

tackle
prostate cancer

Prostate Matters

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August 2022

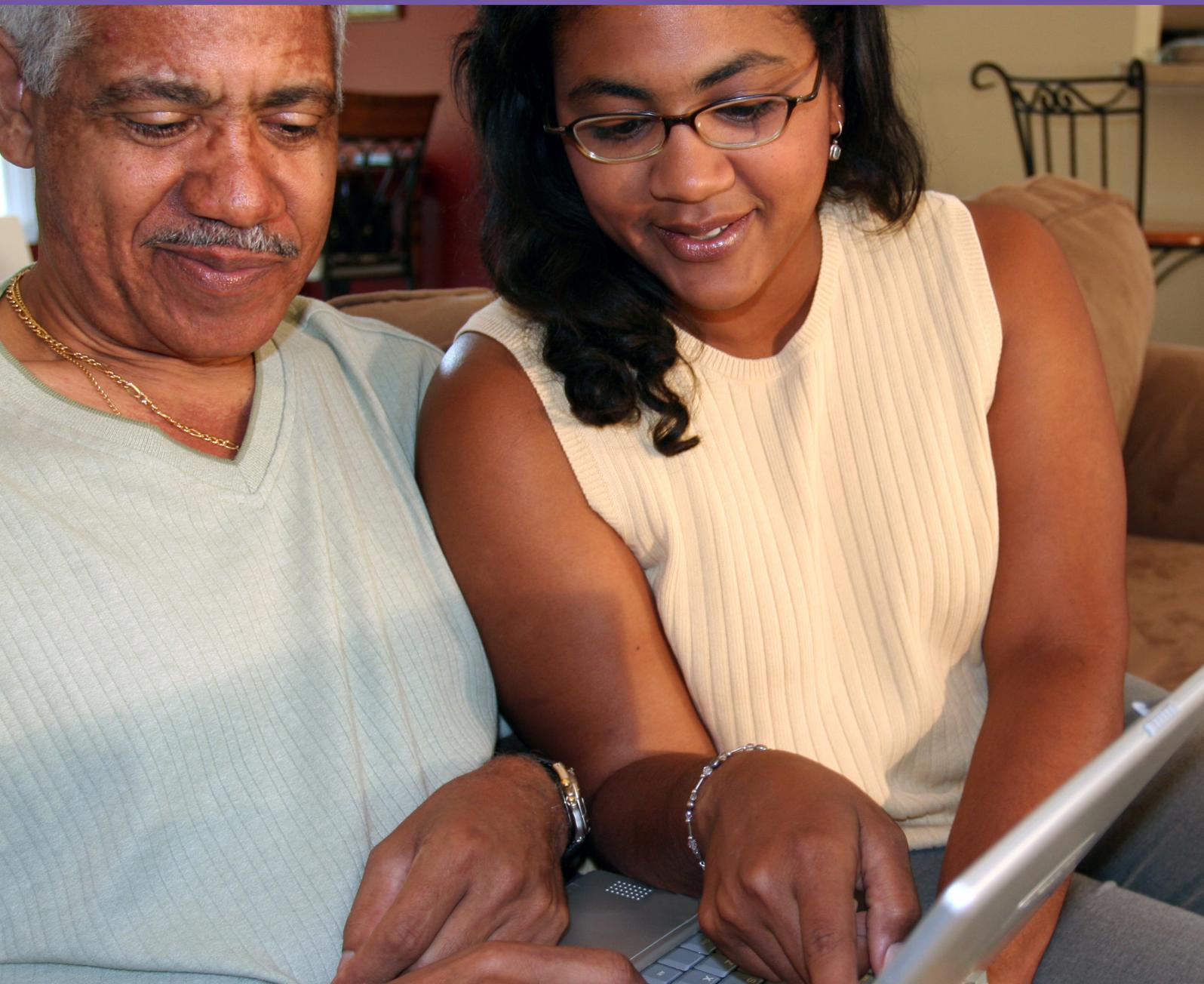




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To find out more go to our website or social media channels
website: www.tackleprostate.org twitter: [tackleprostate](https://twitter.com/tackleprostate) instagram: [tackleprostatecancer](https://www.instagram.com/tackleprostatecancer)
facebook: [tackleprostate](https://www.facebook.com/tackleprostate)

Welcome

It is a great pleasure and a privilege to be writing an opening paragraph or two in this NEW edition of Prostate Matters. I have only been in my position as acting chairman for a few months, and these have been both exciting and challenging. I have been privileged to be part of the evolution that Tackle has been going through over this past year with our upgraded website, new branding and strategy. There are many plans for the future which will be covered elsewhere in this edition. This re-launch of Prostate Matters is just one of them and a visual statement of Tackle's commitment to working with you.

Change does not always come easily. Coming together and working in harmony are the main keystones for success. We all share the same vision of ensuring that the needs of people living with and affected by prostate cancer are met, and that their voices are heard. Tackle is here to support your Group in any way that we can.

I firmly believe that Tackle is now stronger in many ways than it has been for a while. I look forward to our future together.

- Steve Allen

Who's who?



Steve Allen,
Acting Chair, Clinical Advisory Board
Member

A retired medical doctor, Steve had major surgery for prostate cancer 14 years ago and has been closely involved with Tackle for over 5 years.



Aidan Adkins,
Trustee

After a routine work medical led to a diagnosis, Aidan first visited a local community support group in 2015. Now he is determined to share the value of peer support and the need to improve access to it.



Sarah Gray,
National Support and Development
Manager,

Working across health and social care for most of her career, Sarah has previously worked for Macmillan Cancer Support, Prostate Cancer UK and British Lung Foundation. Sarah brings news from across the country, including local forums and campaigns.



Roshani Perera,
Trustee

Roshani is an established healthcare management consultant with over 20 years' experience working within Life Sciences, and across the NHS and charitable sectors. In her article 'Getting to know Tackle' Roshani gives an overview of Tackle Prostate Cancer.



David Manthorpe,
Compass Prostate Cancer Support
Group – Berkshire

A former firefighter, David was diagnosed with Prostate Cancer over 7 years ago. He now brings his plain talking and an open style to lead the Compass Prostate Cancer Support Group.



Allan Roper,
Secretary NHPCSG

Allan was diagnosed with PCa seven years ago and the year after joined the North Hampshire's Prostate Cancer Support Group, where he is Secretary and a valued volunteer.

Around the country

As we shed last year's lockdown restrictions, we are starting to ramp up our activity around the country. May and June were very busy for staff, volunteers, and Tackle Directors.

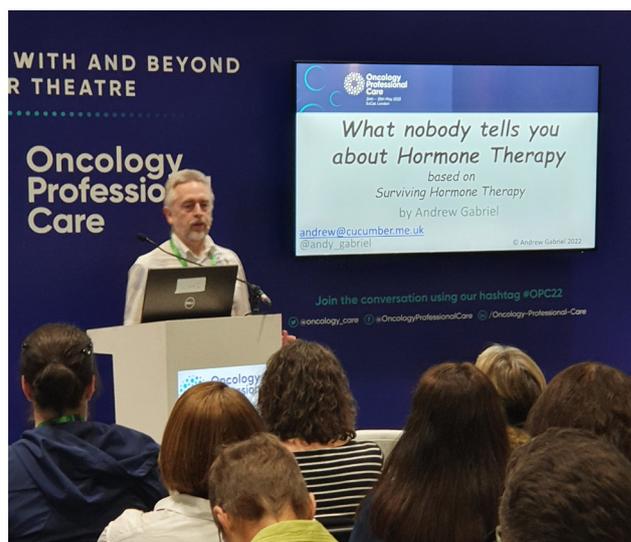
In Birmingham we held our first West Midlands Regional Network Event. 27 people from 6 Support Groups came together to learn from each other, collaborate and share good practice.

Warren from Sutton Coldfield group said "it was a great event, the importance of the event was to bring people together, to encourage and share ideas on how we can encourage more people to attend support groups. In particular a lot of black people are not represented, so by me being here today, hopefully it's a step forward to get more diverse people to come forward".

At the end of May, we took our Tackle stand to our first Oncology Professionals Conference. Thanks to the hard work of volunteers and staff, we spoke to well over 150 people over the 2 days and have connected with around 90 health care professionals who have asked us to send them C-Cards to give out in clinic and want to work with us on supporting the set up of new groups. Steve Allen and Andrew Gabriel featured heavily in the 'Living with and beyond cancer workshops,' both giving excellent presentations, which drove lots of people to our stand.

It was hard work, and incredibly worthwhile as many CNS, radiotherapists, oncologists know much more about the value and importance of the work that support groups do in supporting people living with and affected by prostate cancer.

- Sarah Gray



Community news

Adian takes a look at Twitter and what's useful on the platform

A tweet is a microblog of 280 characters or less, which could include an internet link and images. These could be anything from a photo of a pancake a tweeter has eaten along with their opinion of it – to the publication of the latest results from an important piece of clinical research.

Over 500 million tweets are made each day, some of which are not useful and as twitter accounts can be anonymous, and some of the opinions and comments posted can be vile. It is a bit wild west. So how does this help the prostate cancer patient?

Like all sources of news, if the source is credible and reliable then they may be worth following- and in the clinical world this is how many researchers are communicating globally. A trusted twitter account for me is @andy_gabriel – he posts useful information about his Support Group activities; he retweets posts that he believes his followers would find useful and gives insightful comments and no pictures of pancakes. Well worth following.



Getting to know Tackle

Getting to know Tackle means getting to know you! Tackle, legally known as the National Federation of Prostate Cancer Support Groups, means each member collectively makes up our organisation. Whilst at a central level Tackle is run by a dedicated group of volunteer Trustees and our National Support Development Manager, at a grass root level it is the member groups that represent Tackle, offering peer to peer support to people living with and affected by prostate cancer.

To ensure you are able to offer the best support for your members, our mission as Tackle is to foster a community of peer-to-peer support group leads, through sharing good practice, information and resources.

Our newly designed website, www.tackleprostate.org now offers a dedicated members portal that offers access to valuable resources, digital assets, networking events and discussion forums.

At a national level, **as the only prostate cancer user-voice charity, we continue to work alongside other stakeholders to campaign for national screening for prostate cancer. We work to amplify the voice of all people living with and affected by Prostate cancer through impactful campaigns, as well as helping normalise conversations around taboo topics.** Tackle strives for improvement of health services to ensure those affected by prostate cancer have the best possible advice, care and support available.

- Roshani Perera

Contribute an article

At Tackle our aim is amplify the voice of all people living with and affected by Prostate cancer. Which is why we want to hear from you!

Prostate Matters is looking for articles from anyone one who is living with or has been affected by prostate cancer. Send us news and stories by email editor@tackleprostate.org

Forums

Support for prostate cancer comes in many different forms. Peer Support Groups both face to face and online, helplines, 1 to 1 and buddy services, activity groups, and partner groups can all make a huge difference to people's experience.

Most cancer charities, including Macmillan Cancer Support and Prostate Cancer UK, run online forums, both of these are moderated by specialist nurses and specifically for Prostate Cancer.

There are also groups on Facebook you could join. Let us know if you have joined one and tell us your experience.

Read more at:

https://community.macmillan.org.uk/cancer_types/prostate-cancer-forum

<https://community.prostatecanceruk.org/alltopics>

General news

‘Search and Destroy’ treatment approved

The Institute of Cancer Research, London, welcomes the news that 177Lu-PSMA-617, a potent radioactive medicine has been approved by the US Food and Drug Administration (FDA) for treating some advanced prostate cancers.

Lu-PSMA works as a ‘guided missile’ seeking out cancer by detecting the presence of a target molecule called prostate-specific membrane antigen (PSMA), which is present on the surface of cancer cells, but not healthy ones. Once in contact, it delivers a radioactive payload to destroy them.

The approval means those with advanced prostate cancer previously treated with at least one targeted hormone treatment – such as enzalutamide or abiraterone – alongside taxane chemotherapy will be able to access the treatment in the US. It raises hopes that the medicine, could next be approved in Europe.

Read more at:
<https://www.icr.ac.uk/news-archive/icr-welcomes-fda-approval-of-search-and-destroy-treatment>



One cancer voice

This year, we’re teaming up with Cancer Research UK and more than 50 other cancer charities in a movement to encourage our Secretary of State for Health and Social Care to consider adding key, final details to the forthcoming 10-Year Cancer Plan.

One Cancer Voice (OCV) has brought us, and these other charities together so we can have our say and help shape the future of cancer care, treatment and prevention in the UK.

On 20th June 2022, OCV submitted our collective viewpoints to the Department of Health, asking that the 10-Year Cancer Plan provides information on the following two points:

- Robust, fully costed, and funded plans. These must be visionary and bold to move the UK forward in it’s ambitions
- The plans must address the shortfalls in workforce and equipment to help deliver strategies.

With these points addressed, we believe we can do our bit in ensuring the future of cancer looks brighter, with preventative action, earlier diagnosis and more tailored care. This way, we hope the UK can move closer to offering the best cancer care in Europe.

Advice

Follow up PSA blood tests after your treatment for Prostate Cancer will continue for most patients for a few years. Exactly when and where this gets done will vary based on each individual’s follow-up plan.

It may involve a lot of hassle to arrange, however, it’s important that you stay on top of this. People have lost track of this by moving house and accidentally or deliberately missing follow up tests. Don’t be that person.

Spotlight

North Hampshire Prostate Cancer Support Group

Recently the North Hampshire Prostate Cancer Support Group (NHPCSG) have been thinking about ways we offer support outside of our regular group meetings. This could be on the telephone, or at our newly developed 'Pint and Chat' meetings, or via a regular newsletter, so even if they do not attend on a regular basis, they know where to find us when they feel like they need more support.

We've been contacted either on our group e-mail address or group phone number. Whilst most of these contacts have been men recently diagnosed with PCa, calls and emails can also come from people's partners and on one occasion we received a call from a daughter seeking help for her father.

One of the key ways we can offer support is helping the person think about and prepare questions to ask at their next appointment. On two occasions by asking questions people were able to change the treatment they had been offered.

We also offer "a pint and a chat night" for newly diagnosed men. We have had two meetings so far. After the first meeting one of the men attending sent a testimonial thanking the group for sharing their experiences which he said helped him enormously in making his decision. 'It was the shock and confusion that you will all remember at being diagnosed with a prostate issue. Timing is all in life. My diagnosis coincided with an invitation on a flyer from your Prostate cancer Support Group to meet for a pint and a chat.



For me personally this was so important as I was all at sea, confused. I had been given options for treatment but what did they mean in the real world? The opportunity to meet and talk through all your diverse treatments and experiences enables me to focus on and decide on the treatment I would look for. I am so grateful for the time, unselfish and open the team gave me that night. The meeting for me was beyond value.'

-Allan Roper



In focus

How can we stop too many men being diagnosed too late?

We all strive to do what we can to ensure more people are diagnosed with prostate cancer as early as possible, so people can receive appropriate monitoring, surveillance, or treatment.

With one of the worst PCA mortality rates in the western world, the UK National Screening Committee still opposes a national screening programme. **The policy of Tackle is to fully support the need for a National Screening Programme to coincide with advances in clinical practice.**

Read more at:

<https://view-health-screening-recommendations.service.gov.uk/prostate-cancer/>

Long-term screening studies in Europe and the USA have shown that regular PSA testing over 20 years, commencing in a man's forties and fifties can halve his risk of dying from prostate cancer. The European Commission has accepted expert advice from the European Association of Urology (EAU) and is recommending that all EU countries establish national screening programmes. Furthermore, this benefit can now be achieved without significant "harm" of over-diagnosis and over-treatment. The introduction of MRI scanning has virtually eliminated the former, and active surveillance the latter, from UK clinical practice.

The tragedy is that, despite our efforts so far, the cancer will have already spread outside the



prostate in just under half of men at the time of their first diagnosis and in around 15% of men the cancer will already have become advanced and spread to bone, distant lymph nodes etc. Too many men are being diagnosed too late. Too many men will have their treatment options restricted as a result of late diagnosis.

The pandemic has led to many people missing a timely diagnosis. According to the National Audit for Prostate Cancer there was a 54% reduction in the number of men diagnosed between April - June 2020 compared with same period in 2019. Prostate Cancer UK and the NHS estimate 14,000 men have not started treatment because of the pandemic.

Read more at:

https://www.npca.org.uk/content/uploads/2022/04/NPCA-AR2021-Patient-Summary_Final-April-2022.pdf

The good news is, that **the NHS have planned a number of initiatives to boost the number of men coming forward, especially in high-risk groups.** You may have seen, promoted, and supported the important Find the Missing 14,000 campaign ran by Prostate Cancer UK and NHS England. On a single day the campaign reached through social media an incredible 2.9m and Prostate Cancer UK reported 100,000 visitors to their website in one morning.

Read more at:

<https://prostatecanceruk.org/prostate-information/risk-campaign>

Since the Prostate Cancer UK campaign operated through February and March, over 550,000 people have used their risk checker with over 80% of whom were at higher risk of prostate cancer because of their age, ethnicity, or family history; all these deemed high risk were encouraged to visit their GP. Campaigns like this are an excellent way to get important messages out about one's risk of Prostate Cancer.

The NHS is exploring other ways to look at improving early diagnosis. **For the first time Primary Care Networks are being asked to look at Prostate Cancer as part of the Network Contract Direct Enhanced Service.** Primary Care Networks (Groups of GP surgeries in a locality) are being asked to develop and implement proactive and opportunistic assessment of patients for prostate cancer in populations where referrals have not recovered to pre-pandemic levels. This means that local health care providers working under the direction of Cancer Alliances will need to focus on boosting Prostate Cancer referrals.

Read more at:
<https://www.kingsfund.org.uk/publications/primary-care-networks-explained>

Tackle also supports Chris Booth and the Charity 'CHAPS' with a project that uses risk-based screening criteria not only to target men at high risk but to gain robust data that could reduce over-frequent screening for the majority of men those who are at low risk to avoid the problems of over-diagnosis and over-treatment of non-aggressive, insignificant PCa. Initial results are very positive.

At a more local level, we know from listening to many of our Group Leaders and working with partners such as Graham Fulford Trust (GFT) that there has been a huge increase in promoting opportunistic PSA testing through local events. The GFT has an online booking and results retrieval system, most results are now returned to the men within 48 hours of their test. They have found over 2,200 men with prostate cancer since the charity started.

We spoke to Susan Hart from GFT, who told us 'We are now doing over 3,500 tests per month. We work with Support Groups, other charities such as Cancer Testing South and several Lions groups as well as corporates, throughout the UK. We are finding 10% of men of men tested, have either an Amber or Red result. All men with a RED result can be referred via their GP to participate in the RAPID trial at Imperial College London Hospital. They will be seen within 2 weeks of referral. They will undertake a day's diagnostic testing and at the end of the day they will be informed whether they have PC or another disease of the prostate or nothing at all.' If you'd like to organise an event or just find out more information contact Susan Hart, GFT at susan@psatests.org.uk or contact her on 01926 419959.

With your help we can raise awareness of the importance of testing, so that with earlier diagnosis those affected by prostate cancer have the best possible advice, care and support available.

- Sarah Gray and Steve Allen



What to expect: A guide to Prostate Cancer: A webinar series for people affected by prostate cancer

Do you have questions about prostate cancer that you haven't been able to ask or feel too embarrassed asking? Do you want to know more about what causes prostate cancer and how it is diagnosed?

Every Wednesday for eight weeks, starting from June 8th, our partners Prostate Cancer Research and Ipsen are bringing you eight webinars for anyone affected by prostate cancer. All are welcome – people living with and affected by prostate cancer, or anyone who might benefit from learning more about prostate cancer and its effects. These sessions will help you understand a diagnosis as well as the different treatment options that might be available.

The webinars that have already taken place will be available to watch anytime on PCRs website and if you would like to register to attend the remaining webinars, go to <https://www.prostate-cancer-research.org.uk/what-to-expect/>

Have you phoned our helpline? - 0800 035 5302

Thanks to our amazing Helpline Volunteers our Tackle Helpline is open 365 days a year 9.00 am to 9.00pm. It is always answered by someone with a lived experience of Prostate Cancer.

Callers are encouraged to talk about their current situation; which varies from a new diagnosis to

stage 4 of the disease. With an understanding of being diagnosed, treated, and living with prostate cancer our Volunteer Helpliner can go over with the caller the details of procedures currently offered and potential side effects.

A recent call was from sister of a man who underwent a radical prostatectomy and, as a result, became incontinent. She explained that her brother had been a keen tennis player but, because of the incontinence, did not want to play tennis anymore and was becoming suicidal. The Helpliner talked about the artificial sphincter and shared with her what the treatment entailed. A few months later she called back to say thank you and that her brother had had the artificial sphincter fitted, no longer incontinent and was back playing tennis!

It is important to remember that both the telephone and email helplines are run by volunteers who are not medically trained. Information received should not be taken as medical advice which should always be obtained from qualified medical practitioners.

You can also email us at helpline@tackleprostate.org

Visit our website | tackleprostate.org

Diagnosis

If you've just been diagnosed with prostate cancer, it can be a scary time. Our website has a step by step guide through diagnosis.

Treatment

Learn about the options available after a diagnosis in clear, easy to understand language, as well as a collection of resources to help you.

Support

We are here to offer you the support you need. Whether that's through one of our 90 support groups, our helpline, or our information booklets.



“Keep it simple, keep it friendly”

An interview with David Manthorpe, leader of Compass Support Group

Compass Prostate Cancer Support Group is leading the way with peer support with its straight talking and pragmatic style, offering a place where both men with prostate cancer, and their partners can feel listened to and supported. Compass membership is mainly made up of those receiving treatment at Wexham Park Hospital serving those in South Bucks, East Berks and West London areas. Now in its tenth year, the group meets every 2nd Thursday and has around 25 members. With many members continuing to work the group also offers plenty of support via phone and email.

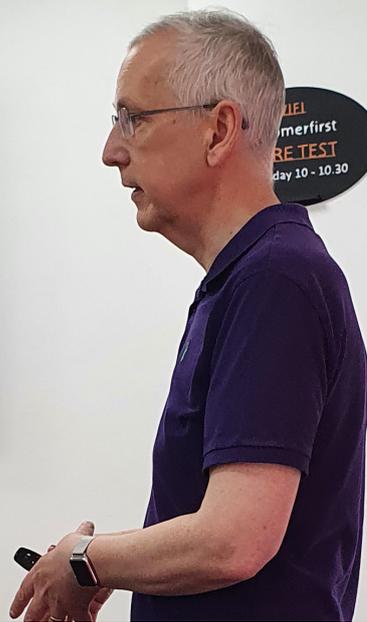
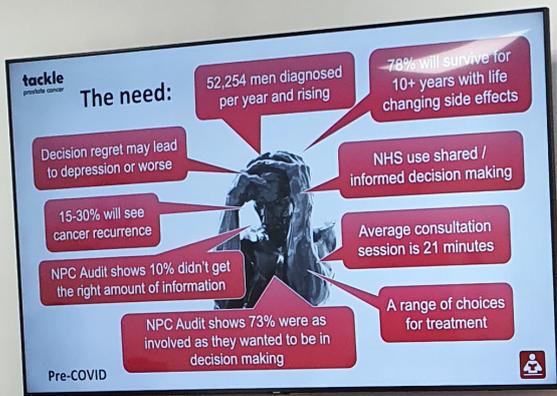
The group is led by David Manthorpe who became involved Compass 7 years ago after seeing a poster in his consultant’s waiting room. A former firefighter he brings plain talking and an open style to the group, definitely helping to normalise conversations about prostate cancer, diagnosis and treatment, and everything in between!

He says

“Compass is a place where everyone is equal. We offer a relaxed space where people can go and have a chat about anything they want to. There is no pressure and between us we have a big knowledge base. If people need help, we’ll just help sort it out. When people come along to the group, it’s because we are all in the same boat, no one judges you. We’re here to give practical advice and support. I’d say there are 3 key elements of how Compass’s peer support community is supporting people:

Firstly, we give people confidence. There are people there who have seen it, done it and know that there is light at the end of the tunnel, who share their experiences with newer members. Secondly, once they have spoken to other members, they can take the heat of their own situation. And thirdly we offer reassurance, knowing that whatever happens, you can deal with it.

Basically, we look to keep it simple. If you would like to register to attend the remaining webinars, go to <https://www.prostate-cancer-research.org.uk/what-to-expect/>



Peer coaching event

A two-day peer buddy training event has been delivered for those attending Tackle Prostate Cancer groups in the West Midlands and it went down a storm.

Hosted and run by Aidan Adkins, the event was held on the 13th-14th of June, and provided the eight participants with the chance to learn about what it means to be a Treatment Decision Support Buddy.

The interactive training session gave the attendees the chance to learn through a mix of presentations and videos, along with audience participation too. Then, they put their newfound skills into action and practiced their buddying skills in a safe environment, where feedback was welcome.

This new course was piloted by Aidan after he released his dissertation, International Journal of Evidence Based Coaching “Peer coaching in treatment decision making for men diagnosed with prostate cancer”, which highlighted the importance of a buddy system in the crucial decision making stages of receiving treatment.

The training is designed to offer additional treatment advice and support to anyone who’s been recently diagnosed with prostate cancer in the form of one-to-one buddy sessions. Treatment decisions can be life changing for some, so it’s essential that Tackle Members have the support available to them, whether that’s as part of the group or through a buddy.

In a very positive feedback report from the training event, **every single attendee said they’d be happy to recommend becoming a Treatment Decision Support Buddy to anyone considering the training.**

By encouraging more buddy training sessions like this, the hope is more Tackle members will be equipped with the right skills and knowledge to help coach their peers through the treatment decision making process.

And next steps include looking for funding to bring this offering to more support groups across the country.

For those who attended the training, they’re keen to keep up the buddy support, with Zoom calls booked in regularly. This way, they can continue to use, and benefit from, the skills they learned at their training event.

Get involved

Tackle relies on the power of real people and is nothing without its team of excellent volunteers. Our helpline, for instance, is run by volunteers who are living with or have been affected by prostate cancer.

If you are interested in getting involved either on a local or national level, then we’d love to hear from you. email us at info@tackleprostate.org