed on top of each other to create one superior image.

IN A NUTSHELL

In January we launched a new campaign to crack prostate cancer - The Sledgehammer Fund. Our chief executive explains why this campaign means so much to him.



Owen Sharp, CEO of Prostate Cancer UK

I was fresh out of college and working as a young trainee nurse in one of Glasgow's inner city hospitals when I first encountered the devastating effect of prostate cancer. On a night shift, on an all-male ward I met a man called

Danny and his experience of this vile disease changed me forever. It wasn't his symptoms, the side-effects he was experiencing or even the fact that he was gravely ill that hit home. It was the fear in his eyes and the overpowering sense that this strong, proud man had been abandoned. That seeming indifference towards Danny, the equivalent of shrugged shoulders and a "Well, what can you do?" made me very, very angry.

That anger has stayed with me throughout my career on the wards, in the A&E departments and sitting in the boardrooms of the NHS - and now as Chief Executive of Prostate Cancer UK I am in the position to fight back. Believe me when I say there is no time to lose.

This is where we stand. We have a test that divides medical opinion and isn't fit for purpose. Treatment options that leave men impotent, incontinent and alone. A gland that can be as vicious as it is silent and awareness levels that should put us all to shame. This, in a nutshell, is prostate cancer in the UK.

Some people say prostate cancer only kills old men. Let's put aside that this accusation and excuse - for this is what it is, an excuse - is misleading, ill-informed and inaccurate, and think about exactly what these people are saying: it doesn't matter that men are dying, they're old. We may live in an ever-changing landscape of advancing technology and scientific

Men like Danny deserve better

endeavour but this thinking drags us straight back into the Stone Age.

Every year in the UK 10,000 men of all ages are killed by prostate cancer. Every year 40,000 new cases are diagnosed and currently 250,000 men are living with the disease. For some, these are meaningless figures, just more statistics on one of many billboards passed on the way into work. But when just one of these thousands of men becomes your grandfather. your father or even your son, the current lack of knowledge, therapeutic limitations of treatment and seeming indifference levelled at this disease will hit you like a sledgehammer. With one in nine men developing prostate cancer in their lifetime, this is not an unlikely scenario. Now is the time for us all to hit back.

Prostate Cancer UK has launched the MANifesto: a call to arms bringing people together to support men, find answers and lead change. Thanks to Movember we will be spending £25 million over the next three years on research to better predict risk, detect aggressive disease, and treat advanced prostate cancer more effectively. But we need to go further than this and will need your help and support with our Sledgehammer Fund. We need to fight prostate cancer on all fronts: in parliament, in the laboratory, in the pubs and in the minds and attitudes of men across the UK. These are our beaches, our landing grounds, our fields and our streets, and this is a fight we cannot afford to lose.

So, this is where we stand. This is where we stand together and put a stop to this rubbish once and for all. Men like Danny deserve better.

PROSTATE Cancer uk News

Bill's TV wake up call: **Do mankind** a favour

On New Year's Dav. comedian Bill Bailey grabbed the attention of men and women across the UK when he launched our first ever mass media advertising campaign: The Sledgehammer Fund. A series of TV adverts took our prostate cancer message to 45 per cent of our target audience (UK adults aged over 45). Bill said he was inspired to speak out about the disease after hearing the stark statistics: "I was shocked. I had no idea it was so common. Blokes are not always good at taking care of themselves. I want The Sledgehammer Fund to help change that."

The aim of the campaign is to wake up the nation and inspire everyone to help us crack prostate cancer by donating. The money we raise will help us fight prostate cancer so more men survive. Look out for our next campaign push in March.



Find out more about our Sledgehammer Fund, and how you can get involved at prostatecanceruk.org

As the Official Charity Partner of The Football League for this season, we're offering ten pairs of free tickets for each of the noower Football League play-off finals at Wembley, including subsidised travel and a VIP tour of the stadium.

Do you think your team's going to make it to Wembley? In that case, for just £3, text FL and your team e.g. FL Brighton to 82772 to be in with a chance of winning. If your team doesn't make it, don't despair - you could still win a great money-can'tbuy experience with your club, for example a signed shirt or meet-theplayers tour.

Proceeds we receive will help us fight to ensure more men survive prostate cancer.

Visit the Road to Wembley page to view the terms and conditions then reward yourself by listening to the legendary Wembley memories of our ambassadors Mark Bright and Les Ferdinand. Go to prostatecanceruk. org/football

Join the road to Wembley As the Official Charity

In October 2012, we launched a new drive to give men with prostate cancer equal access to quality health care wherever they live.

Currently, there are big differences in prostate cancer care and support in different parts of the UK. To address this problem, we have devised a Quality Checklist to help set a national standard for prostate cancer care and to arm men with the information they need to get the care they deserve.

The 15 standards in our Quality Checklist are based on the views of hundreds of men with prostate cancer and have been backed by the Royal College of Nursing and the Royal College of General Practitioners.

We have already launched the checklist in London, Birmingham, Manchester and parts of Scotland. We hope the list will be adopted across the rest of the UK from May onwards.

Visit prostatecanceruk. org/qualitycare

NEW ON THE WEBSITE

Check out our News and debate pages. Visit regularly to keep up to date with prostate cancer news and join the conversation.

You can now set up an In memory tribute fund online. Visit the Get involved section of our website and click on Donate to find out more.

MY EXPERIENCE:

Ray Clemence

Former England goalkeeper Ray Clemence is one of English and European football's most decorated goalkeepers. He has three children and nine grandchildren and he is currently Head of The Football Association Development Team.

> "I was diagnosed with prostate cancer in 2005 after a conversation with the England physio.

"I didn't think there was anything wrong but I mentioned that I wasn't able to pee at my normal speed and I never really felt that I'd emptied my bladder properly. He suggested I should get it checked out and, fortunately, I took his advice,

> "I was given a PSA blood test and my levels were slightly

> > raised

but

six months later the levels had increased, and two biopsies confirmed that I had prostate cancer.

"I was given a few treatment choices but after a long discussion with my wife and family I decided to have the prostate removed followed by six weeks of radiotherapy. I also had hormone injections for two years.

"My treatment was successful and for three or four years I had no problems but in November 2011 I suddenly felt awful and I had a terrible pain in my groin. I went back to the specialist and back on the hormone treatment and I genuinely felt fine. My PSA was less than one and I had regular check-ups.

"Unfortunately at a checkup in November 2012 I discovered that the cancer had returned and I am now undergoing a six-treatment course of chemotherapy, but I am still very positive that we can control it again. I've always been a positive person. When you give in to something it will win and you can't do that.

"Men don't like to think that anything is wrong with them, especially sportsmen, and if you have a slight problem 'down there' it will never be at the forefront of your mind that it could be cancer.

"Now I'm supporting Prostate Cancer UK's partnership with The Football League to make sure that everyone connected to football the players, the fans, the staff and the managers - knows about prostate cancer. We all, that's men I mean, need to know we are more at risk when we hit 50, if we have a father, brother or uncle who has had the disease and if we are African Caribbean.

"You may not have symptoms like me so you need to know your risk. I know only too well that it is not easy talking about health problems that may affect your sex life or how often you go to the loo but it's worth doing. Nothing is too embarrassing if it saves your life."

Ray is an ambassador for Prostate Cancer UK's Official Charity Partnership with The Football League. To find out more visit **prostatecanceruk.org/ football**



MY EXPERIENCE: Bruce Tasker

Bruce Tasker from Fife is 51 and has two children. Bruce was diagnosed with prostate cancer in May 2009. In our new series of films on sex and prostate cancer, he talks frankly about how treatment affected his sex life and relationships.

"When I was diagnosed, it was an absolute shock. I was told I had early advanced prostate cancer and, for me, that meant the cancer had spread outside my prostate. I didn't even know where my prostate was.

"The immediate thing I did when I found out was, of course, cry. At the time I was already in a pretty bad place because my wife and I had separated about three months prior to that.

"I didn't really have anyone to turn to. But soon after I was diagnosed, I started a new relationship. I hadn't seen Pam for about 15 or 20 years but we got back together.

"Unfortunately, my cancer was very aggressive, so I had radiotherapy immediately and I was put on hormone therapy drugs, which I'm still taking now.

"The hormone therapy chemically castrates me. That's its function – to rid me of the testosterone that feeds my prostate cancer. But with a man, that's what gives you your libido and I had been very sexually active before having cancer.

"My penis and testicles reduced in size and it caused a thing called gynecomastia, which is commonly referred to by us blokes as moobs or man boobs. I found that difficult. I started asking myself: 'Am I less of a man now?'

"With Pam, it was slightly awkward to start with. Penetrative sex is more difficult and my libido is different. But I've found someone who is very accepting and practical and I've found that women don't think relationships are all about sex. It's sometimes about walking along the beach, watching a movie or just sitting in each other's company. It has changed my whole perspective on relationships, for the better.

Watch our films on sex and prostate cancer on our website prostatecanceruk.org



"I can still orgasm, although there's no ejaculate, and we still have penetrative sex, with a little bit of medical intervention. I found that tablets work best for me. I take one daily and when I want to have sex I take a stronger one, which is very effective. I'm the envy of all my mates because, as a man with prostate cancer, I get these sex-related drugs for free.

"I would urge guys that are worried about this to talk to your partner about it and talk to the andrology department at your hospital – that's the male equivalent of gynacology. They will help, there are lots of options.

"So am I still a man? Yes. It took me a long time to figure it out, but to me the essence of being a

It's changed my whole perspective on relationships, for the better.

man is in what you do in life. For me it's being the breadwinner, being the father. Living with prostate cancer is challenging because of the side effects, but it is doable. Life's for living."

If you are finding sex difficult after prostate cancer, there are many treatments available, including tablets. If there's no andrology department at your local hospital, your GP, urologist or nurse can help or you can call our Specialist Nurses.

THE MANUAL

Your questions answered about Sex and prostate cancer



`_____

A lot of men ask us what their sex life will be like after prostate cancer treatment. Here Lorraine Grover, a clinical nurse therapist in sexual wellbeing, answers some of the most frequently asked questions.

Will I be able to have sex after treatment for prostate cancer?

In reality, the answer to this is different for every A man and depends on what treatment you've had, whether you're feeling up to it, and whether you've had any sexual problems in the past. It is common for men to have difficulty getting an erection but this can improve with time and treatment. Many men will be able to have sex again but it is likely to be guite different.

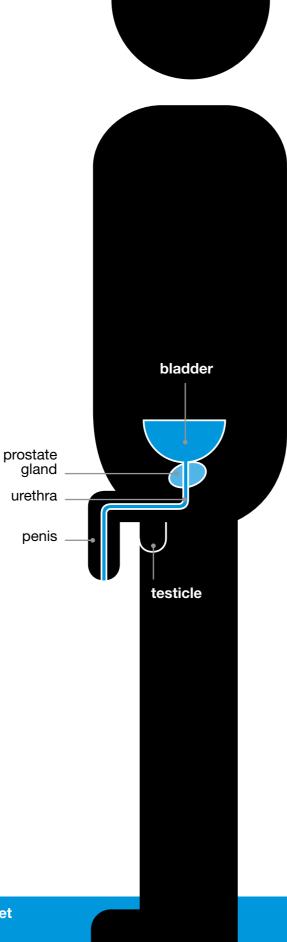
Remember, you can have orgasms without having an erection or ejaculating. And sex doesn't have to be about penetration. You could try different things like massage, mutual masturbation, oral sex, vibrators or dildos.

And you can get treatment on the NHS to help with erections - like tablets or a vacuum pump.

Will sex feel different after treatment?

Yes, sex can feel quite different. You'll still have feeling in your penis and you should be able to have an orgasm but it may not feel the same. If you've had surgery you won't ejaculate when you orgasm, but you will still get the feeling of an orgasm. If you've had other treatments, including hormone therapy, you may notice that you produce less semen and your sexual desire may not be the same. Again, you should still be able to have an orgasm but it may feel different.

Find out more at prostatecanceruk.org or order our new booklet Prostate cancer and your sex life. Call 0800 074 8383



Do the treatments for erection problems actually work?

There are a number of different treatments for R erection problems, such as tablets, pellets, The vaccum pump is one of the many treatments injections, pumps and implants and different treatments that can help men affected by prostate cancer to get will work for different men. These are not always a erections again. We asked men to tell us how they got 'quick fix', and you often have to stick with them or try on with it and share tips and advice. different ones to see what works best for you. Research shows that men who try more treatments are more Don't be too ambitious Practice, practice, likely to find one that works. or impatient. Recovery times vary. aside 10 minutes a few

For some treatments you need to have a desire for sex (libido) but others, like pumps, injections and pellets will work without this.

Why is hormone therapy affecting the way I feel about sex?

Hormone therapy reduces or blocks the effect of 🖰 the testosterone that gives you your sex drive. Not having a sex drive may make you feel less confident about your masculinity and physical changes such as putting on weight, hot flushes or breast swelling, may have the same effect.

There are ways to tackle this. Try focusing on the things you like about yourself, do activities you are good at, or try something new. Being physically active can lift your mood and keep you in shape. Making changes to your diet can help with losing weight. It could help to talk to someone who has been there - use our telephone peer support service, join a support group or our online community.

I don't feel as close to my partner as I used to. What can I do to improve things?

Dealing with cancer and side effects can put a R strain on your emotional and physical relationship. Being open and honest about how you're feeling can help. You could also try some of the medical treatments for erection problems or explore new ways of being close sexually. Don't forget your partner may also benefit from support.

Take time to be together. This could just be going for a walk or having dinner together at home. If you are in a hospital, hospice or have carers coming to your house make sure they know when you need private time.

If you are finding it difficult to talk you could see a relationship counselor. RELATE provide counseling and a range of other support services. A sex therapist can also help you communicate about sex.

Getting to grips with The vacuum pump

It works! A full erection does happen, though doesn't always last long - after ten minutes mine diminishes but does not disappear. Better than nothing by far.

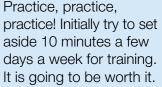
There are different sized rubber inserts and I had the gratifying, but silly, realisation that I needed the larger size when I couldn't get my erection out of the pump! However, all I had to do was release the pressure.

The retaining rings clamp hard around the base of the penis and make sure that what goes up doesn't come down.

Although we did achieve intercourse, my wife and I found setting up a bit of a turn-off.

Talk to your supplier, they normally provide sessions on how to use the pump.

We have a pause for pumpy before resuming the rumpy!



Experiment with different retaining ring tightness.

A smear of lubricating gel around the base of the penis, on the pump's rubber insert and on the retaining ring(s) provides a good seal.

To get the right suction I'd recommend shaving the pubic hair.

I didn't want to use it because of male pride but I kept remembering what my nurse told me; think of it as therapy.

I started using the pump a year after surgery. Within less than a month of daily exercising my penis had started to return to its normal texture and size.

The big disadvantage is the lack of spontaneity.

Don't put it on before foreplay, it has a time limit.



The music that helped me along my prostate cancer journey

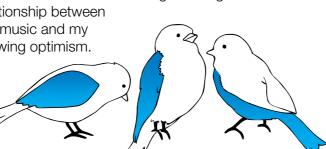
by Keith Talbot

"I was diagnosed with locally advanced prostate cancer in summer 2008. From January onwards I travelled a total of 2,400 miles to and from Southampton General Hospital for radiotherapy. I'd leave the house at 6.30am when it was cold and dark. It was truly exhausting and I had great by Bobby McFerrin and difficulty motivating myself to even start some of the trips.

"Then my daughter reminded me that when we used to go camping we'd have Bob Marley on and we'd all be singing away. So I made a CD with bouncy, upbeat music on it to give me a daily gee up.

"I especially remember Don't Worry Be Happy Three Little Birds by Bob Marley & The Wailers. It was hard not to smile each morning as I tackled

the journey listening - and singing along. Although I imagine if anyone had seen me, a 6ft 7inch Welshman, singing Bob Marley at 7.30am they'd have thought I was nuts! But it created this relationship between the music and my growing optimism.



is low.

Adrian Mole: The Prostrate Years



We're very excited that writer Sue Townsend has kindly agreed to loan us three extracts from the brilliant Adrian Mole: The Prostrate Years. We'll feature them one-by-one over the next few issues. Thank you Sue!

Now thirty nine-and-a-half, Adrian is living in the country in a semi-detached converted pigsty adjoining his parents. The spark has fizzled out of his marriage to his second wife Daisy and Adrian's nightly trips to the lavatory have become alarmingly frequent.

Monday 10th September

I rang Daisy at five thirty and told her that I was going to the Out of Hours Clinic at the Royal Hospital re my bladder.

She said, 'About time.'

The doctor was a young man with ginger hair. He vawned several times during my description of my symptoms.

He snapped on a pair of blue gloves and said, 'Climb on the examination table. Take you pants and trousers down and pull your knees up to your chest. I'm gonna give you a DRE.'

'DRE?' I asked.

'Digital Rectal Examination,' he said sticking his index finger into my rectum and wiggling it about. 'You've

presented with the classic signs of prostate trouble.'

'No, it won't be my prostate,' I said, trying to smile. 'I know I look old beyond my years, but I'm only thirtynine and a half.

Diary, I feel that a man more at ease with himself and his body could well make light of the examination. Could laugh it off or use crude rugby-player like terms. However, I am not that man.

'Try to relax,' he said.

God knows I tried, Diary. I tried to remember a relaxation exercise I had been taught by one of my therapists years ago. It consisted of swimming in a dark blue sea, past a small desert island.

The doctor said, with an attempt at humour, 'If you don't relax, Mr Mole, you could trap my finger up vour bum forever.'

I made a conscious effort to relax my rectal muscles and he finally retrieved his finger.

'Wow,' he said, 'I've rarely come across such

powerful muscles. I pulled my pants and trousers up and said, 'Yes, I have been described as being an anal retentive before.'

He threw his blue gloves into a waste bin and washed his hands at a little basin. 'I'll write a note to your GP asking him to take some blood.' He scribbled a note and put it in a brown envelope.

-----Adrian Mole: The Prostrate Years



the **SPOTLIGHT** (

Andy Clarke. 46 from Blackpool

When Andy Clarke's father was diagnosed with prostate cancer in November 2010 Andy decided to do a 10 kilometre run for Prostate Cancer UK, but he couldn't get a place. Andy was determined to run so he signed up for the next event, which happened to be the Great North Run – 21 kilometres.

diagnosed with prostate cancer himself. But he refused to give up on his goal and just six weeks after finishing radiotherapy he did the run and completed the course.

"When I crossed the finish line, I was absolutely shattered but I was so pleased. I felt relief, euphoria. It had been a goal to focus on and that helped me through."

Andy's cancer has

been in remission since

Four or five months into training Andy was

> "My Dad is an incredible man and he has a job that many men all over the world would be jealous of – he's a Tottenham Hotspurs tour guide!

"He always puts a smile on my face with his bad jokes, great stories and funny ways. And he's incredibly supportive, pushing me to fulfill my

Felicity Jackson, former contestant on The Apprentice, tells us why her dad John, who has recently confronted prostate cancer. is a Top Dad. Next issue it's over to you. If vour dad is fantastic and vou want everyone to know, please get in touch and tell us about him.

(Penguin Books)

Extract 1/3

"Since then, while I've had

minor setbacks, my PSA

"I really hope music has

given others like me the

lift they've needed to

get through."



October 2011. He did the Great North Run again in 2012 and is planning to do it next year too. He is currently trying to persuade everyone he knows to join him.

dreams and aspirations. He's made me feel like l can achieve anything.

"Dad is a genuine person who always puts our family first (even above Spurs!). And with three daughters and my Mum, he has had to bear lots of shopping, dancing festivals and gossiping.

"I know I can call on him whenever I need him - he's been there for me through all my successes, and my failures. During both he's been a rock, but a rock who makes me laugh too. He certainly deserves to be crowned Top Dad."

THANK 310,000 The amount of metres

Simon Lord ran for us in March 2012 – that's 10k every day. This March he's planning to climb 10,000 feet in one day!

One of our volunteers. Jean Holloway, held a golf day in memory of her husband Walter who died from prostate cancer five years ago. Jean raised £5,050.

HOLES

The number of UK Mo Bros and Sistas who

made 2012 a record breaking year for Movember.

The distance Professor Graeme Small and his son rode from Lands end to John O Groats in memory of Prof. Small's father who died from prostate cancer. They raised £4,856.

GET INVOLVED

Ride a Classic

The Jurassic Classic is our flagship cycle ride where over 1,000 riders take to the road to fight prostate cancer. You can choose between 50km, 100km and 100 mile routes around the stunning East Devon countryside and you will be fully supported throughout the day. Join us on Sunday 11 August for a fantastic day of cycling. Go to jurassicclassic.org.uk to sign-up and find out more.



Did you know?

More than two thirds of FTSE 100 companies have a community support approximately 65 per programme where they offer their employees time off to volunteer or give money to the charities they support.

The good news is that the amount of companies contributing to charities has been increasing year on year. And a recent survey has revealed that 58 per cent of employees said they would be very

Get up and go

Get up and go: In Glasgow is a new physical activity service that helps men with prostate cancer get active or stay active. We pair men with a peer motivator, who is trained to support them in taking simple steps to make exercise part of their daily lives. All motivators are volunteers who have personal experience of prostate cancer.

To talk to the team about getting involved as a participant or as a volunteer, call 0141 314 0050 or email alasdair.marshall@ prostatecanceruk.org

or fairly likely to volunteer if their employer offered them help to do so. The bad news is that cent of employees also said they were not aware of the volunteering leave and matched funding their employer offers.

Please don't be one of the 65 per cent! If you support Prostate Cancer UK your employer could provide you with time off to volunteer or with money to match your fundraising efforts. Please get involved.

Fight prostate cancer at the football

Between 2 March and 16 March every club in The Football League will be supporting us as their Official Charity Partner. And we are looking for people to go along to their local club and shake a bucket at one of the 72 games taking place across the fortnight. It's just a few hours of your time and combines our two favourite F words fundraising and football!

For more details on how you can get involved and to see the fixture list, please visit prostatecanceruk.org/ football call 020 8222 7165 or email volunteer@ prostatecanceruk.org



EVENTS CALENDAR Feb 2013 - Sep 2013

March is **Prostate Cancer** Awareness Month and the final push of our Sledgehammer Fund. You can support us by buying pants, a pin badge or a keyring from your local M&S



Study Day for health professionals at the Royal Marsden Hospital: Sex and relationships, supporting men with prostate cancer.

Masterclasses for prostate cancer health professionals at Kings College London: Innovation and service improvement.

Watch out for our Days

of action, when we

head to Westminster

and Holyrood with

people affected by

prostate cancer to ask

politicians to support

our Quality Checklist.





Virgin London marathon With an audience of over a million spectators, this is an event that everyone should experience whether you're running or helping us support our team.

Celebrate the Great British summer and raise money by holding a Vintage Tea Party.





Bupa Great North Run

Join 54,000 runners to take part in the world's most popular half-marathon.

More events

3 March adidas Silverstone Half Marathon 17 March Mizuno Reading Half Marathon 14 April **Brighton Marathon** 18 April Great Wall of China Trek 10-11 Mav Moonrider: London to Cambridge 26 Mav Edinburgh Marathon

27 May Bupa London 10,000 8-9 June Nightrider, Wiggle Dragon Ride 12-13 July Moonrider: London to Brighton 14 July Father's day 4 August Ride London 100 **16 August** Kilimanjaro summit climb **29 September Berlin Marathon**

VOur Services

Specialist Nurses Information on 0800 074 8383

(Mon-Fri, 9am-5pm and Wed 7pm-9pm) **Our Specialist Nurses** have the time to listen and answer your questions on anything to do with prostate cancer and prostate diseases.

One-to-one telephone peer support 0800 074 8383

Talk things over with someone who's been there. We match callers with trained volunteers who've had a similar experience.

Online community

Join the community online and talk to others who know what you're going through. You can ask questions, post information and share your ups and downs.

Get back on track 0800 074 8383

If you have been diagnosed with prostate cancer and are struggling with fatigue, the nurses in our Get back on track team can help you can manage and reduce these symptoms.

Find out more about our services at prostatecanceruk.org/we-can-help

prostate cancer 0800 074 8383

We provide free information on prostate cancer and prostate diseases. Order or download copies from the information section of our website or call our Specialist Nurses for help choosing the publications you need.

The more I learned and understood about prostate cancer, the safer I felt

Get up and go 0141 314 0050

If you have prostate cancer it's important to try and stay active. Get up and go can partner you with a motivator who will help you find a physical activity that works for you. All motivators have had prostate cancer themselves.

Prostate cancer support groups

Meet and talk to other people affected by prostate cancer who understand what you're going through. We run a number of support groups in Scotland and there are over 70 independent groups across the UK.

The blue men on this map represent the locations of support groups who have asked to be listed on our website. Visit the We can help pages on our site to

Please note, some groups run meetings in more locations than the one listed.

find a group near you.



Other useful organisations

British Association for Counselling and **Psychotherapy** www.itsgoodtotalk.org.uk 01455 883 300 Provides information about

counselling and details of therapists in your area.

Cancer Black Care

www.cancerblackcare.org 020 8961 4151 Provides information and support to people from black and minority ethnic communities who are affected by cancer.

CancerHelp UK

http://cancerhelp cancerresearchuk.org 0808 800 4040 (Mon-Fri, 9am-5pm) CancerHelp is the patient information website of Cancer Research UK and provides information about living with cancer.

College of Sexual and **Relationship Therapists** www.cosrt.org.uk

020 8543 2707 For information on sexual and relationship therapy, including a list of therapists.

Health with Pride www.healthwithpride.

nhs.uk An online health resource for lesbian, gay and

bisexual patients. Their website has information on cancer issues and erectile dysfunction for gay men.

Macmillan

Cancer Support www.macmillan.org.uk 0808 808 0000 (Mon-Fri, 9am-8pm) Provides practical, financial

and emotional support for people with cancer, their family and friends

Maggie's Cancer Caring Centres

www.maggiescentres.org 0300 123 1801 Provide information and support to anyone affected by cancer. Their website holds a list of centres across the UK and has an online support group.

NHS Choices

www.nhs.uk Provides information to support you in making decisions about your own health, including an A-Z of treatments and conditions. and information on NHS health services in your local area.

Penny Brohn **Cancer Care**

www.pennybrohn cancercare.org 0845 123 2310 Offers support using complementary therapies and self-help techniques to people affected by cancer. Their approach is designed to work hand-in-hand with medical treatment.

Relate

www.relate.org.uk 0300 100 1234 Relationship counselling and sex therapy for individuals and couples.

Sexual Advice Association

www.sda.uk.net 020 7486 7262 Provides a helpline service for advice and information about erectile dysfunction.

Get back shows the set of the set

Get back on track is a new telephone service we're running to help men with prostate cancer deal with fatigue. We know from our research that over two-thirds of men with prostate cancer experience this problem. However, hardly any receive advice or support to help them cope.

Men who sign up for Get back on track will be called regularly by a Specialist Nurse. The nurse will offer support and encourage them to try techniques and lifestyle changes that can help them manage their symptoms.

We trialled the service successfully in 2012 and launched it in February. John Holtham took part in the trial:

"I thought I was coping well with hormone therapy to begin with, but about six weeks in I just hit a brick wall. My stress levels rose and I became very snappy.

"Get back on track was extremely helpful. It brought structure to my everyday life. The diary helped me note the times I felt worst and plan around them, making sure I rested when I needed to. This helped my family too.

"The nurse encouraged me to make time for things I like as well as things that need to be done. I've gone back to hobbies like walking and photography.

"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."

To sign up for Get back on track call 0800 074 8383 or find our more at prostatecanceruk.org

You can help

We're really proud of the services we provide for men. However, every year in the UK 40,000 more men are diagnosed with prostate cancer. We need to reach a lot more of them.

If you want to join the fight and help more men like Ray, Bruce and John put prostate cancer behind them, please fill out the enclosed form or visit the Get involved section of our website to make a donation.

I'MHELPING CRACK PROSTATE CANCER.

THE SLEDGEHAMMERFUND



Prostate Cancer UK is a registered charity in England and Wales (1005541) and in Scotland (SC039332). Registered company number 2653887.