prostate matters The Newsletter of The National Federation of Prostate Cancer Support Groups Free Help Line - 0800 035 5302



Action for patients

June 2021 Issue 51

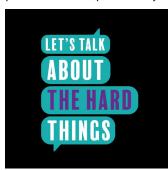
Introduction from Tackle's Chairman Ken Mastris

Firstly, we hope you and your family are staying safe and have received your vaccinations. The government's roadmap gives us cause for cautious optimism, we will re-emerge carefully and slowly into a newly vaccination world in the hope that the release will be 'irreversible'.

Following our Board meeting in March we have appointed Bradford based digital agency Out of Place to revitalise the Tackle website to ensure its content and visuals align our visions and aims. The new website will showcase our campaigns and fundraising efforts, highlight the latest information on prostate cancer and resource links. Include latest news and development in prostate cancer research, treatments, services and policy and have a members portal that allows access to our member groups to additional resources, tools and materials. We are extremely excited about this will be contacting groups for feedback and ideas. Each month we will be sending out a communication email to group leads and committee members. The purpose of this briefing will be to give information that help committee members support their members and to ask for feedback, case studies and ideas from them to campaign ensuring your voice and that of your members is front and centre of all our communications.

It was really good to see so many of you at our Network Days. We had 98 people attend from over 60 groups. Huge thanks go to Sarah Gray, for organising it along with Sue Boyes from PCUK. I am sure any of you who attended will agree it was an inspiring event.

In early 2021, Tackle Prostate Cancer in partnership with Prostate Cancer Research (PCR), and pharmaceutical company Ipsen Ltd, launched a nationwide survey to better understand the experiences faced by people living with prostate cancer, particularly in relation to the challenges



patients face with treatment side effects. The findings from this survey informed a new campaign, spearheaded by Good Morning Britain's Dr. Hilary Jones, which we launched in May – 'Let's Talk about the Hard Things' – to help break down the taboos

around the side effects of treatment and encourage people with prostate cancer to talk about their experiences with family, friends and healthcare professionals.

In our research we found that:

- One of the most common side effects was revealed to be erectile dysfunction, which affects 86% of participants. This was followed by loss of libido (79%). Of those who experienced a loss of libido, almost half (42%) said their sex drive has "completely diminished".
- Nearly two thirds (60%) experienced incontinence, of which nearly three quarters (73%) said it affected their quality of life.
- Over a third (39%) were affected by the growth of breast tissue, which can lead to a loss of confidence and feeling emasculated.
- Over a quarter of participants said changes associated with their physicality have directly affected their mental health. Worryingly, 4 out of 5 were not offered mental health or psychological support from a healthcare professional. Participants also feel uncomfortable talking about their side effects and mental health to the people they have some of the closest personal relationships to.
- Only 2% feel most comfortable discussing the topic with family and even fewer (1%) with friends.

Some of the key reasons expressed for this discomfort were the feelings that others would have a lack of understanding, peer pressure to appear to have a healthy sex life and/or health in general, and feeling as though the problem is 'left for you to sort out yourself'.

This reluctance to talk about both the physical and mental impacts of prostate cancer treatment was felt across all ages, ethnicities and sexualities of the prostate cancer community.

However, we found that over two thirds (69%) said speaking to other patients or having their family and friends understand how they felt, would help them discuss these 'hard' topics, and 62% felt more resources are needed to help improve awareness and understanding, not just amongst the patient community but also for partners, family and friends,

and over half want more mental health support.

Dr Hilary Jones, TV doctor, said: "I want to reassure anyone with prostate cancer that healthcare professionals are here to help: no topic is off limits – we've heard it all before! Nearly one third of men (31%) surveyed said they were not confident that their healthcare professional provided enough information about the specific side effects associated with the therapy they'd been prescribed. While doctors may need to do more, I'd also encourage patients to ask questions and use the time with their consultant to find out as much as possible."

As part of this campaign we launched a series of powerful videos, each showcasing a different pairing discussing their experiences of prostate cancer and the side effects of their treatment. We hope these will help raise awareness among not just the prostate cancer community but a much wider audience and ensure that more informed and supportive conversations can take place across the country.

For more information on this campaign please go to www.tackleprostate.org

We say farewell to Simon and Cheryl Lanyon

Simon Lanyon started working with Tackle Prostate Cancer in the summer of 2014 and retired at the end of March this year. His wife Cheryl also kindly provided her editorial expertise pro bono for seven editions of Prostate Matters.

Tackle would like to thank Simon and his wife Cheryl for all their work and support and wish them well. They will be greatly missed.

Simon reflects upon his eight years with Tackle.

Back in the summer of 2014, Tackle Prostate Cancer had been the new "brand name" of the Prostate Cancer Support Federation for a year - despite some quite substantial misgivings within the membership. Personally, I always thought it was a brilliant name and so did everybody outside the organisation. I think it is more accepted now but some of you may remember a bit of a stir!

The Chairman at the time was Sandy Tyndale-Biscoe who is now Hon President. Four members of the current Board of Trustees were Trustees back then as well: Rob Banner, Frank Chinegwundoh, Erik Friis-Scheel and Ken Mastris who is of course the current Chairman.

We also had a Chief Executive – Rowena Bartlett. It was Rowena that asked me to provide some assistance even though I had really already retired. But I liked the idea of being useful and felt that my background in Operations and having been a Trustee of a number of charities might be of some help.

What I particularly liked was the clear strategic aims of the charity: campaigning, awareness and support. But the vital ingredient is the men and their families that make up the membership across the country who help to drive the charity and allow it to "punch above its weight". I am sure that was an important factor in the success of our Lottery application in 2019.



Even during the short time I was with Tackle, there have been some good improvements in treatment for prostate cancer. Thank goodness for improved MRI scans which reduce the need for frequently unnecessary biopsies, and make targeting of scans that are needed so much better. An increased appreciation of watchful waiting has also reduced the need for treatment that isn't necessarily required.

However, the number of cases and deaths continues to rise inexorably. It really needs to stop. But the holy grail of a national screening programme remains as elusive as ever despite the enormous evidence that a targeted programme should now be implemented. Until such time as screening is routine, your support to provide PSA testing events will be as crucial as ever and I wish you all the best with that.

I very much enjoyed my time at Tackle. It does tremendous work with very few resources and this is due to the dedication and determination of those men with prostate cancer who want desperately to improve the lot of others in the future. Very sadly, some of them succumb to this damn disease and I remember with affection Roger Wotton, Hugh Gunn, Keith Cass and David Smith, Tackle Trustees with whom I had the privilege to work.

Finally, I have been lucky to work with people across the UK who give up their time for the cause and who have been very generous to me. Thank you very much for your support. Keep up the good work!

Working Together Network Event

Tackle and Prostate Cancer UK jointly hosted an online networking event spread over two days in March. It was organised by Sarah our National Support and Development Manager and Sue Boyes, from PCUK, 98 people attended from over 60 groups. The two days focused on learning from each other, sharing, and collaborating together to ensure that more people living with and beyond a diagnosis of prostate cancer are able to benefit from the excellent support that is in our networks. The topics which included how to use social media,

reaching new audiences, delivering alternative offers of support, and how to engage with community and NHS networks were chosen by group leaders and focused on issues and opportunities that have arisen following

the pandemic. Many of our Group Leaders were filmed to showcase the amazing work they do, and delegates were

able to meet in break out rooms to discuss how they might take back the learning from the event to their own regions. There was a real buzz and energy in the room, with 98% of delegates expressing satisfaction with the event. This quote from a delegate, pretty well sums up the feelings of the day 'Just the shot in the arm to get us ready for post lockdown Many thanks to PCUK and Tackle'

If you would like more details or would like to see the presentations and content of the event, please get in touch with Sarah at sarah.gray@tackleprostate.org

Tackle has joined 46 other charities in calling upon the UK and devolved nations' governments to put cancer patients at the centre of their COVID-19 recovery plans. In a statement released in March, the One Cancer Voice charity coalition highlights the importance of the governments across the UK quickly turning their ambitions of restoring and transforming cancer services into a reality.



One Cancer Voice urges swift action in directing resources to not only getting UK cancer services back to pre-pandemic levels, but to work towards them becoming world-leading to achieve improvements to survival rates and patients' quality of life.

Sent to 50 stakeholders in positions to affect change, the One Cancer Voice statement outlines nine key recommendations to the UK's governments and NHS leaders. Governments across the UK have bold ambitions to improve cancer survival and transform patients' quality of life for the 1 in 2 of us who will be diagnosed with the disease. Decades of hard work have resulted in cancer survival doubling over the last half a century – now half of people diagnosed with cancer live for 10 years or more. Progress has been made in recognising and addressing the wider support needs of people with cancer. Despite this, tragically, 165,000 people still die of cancer every year in this country and millions have their lives turned upside down by this unforgiving disease. With the number of people in the UK diagnosed with cancer expected to grow



The pandemic has caused huge disruption to cancer patients.

Tackle's Chairman Ken Mastris receiving his Covid vaccination.

to over 500,000 per year by 2035, it's critical that ambitions to transform cancer survival and patient experience turn into reality, quickly.

Undoubtedly the COVID-19 pandemic has made the challenge much harder. At the height of COVID-19 surges, thousands of people went undiagnosed, tests and treatments were disrupted, and cancer clinical trials were paused or slowed down. In some cases, this was because people did not access help for possible cancer symptoms. In other cases, changes to cancer services were made. Whatever the reason, the disruption is real, and thousands of people have been impacted.

The NHS has put in enormous effort to protect cancer services and return care close to pre-pandemic levels. But we now know that there are around 40,000 people across the UK who should have started cancer treatment in 2020, but did not – most of whom are in the community, living with cancer without knowing it. It will take months if not years to clear the cancer 'backlog' – all the cancer activity that didn't take place, such as people receiving invites to screening, presenting with symptoms or receiving treatment. As a result, sadly, we're likely to see more patients diagnosed at a later stage when chances of survival are lower, likely stalling or even reversing improvements in cancer survival. This has also impacted on the wider needs of people with cancer – resulting in a perfect storm of distress in isolation, with new anxieties adding to someone's experience of cancer.

NHS staff have been the shining light throughout the pandemic. Their commitment, dedication and innovation at a time of huge pressure has been astounding. Staff have collaborated with neighbouring hospitals, made use of the private sector in novel ways and adopted new technologies to ensure as many patients as possible could get the care they need. This willingness to do things differently and adopt innovative practice is the key to driving more productivity, achieving better cancer outcomes, and getting us on track to reaching our cancer ambitions. We must return, as soon as possible, to driving efforts to prevent cancers, diagnose more patients at an early stage when chances of survival are greatest, and get all care and clinical trials back up and running. It's critical that Governments in all four UK nations direct resources towards clearing the cancer backlog quickly, adopting innovative practices to accelerate recovery whilst ensuring personalised care for all patients. It is also vital - and only right - that Governments support NHS staff in recovering from the burnout, stress and wider impact that the pandemic has had on their health. But just getting cancer services back to pre-pandemic levels is simply not enough. We must go further and faster than ever before - so that the NHS can meet the rising demand of cancer incidence, adapt to the added pressure that COVID-19 will likely bring for years to come, and accelerate progress towards the UK's cancer ambitions. This means rectifying the substantial workforce and equipment shortages that held the NHS back even before the pandemic. It means offering every person holistic care, recognising and supporting them with the wider needs sparked by their cancer diagnosis. It means investing in the power of research and innovation to drive us more quickly towards our ambitions. It means resourcing high quality end of life care for those who sadly need it. It means keeping the needs of a cancer patient woven into how health services are structured. And it means being bolder with measures to prevent ill health, so we can build a more resilient society, take pressure off the health system and prevent more cancers altogether.

Inequalities in cancer outcomes exist in every part of the cancer pathway – there are around 20,000 more cancer cases each year in more deprived areas of the UK – so it is critical to ensure that these actions serve all parts of society. The case for investment, innovation and change is a social one, an economic one and a moral one. We urgently need bold political will and leadership. Decisions made now will determine whether we live up to the existing cancer ambitions set by the UK Governments, and drastically improve the lives of people affected by cancer. The cancer community stands ready to work with Governments across the UK to turn ambition into reality for all cancer patients.

We are urging Governments and NHS leaders across the UK to:

1. Direct resources to clear the cancer backlog as quickly as possible: by ensuring cancer services receive adequate funding to enable recovery of care and clinical trials. The NHS – with additional funding provided by Governments as required – should take steps to increase diagnostic capacity, including through continued use of the independent sector. The NHS should evaluate innovations that emerged during the pandemic, which have potential to support recovery

- such as delivering more care at home, tools to inform clinical triage and telemedicine to inform further roll out and adoption. Governments and the NHS should strengthen measures to support staff retention and wellbeing in the existing workforce.
- 2. Continue to encourage people with signs and symptoms of cancer to seek help from their GP: by funding evidence-based public campaigns that raise awareness of signs and symptoms of cancer, encourage people to seek help from their GP, and build confidence that NHS services are open especially in communities and for cancer types of unmet need.
- **3. Expand the number of staff in key cancer professions:** by investing year-on-year in training and employing more cancer staff to fill current vacancies and ensure that the workforce has the capacity to meet increasing demand as well as time to innovate and transform services.
- **4. Drive earlier and faster diagnosis:** by substantially investing to refresh and expand diagnostic equipment, radically reform how diagnostic services are delivered and optimise national screening programmes. Not only will this support ambitions to diagnose cancers at an earlier stage but also create a stronger platform for research and innovation into early detection of disease.
- 5. Ensure personalised care and support for all: by meeting every cancer patient's holistic needs, including appropriate mental health, wellbeing and practical interventions that improve people's quality of life. This should include a holistic needs assessment, recognition of the unique needs of children and young people, personalised care and support plans, and signposting to wider information and support.
- **6. Strengthen the UK's medical R&D base to accelerate improvements in cancer outcomes:** by committing to multi-year funding for medical research (including support for medical research charities), improving the commercialisation and adoption of technology, and better embedding research activity in the healthcare setting. Cancer research should be a pioneering part of the Government's ambition for the UK to be a global science superpower.
- **7. Resource high quality end of life care:** by taking steps to improve capacity and provide high quality end of life care for all those who need it, an important component of comprehensive next steps to meet the needs of some people with cancer.
- **8. Be bolder in measures to prevent cancer:** by introducing measures quickly to restrict junk-food marketing on TV and online to reduce childhood obesity rates, implementing a Smoke-Free 2030 Fund to pay for measures to create a smoke-free UK, and increasing funding for local public health services.
- **9. Reduce inequalities in cancer outcomes:** by ensuring cancer care serves all parts of society, through robust data collection and evaluation, and introducing and reinforcing targeted interventions to reach those groups that need them most.

Europa Uomo signs joint letter offering support to governments





Tackle has joined Europa Uomo and more than 290 international, national and regional cancer organisations around the globe to offer support to governments in efforts to improve the situation for cancer patients globally in the light of the COVID-19 pandemic.

In an open letter, the organisations point out that the pandemic has severely disrupted cancer detection and care services globally, with 2020 seeing a 40% drop in cancer diagnoses.

"We recognise that healthcare systems are under unprecedented pressure due to the COVID-19 pandemic and that the global crisis has not ended yet, but the data show us that we need to take action to actively address the issues in

cancer care if we are to continue improving outcomes," the organisations say.

To improve the situation for cancer patients, governments should:

- Ensure that patients can access diagnosis and treatment safely
- Identify the impact of the pandemic on cancer services and design services to mitigate this
- Resource cancer services properly and safely for the long term

Andre Deschamps, Chairman of Europa Uomo, said that urging such action was important for men prostate cancer.

"As prostate cancer is without symptoms in the early stages, the delay in cancer care due to Covid 19 will have a big negative impact on these patients. The real effect will only be seen in the figures over the next years."

Groups have been adjusting to meeting on Zoom

Jackie Weaver made national headlines after footage of a zoom parish council meeting she was taking part in went viral. The online meeting descended into chaos as members traded insults and threw each other out of the online call and then there was footage of a Texan lawyer denying he was a cat as he appeared with a cat filter. This captured our imagination and quickly became a viral hit.

Jeff Willmot, vice-chairman of East Suffolk Prostate Cancer Support Group tells us how his group is getting on.

We started having committee meetings via Zoom after PC UK offered us a licence free of charge in October 2020. It was new technology for all of us on the committee, but we used the chance to learn from each other and soon got used to this really useful tool. Lockdown not only isolated us socially which we all had to cope with, it also kept us away from the members, which was a real worry to us. We had no chance to welcome and support newly diagnosed men either and this greatly concerned us. Once we'd had a few committee meetings, and seen how useful zoom was, it naturally led us into wanting to get members meetings going again. I attended some other group "Hub" meetings using zoom and quickly learned how to cope with multiple screen sharing and breaking up into chat rooms, to facilitate useful discussions. It can be difficult to keep control when there are lots of people on the screen, and learning how to run meetings in a controlled way is important.

Our first problem was to get the members interested, and this was not easy. The age group our members are in, meant that many were a bit suspicious of the zoom technology and some felt that this was just another "social media" gimmick to invade their privacy and open them up to scams and sales pitches. After much persuasion we succeeded in getting a few members to give it a try and we created a crib sheet for those interested.

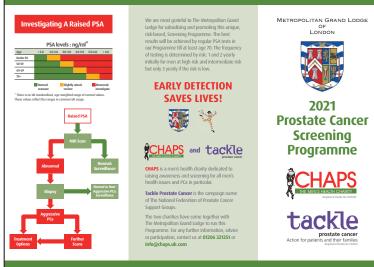
Our first members meeting was held in the afternoon in December, and about a dozen members made it into the forum. We ironed out some problems but felt the number responding was a little disappointing, however over the next few days more people sent apologies for not quite making it, so we guickly arranged another meeting to iron out their problems. This was more encouraging, and went well as members got to chat each other after long periods of separation via lockdown. The next move was to issue a report of the success to all members with an invitation to the next meeting to be held on our normal meeting date. We managed to engage a speaker to attend, and advertised this to the group, and this proved to be the spur to a better attendance. It was a successful event, and the members attending seemed to enjoy the chance to get back to some sort of group socialising. Again a report was issued to all members, and some more have shown interest. We look forward to getting a little normality back to our group and the support that is our purpose.

The Chaps/Tackle/ Masonic Prostate Cancer Screening Project

By Chris Booth, FRCS, FRSA, Clinical Director, CHAPS Charity

As a Charity dedicated to the support of men with Prostate Cancer (PCa), we are only too aware of the problems that beset men with this all-too-common cancer, especially those diagnosed with advanced and metastatic disease. That over 12,000 UK men die every year and half of all our 50,000 new cases present with advanced disease within our modern, integrated health service should be a cause for national concern. It is also deeply ironic that just as the European Parliament is recommending to its member states – not us of course! –the institution of PSA-based, national PCa screening programmes, our own National Screening Committee has again come out against screening. This will no doubt subject the UK to another five years of rising PCa death rates due to continued medico-political inertia.

The European Parliament's decision to support PCa screening is based on evidence from trials running for 20 years that men having regular PSA tests in the screening arm had a 50% lower risk of death from PCa than unscreened men in the control arm. In addition, the UK National Prostate Cancer Audits have shown clearly that the two main disadvantages of screening - "over diagnosis" and "over treatment" - have been virtually eliminated by the introduction of prostate MRI scanning and active surveillance respectively such that there now seems to be a complete disconnect between the NSC and UK clinical practice. The status quo is unacceptable. So, what can be done?



Using internationally agreed criteria, CHAPS and TACKLE have established a programme of risk-based testing with the Metropolitan Grand Lodge in London and the Provincial Grand Lodge of Suffolk. More masonic Provinces and PCa screening charities across the UK are now joining the Project.

The Project is underpinned by a broad base of clinical specialists, independent experts, a national laboratory, the national network of TACKLE, the Graham Fulford Charitable Trust and the Division of Population Health, Health Services Research & Primary Care at Manchester University. Our objective is to halve PCa mortality and demonstrate the practicality and cost-effectiveness of screening at scale. In addition, individual PCa risk assessment will allow us to introduce to participants at high risk the voluntary options of rapid NHS access to advances in diagnostic MRI scanning and to genetic testing.

Chris Booth, FRCS, FRSA, Clinical Director, CHAPS Charity

AWARENESS EVENTS



Carers Week, 7-13 June is an

annual campaign to raise awareness of caring, highlight the challenges unpaid carers face and recognise the contribution they make to families and

communities throughout the UK. It also helps people who don't think of themselves as having caring responsibilities to identify as carers and access much-needed support.



Volunteers Week takes place 1-7 June every year. It's a chance

to recognise the fantastic contribution volunteers make to our communities and say thank you.

Tackle would like to recognise two carers and volunteers who have set up support groups. Caroline Prance set up the Wives and Partners group in Oxfordshire Prostate Cancer Support Group (OPCSG) and Tackle Trustee Jackie Manthorpe set up COMPASS partners/family support group in Stoke Poges, Buckinghamshire.

Jackie Manthorpe decided to set up a partner/family

members support group due to the impact of the Covid-19 pandemic. Jackie initiated the group because she felt it important to reach out to partners and family members who may need support themselves to process the impact of prostate cancer, allowing them a voice. Following a discussion with Sarah Gray, Tackle's National Support and Development Manager, Sarah put Jackie in touch with Caroline Prance, who runs the Partners' group for OPCSG. Caroline shared her learnings from setting up the group to support partners, wives and family members which gave Jackie the confidence to put out a link to see what would materialise from her local group, Compass. Jackie was heartened by the initial response her invitation received and by the overall response by the group, male members regarding the roles of wives and partners in supporting those they love and the need to identify their own needs for support as well, hence Compass PCSG was born.

Caroline Prance, OPCSG felt there was a gap, as a semi-retired nurse who had always had a particular interest in the impact of 'illness' on families. Caroline found herself on the 'other side of the fence' when her partner was diagnosed with prostate cancer. Caroline's partner linked with Oxfordshire Prostate Cancer Support Group and was offered a telephone

call almost immediately. Whilst supporting her partner, Caroline wanted someone to just say the words 'and how are you?' Prostate Cancer is often described as a 'couple's condition' and Caroline attended support group meetings to hear how other partners had managed, what their fears had been and how they had got through. Caroline joined the committee and went on to set up a partner support group for OPCSG. The group has also developed a leaflet specifically for partners to be included in the packs that the Urology nurses give out.

Caroline said: "If reading this has inspired you to set up a group, my advice would be to take the plunge and do it!! Network! I spoke to many other Support Group leads throughout the UK who I met through regular PCUK Support Group Leads meetings. I linked with the Urology nurses at the local hospital. Follow any lead! Keep your ears and eyes peeled for any opportunity – step out of your comfort zone! We are talking to W.I groups to connect people where we can, link with GP Practises, seizing any opportunity to raise the profile. And use the invaluable support offered by Tackle and PCUK."

If you would like support to set up a Partners group in your local area, please contact Sarah, our National Support and Development Manager on 07725 083533, or email her at sarah.gray@tackleprostate.org. We have some small grants available to help you with any advertising or set up costs.



June 6th – 13th

Cycling remains a great way to keep fit and active and is a good way to boost immunity; it's also great for

your mental well-being. Charles Frost, Founder of Prostate Pedallers shares his tips on cycling to beat prostate cancer.

Prostate Pedallers is an unusual cancer support group because we share cycling to enable us to get to know and support each other. We get both physically fitter and mentally more resilient through sharing endeavour, friendship, and our cancer journeys whilst re-learning the joys and challenges of cycling.

I know that exercise is good for us cancer sufferers and enjoying our favourite sport helps us to keep on receiving those benefits. Going to the gym is good but I believe that the seasons, nature, the weather and being a part of a team are helpful in lifting the mind from introspection and rebalancing a

bruised perspective on life.

We all know how to ride a bicycle but very few know how to do so efficiently and safely. At Prostate Pedallers I teach off-road and with no traffic to bother us, we can relax, enjoy the scenery, and concentrate on improving our cycling skills and fitness. Having done some good work, we have earned a café break when we can talk about our ride, catch up with each other and plan the next adventure.

I would encourage everybody with cancer to exercise if they can and outside where possible. The rewards are enormous.





Men's Health Week, June 14 - 20th is

an opportunity to raise awareness of the signs and symptoms of male cancers and how to

access help and support. Tackle Trustee Professor Frank Chinegwundoh, MBE, Consultant Urological Surgeon at Barts Health NHS Trust explains that the risk of prostate cancer is increased in black men and how a blood test for PSA that is available to men over the age of 45 might save a life.

Prostate cancer is the most common cancer in men in the UK. Although it affects all men, black men are 2-3 times more likely to develop this cancer than their white counterparts. The death rate is twice as high. Furthermore, black men are more likely to develop prostate cancer at a younger age. Why it is more common is unknown; there is much research worldwide to discover the reason.

Every black man over the age of 45 years is eligible to have the blood test, called PSA from their GP. Every GP in the land has been sent a document called the Prostate Cancer Risk Management Programme, which says that men, even with no urinary symptoms, can have a PSA on request. There are some limitations of the blood test which the GP can point out. For example, a raised PSA (above 3 units) does not necessarily mean that there is prostate cancer. There are other reasons why a PSA may be raised.

More often than not, prostate cancer in its early and therefore curable stage does not present with symptoms, hence the importance of the blood test. Some men will have urinary symptoms, such as a slow urinary stream or passing urine frequently, or getting up at night, or having to get to the toilet in a hurry. These do not mean the man has prostate cancer. Far more common is an enlarged prostate gland that occurs as men age. However, as these symptoms are indistinguishable from those of prostate cancer, they should be checked out by a health care professional. Black men face an increased risk of prostate cancer so a lack of urinary symptoms, should not be the basis for refusing to conduct a PSA test.

A suspicion of prostate cancer, whether on account of an abnormal blood PSA or an abnormal feeling prostate on rectal examination, will lead to an urgent referral to see an urologist. Further tests include a MRI scan and a biopsy of the prostate gland. A biopsy is where samples of the prostate gland are taken and analysed in the laboratory for signs of cancer. If cancer is diagnosed, keeping an eye on it may be advised as many prostate cancers will never cause a problem ('active surveillance'). If there is more than a minimal amount of cancer a more aggressive treatment may be recommended, such as surgery or radiotherapy.

This **Men's Health Week** I'm urging everyone to talk about prostate cancer, and prostate cancer in black men and their family.



www.tackleprostate.org

The National Federation of Prostate Cancer Support Groups

Tackle Prostate Cancer is the campaign name of The National Federation of Prostate Cancer Support Groups. Charity Registration № 1163152.

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Editor's note

Many of our articles contain links to information on the internet. The best way to access these is to go to our website: www.tackleprostate.org where you will find the web edition of this and past issues of Prostate Matters with live links.

Prostate Matters delivery

Your individual copy of Prostate Matters is delivered to you from your local prostate cancer support group. If you have a change of address or any other notifications, please would you contact your local support group.

Check your details

Unless otherwise requested, your details will appear on the list of groups on our website.

We ask all affiliated groups to check their details on the Tackle website. The information has been updated to include meeting times and places.

See the map at: http://tinyurl.com/omp6y5e
If you require any corrections, please contact
editor@tackleprostate.org

PSA testing events

Due to current Coronavirus restrictions, there are no PSA testing events taking place at the moment. We hope new events will be able to start up again soon. When they do, let us know the details of your event and we'll add it to the list on the Tackle website. Email info@tackleprostate.org

We need your help

Tackle are currently updating their website www.tackleprostate.org and need your help. Whether you have ever visited our website before, please let us know 'what support information are you looking for when you go online'? and 'where would you most likely go to as your first port of call'?

Please let Sarah know by contacting her at sarah.gray@tackleprostate.org

Helpline 0800 035 5302

Our telephone helpline
is manned
by prostate cancer patients,
for patients and their
families

365 days per year9:00am to 9:00pm



We are grateful for the support of Astellas Pharma Ltd in the production of Prostate Matters.

Contribute to Prostate Matters

Without you, we would not exist! Please keep contributions coming to: editor@tackleprostate.org (send photos separately at high resolution).

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Thank you to everyone who contributed to this edition.



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tackleprostatecancer