The Men's Shed is not a wooden structure as you might expect but a concept, a venue to pursue practical interests at leisure, to practice skills and enjoy making and mending or to develop whatever activities / skills our members may wish to pursue.

Paul Markall, the man behind the KWPCSG Men's Shed project said “This is not a new idea, there is an association of Men's Sheds in the UK and I believe that the concept would be an extension to our support role. We are still in the embryo stage but I hope to develop the concept for our group. The Shed will be free to all members, It will be about social connections and friendship building, sharing skills and knowledge, and of course a lot of laughter; in fact anything our members may wish to pursue.”

The first meeting, held at the Methodist Church Hall off the Kidderminster Ringway on 20th November 2018, got the Men's Shed off to a good start. We started with a general discussion on what we were interested in taking forward and we came up with photography, finance, travel, gardening, cooking, healthy exercise, walking football, oil & water colour painting, pottery, engineering, electrics and trips out. One member, Luciano Pilla, who has a vast knowledge of culinary skills, offered to demonstrate the production of dishes with an Italian flavour.

The discussion over, Dr Dick Herbert, a member of our committee, gave a very interesting demonstration of CPR (Cardio Pulmonary Resuscitation) and the group were able to demonstrate what they had learnt on a number of dummies that he had brought along.

Future meetings will be held monthly starting in January 2019. At the January meeting Dick Langley will be demonstrating photographic techniques, and it is hoped that we will also have an independent financial advisor giving a talk.

Article with thanks to Paul Markall Group Treasurer KWPCSG. Nationally there are more than 450 sheds with more in development, some sheds are associated with support groups and some are open to all, to find out more or to find one near you go to the Men's Shed Association website https://menssheds.org.uk.
THE BIG WHITE BUS IN OXFORD

It’s amazing what a beer and cider festival can lead to. In November 2017, Oxfordshire Prostate Cancer Support Group was invited to display leaflets and information at a weekend festival at The King’s Arms in Kidlington, a cosily traditional pub, where the landlord wanted to combine tasting of beers and ciders with raising awareness of prostate cancer.

I went along to distribute leaflets and to chat. In between explaining the finer points of the various brews he was offering, the man tapping the barrels said that he had a publicity idea to put to me: he had worked for 40 years for Oxford Bus Company (OBC) and thought he could persuade them to offer OPCSG some publicity space.

I was quickly convinced that this was not the beer talking, but a serious idea. A year later the result is the Oxford Bus Company/OPCSG big white bus, which hit the streets of Oxford early in November.

The deal was this: OPCSG would design the vinyls to be attached to the bus, and the only cost to us would be the cost of production of the vinyls, around £900. In return OBC would run the bus for three years on various routes, in and around Oxford, so that our message would have a good chance of reaching many thousands of people. Collaboration with OBC, who see the project as part of their programme of social responsibility, was always efficient and enjoyable.

Oxford’s buses are colour coded by route; the OPCSG bus, being a striking white, is not linked to any one route and can therefore travel throughout the city and county carrying OPCSG’s core message (Get Checked!) together with details of our group. Since the bus can run anywhere on OBC’s network we are hoping for maximum exposure.

Tasting that beer in Kidlington definitely paid off!

We are enormously grateful to the Oxford Bus Company for this opportunity. Special thanks are also due to Grahame Wareham, retired OBC employee, who had the initial idea and put us in touch with the company. We are also very grateful to Tackle for providing us with a contribution of £500 from the small grants scheme.

John Grundy, Chairman OPCSG

Tackle Chairman Roger Wotton commented, “This is a really excellent awareness project which hopefully will inspire other groups to follow suit.”

PROSTATE CANCER SURVIVAL IN ENGLAND: NATIONAL ESTIMATES FOR PATIENTS FOLLOWED UP TO 2017

1-year age-standardised survival estimates for men diagnosed with prostate cancer at stages 1 to 3 were just over 100%, meaning that fewer men with prostate cancer died than expected when compared with men in the general population. A statistically significant lower survival estimate was evident for those diagnosed at stage 4, at 87.6%.

Even 5-year survival estimates were over 100% for stages 1 and 2, with good survival at stage 3 at 96.5% and a larger drop at stage 4 to 47.7%. While there is no national screening programme for prostate cancer, some men have a Prostate Specific Antigen (PSA) test at their GPs, which could explain why men who are diagnosed at an early stage have survival rates similar to that of the general (male) population.

1-year and 5-year net-survival estimates for prostate cancer have increased significantly since the net-survival estimates in 2006 to 2010.

Source: Public Health England – National Cancer Registration and Analysis Service, Office for National Statistics

This information was released as we were going to press, we would otherwise have given it greater coverage. The conclusion that a diagnosis of early stage prostate cancer actually increases a man's chances of survival over 1 and 5 years is somewhat counterintuitive. The national press mostly attributed this to a diagnosis giving these men a 'wake-up call' with the result that they became more health conscious. - Editor
It seemed like a good idea at the time! The committee responded eagerly to the prospect of making our contribution to Cycle to the Moon by taking up the generous offer from Stratford-on-Avon Leisure Centre to use their spin studio for free. None of the anxieties of arranging a route on the roads with the worries of the weather and marshals, first aid and recovery vehicles! The challenge was to fill the 26 static bike seats and to persuade everyone to raise sponsorship.

The choice of Father’s Day proved to be inspired. Some who were spinning were doing so in memory of their fathers and others were doing it as a contribution to supporting their fathers who are living with prostate cancer. And many of us were doing it to prove to ourselves that we still could get on our bikes, prostate cancer and other health conditions notwithstanding!

However, spinning is both more and less than road cycling. The static bike is without brakes and continues to rotate even when you want a rest! Resistance is useless as there is some sort of hidden counterweight involved so your legs continue to pump up and down until momentum is gradually lost by which time the instructor, the lovely Paula, is poised to encourage you into even more exertions! Spinning is definitely a group exercise. What is more, it is done to music with rhythms selected to encourage a regular cadence at a pace slightly above your comfort zone. The only let out is that you can select the amount of resistance to pedal against, i.e. choose how hilly a ride you are going to take on. But selecting a low resistance is not the escape that it might appear as your legs now rotate at a fearful rate and you find yourself increasing the resistance to save your knees from parting company with the rest of you!

There is no wobble room on a static bike so when you are encouraged to increase the resistance and to stand up on your pedals there is no risk of falling off. But now you find yourself in a very visible position, possibly at the front of the class, and the demands of continuing to pedal are such that you don’t feel confident to take a hand off the handlebars to wipe yourself down. You struggle on with encouragement in your ears and time goals being set and then tantalizingly reset just as you reach exhaustion point. Eventually you are able to regain the saddle and sit down. You reach for your water bottle and after a swig or two lift the towel off the handlebars to wipe yourself down. And now the beat picks up again. And the spectators, our very own supporters club, now join in the fun by clapping in time with the music and cheering us on. No pressure then!

We managed to fill 22 of the 26 seats available on the day. We had 6 volunteers from the Leisure Centre staff and spin class enthusiasts and 16 of us who were either members of the South Warwickshire Prostate Cancer Support Group or were relatives and friends. In the hour spin class we managed a collective 228.6 miles and two others who had other commitments on the day did 24 miles on the road as their contribution. The money is still coming in but it looks like we will exceed £2500 and that is before Gift Aid is added! More importantly everyone got to the finishing line. There were no fatalities though there were photos! A good time was had by all. Same time next year?

Doug Badger South Warwickshire

This spinning event took place on Father’s day last year, maybe it will inspire other groups to organise their own event this Father's day! Cycle To The Moon has already raised £25,000; mile for pound we are already beyond the orbit of the Sky geostationary satellites!
HOW BEST TO USE A BEER MAT.

Hello everybody, I’m Steve Drury the current Chairman of the Furness Prostate Cancer Support Group, it’s a role I am proud to hold. I think most support groups work hard to get out the message of how serious Prostate Cancer is, yet with early recognition and understanding of the symptoms more men can be cured. As a group we have attended ‘Well-being’ events attempting to persuade men to get to their G.P.s and have the test. To be honest we had more success talking to the wives, girlfriends, mothers and daughters. We have tried social media and a couple of years ago we purchased about a thousand pens with our details printed on them, yet we only ever received one telephone call, so what could we do next?

We discussed having beer mats made and where better to capture men but in familiar surroundings? It was an idea we as a group felt was well worth pursuing. Our hard-working Secretary, Ralph Wilson, contacted a beer mat manufacturer to establish the cost and we made a decision to order 10,000. Luckily for us Tackle were offering grants, we put our idea to them and they were more than happy to help. This gave us the green light.

At our next regular meeting we soon realised nobody had a clue how to design a beer mat, fortunately Ralph knew a man, but he seems always to know a man. His friend Geoff Waters gave up many hours of his time attempting to come up with a design we could agree with and after a few amendments a design was decided upon.

There was one other issue we had to deal with, would the local pubs and clubs be happy and willing to use them? I met with the Chairman of the local Licensees, he had a personal reason to help as he had lost a close friend last year to Prostate Cancer. It was a short meeting, he gave us their blessing to continue.

Our Secretary Ralph placed the order and just over a week later we took delivery and began delivering to the pubs. It was a tough job but someone had to do it.

Radio Cumbria had heard of our efforts and contacted Ralph requesting an interview, he gave them my details and the following week I did a live interview. From the feedback from Radio Cumbria I understand it went exceptionally well.

Later the same day Ralph was contacted by our local newspaper, apparently someone there had heard the interview and wanted to interview me in more detail. We had that interview later in the day. The following morning the story was published, together with a lovely photograph of Ralph, Geoff and our Treasurer Geoff McCready proudly holding the beer mats, we couldn’t have asked for anything better, the publicity was excellent and free.

Ralph recently won a local photographic calendar from a new local news company and left them some beer mats when he went to pick up his prize, as a result we’ve been asked to put together an article for them on Prostate Cancer for the Prostate Cancer Awareness Month.

Only time will tell on the success of our beer mat campaign, it cost less than £500 and I am of a mind if we save just one life it is money well spent.

Many thanks to Tackle for their generous grant and to Prostate Matters for the opportunity to tell our story.

What are we going to try next? Keep reading Prostate Matters.

Our contact is ralph.wilson128@icloud.com and we are on Facebook.

This is a very interesting and simple way to get the message across. We are planning to take the Furness group’s idea further and produce a “Tackle beer mat” as part of our publicity material. Well done Furness!

Roger Wotton, Chairman
KEITH CASS RAISES AWARENESS OF PROSTATE CANCER WITH HIS UNORTHODOX FUNERAL PLANS.

Keith Cass was diagnosed in February 2006 with stage 4 prostate cancer. In 2007 he founded the Red Sock Campaign to raise awareness of prostate cancer (PCa) and support all those affected by the disease. He is also a trustee of Tackle Prostate Cancer.

Keith has never given up campaigning to raise awareness of prostate cancer, sharing his experiences through his treatment ‘journey’ and raising funds for the cause. He has recently been in the news with his plans to raise funds by selling tickets for a party, to take place after he has passed away, to follow his cremation. To date Keith has achieved coverage on ITV Wales, The Mirror, Wales online and the Metro all increasing people’s awareness of prostate cancer.

The planned venue for the event is the Manor Parc hotel in Thornhill, Cardiff. Keith aims to organise and pay for all this himself and it is part of his mission to raise half-a-million pounds for research projects into the early detection of PCa, PCa awareness and for equipment at a PCa clinic/hospital.

In his own words: "I want it to be the best, and the most different funeral, it will be a party with a full programme of entertainment following my pre-recorded presentation on large screen TVs in each room".

“There’ll be a gold room with a ‘lobster and fizz experience’, a silver room (prawns and wine experience) and a bronze room (beer and crisps experience)’.

“I want them to go away saying ‘Keith made a difference’.

Keith was awarded the MBE in 2013 for services to men affected by prostate cancer, he said of the occasion: “It was an honour meeting Prince Charles, his parting words to me were “I’m so pleased you are still alive.” I replied, “So am I.”

We all hope the event will not be taking place any time soon!

LETTERS TO THE EDITOR

Sir

I read your November issue thoroughly and found it most interesting. However, since support groups partial remit is to raise money to help charities it seems to me there should be some reference to how much is raised by different groups and where the money goes to. My support group doesn’t publish any figures which I find disturbing. I’m naturally reluctant to donate to them because of that.

I was recently on a Prostate cancer support group stand at a show and was asked where the money goes to, embarrassingly I could not give an informed answer. Questions like overheads come to mind as well.

I think the public are now becoming wary of giving these days after several scandals with charities, therefore more transparency is needed. If that is not forthcoming one can draw one’s own conclusions.

Regards. (Name given but anonymised)

Response from The Chairman of Tackle:

Our Federation has an obligation to publish our national accounts and I send a summary every quarter to all support groups as part of my “Tackle Talk” newsletter. This shows how the money is raised and where it is spent on a national basis. It is up to each support group to decide if and how they publicise these figures across their local membership. Those of our 92 support groups who are registered charities in their own right will also have an obligation to publish accounts to their support group members. I would hope the remainder do share their finances with their members at their regular meetings. Indeed, those group I have visited do discuss their financial situation at regular meetings. My suggestion is that if you feel you are not receiving sufficient detail of finances for your local group you make contact with your treasurer or secretary to obtain the information you require.

Roger Wotton, Chairman, Tackle Prostate Cancer

Free Help Line - 0800 035 5302
For some time there has been a trickle of prostate cancer patients making their way abroad, to Prague in particular, to have their localised tumours treated by Proton Beam Therapy (PBT). Reading their accounts on the Internet, it seems their treatment experience has generally been a positive one (though obviously the sample is not random).

PBT is a form of radiation therapy that uses high-energy protons rather than X-rays to target tumours; however, under NHS guidelines, PBT will be funded for very few prostate cancer patients, if any.

Two NHS centres are coming, one already operational. In addition to these, Proton Partners International (PPI) a private company, operating as Rutherford Cancer Centres, is now investing in PBT facilities around the country. These centres will be available for self-funded patients and some insured cancer patients, as well as NHS patients should they be referred.

The financial plans of the PPI centres undoubtedly will involve treating patients, including those with prostate cancer, who fall outside the NHS guidelines.

Proton Partners International already has its first high energy PBT centre operational in Newport, South Wales, and has opened two further centres where the PBT units will be commissioned later this year, they aim to have a site within 90 minutes drive of 75% of the population by 2021. Inevitably, with this level of private investment, prostate cancer patients are going to ask themselves whether the lack of availability under the NHS is justified, and many will ask whether it is worth self-funding their own PBT treatment. The first patient treated was in fact a self-funded prostate cancer patient and his treatment is reported on their website (link below).

The question which prostate cancer patients will be asking themselves boils down to ‘Is PBT inherently better than X-ray treatment?’

Over the last decade or so, a more refined version of conventional radiation therapy known as Intensity-Modulated Radiation Therapy (IMRT) has become the gold standard for radiotherapy of prostate tumours. IMRT uses imaging procedures to produce a three-dimensional image of the tumour; this computer image is then used to target the tumour with X-rays from different angles, while the cross section of the beam is simultaneously adjusted to match the target area. This spreads the dose received by healthy tissue while concentrating the dose delivered to the tumour.

PBT is inherently an expensive technology, each facility requiring a cyclotron to generate the high-energy beam of protons (protons are essentially hydrogen atoms ionised by stripping the negatively charged electron) which are targeted on the tumour. Protons have a unique property in that they give up some energy (it is this energy that damages tissue and destroys cancer cells) as they slow down passing through healthy tissue, and then give up the majority of their energy as they come to a stop, This is known as the Bragg Peak. The power of the beam can be controlled so that protons come to a stop in the target area, concentrating the dose in the tumour. The collateral damage to healthy tissue is therefore mitigated.

For those who have an interest in technology and its associated kit there is an informative video on the PPI website here https://www.therutherford.co.uk/treatments/proton-beam-therapy/.

The NHS website (link below) states that “Proton beam therapy is only suitable for certain types of cancer, such as highly complex brain, head and neck cancers and sarcomas, as it does not lead to better outcomes for many cancer cases than using high energy X-rays, which is still considered the most appropriate and effective treatment for the majority of cancers.” This policy seems (to the author) to be largely driven by the fact that any advantages PBT might have over IMRT in terms of side effects and increased life expectancy for prostate cancer patients are thought to be marginal compared with the greatly increased cost. The NHS policy on Proton Beam Therapy for Cancer of the Prostate can be accessed via this link.

PPI themselves believe around 10% of all cancer patients treated with radical radiotherapy – the figure accepted at European level – could be better treated with proton therapy and have been quoted as saying “We should be clear that proton beam therapy is not a panacea in terms of cancer care but is proven to deliver benefits across a range of cancers. For example, it is well established that it is particularly effective in the treatment of children
PROSTATE RADIOTHERAPY CAN BENEFIT MEN WhOSE CANCER HAS SPREAD BUT THE METASTATIC BURDEN IS LOW

Late last year the STAMPEDE trial published results from the radiotherapy comparison. This looked at whether adding radiotherapy to standard treatment for men whose disease has spread beyond the prostate can help men live longer. The results showed no difference overall, but that some men do benefit from having radiotherapy.

These findings mean that radiotherapy, in addition to hormone therapy and chemotherapy, should become the standard treatment for some men with advanced prostate cancer.

In this part of the STAMPEDE trial, more than 2,000 men with prostate cancer that had already spread beyond the prostate were randomly split into two groups:

- **Group A** received standard treatment (hormone therapy, plus docetaxel for those men who were recruited in 2016)
- **Group H** received standard treatment (hormone therapy, plus docetaxel for those men who were recruited in 2016) plus radiotherapy to their prostate.

After three years of follow-up, the researchers found that overall, there was no difference in how long men in the two groups lived, on average.

But, for the sub-group of men whose disease had spread less ('low metastatic burden') at the time of diagnosis, there was a significant benefit from radiotherapy. After 3 years, 81% of men with low metastatic burden in the radiotherapy group were still alive, compared to 73% of men in the standard treatment group. Radiotherapy also delayed the disease getting worse.

Radiotherapy did not help men whose disease had spread further at the time of diagnosis (high metastatic burden disease) to live longer.

The proportion of patients reporting having had severe side-effects was very similar between men who had standard treatment plus radiotherapy and those who had standard treatment alone.

Dr Chris Parker, lead researcher of the study and based at the Royal Marsden, said: “Our results show a powerful effect for certain men with advanced prostate cancer. These findings could and should change standard of care worldwide.

“Until now, it was thought that there was no point in treating the prostate itself if the cancer had already spread because it would be like shutting the stable door after the horse has bolted. However, this study proves the benefit of prostate radiotherapy for these men. Unlike many new drugs for cancer, radiotherapy is a simple, relatively cheap treatment that is readily available in most parts of the world.”


**Article thanks to Annabelle South. Policy, Communications & Research Impact Coordinator STAMPEDE**
THE ISSUE OF INCONTINENCE PAD DISPOSAL

If you are one of those men who have to wear pads to help with urinary continence you may find yourself in the same boat as a number of our members. Where and how to dispose of used pads when out and about?

This question came up recently from members and Tackle has discussed the topic at a recent board meeting. We agreed more needs to be done to help men in this situation. For example, there aren’t enough facilities for men to dispose of used pads, and this can cause embarrassing problems. It’s bad enough having to use pads in the first place.

Our recommendation is for men wishing to dispose of soiled pads to use disabled toilet facilities, just as parents do at the moment with soiled disposable nappies. However, many disabled facilities are locked and can only be opened with a “Radar Key”. Radar keys can be bought at a modest cost from Argos, Amazon, healthcare shops and charities.

If enough support groups indicate this is a problem for their members then Tackle will consider acquiring a bulk supply of radar keys to issue to groups for their members to use.

We hope this guidance helps those men suffering from this problem.

For anyone who might be as confused as I was, RADAR is the acronym of ‘Royal Association for Disability and Rehabilitation’. - Editor

WE NEED MORE CONTRIBUTIONS.
if you are involved in producing a group Newsletter and have an article which might be of interest to other groups please you send it to:

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