

Prostate cancer

Insights

Issue 10 | Summer 2017

People power

How you've helped
drive our latest
campaigns



Prostate
cancer
and me

**LES
FERDINAND**



**PROSTATE
CANCER UK**

Precision medicine

The scientist
and triallist
spearheading
the future
of treatment

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Editor's note

Oncologists and researchers often say: "Every cancer is unique". That's certainly true for anyone who's had prostate cancer and not known how their tumour is going to respond to a particular treatment or to being left alone. Clinicians currently follow a tried-and-tested pathway of treatments with their patients, which is proven to be the best and safest course of action for most men, switching treatment options in response to the cancer's progress and the man's wellbeing.

But rather than this reactive approach to treating prostate cancer, wouldn't it be better to understand the exact make up of a man's tumour beforehand, then pro-actively target it with the treatments that are most effective and work best for him? What I've described is called precision medicine, and it's what Prostate Cancer UK wants to see for all men. That's why we're funding well over a million pounds-worth of research in the area – and we're already seeing some exciting results, as you'll read in our special feature (p10).

But of course, we need more of your donations to crack it. So we're massively grateful for all the money you helped us raise in our recent March for Men events (p18) and to our coverstar, 'Sir Les' Ferdinand, for his superb efforts on this year's Football to Amsterdam bike ride. Thank you all for helping us create better and more personalised treatments for men with prostate cancer.

Dominic

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INBOX

Tell us what you think about the magazine and our stories online at prostatecanceruk.org/news. We want to hear what you've got to say.



Dear Insights

I am becoming increasingly concerned that you have still not made more of the two most important advances in the detection of prostate cancer in recent times, ones which obviate the need for the random biopsies which are currently in place. I refer to the groundbreaking blood test developed at Birmingham University, which shows whether a person has prostate

Dear Stewart

As you suggest, finding a better way to diagnose prostate cancer is a priority. But it's important to bear in mind that when new studies are reported in the media – like the two you've mentioned – there are often many more years of



Dear Insights

The new genetic test for aggressive prostate cancer being developed by the University of East Anglia does give us real encouragement for the future. It's a start in the search for the 'Holy Grail' of prostate cancer diagnosis: determining which cancers are the 'tigers' and which are the 'pussycats'.

cancer and also the aggression or passivity of the cancer. The other is an NHS-sponsored study being carried out in Milton Keynes on the results of detection by sniffer dogs. As I'm sure you are aware, being told that you are suffering from prostate cancer through these non-invasive means would, certainly in my case, be a little more persuasive in making me want to have another biopsy. Why haven't you ever mentioned these two alternative, but very valid tests?

Stewart Porter, via email

research needed before they can be used. Whenever we comment on new research, we are very careful not to offer false hope to men. That doesn't mean we don't also get excited when real breakthroughs happen. We called a study earlier this year that showed the huge potential benefits of mpMRI scans before biopsy 'the biggest leap forward in decades'. That research is now already making a difference to men's lives. In other cases, there is still more research needed: like the diagnostic blood test from Stockholm a couple of years ago that appeared to be very accurate, and which we're working to bring to trial in the UK. We hope to tell you more about this soon.

I have been privileged to attend lectures by Professor Colin Cooper and have also visited his facilities within the Bob Champion Centre by the Norfolk and Norwich University Hospitals. He has a great, dedicated team working on prostate cancer research.

Ray Cossey, Chairman of Trustees, Norfolk and Waveney Prostate Cancer Support Group



Your anger at NHS treatment cost cap

In May, we heard that our 29,000-strong petition wasn't enough to stop the National Institute of Clinical Excellence (NICE) from going ahead with plans to introduce a cost cap on treatments from the NHS in England. Here's how you reacted online:



The UK has the lowest spend on healthcare per head in Europe. Why? We are a wealthy country – what priorities are being chosen over health? My husband is alive because of the fabulous oncology team at the Bristol Royal Infirmary. In the future, is it only those with private healthcare packages who will survive? Shame on the UK.

Janet McClean



Absolute disgrace! This is about thousands of lives. People first – money should not be an excuse.

Rita Debnam



Let's just hope the upper echelons of NICE don't have friends, relatives or someone close to them who desperately require this sort of medication.

Darren Lee



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Email the Insights team:
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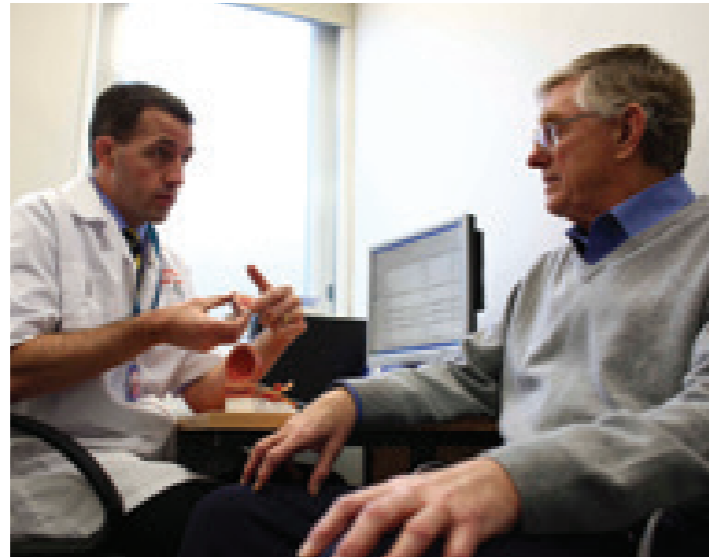
PROSTATE CANCER NEWS

New STAMPEDE trial results show earlier abiraterone could improve survival of men with advanced prostate cancer

The latest results from the extensive STAMPEDE trial show that adding abiraterone to hormone therapy improves survival for men with advanced prostate cancer, compared to hormone therapy alone. Announced at the American Society of Cancer Oncology conference in June, the 2,000-men trial found 83 per cent of those receiving abiraterone alongside androgen deprivation therapy (ADT) survived for over three years, compared to 76 per cent of men who received ADT alone.

This is another example of how earlier and combined use of existing treatments can have a significant impact on advanced disease, after earlier use of docetaxel became standard treatment on the NHS in light of the positive

survival results from a STAMPEDE trial involving that drug in 2015. But questions remain about early abiraterone's suitability for all men. Early docetaxel and abiraterone have not been compared side-by-side, so we can't say yet which treatment works better. But more importantly, we need a way to find out if they will



work differently in different men, or if they might work even better together.

"The potential benefits of giving some men abiraterone alongside hormone therapy are clearly impressive, and we will be working with all relevant bodies to make sure this treatment becomes an option

available for these men via the NHS," says Dr Iain Frame, Director of Research at Prostate Cancer UK.

"However, there are still key questions that need to be answered about which men will gain the most benefit from this treatment combination and which will respond better to earlier use of other treatments, such as docetaxel. This knowledge will be crucial in enabling men and clinicians to make more informed treatment choices, ensuring that men are receiving the right treatments for them, at the right time. Prostate Cancer UK is committed to funding the research that will make sure this kind of personalised approach to treatment happens."

Men dangerously unaware of family link to prostate cancer, new research finds

Two-thirds of men with a family history of prostate cancer are dangerously unaware of their increased risk of the disease, according to new research by Prostate Cancer UK, presented at a Public Health England conference in June. Half of all UK men also don't know that your father or uncle having prostate cancer makes you two-and-a-half times more likely to get it.

It has prompted urgent calls for men and their families to have a potentially life-saving talk about the disease with their relatives and doctor. Especially since an accompanying study also showed that only one-in-10 GPs are likely to always ask a man whether any close relatives have had the disease. Where men did take the lead and initiate a discussion with their doctor, though, it found their experiences were overwhelmingly positive.

"We need men to feel empowered to take control of their own health, find out their family history and proactively ask their GP whether they need tests for the disease due to their risk of developing it," says Angela Culhane, chief executive of Prostate Cancer UK.

"Currently, this isn't happening nearly enough and the increased risk due to family history of prostate cancer is being dangerously overlooked by both men and their GPs. This must change. Every single one of us can do our bit to reduce the number of men who lose their lives to prostate cancer every year in the UK. Ask your dads, brothers, granddads, husbands, partners and friends about prostate cancer and urge them to book an appointment with their doctor if they have a family history of the disease."

New blood test could help 'personalise' treatment for advanced prostate cancer and save NHS cash

A promising new blood test could allow personalised treatment for advanced prostate cancer for the first time. Researchers at the Institute of Cancer Research, funded by Prostate Cancer UK and with support from the Movember Foundation, have developed a cheap blood test that could identify which cancers respond to abiraterone and enzalutamide, and which require alternative treatments.

Currently, men with hormone-resistant prostate cancer are given enzalutamide or abiraterone for 12 weeks

before the doctor can determine if it is having an effect. But the new test could spare some men with advanced prostate cancer the wasted time and side effects of an ineffectual treatment, while also saving thousands of pounds for the NHS.

"Our method costs less than £50, is quick to provide results, and can be implemented in hospital laboratories across the NHS," says Dr Gerhard Attard, who led a trial of the test with 265 men.

With the list price of a months' supply of



abiraterone at more than £2,000, using the new test to identify cancers that are genetically resistant to the drug before administering it could save the NHS huge sums in wasted treatment.

The blood test will now undergo clinical trials as part of the PARADIGM trial,

which is funded through one of our Movember Foundation Translational Awards. Dr Attard hopes it will provide the scientific data required to persuade health regulators to make his blood test available to all men with hormone-resistant prostate cancer.

FROM THE LAB Discovering the link between black men and prostate cancer

Could a virus explain why black men are at a greater risk of prostate cancer? We've just awarded a team of researchers at Imperial College, London, a £75k pilot award to find out.

What's the big idea?

We know that there are some associations between viral infections and other cancers – such as human papilloma virus and cervical cancer, or hepatitis B virus and liver cancer. We also know that black men are at higher risk of getting prostate cancer, but we don't really know why and often put it down to genetics. It might not be that simple, though, and Professor McClure and her team at Imperial College think that some prostate cancers in black men could be caused by a virus.

What are they doing to find out if that's true?

They're going to use some very sophisticated techniques to look at whether there is evidence of viruses in tissue samples from black men with prostate cancer. The technique – called Next Generation Sequencing – will be able to tell not only if there are

viruses there, but how much of them are present. The researchers have access to a lot of tissue from black men with particularly aggressive forms of prostate cancer.

What happens next?

If the researchers do identify a virus, then it would mean that we could start looking at ways to identify the virus sooner to identify those men at highest risk. In the longer term, anti-viral vaccines could be developed, like the ones we have for measles and chickenpox, that would prevent prostate cancer in black men.

Are there any reasons to be cautious about the study's potential success?

Yes, two. Firstly, we don't know yet if they will indeed find a virus in the samples they're examining. And secondly, if there is, they'll need to show that the virus actually causes the prostate cancer to develop in these men. But we have to start somewhere, and it is a fair assumption that the increased rate of prostate cancer in black men is not simply down to genetics and could be caused by an infection.

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

Standing together for change

Campaigning is one of the many ways we're fighting prostate cancer, and we couldn't do it without your support. We know that beating this disease will take changes in public policy as well as scientific discoveries. That's why we've recently been campaigning for improvements to services and access to treatment in three key areas, following a shocking recent survey, technological advancements and NHS cutbacks. Here's an update on what we've achieved so far.

Erectile dysfunction services

Our research found that although 76 per cent of men who are treated for prostate cancer experience erectile dysfunction, only 30 per cent received any support or treatment to address the problem that met their needs. We felt this was unacceptable and all men with prostate cancer who suffer with erectile dysfunction should have best practice treatment available to them, wherever they live.



The recommended guidelines for prostate cancer treatment say that men should have access to five different options for erectile dysfunction. But we carried out Freedom of Information requests in November that showed widespread variation in their provision across the UK, with only 13 per cent of local health commissioners offering all five. Since then, we've been taking action in various ways:

- **Asking men and those affected by prostate cancer to lobby their local health board.** Nearly 600 people have sent a letter to either their local Clinical Commissioning Group (CCG) or the Health Secretary, calling for change.
- **Contacting NHS Trusts in the worst performing areas,** asking what they're doing to meet the needs of prostate cancer patients. We're trying to understand the barriers to providing good provision so we can find ways to help.

- **Writing to all the Cancer Alliances and Cancer Vanguard in England,** highlighting the difference in services across CCGs in their area and demanding that they address the current inequalities.
- **Writing directly to the Health Secretary,** requesting a named person who is responsible for updating the National Commissioning Guidelines, which includes the recommendations for erectile dysfunction treatment that are nearly 18 years old.
- **Developing an education programme for healthcare professionals** to highlight the impact that erectile dysfunction has on an individual and the importance of services to help after prostate cancer treatment.

Check what erectile dysfunction care is like in your area at bettercare.prostatecanceruk.org

We've also recently launched a series of new online self-help guides, where you can read tips from those who've experienced similar side effects, watch real life stories and find out new ways to improve your daily life. See more at prostatecanceruk.org/guides



mpMRI is the biggest leap forward in prostate cancer diagnosis in decades and could have the potential to save many lives.

mpMRI diagnostic scans

We're one step closer to improving diagnosis of prostate cancer thanks to the breakthrough research trial, PROMIS, which found that using multi-parametric MRI (mpMRI) scans first for men with suspected prostate cancer can safely identify a quarter of men who won't need a biopsy. From the mpMRI images alone, we can identify more than 90 per cent of the important cancers that are probably going to require treatment.



Angela Culhane, Prostate Cancer UK's chief executive, explains the next steps we're taking to make sure mpMRI is made available across the UK to eligible men:

"We know that only a third of eligible men with suspected prostate cancer in the UK will receive an mpMRI scan before biopsy. We know that's not good enough, so we're doing something about it.

"We're taking action to support and encourage health bodies at a national and local level across the UK to address their resource challenges. We've carried out Freedom of Information request research with Trusts, Health Boards and Health and Social Care Trusts across the UK to find out which areas are already using this technique, their MRI scanner capacity, and the barriers preventing every eligible man from accessing it. We're working with national commissioners like NHS England to get funding made available for new resource and capacity in those hospitals, which need to adopt or increase the use of mpMRI before biopsy.

"We're working to make sure radiologists have access to training so they build confidence in interpreting mpMRI scans and ruling some men out of a biopsy. We're also supporting the development of clinical standards and a quality assurance system so that we can be sure that, wherever in the UK a man goes for an mpMRI scan, it's done to the same best practice standard.

"mpMRI gives men the chance of a less invasive and more accurate diagnosis. This is the biggest leap forward in prostate cancer diagnosis in decades and could have the potential to save many lives."

Affordability cap for drugs and treatments

In January 2017, the National Institute for Health and Care Excellence (NICE) and NHS England set out plans to introduce a 'budget impact threshold', which outlined the option to postpone any new treatments that would cost more than £20 million in any of the first three years.

Such restrictions would have meant the breakthrough drugs for advanced prostate cancer, enzalutamide and abiraterone, would have been further delayed by negotiations with the manufacturers over costs for many years, arriving in NHS hospitals too late for the thousands of men whose lives they could have extended.

While we recognise the difficult times facing the NHS, we know that delays in treatments getting to patients could be catastrophic. The £20 million budget threshold also includes treatments for end-of-life patients, so there is a real risk of patients dying while life-extending treatments are kept just out of reach.

We strongly opposed these plans, so we teamed up with 18 other charities and sent a joint letter to key officials at NHS England and NICE, outlining our concerns. We also wrote an open letter, signed by 22 leading health charities, which was published in The Times. We then launched a petition, calling for a stop to the plans, which received over 29,000 signatures. We handed the petition in to NHS England on the morning of their board meeting in the hope they'd reconsider their proposals. We also received backing from Sir Michael Parkinson, who strongly criticised the plans in the media.

Despite our best efforts, the proposals were approved by the NICE board on 15 March and came into effect



Above: Our volunteer Jim Newman presents our petition to Cathy Edwards of NHS England.

Below: A few of the 22 charities who backed it.

on 1 April. But there were some changes made to the original proposals, including a commitment to consult on any delay and to assess the impact on patients of any such delay – plus, a commitment to a limit of three years on any delay except in limited circumstances.

At the same time, a Medical Supplies Bill was going through Parliament and contained an amendment to try and lessen the impact of NHS England and NICE's plans. Our work with other charities on this issue meant we were able to influence a few important changes here.

We are disappointed that these plans for a cost cap have come into force, but will be monitoring the impact of them on men living with prostate cancer.

Thank you to everyone who's been a part of our campaigns. Your support is really making a difference to the lives of men affected by this horrible disease.



PROSTATE CANCER UK UPDATE



New partnership puts our Man in the Mirror

In May, we partnered with the Mirror newspaper to raise awareness among their nearly 26 million readers in print and online. Their famous sports columnists wrote exclusive articles about the disease and the services we can offer men. And there was even an historic takeover of the front and back pages on the Saturday 27 May, which saw our 'Man of Men' logo appear in the famous masthead

– a first for the paper! The partnership came about after the Mirror's editor, Gary Jones, discovered he had prostate cancer when he went for tests following a scorpion sting on holiday. He shared his extraordinary story with us and ran for Prostate Cancer UK in the London Marathon in April. You can read more about Gary and the partnership at prostatecanceruk.org/mirror

Cheers to our pub fundraisers!

Thank you to every person and pub who took part in Pub Aid's World's Biggest Quiz on 5 March. More than 800 pubs hosted for the evening, raising more than £50k for us. Next up in our pub fundraisers is the return of the Men United Arms competition, which will be officially re-launching at the Great British Beer Festival in London on Tuesday 8 August. Find out more about how you can register your local pub at prostatecanceruk.org/menunitedarms



Trustee Sir Christopher Bland dies from prostate cancer

Our former trustee, Sir Christopher Bland, has died aged 78, three years after being diagnosed with advanced prostate cancer. Renowned for being chairman of the BBC, London Weekend Television and BT, Sir Christopher also served as Chair of the Hammersmith and Queen Charlotte's hospitals, and was knighted in 1993 for services to the NHS.

His range of skills and interests were hugely varied, and as well as being chair of the Royal Shakespeare Company, he collected wine and was a successful novelist and playwright. To top it all, he even represented Ireland at fencing in the Rome Olympics in 1960. Sir Christopher used

his extensive skills and experience to help guide our work at Prostate Cancer UK. He served as a trustee between December 2014 and July 2016, when ill health forced him to step down.

"Sir Christopher was rigorous as a trustee in scrutinising Prostate Cancer UK's work, which is just as it should be," said our CEO, Angela Culhane. "Once satisfied that all was in order, he was hugely supportive of the team. I am sure that he would have continued to make a significant contribution, had his life not been cut short by prostate cancer."

Sir Christopher is survived by his wife, Jennie (Lady Bland), his son, Archie, and four step-children.

Team Darts raise their first £50k

Team Darts, our incredible group of fundraisers working in the darts community, have raised their first £50k. Led by Tracy Fletcher and backed by World Champion arrowsman Martin 'Wolfie' Adams, it marks the culmination of over six months of selling branded shirts and pin-badges at darts events up and down the UK, as well as encouraging more and more high-profile players to wear our 'Man of Men' in front of the TV cameras.

"We are very proud and overwhelmed," said Tracy, whose husband Danny has been diagnosed with prostate cancer. "It's been a difficult time for Danny,



me and our family. But knowing we have the love and support of so many makes it all worthwhile."

Having successfully brought about a partnership between us and the British Darts Organisation, Tracy and the team are now setting their sights on raising £180k from the sport. Read more about Tracy and Martin's own diagnosis story at prostatecanceruk.org/teamdarts

The art of precision medicine



Prostate cancer is finally catching up with similar diseases in having treatments that can target an individual's specific cancer – and it's thanks to the game-changing research that you help us fund. Dr Ian Le Guillou meets a man who is already benefitting from this new 'precision medicine' approach, and explains how it all works thanks to our brilliant researchers.

Twelve years after first being diagnosed with prostate cancer, Douglas Baker was starting to feel desperate. "The doctor said there wasn't anything left that he could offer me," he says.

Douglas had been through rounds and rounds of treatment, but in the end the cancer had spread to his lymph nodes and his liver. The cancer had become resistant to all available drugs and he'd run out of options.

"I've tried to never worry about my condition and just get on with life, but that was one of my low points," he says. "I was in hospital four times in five months."

That was when his doctor suggested taking part in a clinical trial to test a new treatment. "I was told that it was a drug for ladies with ovarian cancer, so I was a bit surprised that they were giving it to me," says Douglas.



We need to know exactly what changes are driving each man's cancer to get the best treatment for him.

Dr Ian Frame

The trial is led by researchers at The Institute of Cancer Research (ICR), who are testing a drug known as olaparib to see if it could work in certain men with prostate cancer.

Targeting men with missing 'table legs'

Ovarian cancer and prostate cancer might seem poles apart at first glance. But when you look beneath the surface, similarities start to appear. All cancers come from changes to DNA that cause cells to grow out of control.

"As we've learnt more about these genetic changes, it's clear that 'prostate cancer' is not a good enough description," says Dr Iain Frame, director of research at Prostate Cancer UK. "we need to know exactly what changes are driving each man's cancer to get the best treatment for him."

Olaparib is a type of drug known as a PARP inhibitor, which works by stopping one method that cells use to repair breakages in DNA. If a cancer cell is already struggling to repair DNA damage, then olaparib could be enough to kill it.

"It's a bit like a table with a leg missing," says Dr Joaquin Mateo from the ICR. "With just three legs, the table will stay standing – even if it's a bit unstable. If we take out another leg, the table collapses."

Dr Mateo is being funded by Prostate Cancer UK to find out which men might benefit from being given olaparib – which men already have one 'table leg' missing.



Dr Joaquin Mateo (left) and Douglas Baker.



This trial has really turned me around... I went on holiday to Spain last year, which I didn't think I'd be able to manage again but I did. I've been very, very lucky.

Douglas Baker

"They told me that not everyone is suitable for this drug," says Douglas. Before the trial he had a biopsy of his lymph nodes and had several blood tests. "I couldn't believe how many tests they were doing. They were taking lots of samples and putting them on ice."

The samples and test results from men like Douglas are helping Dr Mateo to find biomarkers, or chemicals in

the body, that doctors can test for to see if olaparib will work for them. In Douglas' case, the tests indicated he was suitable and the results of the drug have been clear.

"This trial has really turned me around, it really has," he says. "I went on holiday to Spain last year, which I didn't think I'd be able to manage again but I did. I've been very, very lucky – even if that seems like a funny word to use."

Getting precise to fulfil our treatment ambition

This 'precision medicine' approach – using a test to select the best treatment – has worked successfully in other cancers, too. The breast cancer drug, Herceptin, blocks the activity of a protein known as HER2, which is only present in one-in-five cases of breast cancer.

For those women who are 'HER2 positive', the drug works well and can even help to reduce the chances of the cancer coming back after surgery. But if Herceptin was given to a woman who was 'HER2 negative', then it wouldn't help her at all. So a clinical trial of Herceptin for all women with breast cancer would look like a failure.

This is why precision medicine is so promising, as it could offer a huge range of treatments that target specific cancers. And since one of Prostate Cancer UK's key priorities is to reach the point where each man can get the best treatment for his individual cancer, identifying precision medicines will play a big part in achieving this.

"In 2015, we set out a challenge to scientists, gathering a dozen of the best minds in this area, to design a

number of large-scale clinical trials that could make our vision a reality," says Dr Frame. "Unfortunately, they concluded that there hasn't yet been enough research to understand how potential treatments work and which men would benefit.

"So we launched a funding call, offering over £1 million for a research project to gather the evidence and understanding needed to get several treatments ready for major clinical trials."



Dr Joaquin Mateo is a researcher at the Institute of Cancer Research in Sutton, whose work is in part funded by your donations through the Movember Foundation.

What are you trying to do?

My lab is running a trial to find out if olaparib, an ovarian cancer drug, could help men with prostate cancer. I'm working to find out how we can identify, in advance, which men will benefit from the drug and to find the best treatment regime for them.

What have you done so far?

From a small trial, we've already found that olaparib could help about a third of men. These men have cancers with DNA repair problems, and that's what allows olaparib to work. We've just developed a blood test that can identify these cancers and also track if they develop resistance to olaparib.

Why are you doing this?

I originally trained as an oncologist, which I loved doing but I could see the potential that research has to help so many more people. I was awarded a clinical training fellowship by Prostate Cancer UK and the Medical Research Council, which allows me to bring my clinical expertise to the lab. This is a really exciting position to be in – splitting my time between seeing patients and finding new treatments for them in the lab.

What's next?

For olaparib, we will be testing it in a bigger trial, with more men, to get the evidence needed to show that it can be used everywhere. For me, I am very fortunate to be working with some of the world's experts in precision medicine and after my fellowship, I will continue to work in prostate cancer research.



This is a really exciting position to be in – splitting my time between seeing patients and finding new treatments for them in the lab.

Dr Joaquin Mateo

This project will contain a number of separate but linked studies designed to help us find new, targeted treatments for men with advanced prostate cancer who are still receiving hormone therapy. There traditionally hasn't been as much research into these men, as it's more difficult to find new treatments at this stage. However, it has the potential to help many more men and have greater impact.

Focusing on genetics and what drives the cancer

The treatments are only half of the equation: we also need to know which men are going to benefit. To do this, we need simple, reliable tests to understand what is driving the cancer.

In May, research funded by Prostate Cancer UK (see p5) developed a blood test to detect DNA released by the cancer, which could potentially identify men with advanced prostate cancer who will not respond to the standard treatments, abiraterone and enzalutamide. This test is now going to be confirmed in a trial, also funded by us. If it is successful, it could be used to select men's treatments and potentially become the first precision medicine approach for prostate cancer.

This new test shows that matching genetics to the treatment not only works for new drugs, but also makes the most of what we already have. This relies on a better understanding of which genes are important, precisely how existing treatments work in the body, and when new mutations arise.

Some tests, like the abiraterone blood test mentioned, focus on new genetic mutations that happen as the cancer evolves in response to treatment. However, in the future we might be able to find specific treatments for men with mutations that they have inherited from their parents. Prostate cancer is influenced by genetics, and if a man has a brother or father with prostate cancer then he has a two-and-a-half times greater risk of having the disease himself.

In some cases, families might carry mutations in the BRCA genes, which are most commonly associated with breast cancer but also raise the risk of prostate cancer. Our previous research has suggested that these men might benefit more from surgery than radiotherapy. While this isn't confirmed, it does highlight how a better understanding of what is driving the cancer can help doctors to treat it more effectively.

For Douglas, the benefits of more targeted treatment are already obvious. Scans show that the tumours in his lymph nodes and liver are shrinking in response to olaparib. However, he's aware that there's no way of knowing how long it will continue to work for him.

"Whatever happens with me, I just hope and pray that it helps someone else further down the line. That's my main aim," says Douglas.

Find out more about the game-changing research we're funding and help us do more with a donation at prostatecanceruk.org/research



Les Ferdinand

The former England and Premier League striker – known as ‘Sir Les’ by his adoring Queens Park Rangers fans – recently joined our epic Football to Amsterdam cycle ride and has been a big supporter of our work for many years. Now the director of football at QPR, he talks to us about how prostate cancer has affected his family and why he feels a personal responsibility to change people’s attitudes to men’s health.



When were you first, personally affected by prostate cancer?

I lost my grandfather to prostate cancer in 1988 and it’s also affected other members of my family, too.

My father was diagnosed with prostate cancer, but he had an operation and has now had the all clear. Some of my uncles have also had scares, so it is something that is in the family, which makes it an important issue to me.

But I’ll admit, prostate cancer wasn’t on my radar a decade ago – I knew nothing about it at all.

Why do you think so many men don’t know about the disease?

Someone once said about the dangers of prostate cancer that men should not die of ignorance – and those words are so true.

It’s traditionally always been a taboo subject, that process of men going to the doctors and talking about their health. Men always tended to stay away from it and didn’t want to go to the doctors.

Even today, if they’ve got anything wrong with their waterworks, some will think: ‘Oh it’ll be alright’. We’re good at saying that.

But this is a serious situation and it’s important that people become more aware. If men want to be macho, they shouldn’t walk away from problems – they should face them head on.

Why are you getting more involved with awareness campaigning now?

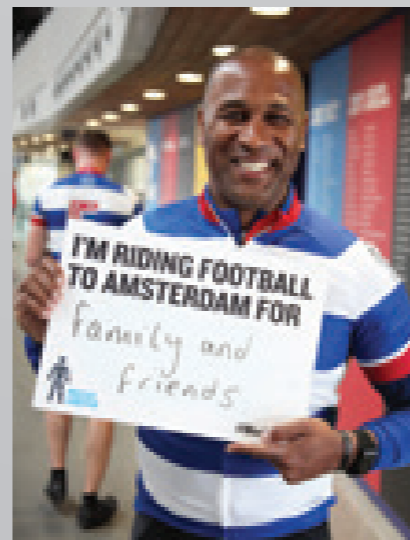
I’ve been in a privileged position as a footballer, coach and now director of football. But I’m also a son and a father, and want to be a role model outside the beautiful game.



If men want to be macho, they shouldn’t walk away from problems – they should face them head on.

It’s up to people like myself to change the philosophy around men’s health. I’ll be 50 in December, and need to set an example to my family and my peers. So I go and see my doctor every year without fail.

One in eight men in the UK will be affected by this disease in their lifetime, but as a black man my risk is even greater at one in four. And if there’s a history of the disease in the family – like mine – those odds are even shorter.



What reactions have you had to our ‘Man of Men’ pin-badge when you wear it?

I have had numerous people, including many Queens Park Rangers fans, come up to me and ask: “Les, what is that badge for?” I’ve then been able to talk to them about prostate cancer.

It’s about raising that awareness and making sure everyone knows about it. I’m proud to wear this badge.

Have you seen people’s understanding of prostate cancer improve over the years?

We are making progress. Thanks to the work of Prostate Cancer UK, particularly their groundbreaking link up with the EFL, a disease that people never spoke about a decade ago is now front and centre.



Les at the start of Football to Amsterdam; below, his reasons for riding.

How involved has your own club been with our work?

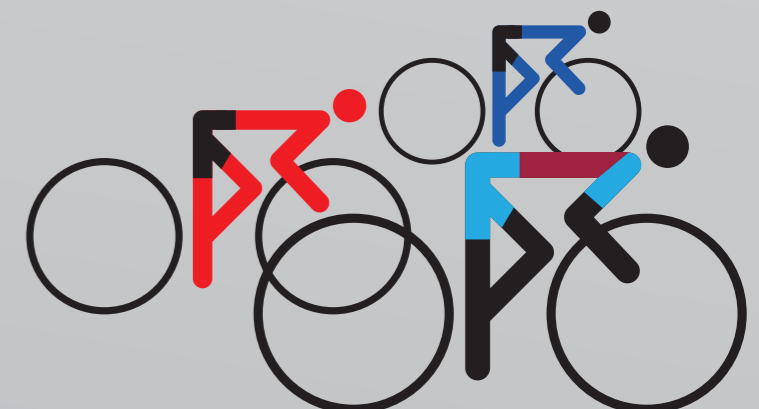
Queens Park Rangers has always been proactive supporting Prostate Cancer UK, with regular matchday collections and awareness days at Loftus Road.

I’m proud to see our squad – and each and every player in the EFL – displaying the charity’s ‘Man of Men’ logo on the back of their shirts. And I’m proud to see managers and club officials up and down the land sporting the iconic Prostate Cancer UK pin-badges.

That man represents you, me and everyone in the fight against prostate cancer.

You joined in our 145-mile Football to Amsterdam cycle ride in June – thank you! Will you be riding again with us next year?

I’m still in recovery from this year! Even if I don’t do it next time, I’ve got a few ideas of some well-known football faces I can ask and see if they can do it in my place.



For more information about your risk of prostate cancer, visit prostatecanceruk.org/risk

THE MANUAL

Your questions answered about **getting the most from your appointments**



Men often tell us that they come out of medical appointments either not sure what they've been told or with lots of unanswered questions. Whether you've just been diagnosed with prostate cancer, are going through treatment or are seeing your health professional as part of your follow-up, your appointments are your time to get the support and information you need. Our Specialist Nurse, Laura, talks about what you can do to make the most of your appointments.

Q There's always so much information. How can I take everything in?

A Whatever the reason for your appointment, it can be really difficult to take everything in. If you're being told you have cancer, you may be in shock and it can be hard to concentrate on anything else. Or if you're discussing treatment options, there's so much to take in about each one that you lose track of what's being said.

This is completely normal. But there are things you can do that will help you know what to expect and take decisions if you need to.

Our top tips are to take someone with you to your appointments to be a second set of ears. They'll hear or remember things that you don't, and can ask questions that maybe you hadn't thought of.

You can also ask to record your appointment, on your phone for example, to listen to when you get home.

And if you're not given any written information to take away with you, ask for some.

Most importantly, never be worried about asking questions, especially if you don't understand something that's being said – like any instructions of what to do in between appointments. It's always better to ask, than to go home and worry.

Q What can I do if my mind goes blank when I'm asked if I have any questions?

A It can be hard to think of, or remember, questions on the spot when you're asked. Take a notebook, if you can, to write down questions as they come to you and make notes to refer to – such as any medical terminology you don't understand. And ask for a bit of time to think if you need it.

If you know you've got an appointment coming up, keep a note of any questions or concerns you've had since your last appointment and bring them along. You can also prepare for your appointment by finding out more information on our website or discussing with your loved ones what things you want to know more about.

Getting answers to your questions can help you feel reassured, know what to expect, make decisions, and know where to go for more support with things like the side effects of treatment. It's your health professional's responsibility to ask, too. But they don't always know what you'll be worried about or what's important to you.

Q What about any questions I have between appointments?

A You should be given the name of someone to contact in between appointments if you need to. If you're not, ask for one. They might be referred to as your key worker. And if you've got any general questions in the meantime, our Specialist Nurses are here to help on **0800 074 8383**, via email and on live chat via our website.

Q How do I bring up things that I find embarrassing to talk about?

A It's not always easy to bring up personal things such as some side effects of prostate cancer treatment, like problems getting erections, incontinence or feeling low or depressed. But your doctor or nurse should be very used to discussing these things and will want to help you get the right treatment and support.

Some practical tips are to plan ahead and decide exactly what you want to talk about. You could bring some of our publications with you to help you start the conversation, or let your doctor or nurse know in advance what you want to talk about. Think about whether you want someone with you at the appointment. You may want someone there for

support when talking about a difficult topic, or you may feel more comfortable talking to your doctor or nurse by yourself.

Be honest about how you're feeling or what you're experiencing, and don't think your concerns aren't important. It's common to downplay the effect that cancer or its treatment is having on you. But by letting your doctor or nurse know exactly what's going on, they'll be able to direct you to the right services or treatments for you.

This might be particularly important if you are no longer having regular hospital appointments. Your GP may not be as familiar with some of the issues that having prostate cancer may cause, so it's even more important to let them know if you're worried about anything.

Here's some of things you've told us about dealing with appointments:



Before and during treatment, I had a lot of support and contact with doctors and nurses. Afterwards, I felt like I didn't know what to expect or where I could go for help. It made me feel that I had to deal with everything on my own.



Ask your doctor or nurse anything, including things that may seem small. This can save confusion later.



The side effects can be managed and there is a lot of expert help out there to get you through it. You need to ask your doctor about what services are available.



When I had side effects, it was good to be able to contact the urology nurses by phone, who were always very helpful.



Ask questions all the time. Write everything down so you're able to digest it at home.



Before my appointments, I find it useful to write down any questions to ask the doctor.

Find out more ways to get help and support with your diagnosis or someone's you know at prostatecanceruk.org/get-support



Find out more about dealing with prostate cancer at prostatecanceruk.org/living

THOUSANDS JOIN JEFF STELLING TO MARCH FOR MEN ACROSS THE UK



Jeff Stelling completes 15 marathons in 15 days

After 15 days, 400 miles and 40 football clubs, Jeff Stelling crossed the finish-line at St James' Park in Newcastle to complete his epic March for Men. More than 640 men and women affected by prostate cancer walked with him over the course of his journey from the other St James Park in Exeter on 2 June, together raising

more than £300k so far. And there were numerous stars from the world of sport to lift Jeff's spirits when the going got tough, too: from Colin Murray and Paul Collingwood to Chris Kamara and Dewi Morris. Even the England Supporters Band turned up on the final day to trumpet him to the finish. Unbelievable effort, Jeff!



Thousands take part in events in London, Leeds and Glasgow

As soon as Jeff had put his feet up, it was the turn of the Great British public to get walking for Prostate Cancer UK, with March for Men events in London, Leeds and Glasgow over the Father's Day weekend. More than 2,000 people turned out in balmy conditions to show their support and commemorate loved ones who've died from the disease. Dancer Wayne Sleep and Emmerdale actor Gemma Oaten were among the buzzing crowds, walking around city parks and raising more than £200k to help us beat prostate cancer.



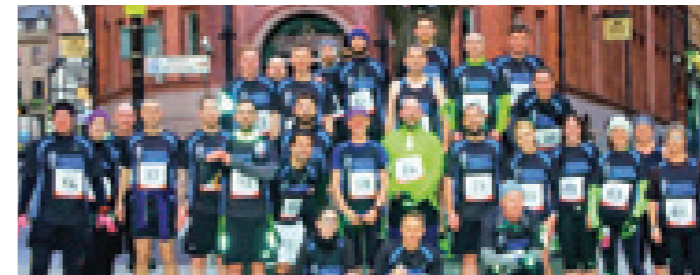
Feeling inspired? You can do your own March for Men and raise vital funds for us, wherever you are and however far you walk! Check out our ideas and get all the support you need at marchformen.org

In the SPOTLIGHT

Des Oldham from Nottingham

When Nottingham Forest fan Des Oldham sent a tweet suggesting a 20-mile fundraising run for Prostate Cancer UK between the City Ground and his Derby County rivals' iPro Stadium, he never thought it would result in £8,000 and the creation of a 100-strong running club.

"We had two aims when we set out," says Des. "We wanted to highlight the importance of such a worthwhile charity, and show unity from the



passionate supporters of both teams. I'm really proud of what we've managed to achieve."

And so he should be. A team of 30 people turned out to run from Nottingham to Derby on a cold, rainy Saturday night, raising the four-figure sum. And now they've grown to a

hundred members that Des leads on a run every Wednesday night.

"I want this running group to be for everyone, regardless of how far they can run or who they support," says Des. "I just want it to be fun and people to get something out of it."



My dad was a really caring father, always looking out for his mother, kids and granddaughters. He didn't smoke, stopped drinking many years ago and tried to live a healthy life. He also loved football, and some of my best memories were watching Ghana and England play with him.

In 2013, dad was told he had between two and five years to live. It broke me. He looked and felt fit until the later stages, and it almost meant we could push it to the back of our minds. He organised a football tournament to raise money for prostate cancer, and often just kept himself busy reading about the disease and passing on his knowledge.

Then, three years after he was diagnosed, he became worse and the

reality sank in again. He had just weeks to live but always remained positive, just happy seeing his kids doing well. He taught us the importance of life being too short, and the importance of getting the balance right between planning for the long and short term. I guess he worked so hard for the perfect retirement, which eventually was not to be.

My dad was big on education and I'm gutted he never made it to my Masters graduation. But even in his last moments, he expressed the importance of raising awareness of prostate cancer. I hope by walking for Prostate Cancer UK in Jeff Stelling's March for Men, I've made my dad proud.



Read Nana's full story at prostatecanceruk.org/nana



THANK YOU

£12,000

To the United Kingdom Air Cargo Club, who made us their charity partner and held various events – like a Christmas Lunch and Gala Dinner – over the past year to fund this huge donation.



£800

To 10-year-old Christie Morrow for cycling 50km to raise this terrific amount.



£6,610

To John Brown in the Isle of Man for celebrating his retirement by raising this fantastic sum.

£353

To 11-year-old Gabriella Ferguson for running a marathon over Lent and raising this brilliant total for us.



£4,753

To Julie Fenelon and friends for raising this incredible figure from a Grand National party in April.



GET INVOLVED

Five ways to get your mates together and raise money for us as Men United

1 Thames Path Challenge 9-10 September

Will you take on this epic endurance walk from Putney over 25, 50, 72 or 100km? You can even do the 100km route in 24 hours, non-stop, if you're feeling really brave. Following the Thames Path National Trail all the way to Henley, it's a fully marshalled and beautiful walk, with free refreshments throughout to help make it a fundraising walk to remember. Full details at prostatecanceruk.org/thamespath



2 Men United Arms August-March

Pubs up and down the UK raised more than £30k for us last year as part of our Men United Arms competition. But we want to do even better this year – and we need your help to do it. Will you speak to your local pub about how they can become our favourite local of 2018? There are great prizes and incentives for pubs raising money to help us beat prostate cancer. Find out more by emailing us at menunitedarms@prostatecanceruk.org



3



Prostate Cancer UK Golf Championship Before 1 September

Want to play on one of the best courses in the UK and be crowned area champion in our national golf competition? Just hold a golf day before 1 September to raise funds for Prostate Cancer UK and win two places

at one of our three area finals at Sandy Lodge (18 September), Hags Castle (20 September) and Lymm (29 September).

Find out more at prostatecanceruk.org/golf

4 Great Scottish Run 1 October



Join Scotland's biggest weekend of running in Glasgow and take your pick from the 10km or half marathon events. While you're soaking up the atmosphere from thousands of supporters lining the streets, bands playing music and our charity cheering points, you'll be helping to fight the most common cancer in men. We've got professional training plans and support from our team to help you on your way. Find out more at prostatecanceruk.org/gsr

5 Donate Your Day All year round

Whether you're planning a birthday, wedding or retirement party, donating your day is a great way of making it even more special. Let us know what you've got planned and we'll give you all the support and advice you need, including posters and collection boxes

to help raise as many donations as possible. prostatecanceruk.org/dydz

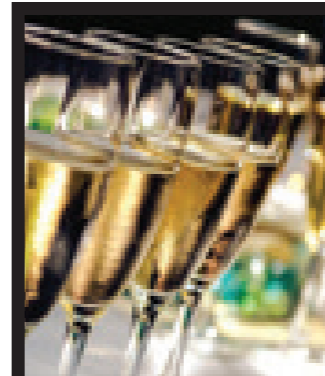


EVENTS

CALENDAR AUGUST-JANUARY 2018

AUGUST

26-27 South Coast Challenge
Take in some of England's finest scenery as you run, jog or walk up Beachy Head, through Seven Sisters Park and along the South Downs Way on this amazing 100km journey through East Sussex. You'll be fully supported and joining more than 2,000 challengers for an unforgettable August bank holiday weekend.



14 Gala Dinner
You're invited to the prestigious Prostate Cancer UK Gala Dinner for a fantastic night of music, entertainment and comedy, where you'll hear about our latest ground-breaking research and the inspiring stories behind them. If you are interested in attending, please contact us on our website at prostatecanceruk.org/galadinner

SEPTEMBER

10 Simplyhealth Great North Run
Firmly established as the world's greatest half marathon, it'll be even greater with you in it, running for men with prostate cancer. The Newcastle route takes in the iconic Tyne Bridge, goes through Gateshead and finishes in the coastal town of South Shields – with live music, refreshments and rowdy support to keep you going!



17 Pedal4Cancer
Ride from London to Cambridge and help us raise over £200k. There's full support along the way, including medical and mechanical back up, with regular refuelling break-stops along the route – so it's suitable for the whole family.



November

Get ready, Mo Bros and Mo Sistas, for another month-long fundraising bonanza for men's health! As well as the face-fuzz heroics, there'll be fitness challenges and other exciting initiatives to give you more ways than ever to get the donations flying in. Register mid-September at movember.com



24 Berlin Marathon
Starting and finishing at the Brandenburg Gate, this international marathon attracts over 40,000 athletes from all over the world – and Men United will be there to add to the fantastic carnival atmosphere. We'd love you and your friends to join us.

24 Loch Ness Marathon
Run alongside the famous Scottish loch, from Fort Augustus to Inverness, in one of the UK's most scenic courses. Choose from marathon distance, 10km or the 5km Fun Run and get your whole family involved in a brilliant day out.



24 Scottish Half Marathon and 10km
These flat and fast races along the magnificent East Lothian Golf Coast, outside Edinburgh, are perfect for first-timers and new personal bests.

OCTOBER

8 Royal Parks Foundation Half Marathon
Enjoy London's world-famous landmarks on closed roads as you run past Buckingham Palace, the London Eye, Houses of Parliament and the Royal Albert Hall, through four of the capital's eight Royal Parks. A must-do event for any runner, whatever your level.

Check out full details and sign up to all these events – plus many more – at prostatecanceruk.org/events



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.

One-to-one telephone 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.
community.prostatecanceruk.org

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.

Information on prostate cancer 0800 074 8383

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



I was already aware of what I can do to overcome erection problems, but reading the guide encouraged me to be more organised

Self-help guide user (see opposite)

Regional services

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

Prostate cancer support groups

Meet and talk to other people affected by prostate cancer who understand what you're going through. There are more than 120 independent groups across the UK.

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.



Other useful organisations

Bladder and Bowel Foundation
www.bladderandbowel.foundation.org
0845 345 0165

Information and support for all types of bladder and bowel problems.

British Association for Counselling & Psychotherapy
www.itsgoodtotalk.org.uk
01455 883 300

Provides information about counselling and details of therapists in your area.

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.

Cancer Research UK
cancerresearchuk.org
0808 800 4040

Provides information about living with cancer.
Complementary and Natural Healthcare Council
www.cnhc.org.uk
020 7653 1971

Details of complementary therapy practitioners who meet national standards of competence and practice.
Health with Pride
www.healthwithpride.nhs.uk

Information on cancer issues for gay and bisexual patients.
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 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 health decisions, including an A-Z of treatments and conditions, and information on NHS health services in your local area.

Penny Brohn UK
www.pennybrohn.org.uk
0303 3000 118

Offers support using complementary therapies and self-help techniques. Working 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.

Tackle Prostate Cancer
www.tackleprostate.org
020 3195 3830

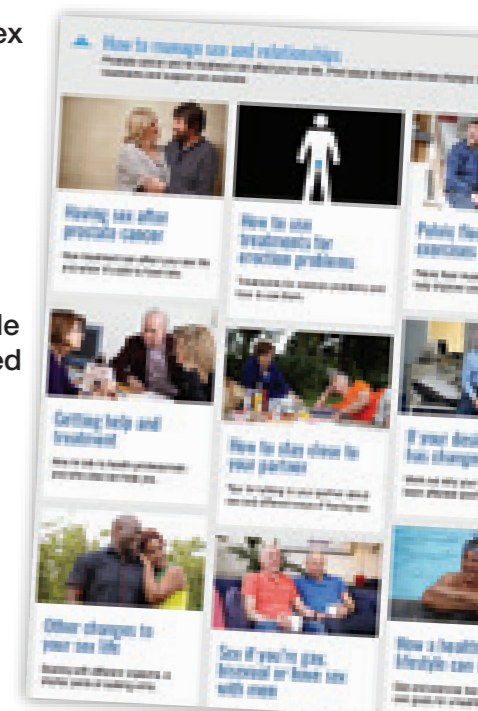
The National Federation of Prostate Cancer Support Groups, working closely with us to provide local support to patients and families.

Our new interactive online guides are tailored to your needs

We've launched a series of new online self-help guides, tackling the most common side effects of prostate disease, where you can read tips from those who've been through similar experiences, watch films of real life stories and find out new ways to improve your daily life.

The five 'How to manage' guides are interactive – we'll ask you to think about your own situation and select the information you want to know about – and cover:

- How to manage sex and relationships
- How to manage fatigue
- How to manage urinary problems
- How to manage symptoms and side effects of advanced prostate cancer
- How to manage chronic prostatitis



We know that many of these side effects can be embarrassing and difficult to talk about with your GP and family, and we also know that care provision to help with them can vary across the UK. So we hope these self-management guides can help you cope better and feel more in control of your health.

All the tips – like setting goals to be more physically active, finding out where the toilets are before you leave home, learning what has helped other men deal with hot flushes, and knowing how to talk to health professionals – come from knowledgeable professionals and real men's experiences.

And they're already helping people in their daily lives. One man told us: "The button approach gave me a feeling of me being in control of the information I wanted to look at, and it gave me the information in bite-size chunks. I really liked the helpful hints to help solve the various problems."

The guides were generously supported by funds from ICAP, and you can try them for yourself now at prostatecanceruk.org/guides

CLUB TO CLUB

MARCH FOR MEN

What football club do you support?

Do you follow a cricket or rugby club, or play for a Sunday team? If you have an answer to any of those questions, a Club to Club march could be for you! Pick your favourite team and set a date to walk from or to their ground – Wembley to West Ham, for instance. Your support will help bring us one step closer to beating prostate cancer.

prostatecanceruk.org/clubtoclub



**PROSTATE
CANCER UK**