

Progress

Prostate cancer news and views
Issue 3 | Spring 2014

Men United

Why we need to
get behind a
movement for men

PETER MOFFAT



Prostate
cancer
and me

Weighing up the costs

What's stopping new drugs
getting into your hands?



PROSTATE
CANCER UK

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Editor's note

Hello and welcome to Issue 3 of Progress. The new year brings new challenges. If you're like me, you may have already broken your resolutions. But if you haven't made any yet, how about joining Men United? We need you to stand up and stand together in the fight against prostate cancer.

In this issue our Chief Executive, Owen Sharp, talks about our new campaign, Men United v Prostate Cancer, and the importance of building a united front (page 8).

Ever wondered who decides if you can be prescribed new drugs? We take a look at drug appraisal and pricing – and ask whether you're getting a fair deal (page 6).

Finally, read writer Peter Moffat's moving story of when his dad was diagnosed with prostate cancer (page 10).

Thanks again to everyone who's shared their thoughts and stories for this issue.

Best wishes,

Jocelyne.

Editorial team

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INBOX

Tell us what you think about the magazine.
All feedback is welcome: the good, the bad and the downright constructive.



Dear Progress

In your last issue, you talked a lot about the PSA test and whether or not there should be a screening programme. While it's important for men to know about the PSA test – what about GPs? We expect them to know everything but should you be doing more to make sure they know enough about prostate cancer?

Alan, Manchester

Dear Alan

We asked our Education Manager, Gemma Borwick, about what work we're doing with GPs. Gemma said, "GPs and practice nurses are really keen for more information from us so they can better support their patients with or at risk of prostate cancer. With busy practices, they have limited time and prostate cancer is only a tiny part of everything they need to know about, but we've seen huge interest in our

training courses. Since we started our education programme, 18 months ago, we've trained over 3,500 GPs and practice nurses, through either face-to-face training days or online courses. Our courses cover everything from benign disease, PSA testing through to treatments and side effects like erectile dysfunction. There are still more GPs to reach, and this year we'll be running even more training days across the UK."



Dear Progress

I find your magazine very interesting but is it possible to receive it by email instead and save you money on print and postage?

Gerry, Herts

Dear Gerry

Yes, you can fill in the form with this magazine, or just email us at progress@prostatecanceruk.org We produce printed copies because lots of people prefer that format for reading and we want everyone who wants to read Progress to read it in the format that's best for them – like all our information – but the choice is yours.



Excellent info on pros and cons of PSA. It makes any decision to have the test harder because of all the variables, but it is good to know that so much worthwhile research is going on, and is indeed making Progress!



Dear Progress

You talk about incontinence and impotence in Progress, quite rightly, but there's no mention of the effect that treatment has on the bowels. I had radiotherapy 15 years ago and now experience bowel problems which have an effect on my day-to-day life. I have grown to live with it over the years but I think it would be good if you talked about it in your publication.



I have just received Issue 2 and I must congratulate you on a first class magazine. I sat down, opened Progress, and didn't stop until I had read the entire magazine.



Correction

In Issue 2, which focussed on the PSA test, we said that all men are entitled to have a PSA test. It is actually all men over 50 who have the right to a PSA test, as long as they've discussed the pros and cons with their GP. For more information about the PSA test, visit prostatecancer.org.uk/information

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PROSTATE CANCER NEWS

Behind the headlines: What does the updated NICE guideline mean for men?

A new set of guidelines for diagnosing and treating prostate cancer made the headlines in January, with two key recommendations around the use of 'active surveillance' and magnetic resonance imaging (MRI) sparking particular interest in the media.

The National Institute for Health and Care Excellence (NICE) guideline, which helps clinicians diagnose and treat men with prostate cancer, recommends offering active surveillance as an alternative to treatment for low risk prostate cancer, and using MRI to improve diagnosis for men.

Monitor or treat?

Active surveillance is a way of monitoring low risk prostate cancer through regular check-ups, rather than treating it straight away. This means men can avoid some of the unpleasant side effects of treatment such as erection problems and incontinence and only have treatment if their cancer shows signs of progressing.

Some news headlines suggested that the new guidance was encouraging monitoring over treatment, but this is not actually the case. Treatment for low risk prostate cancer is still very much an option for men.

However, the guidelines provide a new protocol for active surveillance, which gives clinicians a standard to work to. This is a step towards addressing men's worries that their cancer may spread and get missed, while also helping to avoid too many invasive biopsies.

MRI scans to help diagnose cancer

The other recommendation that was picked up in the media was around using MRI as part of diagnosis. The recommendation is to use a very accurate method of MRI called multiparametric MRI to look for prostate cancer in men whose first biopsy has

come back negative. This is to avoid unnecessary re-biopsies, which can be uncomfortable and carry risks such as infection.

However, there has been some question as to whether the timing of the new guidelines has missed a trick with MRI. Currently there are research trials going on, looking at the benefits of using this type of MRI before a man's first biopsy – to potentially avoid biopsy altogether, or help clinicians target the biopsy needle and get more accurate results. But the results of this research aren't due until 2015 so couldn't be considered for these guidelines.

New research takes us a step closer to detecting aggressive prostate cancers

One of our leading researchers has discovered a protein that can help tell the difference between prostate cancers that are life-threatening and those which are much less aggressive.

Dr Hayley Whitaker, at the Cambridge Research Institute, has carried out a study, part-funded by Prostate Cancer UK, which has found that there are much higher levels of

the protein, NAALADL2 in prostate cancer tissue compared with healthy tissue – and that the protein is linked with the aggressiveness of the disease.

At the moment tests for prostate cancer can't reliably tell us if cancer is fast-growing and needs treating straight away or is slow-growing and won't need any treatment. This means that some men

diagnosed with prostate cancer are faced with an almost impossible decision – to have treatment and risk long-term, potentially debilitating side effects when the tumour might be relatively benign, or to have their cancer monitored and run the risk that the tumour might spread.

Dr Whitaker's research is still at an early stage but it does take us a step closer to our goal where men

with aggressive tumours can have immediate treatment, and men with low-risk tumours can have the confidence to avoid or delay treatment.

Dr Iain Frame, our Director of Research said: "The results of this study are encouraging but we still have a long way to go. The challenge now is to see if this research can be translated into real benefits for diagnosed men."

Big U-turn by NICE means some men may be denied life-extending drug, enzalutamide.

Back in October we reported the good news that The National Institute for Health and Care Excellence (NICE) had provisionally approved the use of enzalutamide, a potentially life-extending drug, for men with advanced prostate cancer that has stopped responding to hormone therapy and chemotherapy.

But NICE has now reversed that decision and is recommending that enzalutamide only

be available to men with advanced prostate cancer, who haven't already had abiraterone. Abiraterone is the only other available treatment for this stage of prostate cancer.

If the decision goes ahead, it would mean that, in England, Wales and possibly Northern Ireland, men who might benefit from enzalutamide may not be able to get hold of it. It will also place a huge burden on doctors, who will have to consider that prescribing

abiraterone will rule out using enzalutamide later on – but without knowing which treatment will work best for their patient. This is an unnecessary complication for men for whom options are already limited.

The news comes even after the Scottish Medicines Consortium (SMC) has approved enzalutamide with no restrictions in Scotland.

Our Chief Executive, Owen Sharp commented,

“This blatant U-turn is at best disheartening. Adding this restriction, leaves hundreds of men, who have few treatments anyway, with no hope of accessing enzalutamide.”

NICE has opened the decision to consultation and we've responded with a call to remove the restrictions. Thank you to everyone who responded to the public consultation with their own comments. prostatecanceruk.org/challengeNICE

FROM THE LAB

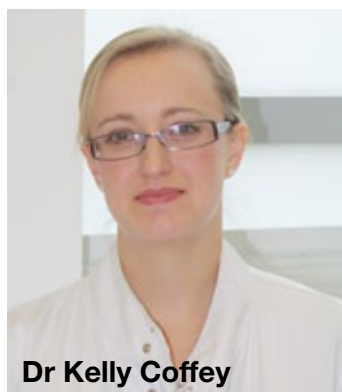
Progress reports on the research we are funding

Welcome to two new Career Development Fellows, joining our team of researchers fighting prostate cancer in the lab.

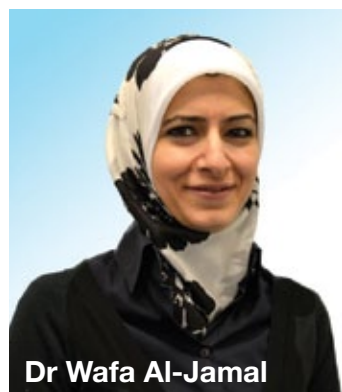
Our Career Development Fellowships not only give young scientists a chance to set up their own lab, but are also vital in safeguarding the future of prostate cancer research, making sure that we have the scientific leaders we need for years to come.

Dr Kelly Coffey, Newcastle University

Dr Kelly Coffey has spent the last 12 years working on the molecular biology of prostate cancer – in short, the nuts and bolts of what's going on inside the cancer cell.



Dr Kelly Coffey



Dr Wafa Al-Jamal

This fellowship will give her the chance to set up her own lab, investigating how and why prostate cancer cells become resistant to hormone therapy.

“I'm really excited about putting my team together over the next few months, and setting my research plan in motion. I hope to identify and validate new therapeutic targets to tackle prostate cancer when conventional therapies have failed. I can't wait to get started.”

Dr Wafa Al-Jamal, University of East Anglia

Dr Wafa Al-Jamal has worked at both UCL and King's College London, finding new ways to deliver drugs around the body. Dr Al-Jamal's lab aims to develop incredibly small drug delivery devices, called nano-carriers that will take drugs directly to prostate cancer cells, so reducing side effects of treatment.

“Thanks to my Prostate Cancer UK fellowship, I have the confidence to develop my lab, knowing that my work will be supported for the next five years. This will let me keep the momentum of my research going. During my fellowship, I aim to develop a way to get drugs to prostate cancer cells that have spread around the body and so prolong patients' survival while reducing side effects.”

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

Weighing up the costs



As the Government in England develops its plans for value-based assessment, a new way of deciding which new drugs it's willing to pay for and how much it's willing to pay, we look at what this could mean for men with prostate cancer and ask, what does value mean when it comes to your health?

Over the past few years we've seen some real breakthroughs in drug treatments for prostate cancer, with new drugs such as abiraterone, enzalutamide and cabazitaxel all offering the chance of extra months of life.

But getting these new drugs into the hands of men can be a long, complicated process and can be very expensive. From identifying molecules in the lab through to clinical trials in men, drug development costs a lot of money. The Association of the British Pharmaceutical Industry (ABPI) estimates it costs a massive £1.2 billion to develop a single new medicine.

From Autumn 2014, when new drugs come onto the market, they'll go through a process called value-based assessment, which involves setting prices based on the perceived value of a drug rather than its actual cost.

This could be a dramatic improvement to the current system. But, how exactly is the government going to decide what drugs they will fund and how much they'll pay for them? And what 'values' will this be based on?

Whose values are they anyway?

Well, unfortunately at the moment, very little is definite. But from what we know, the government wants the price of a drug to reflect its value both to individuals and to wider society. This means they'll take into account things like someone's quality of life with, and without, treatment – including the impact of any side effects. But they're also considering how to weigh up the cost of a treatment



against the cost of illness to society as a whole, like the cost of people being unable to work. This can add up to a lot. To give you an idea, the total cost of cancer in the EU, including productivity losses (due to premature death, and people being unable to work), and time spent by friends and relatives caring for loved ones, was recently calculated at €126 billion a year. That's billion not million.

So the main question that we want to see addressed is: what does value mean, and who gets to decide what's

The facts: Who decides if new drugs are approved?

In England:

The Department of Health recommends new drugs to the National Institute of Health and Care Excellence (NICE) for appraisal. If NICE recommends a drug, the NHS is legally obliged to fund it for patients in England and Wales.

In Wales:

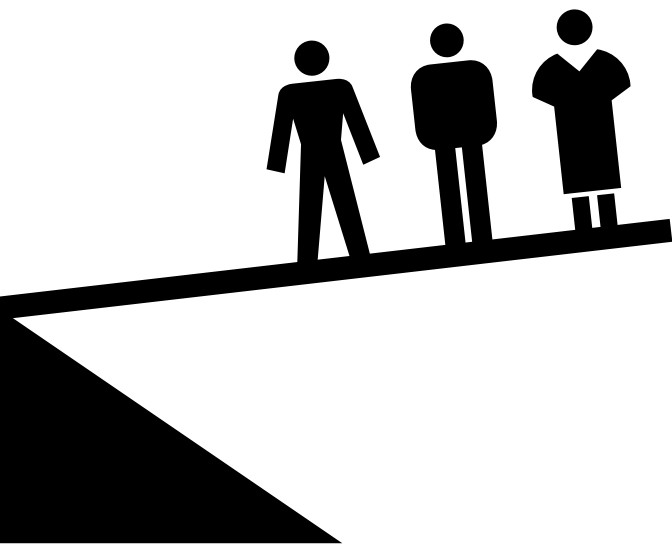
The All Wales Medicine Strategy Group (AWMSG) can decide whether or not to fund a drug – but only until NICE make their decision. After that, the AWMSG must follow NICE's recommendation.

In Northern Ireland:

After a NICE decision, the Northern Ireland Department of Health have one month to consider it; they don't have to follow NICE's recommendation.

In Scotland:

The Scottish Medicines Consortium (SMC) appraises all new drugs and makes a decision about whether or not the NHS will fund a drug. Even if the SMC approve a drug, health boards in Scotland don't have to make it available for free.



Personalised medicine – a cost-effective solution?

With prostate cancer predicted to become the most common cancer by 2030, how will we deal with the escalating cost of treatment?

Knowing in advance which drugs would work for which people might be one possibility. For example all patients get the same hormone therapy, but it works better for some than others. Personalised treatment would mean that the NHS would be paying for treatments

that are more likely to work and at the same time men wouldn't be experiencing unnecessary side effects and wasting time taking drugs that don't work – thus representing 'good value' all round. We're not there yet, but we're funding research into targeted treatments and turning laboratory-proven concepts into clinical trials. You can read more about the research we fund on our website at prostatecanceruk.org/research

'valued'? We're concerned about what they'll term 'societal value'; for example, will it only be about the economic impact of people not working while they're sick? If so, what does this mean when assessing drugs for people who are past working age? Will there still be a 'societal value' to treating the condition?

We're working with the National Institute of Health and Care Excellence (NICE) to ensure that this issue is dealt with, and that the needs of people who are retired or won't return to work after treatment aren't overlooked.

We want men's voices to be heard, especially about what the value of medicines means to them. As one of our volunteers Stuart Watson, who has prostate cancer, says, "How can you put a price on having your life extended even for a few months, or on getting relief from dreadful side effects? These are things that we patients value, but really are beyond price."

Forming a united front

Other groups, such as Breakthrough Breast Cancer are pushing for similar results. In fact, over 80 patient organisations, including us, make up a group called Patients Involved in NICE (PIN), a united front to give patients a louder voice in healthcare decisions.

PIN is chaired by Drew Lindon, our Head of Policy and Campaigns, who can see the potential benefits of the new system but also the need to get it right. He says, "Value-based assessment gives us an opportunity to rethink the system, and make sure that the 'right' drugs, those that benefit people the most, are always made available on the NHS. The work that we're doing as part of PIN and NICE, to make this happen, is hugely important."

Will cost always come first?

The high cost of developing cancer drugs means that price may always be an issue. The NHS has a finite budget. It spends about £2,000 per person per year on healthcare costs.

Now compare that to the cost of new drugs. The recently approved prostate cancer drug abiraterone first came on the market at £2,930 for a 30-day prescription – that's almost £1,000 more for one month's prescription than the NHS can afford to spend per person per year.

And so NICE initially said no to prescribing it on the NHS in England – even though abiraterone worked and extended life for men with advanced prostate cancer, as well as reducing pain.

It took intense campaigning by Prostate Cancer UK and our supporters before the manufacturers dropped the price and NICE reappraised the drug as an 'end of life' drug, allowing them to approve it at a higher cost than a standard drug.

But will we always need to put the pressure on pharmaceutical companies for them to discount their drugs enough to make them affordable? Or will value-based assessment mean new drugs get into the hands of men faster? Whatever happens, we'll keep fighting for men to have access to the drugs they need.

If you want to get involved with campaigning for men's rights to the best healthcare visit prostatecanceruk.org/campaign

Men United v Prostate Cancer

We can win this



Our Chief Executive, Owen Sharp, talks about a new campaign to build a movement for men in the fight against prostate cancer, Men United.

History is full of examples of men and women who stood up – who are remembered for making a difference, who got up and fought the good fight. You can probably think of one or two as you read this.

We've all got our own heroes – but the truth is heroes don't always stand alone. Sometimes heroes need an army behind them. It took a team of 400 men to get Sir Edmund Hillary to the top of Mount Everest. We've got a mountain to climb now and we need to build a team to climb it. We're calling that team Men United.

Why? Because we need men to unite to fight prostate cancer, in the same way that women have united against breast cancer.

Men's health has been too low on the agenda for far too long. Prostate cancer kills 10,000 men every year in the UK and almost as many men are diagnosed with prostate cancer as women are with breast cancer. But research into prostate cancer is badly underfunded, leaving tests

and treatments trailing behind other common cancers. And the quality and availability of treatment and care can vary depending on where men live.

It's time for men to band together against the injustices of prostate cancer. We're asking you and every man you know to sign up to Men United. We cannot afford this fight to be fought by the few.

So go online, get all the men you know to go online, and search Men United to sign up for the team. Then pledge your allegiance by wearing one of our 'Man of men' pin badges. Together we are a legion, together we can start a movement for men that will not stand down but will unite against a common enemy.

Whatever you do – whether you volunteer, hold events, undertake challenges, fundraise or use our services – join Men United. Joining Men United is about men standing together, from the terraces to the pub and beyond, to say, quite simply, men deserve better.

We are Men United v Prostate Cancer.

We can win this.

A handwritten signature in black ink, appearing to read 'Owen Sharp', written in a cursive style.

Owen Sharp

NEW ON THE WEBSITE 
prostatecanceruk.org

Our new Men United awareness test will help us find out much men really know about their prostate. How much do you know? Go to prostatecanceruk.org/MenUnited and take the test.

Find out some of the ways you can join our team on page 16 or go to prostatecanceruk.org/get-involved

A new look for our online community

This March we're launching a brand new platform for our online community to help more people find and use this supportive group.

The new platform will make it easier to find your way around the site, follow conversations that are important to you and discover the most talked about topics.

The group is made up of thousands of active members who learn from others, share their experiences, ask questions and offer support.

If you're already a member, you might get a sneak preview of the new version as we'll be testing it out in February. And we're working to make sure the switchover is as smooth as possible for you. If you haven't discovered the community yet, take a look around.

In the words of one member, "On the forum I found a group of people all connected by the

disease whose collective knowledge helped me understand my situation. I truly believe membership to this forum should be recommended by medical professionals at diagnosis. It's that good."

Find out more at prostatecanceruk.org/online-community

Raising our game, raising awareness

This year, with the help of two new partners, Deloitte and Scotmid, we're upping the ante and pushing out a new wave of awareness-raising activity across the UK.

We'll be on the ground, targeting men at risk of prostate cancer through talks, information stands and roadshows. We want to raise awareness of prostate disease, risk factors, signs and symptoms, and point people towards the information and support available.

To organise a talk or find out about becoming a speaker, call our awareness team on **020 3310 7217**



Bill Bailey

Celebrity squad signs up for Men United

Top names from sport, the arts and industry have signed up to get behind our new campaign Men United v Prostate Cancer.

You've probably already seen Bill Bailey on your TV screens, heading up our call for men to join Men United in the fight against prostate cancer.

On Bill's team are some of Britain's most iconic celebrities including Homeland star Damian Lewis, Game of Thrones actor Charles Dance, Sir Michael Parkinson and rugby legend Will Carling.

Sir Michael Parkinson, who was diagnosed with the disease last year said, "I'm signing up to Men United because I know what it is to confront prostate cancer. Every year, around 40,000 men

are diagnosed in the UK and men need to join together to fight back."

But as Bill says, it's not just celebrities we need on board, "We need men to sign up to the team in their thousands. Clubs, pubs, individuals – let's get everyone on the team."

Now it's over to you. Sign up to Men United prostatecanceruk.org/MenUnited

Listen up

One in nine people over the age of 60 are living with some form of sight loss, so we're working to make sure that our information about prostate cancer is accessible to men who might be experiencing problems with their vision.

We've produced both audio and large print versions of Prostate cancer: A guide for newly diagnosed men. You can listen to it or download it from our website at prostatecanceruk.org/audio

Peter Moffat

Award-winning writer of BBC dramas *Silk* and *The Village*, Peter Moffat, talks to us about his dad's fight with prostate cancer and the impact it's had on his life and work.

Hi Peter, tell us about your dad

If I have a picture of Dad in my mind from my childhood it's seeing him going off in his Land Rover, with his gun, wearing his flak jacket. He was a big man to me, in every way. He was still warm, but he was very much a man's man.

He was a Colonel in the British army and he served for two years in Northern Ireland, during the Troubles. He took that command very seriously. He was enormously proud of his men and never lost a single man under his command. That really mattered to him. He'd made his way up through the ranks and he was a proud man and admired by people he served with and who served under him.

I think that's why the diagnosis of prostate cancer hit him so hard. He found it hugely difficult to speak about. This big man was suddenly frightened by it.

When was he diagnosed?

He was 67 years old when he learned he had prostate cancer. By the time he was diagnosed it had spread all over his body and he was told he might last two years, but probably not that long.



This big man was suddenly frightened

He only told Mum at first. He decided to wait two and a half months to tell me and my sister – until a planned trip down to see us. Dad wanted to protect us – wanted to tell us together face to face, to make it easier for us.

But that meant that for two and a half months my mother was living with this awful secret and couldn't speak to anyone about it. It was very hard for

her. For Dad it had been a massive shock and he didn't want to talk about it or couldn't talk about it. I know he felt he was doing the right thing, trying to help and protect the family, waiting for the right time. But for my Mum, it was dreadful. She needed to share it and talk about it, find out more.

I remember the day he told us so well. We were all spending a day together at our beach hut in Norfolk. Dad said 'I'm making a cup of tea' and asked my sister and I to join him in the beach hut. He sat us down together and he told us he had cancer. It was a total shock. There were words and terms that I didn't really understand, neither did he. I remember him saying, "two years are possible, but not likely".



Peter with his dad

How did you cope as a family?

It was such a shock. As the days and weeks passed we didn't know what should be happening, we didn't even know what questions to ask. It seemed very difficult to get the right information.

I can't remember exactly when we found the Prostate Cancer UK Specialist Nurses, but that's when things began to fall into place. I could ring and speak to a nurse for as long as I needed to, she made it clear she had time to listen and to explain. She would take a whole load of 'stuff' and translate it into meaningful English.

Dad lived five years longer than we had expected. In that time we changed how we were as a family. We became open with each other, we could talk about things that we'd have avoided in the past. I am so grateful we got that time. In the seven years from the day of his diagnosis to the day he died there was an incredible transformation in Dad, to someone who

was so much more open and able to talk about emotions. It was a long journey for him and for all of us as a family.

Has your Dad's illness made you think more about your own health?

After my experience with Dad, you would think I'd be very health aware. I suppose I am, and I'm a bit of a hypochondriac really, but I still find it very hard to go to the doctor with those sort of problems... like so many other men.



It was a total shock. There were words and terms that I didn't really understand, neither did he

Shortly after Dad died, I did have a scare and I did go to the doctor. Luckily it was a 'no consequences' scare. And it's worth



When we found the Prostate Cancer UK Specialist Nurses, that's when things began to fall into place

saying for the record and so other men know – that the digital rectal exam wasn't painful. Within 10 days I got the results of my blood test and it was all fine.

I think 10 years ago, if I had some signs, I might have let it go on for a time perhaps even months. That wouldn't happen now. I'd be straight there. We all pay our taxes, we all pay for the NHS, you're allowed to go to the doctor.

Any man with a close relative who has had prostate cancer is at greater risk themselves.

That's me. I've also turned 50 this year and that, too, gives me an increased risk. I do feel angry about how inconclusive the tests are and how little they've changed over many years. I want to say 'come on world, let's get this sorted, let's spend the money, let's get a test that works'.

Why did you write about a character with prostate cancer in *Silk*?

I wanted men to learn about the risks, the prevalence of prostate cancer – especially men who don't really think about their health. That's why I chose the character of Billy Lamb (played in the show by actor Neil Stuke). He's a real 'man's man' – scotch-drinking, goes to the races, ducking and diving, a good bloke and he's in his late forties. Through him we might be able to reach some men who wouldn't normally want to visit a doctor. I thought watching this 'geezer', someone they identify with, go through the experience might just have an impact.

Silk returns to our screens in the Spring.

For more information about supporting a loved one with prostate cancer visit prostatecanceruk.org/partners-and-family

THE MANUAL

Your questions answered about
work and prostate cancer



Men often want to know how they can best carry on working when they have prostate cancer. Here, Sharon Clovis, prostate cancer specialist nurse, answers some of the questions you've been asking us.

Q Should I tell my employer that I've got prostate cancer and what's the best way?

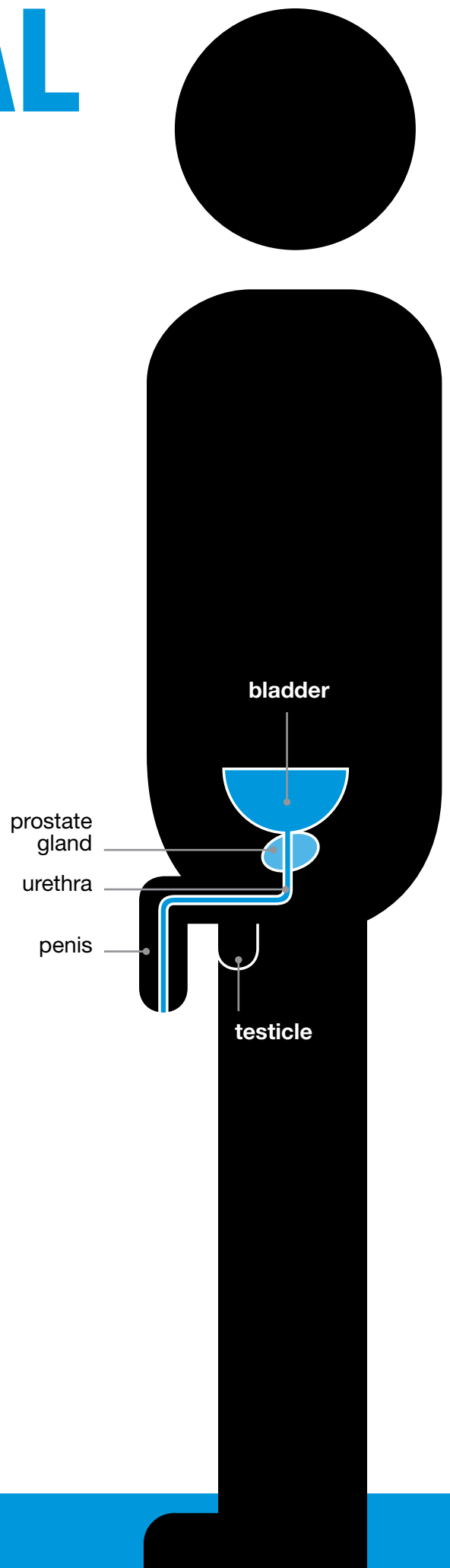
A Some men worry about telling their employer they have prostate cancer because they think they won't be supported or their employer will want to get rid of them.

You don't have to tell your employer about your prostate cancer but they may not be able to support you as well if you don't. The sooner you tell them, the better prepared they will be. And try to be as upfront as you can about how you think prostate cancer and treatment will affect you.

Remember, the law says your employer can't discriminate against you because you have cancer. Anyone who has or has had cancer is protected by the Equality Act (or the Disability Discrimination Act in Northern Ireland). This means that employers have to consider making changes to help you carry on working. This could be anything from letting you take rest breaks to reducing or changing your duties for a while.

Q My employer wasn't that helpful when I told him about having prostate cancer. What can I do?

A Although lots of employers are very supportive, some can be less understanding, especially if they've not had experience of supporting an employee



To find out more about living with prostate cancer visit prostatecanceruk.org/living

with cancer before. You could try explaining some of the issues or give them some information leaflets to read.

If your employer is struggling to know how to help you, a nurse or other health professional at your hospital may be willing to speak to them or write a letter to them explaining what your needs are.

Q How much time will I need off work for treatment?

A You might need to take time off work for treatment and appointments. This will depend on the type of work you do, what treatment you're having and how it affects you. For example, if you've had surgery and work in an office, you could be back at work within two weeks. But if you need to do heavy lifting or travel a lot, it could be four to six weeks.

Many men keep working if they're having radiotherapy, though they might take time off if they have side effects like feeling extremely tired (fatigued). It's a good idea to have warned your employer in advance that you may not feel well and will need time off.

How much time you will need off work is very individual so discuss this with your doctor. Ask them for a note to give to your employer saying how much time you'll need. You should then discuss this with your employer. Find out what your company sickness policy is – as the pay and time off you can have varies between employers.

You might need to try to arrange appointments for as close to the start or end of the day as possible so you don't need to take as much time off.

Q How will the side effects of treatment affect me at work and what can I do to manage these?

A Leaking urine is often the biggest issue for men with prostate cancer to deal with at work.

A lot of men use pads to avoid leaks – if you do, make sure you take enough pads into work.

Having to leave your desk frequently to urinate might make you feel self-conscious. This might be easier if you've told your employer and your colleagues in advance. Although some men won't want to tell anyone and you don't have to, if you don't feel comfortable doing so.

Your employer should, by law, consider ways to make things easier for you – for example, allowing you to sit near a toilet or putting in cubicles rather than urinals to give more privacy.

Make sure that you get hold of drinks at work as not having enough can make urinary problems worse.

Prostate cancer and its treatment can make you feel extremely tired. This can make it harder to concentrate and do your work. Try to get a good night's sleep and, if you can, find some time to do some gentle exercise, such as walking to keep you feeling energised.

You could keep a diary each day to help work out when you work best and do the harder tasks then. Or you could talk to your manager about delaying work or delegating work until you feel better.

Men who are on hormone therapy sometimes have hot flushes. If you do, make sure you have access to a fan or window, wear layers so you can take them off to cool down, and bring in a change of clothes to work.

Q What help can I get when I return to work? And how should I ask for this?

A Make an appointment with your manager. Explain how you think prostate cancer and its treatment will affect you. You might need to ask them to be flexible, as you won't always know exactly how you're going to feel. Go armed with solutions – rather than leave it to your employer – although they might have some helpful suggestions too. You could ask your manager to help you prioritise your work and decide what you're able to manage.

Many employers will consider flexible working. This is where you change your working hours or duties so you can carry on working. If mornings are hard for you, could you start later and finish a bit later? It might help to avoid travelling in rush hour. Could you work from home or have a phased return to work where you slowly build up your hours? Could you take regular short breaks to ensure that you don't tire yourself out too much? Have a think about what would work best for you.

It might help to talk to someone who's been in a similar situation. Prostate Cancer UK has a one-to-one support service where you can talk with a trained volunteer who has experienced going back to work with prostate cancer. There's also a telephone support service called Get back on track that can help with managing fatigue.

You can access both services by calling the Specialist Nurses on 0800 074 8383. There's also lots of information on prostate cancer, treatments, managing side effects and support on the website: **prostatecanceruk.org/information**



The person that helps me through

by Alexander McCrindle

The person that really helps me is Anna, a counsellor at my local cancer support charity.

She was with me from the start of what I can only describe as the most frightening time in my life. I was only 50 when I was diagnosed and had to start thinking about choosing a treatment that was right for me. It was a life-changing decision. But Anna was there to listen, support and encourage me and her kind reassuring words have helped me make very difficult decisions.

I still speak to her a lot. She makes such a difference to my life just by being there to listen to things that I can't always talk to others about. It's so important to get help as it is a very lonely place to be when you are told you have cancer. And it helps to share how you are feeling.

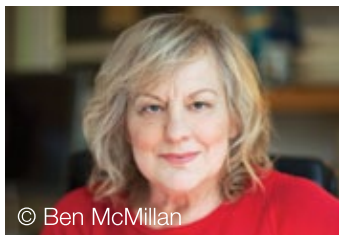
It has been a rollercoaster of ups and downs. But with her care I found the right treatment which has hopefully been successful.

She made me believe in myself; that I would get through it and there was light at the end of the dark tunnel. She was right. I am so grateful for everything that she did and still does to help me.



Adrian Mole: The Prostrate Years

(Penguin Books)
Extract 3/3



Thanks again to Sue Townsend for loaning us extracts from Adrian Mole: The Prostrate Years. Here's the third and final instalment.

Now thirty nine-and-a-half, Adrian is living in the country in a semi-detached converted pigsty adjoining his parents. The spark has fizzled out of his marriage to his second wife Daisy and Adrian's nightly trips to the lavatory have become alarmingly frequent.

Wednesday 10 October

Pandora rang and said that her constituents had demanded to see her in her surgery next Saturday afternoon and asked if we could 'give her supper'.

Daisy said, 'What can I possibly cook for somebody who is godmother to Gordon Ramsey's youngest child?'

I told her that her shepherd's pie always went down well.

To be honest, Diary, I shared her apprehension. She is perfectly capable of starting a meal off, but she falls apart when it comes to serving it up and bringing it to the table.

My mother came round and said that she'd been surfing the internet and found somebody in America who claims that they can cure prostate cancer. All I have to do is send \$500 to an address in Waco, Texas and I will receive my own personal crystal to wear in a bag

around my groin. According to my mother, the crystal will neutralise the antibodies that are attacking my 'prostrate'.

Saturday 14 October

Pandora was what she called 'fashionably late'. Eventually I put the shepherd's pie in the bottom oven to keep warm but it was certainly past its best by 9.07pm when she finally arrived.

Pandora wanted me to tell her the 'story' of my prostate. Halfway through she said, 'I need a fucking fag for this, I've left them in the bloody car.' Daisy pushed her packet of Silk Cut towards Pandora. It was the first companionable gesture the two women had shared all evening.

When I had finished, Pandora started to sob, laying her head on the table and almost knocking over her wine. I waited for Daisy to comfort her but when she made no move to do this I got up, went to Pandora and stood by her side. She wrapped her arms around my waist and soaked my shirt with her tears.

Pandora stayed until two o'clock in the morning, long after Daisy had gone to bed. She talked about the old days, when we were both 13 and three quarters and fell in love.

She said, 'I was totally obsessed with you. I only lived for the next moment when I would glimpse your nerdy face. You were the first person to see my nipples.'

'No,' I corrected her, 'you only showed me your left nipple.'

In the SPOTLIGHT

Paul, Chris and Mike Smith from Hertfordshire

Paul Smith was diagnosed with prostate cancer in October 2012.

Last August, Paul and his sons Mike and Chris cycled all the way from Trafalgar Square, London, to the Arc de Triomphe in Paris to fundraise for us. So far they've raised over £9,000 from this incredible challenge which saw them cycling, on average, 70 miles a day for three days.

"To be told you've got cancer is a nightmare.

I had three appointments which ended in a diagnosis of metastatic prostate cancer – with a secondary in my pelvis.

"I decided that the biggest input I could have in my future was in my mind. So, with the encouragement of my two biking-mad sons, I started training for the London to Paris ride. It was amazing how motivational

it was to have a big target to aim at. Even when I was having three hours of radiotherapy a day during training, I still managed to keep riding!

"It would have been easy to just curl up in a corner but I think that continuing to live a normal, active life has been a major help to me over the last year, and will continue to be!"



In October, Angelina shaved her head to raise money for us in memory of her dad, who sadly died in 2011. Here she tells us why he was such a top dad.

"Three words to describe my dad – strong, loving and protective. And I think everyone – family and

friends – would say the same. People looked up to him for his generosity and helpfulness and if anyone was in need of help, my dad was there.

"He was born in 1919 in Italy and was a farmer for more than 40 years. There were seven of us children and he worked really hard to provide for us all. One of the greatest things I remember about Dad was how hard he saved so we could all go on holiday together every year. They were the most amazing holidays.

"We had noticed for a few years that Dad wasn't looking very well but he said, 'No, I'm fine, nothing wrong with me'. In the end, we had to make doctor's appointments for him but he never wanted us to go

with him. We're not sure how long Dad had known he had prostate cancer but we only found out a year before he died.

"It was devastating. He was in and out of hospital. We were so shocked and upset because we think maybe, if he had told us sooner, we could have got him more help. I felt helpless. I wanted to take away his pain. I sat with my dad when he was ill. He said, 'Promise you will look after your mother'. I held his hand and said, 'Of course we will'. He was always so protective of his family."



THANK YOU

10

To Paul Godbold, who ran 10 half marathons in 10 days in memory of his dad who died a year before. That's a challenge and a half. He raised nearly £6,000.

630 MILES

To Alan MacNair, who walked the 630 mile West Coast Path in 32 days. What a trek! He raised £4,900.

£5,000

To Sheree Pender, who held a fundraising night in memory of her dad. She gave out 150 information leaflets and raised £5,000.

255k



To everyone who took part in Movember this year. Over 255,000 people signed up – to grow a mo or support a mo-grower!

GET INVOLVED

Join our army of volunteers and supporters by getting involved in our work or events – in any way that you want – and become part of our growing movement for men, Men United. With your help, we can do more for men. We can win this.

On yer bike

We have a huge number of cycling events happening across the country with two exciting new events this year.

London to Amsterdam with the Football League 6-8 June

Ride with Luther Blissett and Football League clubs to the home of

Total Football. Setting off from Leyton Orient's Matchroom Stadium, we will cycle a testing 90 miles via Colchester United's Weston Homes Community Stadium to Harwich. After crossing the Channel overnight, we'll ride a further 60 miles across the flat landscape of Dutch Zeeland, before arriving at AFC Ajax.

Saxon Classic – 22 June

The Saxon Classic is the second event in our Team Cycle series. You can choose between 100 mile, 100 or 50km through the stunning Suffolk countryside. If you're looking for your first cycling challenge the relatively flat terrain is perfect and the 100 miles will test experienced riders.

Can you speak for us?

We need to build an army of speakers to raise awareness of the impact of prostate cancer.

With your help, we can reach thousands of men across the UK and give them the facts about prostate cancer and let them know that we're here to support them.

As a volunteer speaker, you'll be representing Prostate Cancer UK at a range of different events, giving talks about prostate cancer, your personal experience (if you want to) and our work.

You'll have the opportunity to meet new people and share your story and know that you could be making a difference to thousands of men.

The latest training dates in your area are on the next page.



Want to know more about managing prostate cancer?

Our one-day 'survivorship' conferences are designed to help give men and their loved ones the practical support they

need to deal with their prostate cancer and lead the life they want to live. The days include expert speakers on topics such as diet and exercise, and relationships and sex. And there'll be taster sessions on a range of holistic therapies and exercise.

We will be holding a number of support days across the country

in 2014 so check our website for the latest dates. At the moment, the following dates are confirmed:

- 1 March, Custard Factory, Birmingham
- 28 March, Stadium of Light, Sunderland

For more information visit prostatecanceruk.org/in-your-area

Get on the ground for match day

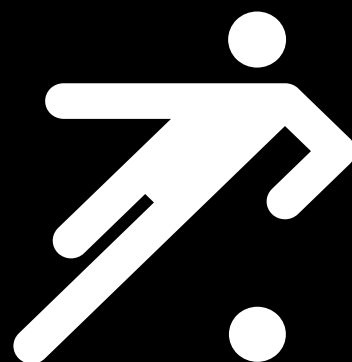
Join us this season to help us raise awareness and funds at Football League matches across the country.

We're looking for volunteers to hold collections in support of the 250,000 men living with prostate cancer in the UK.

We want millions of football fans, thousands of players,

and 72 football mad communities to put aside their rivalries on the pitch and join Men United.

Choose your match at prostatecanceruk.org/matchdays



EVENTS CALENDAR

Feb 2014 - Aug 2014

**Train to become a
volunteer speaker:**

14 Feb
Edinburgh

14 Feb and 13 March
Cardiff

26 February
Bristol

25 Feb and 25 March
Inverness

31 March and 23 April
Coventry

6 May and 3 June
Carlisle

Peer support training:
12 March
Cardiff

**Prostate Cancer UK
Luncheon**

Join us for lunch at the Intercontinental Hotel, Park Lane, London. Starting with a reception at 12pm, for lunch at 1pm, it promises to be a fantastic afternoon, with a traditional auction and an opportunity to hear more about our work.



Edinburgh Marathon

The Edinburgh Marathon is a fast, flat course that makes a fantastic run for first time marathon runners or those trying to set a personal best. The scenic route flows through the historic city centre passing by Holyrood Park through to the spectacular finish in Musselburgh Racecourse. We will support you all the way, with cheering points along the route and a great post-race reception.



Finchley Golf Day

Swing into action and join us for what will be a fantastic day at one of North London's best golf courses.



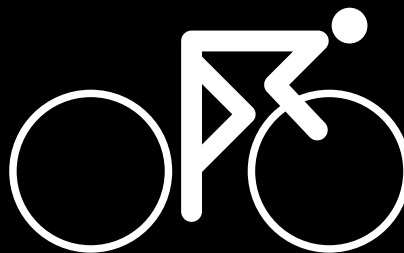
Skydiving Day

Celebrate fathers and grandfathers everywhere by joining our skydiving team on Father's Day 2014 and jumping out of a plane at 10,000 feet. There are locations all over the country but we do have spaces reserved at the Brackley airfield just outside Northampton and Oxford. Go to prostatecanceruk.org/skydive



Jurassic Classic

Take part in our flagship cycle challenge through the spectacular East Devon countryside. Try the 50 or 100km routes




More events


6 April
Brighton Marathon 

13 April
Virgin Money
London Marathon 

May - October
3 Peaks Challenge 

May - October
Hadrian's Wall 


24 May
London to
Brighton Challenge 


7-8 June
Nightrider 

6-8 June
London to
Amsterdam 

10 August
Ride London 

5-7 September
Ben Nevis Challenge 

7 September
Bupa Great
North Run 

13-14 September
Thames Path
Challenge 

if you're attempting your first cycling challenge or, if you're looking for something a bit harder, you can tackle the hilly 100 miles.

Find out more 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 peer 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 to help you 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

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.

Support in your area



Over the past 12 months we've been working across the UK to develop a range of prostate cancer support services in your area.

With offices now in Glasgow, Newcastle, Stockport, Birmingham, Cardiff and Croydon, we've got more people on the ground. We're linking up with NHS trusts, local government and other charities, to bring together a host of expertise and provide you with the very best support. From providing relationship counselling and sex therapy with RELATE, to delivering training for businesses on the impact of prostate cancer, we're trying to deliver the support that makes a difference to you.

Gerry Armstrong is someone who's already benefited from one of our regional services. He took part in a series of group sessions to

help men living with prostate cancer. As part of a 13 week programme, delivered through our new community support centre in Newcastle, these sessions focused on physical activity, nutrition and recovery. They also offered emotional support and addressed issues around fatigue and anxiety.

"I initially signed up to learn about nutrition and recommended exercises. However, on reflection I realised that I just wanted to move on in life.

"Being able to talk openly to people who had suffered similar problems had a profound effect on me. This is the first time since diagnosis that I had been able to talk openly and honestly about my journey with prostate cancer."

We're continuing to work alongside men and their families to find out what's needed where you are.

To find out what's happening in your area visit prostatecanceruk.org/in-your-area

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 Gerry to put prostate cancer behind them, please fill out the enclosed form or visit the Get involved section of our website to find out more or make a donation. Thank you.

**SIGN FOR
MEN
UNITED.
KICK
PROSTATE
CANCER
INTO
TOUCH.**

Search **Men United** now



**PROSTATE
CANCER UK**

Men United v Prostate Cancer
We can win this