ADE AKINBIYI

Prostate cancer and me

Prostate cancer in your genes
Five-page special: what can genetic testing tell us?

Chronic prostatitis
Your questions answered on tackling this condition
Editor’s note

Welcome to the very first issue of Prostate cancer Insights! I hope you like the new name. We think it does everything that Progress did and more and it was a clear favourite with our volunteers. Most importantly though, I hope you continue to enjoy what’s inside the magazine.

This time we have a five-page feature on prostate cancer in your genes, looking into the present, the future and the pros and cons of genetic testing. Former footballer Ade Akinbiyi talks about the shock of losing his father to prostate cancer and what it’s like living with the knowledge that he has a high risk of developing the disease himself.

We try to find out why some men who, like Ade, know they have a high risk, still won’t go to their GP and we bring you the latest news on prostate cancer and Men United.

And I have some news myself – I will soon be going on maternity leave. This time it’s twins I’m expecting so I’m going to be busy! But I’ll be leaving Insights in very capable hands while I’m away and I know you will be well looked after.

Editorial team

Nick Wright
Sophie Lutter
Sarah Lines
Lou Hiller
Catherine Steele (Editor)
INBOX

Tell us what you think about the magazine. All feedback is welcome: we want to hear what you’ve got to say.

Dear Insights

I’ve just read and enjoyed an article on hormone therapy and I wanted to share a tip I found really useful when going through treatment. On my down days and a period of mild depression, I kept a blackboard in my kitchen and wrote on there all the nice things I had planned for the coming days and weeks, such as a walk with my walking group or a trip out in the car. Those small things just kept me feeling positive and bright.

John

Dear John,

Thanks so much for sharing that tip. I’m sure many readers will find that helpful because we know being diagnosed with and living with prostate cancer can change how you feel about life. And hormone therapy can make you feel emotional and down or cause mood swings.

The good news is that there are people who can help and things men can do to help themselves. Like you, some men say keeping up with their usual hobbies and social activities helps them stay happy and relaxed. Getting support from others such as family and friends, support groups or professionals like our Specialist Nurses can really help. There’s lots of useful information in our booklet, Living with and after prostate cancer. You can order a copy on our website or using the enclosed form.

Dear Insights

I’m concerned about the lack of coverage in the magazine on benign prostate disease, especially as the article on incontinence in the last edition did not include incontinence after surgery for enlarged prostate.

Christine

Dear Christine,

Thank you for your comment. I’m sorry that The Manual on incontinence was missing an important aspect for you. Much of the practical advice we gave for managing incontinence also applies to managing this side effect of surgery for an enlarged prostate too, but we should have made that clear. With limited space in the magazine it’s always hard to cover each topic as fully as we’d like to.

However, I hope you were pleased to see Rudolph Walker talking in that edition about his enlarged prostate. And this time round The Manual is all about prostatitis (a non-cancerous prostate condition) which we know can be very frustrating for many men and have a big impact on their lives.

We will definitely consider an article on benign enlargement in future. Please keep an eye on our website where we publish editions of The Manual regularly, or you could sign up for our monthly email version of Insights. As it is more frequent it allows us to cover many more topics than we can in print.

When will we have an update on your work towards a better way for GPs to predict a man’s risk of getting prostate cancer?

You’re referring to the risk assessment tool we talked about in issue 4. Our Director of Research gave an update in a blog earlier this year which you can read on our website: “Risky leap puts us on the path to a big change in prostate cancer diagnosis”. And we will have a significant update on this very soon, but sadly not before this issue goes to print. In the meantime, please keep an eye on the News and views section of our website.

Could you include a feature about gay men and prostate cancer?

In future issues, I’d definitely like to look in more detail at the specific challenges gay men with prostate cancer face. We have already done so on our website – in the last year, we’ve featured two blogs about gay men and prostate cancer: “Living with prostate cancer as a gay or bisexual man” and “Treating all people the same is not equality”. The latter is a report from an event we helped arrange: the first national conference bringing together gay and bisexual men and transwomen, with health professionals and those who work to offer support.

Like us on Facebook: Prostate Cancer UK
Follow us on Twitter: @ProstateUK
Email the Insights team: editor@prostatecanceruk.org
‘Game-changing’ results from the world’s largest prostate cancer clinical trial have been announced at a major US cancer conference. The first results from the much-anticipated STAMPEDE trial were presented at the American Society of Cancer Oncology (ASCO) conference in Chicago in May this year.

STAMPEDE was designed to test the effect of giving different treatments for advanced prostate cancer earlier on. The results were striking, and may well lead to a dramatic shift in the way advanced prostate cancer is treated.

Overall, the trial showed that men taking docetaxel chemotherapy alongside hormone therapy lived for an average of ten months longer than those taking hormone therapy alone.

The average life-extension for men with metastatic prostate cancer (cancer that has spread to other parts of the body) was even more dramatic. Men with metastatic prostate cancer, who were taking docetaxel at the same time as hormone therapy lived for an average of 22 months longer than men taking hormone therapy alone.

Our Director of Research, Dr Iain Frame, said: “The findings of this trial are potentially game-changing. Chemotherapy is currently one of the last resort treatments for advanced prostate cancer. If it is shown to have a much greater impact on survival when prescribed earlier and alongside hormone therapy, that’s incredibly exciting, and we would want to see this brought in to the clinic so it can benefit men without delay.”

**BEHIND THE HEADLINES:** Dogs that sniff out prostate cancer – barking mad or a whiff of truth?

Recently, a team of researchers have tested the abilities of two dogs to detect prostate cancer from urine samples. The dogs correctly sniffed out the prostate cancer samples 100 per cent and 98.7 per cent of the time, and ignored the non-prostate cancer samples 98.6 per cent and 97.6 per cent of the time. So we know some dogs can smell something that means prostate cancer is present.

How does this improve diagnosis for men with prostate cancer?

It’s highly unlikely sniffer dogs will ever be a routine part of prostate cancer diagnosis. But that doesn’t mean there’s nothing to follow up on.

First we need to know whether the dogs can accurately find prostate cancer in the urine of men who haven’t yet been diagnosed, as well as responding to samples where we know it’s present. The researchers plan to test this next.

But to really prove a diagnostic test works, you also need to prove it doesn’t detect prostate cancer that isn’t there (a false positive). This means correctly ignoring ‘suspicious’ samples, like those from men with a raised PSA and maybe other prostate problems, but no prostate cancer.

But you can’t just go around doing biopsies on healthy men to check this, so it’s very difficult to test.

Secondly, this research suggests the dogs respond the same to aggressive and non-aggressive prostate cancer. That means a biopsy would still be needed, and therefore men with very low-risk prostate cancer would still undergo unnecessary biopsies, and biopsies would still miss important cancers.

However, if we could find out exactly what it is the dogs can smell, that might help us design a laboratory test to reproduce these results. We could see if it could distinguish between aggressive and non-aggressive prostate cancer, and whether it could be done on a large enough scale to be of use to all men.
Researchers find prostate cancer ‘Rosetta Stone’ and take us a step closer to personalised treatments

For the first time researchers have found a way to target individual prostate cancer sites in other parts of the body. This story grabbed a lot of press and it’s a piece of research worth getting excited about.

Scientists examined genetic material from 150 men with advanced prostate cancer. They looked at the men’s normal DNA, the DNA in their prostate cancer and the DNA in bits of their prostate cancer that had spread outside the prostate and set up camp elsewhere in the body (metastatic tumours).

This alone is exciting because it’s the first time doctors have been able to get tissue samples from metastatic tumours in men living with advanced prostate cancer. It means doctors will one day be able to use information from these samples to determine the course of treatment for each individual patient.

The DNA inside cancer cells often contains changes, or mutations, which can affect how fast cells grow, how well they move or how they react to drugs. When the researchers examined the prostate cancer DNA from the original cancer, and its spin-off tumours, they found that in general, the metastatic tumours carried more, and often different, mutations than the original prostate tumour. This opens up new possibilities for treating advanced disease and, even better, drugs against most of these mutations already exist and are either in use, or in clinical trials, for other cancer types.

The study is being described as prostate cancer’s Rosetta Stone because of the ability it gives us to decode the genetic complexities of prostate cancer.

The benefits this research could bring to men with advanced prostate cancer may be immense. But there’s still a lot of work to do before we know whether this could become a routine part of advanced prostate cancer treatment. We’ll be supporting this research as it continues, so you’ll hear more on this story.

Mo-growers help us put over £2 million into innovative research

We’ve just announced over £2 million of funding for innovative and exciting research projects that we believe will one day help improve the lives of men with prostate cancer. These Project Grants and Pilot Awards are funded by The Movember Foundation, and cover all areas of our research strategy, from identifying men at risk of aggressive prostate cancer to developing new treatments for advanced disease.

This year, we especially welcomed applications from researchers wanting to answer the question of why Black men are more at risk of prostate cancer than white men.

Can increased prostate cancer risk in Black men be explained by a virus?

We gave a Pilot Award to Professor Myra McClure at Imperial College London, who wants to investigate the possibility that the higher rates of prostate cancer in African and African Caribbean men are because of a virus infection.

Viruses have been linked to other cancer types – for example Human Papilloma Virus and cervical cancer. And historically, there have been examples of viral infections clustering in certain parts of the world, and therefore in people of a certain ethnicity. Over a long time, genetic material from the virus can become embedded in the human DNA, where it can be passed on down through generations.

So far, there’s no evidence of a viral link to prostate cancer, but Professor McClure wants to look at the RNA sequence (a type of genetic material, like DNA) of a group of African and African Caribbean men and see whether there is any viral RNA mixed in with it. If there is, she will try to find out whether this is linked to prostate cancer in these men.

Find out more about the other grants we’ve awarded by searching ‘new awards’ on our website.

If you’d like to comment on this or other news stories, go to prostatecanceruk.org/news and join the conversation.
New advances in genetic medicine have been hitting the headlines a lot recently. And debates around the pros and cons of genetic testing, and what that could mean for preventing disease and creating personalised treatments have spiked this year. In this five-page special Sophie Lutter explores the ins and outs of genetic testing for prostate cancer, and what it might mean for men and their families, in terms of improving treatment and identifying those at risk.

The first description of the DNA double helix in 1953 sparked a revolution in the way we view and understand ourselves and the world we live in. Our genome, that is our entire DNA sequence, and our ever-growing understanding of it, is an immensely powerful thing. It brings possibilities for understanding, fighting and preventing disease – including some prostate cancers.

These possibilities become more likely with every new discovery that confirms prostate cancer isn’t a single disease, but thousands of different diseases. As one scientist put it recently: “How many different prostate cancers are there? How many men with prostate cancer are there? It’s the same thing.”

Many conditions now use genetic testing to match patients to the best possible treatment. Recent research has shown that this type of matchmaking might be possible in prostate cancer too.

**What do we mean by genetic testing?**

Genetic testing involves looking at an individual’s DNA to find out what order their DNA molecules are put together in. The variations in this order, or sequence, are what makes each of us unique. But when people say ‘genetic testing’ it can mean slightly different things.

There are two main types of genetic testing.

Firstly, there’s genetic testing to look at the specific DNA in a person’s cancer cells. This may or may not be different to that of their ‘normal’ cells, and can help clinicians understand that person’s cancer better. Sometimes it can also help them to select the best treatment for that particular patient.

Secondly, there’s genetic testing to look at the genes in normal cells, to find any genetic changes you’ve inherited from your parents, which may increase your risk of cancer or other diseases.

As well as these two types of testing, there are also different techniques that can be used. First, there’s something called whole genome sequencing. This means looking at a person’s complete DNA sequence for any and all variations from what’s expected.

Alternatively, genetic tests can look specifically for known mutations linked to a disease, rather than fishing through the entire genome. This is usually what we mean when we talk about genetic testing for prostate cancer.

We already know that not all drugs work for everyone, and genetic testing could be an essential tool to find out who will respond best to a particular treatment and which treatments might work best for each individual. Scientists also hope to one day use genetic changes in cancer DNA to find out when a treatment stops working. This could save precious time for patients and save money as people can switch earlier to new treatments that have a better chance of working.
There’s still a lot we don’t know about our genetic make-up. And genetic testing alone won’t necessarily give us all the answers. We may still need to develop new treatments, which will take a long time. But we’re on our way.

With The Movember Foundation, we’re already funding research into this. Depending on the results of clinical trials like those below, it may not be long before this type of genetic testing becomes more widely available for men with advanced prostate cancer.

**Studying faulty genes in hard-to-treat prostate cancers**
Professor Johann de Bono and his team have found that almost 25 per cent of men with prostate cancer have a mutation in a gene called CHD1, which is involved in repairing damaged DNA. This mutation stops the gene working, and Professor de Bono’s team is investigating whether this is why some prostate cancers don’t respond to current treatments.

**Targeting drugs to specific mutations**
The drug olaparib is already licensed for use and very effective in treating some subtypes of ovarian cancer, and it also works well for men with prostate cancer who have inherited mutations in the genes BRCA1 or BRCA2. But these mutations can sometimes crop up spontaneously, so Professor de Bono’s team is now testing olaparib in men without inherited BRCA gene mutations, who have advanced prostate cancer. As suspected, they found spontaneous mutations in BRCA and other BRCA-like genes in most of the men who responded well to olaparib. This suggests that clinicians could use genetic tests to work out which patients will respond well to olaparib before they start taking it.

**Monitoring changes in DNA to see how well treatment is working**
Dr Gerhardt Attard is looking at DNA from prostate cancer cells that circulates in the blood. He’s looking for certain mutations in the androgen receptor (a protein that drives prostate cancer growth). He is hoping to find that these mutations can indicate when treatments like abiraterone or enzalutamide have stopped working much sooner than waiting for physical signs or symptoms that the cancer is growing.

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**Other promising developments on the horizon:**

**Finding the men who will and won’t respond to abiraterone:**

- **The non-responders:** A small-scale American study published last year reported that men who have a shortened version of the androgen receptor, called AR-V7, are less likely to respond to abiraterone and enzalutamide than men who don’t. The results still need to be confirmed in a bigger trial, but if they hold true, it could mean that men with the AR-V7 receptor could avoid wasting precious time taking treatments that are unlikely to work for them, and start alternative treatments earlier on.

- **The super-responders:** Other recent research investigated the genes of men on a clinical trial for abiraterone. They found that it took much longer for the disease to start growing when men had a particular mutation in a gene called ERG and were taking abiraterone, compared to men with the same mutation who weren’t taking the drug (the control group). This difference between men taking abiraterone and the control group was less striking when men had either a different type of ERG mutation, or no mutation at all.

These are just a few of many results pointing to a future of more precise treatments for men with prostate cancer, based on their individual genetic status.
Phill Griffith, 36, from Newbury, works in sports hospitality. He lost his father to prostate cancer in February 2002 aged 57. He has three older brothers and is married with two children, including a four-month-old son.

Using genetic testing to predict prostate cancer risk

Whether it was Voltaire, Winston Churchill or someone else who said it, the words ‘with great power comes great responsibility’ have never been truer. There are many benefits of genetic testing and personalised medicine for people who’ve already been diagnosed with a disease. However, there are still serious questions to consider when it comes to using genetic testing for diagnosis, screening and prevention.

We spoke to Sarah Rose, a genetic counsellor at Guy’s and St Thomas’ Hospital to ask about some of the issues she deals with on a daily basis. She said: “Genetic testing is available for men with, or at risk of, prostate cancer on the NHS, but only for men with a very strong family history of prostate, breast and/or ovarian cancer.

“These are the cancers most strongly linked to BRCA1 or BRCA2 mutations, which are the only known ‘prostate cancer’ genes we can test for inherited mutations at the moment. This is because we can only offer testing when we know what the associated risk of a particular gene mutation is, and what to do with the information. There’s no point offering a whole genome test if we don’t know what to say about the results.

“Of course some people do have a strong family history, but don’t have a BRCA mutation, although they may have mutations in other genes that we can’t test for. Instead, we can refer them to various research trials, like the UK Genetic Prostate Cancer Study, which is looking for other genetic changes associated with prostate cancer.

“When we find a BRCA mutation, we then offer testing to all family members. Most of the men we see with prostate cancer who have a BRCA mutation are less concerned for themselves than for their children – especially their daughters – because of the risks of breast and ovarian cancer.

“Deciding whether or not to have a genetic test is not straightforward. It’s a very personal decision. We also encourage people to be open with their children about their genetic risk, otherwise it can be hard to talk to them when they’re older – they may feel like they’ve been lied to, or important information has been kept from them.

“Genetic counselling can help people think about their options around testing. We can explain the risks and the implications of testing, and help people consider the impact on themselves and their family. We’re there to offer support to patients, their partners and families throughout. We try to help people deal with the emotional impact of testing – some people feel guilty for having a mutation and passing it on, even though there’s no question of fault. We also try to make sure people don’t regret their decision to get tested, and that they’re doing it for the right reason – because they want to – not because of family pressure.

“We also keep in touch with our BRCA families to make sure that we share the latest information and research opportunities with them – science is moving so fast that things might change at any time.”

Would you have a genetic test?

When will genetic testing be available to all men?

Before we can get to a point where genetic testing can be rolled out on a large scale, there are likely to be quite a few practical barriers to overcome.

An obvious one would be making the testing technology cheap enough. But we would also need to confirm the benefits of genetic testing for prostate cancer risk, and who should be tested. For example,
“Dad was diagnosed two years before he died, but he was a private person and didn’t tell me until he started chemotherapy. I hadn’t seen him for a while. Then one day he invited me over to dinner and he was just gaunt, this big strapping Caribbean man.

“He explained what he was going through and said it was important that I and my brothers take care of our prostates. He told me to ask the GP about a PSA test. I was only in my twenties. The GP said they wouldn’t normally do it for a man of my age. But when I explained that from 14 I’d been having urinary problems and they didn’t know why, he let me have it. After the tests, they realised I had an enlarged prostate and a benign lump.

“To begin it was a relief to finally know what was wrong with me. But when Dad passed and I saw the way he went, I thought woah hang on a minute. I started to ask questions and do research. I think it will be important for me to be transparent with my son so he can keep an eye on his health. It’ll depend on his age as to what I say. I don’t want to be worrying him. But I want him to have a better understanding than I did.

“I’d definitely have a genetic test to find out more about my risk of getting prostate cancer if I could. I think nine out of ten guys would, especially if you’ve got kids. I like to know the possibilities, so if it does happen, I’m ready. I’d definitely want to be open with my family, but I think I’d go through it by myself then sit them down and explain.

“A lot of people would say it’s playing God I suppose. I mean, could you do it with all diseases like that, looking into the future? I think the important question would be how accurate is it? If it’s not accurate enough, why get it done.”

most prostate cancers aren’t caused by a single genetic mutation, so it wouldn’t necessarily make sense to test everybody. And since we don’t yet know how to prevent prostate cancer developing, we still need to know more about the benefits of genetic testing even for men with a family history of prostate cancer.

Professor Ros Eeles at the Institute of Cancer Research is leading two clinical trials that are designed to answer these questions. The IMPACT trial is asking whether regular monitoring of men with a BRCA1 or BRCA2 mutation leads to earlier diagnosis of aggressive prostate cancer. And in The PROFILE trial, researchers will use existing genetic tests and family history to try and find men at high risk of prostate cancer so that they can also be regularly monitored. They will compare rates of prostate cancer diagnosis between men considered to be at high and low genetic risk of prostate cancer.

In addition, the relevant parts of the health care system would need to be brought up to speed to support increased testing. For example, more genetic counsellors would need to be recruited, and/or more doctors would need to be trained in how to talk to people about the possible consequences of being tested and explain results.
Protecting privacy – who should know the result?
Of course there’s no question that as with all medical information, genetic data needs to be kept securely, and there need to be rules in place to govern who can have access to such sensitive information. But the stakes could be really high with genetic information. If insurance companies and banks were allowed to use your genetic status in their assessments, there could be implications for health, travel and life insurance, as well as for your credit rating or ability to get a mortgage.

There could be implications for employment too. As part of a recent YouGov survey for the Astellas Innovation Debate, one in five bosses (around 22 per cent) admitted that if an employee revealed his or her greater genetic risk of serious illness, they’d also be at higher risk of redundancy and be deemed less eligible for promotion. So it’s just as well that at the moment, European legislation denies employers access to their employees’ genetic data, and prevents insurance companies from demanding it.

What do you think?
Knowing you have a genetic predisposition to prostate cancer might mean that you monitor your health more closely, so may be diagnosed earlier.

On the other hand, it might mean that you spend years worrying about getting a disease that might never develop. It’s not a straightforward issue, so we want to know what you think about it.

Contact us at editor@prostatecanceruk.org

Gary Haines’ father has had prostate cancer and his grandfather died of the disease. Gary is 38 and married with a two-and-a-half-year old son. He has one younger brother. Gary works at Prostate Cancer UK as our Sports PR Manager.

“With my granddad, I knew he’d died of cancer but I didn’t know it was prostate cancer until my dad told me the day before my job interview here. Dad’s 63 now and he was diagnosed nearly eight years ago, after a routine investigation for a suspected kidney stone. He had his prostate removed in February 2009 and has since had the all clear.

“I remember when he told me he had it. We’re a massively close knit family and when you hear ‘cancer’ you always assume the worst. I thought Dad was on his way out.

“Dad’s quite a private guy, so he didn’t go into detail – just said what he’d got and what treatment he was having. But he did say it could affect me and my brother Pete in the future. It was a shock to hear that, especially having seen what he went through. Now I’m kind of assuming I’m going to get it, but I feel quite positive because Dad’s come through it and now I’m aware and I’ll make sure I get checked. If I don’t get it it’s a bonus.

“When we had our son, Joel, I started wondering if it would get passed down to him too. If I were offered a test to find out more about my chances of getting prostate cancer, I think I’d want to do it for his benefit and for my wife. We all want to look into the future don’t we? I’d want to be able to plan and have time to let him know and explain what he might face in the future.

“I think I’d owe it to my family to tell them what I was doing before I had the test and explain. If I didn’t tell them, then I found out I had the gene, I might be more reluctant to say anything. Being open is important, because I’d need their support as well. I don’t think I’d spread it beyond the inner circle though, I don’t think I’d be posting it on Facebook!”

Would you have a genetic test?

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Celebs team up for Men United

In May, mechanic Errol McKellar made his dream of hosting a celeb-filled charity match for Prostate Cancer UK a reality when his Men United team took on Leyton Orient Legends at The Matchroom Stadium. Errol, a former Orient youth coach, was diagnosed with prostate cancer in 2010.

With Harry Redknapp managing, assisted by Russell Brand, Errol’s Men United team, featuring rapper Kano, TV presenter Tommy Walsh and former England international Trevor Sinclair, fought back after falling to a 4-0 deficit. The final score, in front of a 3,000-strong crowd was 4-3. And while Orient were victorious on the pitch, the real winners were Men United with over £20,000 raised for Prostate Cancer UK.

Easy access for all

We believe all men should have access to information and support regardless of their backgrounds. That is why we knew we needed to act when we learned that almost one in three adults over the age of 65 across England don’t have the literacy skills needed to understand health information.

We’ve developed a brand new easy-read guide which uses simple language and clear illustrations to help more men understand the signs and symptoms of prostate cancer and what to expect if they go for tests.

You can read more about the booklet and order copies on our website.

Everyone’s favourite local

Earlier this year, we teamed up with two pubs at opposite ends of the country to help launch our Jurassic and Saxon Classic cycling events. For one weekend only we turned The Dove Street Inn in Ipswich and the Country House Inn in Exmouth into Men United Arms to encourage locals to get their mates together and take on a new challenge this summer. These were just two in a run of Men United pub takeovers that kicked off in January at the Anchor Bankside in London.

We also staged two rugby league takeovers as The Cricketers Arms in Widnes became The Men United Arms during the launch of the rugby league season in March, and The Junction, Haymarket in Newcastle did the same for the sport’s Magic Weekend in May. And there will be more to come this summer.

If you’d like to set up your own pop-up Men United Arms, email events@prostatecanceruk.org

We join forces with European Senior Golf Tour

Prostate Cancer UK and The European Senior Golf Tour have agreed a ground-breaking initiative for us to become the new title sponsor of the Scottish Senior Open. The Prostate Cancer UK Scottish Senior Open will take place at Archerfield Links Golf Club, from August 27-29 this year.

The event will help increase awareness of prostate cancer, as well as raising money to support men across the UK. With a prize fund of £250,000, the tournament will have a field of 60 European Senior Tour professionals. It will have a Pro-Am format, meaning they will play alongside an amateur partner for the first two rounds before the professionals contest the final round on Saturday August 29. To buy tickets visit prostatecanceruk.org/scottishsenioropen

Prostate Cancer UK SCOTTISH SENIOR OPEN
A lot of money has changed hands for footballer Ade (Adeola) Akinbiyi. He’s played in the Premiership for Leicester City and Crystal Palace and internationally for his parents’ native Nigeria. In January 2014, Ade, now 40 and working as a Sports Consultant, lost his father. He was devastated, and it wasn’t until later he found out he’d died of prostate cancer. His dad had kept it to himself. Ade talks about this huge shock, how it’s changed his life and how he feels about his own risk of prostate cancer. Ade is married with three children and lives in Manchester.

“I first heard about prostate cancer about a year-and-a-half ago from Men United’s Errol McKellar, who I’ve known since I was 10. I grew up in Hackney and I used to play in a local youth football team called Senrab that’s produced lots of big name players. Errol helped out with that and he’d pick up kids from anywhere who needed a lift. He’s an amazing guy – everyone looked up to him and he was like a father figure to all of us.

“We stayed in touch and I often pop into his garage when I’m in London seeing my mum. But I’d been a few times and he wasn’t there. Eventually I found out the reason was that he’d had prostate cancer. When I saw him, he told me all about the disease and he said he’s doing everything he can to raise awareness – telling guys who come into his garage about it, doing all sorts with Men United and Prostate Cancer UK.

“About two months after that chat with Errol I found out my dad had died of prostate cancer. It was a huge shock because although I knew he was ill, I’d had no idea he had prostate cancer. He was in Nigeria at the time – he’d
I didn’t even know Dad had prostate cancer until I saw his death certificate.

spend some time there each year, some time in the UK. I got a call to say he’d passed away, but it was only when I went out and saw a copy of the death certificate that I found out it was prostate cancer.

“The hospital out in Lagos was not the best for telling us things – I did wonder if the doctors hadn’t known what was wrong with him, but now I don’t think so. He’d been ill for quite a while. He must have had tests and just decided to keep it quiet. Knowing the older generation (he was 78) that’s what they do.

“And Dad was quite a strong character. If you’d ask him how he was he’d just say yeah he was okay, no more. So I don’t know when he found out, what stage it was at or what treatment he had. He’d gone to all his appointments on his own.

“Through talking to Errol, I knew that if your father or brother has had prostate cancer then you have a higher risk yourself. And he told me that because I’m Black I already have a 1 in 4 chance of getting prostate cancer. So I have a pretty high risk. But I’ve done a lot of reading and, now that I’m aware of my risk and I’ve learned about the disease, it doesn’t bother me. Until a test says I have it, I’m not going to worry or assume it’s going to happen.

“It could be me, it could be one of my two brothers, it could be anyone. I’ll make sure I get checked regularly and that’ll give me a good chance to have treatment. I’m 40 now and I’m talking to the GP about getting tested. My older brother has as well. If there was a genetic test to tell me more about my risk, I would definitely have that, as long as it didn’t harm me. And it’s something I’d definitely want to tell my family about before I had it.

“I’ve got two boys aged 20 and four and a girl who’s 14. I’ve already told my older son about prostate cancer and the fact that it could affect him. And I’ll talk to my younger one when he reaches the right age, maybe in his mid-twenties. I just don’t think it’s something you can hide from them – you’ve got to be open and truthful. I was left wondering why my dad didn’t tell me. I don’t want them to feel the same.

“I’m open about it generally – I talk to my friends about prostate cancer and health – maybe partly because I’m sporty and I like to exercise and stay healthy. But I think a great friendship is all about getting together and talking about things – whether it’s prostate cancer or another problem. And I think guys my age are starting to be aware and talk about it. We’re not as private as Dad’s generation.

“However, there are still a lot of people who don’t know. That’s why I got involved with Prostate Cancer UK and Men United. I’ve been in football for years and, while I’ve still got my name, I want to use it to do what I can to help beat prostate cancer and let people know about it – especially Black men.

“I was with Prostate Cancer UK at a golf show recently as an ambassador. And I organised a barbecue at my local church to raise awareness and money. I raised around £1,000. I’m going to do a sky dive as well. I’ll do anything as long as it can help the cause.

“I’m really proud to say I’m part of Men United and wear my Man of Men badge. It’s great that so many football managers are wearing it and promoting it. People spot mine and say: ‘What’s that? I’ve seen it on TV,’ and they want it. It’s almost becoming a fashion thing, and that’s great because it starts people talking about it.”
Chronic prostatitis is a common condition that can affect men of any age but unfortunately diagnosis and treatment are not always straightforward. Here, our Specialist Nurse, Meg, answers some of your questions.

**Q** What is prostatitis?

**A** Prostatitis is the name given to a set of symptoms, thought to be caused by an infection or by inflammation of the prostate. It's most common in younger and middle aged men, typically between 30 and 50.

Symptoms vary but can include pain or aching in your testicles, the area between your testicles and back passage, the tip of your penis, your groin or your lower back. Prostatitis can also cause urinary symptoms like needing to pee a lot or urgently and pain when you do. And some men describe feeling a discomfort like ‘sitting on a golf ball.’ Sexual problems, like losing your desire for sex, painful ejaculation and difficulty getting an erection, can also be symptoms.

Chronic means long-lasting and chronic prostatitis is when symptoms are long-term or keep coming back after treatment. There are two types of chronic prostatitis – **chronic bacterial prostatitis** and **chronic pelvic pain syndrome** (CPPS). Both have different causes and treatments.

**Q** What causes chronic prostatitis?

**A** Chronic bacterial prostatitis is caused by a bacterial infection and tends to affect men who have had lots of urine infections or problems with inflammation of the urethra.

For more detailed information on prostatitis, read our booklet *Prostatitis: A guide to infection or inflammation of the prostate*. 

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*Insights | Summer 2015*
With CPPS, nobody knows for certain what the cause is but there could be a number of possibilities. This often makes it difficult to diagnose and treat. Some things that are thought to be causes include urine getting into the prostate gland, previous infections in or around the prostate, inflammation of the nerves around the prostate, stress or anxiety and problems in the pelvic floor muscles (muscles that help control urination).

**Q** Can prostatitis turn into prostate cancer?

**A** No, prostatitis doesn’t turn into prostate cancer and at the moment there is no evidence to show that men with prostatitis are more likely to get prostate cancer.

**Q** What is the best treatment for chronic prostatitis?

**A** There is no one best treatment for prostatitis. Because symptoms vary so much the best treatment for one man will be different to the best treatment for another.

If you have chronic bacterial prostatitis, you’ll usually be given a course of antibiotics that lasts about four to six weeks. If symptoms come back you may need further antibiotics or another type of medicine called alpha-blockers. And if you are in a lot of discomfort or pain, you may also need to take pain-relieving drugs.

With CPPS, treatment is often based around what works best to control your symptoms. There are a number of different medicines that can be tried including antibiotics, alpha-blockers, 5-alpha-reductase inhibitors, non-steroidal anti-inflammatory drugs – as well as drugs to relieve pain, such as paracetamol, anti-depressants or anti-epileptic drugs.

Depending on what your doctor thinks has caused your CPPS, other treatments such as physiotherapy or psychological therapy may be offered to you.

**Q** What health professionals or specialists should I be seeing for my prostatitis?

**A** Depending on your symptoms and how much they’re affecting your life, you may see a range of health professionals. These could include your GP, a urologist, a pain specialist, a nurse specialist, a physiotherapist, a sexual health specialist, a cognitive behavioural therapist and a psychologist or counsellor.

**Q** My treatment isn’t working, what else can help?

**A** Each man will respond to treatment differently so if one thing doesn’t work, you should be able to try something else.

Some men find complementary therapies help them manage symptoms, although there isn’t much research behind these. Complementary therapies are usually used alongside medical treatments, rather than instead and can include acupuncture, osteopathy, relaxation therapies like massage or aromatherapy, herbal remedies and supplements.

If you’re thinking about trying complementary therapies or supplements, speak to your doctor or nurse as they may be able to offer advice or refer you to a qualified therapist. Be wary of products that make big promises. Many companies make claims that are not based on proper research. The Complementary and Natural Healthcare Council has advice about finding a therapist.

**Q** Is there anything I can do to help myself?

**A** If you have chronic prostatitis, particularly CPPS, you may find it frustrating that it isn’t well understood and that treatment isn’t always effective. But there are things you can do yourself.

- **Find ways to relax.** Feeling stressed or anxious can make symptoms worse.
- **Sit comfortably.** Use a soft cushion to relieve pressure.
- **Get active.** Exercise can help some men feel better and reduce symptoms, including pain.
- **Avoid cycling.** Avoid activities that put pressure on the area between your back passage and testicles (perineum), such as cycling.
- **Keep a diary.** It can help you spot something that brings on a flare-up. Record things like food, drink, exercise, how stressed you feel and your symptoms.
- **Do pelvic floor muscle exercises.** These strengthen your pelvic floor muscles which can help with urinary symptoms.

**Q** Where can I get support?

**A** You might get all the support you need from your partner, family or a friend. You can also talk to your doctor or nurse, call our Specialist Nurses, or speak to a counsellor. Counsellors can help you understand your feelings and find ways to deal with them. In particular, cognitive behavioural therapy (CBT) can help men find ways to deal with prostatitis. CBT involves talking with a therapist who will help you come up with practical ways to tackle patterns of behaviour that are causing you problems.

Read how one man dealt with chronic prostatitis at prostatecanceruk.org/prostatitis-and-me/james
FOCUS ON

We’ve been out across the UK a lot recently, testing new ways to reach men, encourage them to find out more about prostate cancer and speak to a health professional. And we keep hearing the same thing again and again: “I haven’t got any symptoms, so why would I go to the doctor?” Even men who know they have a high risk of developing prostate cancer are telling us this. Nick Wright asks how we can change their minds.

Over the last year, we’ve worked with Be Clear on Cancer on an awareness campaign in London and we’ve created and tested a risk factor scratch card for men over 50 from lower socio-economic groups in the North East. The majority of men we’ve met through these and other projects know they should visit the GP if they are concerned about prostate cancer. However they generally say they need symptoms to show before they visit the GP. And they don’t see the urgency, even when they have clear prostate cancer risk factors such as being over 50, being Black or having a family history. This was backed up by a YouGov Public Awareness study in 2013, where 75 per cent of UK men at a higher than average risk of prostate cancer said the same.

What’s worrying about this is that we know most men with early prostate cancer do not have any symptoms. So how do you get men who know they’re at risk to go to a GP if they don’t have any symptoms?

We asked one of our Specialist Nurses, John Robertson. John regularly speaks to men, their partners and family over the phone, online and through awareness talks.

“Men can bury their heads in the sand,” John said. “But it’s important for them to take responsibility for their health. It’s also important to emphasise that it can be effectively treated, and you have a better chance with that the earlier it’s caught. So don’t wait for symptoms.”

John added that a lot of men he speaks to aren’t aware they might already be living with symptoms of a prostate problem. “I’ve spoken to men who’ve told me they don’t have symptoms but are getting up through the night to go to the toilet. They just think it’s a sign of age,” John said. “It’s important to say that this might not mean a prostate problem, but it doesn’t mean you should put up with it. If it’s impacting on your life, get it checked out.”

In John’s opinion the most effective way to help overcome these issues is talking about it. “Whether it’s one of us nurses, a friend or a family member, we find a lot of these conversations are what prompt men to go to a GP. You can read something and make an excuse or think it doesn’t apply to you but having a conversation with a friend can really explain why and convince you.”

We find conversations are what prompt men to go to the GP.

1 in 4 black men will get prostate cancer.
Prostate cancer often has no obvious symptoms. If you are a black man over 45 and want to discuss your personal risk of prostate cancer, visit your doctor.
We drew the same conclusion as John from our recent project targeting men in lower socio-economic groups. We created a scratch card based on risk, where men could mark if they were Black, above 50 or had a brother or father who had prostate cancer. They were then given a score which would indicate if they were at higher risk.

We tried giving this out on its own and during prostate information sessions in workplaces, health groups and exercise classes. But it was handing them over in the sessions and the conversations around that that really made the difference. One of the men who attended a session told us about a conversation he had with William, one of our volunteers handing out information, who’s living with prostate cancer.

“I felt more comfortable speaking to someone,” he told us. “Being a joker in nature I could take it more seriously speaking with William about prostate cancer and the questions and concerns I had surrounding that. As a result of talking with him I’m now going to seek a check-up with my GP. If this had just been information left on a table for people to help themselves to, I wouldn’t have picked one up.”

When David Hadley-Smith, 57, was diagnosed with prostate cancer in 2013, he made sure he told his friends at his golf club. “People have very little knowledge of the disease. They hear the word cancer and think ‘oh my god’ – I know I did. I probably spoke to at least 40 members of the club, all guys at a higher risk, about prostate cancer and going to the GP. Ten have since been diagnosed. Talking to people has really made a difference and it’s brought together people who weren’t friends before.”

If you’d like to order some prostate information to pass on to your friends and family visit prostatecanceruk.org/information
DIY CYCLE CHALLENGE:
“How and why we did it for Kelvin”

The Powell family know all too well the devastating effect prostate cancer can have. Father, Harvey and all three sons have been affected by the disease and very sadly, third son Kelvin died. A year after his death, the family decided to raise money for Prostate Cancer UK in his memory by creating their own 480 mile cycle challenge. Find out how getting their friends and family involved was a crucial part of making that happen.

Harvey Powell has been having hormone therapy for prostate cancer for over 20 years. His son Malcolm had his prostate removed in his mid-fifties but the cancer spread and he is also now on hormone therapy. Haydn has also had his prostate removed and is currently free of any signs of the cancer. Third son, Kelvin, sadly passed away from the disease in 2012 at the age of 62.

A year after Kelvin’s death the family decided to raise money in his memory by doing a cycle challenge, riding between the homes of the three brothers and their father, starting at Kelvin’s in Newport and ending at Malcolm’s in Norwich. The ride took seven days and covered over 480 miles. They planned the route using the Sustrans National Cycle Network (sustrans.org.uk).

Haydn said: “The planning involved identifying a safe and pleasant cycle route to link Newport, South Wales, with East London, Clacton-on-Sea and Norwich. The journey was broken down into stages, mostly of between 60 and 80 miles each day. We tried to arrange accommodation with family members, using air beds and sleeping bags when we ran out of bedroom space. And we booked intermediate stops at hotels and campsites.”

The group was made up of eight family members, and they called on neighbours, friends and other family to support the ride by acting as crew and providing meals, accommodation and mechanical support.

“Our support team planned menus for the home stops, the campers and lunches,” said Haydn. “They bought fresh food on route and we had three support vehicles: two that could carry bikes and a motor home to provide warm drinks and food. We arranged rendezvous points for each day as the vehicles couldn’t follow the mainly off-road cycle route.”

The Powells also used all their contacts to help raise money. Haydn said: “None of us had ever fundraised on a large scale before. Each of us had a different technique. Some had a large network of business contacts, some had wide social or community networks. In most cases we shared our story and our Just Giving page, which inspired them to donate.”

Between them, the team managed to raise an incredible £15,600. Haydn said: “We were all delighted with our success and particularly by the enormous generosity of all our friends, family and associates.”

This summer we’re asking you to get together with friends, do what you love and do it for Men United. If cycling is your thing and you’re interested in planning your own challenge, visit our website prostatecanceruk.org/diy-cycling, email events@prostatecanceruk or call 0800 082 1616.

Image right: Kelvin Powell
Below: The Powell family reach Clacton-on-Sea (Malcolm and Haydn – Kelvin’s brothers – are third and fourth from the left)
Dave Garbett lost his father, Stephen, to prostate cancer in September 2014. Since his death, Dave and some family friends have signed up to several fundraising events in his memory. Here Dave tells us what made Stephen a Top Dad.

“I did my first marathon in 2000 after I retired from the army. When I was diagnosed in 2008 I remember running the Great North Run at the start of October and having surgery at the end of the month! It’s a shock to be told you have cancer – it’s quite the life changer. The effects of surgery, like incontinence, put me back a bit but I did my pelvic floor exercises and in 2010 I ran again.”

“This year will probably be my last Great North Run. I’m 70 this summer and my hips and knees are telling me to ease up! I know my grandchildren think Nanna and Grandpa should be doing something more sedentary too. But it’s great for them to see us run and I know I’ll be elated when I get over the finish line. I just want to give something back. I’m still extremely grateful to everyone who helped me.”

John Young from Scarborough

This year, just after his seventieth birthday, John is running his tenth Great North Run alongside his wife Sue. Together they’ll be wearing our Prostate Cancer UK vests. John tells us how being diagnosed with prostate cancer in 2008 didn’t stop his running.

“I’ve heard people say he lost his 10 year battle, but I disagree – you don’t lose a 10 year battle, not when you’ve fought it with such pride and dignity. He was, and always will be, a Top Dad (and Grandad)!"

Dave Garbett lost his father, Stephen, to prostate cancer in September 2014. Since his death, Dave and some family friends have signed up to several fundraising events in his memory. Here Dave tells us what made Stephen a Top Dad.

“Dad was once described as ’5’6 of Yorkshire granite’ and that’s how he was when it came to prostate cancer. He was first diagnosed at the relatively young age of 53 and fought the disease every step of the way for 10 years with a smile on his face. He took every type of treatment offered with an open mind and positive attitude, and his great sense of humour helped keep the mood light.

“His favourite pass-time was playing with his granddaughter Sophie. The cancer had spread throughout his body and his bones. He’d come home from work, aching all over and lay down on the sofa, but Sophie would have him up again in no time to play. He never once said no to her, regardless of the pain he was in. He absolutely adored her – his little princess!

“Dad always had time to help others, whether it was an understanding ear, a few words of encouragement, a good kick up the back side or something amazingly generous. When a friend’s son was diagnosed with a brain tumour, the boy’s family did some fundraising so they could take him to Disneyland. When Dad heard, he paid for a villa so they could use their funds to make it a once in a lifetime holiday!

“I’ve heard people say he lost his 10 year battle, but I disagree – you don’t lose a 10 year battle, not when you’ve fought it with such pride and dignity. He was, and always will be, a Top Dad (and Grandad)!”
GET INVOLVED

Join Men United, our movement for everyone who believes men are worth fighting for. Get your mates together and sign up for one of our events or activities now!

Do what you love – and do something amazing for men everywhere this summer

You probably already do loads of great things with your friends. Maybe you’re part of a local walking group, or you dazzle the locals with your football skills in park kick-about. This summer we need you to do these things not just for fun, but for a great cause: Men United.

To find out more about setting up your own walk or cycling event visit prostatecanceruk.org/get-involved

Shirt2Work

Men United wouldn’t be the same without an opportunity to show your club colours at work. So why not organise a Shirt2Work day and get your colleagues to donate £2 to swap their office togs for their team’s strip for a day?

prostatecanceruk.org/shirt2work

Start chipping-in with Men United

Hitting the green with your mates this summer? Why not start Chipping-in and do something great together to help us beat prostate cancer?

You can make every bunker shot and ball-out-of-bounds a fineable offence (you can decide how much a fine is). After the final hole, count up your fines and donate the proceeds to us. Whether you’re game’s like Rory McIlroy or Rory Bremner, keep on swinging (and save lives when you’re messing up!)

For more information and to order your Chipping-in pack visit prostatecanceruk.org/chippingin

Have a Lads Night In

We’ve teamed up with PokerStars to bring you Lads Night In. Be one of thousands of full houses across the UK doing something amazing to beat prostate cancer on Friday 25 September 2015.

Here’s how it works: order your free poker pack from us, get your friends round, you each put in an agreed amount, half the money is won at the table and the other half is donated to Prostate Cancer UK. Everyone’s a winner.

Keep an eye on our website for details of how to sign up from 17 July.
**Events Calendar**

August 2015 – April 2016

**Movember**
The month formally known as November gives you the chance to commit to changing the face of men’s health by signing up to grow your mo to help men across the UK.

movember.com

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**London to Paris**
13-17 April 2016
Ride the exciting London to Paris route, starting in the heart of London. You’ll cycle through the English countryside before arriving in Paris and finishing at the iconic Eiffel Tower. Definitely a weekend not to be missed.

prostatecanceruk.org/cycling

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**Kilimanjaro Summit Climb**
22-31 January 2016
Trek Mount Kilimanjaro and conquer highest mountain in Africa. This epic challenge covers breath-taking landscapes and terrains from alpine deserts and beautiful rainforests to spectacular views of snow-capped mountains. Take on this challenge with your mates for a once-in-a-lifetime experience.

For more info visit prostatecanceruk.org/overseas

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**We’re going on tour**
Men United is going on the road this summer in our Prostate Cancer UK double decker bus. We’ll be encouraging Black men to be a part of Men United, find out more about their risk and spread the word to their friends and family. Keep an eye on local media, Facebook and Twitter to see when we will be near you.

If you’d like to help, visit: prostatecanceruk.org/roadshow-volunteers

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**More events**

16 August
Jurassic Classic (cycle challenge)

12 September
Thames Path Challenge (walk)

30 September
Volunteer meet and greet in West Midlands
For more info email volunteer@prostatecanceruk.org

**Until October**

Three Peaks challenge (hill walk)

3-4 October
Bournemouth Marathon Festival

3-4 October
Great Scottish Run

4 October
Cardiff Half Marathon

11 October
Royal Parks Half Marathon

**Throughout November**
Mo Runs at various dates and locations throughout the UK.

1 November
Men’s 10K Edinburgh

2 December
Carols by Candlelight

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Check out a full list of events and ways to get involved at prostatecanceruk.org/get-involved
Our services

Specialist Nurses
0800 074 8383
(Mon to Fri 9am-6pm, Wed 10am-8pm)
Our Specialist Nurses have the time to listen and answer your questions on anything to do with prostate cancer and prostate disease.

Information on prostate cancer
0800 074 8383
We provide free information on prostate cancer and prostate disease. Order or download copies from the information section of our website or call our Specialist Nurses for help choosing the publications you need.

Regional services
To find out what local support and services are available in your area visit prostatecanceruk.org/find-local-support

Live chat
Our Specialist Nurses are available online to answer your questions and help you find the information you need.

The blue men on this map represent the locations of support groups who have asked to be listed on our website. Find a group near you prostatecanceruk.org/supportgroups

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

Fatigue support
0800 074 8383
If you have prostate cancer and you’re struggling with fatigue, our Fatigue Support service is designed to help you manage your tiredness so you can do the things you want to do.

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

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

Bladder and Bowel Foundation
bladderandbowelfoundation.org
0845 345 0165
Information and support for all types of bladder and bowel problems.

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.

British Association for Counselling and Psychotherapy
www.itsgoodtotalk.org.uk
01455 883 300
Provides information about counselling and details of therapists in your area.

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.

Cancer Black Care
cancerblackcare.org.uk
020 8961 4151
Provides information and support to people from Black and minority ethnic communities who are affected by cancer.

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

Cancer Research UK
cancerresearchuk.org
0808 800 4040
(Mon-Fri, 9am-5pm)
Provides information about living with cancer.

Penny Brohn Cancer Care
www.pennybrohn.cancercare.org
0845 123 2310

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

Health with Pride
www.healthwithpride.nhs.uk
Information on cancer issues and erectile dysfunction for gay and bisexual patients.

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

Other useful organisations

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 Ade, Phill and Gary to get prostate cancer behind them, please fill out the enclosed form. Or you could visit the Get involved section of our website to find out more or make a donation. Thank you.

Ian Adamson, from South London, reviews Prostate cancer and your sex life, our booklet and DVD which have recently been updated.

“Prostate cancer and its treatment can have a big impact on your sex life. A lot of men don’t get the information, support or treatment they need. This booklet explains the sexual side effects a man may experience and has information about the treatment and support that is available. It’s an essential read for any man who’s had or is about to have prostate cancer treatment.”

You can download or order publications free of charge from our website. Or you call our Specialist Nurses on 0800 074 8383 to find out more.
KEEP PUSHING ON.

Join Men United. See your friends more and help beat prostate cancer. prostatecanceruk.org/menunited

Men United. Keeping friendships alive.