

Progress

Prostate cancer news and views
Issue 2 | Summer 2013

Complementary therapies

Separating fact
from fiction

COLIN JACKSON



Prostate
cancer
and me

PSA test: past, present and future

We delve into the history,
the controversy and
what men think



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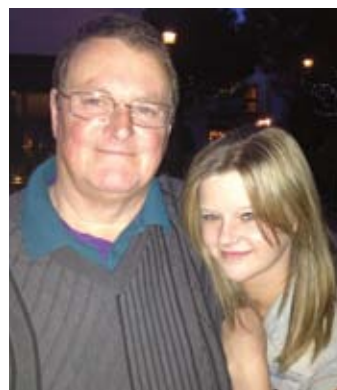
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Editor's note

Dear Readers,

To those of you who read issue one, welcome back and to any new readers, a very warm welcome.

We're very excited to bring you former Olympic athlete Colin Jackson talking about how prostate cancer has affected his family. We also take a look at complementary therapies and supply the latest prostate news.

However, the big focus of this issue is the controversial PSA test. We look at the facts behind the test, its history, our view and your views. We also hear from two experts and investigate the future of testing.

Once again, we are hugely grateful to everyone who has helped us by sharing their stories, experiences and opinions. Please continue to do so – we can't do this without you!

Very best wishes,

A handwritten signature in black ink that reads "Catherine".

Editorial team

Nick Wright

Ben Roche

Penny Eaton

Catherine Steele (Editor)

INBOX

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



Dear Progress

My husband is currently receiving hormone therapy for advanced prostate cancer. When we received the first issue of Progress in February I read Bruce Tasker's "My Experience" and I felt quite relieved in a way that someone out there is experiencing the same as my husband. There is some useful information in that article!

He was also interested in reading your magazine which was amazing as he's usually very reluctant to read anything that comes through the door regarding prostates. He then signed up to walking/jogging a 5km after looking through your Events calendar and that's inspired him to get more involved in these charity runs/walks for Prostate Cancer UK. Thank you.

**Carol Hastie-Davies,
Cardiff**



Dear Progress

As a new fundraising volunteer I was sent issue number one of Progress. I found it interesting, informative and well laid-out. I wish information like that had been available to me 13 years ago when I was diagnosed with prostate cancer.

However there is something you might like to consider in future. There are around two million blind and partially sighted people in the UK and they will be unable to read Progress in its present format. Have you considered making it available in Braille, large print or audio?"

Bob Pow, Cumbria

Dear Bob,

We are very keen to make Progress accessible to as many people as possible. We have recently trialled the magazine using glasses provided by the RNIB, which simulate some common visual impairments, and found it performed pretty well, but we are making some adjustments. The main method we are using to make Progress available in larger print is to produce an electronic copy of the magazine (PDF), available on our website, and an email newsletter. Both of these can be enlarged as much as the reader wishes.

Many thanks for your feedback – we really do appreciate it.

The Progress Team



Received the 1st issue of #ProgressMag today and it's an excellent read - full of useful advice, info and news. Good work!



Really interesting magazine. Informative and easy to read. It has been read by several patients on my urology ward. Thank you.

Write to us:

Prostate Cancer UK
Fourth floor
The Counting House
53 Tooley Street
London SE1 2QN



Dear Progress

In your next newsletter could you please explain what a 'Gleason' reading is and how it is arrived at. Thank you.

**Brian Ovenden,
Canterbury**

Gleason grade

If biopsy samples contain cancer, the pattern made by the cancer cells is given a grade from 1 to 5. This is called the Gleason grade.

Gleason score

There may be more than one grade of cancer in the biopsy sample. The grade of the most common pattern and the pattern with the highest grade are added together to give the Gleason score. The higher the Gleason score, the more aggressive the cancer and the more likely it is to spread. Gleason scores run from 2 to 10. However, today doctors usually only give a Gleason grade of 3 or more, so your Gleason score will normally be between 6 and 10. For more information see our fact sheet, **How prostate cancer is diagnosed**. Visit our website: prostatecanceruk.org to order or download a copy.



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progress@prostatecanceruk.org

PROSTATE CANCER NEWS

Men not getting the help they need with side effects

Health professionals and people affected by prostate cancer have told us that getting support with side effects of treatment is one of the biggest challenges men face. Specifically, men need more help dealing with incontinence and erection problems. This was revealed at the first meeting of our new Policy and campaigns forum.

We started the group to ensure that through our campaigns we tackle the issues that matter most to men.

“The Policy and campaigns forum highlighted the problems men have with getting access to support services for the side effects of prostate cancer treatment,” said Drew

Lindon, Head of Policy and Campaigns. “Now we are looking at what we can do to ensure all men have access to appropriate support to cope with incontinence and erectile dysfunction, if they experience these side effects.”

If you have had trouble getting support for these problems, we'd like to

hear from you to help develop our campaign. And if you have any suggestions for future campaigns, please contact lizzie.flew@prostatecanceruk.org, or call **020 8222 7651**. Any suggestions will be discussed at the next meeting of the Policy and campaigns forum in the autumn.

“John was a surgeon’s surgeon and an inspiration”



**John Anderson FRCS
ChM – 1953-2013**

Friend and fellow prostate cancer expert, Roger Kirby, pays tribute to John Anderson, who has died from prostate cancer.

“With characteristic openness, John was keen for his experience of prostate cancer to be made public to raise awareness of the disease.

He appeared in the national press, and just a few weeks ago recorded several films in which he talked positively about his own diagnosis.

“John trained at the University of Bristol, qualifying as a doctor in 1979. He gained Fellowship of the Royal College of Surgeons of England in 1983 and two years later, returned to a full-time research post at Bristol where he obtained his Mastership in Surgery.

“In 1987 John decided to specialise in urology and moved to Sheffield. While training, he won scholarships, which enabled him to spend time working with the famous Professor Donald Skinner in Los Angeles. Here he learned the techniques of radical prostatectomy for localised prostate cancer.

“In 1991 John was appointed as a Consultant Urological Surgeon with a special interest in oncology (the study and treatment of cancer), at the Royal Hallamshire Hospital in Sheffield. He provided a lead in developing clinical practice and research in prostate cancer, and the unit soon became a regional referral centre for radical prostatectomy.

“Not long before he died, I asked John what his most important professional achievements were. He replied: ‘The real highlights have been helping to introduce major cancer surgery in urology to the UK, setting up the British Association of Urological Surgeons (BAUS) Section of Oncology, and being elected as Secretary and President of BAUS – pity I can’t deliver on that last bit!’

“John was due to become President of BAUS in 2012, but unfortunately fell ill. He gave a most moving account of his prostate cancer diagnosis at the annual meeting, explaining why he was not able to take up the Presidency. However, he never complained. Typically, he went out and bought a powerful motorcycle to ride around Yorkshire, and spent as much precious time as he could with his family.

“John also told me: ‘Equally important for me have been the great friends and colleagues I have worked with along the way and the fantastic fun we have had in the tremendous specialty of urology.’

“John was a surgeon’s surgeon and an inspiration to us all. We shall miss him.”

Researchers discover genetic changes that could mark out aggressive prostate cancer

Recent research has identified gene changes that could be used to distinguish life-threatening prostate cancer from less dangerous forms.

As prostate cancer develops and progresses, the genetic code of the cancer cells starts to mutate and go wrong. This can be caused by making multiple copies of a gene (known as amplification) or by the deletion of a gene (often referred to as a loss). According to a recent study, patients whose cancer cells have lost a gene called PTEN and have many copies of the gene MYC were found to be over 50 times more likely to die than other patients who had similarly staged

tumours and PSA levels at the time of diagnosis.

In this study, the researchers looked at the number of copies of each gene in over 400 prostate cancers that were removed by prostatectomy (surgical removal of the prostate gland) and compared the genetic changes to other data including the Gleason score, PSA, other indicators of tumour stage and outcomes for the patient.

Dr Kate Holmes, Head of Research at Prostate Cancer UK, said: "This study provides information that may be helpful for creating a test to distinguish life-threatening prostate cancer from the more benign form of the

disease. This would be a great step towards having more reliable information that patients and their doctors can use to make treatment decisions with confidence.

"However, this research will need to be confirmed by further studies. One of the weaknesses of this study is that the researchers only studied

one specific type of genetic mutation that occurs during cancer progression. There are many other types of genetic changes which can lead to cell growth going wrong during the development of tumours. The trick for scientists now is to understand which changes occur first, and whether these changes lead to and control further changes, or vice versa."



FROM THE LAB

Progress reports on the research we are funding

Clinical trial of devices designed to prevent or contain persistent urinary leakage following prostate cancer surgery

Professor Mandy Fader

Around 10 to 15 per cent of men experience persistent urinary incontinence after treatment for prostate cancer. Many men use absorbent pads but find them bulky and feminine. This project looked at different devices – urinary drainage sheaths, body-worn urinals or penile clamps – which were all tested by 56 men.

The results suggested that urinary drainage sheaths were good for using over extended periods, body-worn urinals were useful for men who couldn't use sheaths, and the penile clamp was generally viewed as being uncomfortable, so was better for shorter periods. The study demonstrates, for the first time, that different

male devices and pads have different strengths and limitations. It suggests that men should be offered these devices as well as pads, and given support on how to use them in different circumstances.

A new approach to testing markers of prostate cancer – year one report

Professor Colin Cooper and Dr Christopher Parker

Around 80,000 men a year have a biopsy in the UK following a PSA test, but around 50,000 of these biopsies turn out to be unnecessary. This project is looking at whether markers found in blood and urine could be used to identify aggressive prostate cancer that requires a biopsy. In the first year of this three-year study, researchers have set up a system for collecting and storing blood and urine from men about to have a biopsy and have collected 70 samples.

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

PSA: past, present and future

Behind the controversial test



The PSA test has been contentious since it first came into existence. Some think it's unreliable, others that it should be used to screen UK men for prostate cancer. Many men and women tell us they think it's a test that saves lives. We think all men have the right to have a PSA test as long as they know the facts, good and bad, before deciding whether to have it. To explore all the issues behind it, we have delved into the history of its development, gathered opinions, and looked at future alternatives.

PSA stands for Prostate Specific Antigen. An antigen is a substance that causes your immune system (the part that organises cells to fight off disease) to produce antibodies. PSA is an antigen that is specific to the prostate alone. The test measures how much PSA is in a man's blood. It is normal to find some, but a higher level may mean there's a problem with the prostate. It doesn't mean a man has cancer and the test is not and never has been a test that can diagnose cancer.

So who discovered PSA and when? Well, there is no straightforward answer. Although Dr Richard Joel Ablin is most often credited with its discovery, PSA was identified by a number of different researchers who were looking for different reasons and in different places.

In 1960 Dr Rubin Hyman Flocks discovered an antigen in the prostate gland, which he called Species-specific prostate antigens. Later, Dr Mitsuwo Hara (who was looking for a way of gathering forensic evidence for rape cases) found an antigen in semen (the fluid that contains sperm) which he named Unique antigen in the semen. Dr Ablin was the first to use the term Prostate

Specific Antigen in research published in 1970 that described an antigen identified in the prostate.

As you've probably worked out, the antigen in semen was the same as that found in the prostate – PSA. However, research continued down different pathways and it took a while for these paths to meet. In 1980 Dr Lawrence D Papsidero identified PSA in the blood of men with metastatic prostate cancer (cancer that has spread). This finding led to the development of what became the PSA test. The test began to be used by the NHS in the 1990s.

The PSA test now – raising awareness

Currently, every man in the UK is entitled to request a PSA test. In 2002 the UK Government introduced the Prostate Cancer Risk Management Programme to help GPs give men asking about the test accurate and balanced information before they decide whether to have it. However that only works when men request the test. And many men don't know it exists.

To combat this, we launched a programme called Testing Choices to provide all men at a higher risk of prostate cancer (including African Caribbean men and men whose brother or father has had the disease) the information and support they need to make a decision.



Around two thirds of men with a raised PSA do not have prostate cancer

We are currently trying out different ways to reach men, including a community walk-in clinic, then we'll campaign for improvements in information to be rolled out. As we have set out on the facing page, we don't believe the PSA test should be used in a national screening programme. Our focus is on making sure men understand the pros and cons of the test and on funding research to find a better test to diagnose prostate cancer.

The future of testing

Advances in genetic medicine are a new and promising area of investigation for testing. Recent research has linked faults in a gene called BRCA2 with aggressive prostate cancer. Testing men to see if they have this gene could predict whether they will go on to develop the aggressive form of the disease. Researchers have also identified 78 DNA changes that increase the risk of developing cancer, 16 of which are linked to aggressive prostate cancer. Both of these areas need more research and development before any tests become available, but it's a very promising start.

Should all UK men over 50 be screened using the PSA test?

Owen Sharp, Chief Executive of Prostate Cancer UK, explains why we don't think so: "When you look at the extensive research behind screening with the PSA test, the numbers just don't stack up. The negatives far outweigh the positives."

"Research does show that it could prevent some men dying from prostate cancer. However, this comes at the significant cost of many more men being treated unnecessarily, resulting in life-changing side effects. The PSA test is also unreliable. Around two thirds of men with a raised PSA do not have prostate cancer, while one study suggests that around one in six men with a 'normal' PSA may have prostate cancer. Put simply, the test is not accurate enough to be used in national screening."

"What we really need is to find a better test and that is one of the biggest priorities in our research strategy. We have already spent over £15 million on research, and with your support and that of Movember we are going to spend a further £25 million over the next three years."

"Research is the way to defeat prostate cancer and permanently put the issue of the PSA test to rest."

Know the facts about the PSA test

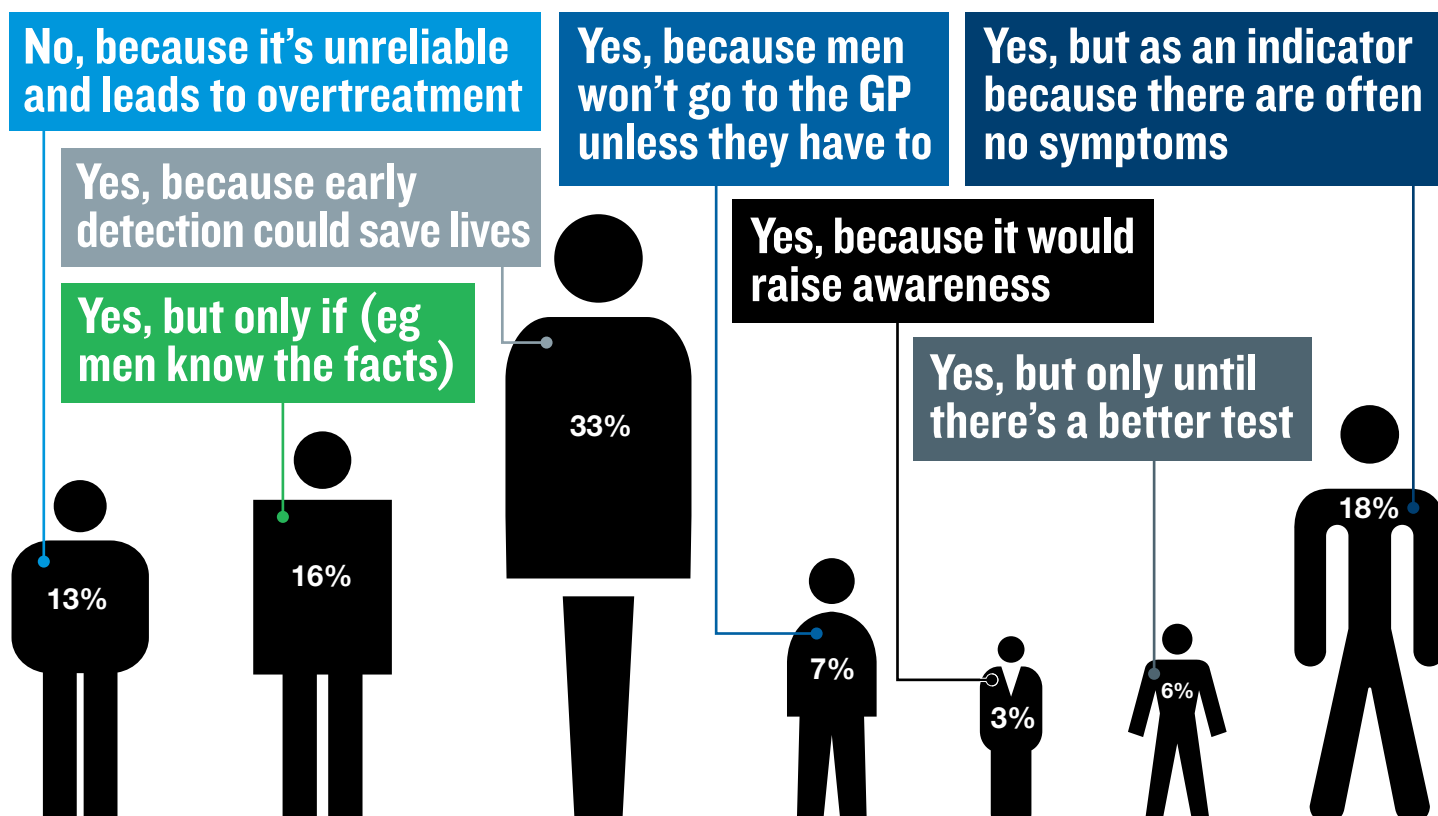
Strengths

- It may detect prostate cancer before symptoms develop.
- It may lead to finding prostate cancer at an early and more treatable stage.
- Repeated tests can provide valuable information on diagnosing prostate cancer and cancer progression.
- Even with a low PSA you could still have prostate cancer.
- To diagnose prostate cancer, more tests are required, some of which come with risks, such as a biopsy.
- A single PSA test cannot distinguish between aggressive and non-aggressive prostate cancer.
- It can lead to unnecessary treatment of non-aggressive prostate cancer and life-changing side effects such as incontinence and erection problems.

Weaknesses

- It's not a cancer test – a raised PSA could be caused by benign prostate disease or a urinary tract infection.

We also asked men with prostate cancer, and their families and friends, and had some responses from health professionals. We heard a huge range of arguments for and against. Here we illustrate this range:



You can read more about our PSA campaign at prostatecanceruk.org/testingchoices

From doctor to patient: The PSA test



John Anderson,
Consultant Urologist



Roger Kirby,
Consultant Urologist

As discussed in our lead article, the PSA test has pros and cons. It can lead to early detection of prostate cancer. However, it is unreliable – some men have a normal PSA, yet still have prostate cancer.

John Anderson was dedicated to improving the lives of men with the disease, even in the last few months of his life. In March 2013 he and his long-time colleague Roger Kirby discussed the pros and cons of the PSA test in a video to help explain the issues around this divisive topic. John's words are a fitting tribute to a life spent working towards a better future for men.

John: "You and I have used the PSA test all our working lives. And before it came along, we saw nothing but patients who had advanced disease when they were presented to us. However, I would say that the PSA test completely failed me. I had a normal PSA four months before I was diagnosed with advanced prostate cancer. I had metastatic disease in my liver and I've had chemotherapy. Even in that position, I would still argue that the PSA is a good test but it has its limitations."

Roger: "At the moment, if a man's PSA is raised, he's likely to be referred to a urologist who is likely

to do a biopsy, which carries some risks – infections and bleeding."

"In my case my PSA rose to 4.3, which can be an indication of prostate cancer but at that level you might decide to watch and wait. I was lucky because I had access to the very latest MRI technology, 3 Tesla scanning, which is not routinely available. I had a scan, which showed a distinct shadow on the right side of the prostate. That told us there was definitely something wrong and that I definitely needed a biopsy. For me the PSA test was providentially sent."

John: "I've met so many men who say: 'Why don't we have screening? Why isn't the PSA test universally available?' I think it should only be used on men when they fully understand its limitations. PSA levels can be elevated by anything that affects the prostate, without the patient having prostate cancer. And you can have a normal PSA and still have very advanced prostate cancer, which was the boat I found myself in. The only way we can be sure of the cause is by doing biopsies. I think better tests will come along which may be useful in a screening programme."

Roger: "I think the way ahead is better imaging of the prostate with 3 Tesla. If there's a shadow, you can target the biopsy. If there's no shadow, you can watch and wait and monitor the PSA. There are other advances coming like genetics. If we can use genes to identify men who are more likely to get it, we could do targeted screening."

"I think a man should know his numbers and be fully informed. A high PSA level doesn't mean you've got prostate cancer but you know you've got a problem in the prostate."

John: "Men should know provided they understand the limitations but to have the test in isolation would be wrong. That is why I think we can't use it in a national screening programme."

Please read our tribute to John's life and work on page four. You can watch the video of his discussion with Roger online: prostatecanceruk.org/news

New ways to give men the information they need

We all know that men can be reluctant to see their GPs so we're looking at new ways to reach them with the health information that they need.

Our research has shown that African Caribbean men and men from some socio-economic groups can be particularly reluctant to talk about their health and are more likely to think about it when information is provided in their local communities.

We are piloting a new programme of community-based talks about prostate cancer where our Specialist Nurses will also offer one-to-one sessions with anyone concerned about the

disease. The nurses will be able to discuss any risk factors, explain signs and symptoms for prostate cancer and ensure men understand the options for diagnosing the disease and the services available to them.

For more information call **0208 563 3913**.

Deloitte joins the fight

We're delighted to announce that Deloitte has chosen us as one of their charity partners for the next three years. They will be supporting a project to reach 300,000 men at highest risk of prostate cancer called Search and rescue. You can find out more about the partnership at prostatecanceruk.org/companies



Actor Ray Winstone

TV film urges men to "talk about it"

This Father's Day a gripping short film hit our TV screens with one big aim: getting people, especially men, to talk about prostate cancer. One in eight UK men will develop the disease and, within 15 to 20 years, it is predicted to become the most common cancer in the UK.

Some of the most well-known actors in the UK united behind that aim to take part in the film, called Father's Day, which aired on ITV4. Ray Winstone, Charles Dance and John Simm joined Neil Stuke (whose character in BBC drama Silk has prostate cancer) and Tamzin Outhwaite whose father was treated for the disease last year. The crew have also been

affected by prostate cancer. Both the executive producer and the director's fathers have had the disease.

Ray Winstone told us: "A couple of friends of mine have got prostate cancer. Thank god they caught it early, it saved their lives. I'm 56 and one of them is 58, the other younger than me. It's not an old man's disease. When you're younger you think you're gonna live forever. It's important to make films like these and say 'boys it's alright to talk about it rather than have your family turning up at your funeral'. That's why I really wanted to be a part of this. Hopefully this film could save thousands of lives."

If you missed Father's Day, you can still watch it at prostatecanceruk.org/fathersdayfilm and find out more about the background behind the film.

NEW ON THE WEBSITE

prostatecanceruk.org

Hear men talk about their experiences of prostate cancer treatments in our new videos. Visit our **Information pages** and click on personal stories, then treatments.

Read about the exciting research projects we've just awarded funding to. Go to our **Research pages**, click on funded research and change the year to 2013.

Colin Jackson



Colin Jackson, 46, is one of our most successful track athletes. During his career he won a huge haul of medals including Olympic silver and World, Commonwealth and European gold. He is now a sports commentator and TV presenter. Colin tells us how prostate cancer has affected his family and talks about his increased risk of developing the disease.

“Two of my uncles have had prostate cancer. My father’s eldest brother, Ronnie, was diagnosed first in 2004. Unfortunately, the disease was very advanced when it was discovered and not long after he passed away.

“Then Uncle Tony, my mother’s eldest brother, was diagnosed in 2010. He was in his late sixties. He’d had urinary problems and because he was African Caribbean and therefore more likely to develop prostate cancer, he was having regular PSA tests. Unfortunately, in one of those his PSA level was

raised and it turned out he had quite advanced prostate cancer. He had to have chemotherapy.

“He had a very positive mind set during his treatment. He said: ‘I’ll keep myself healthy and do exactly what they tell me and what will be, will be.’ Fortunately the cancer retracted a lot. Since then, they’ve been checking him on a regular basis and he’s still fine.

“Although we’re a really close family, neither Tony nor Ronnie spoke to me about their prostate cancer. Caribbean men just don’t like talking about health issues – they’re a proud bunch. And the older generation just say that’s what happens when you get older. However, because my mother’s a nurse, my uncles did talk to her and she let us know what was going on. She also makes sure my Dad is regularly tested.

“As for me, I’m very much aware that as an African Caribbean man with a family history of prostate cancer I have an increased risk. I know all the symptoms – I’m always listening for changes in my body and I’ll definitely get myself tested. I know I’m not guaranteed health and



I know I’m not guaranteed health for life

fitness for life just because I’ve been an athlete.

“Now I want to make other men aware of prostate cancer and their general health and do something about it. That’s why I organised a men only 5k run on Father’s Day (16 June) called Go Dad Run. We asked guys to do it for their health and be fit for Father’s Day. Prostate Cancer UK was the official charity and we urged men to go and see them on the day and find out about their risk of prostate cancer. I’m planning to do a Go Dad Run every year with events all over the UK.

“When cancer affects your family you totally, totally understand the importance of increasing awareness and raising funds for research. We need to get a better test so we can diagnose men like my Uncle Ronnie earlier and get them treated.”

Download our leaflet for African Caribbean men from our website.

Patricia Neeves

Patricia Neeves is 69 and lives in Berkshire. She has two grown up sons, Christopher and Phillip. Patricia's husband Ken was diagnosed with prostate cancer in 1997. She talks frankly about the difficult journey to diagnosis and the impact of the disease on partners.

"Ken was diagnosed by a very circuitous route. He went to his GP in November 1996 because he was worried about his impotency, which was worsening. The doctor said it was all in the mind, and he sent us for sexual counselling.

"That was an interesting experience! As I had been to an all-girls school and Ken was my first sexual partner, I can remember squirming at the intimate questions. When we weren't making the progress the counsellor expected, he decided there was something physically wrong and sent us to a sexually transmitted disease clinic. So there we were squirming again, wondering what on earth people were thinking of us.

"The clinic did various tests including a PSA test, which was raised a little. So they sent us to a urologist who did a rectal examination and took six biopsies without an anaesthetic. Poor Ken said it was like having six of the best.



Partners need to know that treatment can affect them too

"I wasn't with Ken when the results came back. I'd just got a job with a local amateur radio station and it was my first day. My shift had barely started when Ken came in and said: 'I've had a diagnosis and it is malignant.'

"After that, I went to all his appointments and I'd advise any wife to do so. It's very important that you both understand the implications and have a chance to ask questions, because prostate cancer treatment can affect your partner's sexual prowess and that affects you too.

"In August Ken had surgery to remove his prostate. When it was examined, they found the cancer was very aggressive and we were lucky it hadn't spread.

"I wasn't given any information after the operation and we were offered no support on how to cope with the post-operative erectile dysfunction that followed. Eventually I went online and found Prostate Cancer UK. The staff supported us all the way through. It was such a help to call the Specialist Nurses for information or just to say: 'I'm having a really awful day.'

"When you've got cancer yourself, you focus on dealing with it physically but the partner

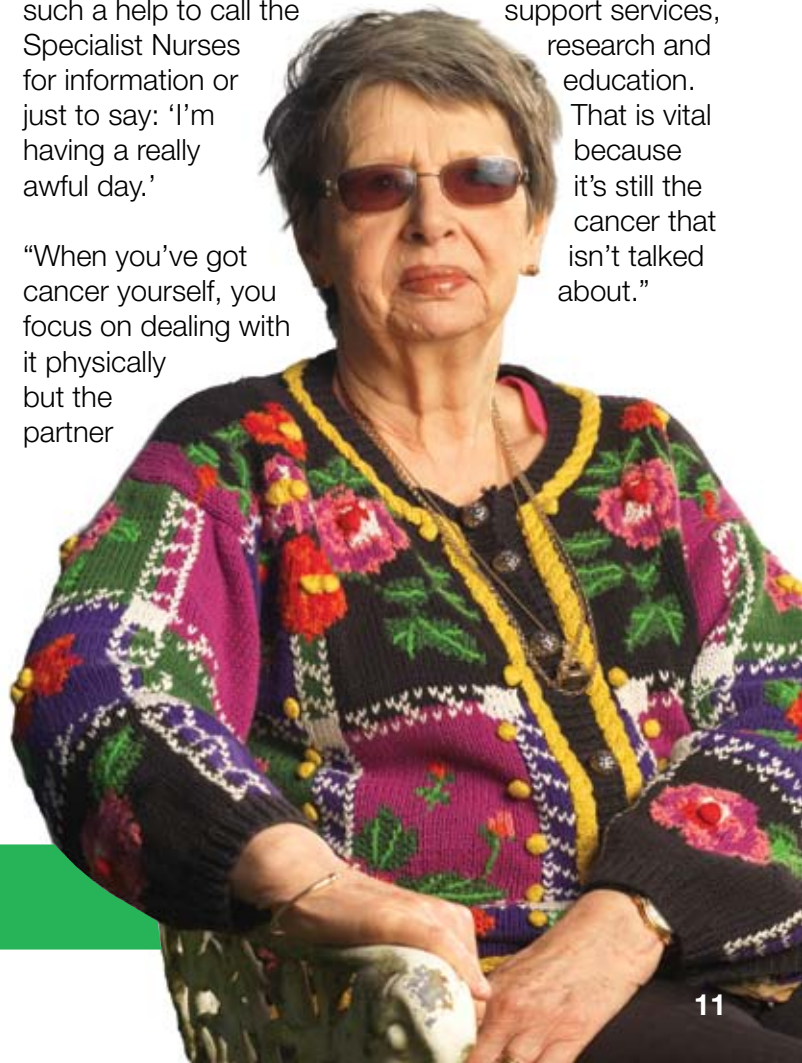
is on the side lines doing more of the coping and supporting.

"Ken recovered completely but at the end of 2000 we discovered he had a brain tumour, unrelated to the prostate cancer. I cared for him, mostly by myself, until he died in October 2002.

"Since I lost Ken, I've done a lot of fundraising for Prostate Cancer UK including a tandem skydive. I've also left a gift in my Will because I'm passionate about their

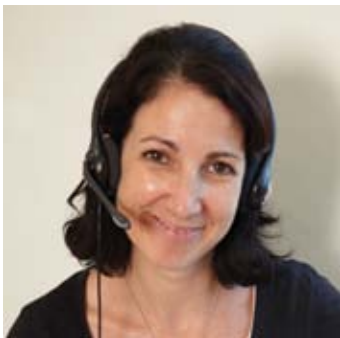
support services, research and education.

That is vital because it's still the cancer that isn't talked about."



THE MANUAL

Your questions answered about
Complementary therapies



Many men want to know if complementary therapies can help to treat their prostate cancer. Here Specialist Nurse, Meg Burgess, answers common questions and separates fact from fiction.

Q What are complementary therapies?

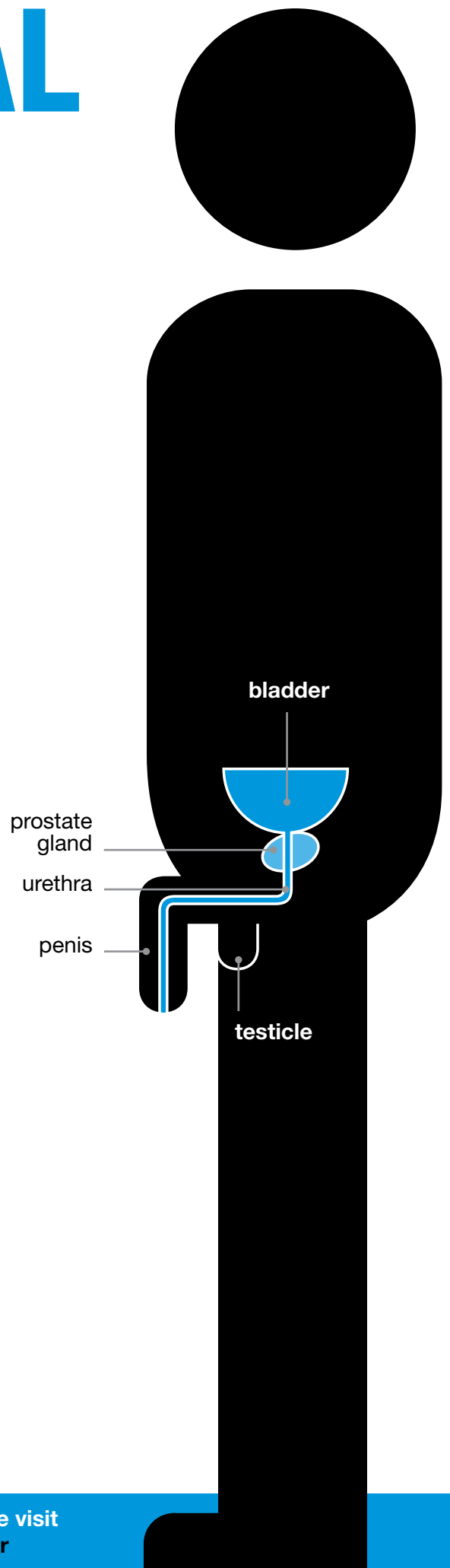
A The term “complementary therapies” covers a huge variety of approaches from diets to massage and from hypnotherapy to yoga. One reason all these different therapies are grouped together is that they are not usually part of mainstream medicine. However, some are available through hospices, GPs and hospitals.

Some men find that complementary therapies help them with their symptoms and the day-to-day impact of their cancer, or with the emotional side, helping them feel in control. For others, they provide a more complete kind of care, looking after their overall health and wellbeing.

There are a few complementary therapies that have research behind them and some are well regulated. But others have neither. It's worth remembering that some therapies cause side effects and can even be harmful or stop other treatments from working. We suggest you take a cautious approach and let your health team know if you're thinking of trying something – just as you would for medical treatments.

Q What's the difference between complementary and alternative therapies?

A Complementary means as well as. So you might use these therapies alongside the treatment choices you make with your GP, nurse or hospital doctor.



To find out more about helping to treat prostate cancer please visit prostatecanceruk.org/information/living-with-prostate-cancer

Alternative means instead of, in other words, choosing only to use these therapies and not to use mainstream treatments.

Mainstream treatments are carefully tested to show that they work, to check for safety, and to highlight side effects. Many alternative or complementary therapies have not had the same sort of testing. Using them carefully alongside treatments could have benefits. Using them instead runs the risk of having no effective treatment. Arm yourself with the facts before you make decisions.

Q Why aren't more complementary therapies available through my doctor?

A Doctors look for treatments with evidence to show they work and what the likely side effects will be. Regulations also guide doctors in how someone should use the treatment – how much, how often, with or without other treatments. For many complementary therapies, this information is very limited, or doesn't exist.

Some people say they benefit from complementary therapies. But others notice no change, or say they've had negative effects from what they tried. Without scientific evidence, this range of experiences makes it hard for a doctor to give you advice.

However many doctors recognise there are things men might find helpful to try, and they should be happy to explain any concerns they have about therapies you discuss with them. They might be aware of some side effects to watch out for and they can check if there are any known effects on other treatments you are having.

Q Is there anything to help me deal with prostate problems?

A There is some research that suggests therapies including aromatherapy, hypnotherapy, acupuncture, reflexology and massage could help you deal with the stress of living with prostate problems. They might help you feel more in control and better in your day-to-day life. They can help relieve anxiety and depression. This in turn could help you cope with the effects of illness such as pain and fatigue. If you have fatigue or ongoing pain, you might find it useful to see our fact sheet, *Managing pain in advanced prostate cancer*, and our *Get back on track* service.

Hot flushes are a common side effect of hormone therapy. Some men try herbal remedies such as sage tea, to help with this. However, there's very little scientific evidence that herbal remedies are effective for managing side effects. A small number of studies have suggested that acupuncture might help with hot flushes. You might get acupuncture through the NHS, or a complementary therapy team linked to a hospice.

Different things work for different people, so you might have to try something to know if it's right for you. Always let your doctor, nurse and other health professionals know if you are thinking of trying something. And tell any complementary therapist involved about your diagnosis and any treatments you are having.

Q It's natural, so what's the harm?

A Complementary therapies are sometimes called 'natural'. But natural doesn't mean harmless. Herbal remedies, for example, are not usually controlled and licensed in the way mainstream medicines are. They can have side effects, they might not be cheap, it's hard to know for sure what they contain, and in almost every case there isn't reliable evidence to say what dose is best or if they work. Be particularly careful about buying herbal remedies over the internet – it can be even harder to know what you're getting.

Q How can I get complementary therapies?

A There are a number of ways. You could get them through:

- your GP, nurse or hospital doctor
- a pain clinic, if you've got lasting pain
- a hospice (they don't only care for people at the end of life, and some offer therapies as day services)

Maggie's Centres are a network of drop-in centres offering cancer information and support, including some complementary therapies. Find out more at www.maggiescentres.org or call 0300 123 1801.

The charity Penny Brohn Cancer Care offers a range of complementary therapies, including residential courses, through their national centre just outside Bristol. Find out more at www.pennybrohncancercare.org or call 0845 123 23 10.

If you'd prefer to find your own therapist, the Complementary and Natural Healthcare Council can help you make sure that they are properly qualified and belong to a professional body www.cnhc.org.uk or call 020 3178 2199. Ask therapists about their knowledge and experience of cancer.

And if you are thinking about using a herbal remedy or supplement, the Medicines and Healthcare products Regulatory Agency (MHRA) has advice about using them safely – www.mhra.gov.uk or call 020 3080 6000.

With thanks to Georgia Diebel and Dr Catherine Zollman at Penny Brohn Cancer Care for their input.



The hobby that helped me

by **Steve Gledhill**

"I was diagnosed with aggressive prostate cancer in early 2009. By October of that year I'd had temporary brachytherapy, six weeks of radiotherapy and had been on hormone drugs for six months. Throughout this my doctor encouraged me to exercise but I felt extremely tired. I'd look outside at the wet and cold and think 'Not today!'"

"One day though, a neighbour told me she

could no longer look after her border terrier, Gypsy, and offered her to me. I wondered if it was a good idea as I'm in my early 60s and the children have fled the nest. We'd had a border terrier when they were younger – a very affectionate and loyal pet. As they say, a dog is a man's best friend so we gave her a new home.

"Receiving hospital treatments can make you very dependent on support and the real world

can become a daunting place. Gypsy got me out of the house. I exercised a great deal and chatted with other dog walkers. She also accompanied me to our local pub where I made friends.

"Having a dog has been very therapeutic for me. She's not as much hard work as I thought she would be and ultimately she got me out again and meeting people. Seeing her charge around puts a smile on my face and she gives

me great companionship about the house."



Adrian Mole: The Prostrate Years

(Penguin Books)
Extract 2/3



© Ben McMillan

Here is the second of three extracts kindly loaned to us by writer Sue Townsend from her fabulous book, Adrian Mole: The Prostrate years.

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.

Thursday 13 September

Dr Wolfowicz lives in an Edwardian house just outside the village.

After typing in my name and asking me if now lived in Belfast, to which I answered, 'No, I live at Number Two the Piggeries,' he sighed and took my medical records. He read the last few pages, including the letter, then said, 'So you've had a DRE?'

'Yes,' I said, 'so I don't need another. All you need to do is take some blood.'

Dr Wolfowicz frowned and said, 'Please Mr Mole, do not tell me how to do my job. I will need to examine you myself. Now are you getting on the couch?'

He put on a pair of gloves and I pulled my trousers down and got into the foetal position for the second

time in two days. It wasn't quite as bad as the last time. When I had dressed myself again, he said, 'Your prostate is not what I would like. I will take some bloods and then we will wait...'

Friday 21 September

As I walked down the lane towards Dr Wolfowicz's surgery, a golden sunshine shone through the branches and somebody was burning leaves somewhere.

When I was called in, he said immediately, "Mr Mole, I have your results and I'm going to refer you to a consultant urologist for further examination.'

It felt as though my blood had turned to water.

'I have written to Mr Tomlinson-Burk at the Royal Hospital. He's one of the best urologists in the East Midlands.'

I said, 'Yes, but how is he rated in the British Isles?'

I stopped at the post office on the way home. Mrs Lewis-Masters was at the counter drawing her pension. She gave me a nod of recognition. We left the shop together and for some reason I found myself telling her about my prostate trouble. She stopped walking and said, 'The men of the desert used to call it the Old Man's Curse. Their cure was to take camel dung and use it as a poultice around their genitals.'

'And did it work?' I asked, as we resumed walking.

'Of course not,' she said, 'but it seemed to relieve the symptoms somewhat.'

In the SPOTLIGHT

Mark O'Flynn, 52 from Hinckley

Mark was diagnosed with prostate cancer in spring 2003. He opted for surgery followed by radiotherapy. While still in his hospital bed, he had an idea to climb Snowdon in Wales to raise money for Prostate Cancer UK.

In September 2003 he did it, raising over £2,500. "It was tough, but I felt my body had let me down and I wanted to be fit."

Ever since then he has been hungry for new challenges. He's climbed Ben Nevis and completed nine triathlons plus a half marathon. In recognition of his incredible fundraising for us and his other community work, Mark was chosen to carry the Olympic torch through Melton Mowbray.

"It gives me goose pimples thinking about it. It was just brilliant."



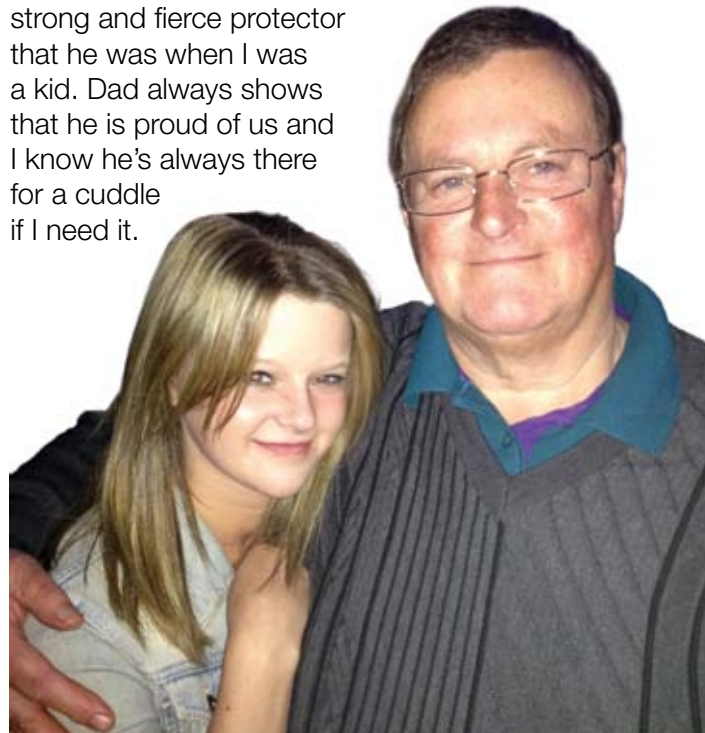
Liz Weston's father, Pat, has been living with prostate cancer for many years. She tells us why he is and always has been a Top Dad.

"My dad was diagnosed with prostate cancer more than 10 years ago. He hasn't let it change his life. He is still the best dad and the most loving husband to my mum. Their relationship is the type that I hope I can find one day.

"After radiotherapy, Dad was put on hormone treatment which has worked better than we, or even the doctors expected. As grateful as we all are for this, I know that sometimes Dad feels as though he is not as masculine as he used to be. I want him to know that he is still the same strong and fierce protector that he was when I was a kid. Dad always shows that he is proud of us and I know he's always there for a cuddle if I need it.

I wouldn't change a thing about him and I know the rest of my family feel the same. I hope he knows just how much I love him."

If your dad is amazing and you'd like everyone to know, please get in touch and tell us about him.



THANK YOU

£1.3m

Prostate Cancer UK Trustee and surgeon Roger Kirby raised this amazing total on five Hikes for Hope in Africa and Asia over the last year.

500 MILES

The distance David Annand walked in support of our Football League partnership.

£1,500

M&S employee Deborah James raised this over three years in support of her dad, uncle and father-in-law, all diagnosed with prostate cancer.

209

The number of politicians in Westminster and Holyrood who supported our Days of Action in March.

£10,000+

John Malcolm and his team cycled from London to Paris and raised this great amount.

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

GET INVOLVED

Join our squad for the next three seasons

We're delighted to announce that our fantastic partnership with The Football League is now set to continue for the next three years. This gives us an incredible opportunity to build on what we achieved together in the 2012-2013 season.

- Thanks to our team of 700 volunteers we raised over £56,000 at more than 60 games and reached over 500,000 fans across the UK.

- More than 50 clubs took part in Movember raising £56,000.
- Twelve clubs wore our logo on their shirts throughout the season with countless players and managers wearing our Man of men pin badge.

Do you fancy joining our squad for the next three seasons? We really need your help to reach more football fans across the country.

Visit prostatecanceruk.org/football to find out how you can get involved.



Tea needs you

This summer we are asking you to grab your rolling pins and give prostate cancer its marching orders by organising a Tea for Victory party. Bake cakes, brew tea, invite everyone you can and raise money for men with prostate cancer.

We can provide all the information, materials and advice to help you get started including exclusive 1940s-style bunting, tablecloths and cake stands designed by Wayne Hemingway.

We will fight it on the tea tables, we will fight it at the street parties and together we'll help more men survive prostate cancer and enjoy a better quality of life.

Visit prostatecanceruk.org/teaforvictory for more information.

Help us decide what research to support

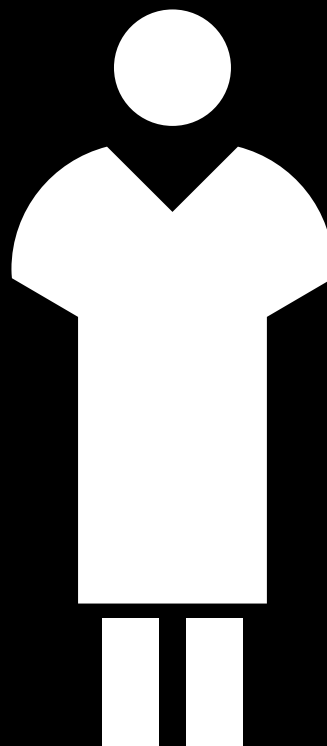
We are looking for volunteers to join our new Grants Advisory Panel and help us ensure the research we fund addresses the most important issues experienced by men living with prostate cancer.

Joining the panel would give you the opportunity to read and discuss research grant applications; represent the views of people living with prostate cancer to our Research Advisory Committee and have an impact on the funding decisions made by the committee.

We are looking for people from within the UK who:

- have experience of living with prostate cancer and awareness of how the disease affects individuals, families and carers
- demonstrate an interest in research studies, and have a basic understanding of research terminology and processes
- can communicate with a range of people and have the confidence to discuss issues in a committee environment
- demonstrate a commitment to representing the views of the wide range of people living with prostate cancer in the UK

For more information please get in touch by emailing volunteer@prostatecanceruk.org or calling **020 8222 7665**.



Could you be a volunteer speaker?

You could represent us at a range of events, giving talks about prostate cancer and prostate problems, your personal experience of the disease and the work we do. Contact us at volunteer@prostatecanceruk.org or call **020 8222 7665** to find out more.

EVENTS CALENDAR

July 2013 - Feb 2014

Give prostate cancer its marching orders by organising a Tea for Victory party this summer.



Train to become one of our volunteer speakers:
3 September and 1 October
Scotland

10 September and 8 October
East Midlands/West Midlands/South West

17 September and 15 October
North West/North East

24 September and 22 October
London/South East

Jurassic Classic

Stunning cycle ride along spectacular coastline. Voted one of the top ten cycle rides in the UK and Europe by the Guardian. Sign up now.



The 3 Peaks Challenge
Conquer the three highest peaks in the UK, Scafell Pike, Ben Nevis and Snowdon, all in 24 hours!

Bupa Great North Run
Sign up now and join 54,000 runners to take part in the world's most popular half-marathon.



Thames path challenge
Starting close to Putney Bridge, this epic endurance walk against the clock follows the unique Thames Path National Trail.

Prostate cancer masterclasses for primary care professionals
These two prostate cancer masterclasses are open to all health professionals working in primary care. Join us on 20 September in Milton Keynes or 22 October in Maidstone.



Movember, the month when men get hairy-lipped to raise money for prostate cancer, is approaching.

More events

21 July
Great Weston Ride

3-4 August
Total Warrior

4 August
Ride London 100

16 August
Kilimanjaro Summit Climb

25 August
Ride UK 24

14-15 September
Silverstone 24

29 September
BMW Berlin Marathon
December
Carols by candlelight

Find out more at
prostatecanceruk.org/get-involved



Our services

Specialist Nurses 0800 074 8383

(Mon-Fri 9am-5pm and Wed 7pm-9pm)
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 been diagnosed with prostate cancer and are struggling with fatigue, the nurses in our Get back on track team can help you manage and reduce these symptoms.

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

Get up and go 0141 314 0050

If you have prostate cancer it's important to try and stay active. Get up and go can partner you with a motivator who will help you find a physical activity that works for you. All of our motivators have had prostate cancer themselves.

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. Visit the We can help pages on our site to find a group near you.

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

<http://cancerhelp.cancerresearchuk.org>
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.

Telephone peer support



When facing a diagnosis of prostate cancer, talking to someone who has been in a similar situation can really help. Our telephone peer support service gives men and those close to them the opportunity to do that.

We match each caller with a trained volunteer who has had a similar experience and can sympathise and share their experiences of treatments or side effects. They can also talk about the impact of the disease on relationships and the experience of losing someone.

Digby Bevan used the service when he was diagnosed with prostate cancer in 2008 at the age of 57: "The telephone peer support service was a great help to me. I'd been given three treatment options: surgery to remove the prostate, external beam radiotherapy and

brachytherapy. I read the literature and did research on the internet. However, I started to feel that it didn't matter how much I read because no treatment was obviously right or wrong.

"I was leaning towards brachytherapy, but being only 57 and quite active, I was really concerned about side effects, particularly incontinence and problems having sex.

"Prostate Cancer UK put me in touch with two men who'd recently had brachytherapy. We had long conversations about the side effects I was worried about and their treatment experiences. They explained in detail what it had been like for them immediately after and in the longer term.

"Talking to them really set my mind at rest and helped me make a decision. I had brachytherapy and have had no serious side effects."

If you'd like to talk to someone who's been there, call **0800 074 8383** to find out more.

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 Digby and Colin's Uncle Ronnie 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.

RAY WINSTONE CHARLES DANCE JOHN SIMM NEIL STUKE
TAMZIN OUTHWAITE CYRIL NRI STUART LANG



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a storyline better than much of Hollywood.”*

Richard Brooks - Sunday Times

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SCREENPLAY BY MARTIN SADOFSKI A COAST PRODUCTION FOR SLEDGEHAMMER FILMS



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