

Prostate cancer Insights

Issue 14 | Summer/Autumn 2019



Prostate
cancer
and me

**BILL
TURNBULL**

**A game
changer
for men**

How the stars
and grassroots of
football tackled
prostate cancer



**PROSTATE
CANCER UK**

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Editor’s note

We all know how important early diagnosis is when it comes to cancer. That’s why we’re working to find better tests and eventually have an accurate screening programme. But even with an early diagnosis, there are no guarantees.

Sometimes the treatment doesn’t kill or remove all of the cancer. As our Specialist Nurse Ali says (p16), this is a common fear for men and it can be difficult to face further treatment after believing the cancer had been cured.

Despite that, we don’t know for sure how big a problem it is – the records simply aren’t collected. We know that most men don’t need further treatment, but it’s still more common than we’d like. That’s why we’re funding research to improve success in surgery or radiotherapy (see p8).

This research may take years to come to fruition but it’s important to get this right. That way, once we have better tests in place, men with aggressive cancers can have peace of mind that their cancer will be dealt with once and for all.

A handwritten signature in black ink, appearing to read 'Ian'.

Editorial team

- Dr Sophie Lutter
- Maxine Creedy
- Hollie Varney
- Penny Eaton
- Dr Ian Le Guillou (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

Thank you for your excellent and helpful article on active surveillance in Insights issue 13. I have been on active surveillance since being diagnosed with prostate cancer aged 74. After seven years, my PSA level has risen and a consultant has recommended starting hormone therapy immediately.

My wife and I are full-time carers and I am concerned that the side effects could possibly affect my ability to continue doing so. I requested a three-month stay, so that I could evaluate what options are open for me, but the lack of information on what other treatments would be available to me is a concern. Thanks for all you are doing and for all the encouragements that appear in Insights.

Keith

Dear Keith,

We are pleased you found our article on active surveillance helpful. We are sorry to hear your PSA is rising after seven years and understand your concerns about starting treatment.

It's difficult to predict what side effects someone may experience and to what degree. You may find it helpful to talk to one of our Specialist Nurses about what your options might be (see page 22 for contact details). They offer confidential support and information, and can help make sense of things at a difficult and stressful time.

You may also find it useful to chat to other men who have been through a similar experience either through our Online Community forum (see page 23) or our One-to-one support service.



Even though the PSA test is not that reliable, it is the only thing we have at this time. Why do men not have screening after a certain age like women do for breast and cervical cancer?

Brian Grimshaw

Dear Mr Grimshaw,

At the moment there is no test that can be used as a screening tool for prostate cancer. The PSA test as you say is the best we have, but it is not reliable enough because it can give false positive and false negative results, which would do more harm than good. Although there's no screening programme available, men over 50 have the right to have a PSA test if they've talked through the advantages and disadvantages with their GP or practice nurse. Men at a higher risk of prostate cancer (men with a family history or black men) can ask for the test before the age of 50.



Dear Insights

I telephoned my surgery and requested a PSA check with my GP. He flatly refused me the test even though my father had died from prostate cancer. He went on to state that the tests were not reliable and that I did not need one, there was no further discussion.

I thought that the NHS was there to help us not to put us down and embarrass people, I now feel that I am unable to speak with my GP for fear of further rebuff.

Liam Bunce

If you're over 50 and talked it through with your GP then you have the right to a PSA test. If you've been refused and you're not sure whether to make a complaint, get in touch with our Specialist Nurses. They can help you understand your risk of prostate cancer so you can decide what to do.



GET IN TOUCH!

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

**Insights magazine
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PROSTATE CANCER NEWS

Study reveals lack of support for sexual side effects of prostate cancer treatment

Over 80 per cent of men struggle with poor sexual function following a diagnosis of prostate cancer 1.5–3.5 years earlier, yet fewer than half of these men are offered any support to cope with it, according to new research.

The study, called Life After Prostate Cancer Diagnosis, was funded by the Movember Foundation in partnership with Prostate Cancer UK. In the largest survey of its kind, over 35,000 men who had been diagnosed

with prostate cancer were asked questions relating to quality of life and wellbeing.

This study provides the most conclusive evidence to date of the scale of problems with sexual function and the lack of services to help men deal with it. In fact, 81 per cent of men responding to the survey reported their overall sexual function as poor or very poor.

No support at all was offered to most men, and only 15 per cent

were offered access to specialist services. The study also found that men under 55 were more likely to be offered support than older men, but even in this age group 22 per cent were not offered any.

“For some men, it can be months before any erection problems are experienced following their treatment, especially if they’ve received radiotherapy. By this stage follow-up appointments may have reduced,” says Heather Blake, our Director of Support and Influencing.

“As a result, too many men are being abandoned without any support for sexual problems – with older men in particular missing out. This simply isn’t good enough. With long term implications including depression and relationship breakdowns, this is a side effect that must not be swept under the carpet, no matter how old the man is, or what treatment he has received.”

See page 12 for more about our work to help men get the right support.

New guidelines prompt doctors to offer active surveillance for low risk cancers

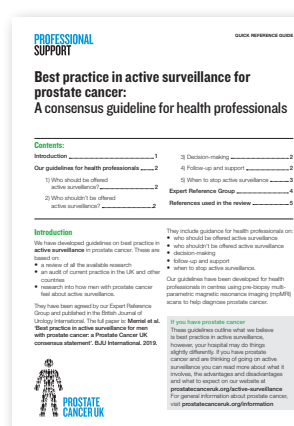
The National Institute for Health and Care Excellence (NICE) has updated their guidelines for prostate cancer in England and Wales, including recognition that active surveillance offers men with low risk localised prostate cancer the same survival benefit as radiotherapy and surgery.

“This could potentially provide thousands of men with the opportunity to delay or avoid radical treatment and its associated side effects,” says Heather Blake, our Director of Support and Influencing, who also warned of the need for tailored support for men considering active surveillance.

“From our discussions with men we have discovered that the language used and information provided by clinicians about their individual cancer risk has a huge impact on their treatment decision. Regular, open communication with a trusted health professional and a personalised treatment plan are also crucial to ensuring men feel reassured and can maintain a good quality of life during their time on active surveillance.”

To help health professionals give men the support they need, we have worked with experts to develop a suite of materials to

be used alongside the NICE guidelines to make sure active surveillance is delivered to best effect.



These best practice approaches are published in the BJU International journal and have been summarised in videos and an e-learning module.



Enzalutamide has similar benefit to chemo when taken with hormone therapy

A new clinical trial shows that taking the drug enzalutamide extends survival for men newly diagnosed with advanced prostate cancer compared to taking hormone therapy alone.

Currently in the UK, men diagnosed with advanced prostate cancer are given hormone therapy together with docetaxel chemotherapy. A second therapy, abiraterone, also similarly improves survival in these men, however it's still being appraised for this use on the NHS.

The new results show that enzalutamide, which is already licenced and available on the NHS for men who are resistant to hormone therapy, could be an additional treatment option to take alongside hormone therapy.

In the study, 1,125 men with hormone-sensitive metastatic prostate cancer were randomly assigned to receive either enzalutamide or another anti-androgen treatment alongside the standard of care (hormone therapy with or without docetaxel).

It revealed that men taking enzalutamide were more likely to be alive after three years than men who had taken other anti-androgen treatments.

Dr Matthew Hobbs, Deputy Director of Research at Prostate Cancer UK said that the trial was positive but added: "It does not show that this is any more effective than the UK's current standard practice of giving docetaxel chemotherapy upfront in combination with hormone injections. We therefore

expect that to remain standard UK practice."

"There are some men diagnosed with advanced prostate cancer who cannot have chemotherapies like docetaxel, and we want to see another treatment option made available to them so that they can benefit from the additional months of life that having abiraterone or enzalutamide can provide. We will be working with appraisal bodies and the manufacturers to find a way to make this happen."

FROM THE LAB Focal therapy put to the test



Professor Hash Ahmed

Current treatments like surgery and radiotherapy for early-stage prostate cancer often cause a wide range of side effects. That's why there is a lot of interest in what's known as focal therapy, which could help to reduce the impact of treatment for some men.

Focal therapy means treating just the area with cancer, while leaving the rest of the prostate undamaged. However, these treatments are only available in specialist centres or as part of clinical trials. Before they can be a standard treatment across the UK, we need to know whether they really work as well as traditional treatments like surgery and radiotherapy.

That's why we've given a £500,000 Research Innovation Award to Mr Taimur Shah and Professor Hash Ahmed at Imperial College London to run a small clinical trial comparing focal therapy to surgery or radiotherapy.

To make sure that the results of a study like this are reliable, hundreds of men need to take part. So before time and money is invested in a large clinical trial, the researchers need to be sure that men will want to join the trial. To test this, they will use their Research Innovation Award to run a pilot study called CHRONOS with 60 men.

At the end of the trial, the researchers should be able to compare focal therapy, whole gland therapy, and focal therapy plus medication to see which has the best chance of controlling the cancer while minimising side effects.

"CHRONOS is the next step to making focal therapy a reality. If we can confirm focal therapy is an effective treatment for cancer that also minimises side-effects, the potential impact to men will be immense," says Professor Ahmed.

If the pilot study is a success, Professor Ahmed and his team will try to get funding for a larger trial. This would aim to confirm that focal therapy is an effective treatment for prostate cancer, and causes fewer side effects than standard treatments.

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



One man dies every 45 minutes of prostate cancer in the UK – that's two men during every football match. It's a statistic that's shocked people across the UK and won the support of football fans everywhere.

We always aim to be wherever men are and reach them on their terms. So what better way to speak to millions of men each weekend than through the power of football? We've become difficult to ignore in football, especially with the growing popularity of our 'Man of Men' pin badge.

Our badge has graced the lapel of almost every football manager and Sky Sports pundit in recent years including Manchester City boss Pep Guardiola, England manager Gareth Southgate and Sky Sports presenter Jeff Stelling, as well as thousands of fans. We've grown an army of supporters through our work in football, raising millions of pounds along the way and making more men aware of prostate cancer and their risk.

"In my era, nobody spoke about it. But we do need to talk. It's amazing when people realise that I've got it, they will come up and talk about little doubts in their mind," says former England goalkeeper Ray Clemence, who has advanced prostate cancer.

"I think there is genuine awareness now which five years ago, there wasn't at all. It's amazing really. You never see an interview without the manager having the badge on and all the lads are wearing it on Sky Sports."

Raising awareness

Our long-standing ambassador Jeff Stelling has not only raised awareness of prostate cancer by wearing our pin badge with the rest of the panel on Soccer Saturday, but he's also on a mission to raise £1 million. The backing from football fans has been astounding – over 1,000 supporters have joined Jeff on his challenges and hundreds more will join him in September as he takes on four marathons in four days across the four home nations.

One supporter recently wrote to Jeff saying, "I watch you and the team every Saturday and this makes my weekend a happy time. I must thank you and the team for making everyone aware of this disease. I've been fighting it for five years. I've sent a donation to the charity. I'd be very grateful if you could send me a pin badge to wear with pride."

We've partnered with the League Managers Association since 2013, working with many of their high-profile members to raise awareness of prostate cancer. The likes of Alan Shearer, Sam Allardyce, Eddie Howe, Chris Hughton and Rafa Benitez have all backed our cause.

"I think what I've seen in the last 20 years is the power of sports like football, in terms of its influence and how it can raise awareness of different types of issues," says Gary Neville.

"I see most managers up and down the country on a Saturday or Sunday afternoon, when I'm covering the games on Sky, wearing this 'Man of Men' badge. People in prominent positions in football can have such a powerful influence."

Another partnership with the English Football League for six years led to raising £4 million with the support of 85 EFL clubs, 3,500 match day volunteers, and over 2,000 football fans who took part in our annual Football to Amsterdam fundraising cycle ride.

"Football to Amsterdam is always a highlight for me. The camaraderie on the ride is fantastic," says Charlton fan Tracy Leaburn, whose dad died from prostate cancer. "Everyone mucks in to help each other over the finish line. It's just a great weekend that really brings the football community together. I'm so proud that our team has grown from three riders to 40 riders in just four years."



Our badge has graced the lapel of almost every football manager and Sky Sports pundit in recent years.

We've since joined forces with The Vanarama National League to continue our work supporting Non-League Day every October. Last year, Vanarama officially changed their name to MANarama for a six-week period raising a further £150,000 to support more funding for research.



I think what I've seen in the last 20 years is the power of sports like football, in terms of its influence and how it can raise awareness of different issues.

Gary Neville



Saving lives

The 2018/19 football season welcomed a host of new opportunities as we partnered with Millwall, Nottingham Forest, Derby County, Northampton Town and Queens Park Rangers.

We teamed up with League One's Southend United to become their official shirt sponsor for the season and it's a partnership which has proved a life-saving success. Keith Smith, from Basildon, was prompted to visit his doctors after noticing the work the League One club and its former manager Chris Powell had been doing with us.

"I was looking at Southend United's website to see if there was any news on us signing a player, and I saw an article on there with Southend regarding prostate cancer. I was looking through and reading what you should look out for, and I thought 'that's me, I've got one of them symptoms.' I looked it up further and eventually went to the doctor, and after a range of tests it was confirmed I had prostate cancer," Keith recalls.

"Basically, I knew very little about prostate cancer until a year ago. My dad had it, unfortunately, my uncle had it as well and I didn't realise it was hereditary. Until I discovered I had prostate cancer, I never realised there were so many risks that I had. I should've really been checked out earlier, but I was so oblivious to it."

Together, fans, players, managers and pundits are helping to bring awareness of prostate cancer to millions of football fans every week, who outside of football might not have known anything about it. Our mission remains to show that no matter what team people support, we are united for one cause.



I had a feeling that it wasn't over:

A diagnosis of prostate cancer can trigger a lot of questions for a man and his family, and this can be amplified even more if the cancer has been spotted for the second time. But there is still so much that we don't know about recurrence. Who are the men this happens to? How many of them are there? And how can we stop it? Dr Sophie Lutter tries to find some answers and shares the research that we're funding to help improve the situation for men.

Prostate cancer that's caught while it's still contained within the prostate is curable with surgery or radiotherapy. But that doesn't mean that it is always cured.

The elephant in the room; an obvious stumbling block in our ambition to save lives through early detection of prostate cancer, and the haunting question that's likely to worry most men who've been treated for localised prostate cancer is... what if it comes back?

That fear unfortunately became a reality for Martin Wells. The self-employed trainer was diagnosed in December 2007, aged 54. "Initially, the doctors thought they'd caught the cancer early, and that it was contained within my prostate. But somehow, even after I had the prostatectomy, I had a feeling that it wasn't over," he says.

"So, on one level it wasn't really a surprise to find out five months later that some of the cancer had escaped before the surgery after all, and I'd need radiotherapy and over two years of hormone suppression to get my cancer back under control.

"Statistically, I knew even that wasn't the end of it."

Cutting off escape routes

Although we might often talk about the cancer 'coming back', that doesn't really describe what's happening – the cancer never really went away in the first place. This is either because some cancer cells had already escaped the prostate undetected before a first treatment, like Martin's surgery, or because the treatment didn't kill all the cancer cells first time round.

This is something that our researchers are working hard to address. Dr Richard Clarkson, at Cardiff University, has identified some very resilient cancer stem cells in the tumour that are resistant to, or somehow escape, treatment. He thinks that these are the cells responsible for the spread of prostate cancer around the body, even after surgery or radiotherapy.

Dr Clarkson's team has developed a new drug that specifically targets these cancer stem cells and is currently testing it in prostate cancer samples in the lab. If successful, they believe that this drug could help to prevent recurrence in men with high risk cancers.

Meanwhile, Dr Susan Heavey from University College London is taking a slightly different approach. Dr Heavey has perfected a technique to keep prostate cancer samples alive in the lab for a couple of days. In this Movember-funded project, she will use these 'direct from patient' samples to test new drugs and drug combinations to shrink the cancer. Dr Heavey hopes that giving additional drugs immediately before and after surgery could reduce the risk of the cancer coming back.



The doctors thought they'd caught the cancer early, and that it was contained within my prostate. But somehow, even after I had surgery, I had a feeling that it wasn't over.

Martin Wells

The The The problem of recurrence

Dealing with it coming back

As if it wasn't complicated enough, recurrent prostate cancer also comes with its own dictionary of confusing language. For many men, the first sign that their cancer is back is a continuous rise in PSA levels, following a sharp decline after treatment. This is called biochemical recurrence, and it can occur without any symptoms and before the cancer can be detected on a scan.

While there are plenty of treatment options for prostate cancer that has come back after a first treatment, the debate about whether or when to treat remains just as fierce as it is after a man is first diagnosed.

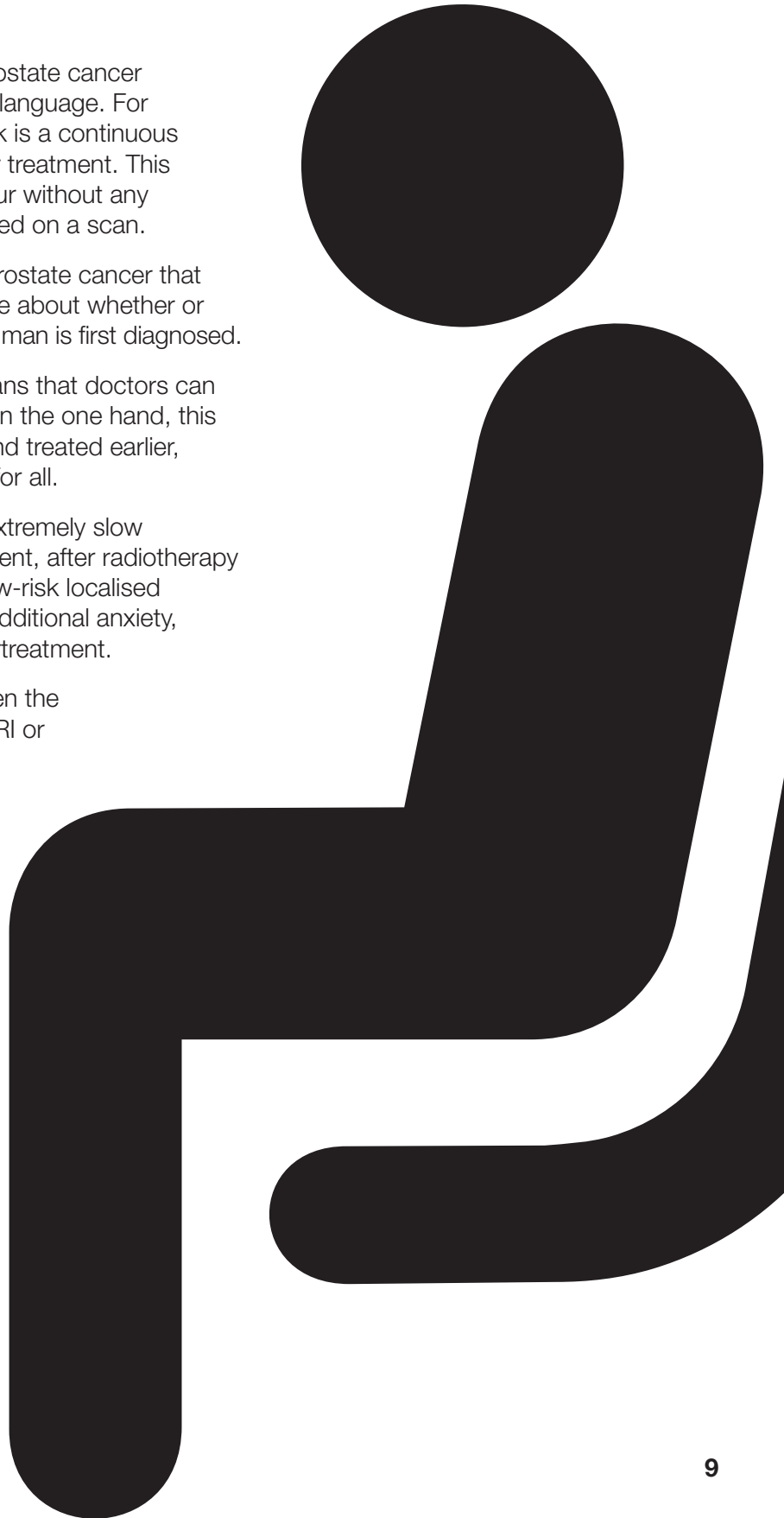
PSA tests are getting more sensitive, which means that doctors can detect lower PSA levels and smaller changes. On the one hand, this means that recurrent cancer can be detected and treated earlier, maximising the chance of stopping it once and for all.

On the other hand, these cancer cells may be extremely slow growing, and not need immediate further treatment, after radiotherapy in particular. In this case, as with diagnosis of low-risk localised disease, early detection may just contribute to additional anxiety, and perhaps unnecessary side effects from overtreatment.

For some men, this debate comes too late. When the doctor can see evidence of the cancer on an MRI or bone scan, you may hear it called radiographic recurrence. At this point, there's no question that it needs additional treatment.

"Eight years after I finished hormone therapy, my PSA levels started to rise again. They continued to increase every three months and eventually my oncologist and I jointly agreed it was time for another scan. These confirmed that the cancer was back, and that it had spread to my hip and lung," Martin recalls.

"At my last appointment, I formally requested to see all my CT and bone scans. Even though I don't really know what I'm really looking for, it helps me feel more in control to think that I can see the cancer now. It's not in control of me. I can see it, and I can manage it."



Known unknowns

There is surprisingly little data available about the number of men who experience recurrence after first line surgery or radiotherapy for prostate cancer, although a couple of recent clinical trials suggest that it's likely to be around 10–15 per cent for men with low- to intermediate-risk disease.

But we do know that the chances of a man's first treatment being completely successful varies depending on the location of the cancer, the aggressiveness of the disease, and the stage at diagnosis. Collectively, these factors contribute to determining a man's risk status. Unsurprisingly, it's more likely that a man with high-risk prostate cancer will find that his cancer comes back after treatment than a man with lower risk disease.

There are two important ways that we can tackle this. The first is to get better at diagnosing the disease accurately in the first place – that means working out whether any cancer cells have escaped the prostate even before you can see them. This is something that Professor Ananya Choudhury at the University of Manchester is concentrating on.

She and her team are analysing patient data to see how treatment success is affected by how much radiotherapy a man received, how it was delivered, and his risk factors. They will use the results of this analysis to create an algorithm that predicts which men are likely to have cancer that's already escaped the prostate, and so will benefit from additional lymph node radiation.

Reducing risk

The other thing we can do is to get better at treating the cancer upfront to reduce the risk of recurrence, even in high risk men like Martin. Prof. Choudhury aims to do this in a second project that we've funded, with support from the Movember Foundation. The researchers have evidence that radiotherapy works less well in men whose tumours have very low oxygen levels.

They are developing a test to identify these men by looking for a particular gene signature in the cancer. If we can identify these men before they start treatment, they can be given additional drugs to increase the oxygen levels in their tumour and improve how well the cancer responds to radiotherapy. The team are currently validating this predictive tool and aim to test it in clinical trials soon.



Prof. Ananya Choudhury

Professor Claire Lewis and Dr Janet Brown at the University of Sheffield are also trying to improve upfront treatment for high-risk localised cancers, but their approach will turn the cancer's own protective mechanisms against it. They think that the same immune response that helps wounds to heal may also help the cancer to recover from radiotherapy.

The researchers have identified a specific type of immune cell that is responsible and are working to reprogramme these cells to produce anti-cancer proteins instead. They will test this approach first in mice and then, if successful, apply for further funding to start a clinical trial in men with high-risk localised prostate cancer.



Help us fund more research like Prof. Choudhury's to treat prostate cancer more effectively.
Go to prostatecanceruk.org/ins-donate

Looking to the future

The more critical question than how many men experience their cancer coming back, is how many of those men, like Martin, are diagnosed with advanced disease after a previous treatment for localised prostate cancer. Staggeringly, there is no data available to answer this question. One oncologist we spoke to estimated that up to half of men with advanced prostate cancer have previously had treatment for localised cancer.

However, there is research to suggest that three per cent of all men who are treated for localised disease still die from prostate cancer, but this is higher for men with the most aggressive disease.

For Martin, it's still very unclear what the future holds: "My oncologist won't and can't give me a definitive answer as to how long I'll survive. I know it's all statistical. Lots of things are vague.

"As far as I know the cancer will probably grow again in about two years and I've a five-year survival chance of about 30 per cent. What I'm actively working on now is to be upbeat, positive and happy that I'm alive and well, and not to let those frequent negative conversations that go on in my head get to me before the cancer does."

To stop this happening to men like Martin in the future we have to improve both diagnosis and treatment. We need to get a lot better at working out a man's risk of recurrence and improving treatments for those who are at high risk.

"We are looking at it from both angles and will hopefully shed some light in both those areas," says Prof. Choudhury.

"It's exciting and hopefully within the next 12 months we'll have a good steer as to whether we do have a biomarker that is ready to be tested in a clinical trial.

"None of this would exist without the generous donations and the belief that Prostate Cancer UK supporters have in the work that we do. And if we couldn't do that work, I couldn't offer that potential of hope to the patient sitting in my clinic."



If we couldn't do that work, I couldn't offer that potential of hope to the patient sitting in my clinic.

Prof. Ananya Choudhury

If you're worried about your cancer coming back after treatment, there's some information about what you can do and further treatment options in The Manual on page 16. You can also call and speak to our Specialist Nurses directly on **0800 074 8383**.



It's the thing that's been missing for several years.

Many men face side effects that affect their lives long after prostate cancer treatment. This could be sexual problems such as trouble getting erections, mental health issues such as depression and problems with incontinence.

The TrueNTH programme is using research to tackle these critical areas of prostate cancer care. It aims to improve the quality of life for men with prostate cancer and for them to feel knowledgeable and confident about managing their condition.

TrueNTH is an international programme funded by the Movember Foundation. In the UK, all of the projects are delivered in partnership with us and two of these have recently developed new resources for men and health professionals to improve sexual wellbeing and physical activity.

Getting healthy

The TrueNTH Exercise and Diet study was the first in the UK to test whether a programme in pharmacies could increase physical activity and improve the health of men with prostate cancer. This was based on evidence that men who increase their physical activity by three to four hours per week reduced the risk of cancer recurrence and symptoms after prostate cancer treatment.

Each of the men received a personalised assessment and lifestyle prescription, and 88 men completed the six-month study. Most of the men taking part had poor physical fitness to begin with and were considered obese.

More than a quarter of the men improved their levels of physical activity and most were happy to take part in the pharmacy programme, with one saying: "I'm just glad that I had the opportunity to do it because it has kick started me. I jumped at the chance because I thought I've either got to do this or just bin it and carry on with how I'm going. It's the thing that's been missing for several years – I haven't looked after myself."

Following on from this small study, the researchers are now scaling it up into a larger trial. For more information and resources visit www.redi.help

Talking about sex

Sexual dysfunction is the most common side effect of prostate cancer treatment and most men feel they haven't had sufficient support for dealing with it. Researchers at Ulster University developed three resources to help address this problem: an e-learning module for clinicians, a tool to help guide conversations during appointments and a website to provide support and information for men.

The team saw that both men and health professionals found it useful and liked that it could be used flexibly.

One man said, "I actually found it quite encouraging to be told that erectile problems are a common issue for lots of men, not just me."

While a specialist nurse commented, "I found it really helpful, having not always had a lot of those conversations, just to bring it to the forefront."

The website for men affected is www.prostate.lifeguidewebsites.org



For more support on these and other areas, contact our Specialist Nurses on 0800 074 8383

PROSTATE CANCER UK UPDATE



New Director of Research

In March, we welcomed Dr David Montgomery to lead our research programme into a new era of growth. David trained as a surgeon and worked in breast cancer research before moving to the pharmaceutical industry, so he brings a wealth of experience to the charity.

“It’s a real honour to be appointed to such a fantastic charity. 1 in 8 men in the UK will get prostate cancer in their lifetime, and I’m excited to have the opportunity to use my experience both in medicine and the pharmaceutical industry to help make a real difference for these men,” says David.

Investing in volunteers

Prostate Cancer UK has been awarded the Investing in Volunteers accreditation for the second time. This quality standard is only held by six national organisations and involves a rigorous assessment process with more than 300 people interviewed.

We rely heavily on the support of our volunteers, so it is great to see that we can give them the best experience possible.



£50m total spent on research

We have funded eight new research projects this year, which has taken our total spend to £50 million since the charity began in 1996. The new projects are part of our Research Innovation Awards – a scheme dedicated to funding the most impactful and imaginative research the field has to offer. They focus on new ideas that tackle taming prostate cancer from a completely new angle.

Seven of the eight projects are honing in on finding better treatments for prostate cancer, such as

slowing and preventing hormone therapy resistance and trialling more targeted, precision medicine. They will lay crucial groundwork so more men can survive prostate cancer, with fewer life-changing side effects.



Men, we are with you

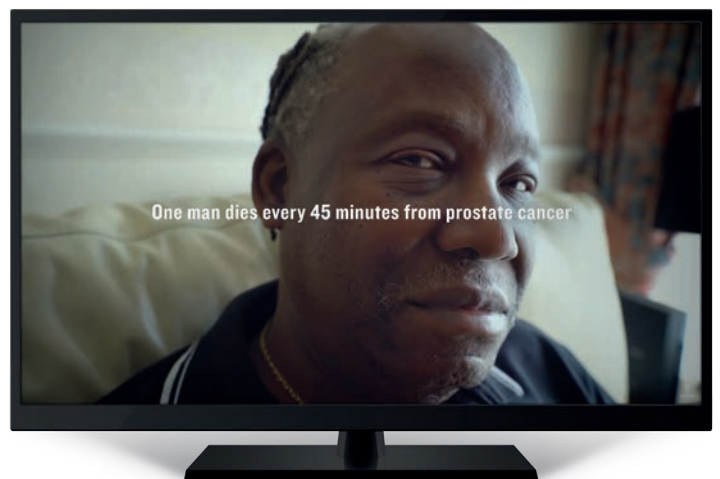
This summer we have launched a major new campaign to highlight the impact of prostate cancer.

Our advert focuses on the incredible things that men do in their lives and highlights what we lose when one dies every 45 minutes. We want to take the opportunity to celebrate men and to

share our philosophy: **Men, we are with you.**

The advert also features men and families affected by prostate cancer, such as Ally below. He has advanced prostate cancer but is now taking part in one of our clinical trials after his treatment stopped working.

Our main aim with this campaign is to inspire people to join us and be a part of solving the problem.



Bill Turnbull



When our ambassador, former BBC Breakfast presenter Bill Turnbull revealed he had advanced prostate cancer in March last year no one could have foreseen the positive impact sharing his diagnosis would have. We caught up with him ahead of a major new Channel 4 documentary.

It's been over a year since you revealed your diagnosis, and a lot has happened in that time.

Bill: When you're diagnosed with prostate cancer it can be a pretty

scary moment. It was for me. Particularly because it had already spread to my bones and the long-term outlook wasn't good at all. It was a big shock for me and for my family, and we had some pretty dark times. But luckily, I started treatment very quickly after my diagnosis.

You had nine rounds of chemotherapy. How are you doing now?

Bill: The chemo wasn't pretty, but was fairly effective. Since then I have felt a lot better as time has gone on. My immune system has improved and my body is more back to 'normal'. I did put on more than a stone in weight due to the steroids I had to take, but that's all come off again now, thank heaven.

I'm currently on a more gentle treatment, just a hormone injection every twelve weeks, and another to strengthen the bones. I've gone meat and dairy free, and as a result feel pretty good at the moment. I've also started doing yoga again regularly – and meditating, which I find particularly useful.



Hearing from men who have been diagnosed as a result of me speaking out – I can't tell you how much that means to me.

The continued outpouring of support must also have helped.

Bill: I like to say I have been buoyed by a thousand points of love! From friends and colleagues, my footballing family at Wycombe Wanderers, and from countless messages from people just wishing me luck.

Also hearing from men who have been diagnosed and treated as a result of me speaking out – I can't tell you how much that means to me, and gives me strength for the time that lies ahead.

How important has keeping a positive mental attitude been for you?

Bill: It's hugely important to stay positive – that's part of the treatment really. You can't let this disease get on top of you because psychology has a lot to do with it. One thing I'm not going to let it do is get me down because then it wins. And I'm not going to let it win.

You mentioned your beloved Wycombe Wanderers football club where you often commentate on games. How important is sport in getting the message out there?

Bill: I would estimate that at least half the men who attend games are middle-aged, and so potentially at risk. One man in eight gets it, so we need to reiterate that if you are over 50, black, or have a family history of the disease you should speak to your doctor. It may just save your life.

It's also really useful to take some form of exercise, even if it's just a walk around the block once a day.

You met Stephen Fry recently for a Channel 4 documentary you've been filming. How was that?

Bill: We started making the documentary after my appearance on *Celebrity Bake Off*, when I revealed my diagnosis. All of a sudden, after years of covering the news, I was the news, which felt a bit odd.

Stephen had announced that he had been treated successfully for prostate cancer a little earlier, so it made sense to talk to him for the programme. And he very graciously agreed to meet us. Like me, he's happy that his experience has had such a positive effect.

The NHS had a huge surge in men speaking to their doctors about prostate cancer last year. Were you shocked by the impact the so-called 'Turnbull/Fry' effect had?

Bill: I was amazed to hear how many people had got themselves tested.

It's a great consolation to me to know that while my disease is advanced, many men have been saved a lot of difficulty by getting an earlier diagnosis.

Tell us a little more about what else we can expect from the film.

Bill: We're trying to paint a picture of what it's like to live with prostate cancer, to show how it feels to ride the Big C rollercoaster. There'll be one or two surprises in it. If the final result is anything like the making of it, you'll laugh and you might cry, but most of all I hope you'll learn a lot.

Bill shortly after his chemo treatment with football managers Gareth Ainsworth and Chris Powell



To find out more about your risk of prostate cancer visit prostatecanceruk.org/risk

THE MANUAL

Your questions answered about
if your prostate cancer comes back after treatment



Although many men with localised or locally advanced prostate cancer will have treatment that aims to cure the cancer, there's always a chance that treatment might not be successful and it might come back. This is known as recurrence and can be a worrying thought for many men.

Our Specialist Nurse, Ali, answers some of your questions about prostate cancer coming back after treatment.

Q How will I know if my prostate cancer comes back?

A Some men ask us if they should be looking out for any signs of their cancer returning. But actually, the first sign that your cancer might be coming back is more likely to be a continuous rise in the level of prostate specific antigen (PSA) in your blood over a number of tests, than any physical signs. Any rise in your PSA should be picked up by the regular PSA tests you will have after treatment (called 'follow-up'), usually about every three months. You can write them down each time, so you have a record to refer to.

The exact change in PSA level that suggests your cancer has come back depends on which treatment you had. And if you do have a rising PSA level, your doctor may do other tests to check if, and where, your cancer has come back such as PET-CT, CT, MRI or bone scan.

Q Why has my cancer come back?

A A common question we get is, "how can my prostate cancer come back if my prostate gland has gone or all my cancer was destroyed?" Although we talk about prostate cancer 'coming back,' in fact, if it does come back, it's likely it will have been there all along.

This could be if your first treatment didn't get rid of all of the cancer cells in your prostate or there were tiny clusters of cells left behind in, or just outside, the prostate.

Over time, these may have grown large enough to be picked up by tests or to cause symptoms. It's also possible that tests or scans you had when you were diagnosed might have missed small clusters of cancer cells outside your prostate, for example in your lymph nodes or bones. In this case, your first treatment would not have been aimed at these cells.



Although we talk about prostate cancer 'coming back,' in fact, if it does come back, it's likely it will have been there all along.

Q Can cancer that comes back be treated?

A Yes, there are plenty of treatments for prostate cancer that comes back (recurrent prostate cancer) and these are sometimes called second-line or salvage treatments. Many of them are the same as treatments for prostate cancer when it's first diagnosed, such as radiotherapy, brachytherapy, hormone therapy or high-intensity focused ultrasound (HIFU).

The choice of second-line treatment will depend on what you had first. For example, surgery isn't often available as a second-line treatment because first treatments, such as radiotherapy, damage the prostate and surrounding tissues, making it harder for a surgeon to remove the prostate.

There are two main types of treatments – those that aim to get rid of the cancer (curative treatments) and those that aim to delay the cancer growing but won't get rid of it. What you're offered will depend on a number of things, including where your cancer is, your general health, your PSA level and what treatment you've had already.

Q I already have side effects from my first treatment. Will I get more if I have more treatment?

A If you're already experiencing side effects from treatment, such as leaking urine or problems getting an erection, it can be natural to worry about what the side effects might be if you have more treatment.

The risk of side effects is usually higher for a second-line treatment compared to a first treatment. This is because your first treatment may have already caused some damage to the tissue surrounding the prostate. Side effects may also be more severe with a second-line treatment.

Ask your doctor or nurse to talk you through the possible side effects from the second-line treatments they offer you. If you do experience side effects, there are treatments and support available to help manage them.



If you do experience side effects, there are treatments and support available to help manage them.

It can be very difficult to learn that your prostate cancer has come back. All the thoughts and feelings you had when you were first diagnosed can come back again and they may be even stronger than before. Lots of men find it helpful to talk to someone about their feelings. This might be a friend or family member or someone who is trained to listen, like a counsellor or your doctor or nurse. You can also call one of our Specialist Nurses on **0800 074 8383**.

Remember, for many men, prostate cancer is slow-growing even when it comes back after treatment. Lots of men with recurrent prostate cancer continue to live long and active lives.



**For more information, read our booklet
'If your prostate cancer comes back: A guide to treatment and support'**

The magnificent marchers

Come rain or shine, you turned out in droves

A huge thank you to everyone who marched with us at our 10 local March for Men events in June. It was the biggest year yet.

More than 7,000 of you came together across the UK in Belfast, Birmingham, Bristol, Cardiff, Glasgow, Leeds, Liverpool, London, Manchester and Nottingham to

raise funds for vital research and to support men and their families.

Here are just a few of the photos and stories from our walkers. You can find more on our website at prostatecanceruk.org/marchstories



Brian and Specialist Nurse Meg finally meet in Bristol after talking for hours on our helpline.



Glandel Thompson cuts the ribbon in Bristol, a year on from his own treatment for prostate cancer.



Ralph Ellis's family walks to remember him, one year after his Football to Amsterdam ride for us.



Mason was the first across the line in Liverpool last year and came back to march again in 2019.



**If you couldn't make one of our arranged events, don't worry!
See page 20 for details on how to organise your own.**

In the SPOTLIGHT

Fraser Love

"I have been honoured with the chance to wear my brother's kilt for the walk, so he will be there in spirit to push me on through the toughest parts."

Fraser Love's brother died from prostate cancer a few years ago and his dad had also been diagnosed with the disease.

In September 2018, Fraser began to experience symptoms and, after he happened to mention his family history to the GP, he was eventually diagnosed with the disease himself.

"They are the words no one ever wants to hear – 'you have prostate cancer.'"



It was during this time that Fraser decided to do a 15-mile Kiltwalk for Prostate Cancer UK to help fund research into the disease. Fraser had surgery on 29 January and has been slowly training for the Kiltwalk throughout his recovery.

"From the third day of being home I started my training. First, I walked to the nearest lamp to my house, the second the next day and so on. At three weeks, I was at three miles and have just built up from there.

"I class myself as so lucky. Lucky to have cancer? No. But I'm lucky that me mentioning about my brother and dad to the doctor in a passing statement has saved my life, and that's what I count myself lucky for.

"I hope this money goes towards a screening programme, as that can ultimately save men's lives."

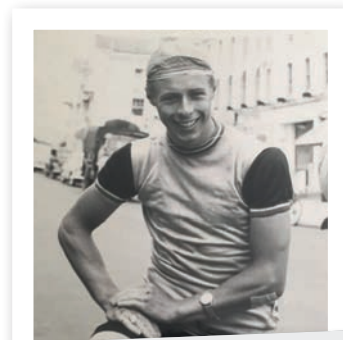


"We'll not admire Pat's garden again, complete DIY tasks under his meticulous guidance, or watch his grandchildren's faces as he flops to the floor and becomes a multitude of animals, each with a different voice.

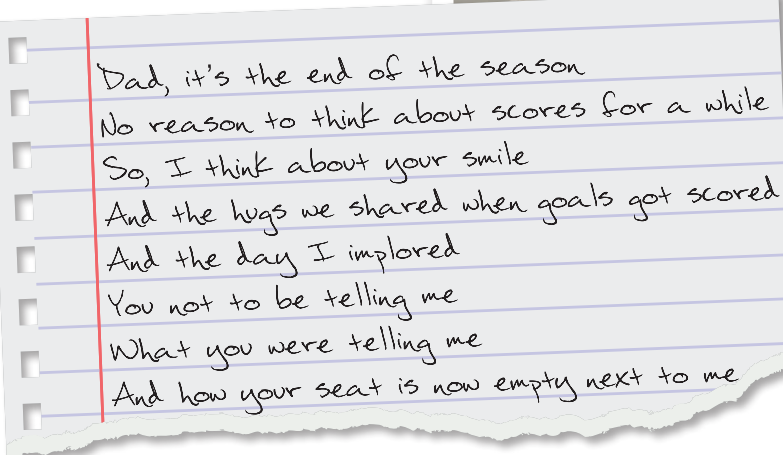
"I wear [the badge] all the time now; it has become as much of my routine as putting a watch on my wrist, and I feel something important is missing if I don't have it.

"To me, the badge is a reminder, a comfort, and a call to action."

For the full poem, visit prostatecanceruk.org/topdad



"Raising awareness of prostate cancer is a big deal and I'm keen to do whatever I can to spread the message to men about the disease," says David, whose father-in-law, Pat, was diagnosed with advanced prostate cancer in 2013 and died of the disease in July 2018.



THANK YOU

£9,500

The Boot Inn in Lapworth raised an incredible amount from their annual Christmas lunch.



4 rides



Matt Dainty is taking part in four of our big cycling challenges in 2019 to raise money for prostate cancer researchers, like his wife Hayley.

88 golfers



Rick Shiels hosted the first ever YouTube golf day and brought together many well-known faces for an amazing event.

40 singers



The Men United in Song choir in Peterborough is training singers of all abilities to put on a charity concert.

£13,000

After Phil True died from prostate cancer before doing a planned 10K run to raise money for research, his family completed it in his memory.



GET INVOLVED

Five things you can do to support us

1 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



4 Golf championship Autumn

Could you be crowned one of our champion golfers in 2019? Host a golf day to raise funds for us and the winning player will earn a place at one of three regional finals at the world-class courses of

Cathkin Braes, Shandon Park, Little Aston, Lymm and Sandy Lodge. Former European Open Champion Andrew Murray will be offering a free golf clinic for every finalist on the day, too.

Find out more at prostatecanceruk.org/golf or call 020 3310 7041.

2 Free Wills Month October

This October, you can have your Will written or updated for free by a local solicitor. There is no obligation to include a gift to Prostate Cancer UK, but we would be extremely grateful if you considered remembering us in this way.

For more information or to take part, please visit freewillsmoth.org.uk or call 0345 686 4309 from 9am on 1 October.

The number of appointments are limited, so we recommend you book as early as you can.

3 Donate your day All year round

Got a special day coming up? Whether it's a birthday or your wedding day, you can support us while you celebrate by taking a collection or selling badges to your guests. It's a great way to mark your occasion and we've lots of ideas, resources and support to help you.

Find out more at prostatecanceruk.org/dyd

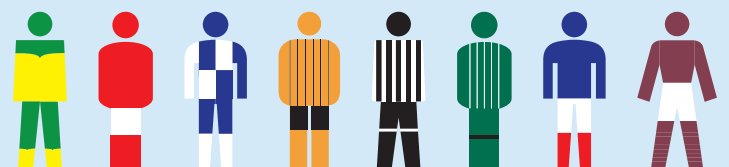


5 Men United match days Various dates

Join us at football grounds around the country to collect money from fans for the most common cancer in men.

You'll meet lots of like-minded people, enjoy the match day buzz, and get a ticket to watch the match afterwards.

Find out more at prostatecanceruk.org/matchday



EVENING EVENTS

CALENDAR SEPT – DECEMBER 2019

SEPTEMBER

5-8 Jeff Stelling's March for Men

Having already completed 25 walking marathons, Jeff takes on a new challenge across four nations in four days. Walk with him as he visits Glasgow, Belfast, Cardiff and London, and help him smash his £1 million target.



15 Edinburgh Kiltwalk

Join thousands of people as they don some tartan and tackle a 5, 13 or 26 mile walk raising funds that receive an incredible 40 per cent top up from the Sir Tom Hunter Foundation.

28-29 Great Scottish Run

Experience the electric atmosphere, friendly welcome and excellent race day experience, by taking on a 10K or half marathon in Glasgow city centre.

OCTOBER

6 Cardiff Half Marathon

Take part in one of the UK's biggest and best road races on an iconic course around Wales' capital city.

12 Non-League Day

We are the proud official charity partner of this memorable day once again. Visit your local Non-League Club, get behind them and encourage them to support Prostate Cancer UK this October.



13 Royal Parks Half Marathon

This stunning central London Half Marathon, takes in some of the capital's world-famous landmarks on closed roads, and four of London's eight Royal Parks.



NOVEMBER

1-30 Movember

We want men and women to sign up and grow a Mo, commit to Move, or throw a Movember event to raise funds for men's health and stop men dying too young.

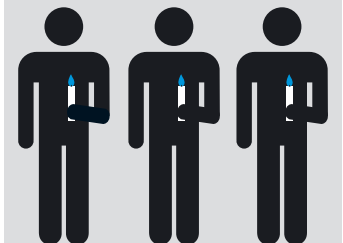
3 Men's 10K Edinburgh

Join thousands in this stunning 10K closed roads run through the heart of Scotland's beautiful capital city. The route passes Edinburgh Castle, Arthur's Seat and Holyrood Palace before finishing at the Murrayfield stadium.

DECEMBER

2, 4 Carols by Candlelight

Join us to celebrate the start of the festive season at our annual sell-out Carols by Candlelight events in London and Liverpool. Expect readings from celebrity guests, mince pies and plenty of festive cheer. Sign up to find out when tickets go on sale prostatecanceruk.org/carols



March the Month

How many steps will you complete in one month? This September we're challenging you to March the Month by walking 11,000 steps a day – the same amount of men who die each year of prostate cancer – to get fit and raise money to help us beat prostate cancer.



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 can match you 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.



All I heard the doctor say was, 'you've got cancer'. Things only started falling into place after I spoke to a Specialist Nurse at Prostate Cancer UK.

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.



Find out more about our services at prostatecanceruk.org/get-support

Other useful organisations

Bladder and Bowel UK

www.bbuk.org.uk
0161 607 8219

Information and support for anyone experiencing bladder and bowel problems.

British Association for Counselling and Psychotherapy

www.itsgoodtotalk.org.uk
01455 883 300

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

Cancer Black Care

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

Also known as the National Federation of Prostate Cancer Support Groups, it works closely with us to provide local support to patients and families.



Every month, thousands of people use our online community, posting messages in hundreds of active conversations. The community is for a wide range of people who may have been affected by cancer.

It is a welcoming and supportive place where men and those close to them can openly seek and offer support, ask questions and share information. Many also share their personal stories and experiences of prostate cancer.

Being a part of our online community can provide great comfort:



“On the forum I found a group of people all connected by the disease whose collective knowledge and understanding helped me understand my situation. I truly believe membership to this forum should be recommended by medical professionals at diagnosis.”



“It has been four months since my husband received his difficult diagnosis and I want you all on the forum to know how much you have meant to us as we learn about this disease.”

The online forum is open for people to take a look around and read through the conversations without becoming a member. Forum questions, answers, advice, support and information are viewable whether you're a member or not.

If you'd like to become a member and participate more, all you need to register is an email address and a username.

As part of this community, you can talk about whatever you want, from diagnosis to dealing with treatment. Simply browse the conversations to join one, or start your own if you'd prefer.

Visit prostatecanceruk.org/online-community

MEN

We are with you



PROSTATE CANCER UK