Editor’s note

A warm welcome to Issue 4. Since the last issue our Men United movement has grown massively with over 184,000 people taking the online awareness test and thousands joining the fight.

In this issue we’re asking you, Men United, to get barbecuing in MAN v BBQ (page 20) and help raise money to fund research into a risk calculator that will help us find out who’s most at risk (page 6).

We also take a look at how magnetic resonance imaging (MRI) might help men get a more accurate diagnosis (page 8).

And our cover star, rock legend Kenney Jones, talks openly about his experience of prostate cancer and why he thinks we should all be talking more (page 12).

Finally, there are lots more stories from you (page 17) so thanks to everyone who sent something in.

Best wishes,

Jocelyne.

Editorial team
Nick Wright
Dr Sophie Lutter
Sarah Lines
Sonia Barbate
Jocelyne James (Editor)
Correction

In the last issue we said that some men may be able to go back to work two weeks after surgery. This is occasionally possible, but it’s more common for it to take longer, about four to eight weeks, before men feel up to going back. It depends on the type of surgery, what side effects you are experiencing and the type of work you do. Your specialist can give you advice.

Dear Progress

Men United is an excellent idea to raise awareness in football. But what is being done to bring in Rugby Union and Rugby League, given all the men involved and the number of supporters?

David, Cheshire

Dear David

Thanks for supporting Men United. We’re really excited about our partnership with The Football League and the number of men we’re reaching. But Men United isn’t just about football – it’s for all men. We’re always looking for ways to get involved in sport as it’s a great way to get in touch with all you men out there and raise awareness of prostate cancer. We’ve already done a lot of work with Rugby League teams and are hoping to do more with Rugby Union. So watch this space!

I had regular PSA tests and was diagnosed three years ago but suffered badly from septicaemia after I had a biopsy. I think we need more research into a less dangerous method of establishing the type and aggressiveness of prostate cancer.

Anon, Surrey

Dear Sir

We’re so sorry to hear you had a bad biopsy experience. Although septicaemia isn’t common, there are risks involved with biopsies. Research is going on at the moment into better tests for prostate cancer. Researchers are looking at how things like magnetic resonance imaging (MRI) and blood tests for genetic or protein markers can play a part in this. You can read more about MRI on page 8.

Dear Progress

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

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Dear Progress

I love receiving these magazines. Every time I get them I learn more about prostate cancer and learn more about what my family goes through day by day.

I think it is important that my sons and my brother, and his sons, know as much as possible about prostate cancer before they need to. Thanks for this magazine.
The papers recently reported that having a vasectomy can increase a man’s risk of developing aggressive prostate cancer. We take a look at the research behind the headline.

This story was based on a 24 year follow-up study of 49,405 men in the United States. Of these, 12,321 (25 per cent) men had a vasectomy.

In total 12.4 per cent of men in the study who’d had a vasectomy developed prostate cancer, compared to 12.1 per cent of men who hadn’t.

They found no link between having a vasectomy and developing non-aggressive, localised prostate cancer.

But they did find that there was a 22 per cent increased relative risk of developing aggressive prostate cancer for men who’d had a vasectomy compared to men who hadn’t.

Although this sounds quite a lot when you talk in terms of relative risk (comparing two groups), when you turn it into actual numbers, it’s really pretty small. It translates to 17 out of 1,000 men who didn’t have a vasectomy developing aggressive prostate cancer, compared to 19 out of 1,000 men who did.

The other important thing about this research is that although it shows us a link between having a vasectomy and having aggressive prostate cancer, it can’t and doesn’t tell us that one causes the other, or why the link is there. We’d need a different type of research to understand that.

Can having a vasectomy increase a man’s risk of aggressive prostate cancer?

Small studies suggest that using a special type of MRI before a biopsy can help to achieve these aims. This funding allows me and my team to expand these studies into a large trial, with better comparison methods and more rigorous protocols.”

Mr Nabi said, “The current process for diagnosing prostate cancer involves several steps, each with their own uncertainties. It is my hope that the work I am able to do with this funding will lead to a more streamlined diagnosis.

Scotland’s Cabinet Secretary for Health and Wellbeing, Alex Neil MSP, said, “I’m delighted that the Scottish Government and Prostate Cancer UK, through their partnership with The Movember Foundation, have been able to jointly fund the research at one of Scotland’s top universities. We can, and will, beat prostate cancer – and today’s announcement is another step towards this ultimate destination.”

Prostate Cancer UK, The Movember Foundation and the Scottish Government have handed researchers at Dundee University £500,000 to investigate ways to improve the diagnosis of aggressive prostate cancer and reduce the number of unnecessary biopsies.

Work on the five year research project will be led by Mr Ghulam Nabi, from the University of Dundee’s School of Medicine. Mr Nabi’s project is to investigate whether magnetic resonance imaging (MRI) and ultrasound scans could be used to reduce the number of biopsies that are needed to diagnose prostate cancer, and to more easily spot the difference between aggressive prostate cancer and non-aggressive prostate cancer.

Researchers in Scotland get £500,000 to help improve diagnosis

Deciding whether or not to have a vasectomy is highly personal, and should be discussed with a GP.

We don’t think men need to be too concerned about these results at this stage.
UK sees first ever centres of excellence in prostate cancer research

The Movember Foundation in partnership with Prostate Cancer UK have launched the UK’s first ever centres of excellence programme in prostate cancer research.

The two centres, one split between Belfast and Manchester and the other in London, will bring together 22 leading researchers across different scientific disciplines to tackle important unanswered questions.

They are part of a coordinated attack on prostate cancer in the lab and in the clinic and represent a big move forward for the future of prostate cancer research in the UK.

The Movember Centres of Excellence will see an injection of £10 million over a five year period – the largest single investment into the disease by the partnership to date.

The aim is to speed up our understanding of the disease through innovation, making sure lab breakthroughs turn into actual benefits for men as quickly as possible.

The two new centres will work together for the next five years on programmes that will tackle three crucial areas of prostate cancer research – telling the difference between aggressive and non-aggressive prostate cancer, identifying men at high risk of aggressive disease, and finding better treatments for men with advanced prostate cancer.

The centres are about long term impact. They will support the careers of future leaders in prostate cancer research through a strong emphasis on training, so that men will benefit from this investment for years to come.

FROM THE LAB

Progress reports on the research we are funding

Can we improve radiotherapy to reduce side effects?

We’ve just awarded Ashley D’Aquino at the Royal Marsden Hospital a Prostate Cancer UK/College of Radiographers Clinical Training Fellowship, funded by The Movember Foundation.

Ashley will be looking at whether taking pictures (imaging) of the prostate and surrounding organs, before each radiotherapy treatment, can help the radiographer lower the dose of radiotherapy men receive. This would reduce the impact of the treatment on healthy tissue and therefore potentially reduce side effects.

Giving higher doses of radiotherapy to the prostate can improve how well treatment works – especially if you can target the cancerous parts of the prostate to get the higher dose. But increasing the dose also risks increasing some side effects of treatment, like bowel problems. This is because sometimes healthy organs near the prostate, particularly the rectum, can get the higher dose too.

At the moment, radiographers try to limit the amount of radiotherapy to healthy organs by scanning the prostate and surrounding area, and mapping everything before treatment starts.

But Ashley D’Aquino thinks that because the rectum can change size or position during the course of treatment, which usually lasts seven to eight weeks, just taking images before the first radiotherapy dose might not be the best way to limit side effects.

Instead, during the course of her research, she will take images of the prostate and rectum before every dose. She’ll then measure the radiotherapy that builds up in the rectum each time, and compare this with what the planned dose was.

Ashley thinks this project will demonstrate that taking pictures of the surrounding organs before each radiotherapy dose can help reduce damage to healthy tissues, like the rectum, and so reduce side effects, which can have a big impact of men’s lives. If so, this could change the way radiotherapy is given within the next three years.

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

Can we tell who’s going to get prostate cancer?

Results from a recent public survey showed us that we need to do more to help men understand their risk of prostate cancer. But while we’re working to get everyone talking about the disease through our Men United campaign, how much can your doctor even tell you about your personal risk of prostate cancer, especially the aggressive kind?

We take a look at the critical research that we need to fund to help stop one man from dying every hour from prostate cancer.

Men are at increased risk of developing prostate cancer if they are over 50, if they are Black or if their father or brother have been diagnosed with prostate cancer. A recent survey we commissioned from YouGov has shown us that 4 out of 5 men at increased risk of developing prostate cancer are unaware of their risk.

Without this knowledge, and with most early prostate cancer causing no symptoms, what is there to prompt a man at greater risk to go and visit his GP?

And even if a man is diagnosed, can doctors tell him which type of prostate cancer he has – the aggressive cancer that might threaten his life or the non-aggressive type?

At the moment, there’s no reliable way of doing this. And while catching aggressive prostate cancer early can help save lives, detecting non-aggressive cancer may lead to men having unnecessary treatment – leaving them to deal with life-altering side effects like incontinence and sexual problems.

We need to be able to identify those men at risk of developing aggressive prostate cancer before it develops.

In order to do this, we want to create something called a risk calculator. This would be a way of putting together everything we know about prostate cancer risk to then tell an individual man his chances of developing the disease.

At the moment we don’t know exactly what this risk calculator might look like, because it doesn’t exist yet. But we’re currently raising money to fund research into developing it.

What we’re looking for is something practical that a GP can use. So that, when a man visits his GP, they can use the risk calculator to pull together information about that man’s age, family history, ethnicity and prostate specific antigen (PSA) levels and any genetic changes in his DNA.

We hope that the risk calculator will turn all this information into a simple score for each man’s risk of developing prostate cancer. The GP would then be able to give each man, as an individual, a much clearer picture of what he should do next.

The good news is that we don’t need to start completely from scratch. A lot of research has already been done into different areas of risk that researchers can draw on. And successful ways to calculate risk already exist in other countries and populations. We just need to find one that works here in the UK.

If researchers are successful, such a tool could be ready to roll out across GP surgeries throughout the UK within the next five years and could revolutionise how we diagnose and treat prostate cancer.

To find out more about the risk of developing prostate cancer visit prostatecanceruk.org/risk
We still don’t have all the answers about risk and prostate cancer – but we’re working hard to find them. Here are three more research projects we’re funding into risk.

**Dr Christine Galustian** from King’s College London is looking at whether a protein called DARC, which is missing in over 60% of the African Caribbean population, can help protect against developing aggressive prostate cancer. DARC works by removing certain proteins, called chemokines that can affect how cancer grows and spreads.

*Funded by The Movember Foundation*

**Dr Hayley Whitaker** is researching a protein called NAALADL2. This protein is found at higher levels in aggressive than non-aggressive prostate cancers and may one day help to tell the difference between those men whose cancers need immediate treatment, and those men who don’t.

*Funded by Prostate Cancer UK and the Masonic Samaritan Trust*

**Professor Ros Eeles** at the Institute of Cancer Research in London, is using prostate cancer genetics to understand which men are at risk of aggressive disease. Her lab has identified many of the genetic changes we currently know about, including those in the BRCA1 and BRCA2 genes, which give an increased risk of prostate cancer. At the moment she’s investigating whether mutations in any of 193 genes that repair DNA damage, increase a man’s risk of developing aggressive prostate cancer.

*Funded by Prostate Cancer UK and The Movember Foundation*

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**What do you know about risk?**

If you’re a regular Progress reader, you may know more than the average man on the street. But when we surveyed almost 3,000 members of the public*, we found a big knowledge gap, especially in men’s awareness of their own risk.

- **Only 2 in 5 people (40%)** know that being aged 50 or over increases a man’s risk of prostate cancer.
- **Only 1 in 20 people (5%)** know that being black increases a man’s risk of prostate cancer.
- **Only half** of the UK population (47%) know that having a family history of prostate cancer increases your risk of getting the disease.

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*Figures from YouGov Plc. Total sample size was 2,864 adults. Fieldwork was undertaken between 13 January and 4 February 2014. The survey was carried out online. The figures have been weighted and are representative of all UK adults (aged 18+). 2014.*
OPENING A WINDOW INTO YOUR PROSTATE

It’s not quite like looking for a needle in a haystack, but the random nature of taking samples means that at the moment up to 30 per cent of tumours are missed.

Professor Mark Emberton, who is currently looking at using MRI before a TRUS biopsy to pin point where and if there is cancer, explains it like this:

“Our current approach – a PSA test followed by TRUS biopsy – misses significant cancer far too often. It also misclassifies prostate cancer in about a third of men who are diagnosed. This misclassification is almost always in the direction of telling men they have low risk disease when they have not.

“The other problem is that random biopsy identifies a lot of disease that is insignificant. What we mean by this is that men are told they have prostate cancer when actually that cancer is so small it cannot be felt by the finger, nor seen on any form of imaging.”

A prostate biopsy is also an invasive procedure that carries risks for men. One third of men experience pain, fever, bleeding, infection, problems urinating or other issues after biopsy. And up to 3 in 50 men (6 per cent) may get a more serious infection. If there was a way for men to avoid having a biopsy unless they really needed one, then they would also avoid these risks.

Multi-parametric MRI – a revolution?

A new more accurate way of using MRI, called multi-parametric (mp) MRI, may be able to help doctors find cancer before biopsy and help to guide the biopsy needles to where they know the cancer is.

An mpMRI is made up of up to three different types of MRI scan which radiologists look at together to give a clearer picture of what’s going on in the prostate – such as if and where there might be a tumour.

The potential benefits of using this type of MRI include being able to spot, and more accurately investigate, cancers that need treating – as well as ruling out the need for some men to have a biopsy.
in the first place. And Professor Emberton is positive about its future.

“I believe mpMRI will revolutionise diagnosing prostate cancer,” he told us. “This is a big moment – for the first time in history we can actually see the cancer we’re treating. On the other hand, we can also see – and show our patients – when there’s no cancer, which is reassuring.”

Professor Emberton is currently running a large scale trial, the PROMIS trial, looking at multi-parametric MRI. It is has been running since 2012, and is also looking at the cost-effectiveness of using mpMRI before biopsy – vital information if it is to become part of standard practice in the UK.

**But is this revolution realistic?**

Although mpMRI may seem like an obvious next step in improving how men are diagnosed with prostate cancer, there are reasons why it isn’t standard practice.

Firstly it takes a good deal of skill and expertise to effectively produce and interpret mpMRI images and learning this takes time.

Secondly, The National Institute for Health and Care Excellence (NICE) will need strong evidence that it works for it to be able to recommend using it in practice before biopsy. So, if mpMRI is really as effective as it is claimed, we hope that the data from Professor Emberton’s trial, which finishes in 2015, will provide this evidence.

“The results of the PROMIS study will be key,” says Dr Chris Parker, Consultant Clinical Oncologist at the Royal Marsden, who, like Professor Emberton, is optimistic about the difference that MRI could make to men being diagnosed with prostate cancer. “PROMIS is currently recruiting over 700 men who are about to undergo their first prostate biopsy. In the study, men have a state-of-the-art multi-parametric MRI scan prior to a comprehensive biopsy. The future of pre-biopsy MRI rests to a large extent on the results of this vitally important ongoing trial.”

**Is the future bright for mpMRI?**

In an update to its guidance earlier this year, NICE has in fact recommended that doctors consider using multi-parametric MRI for men who’ve already had a biopsy that hasn’t found cancer. This is a great step and could help men avoid more unnecessary biopsies by confirming that there is no significant cancer in their prostate.

**This is a big moment – for the first time we can see the cancer we’re treating.**

And experts are also starting to talk about how it could be used in helping to better target and treat some types of prostate cancer.

But it will take evidence of effectiveness and importantly cost-effectiveness, as well as significant investment in training, before multi-parametric MRI can truly make a difference to men being diagnosed with prostate cancer.

At our recent Research Forum (see page 10) we asked prostate cancer experts from around the world their thoughts on the future of mpMRI. The feeling was generally positive but also realistic.

**Professor Ken Muir,** Professor of Epidemiology at the University of Manchester, summed it up like this, “Using imaging in prostate cancer is a really exciting development, but it’s still relatively new. Will it be able to do everything we hope? We’ll just have to wait and see.”

*If you’d like to comment on this or other news stories, go to prostatecanceruk.org/news and join the conversation.*
From food scientists to geneticists, molecular biologists to surgeons, the Prostate Cancer UK Research Forum brings together experts from every area of prostate cancer research across the globe. With all these amazing brains in one room, we had one thing in mind – to get them talking. Dr Sophie Lutter reports from this year’s conference in Baltimore.

The Prostate Cancer UK Research Forum happens every two years and is three days of intense discussion between prostate cancer experts – all with different ideas and approaches to research. The beauty of this meeting is that it gives these experts time to think up ways to weave their different approaches together and then make them happen.

This year we saw hours of really interesting discussion into new prostate cancer biomarkers. A biomarker is something – usually a gene or a protein – that can be measured to identify a particular medical condition.

There was discussion about the number of prostate cancer biomarkers that are being investigated at the moment – biomarkers that can be used when diagnosing prostate cancer, to distinguish between aggressive and non-aggressive disease, and biomarkers that can predict if cancer will come back after treatment or how well treatment will work.

And perhaps the most useful part of the discussion came from the scientists acknowledging that they’ll need to work together to get these new molecules to a point where they won’t be one-off discoveries in a lab, but can actually be used in the doctor’s surgery.

For Professor Christopher Woodhouse, who has organised the forum for the last 22 years, hammering out ideas in this way is exactly what the forum is designed for. He told us, “The forum provides a platform for researchers to hear about challenges faced by clinicians (eg doctors), so they can target their work to maximise clinical benefit for men. Equally, clinicians learn about the latest research developments and can transfer that knowledge into their everyday clinical practice. It’s a win-win for everyone involved, especially men with prostate cancer.”

We also spoke to some of the researchers we already fund, to find out what they thought.

Caroline Moore, from University College London (UCL), told us how pleased she was to meet molecular biologists and food scientists, because they’re not people she would usually come across, and she was hoping that they could work together on a project she’s currently planning.

Dr Gerhardt Attard from the Institute of Cancer Research told us how useful it was to talk to other scientists who were working on similar questions, but tackling them from a completely different angle.

And finally, Professor Mark Emberton (pictured above left), also from UCL, told us that within the three days of the conference he’d come up with ideas for five new research proposals that he’d never have thought up otherwise.

We hope that all of these conversations will lead to new research projects that we can fund to bring clear benefits to men with prostate cancer.

Watch our researchers talk about their work in our new online films prostatecanceruk.org/research
It’s time to chat

This month we are launching two new online services for men with prostate cancer – live chat and relationship chat.

Live chat is a way for you to instantly message one of our Specialist Nurses when you’re on our website. If you’re looking for information, need a quick answer or need help finding your way around, look for the prompt at the bottom of the screen to instantly chat to one of our nurses.

Relationship chat is a new partnership with well-established counselling service Relate. We know that having prostate cancer can often have a big impact on men’s relationships. If you, or your partner, want to chat online to a trained relationship counsellor you can now access one through our website.

prostatecanceruk.org/we-can-help

Challenging inequality

We’ve just published a report highlighting some of the inequalities faced by men with prostate cancer across the UK.

The report, ‘Five inequalities, five solutions’ picks out the key challenges that need to be addressed by all UK healthcare agencies, around awareness, ethnicity, age, differences in care and access to treatment.

We launched it in June at Westminster where our team of 31 supporter campaigners did a fantastic job of getting our messages out there and persuading MPs to get behind our fight for better care for men with prostate cancer. It was a great example of Men United in action.

The next General Election is now less than a year away in May 2015. To help us make sure these inequalities are addressed by all the political parties, join our campaign at: prostatecanceruk.org/inequalities

The numbers game

This coming season you will see our logo on all players’ shirts in The Football League.

As their official charity partner, our Man of Men symbol will be included on players’ kits on the number on the back of each player’s shirt from the start of the 2014/15 campaign.

It’s the first time a charity’s logo has been included by a domestic league on every single player’s strip. Supporters of all 72 clubs will also be able to purchase the branded numbers to accompany the replica shirts.

Our pioneering partnership with The Football League aims to reach over 16 million fans up and down the country. See how you can support the partnership by taking part in #shirt2work (page 20).

Fancy a pint?

We’ve just teamed up with some new retail partners to try and reach more men at their watering holes.

Leading sports bar company Rileys has pledged to raise £100,000, as well as raising awareness, through sports-related events for staff and their loyal customers, 90 per cent of whom are men.

Hot on its heels is the Spirit Pub Company, who will be hoping to raise £70,000 through football-related activities at 750 of its pubs across the UK.

But if you fancy a drink at home instead of away, Two Fingers Brewing Company, has produced a new craft beer called Aurelio Beer, a British-brewed golden ale, the sale of which gives all profits to us. Aurelio Beer is available at Tesco and Ocado.com
“In fact my biggest worry was about if the cancer had spread. I remember having the MRI scan and thinking ‘what else will they find?’ So it was a huge relief when they didn’t find anything.

“In fact my biggest worry was about if the cancer had spread. I remember having the MRI scan and thinking ‘what else will they find?’ So it was a huge relief when they didn’t find anything.

Kenney found that getting as much information as possible really helped. “I can’t stress how important it is to know what’s happening. I’d say read up, and re-read. I wanted to know everything – all the options, how the treatment worked, the possible side effects.

“At hospital I was given an information pack so when I got home, if there was something I wanted to check, I just looked it up.

“I nearly drove the family mad! I kept reading bits out to them all the time. I watched the information DVDs with my family – my wife Jayne and my children – it meant that everything was out in the open and we could all discuss the options. I think they saw I was dealing with it okay so that put their minds at rest. They were worried, of course, but we could talk everything through, which helped me a great deal.”

Choosing brachytherapy, which is a type of radiotherapy to the prostate, meant that Kenney had to deal with some not so nice side effects.

“The worst side effect of treatment was not sleeping because I just couldn’t pee. I would go to bed and just lie there. It was a constant feeling of wanting to wee and nothing happening. I can’t describe it.
“It felt like it was never getting better. I ended up sleeping in another room where I could watch the TV – anything to try to take my mind off it.

“A few weeks after my op I started getting out and about but wherever I drove I would work out where the service stations were, in case I needed to stop. I even bought this special wee container, like a bottle, that you can use if you get caught out. I never needed it but knowing it was there helped me. I wanted to be prepared for the worst.

“Now, around four months down the line and I’m starting to see a difference. It’s gradual – but I always knew it would take a while to recover. I just can’t wait for the side effects to wear off. But I’d say – it’s nothing you can’t deal with.”

Getting people to talk about the disease is something Kenney is passionate about.

“Most men are like me and will live in denial. There were probably 15 years when I had all the symptoms (of a prostate problem), weak flow, getting up to go in the night, but I just put it all to one side, like lots of men do.

“I think the best thing I ever did was talking it all through with my family, being completely honest about it, with them and everyone else. I think all men need to talk about this. It’s going to affect a lot of them and we need to get rid of the taboos.

“I talked to everybody, but I did notice that other people find it hard to talk about. When I first got my diagnosis and was out and about, I’d say I had prostate cancer and people would sometimes try to change the subject.

“Men of my age still remember horror stories around prostate cancer from years ago – how the treatment leaves you impotent. But men need to know things have changed a lot. Yes, some people do have problems, but there’s a lot that can be done to help that now. For me everything works, if you want to put it like that. I think men need to be less inhibited about this – talk about their worries. There is so much help now.

“Now it seems odd that, as I sat there all that time ago, talking about this event, I had prostate cancer inside me, I just didn’t know. And it’s not just fundraising, it’s a chance for me to raise awareness and get people talking about it.

“I’ve had terrific support from friends in the music industry, everyone’s rallied round. That’s been great.”

“I think you do have to be positive with any cancer. I believe in a ‘heal thy self’ attitude. I talked to my body and I said to the cancer, ‘I don’t want you here – get out’.

Having prostate cancer hasn’t slowed Kenney down. When we met him he was busy organising a fundraising event – a mixture of polo, classic cars and rock, ‘Rock n Horsepower’.

For more information about living with prostate cancer visit prostatecanceruk.org/living
Physical activity has many health benefits for men with prostate cancer, but staying active during cancer treatment can be a challenge. Here, our Specialist Nurse Naomi answers your questions about keeping fit with prostate cancer.

Q Why do I need to stay physically active?

A Staying active is good for your general health and wellbeing. It helps improve your circulation which means the blood flows around your body and delivers the oxygen and nutrients that your tissues need to work well.

Physical activity helps to use up any spare calories, which makes it easier for you to stay a healthy weight. It can improve your energy levels, lift your mood and help with some of the side effects of treatment, such as fatigue. Being a healthy weight can also help erection problems and bowel problems, like constipation. It can also reduce your risk of heart disease and diabetes.

Some research also suggests that physical activity and being a healthy weight can slow down the growth of prostate cancer.

Q How can physical activity help with the side effects I’m experiencing?

A There are many side effects of treatment which regular physical activity can help you manage. For example, extreme tiredness (fatigue) can be a side effect of most cancer treatments. Regular physical activity can help boost your energy levels and help you feel less tired.

To find out more about living with prostate cancer visit prostatecanceruk.org/living
If you’re on hormone therapy staying active is even more important. Hormone therapy, apart from causing fatigue and tiredness, can also cause weight gain, mood swings, muscle loss and thinning of the bones. Staying active helps keep the weight in check and lifts the ‘blues’. Resistance exercises such as swimming and lifting light weights can help to reduce muscle loss and keep you stronger.

Staying physically active can also help with side effects such as anxiety and depression.

Talk to your doctor or nurse before starting any exercise. They may be able to refer you to a physiotherapist who can suggest a specific exercise programme for your needs.

They may also be able to put you in touch with a local exercise programme run by qualified trainers, which, depending on your circumstances and what’s available, may be offered free or at a reduced cost.

**Q** How can I stay active when I feel exhausted all the time?

**A** Tiredness (or fatigue) is one of the most common effects of cancer. It can be the result of the cancer itself, or its treatment. Just the experience of a cancer diagnosis or going through treatment can be stressful and worrying, and this can leave you feeling exhausted.

It’s good to have some periods of rest, but not doing anything all day can make you feel more tired and less motivated. Try and stay active with some gentle exercise – even if it’s just a stroll around the block. It can help lift your mood and make you feel more energised and awake.

If you’re feeling too tired to walk outdoors, simply move around your home. You can even exercise from your chair or bed. Try lifting and stretching your arms and legs, which can help improve your muscle strength.

**Q** What sort of physical activity should I do?

**A** Physical activity can be any activity that makes your heart beat faster so that you’re slightly breathless – but still able to talk. Walking, swimming, cycling, pottering around the garden, mowing the lawn, dancing or even doing some household chores are all good ways of keeping yourself active. Don’t be afraid to try something new. If you find something you like, and that fits around your everyday life, you might be more likely to stick with it.

**Q** How much physical activity should I do?

**A** This will depend on the stage of your cancer and what treatment you’re having, as well as your fitness levels. Even if you don’t feel able to do a lot of physical activity, regular small amounts will help.

Start with an activity that fits around your day, like walking to the local shop instead of driving. Gradually increase the amount you do as you become fitter. If you can, build up to 30 minutes of physical activity three to five days a week. Half an hour of activity may seem daunting, but remember you can reach this amount by doing 10 minutes of activity three times a day.

Speak to your doctor before you start any kind of exercise plan. This is particularly important if you have any other health problems, such as heart disease or problems with your joints or muscles. Your doctor can give you advice and help you get started.

**Q** Is it safe for me to exercise when I’m having treatment?

**A** Gentle exercise is usually safe for men with prostate cancer and those having treatment. But it’s a good idea to talk to your doctor or nurse about the activities you want to do. Your doctor may suggest you avoid certain activities. For example, radiotherapy can cause skin irritation so if you enjoy swimming you may need to stop doing this during your treatment as the chlorine can make any skin problems worse.

If you’ve had surgery, your doctor may suggest you avoid swimming, long walks and heavy lifting for a period of time. Ask your doctor when you can begin normal activities again.

**Q** I’m finding it hard to get motivated, what can help?

**A** Staying active can be fun and doesn’t have to be a chore. Find an activity you enjoy, take things at your own pace and keep your exercise goals realistic. Ask friends or family to be involved and choose an activity which fits in with your life. For example, meeting up with friends to go for a walk together.

Joining a local walking, gardening or dance and drama group is another great way to stay active. Contact your local library or community centre to find out what’s happening near you.

Following an exercise programme, such as 10,000 steps a day can also help you stay motivated. You can get more information about walking 10,000 steps a day from the NHS Choices website.
FOCUS ON

You’ve probably read stories in the news over the past year about new drugs for advanced prostate cancer (cancer that’s spread to other parts of the body) – particularly about life-extending drugs and whether or not they’re going to be made available to the men who need them.

It can sometimes be hard to get hold of information about these drugs or find out if you can get them. Ask your doctor or nurse about what’s suitable for you or call our Specialist Nurses on 0800 074 8383.

**ENZALUTAMIDE (XTANDI®)**

What is it? A type of hormone therapy, taken as a tablet, that works by stopping the hormone testosterone from reaching the prostate cancer cells. Without testosterone, the cancer cells are not able to grow, wherever they are in the body. In a recent clinical trial, men who took enzalutamide lived for about four months longer than those who were given a placebo (dummy treatment).

Who can have it? It’s for men with advanced prostate cancer that’s no longer responding to hormone therapy or chemotherapy. It’s available in England, Scotland and Wales but you may not be able to have it if you’ve already had abiraterone.

**ABIRATERONE (ZYTIGA®)**

What is it? Like enzalutamide, it’s a type of hormone therapy taken as a tablet. It works by stopping the production of testosterone, so cancer cells can’t grow. It may help some men to live longer. It can also help control symptoms.

Who can have it? It’s for men whose prostate cancer has spread to other parts of the body and has stopped responding to other hormone therapy and chemotherapy. It also works well before chemotherapy. You may be able to get it before chemotherapy through the Cancer Drugs Fund or if your doctor puts in a treatment request for you to your local health board.

**CABAZITAXEL (JEVTANA®)**

What is it? A type of chemotherapy that uses anti-cancer drugs to kill cancer cells. In a clinical trial, men who were given cabazitaxel lived about two and a half months longer than men who were given a different type of chemotherapy.

Who can have it? It’s for men whose prostate cancer has spread to other parts of the body and has stopped responding to hormone therapy and the chemotherapy docetaxel (Taxotere®). It’s not widely available on the NHS but you may be able to get it through the Cancer Drugs Fund in England and in the rest of the UK, if your doctor requests it from your local health board.

**RADIUM-223 (XOFIGO®)**

What is it? A type of radiotherapy, injected into a vein, which treats prostate cancer cells that have spread to the bone. It travels around the body and is taken up by the bones where it kills cancerous cells. It improves symptoms such as pain and may also help men live longer. In a recent clinical trial, men on radium-223 lived on average four months longer than men on placebo.

Who can have it? It’s for men with cancer that has spread to the bones and has stopped responding to hormone therapy. It is available in England through the Cancer Drugs Fund and in Scotland, Wales or Northern Ireland if your doctor requests it from your local health board.

Read more about getting hold of new treatments prostatecanceruk.org/getting-new-treatments and the latest on abiraterone and enzalutamide prostatecanceruk.org/challengenice
PROSTATE CANCER AND ME

Errol Mckellar

56 year old Errol Mckellar is one of the stars of the recent BBC Lifeline Appeal and a champion of our Men United movement. He is a car mechanic who owns a garage in Hackney, London and was diagnosed with prostate cancer in 2010 after his wife prompted him to go and see his GP.

“My wife was complaining about my snoring so I said to her if she made an appointment with the GP for me, then I’d go.

“So I went along to the doctors and while I was sitting in the waiting room, I was bit bored, and something made me go and pick up this leaflet about prostate cancer. I asked them, ‘how long will it take to do this prostate test?’ and they said, ‘10 minutes - and we can do it now.’ That 10 minutes changed my life.”

Errol’s PSA level came back a bit high and further tests revealed he had prostate cancer.

At first he found it incredibly difficult to come to terms with.

“When I got my results the doctor said to me, ‘look, your prostate is covered in cancer, you could be dead in six months.’ I broke down. I literally just broke down, I was distraught, I was in tears. You know, I’m not ashamed to admit, I really cried. You imagine going into a room with no light. That’s what it felt like. It felt as if someone had pulled the plug on me. It was a very difficult period and took me a long time to get positive again.

“And my wife, she let me cry and then she turned around and said to me, ‘right, you’ve never quit at anything in your life, so what are you going to do now?’ And that’s when I made this decision to turn this negative thing into a positive thing. I told myself, I’m going beat this.”

In February 2011 Errol had an operation to remove his prostate and went on to have three months of radiotherapy and has now been given the all clear, although he is dealing with some side effects from his treatment.

“Since having treatment, I do have a numbness, down there, in the lower part of my body. I’m a young person, I’m an active person and when certain ‘tools of your trade’ are taken away from you – it’s difficult to deal with. But for me, I’m alive, and that’s what’s important to me.”

Now Errol is determined to overcome the disease and has pledged to raise awareness amongst men of his age. He encourages men who come into his garage to go and speak to their GP about their risk.

“I say to my customers, ‘when was the last time you had your prostate checked? You brought your car in here for me to check because there’s a problem. Do you know what’s going on in your own inside?’ Men need to talk about it – even if they don’t want to.

“I talk to men of all ages. I talk to women too – because they get the message across to their men. I try and spread the message every single day. I want to reach men before it’s too late. As Men United, I really believe we can beat this.”
PROSTATE CANCER AND ME

The book that helped me through

from Chris, Stephen, Andy and David
Books are sometimes an escape from reality but when we asked you what books helped you deal with having prostate cancer, you favoured fact over fiction.

Chris Bell told us about ‘Prostate Cancer – Understand, Prevent and Overcome’ by Professor Jane Plant. “I thought my cancer was beyond my control. But this book helped me understand the influence of my diet and made me realise that I do have some control after all.”

Stephen Hyett chose, ‘Betrayed by Nature’ by Dr Robin Hesketh. “I felt much more optimistic about the future. I learnt about the great strides being made by scientists and how these will help in the development of new treatments.”

Yet for some, it wasn’t reading which provided the greatest inspiration but writing instead. Brothers Andy and David Barnham were diagnosed with prostate cancer within nine months of each other. “My brother had radiotherapy and hormone treatment and I went down the surgery route,” Andy told us.

They decided to put their stories to paper and their rally against cancer, ‘You can stick that up your arse’, gave them a unique way of dealing with their situation. As Andy said, “It helped us both enormously to detail our journeys and allowed family and friends to better understand and empathise.”

So what book has inspired you? Join the conversation on our online community at prostatecanceuk.org/forum

My motivation: My dad

by Susan Childs
Susan Childs (pictured below with Liam Fox MP) started volunteering for us in 2012 after losing her father to prostate cancer.

“My dad was diagnosed in 2004. It came as a massive shock to both him and us, his family. We didn’t know anything about prostate cancer.

Sadly my dad passed away in 2012. He had a poor experience due to lack of communication between his health professionals and I am absolutely determined to try and stop this happening to anyone else. This is the reason I started volunteering. It’s a cliché but if I can just help one man, I would be delighted.

“Dad was always the first person to help others or to raise money for charities, I feel that this is his legacy, he is still helping others even after his death.

“Volunteering for Prostate Cancer UK gave me the chance to turn something so devastating into something more positive and kept me focused during my darkest days. I am not normally the type of person who speaks out publicly but I want to empower men to know their rights regarding treatment and support.

“After a nervous start I have been to Parliament, the Conservative conference, cheered on runners and handed out medals for Movember. I also ran an information stand at the Royal British pigeon show in Blackpool, along with a fellow volunteer. We spoke and gave information to hundreds of men. I felt fantastic afterwards, it was so rewarding. I have now decided that I am ready for Prostate Cancer UK speaker training, which I will be doing next month.

“Volunteering has given me so much confidence, a sense of well being and fun experiences that I never dreamt I would have. When I look back over the last 18 months, I can’t believe what I have achieved and it is all down to volunteering for Prostate Cancer UK.”
In the SPOTLIGHT

Stephen Crozier from Motherwell, Lanarkshire.

Stephen was diagnosed with prostate cancer in 2013 aged 51. Although it came as a big shock, Stephen’s cancer was caught early and at the moment he’s having his cancer monitored.

“Being ex-services, I’m in reasonably good shape – and I don’t smoke or drink really. So I was shocked to find out I had cancer. And it’s taken me a long, long time to come to terms with the fact that this can happen to anyone, however fit and healthy you think you are.”

Stephen decided to channel his energy into raising funds and awareness for us. First up was a sponsored bungee jump - the Highland Fling Bungee in Perthshire. After that Stephen organised a charity night at his local pub, with a raffle, live music and awareness leaflets.

“I was overwhelmed with the support I got from family and friends. People who I hadn’t heard from in 30 odd years got in touch. The night was a great success and a lot of fun. I even managed to talk to a few friends who had questions about prostate cancer and gave them leaflets to take away.”

“I’m up for anything and enjoy a challenge – so maybe I’ll do something more exciting than a bungee jump next time!”

THANK YOU

151 CYCLISTS

To the 151 cyclists who rode 150 miles from London to Amsterdam raising over £150,000.

£6,000

To Mike Willgoss who has raised over £6,000 from two months’ worth of supermarket collections. His grand total is now over £30,000.

1250 CAKES

To Stacey Marshall who baked her socks off, held 20 bakes sales and raised over £5,550.

160 GOLFERS

To David Hadley Smith, Rob Saunders and Cameron Clarke for swinging into action and organising a golf day that raised £5,535.

Read more Prostate cancer and me stories on our website prostatecanceruk.org/news

TOP DAD

Sophie’s dad Stratford has advanced prostate cancer. A huge fan of Marvel Comics, when he was too ill to see the latest Captain America film at the cinema, Sophie took action.

Here Sophie tells us about the campaign and her top dad.

“Top Dad

My father is one of the gentlest, best men I know. His kind wisdom, sense of humour, and child-like curiosity about the world have filled my life with love and fun. He always taught me to seek the truth with an open mind, to climb trees, to love books and heroes, and to try to leave the world a better place than I found it.

“When he was diagnosed with prostate cancer in 2011, I felt so powerless. He’s faced all his treatment with patience, courage, and good humour.

“When we found out recently that he is nearing the end, I realised there was one small thing I could do. I launched a Twitter campaign for dad to get a copy of Captain America: The Winter Soldier, before its general release.

“It was a huge success. And the flood of goodwill from the campaign and celebrities is helping raise awareness about prostate cancer too.

Progress | Summer 2014
Get your grill on
This summer, dust off your tongs, fire up the grill and get involved in MAN v BBQ.

Your challenge, if you choose to accept it, is to host a barbecue for family, friends or your local community and help raise funds towards research which could help us revolutionise the way we detect and treat prostate cancer in the UK (see page 6).

Gregg Wallace, who stars in our spoof promo film for MAN v BBQ says, “I turn 50 this year and prostate cancer is something that every bloke my age needs to bear in mind. MAN v BBQ is great way of having fun whilst doing something very important. Invite your mates and do something to help each other be there in 20 years’ time.”

So be it sausage or steak, beef burger or bean burger, whack something on the grill and stand up for Men United in the fight against prostate cancer.

Read about MAN v BBQ, watch Gregg’s film or get fundraising tips and celebrity recipes at prostatecanceruk.org/bbq

The ’taches are back
Men, have you been feeling a sense of loss since last November? Are you chilled by the cold wind that blows across your upper lip?

Fear not, this year Movember will be back and as hairy as ever. Are you ready?

Keep an eye out for updates here prostatecanceruk.org/Movember

Can you take on our 10,000 challenge?
10,000 men die from prostate cancer every year. We need to change this and need your help to do it. Create a challenge involving the number 10,000 and raise money to fight prostate cancer.

Collect 10,000 pennies (like William, left), run 10,000 metres, play 10,000 yards of golf, do a 10,000 second silence – or dream up your own 10,000 challenge. Need some inspiration? Visit our website to watch our 10,000 challenge film.

Show off your true colours
As the Official Charity Partner of The Football League, we’re celebrating the opening fixtures of the 2014/15 season with a splash of colour and we want you to do the same by taking part in a #shirt2work day. How? It’s simple. Ask your colleagues to wear their favourite club’s shirt or colours to work on your chosen day. And then charge them £2. You don’t even have to be a football fan – any colours of any sporting team will do. Find out more at prostatecanceruk.org/shirt2work
EVENTS CALENDAR
Aug 2014 - Feb 2015

Speaker training:
We are running speaker training for volunteers on the following dates:

20 Aug and 17 Sept
Aberdeen

5 Aug and 2 Sept
Swansea

Great Scottish Run
Take on a 10km or a half marathon running challenge for a fantastic day out taking in some of Glasgow’s most iconic landmarks and buildings.

Conquer Britain’s highest peak
Join us to tackle Ben Nevis. At 4,406 feet it’s a great challenge.

This exciting group adventure takes you to the summit of Great Britain – a memory that will last a lifetime.

We’ll prepare you for the challenge with our fundraising and training guides, support you throughout the weekend, and be on hand to celebrate with you as you complete this tough hike. We’ll also send you a Prostate Cancer UK walking top.

Jurassic Classic
There’s still time to sign up for the Jurassic Classic.

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

More events

2-3 August
Total Warrior

10 August
Prudential RideLondon 100

17 August
Jurassic Classic

30-31 August
Ride 24 London to Newcastle

5-7 September
Ben Nevis Challenge

6-8 September
Ride 24 London to Paris

7 September
Bupa Great North Run

London to Brighton

13-14 September
Thames Path Challenge

14 September
Zip Slide the Clyde

28 September
Berlin Marathon

5 October
Great Scottish Run

12 October
Royal Parks Half Marathon

Until October
3 Peaks Challenge

1-30 November
Movember

1-30 November
Movember

Until December
Wiggle Super Series

5 October
Great Scottish Run

12 October
Royal Parks Half Marathon

Until October
3 Peaks Challenge

1-30 November
Movember

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Until December
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5 October
Great Scottish Run

12 October
Royal Parks Half Marathon

Until October
3 Peaks Challenge

1-30 November
Movember

1-30 November
Movember

Until December
Wiggle Super Series
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.

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.

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

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 to help you do the things you want to do.

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.

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
### Expert sessions on living with prostate cancer

We know that men don’t always get the support they need when they’re diagnosed with prostate cancer and can often be left not knowing what support is available.

We’ve started to run conferences for men who are going through or have finished treatment. They’re a place for men to go and find out what support is out there and get information on how to manage their life with or after prostate cancer.

The conferences offer men and their families the opportunity to listen to experts in prostate cancer, talk about topics including, relationships and sex, diet and exercise, signs of recurrence and living with incurable prostate cancer.

Peter Robinson, who recently went to one of our conferences in Edinburgh, said this:

> “I went along to refresh and improve my knowledge of prostate cancer to help me in my role as a one-to-one support volunteer.

> “The speakers were excellent. In particular the presentation on the sexual consequences of prostate cancer was the most comprehensive treatment of the subject I have heard – giving rise to much introspection.

> “The presentation of developments in treatments gave me a good insight into the benefits of the latest chemo drugs, and an overall review of the treatments available.

> “Overall this was a day well spent, leaving me refreshed and thoughtful.”

We’ll be holding these events throughout the country. Visit our website to find out if there’s a conference near you.

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### Other useful organisations

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<thead>
<tr>
<th>Organisation</th>
<th>Website</th>
<th>Contact Information</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>British Association for Counselling and Psychotherapy</td>
<td><a href="http://www.itsgoodtotalk.org.uk">www.itsgoodtotalk.org.uk</a></td>
<td>01455 883 300</td>
<td>Provides information about counselling and details of therapists in your area.</td>
</tr>
<tr>
<td>Cancer Black Care</td>
<td><a href="http://www.cancerblackcare.org.uk">www.cancerblackcare.org.uk</a></td>
<td>020 8961 4151</td>
<td>Provides information and support to people from black and minority ethnic communities who are affected by cancer.</td>
</tr>
<tr>
<td>CancerHelp UK</td>
<td><a href="http://www.cancerresearchuk.org/cancer-help">www.cancerresearchuk.org/cancer-help</a></td>
<td>0808 800 4040</td>
<td>(Mon-Fri, 9am-5pm) CancerHelp is the patient information website of Cancer Research UK and provides information about living with cancer.</td>
</tr>
<tr>
<td>College of Sexual and Relationship Therapists</td>
<td><a href="http://www.cosrt.org.uk">www.cosrt.org.uk</a></td>
<td>020 8543 2707</td>
<td>For information on sexual and relationship therapy, including a list of therapists.</td>
</tr>
<tr>
<td>Health with Pride</td>
<td><a href="http://www.healthwithpride.nhs.uk">www.healthwithpride.nhs.uk</a></td>
<td></td>
<td>An online health resource for lesbian, gay and bisexual patients. Their website has information on cancer issues and erectile dysfunction for gay men.</td>
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<tr>
<td>Macmillan Cancer Support</td>
<td><a href="http://www.macmillan.org.uk">www.macmillan.org.uk</a></td>
<td>0808 808 0000</td>
<td>(Mon-Fri, 9am-8pm) Provides practical, financial and emotional support for people with cancer, their family and friends.</td>
</tr>
<tr>
<td>Maggie’s Cancer Caring Centres</td>
<td><a href="http://www.maggiescentres.org">www.maggiescentres.org</a></td>
<td>0300 123 1801</td>
<td>Provides information and support to anyone affected by cancer. Their website holds a list of centres across the UK and has an online support group.</td>
</tr>
<tr>
<td>NHS Choices</td>
<td><a href="http://www.nhs.uk">www.nhs.uk</a></td>
<td></td>
<td>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.</td>
</tr>
<tr>
<td>Penny Brohn Cancer Care</td>
<td><a href="http://www.pennybrohn.cancercare.org">www.pennybrohn.cancercare.org</a></td>
<td>0845 123 2310</td>
<td>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.</td>
</tr>
<tr>
<td>Relate</td>
<td><a href="http://www.relate.org.uk">www.relate.org.uk</a></td>
<td>0300 100 1234</td>
<td>Relationship counselling and sex therapy for individuals and couples.</td>
</tr>
<tr>
<td>Sexual Advice Association</td>
<td><a href="http://www.sda.uk.net">www.sda.uk.net</a></td>
<td>020 7486 7262</td>
<td>Provides a helpline service for advice and information about erectile dysfunction.</td>
</tr>
</tbody>
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### 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 Peter 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.
MAN v BBQ

This summer, dust off the tongs, fire up the grill and pit your wits against the BBQ beast. Hold the ultimate MAN v BBQ and help us fight prostate cancer.

WIN great prizes!

Sign up now at prostatecanceruk.org/bbq