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To find out more go to our website or social media channels
website: www.tackleprostate.org  twitter: tackleprostate  instagram: tackleprostatecancer
facebook: tackleprostate
Welcome

Welcome to this latest edition of Prostate Matters. It is now widely recognised that the treatment of prostate cancer is not just treating the physical disease — so many other factors are important: ‘Wellbeing and Health’ and ‘Wholeness and Healing’ are phrases that are often used. But what does they actually mean?

Wholeness not only includes the relevant medical treatments but also looking at social, financial, emotional and many other facets of an individual’s life. As support groups, we need to be very aware that we understand the many needs of the very diverse people that can come our way.

Healing again can take many different forms. It could obviously mean ‘cure’ of the disease, but what does it mean to someone who has already advanced disease? Acceptance is a form of healing, management is a form of healing. The stunning success of the newly formed Tackle group for men with advanced disease has shown there is a great need here. Cancer can lead to changes in relationships with a partner or family — such changes can also need healing.

We have a unique place as local support groups to aid this process of Wholeness and Healing by sharing personal experiences and ways of coping, by providing avenues for easy conversations about difficult subjects, collaborating with other local support groups in sharing group activities and so much more. Tackling these problems together is the key. It is only by working together that we can achieve our aim of meeting the needs of all those whose lives are affected by prostate cancer. Together we can be the ‘go to charity’ for peer support.

On behalf of the whole Tackle team, I’d like to wish you health and happiness over this festive period.

- Steve Allen
December 2022
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.

Prof. Frank Chinegwundoh MBE
Trustee and Chair of the Clinical Advisory Board

After completing his medical degree at St George’s University Hospital London and training in various places in the UK and USA, plus many other professional achievements. Frank’s services to the NHS were recognised with an MBE in 2015. His passion and knowledge about prostate cancer are real assets to the Tackle team.

Ken Mastris,
Patient Representative

Ken Mastris, is the Group Leader of APPLE (Association of Prostate Patients in London and Essex). Ken was diagnosed with Prostate Cancer in 2005 and has lived with the consequences of Prostate Cancer for many years. Ken, has been a long term champion of and advocate for the rights and needs of people living with Prostate Cancer, through his past roles as both Secretary and Chair of Tackle, and at Europa Uomo, a European advocacy movement representing 27 prostate patients’ groups in countries across Europe.
Around the country

Northampton Prostate Cancer Support Group

The side effects of prostate cancer treatment commonly include the lack of mobility, breathing issues, mood swings and emotion to name just a few. To combat these consequences of treatment Northampton PCSG have been trialling a yoga class.

It is proven that Yoga improves strength, balance and flexibility and eases arthritis symptoms which can be associated with hormone treatment, it also benefits heart health and breathing. Richard Truby who leads the Northampton PCSG says ‘Men who have attended these sessions report that they feel a boost in mental and physical energy’

South Bucks Hospice

Tackle have been supporting South Bucks Hospice with a facilitated weekly prostate cancer Support Group for the past year. The group counselling sessions have been led by a palliative care nurse and has proved a great success, providing a safe space for men to discuss treatments, side effects and recovery, as well as non-medical issues. One group member reported ‘when I first came to the group, I had a great deal of negativity to deal with; I’ve really changed’ ‘I get tremendous amount of support from the Prostate Support Group, in all aspects and attending it has really improved my positivity’

Worcestershire Exercise Group

Tackle prostate cancer commissioned Active Always Health and Wellbeing to run a study into the emotional and physical benefits of an 8-week activity programme on those who have had a prostate cancer diagnosis. Although this group had a limited take up, the benefits of exercise were evident in the men who attended. One participant reported reduced pain levels at the end of the study, another participant reported improved mobility and self-care and all participants have increased their activity levels and are continuing with some form of activity, including fortnightly

Adapted Pilates and Strength sessions, and an oncology walking football group.

Digi Bite

The Cancer-App

Do you sometimes struggle to keep everything related to your cancer journey in one place? Well, The Cancer-App, has been designed to help you stay in control of your care, appointments, medications and contacts, with relevant, expert information specific to your cancer. It is their mission to make living with cancer that little bit easier. Available to download on Google Play or the Apple Store.
Get Involved

Are you interested in becoming a Trustee for Tackle?

Being a trustee can be very rewarding. As a trustee you have the chance to support and shape the work and strategic direction of our organisation.

We are looking for individuals who have a strong interest in Tackle’s work and a passion for supporting men’s health and improving user involvement in cancer care. Knowledge and experience of Voluntary Sector and governance are desirable. Candidates should possess a positive, ‘can-do’ outlook as well as a good sense of humour. You will be joining us at a pivotal point in our history, with the potential to make a real difference to people living with and affected by prostate cancer.

To find out more about our trustee opportunities please visit our website or email: info@tackleprostate.org

Forums

Local support groups provide support to those with a wide range of diagnoses but sometimes there is a specific need that cannot be met locally.

Two National groups meet on Zoom regularly, one for Brachytherapy and one for partners or those close to people diagnosed with prostate cancer.

Prostate Brachytherapy UK Support Group (for those who have had, or who are considering Prostate Brachytherapy): support@prostate-brachytherapy.uk

National Prostate Cancer Partner Support Group. janetldaykin@gmail.com carolineopcs@gmail.com

A third nationwide virtual support group “Living Well with Advanced Prostate Cancer”, meets on Zoom on the last Monday of the Month at 6pm. aidan.adkins@tackleprostate.org

Together We Tackle

It is encouraging that some types of cancer are being managed as a Long-Term Condition. With over 70% of men living with prostate cancer expected to live for 10 years or more from the time of diagnosis, it is important to consider the psychological impact of living with and beyond a cancer diagnosis. Not only in terms of quality of life but also emotional consequences and supportive care needs, as well as the emotional well-being of families and carers.

To date there is no national view of what level of psychological services are being offered to men living with prostate cancer and their families and
When I took up my position as consultant urological surgeon at St Bartholomew's Hospital (Barts) in 1996, I noticed many black men with prostate cancer in my clinics. I approached the Office of National Statistics to ask how many black men had prostate cancer and was told that there was no data! A review of the American literature indicated that prostate cancer was more prevalent in black men. I wondered whether the same held in the UK.

I assembled a team to research this and obtained a list of the prostate cancer diagnoses at Barts from the pathology department. We called the patients to ascertain their ethnicity. My epidemiology colleague determined the local population ethnicities, and we were able to link the numbers of men of different ethnicities with prostate cancer to their underlying numbers in the population.

We were able to show that black men had a 2-3 fold increased risk of developing prostate cancer, compared with white men. Further research with other centres in London and Bristol confirmed this and furthermore showed that black men developed prostate cancer on average five years younger.

- Professor Frank Chinegwundoh, Consultant Urological Surgeon

Further Research

It is important that the awareness of Frank’s research is raised in order to reduce the rates of cancer deaths through early diagnosis. The updated version of Frank’s study which was conducted in 2014, can be found at bit.ly/3YAMc1h

‘Hear me now: The uncomfortable reality of prostate cancer in black African-Carribean men’, is a report written by Rose Thompson, Director of the BME Cancer Community, and sets out clear recommendations on improving the outcomes of black men with prostate cancer. You can download it at bit.ly/3V66e0N

Charities such as Tackle Prostate Cancer, Prostate Cancer UK and Macmillan provide extensive support through their nurses, support groups, telephone helplines and online resources. This valuable support offers men living with prostate cancer and their families and carers access to information to help make decisions on treatment choices, manage adverse events, and access psychological support through commissioned services or local peer to peer support groups. Just as patients need access to the latest cancer drugs they also depend on charities to help them better understand their disease, fight for their rights in policy-related discussions and support their mental well-being.

Most of the services offered by charitable organisations are volunteer-led or supported through their national/local fundraising efforts. For these services to be sustainable and fit for purpose there needs to be a national framework in line with clinical guidelines and service user involvement and underpinned with government funding so that there is a more consistent and equitable approach to providing psychological support across England. Tackle Prostate Cancer continues to work with other to make this a reality.

- Roshani Perera, Tackle Trustee
**General news**

**Update on PSA testing**

The PSA blood test is still the standard investigation used for mass prostate testing. It has often been criticised but this is mainly because people have assumed it to be a screening test for prostate cancer rather than prostate health.

Currently in UK there is no screening programme for PCa as there is for many other cancers. The National Screening Committee (NSC) have rejected such a programme on several occasions in the past. Along with other patient-focussed PCa charities, Tackle are adamant that this has to change. We believe there is now sufficient good evidence from Europe and elsewhere to support this. Our aim is to re-evaluate current NSC recommendations and to re-align them with accepted practice in Europe.

By employing a risk-based model of testing, PSA can be used effectively to reduce both mortality and treatment morbidity. Such a model also can reduce un-needed repeat testing in people with a normal PSA and do not have significant risk factors.

We believe current NSC policy is based on outdated opinions and evidence. We are now in collaboration with Prostate Cancer UK, Orchid and Prostate Cancer Research to submit a new proposal to NSC.

I have been involved with PSA testing for many years and this is the first time that we have begun to speak with one voice. We are at an early stage and aware that this could be a slow process.

Nevertheless we are all determined to improve the early detection of PCa and ultimately obtain the best possible outcomes for all whose lives are affected by prostate cancer.

- Ken Mastris
  Patient Representative & Past Chair of Tackle

**Tackling the bad weather**

As the days shorten and the weather gets cold, wet and windy and you are tempted to stay indoors on the couch, remember what the famous fell walker Alfred Wainwright said: “There’s no such thing as bad weather, only unsuitable clothing”. So wrap up warm, put your big coat on and go out for a walk, make it a habit, no matter how short a walk or whatever the weather.

**Spotlight**

**Making sense of touch at the University of Birmingham**

Of the five basic human senses of sight, hearing, smell, taste and touch, perhaps touch is the most overlooked despite our emotions also being called ‘feelings’.

As we age, we begin to lose our sense of touch and yet, unlike our sight and hearing, there isn’t a place on the High Street where we can get devices to help overcome this gradual loss of one of our senses.

As is often the case you only miss something when it’s gone, so it’s worth exploring what our sense of touch does for us on a daily basis. Under our skin we have at least four different types of touch receptor and our fingertips have the densest population with over 3000 touch receptors. Their
roles are to sense pain, pressure, temperature and vibration that help us determine or discriminate texture, hardness, weight, size, shape and which enables us to grip appropriately and even to balance.

Along with age another possible cause of the loss of our sense of touch is Chemotherapy Induced Peripheral Neuropathy (CIPN), that is damage to the nerves as an unwelcome side effect of chemotherapy for many people. It’s not known how many, or when it starts or how long it lasts for. The symptoms may even cause the Chemotherapy dose to be reduced or stopped altogether depending on the severity. Symptoms, according to Macmillan, usually affect the hands, feet and lower legs and include:

- tingling, pins and needles or numbness in the affected area
- pain, which can be mild or more severe
- muscle weakness that makes it hard to walk, climb stairs or do other tasks
- constipation and feeling bloated, if the nerves in the bowel have been damaged
- feeling light-headed or dizzy when you sit up or stand up
- difficulty doing up buttons on clothing or picking up small objects
- problems with balance, walking and coordination.

Alan Wing, a Professor of Human Movement at the University of Birmingham was, himself, diagnosed with prostate cancer and had CIPN as a side effect. He and his research team are now looking to embark on a research project looking at CIPN with expected benefits that include the development of a more sensitive measure of touch which in turn can help with improvements in prevention measures, healing therapies and coping strategies as well as delivering improvements in the scientific understanding of touch.

All research like this needs willing participants and Alan reached out to the Solihull Prostate Cancer Support Group as his nearest group and I went along to his laboratory to go through a dry run of some of the tests that had been developed to measure touch in participants.

The photographs show some of the tests that are to be used to measure the different elements of touch. The research will start with a questionnaire and then participants that are local to the University will be invited in for further data gathering.
Upcoming Campaigns

Boys NEED bins

Article contribution from Sarah Gray, National Support Development Manager

Over the past few years, I have listened to many men tell me stories of difficulties in disposing of their incontinence pads when they are out and about. As a woman who takes it for granted that there will always be a bin in any public toilet cubicle for me to dispose of my sanitary pads this was something that I am not ashamed to admit I hadn't thought of before.

I have heard of men stuffing their soiled incontinence pads in their bags and carrying them home, I have heard stories of men hiding the pads behind pipes in toilet cubicles, and I have listened whilst men have told me harrowing stories of sodden pads leaking over their trousers, because they haven't been able to change their pad.

We started to investigate why there aren't bins in men's cubicles, and discovered that whilst there is a statutory provision in law for bins in women's toilet cubicles, there is currently no such provision for bins in men's cubicles. This is clearly an equality issue that needs to be addressed for both men, trans men and trans women.

Roll forward to this summer the issue was picked up by the BBC and subsequently other media outlets, following an interview to Evan Davis had with a prostate cancer patient. Jonathan from Hampshire has suffered with urinary incontinence since his prostate cancer treatment, said:

“There’s a time when you suddenly realise, perhaps because you’ve been laughing too heavily with somebody, you feel [the pad is] full and you’ve got to change it. When I was first confronted by this, I was walking in a car park. And you go to the loo and you realise there’s nowhere to put this thing. You have to plan your day in a different way.”

Tackle Prostate Cancer are now campaigning alongside other charities including Prostate Cancer UK, and Bladder and Bowel UK, under the campaign name Boys NEED Bins. We are very much in the early stages of developing our campaigning messaging and campaign asks.

Steve Allen, Sarah Gray and Ken Mastris recently attended the APPG on Bladder and Bowel Care at the House of Commons. This All-Party Parliamentary Group is championing the Boys NEED Bins campaign, and we are looking at the Levelling Up Bill which is currently going through parliament to does offer some opportunities and our involvement the APPG on Bladder and Bowel Care may mean we will be able to ask to table some amendments to make the ask more robust in terms of bin provision in men's cubicles.

We will keep you informed, and in the meantime if you had an experience with any aspect of incontinence and how if has affected your daily living activities you would like to share, do please get in touch editor@tackleprostate.org
In focus

Bridging the gap between knowing physical activity is good for you and doing it

Article contribution from Aidan Adkins, Trustee

“If physical activity were a drug, we would refer to it as a miracle cure, due to the great many illnesses it can prevent and help treat.” This was a comment from the UK Chief Medical Officers’ Guidelines for Physical Activity published in Sept 2019. We all know this, yet 1 in 5 men and 1 in 4 women do less than 30 minutes of moderate intensity physical activity per week. Where we should be completing at least 150 minutes a week.

This classes as activity where your breathing increases, yet you can still talk. For example, brisk walking and swimming would tick those boxes. If you’re unsure, take a look at our our helpful diagram.

The Cancer Research UK website says: “Studies have found that men with prostate cancer who exercise live longer than those that don’t. Even a small amount of moderate or vigorous physical activity every week can help” Read more here. Let’s hear from some people who have found ways to become more physically active and perhaps they can inspire you too?

Tony Collier, was diagnosed with advanced prostate cancer in May 2017, aged 60, enjoys his weekly Park Run and is also an ambassador for 5k My Way.

Read more at bit.ly/3G4uAUz
Martin Wells attended an on-line Education Session that was organised for Support Group Leaders with Dr Ross Wilkinson the GP Champion for Physical Activity from Public Health England back in July 2021 to help them promote Physical Activity in their local groups and had the following reflections:

“I stopped going to the gym as the pandemic hit in March 2020. Having finished my chemotherapy not long before the start of Covid-19, I felt the effects of fatigue and I was tired of beating myself up, about me not being able to do as much exercise as I did before chemotherapy.”

Within a few minutes of listening to Ross I got to see that I had been constantly beating myself up (unnecessarily) for not doing enough Physical “EXERCISE” when in fact when I saw what I now do as Physical “ACTIVITY” I was, and I am, doing great.

Like most who are on Androgen Deprivation Therapy (or chemical castration as I call it, when I feel I need to make a statement to people who think it is just a jab every 12 weeks), I’m concerned about my muscle wastage and my bone health. I got to see yesterday with Ross that I was doing far more than most of the UK population when I see what I do as ACTIVITY and not EXERCISE.

I downloaded the Activite10 App and used it for the first time recently and already feel good about what I do as physical activity.

I cannot recall how many times I have walked past these FREE purpose-built bits of equipment. One set is in Scott Park and the other in lightenhill Park. Both sets are available to me on the walk I do daily.

On Saturday, I tentatively went up to the equipment and fought off the (negative) “what will people think of me?” conversation in my head. I started to use the shoulder raise and a kid came up to me and said “hey if you lift your feet off the ground it’s much harder!” I did, it was, and I (genuinely) thanked him. I also remembered to take my time and not to rush.

I completed two lots of 10 on one piece of equipment and two lots of 10 on the rower. I felt really good - not just because of the “exercise” but because of the ACTIVITY I was doing and that was good - medicine doesn’t always have to come in the form of a pill. I could “feel” parts of my body I hadn’t felt for 18 months since lockdown. I also felt good because I had quietened my negative self-talk too.

I said to myself: “I’ll have a proper go tomorrow” (then my ever-present self-talk kicked in again: “I’ll do it early when no one’s about!”). Sod it: “I’ll do it no matter whoever is about!”

So, I was out the very next morning looking forward to doing some ACTIVITY on my “newly” discovered ACTIVITY “helpers”. I thought I’ll snap a quick selfie video too, and here it is!

Parkrun is a free weekly timed run that takes place in just over 1100 venues in the UK and many more overseas. It’s completely free to attend and once you’ve registered you can attend any parkrun in the world. Parkrun actively encourages walkers and recently promoted walking by adding a new volunteer role, parkwalker and October was designated as parkwalk month.

For people living with and beyond cancer, certain parkrun venues across the UK are also 5k Your Way venues. 5kyw is a cancer support group that encourages people living with and beyond cancer as well as their families and health care professionals, to attend at 5kyw on the last Saturday of every month and do the 5k their way. Most participants walk but you can jog, run or simply cheer or volunteer (parkrun is entirely run by volunteers). After the 5k, participants then go for a coffee and cake and become a coffee morning support group!”

Read more at: https://www.parkrun.org.uk/ https://5kyourway.org/
Neal Bloom, wrote to us and shared the journey he’s had with advanced prostate cancer. Although Neal found the news difficult initially, especially with his wife recovering from two major operations at a similar time. His perseverance and positive attitude towards his diagnosis was really admirable.

So, whether your experiencing prostate cancer yourself, or you know someone who is. The below acts as a little reminder, that along with Neal, we’re here cheer leading you from the sidelines...and, you know we’re here through our support groups if you ever need to reach out.

Find a support groups at www.tackleprostate.org/supportgroups
Look Good Feel Better

Article contribution from, Lisa Curtis, New Services Manager at Look Good Feel Better

Look Good Feel Better is a national cancer charity who know how challenging it can be to process a cancer diagnosis and manage the physical and emotional side-effects of treatment. This is why we run free workshops and classes both virtually and at Cancer Centres and Hospitals across the UK to support women, men and young adults. Our services are led by trained volunteers from the beauty and barbering world who provide practical advice about changes to skin, hair, nails and body confidence. We also work with volunteers from the health industry who run our wellbeing classes covering meditation and gentle exercise, helping to reduce feelings of isolation and anxiety.

We run two workshops specifically for men covering skincare advice, safe shaving tips, sun protection and how to deal with scars.

Additionally, we cover body positivity through learning how to deal with challenges such as weight change, understanding body shapes and how to best dress for them. Our exercise classes are open to men, and we’d love to see more attend!

The best thing about all our workshops and classes? They offer an invaluable opportunity to meet others on a similar journey.

For more information, please visit www.lookgoodfeelbetter.co.uk
Pharma Times Awards Event!

Back in November, we had the privilege of being the Charity Sponsor for the Pharma Times Communications Awards. These awards give the opportunity for communications professionals to demonstrate their teamwork, leadership and creative skills in a variety of fun and engaging virtual challenges.

It was such a wonderful evening where we met many industry professionals and came away so inspired by the ambitious and innovative plans of the pharmaceutical industry. Our patient representative and previous trustee, Ken Mastris spoke on behalf of Tackle and had a really interesting conversation with Dr Phil Hammond about the importance of collaboration in order to achieve change.

We’re very much looking forward to seeing what our peers achieve in the future and we will be right by their side doing all that we can to improve people’s lives.

Read more at https://www.pharmatimes.com/communications_awards

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

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, have a nosy through our website www.tackleprostate.org.uk. Here is where you’ll find information about your nearest support group.