

# Prostate Matters

Issue 55  
Autumn 2023



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To find out more go to our website or social media channels

website: [www.tackleprostate.org](http://www.tackleprostate.org) twitter: [tackleprostate](https://twitter.com/tackleprostate) instagram: [tackleprostatecancer](https://www.instagram.com/tackleprostatecancer)

facebook: [tackleprostate](https://www.facebook.com/tackleprostate)

## Welcome

Welcome to this edition of Prostate Matters - the newsletter of the National Federation of Support Groups, and at the time of publication we have 110 support groups in our Federation, a number that is growing. This edition is dedicated to Ryland, shown on our front cover, whose journey with prostate cancer ended too soon in 2021. His partner, Ailie has kindly donated the funding to help us print and distribute this copy to you.

You will find inside a wide range of contributions that are as diverse as we expect the groups in our Federation to be, ensuring that all are welcome. You will read about the benefits of attending support groups, how as a Federation we campaign and are collaborating with other organisations to

ensure your voice is heard, two excellent articles from clinicians with global reputations and some signposting to some great resources to help you with your journey.

Whether you are already a member of a support group, a leader of a support group, a clinician, or an interested person reading this in your GPs waiting room, there is something here for you. Thank you for taking the time to read Prostate Matters, I hope you enjoy reading it. As ever, please do get in touch if you have any questions or would like to contribute to future editions.

**Best wishes,**  
**Aidan Adkins – Co-chair**

## Editorial team



Aidan Adkins,  
Co-chair

Aidan was diagnosed with aggressive, high-risk prostate cancer in 2015 through a routine work medical. Having joined a local support group soon after, he now leads 3 groups across the West Midlands and champions the value of peer support and the need to improve access to this vital service across the country.



Andrew Moffatt,  
Fundraising Manager

Andrew has been working in the charity sector for over 30 years, leading fundraising and communications for various causes. He has a wealth of experience with campaigning for organisations in the UK and internationally, supporting them with strategy, cases for support and hands on applications.



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.



Molly Jewitt,  
Marketing and  
Communications Manager

Molly is a freelance communications consultant, with experience in the third and public sectors. She is passionate about using people's stories to increase further awareness of important topics and using the power of communications to make positive change.



## Around the country 20th Anniversary - APPLE

In October APPLE (The Association of Prostate Patients in London and Essex) will celebrate their 20th anniversary. This comes a little belated due to the pandemic, however over the past 20 years, APPLE has been committed to raising the awareness of prostate cancer through different methods, including fundraising events and awareness campaigns.

APPLE has had the support of one of the group's former members, Mr Ernest Smith, who has now sadly passed. With the help of Nell (his wife) and his daughters, Clair and Jane, APPLE has managed to sustain its intimate, family-feel offering. With Nell, being at the forefront of the APPLE meetings, providing tea and coffee to members, Clair, being the administrator and Jane, being the secretary and the group's patient representative on the Northeast London Cancer Alliance, have added such value to the group. Alongside the family trio, APPLE has Innocent Ohari as Treasurer and one of Tackle's trustees, Ken Mastris as Chair, both of whom were diagnosed with prostate cancer in 2005.

With 95 subscribers on their mailing list and having over thirty people at their latest meeting, APPLE are looking forward to what's to come. If you're in the area and fancy reaching out, find them at [bit.ly/44zRiwD](https://bit.ly/44zRiwD)

## Community chat A little peace and quiet.

With thanks to the Templar Aquila Masonic Lodge and Sussex Masonic Foundation, the Urology Investigations Suite at Eastbourne's District General Hospital has had an uplift! Our friends at Prostate Cancer Support Group Organisation (PCaSO) had the chance to go to the reveal of the Quiet Room's new furniture and artwork.

Spaces like these are so needed in hospitals as they give loved ones a place to go to get some much needed peace and quiet.



## Get involved

As we know, exercise is beneficial in so many ways for our overall wellbeing. We also know that group members find exercise equally as important when coping with their diagnosis as it keeps them mentally and physically fitter. As of late, we've had a lot of enquiries about how people can support our work. So, we've been doing some work on our Justgiving page to make fundraising for Tackle that little bit easier.

Now, you can set up your own page that links directly to Tackle's page to raise money. The best bit? Any money that's raised will go towards the setup or contribute towards the maintenance / support of the prostate cancer support groups; directly supporting those who are affected or who are living with prostate cancer.

So, if there's a physical challenge you've got your eye set on, or something you've wanted to do for a while but want to make a difference to those who live with or are affected by prostate cancer then why not fundraise for Tackle.

We're also in the early stages of developing a small range of fundraising merchandise over the coming months, such as t-shirts and running vests, so do keep an eye out on our social media, website and newsletters for more information.

Head here to our JustGiving page:  
[justgiving.com/tackleprostatecancer](https://justgiving.com/tackleprostatecancer)



## Hear from an expert

In this edition, we hear from one of Tackle's trustees and Chair of the Clinical Advisory Board, Professor Frank Chinegwundoh MBE who's talking about Focal Therapy\*.

"Traditionally treatments for organ confined prostate cancer have been 'whole gland' treatments. Results, whether from radical surgery or brachytherapy or external radiation are excellent. However, the side effects can be troublesome. What if one can just destroy a targeted area of the prostate and leave the gland intact, would that 'cure' the cancer, but minimise side effects. Thus the concept of focal therapy, can be somewhat compared to lumpectomy in breast cancer.

For suitable patients, focal therapy is an option, albeit a relatively new tool in the armamentarium. High intensity focused ultrasound or cryotherapy can be used to target a specific localised area within the prostate. In the right patient, the outcomes are very good."

\*Focal therapy means removing the cancer, while leaving the rest of the organ intact. This is to help retain as much normal function as possible.

Want to know a secret?  
Prostate cancer rarely causes urinary symptoms



# PROSTATE CANCER IS SILENT

GET  
CHECKED

Speak to your doctor about your risk and how to get tested



## General news

### Silent Killer Campaign - we hear from Professor Vincent J Gnanapragasam

The idea that prostate cancer directly causes urinary symptoms is so prevalent that it is hard to believe that this was never based on any objective evidence. Yet this lack of association is a clear fact that emerges from a simple perusal of the literature but has been lost or ignored in favour of the narrative that because of the location of the gland, any malignancy within it must surely cause symptoms. Paradoxically, the data reveals that the association between urinary symptoms and prostate cancer is in fact an inverse one. In other words, on average a man is less likely to have prostate cancer if he has urinary symptoms, than if he doesn't. Although a seemingly simple misinterpretation, the likelihood of this false messaging having a consequential adverse impact may be very significant.

If in the absence of a screening or formal testing program men are encouraged to see GPs only when they have urinary symptoms then they are not likely to seek testing if they don't have any. Believing (falsely) that it is not possible for them to harbour prostate cancer because they don't have anything to complain about. This misconception may result in men delaying or not presenting to GPs and hence a later diagnosis. Indeed, we have some evidence for this. In a recent review, comparative data showed that men diagnosed through "symptomatic presentation" to GPs were more likely to have much later stage disease compared with a screening program or an opportunistic testing program. Unfortunately, many news, media and healthcare outlets continue to pedal this myth of urinary symptoms and prostate cancer, often based on the notion that "having any type of message to present" is better than none. Indeed, in a survey of the general population only 1% are aware that prostate cancer is actually a silent disease.

Continues on page 7



Thus, there is a great need to actively dispel the notion that men can feel safe because they are the envy of their colleagues and friends in the "lack of urinary symptoms" department. To address this, a campaign to highlight the fact that prostate cancer is silent has been launched recently by researchers at the University of Cambridge and charity partners.

With the assistance of Tackle and other bodies it is hoped this message can be disseminated to help raise awareness on the silent nature of prostate cancer. If supporters of Tackle and their families could further help to disseminate this message, this would be most welcome and go some way to dispel this very prevalent misconception.



men are able to dispose of their sanitary products. A survey of 84 men who have experienced incontinence, completed between March and May this year, reveals the desperate need for sanitary bins. A shocking 95% of respondents to the survey said reported feeling anxiety due to a lack of sanitary bins in men's toilets for disposing of pads hygienically.

Sarah Gray, our National Support and Development Manager who attended the event alongside some of our Group Leaders said 'Through our network of peer support groups, we often hear harrowing stories of the struggles men face due to incontinence. Tackle Prostate Cancer are committed to reducing these struggles and are proud to campaign alongside our partners to ensure all people have equitable access to safe and dignified disposal of incontinence products and the same levels of dignity afforded to women.'

Let us know if you or your partner, loved one has been affected by the lack of provision of sanitary bins in men's cubicles. Email us at [support@tackleprostatecancer.org](mailto:support@tackleprostatecancer.org)

### Boys NEED bins

1 in 3 men over 65 in the UK experience urinary incontinence, and 1 in 20 men aged 60 and over live with bowel incontinence. The 'Boys need Bins' campaign, led by Prostate Cancer UK, and made up of several other charities including Tackle Prostate Cancer, is calling on the government to change existing legislation so that sanitary bins are provided in all men's toilets.

At the beginning of September members of several of Tackle support groups attended an event Westminster for the 'Boys Need Bins' campaign. The event served to launch a report 'Lifting the Lid on Male Incontinence' link: [bit.ly/3sNclt4](http://bit.ly/3sNclt4) The report highlights the issues men face on a daily basis due to the lack of provision of bins where



*Want to know more  
about prostate cancer?*

# The infopool

A website all about testing,  
treatments, side effects,  
clinical trials and more



Scan the QR code to visit  
[www.theinfopool.co.uk](http://www.theinfopool.co.uk)

Prostate Cancer Research is a registered charity in England and Wales (1156027)

Document Creation: April 2023

In depth

## A problem shared, is a problem halved

Whether you've lived with or have been affected by prostate cancer, we think it's fair to say that it's probably triggered negative feelings or emotions. Whether it be that sinking feeling when you've been first diagnosed, or you witness the struggles someone faces when they're experiencing the side effects of their treatment, or, the vacant space left between two lovers, because things have simply changed and you question whether the relationship will ever be the same again.

Whichever the circumstance, whether it's written here or not, we want you to imagine what it would feel like if you were going through the hardships alone. With no-one to talk to apart from your GP, no-one by your side to help you through the tough times.

Now, we want you to imagine the same scenario, with the one person you can rely on the most. The one who you know will be there with you through thick and thin. The person who will cry and laugh with you, through the ups and downs. Got them in your head? Great. Now, we want to add a little detail...

So, although this person will be by your side no matter what. What this person doesn't have - through no fault of their own - is the lived experience of prostate cancer. They haven't felt what it's like to lose their libido during their first intimate moment with someone they're dating. They haven't felt the uncomfortability of sitting through a celebratory dinner wearing a saturated incontinence pad, because the restaurant's bathroom didn't have anywhere to dispose of it.

Now, we're not saying that you need to dismiss all support from people unless they've got lived experience of prostate cancer. But, what we are

saying is that perhaps some additional reassurance from somebody who has gone through something similar, would be helpful.

As you know, we have over 90 support groups across the country as well as volunteers on our telephone helpline; all of whom have lived experience of prostate cancer. If you haven't explored our services, everything you need to know about this can be found at [tackleprostate.org/supportgroups](http://tackleprostate.org/supportgroups).

In addition to our core offering, we are also working on a project that aims to strengthen our wraparound support for people of all ages, cultures and communities. We're looking to amplify the stories of people who have lived with prostate cancer online, to help others through the ups, the downs and everything in-between; because as we've discovered - a problem shared, is a problem halved. With 5.3 billion people world-wide accessing the internet, means that we have to use these methods to our advantage in order to raise the awareness to ultimately tackle prostate cancer.

Keep an eye on our social media for what's to come and if you, or anyone else you know would like to help others by sharing your story, please get in touch at [info@tackleprostate.org](mailto:info@tackleprostate.org).





## In depth Hello Prostate Cancer: It's Good To Talk.

Sometimes we have a conversation that is a real catalyst for our own perception, interpretation and change. This is what Chorley based photographer, Ian Smith, discovered after he was diagnosed with prostate cancer in 2010.

Since his diagnosis, he fell in love with photography, became a mature student at the University of Bolton, and decided to do his final year project on prostate cancer. He graduated in 2018 with a first.

To this day, he continues to use his camera as a tool to explore and challenge the public's understanding of prostate cancer, to inform partners ultimately raise awareness of the condition.

He developed his final year project, 'Prostate Cancer Every Picture Tells a Story', for the public. The project depicts the narrative of men 'living a new norm' after treatment for prostate cancer, while celebrating their partners' support through their journey.

Ian's second photography project, 'The Prostate Gap', explores people who are under-represented in society who have prostate cancer. Passionate and courageous individuals from LGBTQ+ and black communities, shared their stories about the barriers and obstacles faced through their prostate cancer journeys.

During the course of his research which involved many interesting conversations as well as photographing people's portraits, Ian uncovered many gaps:

- Gaps in information
- Gaps in knowledge
- Gaps in experience

Exposing these facts as a collective, props up the work still to be done on striving for a more equal society.

Ian's work highlights that no two people's prostate cancer journeys and stories are the same; while revealing the common ground in their lived experiences.

Shared experiences include the similar way people with prostate cancer have been treated by healthcare professionals, an experience with incontinence, ways in which they can have intimate relations without intercourse, among many others.

Very often we hear people identify the differences between one another before they've even considered any similarities. This can make it hard to form bonds, allyship, advocacy, and raise awareness, support each other and our families and strive to make an important difference in our communities.

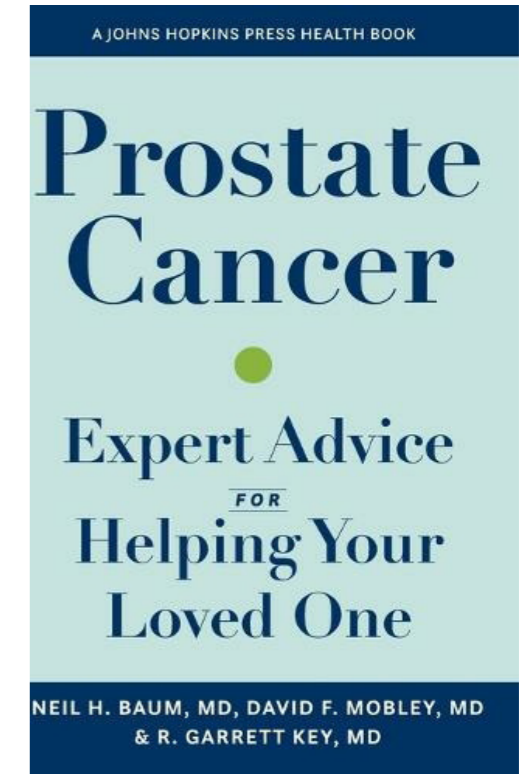
Ian believes it is his personal responsibility — as an individual and as part of the prostate cancer community — to continue conversations with his camera in hand around taboo topics to help fill the gaps in men's health knowledge in this area to ultimately save lives.

For more information on Ian Smith's work, you can visit: Smith's YouTube channel can be found at [bit.ly/45MRES6](https://bit.ly/45MRES6) or on social media at [@iansmith2580](https://twitter.com/iansmith2580).

## Advice

Looking for a book that can help partners of those living with prostate cancer? Caroline Prance, who co-leads the National Prostate Cancer Partners' Support Group, recently reviewed Prostate Cancer — Expert advice on helping your loved one and here's what she had to say:

"This book gives a clear overview of prostate cancer, its stages, and treatments. The book explains and demystifies medical language and the inclusion of clear diagrams is particularly useful. Each chapter is described at the beginning of the book and advice to dip in and out of the book. Written by an American team there are inevitably some cultural differences, however, this doesn't distract from overall reading.



Case studies within each chapter give context and include the couple's voice. The book is inclusive and respectful of diversity. Each chapter ends with suggested questions to ask the clinician and could act as a springboard for one's own questions.

The message throughout is the need for partners to take care of themselves in order to care for and support. How to navigate different stages and tips on how to communicate with one another were practical and thought provoking.

Certainly I would have valued having a book like this at the beginning of my path as a partner to a man with prostate cancer, and will certainly use this book as a reference for our future journey together wherever the cancer takes us.

Overall a great resource that has presented a difficult topic with huge compassion. Whilst written primarily for partners, I would suggest this book would be an invaluable book to share as a couple. I will certainly highly recommend it to other partners."

You can purchase the book at **(WHSmiths)**

## Online meetings

**National Prostate Cancer Partner Support Group.**  
Wednesday 1st November at 18.30

Supporting partners, families & those close to people diagnosed with Prostate Cancer. Partners should email Janet Daykin [janetdaykin@gmail.com](mailto:janetdaykin@gmail.com) and Caroline [carolineopcs@gmail.com](mailto:carolineopcs@gmail.com) if they wish to attend.

**Prostate Cancer UK presents Prostate Cancer and your sex life**  
Thursday 5 October at 6 - 7.15pm

Register here: [bit.ly/44TXH5T](https://bit.ly/44TXH5T)



Two of Tackle's trustees (Steve Allen and Peter Corbishley) plus two members from the Kidderminster group, represented Tackle at ShedFest and networked amongst those who attended the conference. It was a great event that enabled us to raise the awareness of support groups that are specific to those living with or affected by prostate cancer.

With 143 men being diagnosed with prostate cancer every day, means that we need to continue the conversations around PC to avoid late diagnosis. One of the Sheddors, in Dalbeattie thankfully caught his prostate cancer early.

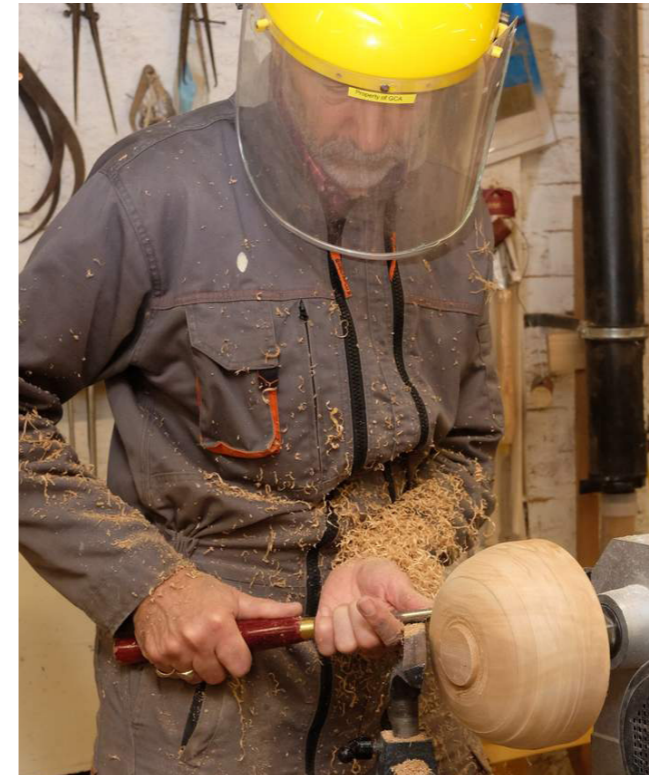
We hear from Rolf:

"I've been a member of Dalbeattie Men's Shed for a few years now, not because I thought I needed the type of support and camaraderie that Sheds are so well known for, but because I am a wood turner and they had some wood that I wanted. I bartered 4 hours of my turning tuition for two pieces of Lime wood. 4 hours is now more than 4 years.

During tea breaks in the Shed there is general chat and the occasional visitor that brings us relevant information (or surveys). Mostly we politely listen and then carry on... as we are men and don't like to make a fuss about our physical or mental health.

## Spotlight

At Tackle we're all about peer support and connecting with others to aid one's overall wellbeing. So when we had the chance to host a stand at Men's Sheds' annual conference, ShedFest, we jumped at the opportunity. Men's Sheds featured at our annual conference earlier this year, so it was great to see what their AGM involved. If you haven't heard of Men's Sheds before, they offer community spaces where people can come together to create, converse and connect. They come in all shapes and sizes and activities can range from woodwork and crafts to cookery, music making and even raising koi carp. Men's Sheds can support health and wellbeing through activity, offering a safe space for men to get together and talk if they want to, without conversation being the main focus. Sheds vary in size and structure, with many allowing members of all genders and most welcoming members of all ages.



As one of the younger guys when I joined (just turned 60) with the average age being about 74, any health issues were for the 'old guys', not me, but as a former boy scout I took note so that I could "Be Prepared". My health and level of fitness was good, and I had no reason to doubt that I would live to a ripe old age without needing a walking aid, muttering to myself or smelling of pee.

Occasionally a place at the Shed would 'become free' for a new member, and that was just the way of things. At tea time there would be kind words spoken, and at the workbenches there would be more chat about the 'thing' that took him, with various degrees of chat that would remind us of our mortality and some visitors that had mentioned tests, surveys, treatments etc.

When I turned 60 I asked my GP for a PSA test while seeing him about another very minor issue. I had no major prostate symptoms, nor concerns, but had read one of the leaflets left by a visiting nurse to the Shed. A few days later my GP phoned me and said "Your PSA should be between 2 and 5, as you get older it might get as high as 10 before you should get worried. Yours is 27, you need to come and see me ASAP. Happy Christmas".

Over the next two years I've had a few low-key chats with guys at the shed, who have gently supported me and helped keep me moving on the path of treatment. My age and fitness were in my favour. Nine weeks ago I had my prostate removed. The tiny, slow growing cancer had decided to grow rapidly and my prostate was very large. We got it out just in time.

Four weeks after surgery I drove back to the Shed and picked up where I left off. Delighted to see the guys who helped me along the road, and they seemed pleased to see me, and that I had not 'freed up a place' at the shed yet.

If you're in the area, you may be interested in their facebook page [facebook.com/dalbeattiemensshed/](https://facebook.com/dalbeattiemensshed/)





Tackle news

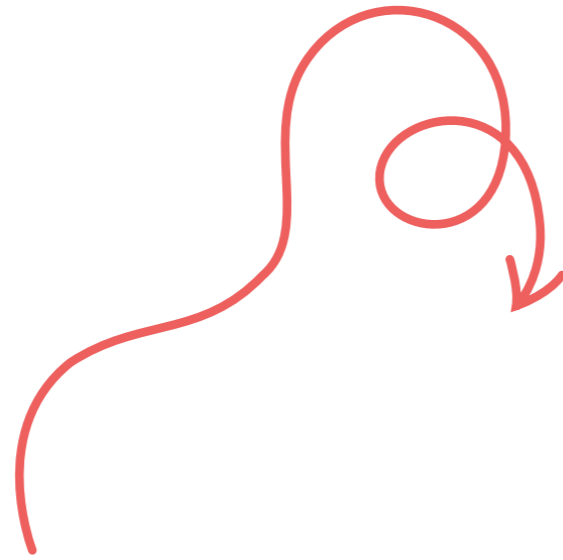
## WE CAN master-class Frankfurt, Germany

One of our trustees, Ken Mastris, recently attended the WE CAN Masterclass in Frankfurt, Germany. WE CAN is an informal network of twenty-two umbrella cancer patient's advocacy organisations who are active in Europe. Their aim is to build trust, collaboration, and alignment to strengthen Cancer Patient Advocacy across Europe.

Over the four days, over one hundred people attended, with people from twenty-six different countries. WE CAN's format gave opportunities to patient advocates who were starting their journey in the field of advocacy to learn the basics and meet the experts as well as providing a space for networking. For the more experienced patient advocates, the WE CAN Academy training event offered room to exchange knowledge and dig into the topics that help to make patient advocacy even more effective.

Using WE CAN's three knowledge pillars (Tools and skills, Healthcare Systems, Policy & Access and: Research and Data), the masterclasses covered different topics; such as developing good governance for non-for-profit patient groups, understanding health economics, gaining financial sustainability, plus, partnering beyond patient advocacy to reach those still underrepresented.

For more information about WE CAN, please visit the website at [wecanadvocate.eu](http://wecanadvocate.eu).



### 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 volunteers can offer emotional support and advice based on their lived experience. You can also email us at [helpline@tackleprostate.org](mailto:helpline@tackleprostate.org)

For regular updates on industry news, what we and our support groups are up to, why not follow us on social media!

-  @tackleprostate
-  @tackleprostate
-  @tackleprostatecancer
-  @tackleprostatecancer

Or, browse our website [www.tackleprostate.org.uk](http://www.tackleprostate.org.uk). Here is where you'll find information about your nearest support group.



## A special dedication

This edition of Prostate Matters is dedicated to Ryland, who sadly lost his battle to prostate cancer in 2021. His partner, Ailie has kindly donated enough funds to help us print and distribute this copy to you. A huge thank you Ailie, we are so grateful.

Here's a little snippet into Ailie and Rylands beautiful life they had together...

"Ryland and I met in 2010 when he taught me to scuba dive. Neither of us were looking for love, but love found us! Ryland was one of the most unusual people i have ever met. Eccentric, intelligent, messy, funny, disorganised, generous. An eclectic mix of chaos. We married in 2014, scuba diving in Thailand for our honeymoon. Life was lovely."

In 2017 Ryland found a lump in his neck, which turned out to be Advanced Prostate Cancer. And so started a relentless journey of chemotherapy, radiotherapy, a clinical trial. We were lucky to have an amazing team at our hospital who helped us through the worst time of our life. Unfortunately Ryland died in December 2021. I could not be more proud of how he handled his illness, with humour, dignity and good grace.

Before he died Ryland asked for donations to split between causes close to his heart. He was humbled by the donations and how much he was loved, writing

"I've just tried to have a fun life, do unto others as you'd like back, and bring a little joy, help, and encouragement into others lives. I urge you all to follow those and you will be happier yourselves"







# Together we tackle

*"Tackle Prostate is a brilliant charity. There are a lot of people who are diagnosed but aren't coming forward, especially those from the Black community. Maybe they don't know how, or they're scared. We encourage people to come forward & join the Tackle Prostate support groups."*

- Warren | West Midlands Support Group member



Through our national network of support groups we unite, guide & hero those living with or affected by Prostate Cancer. Find a local support group today at [tackleprostate.org/supportgroups](https://tackleprostate.org/supportgroups)

Tackle Prostate Cancer is the campaign name of The National Federation of Prostate Cancer Support Groups, Registered Charity No 1163152. A Company Limited by Guarantee. Registered in England No: 9672970. Contact us at [info.tackleprostate.org](mailto:info.tackleprostate.org)