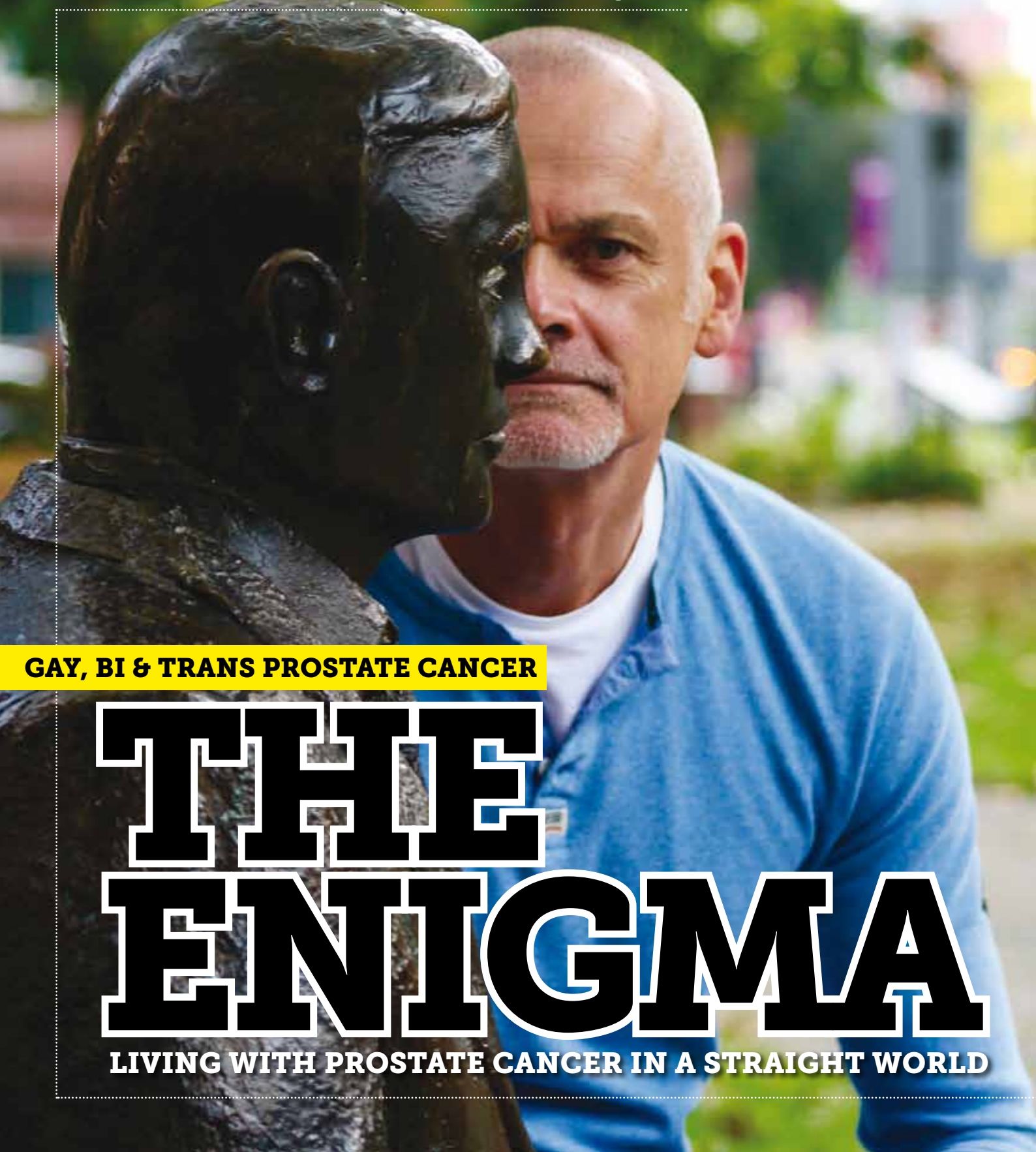


OUT WITH PROSTATE CANCER MAGAZINE

WINTER
2015/16

OWPC

www.outwithprostatecancer.org.uk



GAY, BI & TRANS PROSTATE CANCER

THE ENIGMA

LIVING WITH PROSTATE CANCER IN A STRAIGHT WORLD

START

OWPC

OUT WITH PROSTATE CANCER MAGAZINE

WHY

THE NEED FOR THIS MAGAZINE?

This is a stand- alone information resource to help develop the conversation around prostate cancer for gay, bisexual and other men who have sex with men and trans women. We are real people with real problems which aren't being easily addressed which we are talking about openly and addressing in our own way. All our stories are about us 'now' and what we want and what we are doing about the things that are troubling us - upbeat and positive.

Many people for understandable reasons want to remain anonymous and I thank them for all their contributions, their love, support and being here with me for the long haul.

I (Martin - let's make it personal) was diagnosed with Prostate Cancer in 2007. I wasn't happy that there wasn't a support group where I live and started an East Lancashire Support Group, regularly attended every month by around fifty people.

After two years even though everyone was really sweet I wasn't getting my personal needs met . . . so after meeting Andrew Gilliver at Manchester's LGBT Foundation, someone who doesn't take 'no' or 'can't' for an answer almost a decade ago, and Sean Ralph a young radiographer who isn't afraid of opening a can of worms to highlight the needs of LGBT people in health care, we started OWPC (Out With Prostate Cancer). The UK's first group exclusively for men who have sex with men and trans women. Since then we have been supporting people across the country and working with Prostate Cancer UK, MacMillan, Cancer Research UK and so many more great organisations.

My surgical, radiotherapy and chemical treatments were well managed by the NHS but my psycho-sexual needs were not .So in the group I've been facilitating we have been pushing the envelope by creating an environment where we explore our real issues and we've finally decided to publish this supplement for people affected by prostate cancer (believe me you really are not on your own) and those who support them, treat them who want to (and need to) know what it's like for men who may not happen to be heterosexual.

Martin

We've got a long way to go and, boy, are we on the journey of a lifetime...

Cover shows Alan Turing - 1912-1954 ,chemically castrated to cure his homosexuality and committed suicide in 1954,with Martin Wells b.1954 chemically castrated to cure his prostate cancer.

WHAT HAVE WE LEARNED?

Dr. Daniel Saunders is an out gay doctor and Consultant Oncologist at Nottingham University Hospital.



Prostate cancer is one of the most common cancers diagnosed in men in the UK.

There is a bewildering variety of treatments available, dependent partly on the behaviour of the cancer itself but also based on a balanced discussion of the pros and cons of different treatment options with the patient.

For some, treatment with surgery to remove the prostate gland is appropriate, for others treatment with radiotherapy, often combined with hormonal therapy may be just as suitable; the number of different drug treatments available for incurable prostate cancer has increased exponentially in the last

five years. This should all be good news for patients with prostate cancer but unfortunately all treatments also produce side effects, some of which can be devastating. The impact of treatment on patients and their loved ones should not be underestimated. Making decisions about treatment requires a good working relationship with the doctors treating you who should be able to take into account your medical needs balancing these against preferences regarding side effects and the impact these may have on you as a person.

There is evidence that healthcare professionals are not as good as they might be at understanding and empathising with the needs of gay men. This is borne out in the National Cancer Patient Experience Survey and also a more detailed piece of work done in 2014 by the cancer charity MacMillan.

Both of these pieces of work show that the "therapeutic relationship" between healthcare professional and LGBT patients could be improved upon. Without this improved working relationship there is a risk that gay men with prostate cancer may make less than ideal decisions about their treatment and care preferences.

Although there is certainly a need to improve the education and training of healthcare professionals (important work has already been started e.g. by Out With Prostate Cancer and work by the LGBT Foundation) some work could and should also be undertaken to improve the ability of LGBT patients to articulate their individual needs.

TRANS WOMEN & PROSTATE CANCER

LITTLE IS KNOWN about the cancer risks of transgender women and hormone use and further research is needed. Transgender people experience high rates of smoking, drinking and HIV, all increasing risk for developing cancers. Trans women who are not taking hormones are at the same risk for prostate cancer as non-trans men. Female hormones cause the prostate to shrink, which reduces the risk of cancer, but it's not known how much the risk is reduced.

There have been reported cases of prostate cancer in trans women taking hormones both before and after genital surgery. Some doctors speculate that it might be better to check the prostate through the neovagina instead of via the rectum. A blood test for prostate-specific antigen (PSA), a protein produced by the prostate, is recommended if a rectal test is suspicious. Trans women's hormones can lower PSA levels but this is not a reliable sign of good prostate health. For further info: cancer-network.org

BLACK GAY MEN

WE KNOW THAT one in four Black men will get prostate cancer, double the 1 in 8 lifetime risk for all men. Proportionally, more Black men are dying from prostate cancer in the UK than white men. In fact, Black men are twice as likely to be diagnosed with, and die from, prostate cancer. However only 8% of Black men in the UK know that they're at higher than average risk of prostate cancer. We do not know the risk for black men who are not heterosexual.

Research suggests that gay and bisexual black men are less likely to be tested for prostate cancer than men of any other racial and ethnic backgrounds regardless of their sexual orientation, according to a study by a researcher at Charles Drew University of Medicine and Science. Check out 'A Black man's risk' at: prostatecanceruk.org



We're going to need to talk about a lot of things that would make men's toes curl and for both exciting and scary reasons. Be brave, be bold. You can do this. //

WHAT THE PRO'S NEED

TO KNOW BEFORE I BEGAN MY PROSTATE CANCER JOURNEY

I didn't know how to use the NHS

If I can first determine what's really best for me and get my "head sorted" with all the medical technicalities (treatment options, biology of the prostate, there's a lot to find out)

I didn't know how best to handle change

So I need to negotiate MY best treatment plan/journey with other human beings and resources (doctors, surgeons, consultants, nurses, hospital admin, family etc)

I didn't know how the NHS worked

So I need to understand that (for the most part) surgeons like doing surgery, radiologists like doing

radiotherapy, hospital admin like doing admin, people like doing politics and money (and to most I am NOT the centre of their universe).

I didn't know what being a gay man with prostate cancer could mean

So I'm different. I'm me. My sexual orientation cannot be presumed. My sexuality cannot be ignored. I have to talk about this but first I have to be honest with myself about what is important to me.

Being a man gets in the way of being a man with cancer

It's a joke that most men's brains are in their trousers but when things go wrong in the trouser department, you're whole way of thinking becomes...erm...unzipped.

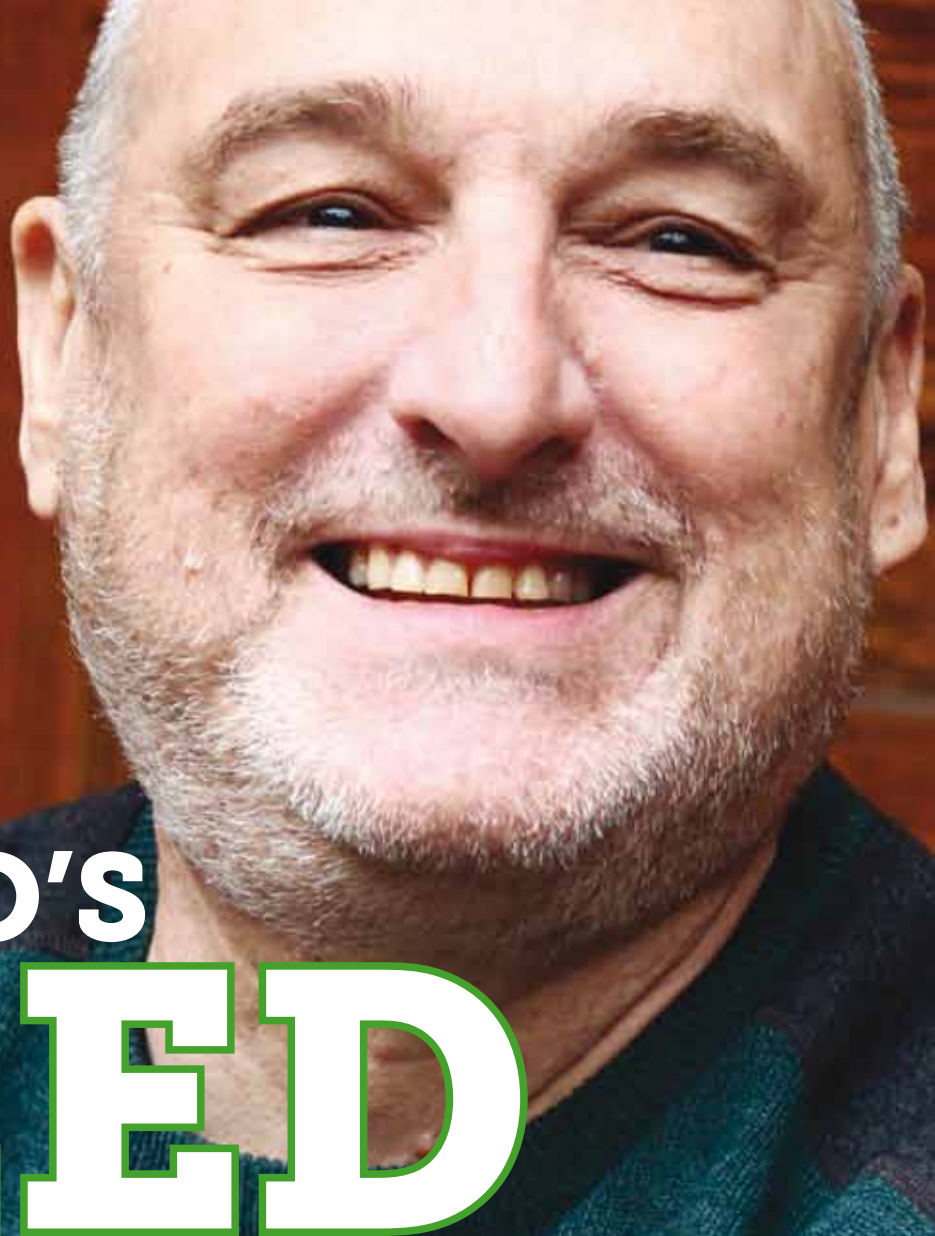
I didn't know what my prostate does

Not many men do, but I needed to learn. Furthermore i need to make sure that every health professional I talk to does as well, and that I am happy with the answers they give me. How will their recommendations affect my decisions?

I didn't know how to be a good patient

Having 2 or 3 supporters "carers" (people who have my interests at heart) around me who understand me is so important. I don't need to go through this all on my own..

I didn't know how to use (Prostate) Cancer Charities and other resources Making sure myself and those I need support from keep doing the research and asking the right questions. Constantly.



WHICH PENIS PUMP?



**clonezone
direct.co.uk**

MEN COME IN ALL SHAPES AND SIZES, AS DO PENIS PUMPS, so finding the right one for you often involves doing a bit of research. The cylindrical vacuum device, usually plastic that you place over the penis contains a pump and a specially designed constriction ring. Using the pump removes air from the cylinder and the fall in pressure pulls blood into the penis like a sucking action. When the penis is stiff, the ring helps to hold the erection. There's a bewildering choice of pumps out there, so why not experiment? Visit the Clone Zone website.

COCK RINGS & ELECTRO STIMULATION

robmanchester.xxx



OK, THIS STUFF MAY NOT BE FOR EVERYONE BUT WHY SHOULDN'T YOU HAVE ALL THE MEANS AVAILABLE TO HELP YOU BRING SEX BACK INTO YOUR LIFE? We know that some

guys aren't used to talking about sex in a direct way but we also know that's what many guys really need to talk about. Just come along to any OWPC group meeting and there's no end of discussions on how to get an erection, how to keep it and what tips work best for different guys. You should never feel embarrassed about discussing your feelings about the sex you want but often we all do so just to help you out here's a few links to products you can get without the need for NHS approval.

THE WIT & WISDOM OF TENA MEN'S STIRLING GRAVITAS

IT'S ALWAYS AWKWARD TALKING ABOUT CERTAIN BODILY FUNCTIONS which is why the subject of incontinence is often dealt with using humour. And that's just what TENA Men have done with their very much 'in control' spokesman. Through a series of videos, Stirling will show you how he stays in control of his life as well as offer lifestyle tips, hints and exercises to control urine leakage. Watch the videos here www.tena.co.uk/men/how-to-keep-control, and get free samples here: www.tena.co.uk/men/products/free-sample



Lorraine Grover
Psychosexual Nurse Specialist

THINGS YOU DIDN'T KNOW YOU MIGHT NEED TO KNOW!

"I have been seeing patients on their own or with a partner (if in a relationship) for the past 21 years.

I started seeing men whilst running a drug trial (Viagra) for erectile dysfunction (ED) as a research nursing sister. What was clear to me was the fact that we should be addressing sexual function when managing patients health. Frequently sexuality was discussed and I thought how things need to change to the improve care we provide. How there can be such shame, taboo, myths and misconceptions around sex. I trained as a sex therapist to help me improve my patient care. As I say 'The penis is attached to a man who may or may not be in a relationship and the brain is the biggest sex organ'. I think seeing people at the time of diagnosis would be a step forward and it should also include not just radical prostatectomy patients but also active surveillance, radiotherapy hormone and brachytherapy patients. We can become too focused on drugs to help the erection and forget about men and their emotions. Traditionally, marketing for ED treatments has been heterosexual and featured older men. I have been on advisory boards and am always saying this is not ideal but it has often persisted."

lorrainegrover.com



I just didn't want the cancer to rob me of the last vestiges of being able to be a sexual person.



BREAKING THE ENIGMA

Some of our members wanted to share a little about their experiences of Prostate Cancer and this is their no holds barred experience...

"The actual cancer is the initial thing, but it's the after effects or the side effects that come with prostate cancer that a lot of people don't like talking about and I was fairly open, I asked questions and yes, a lot of people would then open up and it would turn out to be quite an interesting conversation."

"I'd been through all the other avenues of pills, potions and injections and it wasn't working and there's just one last resort, a Penile Implant . I spoke to a couple of people about it and they were very dismissive. 'Oh forget everything, why do you want people doing stuff to your willy when it may not work?' But in my own head, I thought it's a last resort."

"I had the radical prostatectomy in the assumption that it was very early stages and that I trusted the surgeon when he said, 'it should be easy enough, there should be no nerve damage, I'll do nerve sparing surgery' and that's why I went down that route and it didn't work out quite exactly as he had indicated it would do. But there again, you can't tell, just because everything on paper looks good, until they actually do something, what the damage is. I came out of the surgery and then I had to push to start getting the consultations on Erectile Dysfunction. It wasn't pushed at me, I had to push for it."

"I kind of accepted earlier that there would be no return to erections and even if you do resume erections, you'll always be dry again (unable to produce ejaculate). I just didn't want the cancer to rob me of the last vestiges of being able to be a sexual person."

"I went down the various routes of Viagra and it had a very limited effect, a pump was issued, that was reasonable but the pump they give you is a little bit awkward because you've got to keep a big ring on. .. So the GP was only allowed to prescribe the equivalent of two (Viagra) a week, you could have all eight at once or keep going on a weekly basis. So I just thought well, it's not what I really want in life. I just want to be able to return back to how it used to be."

"Talking in a medical context, the doctors may have zapped the cancer but it's the after effects and the war wounds and trying to get anyone really to talk properly about sex and what to do about it that's the problem. I still regularly ask about all the electronic gadgets that you can get in Clone Zone or you can send off for. 'Oh we don't know about any of that' is the answer and, my reaction is yeah well, you bloody well ought to... It's an inexcusable void."

"The only positive thing about (not being able to cum) is that there's no mess to go with it."

"With hindsight, I think I'd have had a lot more sex than I've had through my life. Parts of my sex life have been quite adventurous but although sex has been a very nice part of it, it's not been the whole part and parcel of it, a bit of the icing on the cake."

"I think because of our support group and the conversations that we can have here that we can't have in other places, we have focused much more on the sexual side of things. If prostate cancer had the same sort of

energy behind it as breast cancer has had for women, we'd be a lot further forward I think."

"I'm not getting the erections, I'm getting sexually turned on but absolutely zero happening down below which is worrying . I have a younger partner and we have discussed the sexual side of our relationship, even though he does advise it's not the be all and end all, which I know it isn't, but you want to be able to fulfil the sexual needs of your partner. We have discussed anal sex, we have discussed sex, he understands the situation of basically being turned on, being sexually aroused but for want of a better word, it's dead, it doesn't work."

"To have a hard-on, to have ejaculation is about being a man, you don't feel a man if you don't have that. That is part of being male, a man , not being able to have the hard cock you're not actually a man."

"Potions, pills, tablets, injections, implants – there's so many things that are out there but you have to go out yourself and find them. It doesn't seem that it's readily available and it's readily knowledgeable by the medical profession what is actually out there. You research it yourself and they just follow."

"Before, living was the important part of my life, now, because I've found a partner that I love, sex now becomes top of the list... But I want to be able to have a hard cock, I want sex. Is that too much to ask for?"



SO... WHAT NEXT?

Prostate Cancer Groups for men who have sex with men and trans women

MANCHESTER

Out with Prostate Cancer Support Group

c/o LGBT Foundation
5 Richmond Street, Manchester M1 3HF
E: outwithprostatecancer@yahoo.co.uk
Twitter: @OwProstateCa
www.outwithprostatecancer.org.uk

MIDLANDS

Out with Prostate Cancer Midlands

c/o Birmingham LGBT Centre
38/40 Holloway Circus
Birmingham, B1 1EQ
E: owprostatecancermidlands@gmail.com
Twitter: @OwProstateCaMid

LONDON

METRO Walnut Support Group

METRO Greenwich
141 Greenwich High Road
London, SE10 8JA
E: simon@metrocentreonline.org
Facebook: METROWalnut

Trans Women & Prostate Cancer

There is very little information available on this issue but new research is being undertaken for Tran's women living with and beyond prostate cancer. If you would like to find out more support please contact: natalie.williams@cancer.org.uk

LGBT Cancer Support Alliance

A group of health and social care professionals seeking to improve the experience and outcomes for all LGBT patients with a cancer diagnosis in Greater Manchester and the North West. Follow on Twitter: @LGBTCancerSA

Macmillan LGBT Project Worker

Macmillan have funded a full time LGBT Project Worker based at The Christie

Hospital NHS Foundation Trust and also at LGBT Foundation, with the support of an LGBT Strategy Manager. For more information contact: Benjamin.Heyworth@christie.nhs.uk

Prostate Cancer UK

Don't forget PCUK exist to support everyone affected by Prostate Cancer. They have produced specific resources for gay and bisexual men and are aware of the need to provide more information to trans women. Give them a call: 0800 074 8383

LGBT Foundation

Our constant partners throughout our work based in Manchester and always available to support all members of the LGBT Community.

Helpline: 0345 3 30 30 30
lgbt.foundation

OWPC

If you would like to contribute to the next issue of OWPC please contact: outwithprostatecancer@yahoo.co.uk

OUT WITH PROSTATE CANCER MAGAZINE

THANK YOU...

The production of this magazine wouldn't have been possible without the contribution of all the guys who are part of the **Out With Prostate Cancer** group in Manchester. Thanks to Sean Ralph for pushing LGBT inclusion in professional networks. Paul Nethercott and NHS Manchester for enabling this magazine to come to life. Andrew Gilliver for providing resources & support. Dargie Lynch for the photography (www.fundamentalspark.co.uk); and to Grahame Robertson from Gr! Design for the editing and design (www.grahamedesigns.com)

