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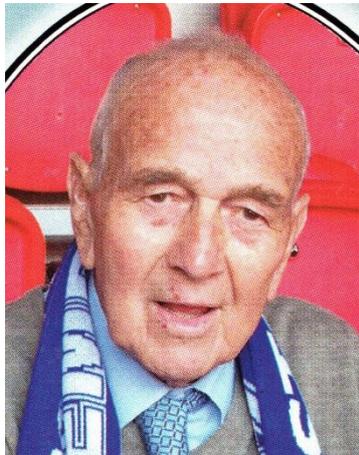
Next meetings

PROSPECT is a local support group for prostate cancer patients, their carers and friends.

We provide help support and information and our newsletter is published four times a year. Any articles you think would interest our members please email to me, David Casley at: [prospect.bristol@gmail.com](mailto:prospect.bristol@gmail.com)



## TERRY RUSSELL



Terry Russell, who has died aged 91, was an active member of Prospect for many years. Malcolm Gamlin, our chairman, writes this tribute:

Terry was the Group's treasurer for several years and did lots to keep our accounts in order. But before and after his treasurer's role he was an active supporter of our Group.

Back in 2007 Prospect went through a very difficult time with dwindling numbers and a certain lack of direction. Shortly afterwards I took over as Chairman and I will always be grateful for the help and support Terry gave me in revitalising the group.

He was always so positive and approachable. He came regularly to our meetings and I knew I could rely upon him to talk openly and directly but gently to newly diagnosed men who came along to our meetings.

Our Group owes him a great deal.

## BUDDYING SERVICES

Malcolm also writes about this workshop he attended recently:

I attended a workshop run by Macmillan to look into their

Buddying Services and examine what makes a successful support team and any learning which could be used to improve services.

Macmillan has six 'buddying' services in our area. They offer practical and emotional support to people affected by cancer across Bristol, South Gloucestershire, North Somerset, Bath and North East Somerset and West Wiltshire. Typical support includes light housework, gardening, shopping, transport, and/or a listening ear. The same volunteer visits weekly for up to two hours. Referrals are mainly from the acute hospitals.

The structure of the day was based on a selection of stories about how Macmillan buddies had helped their clients gathered by the Macmillan volunteering services team.

Workshop participants were split into groups and each group chose two stories which it felt had the most significant impact through what had or indeed had not been done. Participants were a mix of Macmillan staff, Buddies, service users and support groups.

Discussion over the most significant two stories at a group level and then over the most significant story of all were frank, passionate and well argued. And out of all these discussions the Macmillan team were able to record a number of key themes to learn from and develop.

I found the day very worthwhile understanding the Buddying services, feeling that my comments mattered, listening to a variety of arguments as to what leads to a first class support service and meeting a bunch of very dedicated people.

## DE-PAL UK



De-Pal members in prostate cancer awareness T-shirts with members of the Prospect support group.

Malcolm reports on another successful De-Pal UK workshop:

On the 6<sup>th</sup> April several members of our Group attended for a second time a workshop run by De-Pal UK to raise awareness of prostate cancer amongst the African Caribbean community.

The event was held at the Salvation Army Citadel in St Pauls Bristol with about 40 attendees.

Mike Broxton gave our Prospect presentation on prostate cancer and then the rest of us helped field questions from the audience. Two hours later we had a short break!

The next speaker was Sahr James Momoh from Berkshire Health Care NHS. His talk on why African Caribbean men were so reluctant to go and talk to a GP was as enlightening as it was worrying. Issues such as - if I don't feel ill why should I see a GP, I need to work, if I don't earn enough money I cannot send funds back home.

We ran a full table of prostate cancer literature which was stripped bare by the end of the day and had informal one-to-one chats with participants over a delicious hot food buffet.

This was a very worthwhile event in helping promote awareness of prostate cancer. We were made to feel very welcome and at the end of the session were presented with a £150 cheque for Prospect funds.

## APRIL MEETING & AGM

Our speaker at the BAWA meeting on the 10<sup>th</sup> April was Anna Tharn, who gave us a fascinating presentation and talk on the Medical Detection Dogs charity.

The dogs are trained to detect medical symptoms in patients suffering from many different types of diseases, including prostate cancer. If you would like to find out more about this charity check out their website at [www.medicaldetectiondogs.org.uk](http://www.medicaldetectiondogs.org.uk)



Anna Tharn & Malcolm Gamlin

The AGM followed with reports from the committee. Members present seemed very satisfied and quickly approved the reports so that we could all enjoy the famous BAWA buffet.

## WEBSITE UPDATE

Bernard Smyth writes as follows:

Our website is doing well. It showed a remarkable upturn in visits in March, for some reason. There were 2,004 visits which led to 3,726 pages being viewed. That's an average of 77 visits a day. That compares with the worst month in that 12-month period when we had 356 visits with 520 pages viewed.

We have used the statistics only for https address visits as we moved to a more secure site and asked members to use that in place of the less secure one. We had also made an automatic re-direct from the old site to the new. I keep the site up to date with information on our meetings and walks, and also add any interesting new research items that I come across. The left column on the "front page" will hold only 10 items so I started putting some news on the Newsletter page,

One success story was a PhD student who found our site useful in finding members to help with a project approached us again for a new online study. A senior lecturer also had a "wonderful" response from members when she asked for them to contact her.

Recent updates to our website include a note about a Prostate Cancer UK summary of the key findings of the results a survey for partners and family members of men with prostate cancer. Another item added to the Helpful links page was a link to a website on how to look after yourself during cancer treatment and chemotherapy. On the same page there is a link to a site about help with travel arrangements for cancer patients.

If anybody identifies problems or broken links in our website could they email us at [prospect.bristol@gmail.com](mailto:prospect.bristol@gmail.com)

## BCfm

Bernard was interviewed on BCfm community radio recently by member Michael MacMahon, who regularly broadcasts on this station.

The discussion was about Bernard's interesting life and of course included Prospect and the website. It's recorded here under the 18<sup>th</sup> date.

<http://bcfmradio.com/silversound>  
(You may enjoy the occasional jazz during the broadcast!)

## ALAN SHRIMPTON'S EXPERIENCE OF IRE

In August 2018 I was diagnosed with early stage Prostate Cancer (Gleason 7, 3+4) and referred for treatment. In the UK my treatment options were radical prostatectomy or radiotherapy - and I was quickly talking to consultants from both fields about the procedures, outcomes and potential side effects. Both were keen to stress that aged 64 and fit with early stage cancer the oncological outcomes were likely to be very good. The likelihood of any side effects (incontinence and/or erectile dysfunction) was very small but not completely absent. I decided to see if there were any alternative treatments available to me.

There are, of course, other options but it seemed to me that they all carried some risk of side effects because of secondary damage to the surrounding soft tissues and nerves, but then I discovered **IRE** or **Irreversible Electroporation**.

This new treatment, developed in Germany over seven years ago, uses ultra-short pulses of strong electrical fields delivered through fine needles (carefully inserted and positioned into the prostate through the perineum) to induce cell death in the cancer cells. Nerves, arteries, connective tissues remain undamaged and the process is only minimally

invasive (no surgery required). Oncological outcomes are as good as the 'gold standard' of radical prostatectomy (so I was getting quite excited by this point in my research) and side effects (because of the focal nature of the treatment) are almost zero.



Alan Shrimpton

I was hooked. I booked a flight to Frankfurt and went for a very detailed MRI scan (which is key to this treatment) and a consultation with Professor Stehling - the man who developed the procedure, runs the clinic, and insists on seeing every patient personally. He confirmed that my cancer was eminently treatable using IRE and that I could expect a full recovery with no side effects. In over 800 patients, the clinic has yet to see anyone suffer from urinary incontinence as a result of the procedure, and the incidence of erectile dysfunction is very low (less than 10%). I made my decision sitting in his office and booked to go back for the treatment a few weeks later.

All went as advertised. I flew into Germany on a Monday for the usual pre-op checks, had the procedure first thing on Tuesday morning under a general anaesthetic (which included having a catheter fitted), stayed in clinic overnight for observations, and was discharged the next day after a further MRI scan to make

sure everything was as it should be. It was, and after taking the clinic's advice to 'not exert myself for a day', I flew home on the Thursday. The only problem I experienced was with the catheter, which I never quite got used to (though many people do) and it remained a little uncomfortable until it was removed two weeks later. From personal experience, I would say that removing the urine collection bag and replacing that with a flip-flop valve (the clinic provided both methods) which allowed me to go to the toilet normally and shower without special preparations made life so much easier. In any event, the catheter was removed without incident and normal urinary functions were resumed almost immediately. Likewise erectile function, so the Professor was spot on.

I've just had my 3-month MRI scan which showed no evidence of any remaining cancer and my PSA level is now 0.8 - not zero, because I still have a prostate.

NICE have announced that they will review IRE in December 2019 and I hope that they will find in its favour and allow this alternative treatment to be offered in the UK.

## tackle talk

Roger Wotton Chairman, of Tackle Prostate Cancer updates us with their latest news:

### THE NATIONAL LOTTERY

I am pleased to report our application for National Lottery funding has cleared the first hurdle. We made an application for bringing on a full-time resource to help us grow our support organisation with a three-year programme to try and make sure every man diagnosed with prostate cancer is signposted to a support group. This means

looking at all the urology and oncology centres across the country and working with Clinical Nurse Specialists to set up additional patient-led support groups. Having a full-time resource will also give us better coverage instead of relying on the goodwill of Trustees.

### **CYCLE/BIKE TO THE MOON!**

This year we are relaunching our Cycle to the Moon campaign, aimed at raising £250,000 in support of our #Save A Dad campaign. We have secured a number of Tackle places on two prestigious charity bike rides in 2019 – The Liverpool Nightrider event in July and the London to Brighton ride in September. These are available on a first come, first served basis. See <https://www.tackleprostate.org/cycling-events.php> for more details. In addition, we are targeting the motorcycling community this year with “Bike to the Moon”, encouraging the motorcycling community to take part, raise awareness and funds at the same time by promoting Tackle at their events. We are hoping to have a presence at several motorcycling events this year. See the latest news at <https://cycletothemoon.tackleprostate.org/>

### **PUSHING THE SCREENING DEBATE FORWARD**

You will be aware there is increasing media coverage about screening for prostate cancer, why we do not have a screening programme and the need to have more widespread, earlier and better testing. This is nothing new. We have been pushing for earlier diagnosis for some time, and through our efforts with Chris Booth, one of our Clinical Advisers and head of the CHAPS charity, together with the ORCHID male cancer charity, we have embarked up on a number of initiatives to raise awareness in

the political arena. We recently held an event at the House of Commons, with invited speakers from UK and Europe, to share the latest thinking on prostate cancer screening. I have to say the passion with which some of our speakers talked about the need to do more on earlier diagnosis certainly made an impact with the politicians present at the event. We are also participating in a new All-Party Parliamentary Group on Male Cancer to try and push the debate further.

### **AGM & CONFERENCE**

This year, we have set our theme of the annual conference as “Prostate Cancer – To Screen or not to Screen”. Groups should have seen a recent email from our Secretary, Ken Mastris about signing up to attend. The AGM and Conference will be held on Thursday June 13th at Hornton Grange Conference Centre, Edgbaston, the same venue as last year (but with improved facilities!). There is a new hotel next door, should members have to stay overnight if they are travelling a distance. As usual, we will reimburse expenses for up to two people per support group. We have assembled a really good set of speakers on the topic and I know it will be an informative and stimulating day – not everyone has the same view on screening! We have speakers from Europe, from those conducting studies in the UK, from the Graham Fulford Charitable Trust, from a GP and from Prostate Cancer UK. For more details go to <https://www.tackleprostate.org/2019-agm.php> (*We are grateful to member Paul Williams, who has offered to represent Prospect at the AGM*).

### **SAVE A DAD**

You will have heard me mention previously about our wish to try and influence the next generation

to get their Dad to be more aware of prostate issues, what to look out for and the importance of getting tested. This is a challenge, but we are in discussion with secondary schools in the North West, building on some earlier work undertaken by Phil Ormesher, one of our stalwarts in that region. This looks promising, as we would like to get prostate cancer on the National Curriculum, just as breast cancer is today. To this end we have reviewed and updated our merchandise and we now have a wider range of material available. We have Tackle beer mats (for the dads!), Tackle origami paper aeroplanes, wrist bands, larger badges, and a new credit card sized leaflet to get the message across. My plan is to send a selection to each support group to kick-start the awareness message. At the same time, I’m working with ORCHID Male Cancer to produce a leaflet specifically aimed at encouraging conversations between teenagers and their dads about prostate cancer. Watch this space for more information.

### **NEXT MEETINGS**

Coffee morning at the Macmillan Wellbeing Centre on the Southmead Hospital site on Thursday 6<sup>th</sup> June. Our annual docks walk followed by a pub lunch will be on the 7th June and our Penny Brohn lunch in July. Emails will be sent later confirming the details. Or check our website <https://www.prostatecancerbristol.org.uk> closer to June and July for details and the Penny Brohn date & speaker. Contact us by email at [prospect.bristol@gmail.com](mailto:prospect.bristol@gmail.com) or telephone our “Tackle” helpline 0800 035 5302.