

Progress

Prostate cancer news and views
Issue 5 | Winter 2015

Managing incontinence

How you can deal with this side effect

RUDOLPH WALKER



Prostate cancer and me



PROSTATE
CANCER UK

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Editor's note

Welcome to Issue 5 of Progress. In this issue we bring you our first four-page special on clinical trials and answer the questions that men are often embarrassed to ask about incontinence in the Manual. You can read all the latest research and charity news and hear our cover star, Rudolph Walker, talking about how prostate cancer has touched his life.

I also want to let you know that Issue 6 will come to you under a new name. Nothing at all will change inside the cover – we'll still bring you the same high quality news and views and keep answering your prostate cancer questions. We have become aware that a similar organisation uses the same name for its newsletter. So, while we love the name Progress, we are taking this opportunity to come up with something even better.

Catherine

Cover photo by Adrian White



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INBOX

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



Dear Progress

It would be useful to see a feature on erectile dysfunction as a common problem after treatment. It would also be good to highlight the lack of treatment available to men nationwide who have had prostate cancer. It is a postcode lottery and health authorities refuse to fund penile implants, which is a disgrace. This issue needs to be more nationally publicised!

Mark, Kent

Dear Mark,
We couldn't agree more! In the first issue of Progress we addressed men's questions around sex and prostate cancer and you can read that article on our website.

But there's even better news. We've teamed up with Macmillan to publish guidelines to help health professionals support men who have trouble with erections after prostate cancer treatment. Until now, there was nothing available to help health professionals manage this condition in the best way. The guides set out treatment pathways (what to do when) and the pros and cons of every treatment option.

They're an important tool for men too. They describe the best possible support and treatment, so men will know what they can ask their doctor or nurse for and when to ask. And that's critical because early intervention offers men the best chance of making a full recovery.

We're also working to make sure men can get all the treatments they need (including tablets, pumps, injections and gels) wherever they are in the UK.

You can read about the guidelines here: prostatecanceruk.org/guidelines-erection-problems

If possible I would like to see issues 1-3 of Progress. Please let me know how I order these?

You can download all the previous issues of Progress on our website prostatecanceruk.org/progress or get in touch with our Supporter Care team supportercare@prostatecanceruk.org to order printed copies.



Dear Progress

I think it would be a good idea to email Progress recipients about fundraising events in their areas, do it by postcode selection.
Peter, Solihull

Dear Peter,
In our monthly Progress email newsletter we already tailor some content by region, such as events, and we're looking at ways to do this more. Soon our website will have a feature for you to enter your postcode and find out what's happening on your doorstep – not just events, it'll tell you about volunteering opportunities and even research projects near you. You can sign up for email Progress on our website or with the enclosed form.

Write to us:
Prostate Cancer UK
Fourth floor
The Counting House
53 Tooley Street
London SE1 2QN



Dear Progress

I work in a pub and the ladies' toilet has posters with what to look out for regarding breast cancer. Do you know where I could get one for prostate cancer to put up in the gents? Keep up the good work.
Medwyn, Anglesey

Dear Medwyn,
We have a poster titled 'Toilet trouble? Could be a prostate problem', which might work for you. We also have pocket-sized guides which give more detail about prostate problems. You can order both and more information about prostate cancer on our website: prostatecanceruk.org/information/our-publications



I am impressed by your coverage of new treatments for and research into prostate cancer. You do not talk down to your readers. Please do not change too much.

Like us on Facebook:
Prostate Cancer UK

Follow us on Twitter:
@ProstateUK

Email the Progress team:
progress@prostatecanceruk.org

PROSTATE CANCER NEWS

Calculating your risk: a funding update

In the last issue of Progress (Summer 2014) we told you that we wanted to fund a research project that would enable GPs to give an individual man an accurate estimate of his risk of developing prostate cancer. That's still the plan, and here's an update on a new and exciting way we're hoping to achieve it.

At first, we put out a call for research proposals that would answer our questions, which is the way we normally fund research. But this isn't a normal project because we

have a list of very detailed questions that we need answers to. We think this is why we didn't manage to find the right project to fund through the call.

Instead, we've decided to handpick a group of experts who we hope will work together to develop a research programme to answer those very precise questions. We've got a group of 15 world leading researchers from the UK, Scandinavia, Europe, the United States and Canada coming to a two day meeting in London. The

group includes researchers responsible for developing risk calculators in other parts of the world. We'll ask them to talk about what's working in other countries, what could be translated directly into the UK and what the stumbling blocks might be. Finally we'll encourage them to work together to develop a research programme.

We're confident that this meeting will generate a fundable project, but even if it doesn't, it will at least give us a clear picture of what research is going on

into prostate cancer risk around the world, and what needs to change so that we can do the same in the UK. We think this approach will give us the best possible chance of revolutionising how we work out a man's personal risk of developing prostate cancer.



Behind the headlines: Can having sex with lots of women reduce your risk of prostate cancer?

You may have seen this headline splashed across the papers recently, but should men really start racking up the notches on their bedposts to avoid prostate cancer? To put it bluntly, no.

Researchers at the University of Montreal found that men who said they'd had sex with more than 20 women were 28 per cent less likely to have been diagnosed with prostate cancer than men who'd only slept with one woman.

If this meant that having sex with lots of women protected you from prostate cancer, you'd expect that the more women a man had slept with, the lower his risk would be. But that isn't what they saw here. They only saw a reduced risk in men who'd had sex with over 21 women. Having sex with anything from 1 to 20 women had no significant effect on risk.

Some papers also picked up that of the men with prostate cancer, those

who said they'd had sex with more than 20 women were 19 per cent less likely to have aggressive prostate cancer than men who'd only slept with one woman. But this finding wasn't statistically significant – in other words we can't be sure that this wasn't just down to chance.

The important point here is that the research team spotted a link between two things – having sex with lots of women and risk of prostate cancer.

But this is absolutely not the same as saying that one factor causes or prevents the other.

It's an eye-catching story, but it's incredibly difficult to draw any concrete conclusions on the association between the number of women a man has had sex with and his prostate cancer risk. And the results of this research should not encourage men to sleep with more women to protect themselves against the disease. Sorry guys.



Early results from drug trial reveal promising findings in men with advanced prostate cancer

At the 2014 National Cancer Research Institute (NCRI) cancer conference, Professor Johann De Bono revealed exciting new results from a clinical trial he's leading for men with advanced prostate cancer. The trial, funded in part by Prostate Cancer UK and the Movember Foundation, is investigating the use of a drug called olaparib in men with advanced prostate cancer.

Olaparib is one of a class of drugs called PARP inhibitors. It is already licensed for use and very effective in treating ovarian

cancer. In normal cells, damaged DNA is quickly repaired. But when the genes responsible for repairing the broken DNA are mutated, this damage goes unchecked. This can lead to errors in the DNA which can eventually cause cancer. PARP inhibitors work by killing cells with damaged DNA, so preventing tumours from growing.

Professor de Bono and his team at the Institute of Cancer Research (ICR) and the Royal Marsden NHS Foundation Trust are testing olaparib in men with advanced prostate

cancer who don't have inherited mutations in their DNA. So far the results have been positive, with some patients with advanced, aggressive prostate cancer having an impressive response to the drug.

Other new research from the ICR (see article below) has enabled researchers to take this trial even further. It's now possible for the researchers to test men for mutations in DNA damage repair genes which occur throughout the course of their disease. This means in future we might be able to test men

during treatment, identify those who are most likely to respond to PARP inhibitors and switch them to this treatment, at the earliest possible time.

These are still very early results, so it's too soon to say for certain that these treatments will definitely be beneficial. But it's really exciting to see clinical trials investigating new uses for drugs we already know work well for other cancer types. This should make it quicker to get effective drugs to the men who need them. And not a moment too soon.

FROM THE LAB Progress reports on the research we are funding

Matchmaking men with prostate cancer and the drugs that will benefit them

Dr Joaquin Mateo works in Professor Johann De Bono's lab at the Institute of Cancer Research. He is working with the men on Professor De Bono's olaparib clinical trial (see above) to find out how often changes in DNA damage repair genes occur in men with no inherited mutation. And he wants to find out how these changes affect their chance of developing aggressive prostate cancer.

Dr Mateo holds a Prostate Cancer UK – Medical Research Council (MRC) Clinical Training Fellowship, funded jointly by the Movember Foundation and the MRC.

Dr Mateo will further develop the laboratory test Professor De Bono is using to show which patients are most likely to respond well to PARP inhibitors.

He will compare the genetic information of men on the trial who responded well to olaparib with those who didn't. His aim is to see whether the men who

responded well are the same men who have a non-inherited mutation in a DNA damage repair gene. After that, Dr Mateo will do laboratory studies to work out exactly how these mutations affect the cell's ability to repair its DNA and how this changes the way it reacts to different treatments.

This is a great example of how new research can build on the solid foundations of previous studies to turn preliminary results into gold standard patient care as soon as possible.



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

How does groundbreaking research become reality for men?

We examine a crucial stage in the process of developing new treatments, which patients are a vital part of – the clinical trial



We know it can take scientists years of hard work to make big breakthroughs. But what happens once they have? There are many stages in the process of developing a new medicine or medical procedure.

And before a new treatment can be widely used, researchers must test how well it works in patients and how it compares to the best treatment currently available.

This process is called a clinical trial. A new treatment has to perform well in several different clinical trials, with increasing numbers of patients, before it can be made widely available. Treatments for prostate cancer are no exception.

Clinical trials can also be a way to access the newest treatments and many men contact us to find out more about this and how they can take part.

In this four-page special we look at different types of clinical trials, what it takes to get one off the ground and we examine the pros and cons of taking part.

Clinical trial phases

Clinical trials are divided into different steps, or phases. If a new drug or procedure does well in one phase, it is tested in the next.



A **phase 0 trial** is the first time a drug has been used in people. The dose of drug patients receive in these types of study are too small to treat the cancer, but should tell the researchers whether the drug reaches the cancer, and how the body and the cancer cells respond. The small doses mean patients are unlikely to benefit from the treatment at this stage, but this also reduces the risk of side effects.

A **phase 1 trial** will generally involve a small number of patients. The patients may be people with advanced disease who have tried all other available treatments. These trials are designed to find out about the safety and side effects of a new treatment and if it could work well in humans.

A **phase 2 trial** often involves more patients than a phase 1. It is designed to look at how well a treatment works and to collect more information about the dose, safety and side effects. These trials may either test a new treatment against an existing treatment or against a placebo (dummy) drug.

A **phase 3 trial** tests a new treatment against the best existing treatment, if there is one available. These may involve thousands of patients at different hospitals and even in different countries. This is where most potential new treatments fail.

A **phase 4 trial** may happen after a new treatment is in use. It is intended to collect information about long-term risks and benefits and find out more about the safety and side effects, as well as how well the treatment works when it's used more widely.

Blinded trials Sometimes, a trial might be blinded. This means that the patients don't know which treatment they're getting. Trials need to be blind because just knowing that you are getting a new treatment can affect how you respond to it and make the results unreliable. If a trial is double-blinded, neither the patients nor the doctors know which treatment each patient is getting.

Randomised trials Most phase 3 and some phase 2 trials are randomised. This means that there are at least two groups of patients, often those who will get the treatment and those who won't. People are put into one group or the other randomly. This is important to make sure that nothing in the way people are chosen for each group will affect the results – for example patient age, gender, or even how well they feel.

What does it take to make a clinical trial happen?

We spoke to **Mr Hashim Ahmed**, MRC Clinician Scientist and Honorary Consultant Urological Surgeon at University College London Hospital to find out. He told us: “Having the idea is the most enjoyable, but also most difficult part of getting a clinical trial off the ground. It can then take two or three years to get from having this good idea to recruiting the first patient.”

So what are the hold ups?

Well, there are a lot of approval processes to go through. This is mainly because it's so important to make sure that patients' safety during the trial has been properly considered.

It's also down to the fact that clinical trials are very expensive. They can cost anything from £50,000 to more than £100million, depending on the type, length and complexity of the trial and how many hospitals are involved.

The first port of call is the ethics committee. This is a group of health professionals, patients, lawyers and members of the public, who are there to look after the best interests of patients involved in the trial. Mr Ahmed said getting approval here used to be the biggest hold up, until the Westminster Government introduced compulsory turnaround times.



It can take two or three years to get from having a good idea to recruiting the first patient.



“Now you can expect final approval or rejection in a maximum of 90 days, if you respond to their questions quickly. It's the hospital R and D (Research and Development) that's the biggest obstacle now. This can take up to six months.”

The local R and D process is one of the approval steps needed for an NHS hospital to agree to host a trial, and the time this takes can vary from hospital to hospital. In hospitals that run a lot of clinical trials, the R and D office is likely to be extremely busy, considering lots of applications for trials in all disease areas at the same time.

Trials of new medicines or experimental medical equipment will also need approval from the Medicines and Healthcare Products Regulatory Agency (MHRA), which is responsible for making sure that all medicines and medical devices in the UK work and are safe to use.

If a trial is taking place in more than one hospital, there may be more complications. They also need something called coordinated NHS permission. This means the NHS has approved the trial at a high level and should mean that local R and D permissions can be faster and less in depth, and help avoid some of the delays.

Once all the checks are complete, the researchers visit the hospital to make sure everyone involved in the trial, including doctors, researchers and nurses, knows exactly how it will work and what to expect. However there may still be delays from issues such as drug supply and staff training.

The Health Research Authority recognises that this process is not efficient. It's attempting to streamline it by introducing a single approval method to cover all ethical, legal and practical aspects of a research study – regardless of how many hospitals are involved. This should mean each hospital will just have to decide whether they are able to host the trial. This new system is intended to be in place in all hospitals in England by the end of 2015.

Feature continues on pages 8 and 9

Find out more about clinical trials in our factsheet prostatecanceruk.org/clinical-trials

Deciding to be part of a clinical trial

Taking part in a clinical trial can be a way to access the newest treatments. Not everyone is going to be suitable for every trial but, if you find that you are, deciding whether or not to take part is something to think very carefully about. It's really important to find out as much as possible and ask questions before you sign up.

It is important to remember that not everyone will benefit from taking part in a clinical trial. And, to some people, being part of a process to test a brand new treatment can sound scary. But, as explained above, there are many checks in place to ensure clinical trials are as safe as possible. And there can be important benefits to taking part.

One recent study found that men with advanced prostate cancer that had stopped responding to hormone therapy lived for longer, on average, than they would have done 10 years ago. The men in this study had taken part in clinical trials and received experimental treatments like docetaxel, abiraterone, enzalutamide or radium 223. Since then, these treatments have become more widely available and can make a real difference to life expectancy for men with advanced prostate cancer.

You can read through all the pros and cons opposite and hear from two men who've taken part themselves.

How do I find out about clinical trials?



Speak to your GP or consultant



Get in touch with our Specialist Nurses



Or have a look at the Cancer Research UK website at www.cancerresearchuk.org/about-cancer/trials/

Pros and cons of taking part in a trial

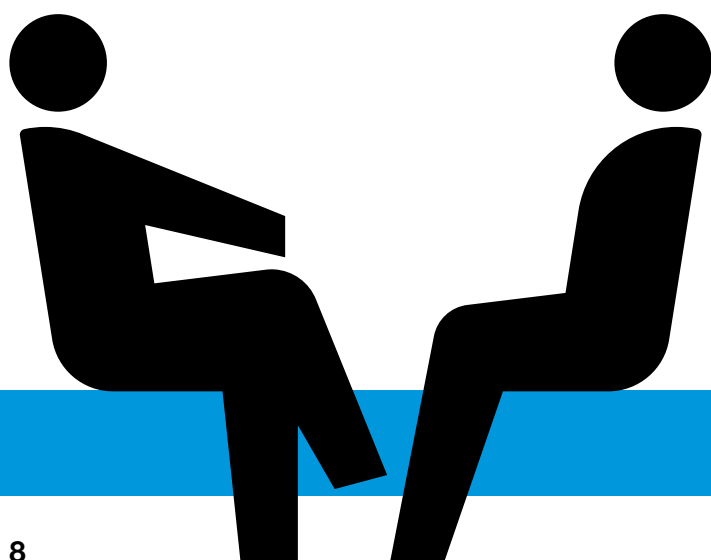
To find out more on clinical trials you can also read our factsheet or call our Specialist Nurses.

Pros

- You might get early access to new, potentially more effective therapies that may not be routinely available on the NHS for years.
- You may have more regular check-ups, tests and support from doctors and nurses than usual – some people find this reassuring.
- You are helping to improve future cancer treatment for others.
- You feel you're doing something positive about your health and taking an active role in your treatment and recovery.

Cons

- You may have more frequent testing as well as treatment, which might be inconvenient. This can go on for a long time. Some people also find this makes them more anxious about their cancer.
- There could be check-ups for many months or years afterwards, with questionnaires, tests or scans.
- You might not know in advance about all the possible side effects – the researchers themselves might not know them all yet.
- If the trial is randomised you won't get a choice about which treatment you have, and if the trial is blinded, you won't know which treatment you're getting.
- The new treatment may turn out to be no better than the existing treatment.
- There is the risk that the new treatment may not help you, even if it helps others.



Find out more about clinical trials in our factsheet prostatecanceruk.org/clinical-trials

What do the patients say?

Chris



Chris was diagnosed with localised prostate cancer in 2011, aged 56.

“I didn’t have any symptoms. I was diagnosed by chance when an email came round at work, offering PSA testing at a local rugby club. My GP referred me to the specialists. I spoke to a surgeon and a radiotherapist, but it seemed to me that these treatments had a lot of possible side effects.

“I also did a lot of internet research and found out about possible clinical trials. I’d asked the other specialists about some options like high intensity focused ultrasound (HIFU), but they mostly said ‘It’s experimental. It sounds good, but how do they know where the cancer is?’ So I had a good question to ask once I’d found out about a HIFU trial at University College London Hospital (UCLH) – the INDEX trial.

“They did an MRI scan to check I was suitable – and I was, because the cancer was only in half my prostate. They showed me the scans and pictures, but also told me how they analysed them, told me the pros and cons of the trial and went through the procedure fully. I quickly became more and more comfortable there.

“I liked the idea of a clinical trial and experimental treatment. It made me interested in medical science and how it works. If no-one took part in trials, then no medical innovations – even things that are widely available now – would ever happen. I always knew what to expect and I could ask a lot of questions.

“The UCLH team was in constant touch – not like normal care. They have a lot of time for you. And I knew if something went wrong there were still options that wouldn’t be worse than the standard treatment. I found the whole experience very positive.”

Ian



In 2003 Ian, aged 55, was diagnosed with advanced prostate cancer, which had spread to his bones.

“I was put on hormone therapy for almost two years, before it stopped working. My oncologist told me there were no treatment options left, except palliative care (treating my symptoms but not the cancer).

“I wasn’t going to accept this so I started looking for other possibilities, and my oncologist referred me to the Royal Marsden Hospital. They called a couple of weeks later to tell me I was eligible for a clinical trial of docetaxel and another drug called figitumumab.

“The treatments were experimental, but I didn’t have any other options, so I thought I’d give it a go. I’d been given very good information about the drugs and possible side effects. And I knew if I decided to stop the trial, it wouldn’t affect my care. Eventually, after nearly three years, my prostate cancer started to progress. After taking part in a couple more trials, I started on one for abiraterone, which I took for three-and-a-half years before my cancer started to grow again.

“At that point, I mentioned to my study nurse that four of my cousins had prostate cancer and that led to me taking part in a genetics study trialling a drug called olaparib. I took that for two-and-a-half years before it stopped being so effective.

“By now, all the trials had kept me alive for seven years. In that time, clinical understanding of a type of radiotherapy (intensity modulated radiotherapy) had progressed and was now feasible for me. I had 36 days of IMRT in 2013 as part of a trial. The side effects have been difficult but manageable. And, touch wood, it’s knocked out a cancer that I’d been told was going to kill me in the near future.”

Men United

Keeping friendships alive

We launched Men United last year, our movement for everyone who believes men are worth fighting for, and we were surprised at the results – in a good way.

People took our online awareness test in their thousands, many pledging to do more to support Men United. And the vast majority of these people – more than 80 per cent – were men, busting, once and for all, outdated myths that men do not engage with their health. And it wasn't just one subset of society getting involved. There were men from all walks of life: footballers, cabbies, politicians, musicians, lawyers, carpenters. You get the picture.

Last year was great – but we are not about the crack open the beers and rest on our laurels. We need to build on it.

So this January we are launching our next wave of advertising, which has at its heart the notion of men coming together for Men United and keeping friendships alive. We're encouraging men to do more of what they enjoy with their mates, whether it's cycling up hills or playing dominoes, and to do it for Men United. And we're offering you inspiration and support to help make it happen.

This is so much more than an ad campaign or a marketing initiative. It is a real testament to the momentum around men's health and the ambition of ordinary people, like you, who've signed for Men United to make things better for the 40,000 men diagnosed with prostate cancer every year.

Behind the scenes at the shoot for the new advert, the passion men feel for this cause was palpable. The advert, which first airs on 29 January, features a mixture of real mates, actors and our fabulous volunteers in a series of scenes about friendships. Without fail, someone at each location (and often several men)



had had some experience of prostate cancer. Take Andy and Dave Barham, brothers who have both been treated, who appear in the pub quiz scene. And Dennis Rootical, from the record shop, whose father and uncle both died from prostate cancer. Cast, crew, volunteers – the overwhelming theme of the day was not only the prevalence of prostate cancer, but the absolute drive to keep it on the radar until we beat it. It was great to hear how many are already supporters and chose to be part of the ad to show their allegiance.

And we need to carry on building this army and uniting men to do something great together to beat prostate cancer – whether that's running a marathon or taking part in a quiz. Because we know that what starts with a quick 'hello' or a chat in the pub can end with a nationwide movement for men.

**We are doing this for Andy, Dave and Dennis.
We are doing this for all men.**

Please, if you haven't already, sign up.

Owen Sharp
[#MenUnited](#)

To help keep friendships alive visit prostatecanceruk.org/menunited



Going global

Towards the end of 2014, The Movember Foundation announced the largest ever global investment to improve life for men with prostate cancer.

The project, named True NTH, will find and demonstrate the best and most cost-effective ways to improve prostate cancer care and support. What's really exciting is that, through the project, this knowledge will be shared around the world so all men can benefit from the best ideas.

We're really pleased to be a part of this programme and we're leading the way with five ground-breaking projects.

You can read more about True Nth and our projects on our website. prostatecanceruk.org/truenth



Get together more in 2015

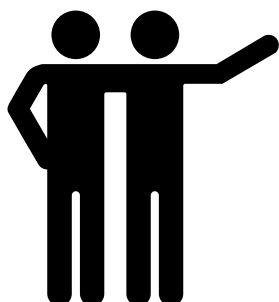
Men United is our movement for everyone who believes men are worth fighting for.

By joining Men United you'll get to see your mates more, do something great together and help beat prostate cancer.

Whether it's big or small, signing a petition or running a marathon, doing it together is what really matters.

Whatever you do, you'll be helping us push for real change, from more effective testing to better treatments. We've made some good strides with addressing the injustice around prostate cancer, but there's still a long way to go.

Search Men United now and help keep friendships alive.



Life's just better when you're with your mates

Life after prostate cancer

We've launched a new study, funded by the Movember Foundation, which aims to find out what life is really like after a prostate cancer diagnosis by asking the only people who know – men who've been there.

The insights from the Life after prostate cancer diagnosis study will help shape prostate cancer care and support available for men diagnosed with the disease.

Read more online: prostatecanceruk.org/lifeafterprostatecancer



Putting help where it's needed

Movember's funding has enabled us to expand our services across the UK to make sure more men living with prostate cancer have access to the care and support they need.

From support groups and relationship counselling to exercise classes and healthy living education, we're working with local service providers to ensure men with prostate cancer receive the care and support they need.

You can see a full list of our services on our website at: prostatecanceruk.org/in-your-area



Rudolph Walker

These days Rudolph Walker OBE is probably best known for his role as Patrick Trueman on BBC's EastEnders. But the actor, famous for many TV roles, has also been an ambassador for Prostate Cancer UK for 10 years. Rudolph, now 75, came to England in 1960 from Trinidad and Tobago. A proud father and grandfather, he tells us how prostate cancer has touched his

life and his family and why he's so committed to making Black men aware of their increased risk.

"I first heard about prostate cancer when my uncle was diagnosed over 20 years ago. He and his family had migrated to the United States from Trinidad. I spent a lot of time with them before coming to the UK. However, I only found out about his diagnosis after talking to his brother, another of my uncles, in Trinidad. At that point prostate cancer wasn't really talked about in any detail in the family.

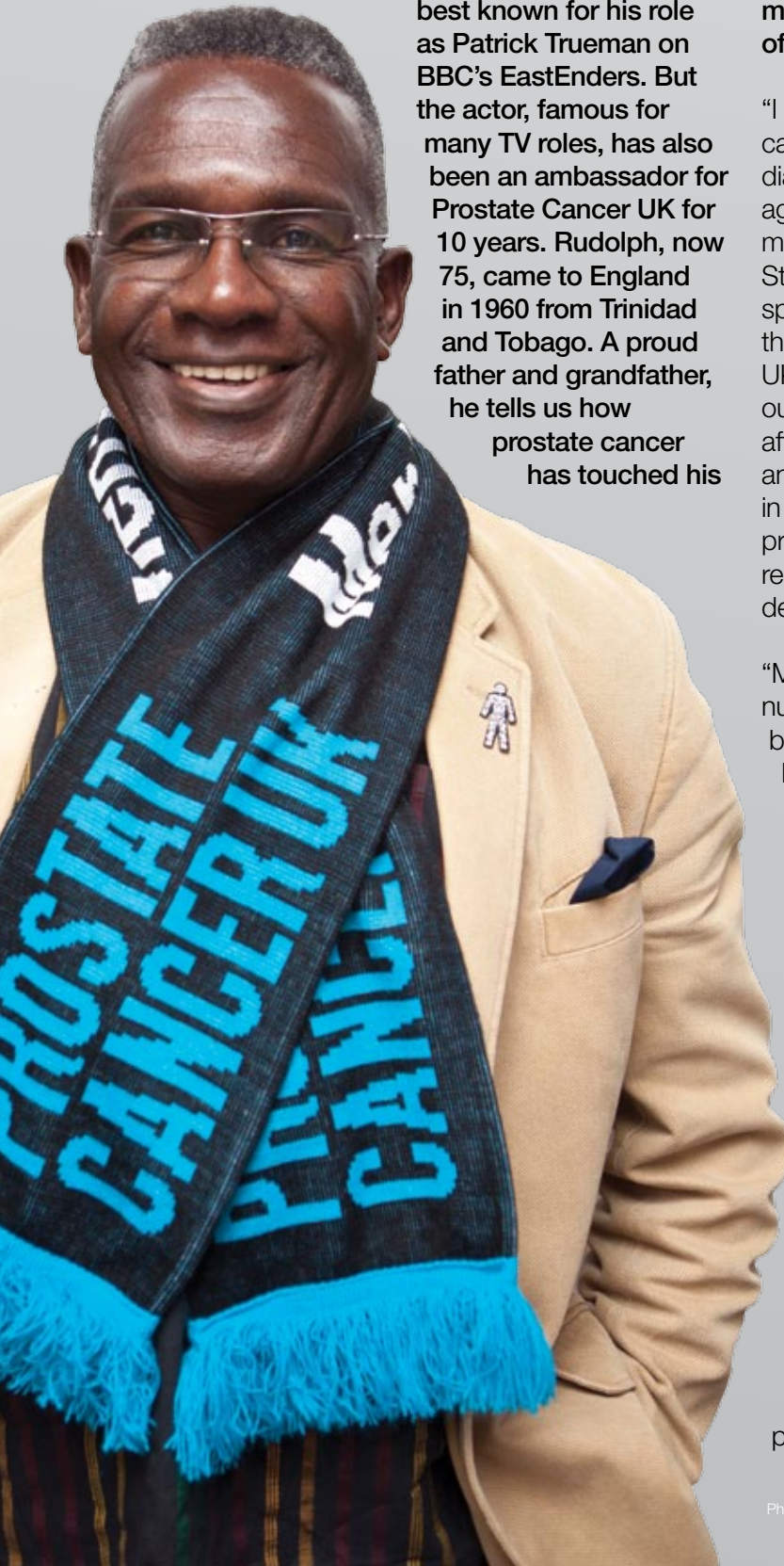
"My uncle lived quite a number of years after being diagnosed. I know he was treated with chemotherapy but I don't know much more than that. When I'd call, my aunt would say he was having further tests or treatment at the hospital, but it was never a long conversation. He certainly didn't talk about it – never mentioned the serious nature of what he was dealing with, neither did I really understand how serious it was until one day I had a call to tell me he'd died of prostate cancer.



I want to spread the word that there is no need for embarrassment.

"Since then the disease has had an impact upon my life in many ways. Hardly a month goes by without hearing of someone who has been affected. Either I'll get a call from Trinidad to say that someone I went to school with has died, or a friend-of-a-friend, or a distant relative. It's just there in front of me all the time, and not just in Trinidad, but over here as well.

"I started to learn more about prostate cancer around 10 years ago when I was asked to get involved with Prostate Cancer UK. It was only then I found out that if you have a father or brother with prostate cancer you are at a greater risk yourself – no one in my family was aware of this. And I discovered that Black men have a much greater risk than white men of the same age. It made me realise how important



it is to make people aware of it and I've been campaigning ever since.

"I was really thrilled to help out with the Men United campaign last year and it's encouraging to hear nearly 200,000 people have taken the Men United awareness test. It means that the message is starting to get through. Now we have to push it even further.

"One of the earlier events I did with Prostate Cancer UK was a cycle ride in London's East End. I thought it was an effective way of targeting African Caribbean men in their communities. Prostate cancer can be shrouded in secrecy because African Caribbean men, including me I suppose, see that part of the body as taboo. They don't want to be examined 'down there'.

"I think machoism is a characteristic in some African Caribbean men. They guard their maleness aggressively, saying 'nothing is wrong with me'. And they are thinking of the old story that if you have something wrong with your prostate and you



Rudolph in character as Patrick Trueman

get treated it's the end of your sex life. Of course this isn't always the case, especially these days with all the treatments available, but it's something they can't bear the thought of.

"I want to spread the word that there is no need for embarrassment. Now we've found out that 1 in every 4 Black men will get prostate cancer it's even more important to make them aware of the facts.

"I'm so pleased EastEnders has turned the spotlight to prostate cancer with Stan Carter's story. Through shows like this and campaigns like Men United we can get the message out there.

"Unfortunately the character I play, Patrick, is not the sort of man who discusses his health. He'd

probably make a joke of it. But then he had a stroke, and with a stroke, like with prostate cancer, you mustn't ignore the little symptoms if you have them. And Patrick did. He had a particular lifestyle, he drank quite a bit and didn't pay attention to the warning signs, such as when he collapsed.

"Men ought to take their health seriously, not just African Caribbean men, but right across the board. I think each of us should know our body and if things are not quite right – go to the doctor. And if you have a health problem it's important to discuss it with your partner, your family or trusted friends.

"I try to take good care of my health. I take my exercise – I play tennis. And I think laughter is a great recipe for good health. I try to be around people who have a good sense of humour.

"My doctor has told me many men over the age of 60 are often diagnosed with enlarged prostate and at 75 it's not surprising that I fall into that category. But I follow his advice and have

check-ups and PSA tests regularly, and I try not to abuse my body.

"I strongly appeal to all Black men to look after your health. Find out about your risk of prostate cancer and once you hit 40 or 50, go and talk to your doctor. And I think women need to urge their men to do this. They stand a chance of getting through to them, and it's in their interest because if a man has prostate cancer it affects the whole family."

Prostate cancer in Albert Square

As EastEnders fans will know, back in November character Stan Carter told his family he has advanced prostate cancer.

Health stories in soaps have a great record of drawing attention to the issues. We've been advising the show's writers on details of the story. And as Stan's journey unfolds, we expect this will make many more men aware of prostate cancer.

THE MANUAL

Your questions answered about
bladder and bowel incontinence



Treatments for prostate cancer can cause leaking from the bladder or bowel (incontinence). Men often want to know how common these problems are, and how to deal with them. Here, Specialist Nurse Meg Burgess answers your questions.

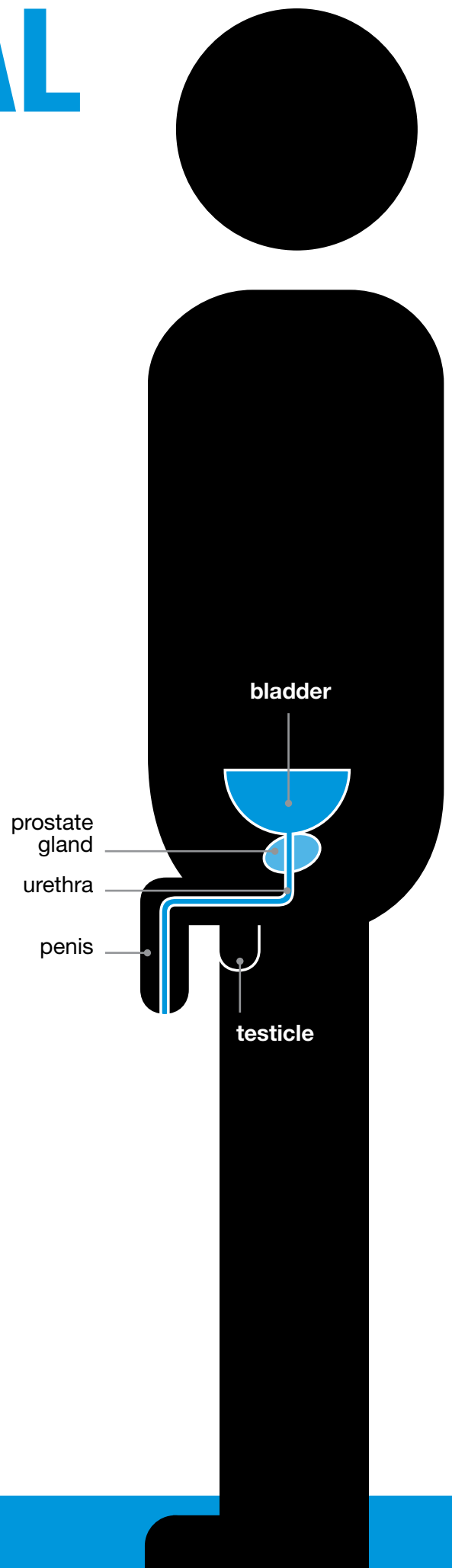
Q I've heard that some treatments can cause leaking urine. How common is this?

A Incontinence is the most common urinary problem after surgery for prostate cancer. Most men can't control their bladder properly at first, because surgery can affect the muscles and nerves that control urination. Some men just leak a few drops when they exercise, cough or sneeze (stress incontinence), while others leak more.

Leaking urine is less common after radiotherapy and brachytherapy, but a small number of men get urge incontinence. This is where you get a sudden urge to urinate and you leak before reaching a toilet. Leaking isn't very common after HIFU (high intensity focused ultrasound) and cryotherapy, although it's more likely if you've previously had radiotherapy.

Q How do I manage leaking urine?

A There are a range of products available, including absorbent pads and pants, bed pads, urinary sheaths and body-worn urinals. Many men use different products at different times, such as larger pads at night or a urinary sheath for long journeys. Every man is different, so find out what works best for you. You can read more at www.continenceproductadvisor.org



To find out more about managing incontinence please go to
prostatecanceruk.org/incontinence

Q How do I get hold of these products?

A Your local NHS service may provide some products free of charge. But services vary, so you may have to purchase your own, especially if you don't just want standard pads. Ask your GP to put you in touch with a district nurse. You could also try contacting Citizens Advice to see if you're eligible for financial support.

If you do need to buy your own pads, you may want to think about using washable ones to save money.

Q Does leaking urine improve over time?

A Usually yes. A small number of men are dry almost immediately after their surgery, and most see an improvement in the first few weeks and months. Leaking urine often improves after radiotherapy as well. It's important to be patient. Men often feel frustrated when they don't see a day-to-day improvement. But if you look at things on a weekly or monthly basis, the improvements can be much easier to see.

Unfortunately, some men may have longer-term incontinence. But there are treatments that can help, including medicines and surgery. You can read more about these in our fact sheet, Urinary problems after prostate cancer treatment. Your treatment options will depend on how much urine you're leaking, and how recently you had treatment. Talk to your doctor or nurse about treatments that might be suitable for you and referral to a continence service.

Q Is there anything I can do to help myself?

A Yes, there are a number of things. Regular pelvic floor muscle exercises can help if you leak urine. You can learn more about these in our fact sheet, Pelvic floor muscle exercises. And a technique called bladder retraining can help with urge incontinence.

Changing your lifestyle can also make a difference. For example, you could cut down on fizzy drinks, alcohol and caffeine, as these can irritate the bladder. You can also try to reduce the pressure on your pelvic floor by staying a healthy weight and eating lots of fibre to avoid constipation. And avoid smoking, as a smoker's cough can make the leaking worse.

Planning ahead can also make a big difference. Whenever you leave the house, make sure you know where to find a public toilet. You may want to carry an 'urgent' toilet card to show to staff in shops or restaurants. And Disability Rights UK runs a National

Key Scheme, which gives access to locked public toilets. It's also an idea to carry a bag with extra pads, underwear, wet wipes and a screw-top container in case you can't find a toilet.

Q What about bowel incontinence?

A Leaking from the back passage is rare. Many men get bowel changes after radiotherapy, as the treatment can irritate the lining of the bowel and back passage. But these are often minor, such as loose bowel movements or excess wind, and they usually settle down after finishing treatment. Men often need to rush to the toilet in the short term after radiotherapy, but very few men get long-term bowel incontinence, and it's even less likely after brachytherapy.

Q How can I manage bowel incontinence?

A You can get special pads to help manage bowel leakage, although men often use pads designed for leaking urine instead. You can read more about products for bowel incontinence at www.continenceproductadvisor.org

It can be embarrassing to talk about bowel incontinence. But do talk to your doctor, as there are treatments, products, and things you can do to help yourself. Your doctor may suggest changing your diet, and keeping a food diary to help identify any problem foods. Pelvic floor muscle exercises may also help, as these muscles support your bowel as well as your bladder. If diet and lifestyle changes don't help, medicines or other treatments may be an option.

Q My incontinence is really getting me down. Who can I talk to?

A Living with incontinence can affect your self-esteem and make you feel isolated. But seeking advice could improve your confidence and give you greater control. GPs and nurses see many men with bladder and bowel problems, and they can give you practical and emotional support. You could also ask them for information about professional counsellors or support groups.

You could also ask our Specialist Nurses about our One-to-one support service. We can put you in touch with someone with experience of incontinence who knows what you're going through. Or, if you find it difficult to talk about your incontinence, you may prefer to join our online community. It's a forum where men can find and offer support. Even if you don't feel like writing anything, it can help to read the conversations and see that you're not alone.

Health professionals who deal with prostate cancer

FOCUS ON

If you've got prostate cancer, you'll probably see many different health professionals. This team of experts involved in your diagnosis, treatment and care is called your multi-disciplinary team (MDT). It can be hard to keep track of who is who, what they do and when you'll see them. So to clear this up here's the lowdown on who is likely to be part of your MDT. (Remember, each hospital does things differently and you may not see everyone we mention here. They may also have slightly different titles.)

SPECIALIST NURSE



Who are they? A specialist in caring for men with prostate cancer. They may sometimes be called a clinical nurse specialist (CNS).

What do they do? They support you, answer questions and in some hospitals do biopsies and help with treatment. They're usually the health professional you'll see most and are likely to be your key worker or main contact.

UROLOGIST



Who are they? A surgeon who specialises in treating problems with the urinary and reproductive systems, including the prostate.

What do they do? They may carry out biopsies to help diagnose prostate cancer. And they carry out treatments including surgery to remove the prostate (radical prostatectomy), cryotherapy and high intensity focused ultrasound (HIFU).

ONCOLOGIST



Who are they? A specialist in treating cancer using treatments other than surgery.

What do they do? If you need hormone therapy to shrink your prostate before having other treatments, you may see an oncologist. They also carry out treatments including external beam radiotherapy, brachytherapy, hormone therapy and chemotherapy.

RADIOLOGIST



Who are they? A specialist in understanding medical scans and images to diagnose prostate cancer.

What do they do? They will look at the scans and images taken by the diagnostic radiographer and explain these to the rest of your MDT. Looking at the size, shape and position of your prostate cancer and whether it has spread to other parts of your body.

DIAGNOSTIC RADIOGRAPHER



Who are they? A specialist in taking images of the body.

What do they do? They will do any scans you need during your diagnosis and care and send these to your radiologist. These may include X-rays, MRI (magnetic resonance imaging) scans, CT (computerised tomography) scans and bone scans.

THERAPEUTIC RADIOGRAPHER



Who are they? Sometimes called a radiotherapy radiographer. They specialise in giving radiotherapy to treat cancer.

What do they do? They may work with the oncologist to give external beam radiotherapy or brachytherapy.

Read more about prostate cancer treatment at prostatecanceruk.org/information

Colin Taylor

Colin Taylor lives in Leeds with his wife Tracey. He works as a rep for a dental company. When Colin was diagnosed with prostate cancer at the age of 49 he found it hard to accept, having always thought of it as “an old man’s disease”. Here Colin talks about one of the side effects of his treatment he’s worked hard to manage – incontinence.

“It was Tracey who noticed changes to my urinary habits. I hadn’t thought it was a problem but she did. So I went and had a chat with my doctor who did a few general ‘well man tests’. When he called me back, he started talking about a raised PSA level and my prostate and I thought: ‘No I can’t have prostate cancer.’ It wasn’t until four months later after biopsies and other tests that it was confirmed.

“I decided to have surgery to remove my prostate. I walked into Leeds General Infirmary for the operation on a Thursday and was back home by the Friday evening

which was superb. But I didn’t realise it was the start of another journey – the recovery.

“The surgeon had pointed out the side effects before I had the operation. One was impotence (erection problems), the other was incontinence (leaking urine). Probably the last words you want to hear aged 49. He explained the incontinence would be worse at the start then better as time went on. Sure enough that was my experience. However I wasn’t expecting the level of incontinence I got initially.

“After I left hospital I had a catheter in and when I had it removed it was the best feeling in the world. But then the incontinence started.



I remember leaving the clinic and I couldn’t walk up the hill without completely emptying my bladder into an incontinence pad. It wasn’t nice at all.

“I got home, sat on the sofa and thought: ‘Right I’m going to beat this incontinence’. And then I got up to go to the loo and that prompted my bladder to empty. At that point I started to think: ‘Am I going to beat this? How am I going to do my job?’

“About six weeks after surgery I received an appointment for the incontinence clinic. I went along and the nurse explained everything and we discussed my level of incontinence. She gave me various options of protection. I wanted something that wouldn’t affect my ability to get back to work.

“The next day the Leeds PCT delivered a package of incontinence pads and things. Prior to that I really hadn’t got an idea what incontinence

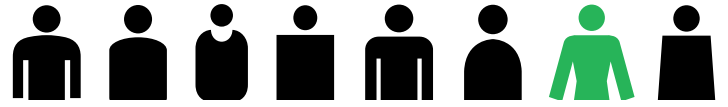
pads were like. I’d seen some in the supermarket but the level of incontinence I had at first called for something a lot greater than that.

“The first set of pads they gave me were up to my tummy and I thought that was what I’d have to deal with for a long time – but it wasn’t.

“The nurse at the clinic also organised an exercise programme for me, which was a really important part of my recovery. I did pelvic floor exercises to strengthen the muscles underneath my body, between my scrotum and anus. Over time I found I could feel them getting stronger and stronger. And my incontinence got better every week. It got better every month to a point where it’s non-existent now. I can go to work as normal, I can play rugby with my son, I can pick up my grandkids and throw them around.

“I’d advise other men to really put effort into pelvic floor exercises because I think it’s key in getting your incontinence to a manageable condition”.

Read more about managing incontinence on pages 14 and 15
prostatecanceruk.org/incontinence



The friend who got me through radiotherapy

by Ally Clarke

"I was diagnosed with stage three prostate cancer in January 2010. There were lots of tears, lots of hugs and a lot of reassurance from my wife saying: 'We are going to get through this'. That was very important for me. When the dust settled I decided to have radiotherapy. So it was eight or nine weeks of that – 37 treatments.

"There were days when I just didn't want to get out to go and have the radiotherapy – I was that tired. But my brother-in-law actually went with me every day. He was the one who said: 'Come on Clarkey we have got to go.' I would say: 'Five minutes more.' and he'd say: 'No, we have got to go now.' When we'd travel there, he'd be chatting to me all the time and then after a couple of treatments he realised, maybe he doesn't want to talk, so he never said anything, but he was always there.

"Every time we came up the stairs at the hospital, he would count down the treatments. He would say: '36 down, 35 to go'. And we did that right the way through. When I had the last one, we came up the stairs and he said: 'One down none to go. Let's go to that pub over there and have a beer.'

"I'm so grateful to him because I've always maintained that if it hadn't been for him, I'm pretty sure I wouldn't have finished the treatment. I would have skipped out."



Test your knowledge – it's quiz time

- 1) In which year was David Beckham sent off for his reaction after a tackle during a last 16 knockout match for England vs Argentina?
- 2) Which brand featured Roberta Flack's track 'First Time Ever I Saw Your Face' in their 2014 TV advert?
- 3) Name the 1988 romantic comedy film directed by John Landis, based on a story originally created by Eddie Murphy, who also starred in the lead role.

We love a good quiz. It's a great thing to do with friends. These are a few practice questions from our new quiz pack, which includes questions on culture, science, brands and puzzles. Could you use it to

get your mates together and host your own quiz to raise money for us?

We've made it simple. We give you question and answer sheets, audio files, a host script, and posters. And you give everyone a great night out. To host a quiz, register at prostatecanceruk.org/quiz



Answers 1: 1998 2: Vision Express 3: Coming to America

In the SPOTLIGHT

Peter Lamb from Somersham, Cambridgeshire

Peter lost his father to prostate cancer a few years ago. He had donated to Prostate Cancer UK but wanted to do something memorable. In September, he and a friend cycled from John O’Groats to Land End – over 890 miles.

“In the past I was a racing cyclist, so I had an idea of what it is to ride day after day and how to train for an event like this. However, we had never

undertaken a journey like this and the first few days were hilly. The training got us through, the scenery was stunning and the people were so supportive. It was a great experience.”

Peter raised over £5,000, a brilliant total. And a lot of that was thanks to a quiz he hosted to boost sponsorship before the race.

“We had over 100 participants and at the start I gave a small talk about why we were doing this and what we hoped to achieve. This meant a lot



as our compere was also undergoing treatment for prostate cancer. But the mood was jovial and the highlight was getting half the participants to dance to ‘Is this the way to Amarillo’! We raised over £1,100 and people who I didn’t even know sponsored me. It was just fantastic.”



“We have so many happy memories of our dad, who was a hero to us. We remember the many camping holidays we had, setting off early in the morning to ‘beat the rush’.

“He was kind, gentle, sociable, popular and was admired and loved. He guided us through everything and supported what we wanted in life. He worked very hard to provide for us. Dad was always there

no matter what. His love was forever strong, and cuddles forever tight.

“Our lives were shattered when he was diagnosed. We assured ourselves, ‘Dad can fight it’. And he shielded us from the severity of the illness and carried on as normal until the cancer spread. The illness deprived Dad of his mobility and independence but he fought with dignity and bravery.

Rebecca and Naomi Smith lost their dad, David, to prostate cancer earlier this year. David was diagnosed aged just 50. Since his death they have raised over £9,000 in his memory. Here they tell us why David was a Top Dad.



“Our lives have changed forever. We try to cope, but we’ve lost our support and inspiration and his guidance and love. We just wish he could still be with us.”

THANK YOU

1,485 VOLUNTEERS

To our volunteers. Without you our life-saving work wouldn’t be possible.

630 

To Paul Beevers who walked the 630-mile South West Coast Path in June and raised over £7,000.

2,500

To Michael O’Connor who cycled 2,500km from Monaco to Yorkshire and raised a whopping £15,983.

£11,000

To William Kilgannon and family who took part in our BBC lifeline appeal and helped raise £11,000.

6 

To six-year-old Connor and his mum who took on the Yorkshire Three Peaks challenge and raised £260.



To all the Mo Bros and Mo Sistas who took part in Movember this year.

GET INVOLVED

Get together to help with our work and become part of Men United – our growing movement for everyone who believes that men are worth righting for. There are opportunities and events throughout the year.

Hold a quiz for Men United

Q: How many quizzes are held every year in the UK?

A: Not enough, it's been decided.

Get your friends together and help win the fight against prostate cancer. We've made it simple and can provide everything you need in our quiz pack – from questions and answers to posters and signs.

With eight rounds full of questions on culture, science, sport and music there's something for everyone.

Sign up now and we'll send you everything you need: prostatecanceruk.org/quiz



Team up for le tour de football

12-15 June 2015

The London to Amsterdam Challenge is the perfect ride for football fans and cyclists. Why not make this football pilgrimage as a group?



On day one you'll cycle 90 miles from Leyton Orient's Matchroom Stadium via Colchester United's Weston Homes Community Stadium to Harwich. After a ferry crossing overnight, you'll explore a further 60 miles of the flat landscape of Dutch Zeeland before arriving at AFC Ajax.

Volunteer as a cheerer

Enjoy a fantastic day out and help us support the men and women taking on sporting challenges for men with prostate cancer. We have events across the country and volunteers are vital at every one.

You could get involved in registering competitors, cheering fundraisers, manning food stations, handing out medals and more.

There's always a great atmosphere and, as well as working for a good cause, you'll find out what it takes to run a busy sporting event.

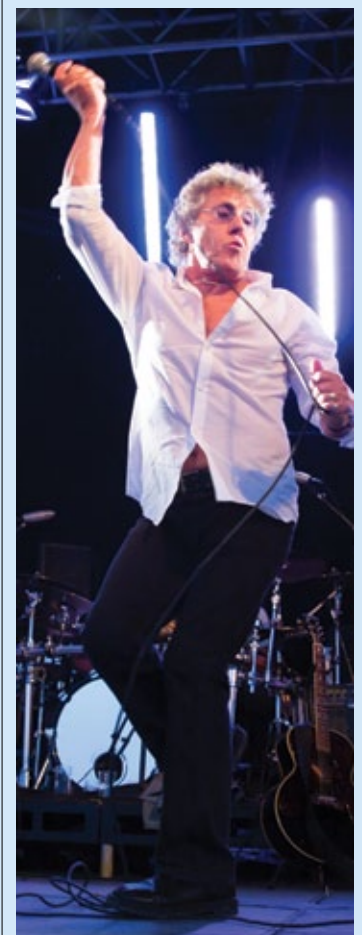
You can make a day of it with friends or volunteer on your own. There will be plenty of other volunteers and staff there to make sure you have a great time.

Find out more at: prostatecanceruk.org/volunteer

Rev up and rock out with The Who

13 June 2015

Get together to celebrate Father's Day with power cars, polo and great music from legendary artists. The Rock 'n' Horsepower event at Hurtwood Park Polo Club, on Saturday 13 June showcases all the excitement of polo plus a line up of high performance supercars and classic cars. The day will end with Kenney Jones performing live with some very special friends plus a set by The Who.

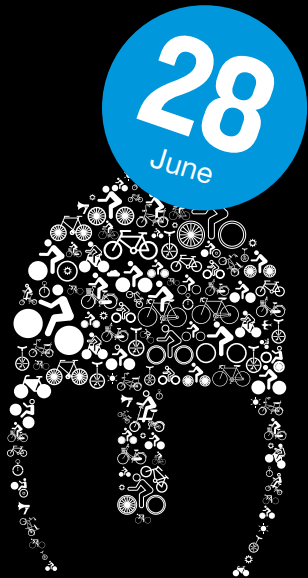


EVENTS CALENDAR

January 2015 – September 2015

Don't miss a classic

Weave your way through the stunning Suffolk countryside on our Saxon Classic cycle ride. You can choose between routes of 55km, 100km or 160km. With music, activities and hot food and drink at the finish, this is a fun day out for friends and family. So get them along to support you or join the ride.



More events

January-May

Hold a quiz for Men United



16 August

Jurassic Classic



26 April

London Marathon



1-2 August

Ride London



30-31 May

Edinburgh Marathon Festival



13 September

Great North Run



12-14 June

London to Amsterdam Challenge



28 June

Saxon Classic



16 August

Jurassic Classic



Man v BBQ

June-September
Get the gang together, fire up the grill and hold a BBQ to raise money to help beat prostate cancer.



Charity music gala night at Cadogan Hall, London

9 April, 7pm

Enjoy a unique concert of piano concertos by Liszt, Prokofiev, and Mendelssohn, as well as a debut composition by Prostate Cancer UK supporter, Adrian Goldsmith. Book your tickets now on the Cadogan Hall website or call the Cadogan Hall box office on 020 7730 4500.

Live Well with prostate cancer conference, Sunderland March

Hear from prostate cancer experts and find out about the services and support available for you if you're facing or recovering from treatment for prostate cancer.

Football League Collections

We'll be holding collections at football clubs across the country in March and April 2015. To find out more contact: volunteer@prostatecanceruk.org



Golf Day at Wentworth Club, Surrey

Join Ray Clemence OBE at our annual flagship Golf Day. It's a fun-filled, challenging and iconic 18 holes

on the prestigious Edinburgh course at Wentworth – just weeks before the PGA Championship. Email specialevents@prostatecanceruk.org to find out more.

Find out more about how you can get involved and become part of Men United at prostatecanceruk.org/get-involved



Our services

Specialist Nurses 0800 074 8383

(Mon to Fri 9am-6pm,
Wed 9am-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.

Get back on track 0800 074 8383

If you have prostate cancer and you're struggling with fatigue, our Get back on track team can 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 information section of our website or call our Specialist Nurses for help choosing the publications you need.



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

Prostate cancer support groups

Meet and talk to other people affected by prostate cancer who understand what you're going through. We run a number of support groups in Scotland and there are over 70 independent groups across the UK.

Regional services

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

Live chat

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

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

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



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

Other useful organisations

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

www.cancerblackcare.org.uk
020 8961 4151

Provides information and support to people from black and minority ethnic communities who are affected by cancer.

CancerHelp UK

www.cancerresearchuk.org/cancer-help
0808 800 4040

(Mon-Fri, 9am-5pm)

CancerHelp is the patient information website of Cancer Research UK and provides information about living with cancer.

College of Sexual and Relationship Therapists

www.cosrt.org.uk
020 8543 2707

For information on sexual and relationship therapy, including a list of therapists.

Health with Pride

www.healthwithpride.nhs.uk

An online health resource for lesbian, gay and bisexual patients. Their website has information on cancer issues and erectile dysfunction for gay men.

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 Cancer Caring Centres

www.maggiescentres.org
0300 123 1801

Provide information and support to anyone affected by cancer. Their website holds a list of centres across the UK and has an online support group.

NHS Choices

www.nhs.uk

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

Penny Brohn Cancer Care

www.pennybrohn.cancercare.org
0845 123 2310

Offers support using complementary therapies and self-help techniques to people affected by cancer. Their approach is designed to work hand-in-hand with medical treatment.

Relate

www.relate.org.uk
0300 100 1234

Relationship counselling and sex therapy for individuals and couples.

Sexual Advice Association

www.sda.uk.net
020 7486 7262

Provides a helpline service for advice and information about erectile dysfunction.

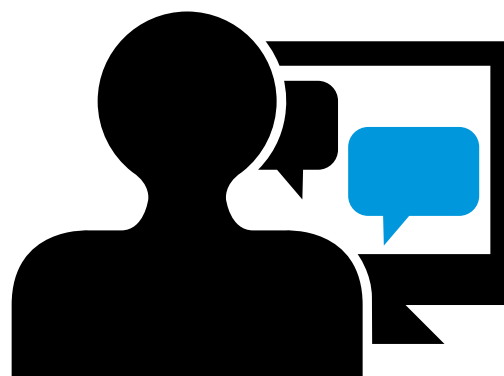
You can talk to our nurses online now

We know that some people find it difficult to talk about sensitive issues over the phone, and it can be hard to find the time for a telephone conversation.

That's why we've introduced Live chat, our online messenger service which allows you to talk with a Specialist Nurse at a time that suits you, by typing in questions. So, if you're concerned about prostate health or if you have been diagnosed with prostate cancer or other prostate diseases, you can

use Live chat to speak to our nurses about anything. If you're the partner, family or friend of someone affected, the service is for you too.

Live chat is available
Monday to Friday
10am-4pm
and Wednesday
10am-8pm

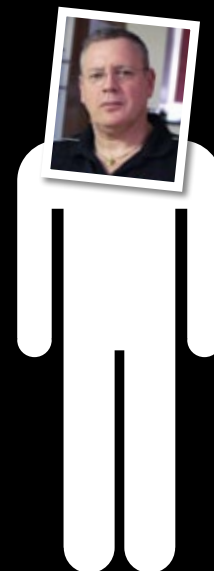


Go to prostatecanceruk.org/livechat for more information and to speak to a Specialist Nurse

You can help

We're really proud of the services we provide for men. However, every year in the UK 40,000 more men are diagnosed with prostate cancer. We need to reach a lot more of them.

If you want to join the fight and help more men like Colin, Chris and Ian to put prostate cancer behind them, please fill out the enclosed form. Or you could visit the Get involved section of our website to find out more or make a donation. Thank you.





KEEP STANDING TOGETHER.

See your friends more.
Join Men United and do something great
together to help beat prostate cancer at
prostatecanceruk.org/menunited

Men United. Keeping friendships alive.



**PROSTATE
CANCER UK**