

Prostate cancer

Insights

Issue 12 | Summer/Autumn 2018



Prostate cancer and us

**RAY AND
STEPHEN
CLEMENCE**

**The route
to prostate
cancer
screening**

See our vision for a screening programme and meet one of the researchers working towards it

Behind the headlines

Is it true that a one-off PSA test doesn't save lives?



**PROSTATE
CANCER UK**



4 Prostate cancer news
Headlines around the PSA test caused confusion earlier this year – we straighten things out

6 Our time is now: Chief Executive Angela Culhane
After a mega year of media coverage for prostate cancer, Angela explains why we are at a decisive moment in our bid to stop the disease killing men and why we need you

9 Marking out the route to a screening programme
Researcher Hayley Whitaker and supporter Kevin Webber have a shared goal: to ensure Kevin's sons don't face prostate cancer as a killer. Could Hayley's research into biomarkers be the answer?

12 Prostate Cancer UK update
We've been busy! Here's a taster of what we've been up to together

13 Prostate cancer and us: Ray and Stephen Clemence
Football legend Ray Clemence graced our first cover back in 2013. We catch up with Ray and his son and talk about how they deal with the disease as a family



16 The Manual
Staying active when you have prostate cancer can be challenging. We look at ways to help you get moving this summer

18 Marching for men 2018
You came, you marched, you conquered. And if you didn't, there's still time

19 Meet the two boys running 10km a week for a year
And our own Marlene Graham on her Top Dad

20 Get involved
From buying a pint to climbing a mountain, we have something for everyone

22 Our support and services
We can help you deal with prostate cancer



Editor's note

In an email opposite, one of our readers poses a question we're often asked: "How can we make sure men go to their doctor so we can catch prostate cancer early?"

It is a critical question and one of the most important things we're working on. The obvious answer is a national screening programme, but currently there is no single test reliable enough to give to all men over a certain age. (We touch on the reasons for this on page 4.) So we're working hard to improve and develop tests and tools to solve this. Chief Executive Angela Culhane talks about our vision for a screening programme on page 6 and reflects on a year of unprecedented media attention around prostate cancer, thanks to your support and years of hard work.

As Angela says, our efforts together have given us a golden opportunity to push through our plans to stop prostate cancer killing men. The nation is listening and we need to keep working together to take this movement for men to the next level.

Catherine

Editorial team

Dr Ian le Guillou
Dominic Bates
Nicholas Wright
Sarita Lowton
Sonia Barbate
Catherine Steele (Editor)

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

We read so much in the media about this or that 'breakthrough' in the treatment of this disease but is the long-term prognosis any better today than say five years ago? What treatments are giving optimism for the future and what representations are made to the government for funding research into the third biggest cancer killer in the UK? Is research co-ordinated worldwide or does Prostate Cancer UK operate in isolation?

D Smitherman

Dear Mr Smitherman,

Yes, the outlook for men diagnosed with prostate cancer is better – once diagnosed, a man's chances of surviving longer are higher than ever before. But we need to invest a lot more if we're to reach our goal of halving deaths from prostate cancer by 2026.



We don't receive any government money for the research we fund – we do that with help from supporters like you. But our work can leverage larger sums of government funding.



Dear Insights

I find your magazine informative and useful. To publicise the cause further, can you please tell me where I can obtain the prostate cancer logo badges that sportspeople wear on their lapels?
Brian

Our Research Innovation Awards are a good example of this. We select groundbreaking research projects to invest in, then once we've shown the potential, government funding can support the large-scale multi-million pound trials that will change clinical practice.

Our work on multiparametric MRI scanning (mpMRI), the biggest leap forward in diagnosis in recent years, developed in this way. It's now being rolled out across the country and is already making a difference to men's lives.

Improving diagnosis is a really big focus for us in our bid to stop prostate cancer being a killer. Another of our projects in this area is our work to develop a tool that GPs can use to assess a man's risk of prostate cancer and this is a great example of how we're coordinating research globally. We've pulled in experts from across the world to help us develop it.

We're really pleased to see your interest in the bigger picture. To get an even clearer idea of this, read our strategy document, 10 years to tame prostate cancer at strategy.prostatecanceruk.org It sets out the issues, what we need to do to stop prostate cancer taking lives and how we plan to do that. And you can keep an eye on our progress by signing up to our monthly Insights email: prostatecanceruk.org/insights

Dear Brian,

Thanks for your message. We get asked this question a lot! Our 'Man of Men' pin badge is a very popular guy. You can now buy pin badges from our online shop: prostatecanceruk.org/shop



Dear Insights

Just wondering, how do we get men over that certain age to go to their doctor or nurse for a prostate check? Without this check we are not going to save lives.

Maybe it's the funding from the NHS for this in England, but I live in Scotland and we need this to get sorted out now.

F Watson

Dear Mr Watson,

This is a big priority for us. The best way would be to have a national screening programme, however we don't currently have one single test that is reliable enough to achieve that. We're working hard to get the tools and evidence needed for a UK-wide screening programme and we hope to be in a position to call for this in the next five years. (See pages 6-8 to find out more.)



GET IN TOUCH!

You can contact us via social media or email on the addresses below, or write to us at:

Insights magazine
Prostate Cancer UK
Fourth Floor,
The Counting House
53 Tooley Street
London SE1 2QN



Like us on Facebook:
Prostate Cancer UK



Follow us on Twitter:
@ProstateUK



Email the Insights team:
editor@prostatecanceruk.org

PROSTATE CANCER NEWS

BEHIND THE HEADLINES: Is it true that giving men a one-off PSA test does not save lives?



Earlier this year, the PSA test was in the media spotlight again after results from a large prostate cancer screening study that began 10 years ago – the CAP trial were released.

Some of the headlines challenged the use of the PSA test in detecting

prostate cancer, so we first want to reassure you that these results do not change our stance on PSA testing. The PSA test is still the best early indicator we have of a problem in the prostate in men without symptoms. It is still very important to speak to your GP if you are worried about prostate cancer, especially if you're at higher risk (men aged 50 or over, black men and men with a family history of the disease).

The CAP trial showed that inviting men aged 50 to 69 for a one-off PSA test when they had no prostate cancer symptoms did not help to save lives over the next 10 years. While this might

sound surprising, these results are what we would expect to see. This is partly because a follow-up period longer than 10 years is needed and partly because of the unreliability of the PSA test. You can read more about this in the box below.

What the CAP trial results really underscore is the fact that the PSA test on its own isn't reliable enough to be the basis for a national screening programme.

Since the trial began 10 years ago, multiparametric MRI scans (mpMRI) have also been introduced to help diagnose prostate cancer. When used before a biopsy, mpMRI

could provide men with a more accurate and less invasive diagnosis and help to identify fast-growing cancers. We're working across the UK to make sure mpMRI before biopsy is available to men with suspected prostate cancer by 2020 at the latest.

One of our biggest priorities is to create a screening programme for prostate cancer, which you can read more about on pages 6-8. To achieve this, we're focusing not only on finding better tests but also on using the PSA test to the best of its ability alongside other methods, like mpMRI.

PSA testing – what you need to know:

The PSA test is a blood test that measures the levels of a protein called prostate specific antigen (PSA). A raised level can indicate a problem, but not necessarily cancer.

Pros:

- A PSA test can help pick up prostate cancer before you have any symptoms, and could pick up a fast-growing cancer early, when treatment could stop it spreading.
- Regular PSA tests could be helpful for men at higher risk of prostate cancer, to spot any changes in PSA level. (Black men, men aged 50 or over and men with a family history of prostate cancer all have a higher risk of prostate cancer.)

Cons:

- The PSA test can miss prostate cancer. 1 in 7 men with a normal PSA level may have prostate cancer and 1 in 50 men with a normal level may have a fast-growing cancer.
- Many men with a raised PSA level don't have prostate cancer but may need a biopsy, which has risks and side effects. Or you might have a slow-growing cancer that would never shorten your life, but decide to have treatment you don't need, potentially causing side effects such as urinary, bowel and erection problems.



Read more at prostatecanceruk.org/psa

New type of ultrasound shows promise at spotting aggressive prostate cancer in study we funded

New research backed by us and the Movember Foundation has shown that a type of ultrasound scan, called shear wave elastography, can detect the stiffness of the prostate and may be able to spot aggressive prostate cancer. Think of it as a virtual doctor's finger feeling for a lump.

The study, which took place in Dundee, involved 200 men who were about to undergo surgery to have their prostates removed.

One of the biggest challenges in diagnosing prostate cancer until recently was the difficulty

in accurately detecting the disease before having a biopsy. The roll out of multiparametric MRI scans (mpMRI) over the last year has helped doctors to ensure fewer men have biopsies they don't need and can guide the needles to areas that look suspicious. This has been a major advance and mpMRI technology is improving all the time, but currently they do not always give a definitive answer.

Shear wave elastography could be a promising and cost-effective solution. While still at an early stage, this new technology shows

potential for being able to improve the detection of the disease as well as guiding biopsies. The next steps will be to test this technology in more men from different areas of the country.

This discovery would not have been possible without your support so thank you!

Ghulam Nabi, Professor of Surgical Uro-oncology at the University of Dundee and Lead for Prostate Cancer Surgery with NHS Tayside, said: "The new method we have developed shows we can achieve much greater levels of diagnosis,

including identifying the difference between cancerous and benign tissue without the need for invasive surgery.

"It is like someone has turned the lights on in a darkened room. We can now see with much greater accuracy what tissue is cancerous, where it is and what level of treatment it needs."



FROM THE LAB

Could exercise prevent prostate cancer spreading to the bones?

A new research project, grant-funded by us, is working to understand the effect of exercise on preventing prostate cancer spreading to the bone, one of the common problems with treating advanced prostate cancer.

We awarded the grant to researchers at the University of Sheffield as part of our £2.7 million Research Innovation Awards scheme.

What's the big idea?

We know that exercise promotes bone formation, while cancer spread to the bone can cause damage and weaken bones. Dr Ning Wang, who is leading the project, hopes that promoting new bone cell growth can, in turn, prevent cancer cells spreading into the bone.

How will they test this?

Dr Wang's team will test this theory by injecting prostate cancer cells containing a fluorescent dye into mice. They will then examine cancer growth in the bones of

the mice at different stages. They will be looking to try to work out the best pattern and timing for exercise to prevent tumour spread.

If the researchers see an effect, they will compare different forms of exercise, to try to establish a clear link between exercise and prevention of prostate cancer spread that could go on to be tested in men with the disease.

Dr Wang said: "There's no denying that exercise is good for us but it could prove to be especially beneficial for the thousands of men diagnosed with prostate cancer every year."

Our Research Innovation Awards scheme encourages researchers to develop ambitious proposals which challenge the status quo. Read about other projects we're funding at prostatecanceruk.org/research Specialist Nurse Meg answers your questions about exercising with prostate cancer on pages 16-17.



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

Our time is now



This year, we've grabbed the attention of the media, the public and the government. We're gathering the tools for a screening programme – and we have a golden opportunity to push through our plans to stop prostate cancer killing men. Chief Executive, Angela Culhane explains why.

Prostate cancer research has been underfunded for far too long. In the UK, one man dies from the disease every 45 minutes – and that's not simply because men don't know when they're at risk.

Tests to diagnose the disease early are not accurate enough and the treatments currently available aren't always effective for each man's cancer.

Earlier this year, we shone a spotlight on the shocking statistic that deaths from prostate cancer now outnumber those from breast cancer, making it the third biggest cancer killer in the UK for the first time.

The story dominated the news across the media and, thanks to the public response, has kept prostate cancer on the agenda.

Shortly after, TV personalities Stephen Fry and Bill Turnbull spoke about being diagnosed with aggressive prostate cancer, helping to raise the profile of the disease even further.

The work we have done together has made prostate cancer a problem that society can no longer ignore. But, as the statistics show, we are at a critical point in our mission to halve the number of men dying from prostate cancer. We have to turn these numbers around urgently.

Long-term investment in research can turn the tide

Prostate Cancer UK was formed as a charity not only to support the hundreds-of-thousands of men living with the disease, but also to tackle the unjust lack of research into stopping prostate cancer being a killer. In 1998, the government spent just £47,000 on prostate cancer research. Back then, relatively little was known about the disease, but now understanding of it is approaching the point where we can begin to see real change in how we diagnose and treat men.

With the heavy focus on prostate cancer in the media this year, Theresa May announced an additional £75 million (spread over five years) towards recruiting more men into prostate cancer clinical trials. This at last shows recognition of what a huge issue prostate cancer is and the focus needed to stop it being a killer. It's further testament to what we have achieved together, but there is still a long way to go.

The difference you can make through serious, long-term investment in research is clear when you look at the impact it has had in other diseases.



Prostate cancer has caught the public's attention in a way that it never has before. We are at a critical point in our mission.

WE NEED BETTER SCREENING – AND NEW DRUGS

By the late 1990s, there was already a screening programme for breast cancer, as well as genetic tests and precision medicine – all things that we are still working towards.

Since that time, there has been only half as much spent on research into prostate cancer compared to breast cancer with the shortfall totalling hundreds of millions. The effect of that has been that the number of men dying from prostate cancer continues to rise.

If we want to reverse that trend for men, we need to invest heavily in research. One of the biggest and most important aspects of our research strategy that we need to fund is our work towards a screening programme.

Our plan for screening in the next five years

We know that getting diagnosed early gives men the best chance possible, but the current tests are not reliable enough to be offered to all men regardless of their risk or potential symptoms. Too many men would have unnecessary biopsies and treatments, while lethal cancers continued to be missed. The harms would outweigh the benefits. But with better tests, we could have a system where all men over a certain age would be invited for screening on a regular basis, similar to the way it works for breast and bowel cancer.

In the graphic on the next page, we set out what this could look like. We know that there won't be a single perfect test. Instead we expect it to be a series of tests that can help to filter men out based on establishing their risk of having significant prostate cancer, so that only those who really need a biopsy have one.

Until recently, the standard approach was to have a biopsy after a suspicious PSA test result. Now, thanks to our work, many men have access to multiparametric MRI scans (mpMRI) before biopsy. This has already been a major step forward but isn't enough on its own.

We need new tests and improvements at each stage of diagnosis, including a more specific test that could follow the PSA test to rule out some false positives (men who have a raised PSA but don't have cancer) before an mpMRI scan. This will most likely be an advanced type of blood test that looks for several markers of cancer, including proteins and genes that

are linked to a high-risk of cancer. It is difficult to find reliable markers that will work for everyone, which is why we're investing heavily in this area – including Dr Hayley Whitaker's research which you can read more about on pages 9–11.

There are a few promising tests on the horizon. One of the best established is the STHLM3 blood test – this was tested in Stockholm in 2015 in almost 60,000 men and showed that it could reduce biopsies by 27 per cent as well as being better at detecting potentially dangerous prostate cancers than PSA alone. We are now working towards validating this test to see how well it could work within the NHS and with a more ethnically diverse population.

We can make the PSA test work harder

We also want to improve our understanding of what a PSA result means for an individual man. We are currently funding research into a risk assessment tool, which will be able to take into account various different factors that influence a man's risk of prostate cancer. This will help GPs to decide the best course of action for a man with a suspicious result.

Building on the progress that we've made so far, and other research evidence we want to collect over coming years, our hope is to be able to call for a UK-wide screening programme within five years. By then, we hope to be able to approach the National Screening Committee to present the evidence from our research and get a screening programme approved.

That is the scale of our ambition and what we think is needed to halve the expected number of men dying from prostate cancer. But if we're to stay on track to deliver that, we need to raise significant sums.

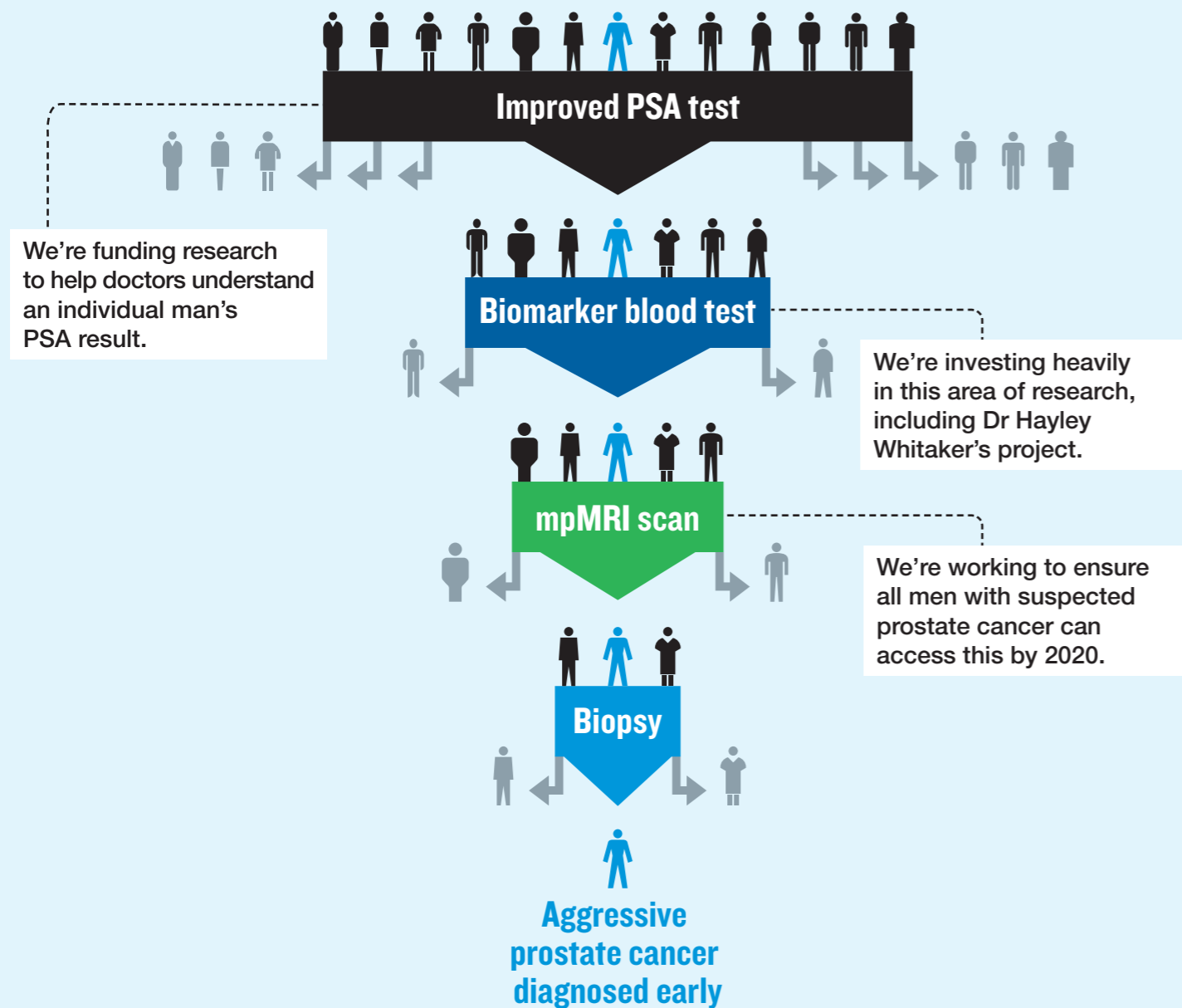
Prostate cancer has caught the public's attention in a way that it never has before. The UK is listening, but to take this movement for men to the next level, to make the progress that can stop prostate cancer killing men, we need their support and yours. To donate visit prostatecanceruk.org/ins-donate

PROSTATE CANCER NOW THE THIRD DEADLIEST FORM OF DISEASE IN UK

Our vision for a screening programme

A series of tests could filter out men at each stage, reducing unnecessary biopsies

To make our vision a reality, we need improvements at each stage of diagnosis and we're working on this. With better tests, we could have a system where all men over a certain age would be invited for prostate cancer screening on a regular basis, as we currently have for breast and bowel cancer. The graphic below shows what we think this could look like. We know there won't be a single perfect test. Instead we expect it to be a series of tests, getting progressively more comprehensive. To find out more about how prostate cancer is currently diagnosed, visit prostatecanceruk.org/prostate-tests



KEY

-  **No prostate cancer detected**
-  **Man with prostate cancer**
-  **Man who needs further tests**

“Kevin’s letter reminds us why we need to carry on until we get it right”

In a laboratory in London, nestled between the test tube racks and centrifuges, there's a framed letter hanging on the wall. The lab is Dr Hayley Whitaker's.

Hayley has been in prostate cancer research for over 20 years, since we funded her PhD project. Throughout her career, she has worked to improve diagnosis by looking for biomarkers – chemical markers in the body that could be a sign of cancer.

One of the ways Hayley keeps up her motivation to find a breakthrough is by staying connected to the men she's working to help. She does this by sitting in when doctors or consultants discuss treatment options with men and by meeting regularly with a prostate cancer support group. That is why the letter on her wall means so much. “I've said to the team: on days when your experiments aren't working, we'll read that and remember why we need to carry on until we get it right,” says Hayley.

The letter is from Kevin Webber, a dedicated Prostate Cancer UK supporter, who has advanced prostate cancer.

Kevin, a father of three, was diagnosed four years ago, at the age of 49. He went to visit the doctor as soon as he noticed symptoms, but it was already too late – the cancer had spread and he was told he might only have two years left.



Your research will ensure that my sons never have to face prostate cancer as a killer.

Fortunately, he's outlived that original prognosis, saying: “I'm on abiraterone now and, with a fair wind, I hope to still have a couple of years left.” He has dedicated himself to raising money for Prostate Cancer UK, challenging himself to get up and carry on again and again by taking on ever more gruelling endurance races. He started by running a marathon while having



chemotherapy shortly after his diagnosis and has recently completed back-to-back ultra-marathon races in the Arctic and the Sahara.

In his letter to Hayley he writes: “I am thankfully still here and know a lot more about prostate cancer than I ever wanted to. That knowledge of the disease and the way it manifests itself with men and destroys families has given me an insight into how important research is to find a better test so a screening process can happen in the future.

“I was told about how tirelessly you have worked to find that holy grail of tests for so many years, how you have constantly gone above and beyond what most people do.

“On a personal level, your research, with the support of your colleagues, will hopefully ensure that my two sons, brother and nephew will never have to face prostate cancer as a killer. They all have a higher risk of prostate cancer because of me and my father (who also had prostate cancer). That screening process will probably save one of their lives at some stage in the future.

“Thank you from the bottom of my heart. Please never give up doing what you are doing, never let any setbacks stop you because even though you won’t see it, I and millions of others are behind you, willing you to get up and carry on every day.”

Like many men with advanced prostate cancer, Kevin is very familiar with getting up and carrying on in the face of setbacks. He tests his ability to do this to its limit with the endurance races he takes part in and he’s determined to keep on pushing to help Hayley and others like her keep the research going.

“I will carry on doing what I can to raise funds for your research,” Kevin says in his letter. Even when I am no more, I will have hopefully inspired others so that you and other researchers can carry on.”



Please never give up, never let any setbacks stop you.



Hayley’s research: marking out a route to prostate cancer screening

We are funding Hayley’s research to help us improve diagnostic tests to the point that they are reliable enough to screen all men for prostate cancer. For someone like Kevin, better tests could have made all the difference in the world and allowed the disease to be caught in time for him to be cured. Kevin was at a greater risk of prostate cancer because of his family history, but he had no idea there might be a genetic link.

Searching for another blood test

We need a cheap, reliable test that could follow the PSA test to rule out men with false positive results (men who have a raised PSA but don’t have cancer) before they go on to the next stage test – a multiparametric MRI scan (mpMRI). This will most likely be an advanced type of blood test that looks for several markers of cancer, including proteins and genes that are linked to a high risk of cancer.

Hayley and her team are studying a range of biomarkers, including markers in the blood, to see how well they predict the results from an mpMRI scan. By combining the best markers, she hopes to be able to reduce the number of men needing scans.

Improving scans

Hayley’s team is also trying to see if they can improve the quality of the mpMRI scans. Although mpMRI represents a huge leap forward in our ability to visualise prostate cancer, currently about 40 per cent of scans do not give a definitive result. So, as part of this research, they are testing a more advanced type of scan called VERDICT, which could help to give a clearer picture.

Based on their previous work, they expect that this will allow us to image the prostate in much greater detail and reduce the number of unclear results. This requires an additional 15 minutes of time with the scanner, so it will be important to show that it is worth the extra cost.

Homing in on aggressive prostate cancer

The team are conducting a trial involving around 350 men who have been referred for an mpMRI scan. Men on the trial will be undergoing new blood tests for markers known to be associated with aggressive prostate cancer, as well as mpMRI scans and – if needed – a biopsy. The researchers will then compare results from blood tests with the tissue from the biopsy specimens and mpMRI scans to see if the blood tests are helpful in selecting patients with aggressive disease.



We’re so close to potentially saving thousands of lives each year.

Hayley is proud to be a big supporter of Prostate Cancer UK, and she and the researchers in her lab have run fundraising events and bake sales, and volunteered at our March for Men. She said: “Prostate Cancer UK were really supportive when I started to set up my own research group, which allowed me to do the work I’m doing now. And it’s the supporters of Prostate Cancer UK who allow all of this to happen. I dread to think how far behind we’d be otherwise.”

“After years of building up our knowledge and understanding of prostate cancer, we’re so close to putting it into practice and potentially saving thousands of lives each year.”



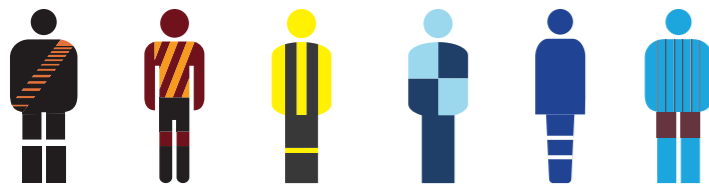
Help us fund more research like Hayley’s to get men diagnosed earlier. Go to prostatecanceruk.org/ins-donate

PROSTATE CANCER UK UPDATE

£4m up after the first half

This summer, our incredible six-year partnership with the English Football League drew to a close. We've achieved a huge amount together so here are just a few of the headlines: Our 'Man of Men' pin badge has been worn 60,000 times every season by players, 3,500 of you have volunteered at match day collections and we've raised an incredible £4 million. We've also reached thousands of people to educate them about the disease and who is at risk. So a huge thank you to the EFL and everyone who has made this partnership so successful.

As every fan knows, football is a game of two halves. Our work in the sport is far from over, and the second half is just kicking off. Next season, we'll work more closely with specific clubs, governing bodies, celebrities, fans and influential figures in football who will help us fight this disease. Our events, such as the Football to Amsterdam cycle ride and our match day collections, will continue too. With the new season almost upon us, we'll be announcing new fixtures for you to get involved in very soon. Help us relegate prostate cancer for good at: prostatecanceruk.org/football



Classic day out

Earlier this month, with help from our volunteers, we took Prostate Cancer UK to the Silverstone Classic – the world's biggest classic motor racing festival – where we've been official charity partner for the last three years.

The event, which sees more than 100,000 visitors over three days, helped us raise vital funds and speak to men and their families. We had a stand and a number of the festival's partners fundraising for us over the weekend. Thank you to the organisers, all our volunteers and everyone involved.

Stronger Knowing More

This year we've ramped up our Stronger Knowing More campaign with adverts and activity around the West Midlands and London, drawing attention to the shocking fact that one-in-four black men will get prostate cancer, twice the risk of all men. This included a question-and-answer event with former players Tony Daley and Brian Little at the home of Aston Villa FC. And we're set to be charity partner at the biggest reggae

festival in Birmingham for the second year – the Simmer Down Festival in Handsworth Park in August.

Former politician and equalities tsar Trevor Phillips joined Southend United manager Chris Powell to lead a unique team of four black men running the Virgin London Marathon. The team raised over £18,000. To find out more about the work we're doing, and to hear stories from black men about their prostate cancer journey, visit strongerknowingmore.org



Left to Right: Chris Powell, Thomas Kagezi, DJ Discipline, Trevor Phillips OBE

We raise a glass to pub winners

We've been scouring the UK to find our favourite local pub and landlord of 2018 as part of our Men United Arms pub-fundraising campaign. And the winners of this year's competition are:

Favourite Local of the year: [The Engine and Tender, Ampthill, Bedfordshire](#)

After discovering that more men are now dying from prostate cancer than women from breast cancer, a group of Engine and Tender regulars were spurred into fundraising

for us. They have already raised over £8,000 and are pushing on towards a £20,000 target.

Landlord of the year: [Kim Spickett, The Grafton Club, New Malden](#)

The club's 200 members signed up to raise funds after Kim's husband was diagnosed with prostate cancer. Kim said: "It's been a huge team effort. I'm thrilled we were able to raise awareness. One of our members has since been diagnosed but thankfully it's been caught early enough."

Could your local be a winner next year? Find out how to sign up at prostatecanceruk.org/menunitedarms

PROSTATE CANCER AND US

Ray and Stephen Clemence

Former England goalkeeper Ray Clemence, aged 69, has been living with advanced prostate cancer since 2005. A long-time ambassador for us, he appeared on our cover back in 2013 and spoke openly about his experience of the disease. We met up with him and his son, Stephen, who is a first-team coach at Aston Villa, to find out what impact prostate cancer has had on their relationship, how they feel about their future living with the disease, and why they're the best of friends (when they're not on the golf course).



How did your diagnosis come about?

Ray: It came out of nothing, really. When I went to the toilet, the flow of urine wasn't as strong as it used to be and I never felt like I emptied my bladder. I was a coach with the England team at the time so I spoke to the physio, and he immediately said I should get a PSA test as I was over 50.

When you first hear the word 'cancer' you think: oh my God, this is a big problem. But after that initial shock you think about how you're going to deal with it. I'm very fortunate that I have a very strong wife who has suffered me for 46 years. She knows me inside out and had cancer herself 19 years ago and came through it. I also have three fantastic kids, who have always supported me. They're strong, so I was honest with them from the start and they know everything that's going on in terms of my treatments.

How did it affect you watching your dad go through it all?

Stephen: It was obviously a difficult period. He's had a tumour on his brain, chemotherapy

and lots of radiotherapy. I remember my son was born the day after he was in for his first operation [which included a prostatectomy]. It wasn't nice seeing my dad in intensive care, cut from his chest right down to his stomach with tubes coming out of him. So, he's been through a hell of a lot but he's a strong, strong man. It's been tough on him mentally, but he doesn't really let anyone see that. My sisters and I try to be there and be as positive as we can – not just for my dad but my mum as well, because it's difficult for her too. We are a close family.

He's been through a hell of a lot but he's a strong, strong man. It's been tough on him mentally, but he doesn't really let anyone see that.

Has it drawn you closer together as father and son?

Stephen: I think we were very, very close before that. We've always had a great relationship. A lot of people see him as this England, Liverpool and Tottenham legend, but to me he's just my dad. I went on to have a career nowhere near as good as him, but he's been very helpful to me throughout it. I'd always phone him before a game. We also play a lot of golf together.

Ray: He regularly beats me now! We're both just so competitive that if you walked around with the two of us on the course you'd think we hated each other. It's fantastic what Stephen's done in football. I've been lucky enough to have many, many big moments in the game, but the most emotional one at Wembley was with my wife to watch Stephen play for England schoolboys. To see my son, at 15 years of age, walk out with an England shirt on to play against Germany at a place that I'd played 50 times – that takes some beating. I've always said our relationship isn't a father-son thing. We're mates. And if a father and son can be mates then that's special.

Do you worry about your son's increased risk of prostate cancer?

Ray: Obviously, I would like him not to have that risk but unfortunately, it's a fact of life. My father had it so it does pass down the chain. I don't think it's something to worry about, though. You've just got to be aware and make sure you're checked early. Then if there's anything wrong, it can be sorted out before it's gone too far – which in my case, it had done.

Are men more open about prostate cancer now?

Stephen: I think that Prostate Cancer UK has really helped to raise awareness and it's a subject that is more talked about now, especially at my football club. Coaches and staff get checked on a regular basis. The younger players in their 20s are still enjoying life – and rightly so. But I think there is an awareness that once you get over 40, or especially 50, you have to get these things checked out. I do try to tell my friends to get checked too and all members of my family are aware of the disease.

Ray: In my era, nobody spoke about it. Men are macho and don't want to

think we've got anything wrong with us – unless it's a cold, obviously. That's serious. But we do need to talk. It's amazing when I play in Prostate Cancer UK's golf days and people realise that I've got it, they will come up and talk about little doubts in their mind. They want to speak to somebody who's actually been there to tell them it's nothing to be afraid of. It's something you've just got to confront and go and get tested.

Since appearing on the cover of our magazine in 2013, are you pleased with how much football has embraced our cause?

Ray: I think it's great that the English Football League (EFL) have taken it on board. You never see



an interview without the manager having the ['Man of Men'] badge on. All the lads are wearing it on Sky Sports, too, and Jeff Stelling is a massive help giving publicity to prostate cancer. I think there is genuine awareness now which five years ago, certainly 10, there wasn't at all. It's amazing really.

How do you feel about the future living with prostate cancer?

Ray: It's a mental thing, for me. As long as I can be strong mentally, I'll get through it. There are days when I don't feel the best, but hopefully it's when nobody's around. I just want to give a positive attitude to everybody who

has a connection with prostate cancer, whether they're helping to find cures or they've got it. There's lots of talk about men like me only lasting five or six years with it. Well I'm 13 going on 14 years now, and I'm doing all the things that I want. I'm a survivor, basically, and I want to continue enjoying life for as long as possible.

Stephen: Dad is one of the most positive people I've ever known, but there are times I can see he's not quite right. He wouldn't show that to the general public, but my mum, my wife and my sisters – we see that and it's our job to try and pick him up. He's still got a lot to look forward to in his life, and that's what we try to tell him.



It's been very inspiring to meet Ray because he's in the 30 per cent.

This interview was conducted by **Ralph Ellis**, a freelance sports journalist who, like Ray, also has stage-four advanced prostate cancer.

Statistically, only 30 per cent of men with this type of disease survive more than five years and Ralph is determined to be one of them. He cycled our Football to Amsterdam bike ride with his son in June and tells us about his prostate cancer journey on our website at prostatecanceruk.org/ralph



THE MANUAL

Your questions answered about getting active when you have prostate cancer



Regular physical activity can have a number of benefits if you've got prostate cancer. It can help you manage some of the side effects of treatment, such as weight gain, fatigue and urinary and sexual problems. And it can also help you stay a healthy weight, which could be important in making your cancer less likely to come back after some treatments.

But getting active is often easier said than done. Our Specialist Nurse, Meg Burgess, answers some of your questions and concerns about getting active with or after prostate cancer.

Q I've not done much exercise before – where do I start?

A If you're starting from scratch or you've not been active for a while, make sure you start slowly. Set some small goals like 'I will walk up the stairs three times today' or 'I will walk around the garden and then gradually build up to walking to the park'. Try wearing a pedometer to track how many steps you are doing each day. You'll be surprised how much you're adding just by getting up and about.

To help you keep on track, set goals with someone else like a friend or family member – or keep a diary to see your progress. If you are still struggling with ideas or are not confident about what you should do, speak to a physiotherapist or trained exercise specialist.

Q I'm worried it's not safe for me to do exercise. Should I be?

A Evidence suggests that it is safe for men with prostate cancer to be physically active before, during and after treatment. But always check with your doctor or nurse if you're starting any new activity; if your cancer has spread, especially into the bones; or if you already have medical conditions, such as heart disease or problems with joints or muscles. They will be able to let you know any precautions you might need to take. You could also ask to be referred to a specific exercise programme, a physiotherapist or trained personal trainer/exercise specialist for further advice.

Q I've got no motivation to do any physical activity. What can I do about this?

A Sometimes it can be difficult to find the energy or the motivation to get up and get active. There could be a few reasons for why you aren't feeling motivated, including if you are not feeling as fit or strong as before or generally just feeling exhausted from your treatment.

Think about what you want to achieve and why, and how you might go about it. Try to do things that fit in with your life and that are fun, like 'I want to go to the park to play with my grandchildren' or 'I want to join my local walking group'. If you find an activity you enjoy and that fits in with your life, you'll be more likely to keep doing it.

You may also feel more motivated if you exercise with someone else – so ask a friend or family member to get active with you.

Q What if the exhaustion is just too much for me?

A There's evidence to suggest that being physically active can reduce exhaustion. If you feel extremely exhausted, it's important to speak to your doctor before you start physical activity. Sometimes exhaustion or fatigue can be a result of other medical conditions, such as anaemia.

Start gently and work up, and make sure you balance activity with rest and relaxation. Also try to plan activities at times when you usually have more energy. You might find it helpful to write a diary to help work out when those times are.

Q I'm worried about being physically active because I leak urine. What can I do?

A This is a common problem for a number of men. You can train up your pelvic floor muscles just like any other muscles and if you have strong pelvic floor muscles, this can help reduce or prevent leaking urine and needing to rush to the toilet. Pelvic floor muscle exercises can be tricky to get right so if you are struggling to do this, ask if you can be referred to a men's health physiotherapist or continence service.

You could also cut down on fizzy drinks, alcohol and drinks that contain caffeine (tea, coffee and cola) as these can irritate the bladder and make you need to urinate more often.

If you leak quite a lot of urine, there are products you could try to help manage this, including absorbent pads and pants, urinary sheaths and penile clamps.

Q I can't afford classes or to join a gym. Is there anything I can do for free?

A There are lots of free activities that you can do – go for a walk around the park or join a walking group. Ask your doctor or Specialist Nurse if there is an exercise referral scheme in your area. These are exercise programmes for people with health problems, including prostate cancer and fatigue. They are run by health professionals or fitness trainers who have experience of working with people who have health problems.

Alternatively, you could keep physically active at home. Some people enjoy following exercise programmes on DVDs or online. But even doing regular household chores and gardening count as physical activity.

If you want something more structured, you could come up with a home circuit – for example, lifting and stretching your arms and legs from a chair or bed, lifting cans of beans and walking up and down the stairs. For more ideas on getting physically active at home watch Macmillan's 'Get active, feel good' exercise DVD (see page 23 for Macmillan's contact details).



To find out more about diet, physical activity and prostate cancer, visit prostatecanceruk.org/exercise

You came, you marched, you conquered

And if you didn't, it's not too late to get involved



A huge thank you to everyone who took to parks across the UK to March for Men with us in June. In Bristol, London, Glasgow, Manchester, Liverpool and Nottingham, thousands of you came together – families, friends, teammates, colleagues and four-legged friends, raising more than £700,000. Here are just a handful of photos and stories from the events. You can find more on our website and social media.



Glasgow: Big Al's Bravehearts, a group of around 50 friends and family, marched together to remember Al, who died from prostate cancer two months before the event.



Top: In Bristol, Jackie, Glandel (who has prostate cancer) and Mike walked in memory of their dad and for other family members who have the disease. Bottom left: In Liverpool, all ages took part. Bottom right: In Liverpool, Brothers Peter, Paul and Simon, who've all had prostate cancer.

Worried you've missed out? You can still March for Men.

1. Organise your own march, your way, anytime you like. Whether you decide to march up a mountain, get your local community behind you or walk around the park, we can help. And we'll send you a free pack of tips, ideas and goodies.
2. Search on our website to find other people organising marches near you.
3. Sign up to be the first to hear about March for Men 2019.

Visit marchformen.org

In the SPOTLIGHT

James and Daniel Kingsbeer from Swindon

James and Daniel, aged 11 and 9, are running 10km a week for a year in memory of their grandads, one of whom died of prostate cancer and one who died from cardiac problems. The boys will split what they raise between us and the British Heart Foundation.

So far they have run over 300 miles and raised more than £3,000.

The boys' family are supporting them with family runs and boosting their total with other fundraising events. Mum, Kelly, said:



"We've had sun, rain, snow, giggles and a whole lot of memories made. I'm super proud of these two little heroes."

And it hasn't been easy. In one Facebook post, Kelly said: "Grief is an unpredictable force. Boys had a wobble today. I'm sharing because, even though they're doing so well, the feeling of loss is still raw. All you can do is

be there for each other. When one falls, you pick them up. Family is the best team ever."

But Liverpool fan, James, and Everton fan, Daniel, had their incredible efforts rewarded when they were invited to run a lap of honour around the pitch at Goodison Park during the Merseyside derby. The boys were given a rousing reception by the crowd and had photos with star players and the managers.

Their dad, Martin, described himself as "one proud father". We don't blame him – well done boys for keeping this up and good luck for the last few months of your challenge!



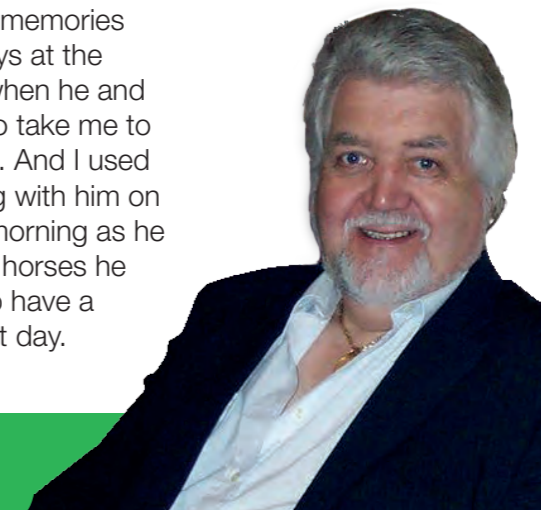
works in our fundraising team in Glasgow, tells us what she misses most about him. You can read more of Marlene's story on our website.

"Dad was a hardworking businessman but also had a silly side and a talent for making me cringe with bad dad jokes. I always admired his kindness, generosity and patience.

"My fondest memories are of holidays at the caravan or when he and Mum used to take me to theme parks. And I used to love sitting with him on a Saturday morning as he selected the horses he was going to have a flutter on that day.

Marlene Graham's dad, John Watson Graham, was diagnosed with prostate cancer in early 2005 at the age of 62. He died from the disease just 10 weeks later. Marlene, who now

"If I could speak to him today, I'd say: 'Dad, you were completely right when you said I'd mellow out as I got older. I'm just sorry you didn't get to witness it and even more sorry for all the grief I put you through at various stages of my life. I never used to say it enough but I love you very much and still think about you every day."



Tell us about your Top Dad: email editor@prostatecanceruk.org

THANK YOU

792 balls

To everyone who came to our official golf day at The Berkshire and to Bill Elliott, Ray Clemence and Sir Trevor Brooking who led the teams.



£25,000

To first time supporter Gordon Gilby on his incredible donation. Thanks to Gordon's Gift Aid declaration, we can claim an extra £6,250!

74 matches

To everyone who took part in bucket collections at football matches this season!



£30,000

To Adam Pearce and his colleagues at Transport for London who raised this incredible sum with collections at stations.

1 proposal

Harry Frith popped the question to fiancée Beanie, whose dad has prostate cancer, while walking 2,669 miles of the Pacific Crest Path in America to raise money for us.



GET INVOLVED

Five things you can do to support us

1 Funding the Future October

Find out more about the innovative research you've helped to support and meet the scientists working at the forefront of prostate cancer research at our Funding the Future events. At Newcastle University on 28 September and Cardiff and Manchester

universities on 4 and 10 October respectively we'll be unveiling our latest scientific discoveries, as well showcasing other ways you can help our vital work. For more details and to book your place, visit prostatecanceruk.org/legacy



2 Walking Football All year round

We've recently teamed up with the Walking Football Association to keep men on the pitch for longer. One of the fastest-growing sports among older men, it's also proving popular with men recovering from cancer treatment and other health issues. So why not organise a match

with your local walking football club and we'll send you a free fundraising pack. Find out more at prostatecanceruk.org/walkingfootball



3 Men United Arms Until March 2019

Could your local pub and the community it serves help us raise the bar this year? Our Men United Arms pub fundraising competition saw 650 pubs join in last time, raising more than £109k between them. It's brilliant

fun and there are great prizes and incentives for pubs to get involved. Find out more about what you can do at prostatecanceruk.org/menunitedarms

4 Organise your own March for Men All year round

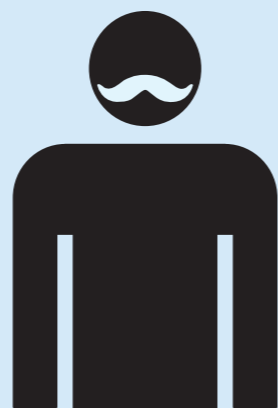
Couldn't make it to one of our March for Men events this summer? Well how about organising your own? You could hike solo up a mountain or walk around your local park with the whole community alongside you. Whatever you choose, it's your march, your way – and

we're with you every step of the way. Register your walk and we'll send you a free fundraising pack including lots of tips, ideas and goodies to make your march a success. Find out more at marchformen.org/yourmarch

5 Movember 1-30 November

Stand by your top lips! Another month-long fundraising extravaganza is set to raise millions for men's health causes – including prostate cancer. You don't have to cultivate a 'tache, as there are plenty of fitness challenges and other fuzz-free and fun activities you can do to get the donations flying in.

For more info and to register your Mo Bro or Mo Sista fundraising page, visit movember.com



EVENING EVENTS

CALENDAR AUGUST-JANUARY 2019

AUGUST

12 Simmer Down Festival
We've partnered with this free family music festival at Handsworth Park in Birmingham to raise awareness of black men's increased risk of prostate cancer. Come and see us in our marquee!

23 Baxters Loch Ness Marathon Running Festival
This award-winning marathon offers extraordinary scenery and unrestricted views throughout your journey from Fort Augustus to Inverness along the famous Loch Ness. The atmosphere is informal and friendly and there are shorter 5 and 10km River Ness runs available too.

29-30 Great Scottish Run
This is Scotland's biggest running weekend, with 30,000 runners set to race around Glasgow as the BBC's cameras film the event! Choose from either 10km or the half-marathon and enjoy support from the crowd of thousands and the city's most iconic landmarks.

NOVEMBER

4 Men's 10k Edinburgh
Join thousands in this iconic race around some of the city's most iconic landmarks, including Edinburgh Castle, Arthur's Seat and Holyrood Palace, before finishing in style at the BT Murrayfield Stadium. By running for us, you'll be helping to support more than 26,000 men who are living with and after prostate cancer in Scotland.



SEPTEMBER

16 Edinburgh Kiltwalk
Choose either a Wee Wander, a Big Stroll or a Mighty Stride in this distinctively Scottish and fun charity walk! You'll be joining thousands of others and if you walk for us, your donations will be topped up by 40 per cent thanks to the Hunter Foundation.

25-26 South Coast Challenge
Take in some of England's finest scenery as you run, walk or jog from Eastbourne to Arundel. You can do 25, 50 or the full 100km solo or as a team. There's full support and refreshments.

OCTOBER

13 Non-League Day
Prostate Cancer UK is proud to be the official charity partner of Non-League Day once again. We're asking fans across the UK to get behind their local club to celebrate lower league football and help us raise the profile of the most common cancer in men. So wear your 'Man of Men' badge and encourage others to donate generously into the buckets we'll have out at grounds up and down England and Wales.



London to Paris/Paris to Geneva bike rides

Experience the thrill of cycling to another continent or tackling the famous hair-pin bends of the Jura Mountains made famous by the Tour de France. We have dates throughout 2018 and 2019 for both these epic, multi-day fundraising rides with all your logistics taken care of. Find out more at prostatecanceruk.org/cycling



DECEMBER

5 Carols by Candlelight
Join us at St Paul's Church, Knightsbridge, for our annual sell-out Carols by Candlelight event. Expect readings from celebrity guests, mince pies and plenty of festive cheer. Join our mailing list to find out when tickets go on sale prostatecanceruk.org/carols

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 could see a bit of a light at the end of the tunnel. It gave me back my enthusiasm for life.

Fatigue support service user

Regional services

To find out what local support and services are available in your area go to 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 at: 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
0800 031 5412

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 3668 0406
Details of complementary therapy practitioners who meet national standards of competence and practice.

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
Website and app with advice and information about erectile dysfunction.

Tackle Prostate Cancer

www.tackleprostate.org
0800 035 5302
The National Federation of Prostate Cancer Support Groups, working closely with us to provide local support to patients and families.

Don't let fatigue hold you back: we can help you take charge

Around three quarters of men with prostate cancer will experience fatigue (extreme tiredness) at some point. Normal tiredness gets better once you've rested, but fatigue can be a debilitating problem that has a big impact on your quality of life. However, you don't have to simply accept this.

We offer a unique Fatigue support service to help men get back on track.

How can the Fatigue service help me?

We want to help you normalise your fatigue – in other words, we want to help you take control of it and share tips and tools to help you manage it.

How does the Fatigue service work?

We'll assign you a Specialist Nurse, who will call you four times over a period of 10-12 weeks. The calls are not usually longer than 45 minutes. We'll also send you a tailored diary, factsheet and a booklet about coping with fatigue day-to-day.

We encourage you to use the diary to explore any patterns that emerge in your fatigue. This can allow you to plan your activities around the times when you have more energy. Your nurse will support you in making practical changes to your lifestyle and habits to manage your tiredness in a way that works for you.

Who can take part?

Anyone who has had a prostate cancer diagnosis and is experiencing fatigue can ask us for an assessment. If you're having treatment, you may need to have completed this before starting. What's really important is that you're enthusiastic for change.

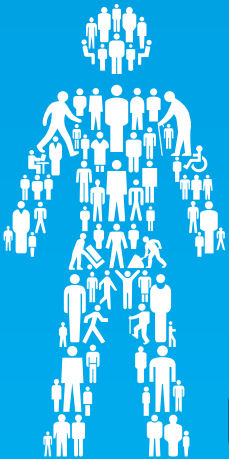
Will my fatigue go away completely after I take part in the service?

We can't guarantee that, as fatigue is often caused by treatments or the cancer itself. However, we'll look for ways to help you to be less dominated by it and get back to doing the things you enjoy.

Call us on **0800 074 8383** to find out whether the service is suitable for you or find more information online at prostatecanceruk.org/fatigue



Ready, steady, SHOP!



**PROSTATE
CANCER UK**

Get kitted out at our online shop:
shop.prostatecanceruk.org