



## Tackle Evaluation of Psychological Support Services

*available for men living with Prostate Cancer and their carers across England*

The response rate to the Freedom of Information (FOI) request to all NHS Trusts was 87% (18 Trusts did not respond).

- Only 28% of Trusts had a record of the number of men being offered and referred to psychological support services.
- 36% of Trusts offered psychological support services to the majority (90% or more) of men with Prostate Cancer.
- 74% of Trusts offered families and carers a psychological support service.
- 93% of men living with Prostate Cancer beyond active treatment had access to psychological support services.
- Only 3 Trusts said all men living with Prostate Cancer were referred to a psychological support service when offered.
- 7 Trusts did not routinely offer or have access to psychological support services.

The services varied enormously from specialist support to providing a Macmillan booklet on the subject. It seems likely that psychological distress for men living with Prostate Cancer is ongoing, with peaks and troughs during the cancer journey, and that therefore

many levels of support should be available in each Trust.

- 76% of existing psychological support services are delivered by Charitable Organisations.
- 67% are delivered by NHS-commissioned services.

The findings show that the NHS seems over reliant on charities, some of which are starting to raise concern about the sustainability of this model. Most services offered by charities are volunteer-led or supported by fundraising.

### The report concludes:

For these services to be sustainable and fit for purpose there needs to be a national framework in line with clinical guidelines and underpinned with Government funding, so that there is a more consistent and equitable approach to providing psychological support for men with Prostate Cancer across England.

Read full report in BJU international <https://onlinelibrary.wiley.com/doi/10.1111/bju.14959>

*From a Tackle report prepared by Frank Chinegwundoh an Roshani Perera of Wicked Minds.*

## Christmas Cards

It was proposed by our Vice Chairman Tony Wheatley that in the event of only limited sales of the support groups' new Christmas cards, we should send one to all our members. This idea was extended to inserting two smaller cards within the main card and also a note to encourage our members to send on these two smaller replicas of the main card to family, friends or neighbours, so that's why you received your Christmas card from the Trustees. We must thank the Trustees Pam Blayney, Roger Denness and Elenid

Perry-Lowe with myself who took on the task of writing the envelopes and in some cases hand delivering the cards to members' addresses around the Island, Angela Taylor for sorting out the addresses into area groups and finding missing addresses. Also thanks to Vic Vine for the rapid production of the small replica cards and envelopes to help with the awareness campaign. We hope you and your family enjoyed the card, and a big thank you to all those who purchased our first attempt at producing a Support Christmas Card.

## Chairman's Chat

I have been speaking to a number of Support Group Leaders this week and all envy our Tier 1 situation. Now with a new Tier 4 in operation and Portsmouth being placed in it, the reality of this virus grows daily. The light is of course the vaccine which is now on the Island, so let's hope the roll-out of this can overcome the threat of the new strain of virus and its increased contagious level. I hope you were able to make the Special Christmas Zoom meeting, an excellent presentation and Quiz – so many positive email messages have been received after the event.

Thank you all for supporting the Christmas Card Awareness campaign, and your generous support throughout this very difficult year. Also a big thank you to all the companies and donors who have helped us put on events during this difficult year. You all know how hard the Trustees work to enhance this group, amply demonstrated by the success of the September PSA event. Again thanks to all who volunteered and promoted this event.

Like many, my family will not be getting together for the first time in my lifetime over Christmas, but will be using Zoom to make contact. My sincere commiseration to those who have booked and planned Christmas get togethers, and have hung on through these difficult times hoping for this to happen. Angela and I wish you all some measure of joy during this festive season, and to restrengthen your resolve to overcome all the difficulties that the New Year may bring and know always that we are a Support Group, here to try and help all our members.

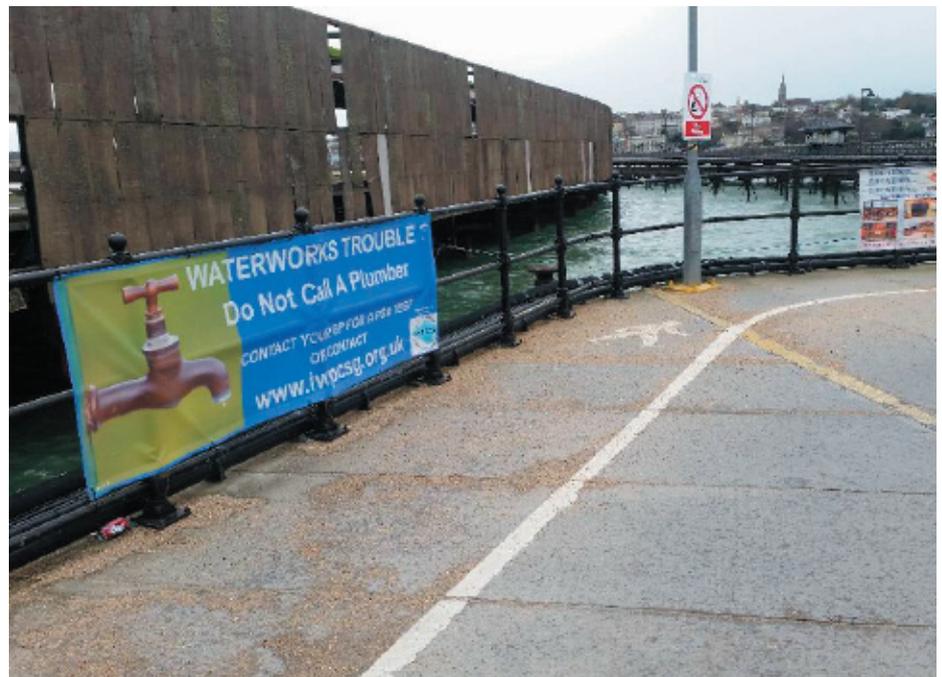
*Alan Taylor*

# Awareness Campaign

With the lifting of lockdown, Tony Sallabanks and myself (Chairman) were back on the road again looking for new sites for banners and popping into established sites.

Because of the recent storms, it has been necessary to replace the banners at the Tractor Centre on Forrest Road, and a new one was put up outside the Co-op in Ryde, thanks to Paul the Manager for this prime location. Photos were taken of the Ryde Pier and Fishbourne banners and there is now one in Lymington on the entry to the ferry terminal. The Jewson's site in the Industrial Estate in Newport also has a banner and our thanks again to Jewson's management. This is our 5th banner at a Jewson site.

Our thanks to all the members who sent on the two Christmas cards they received from the Trustees. This again will help spread the word about the Group and make awareness of us more Island-wide.



## Apologies

1 To the Macmillan Nurse for writing Kathy instead of Katie, in our last Newsletter, typo error sorry.

2 The mix-up in telephone numbers re the Christmas Cards where two numbers were the same, and some confusion occurred from members who wanted to purchase Christmas cards. Again our apologies for the confusion.



## Trustee Thoughts

With the New Year at our door, plans and ideas for 2021 are on everyone's lips.

A calendar for 2022 was suggested, and the need to have it ready for July to go to the printers so that it could go on sale in September.

There was discussion about another Christmas card for 2021, with a new design, and possibly wrapping paper as well.

The Covid19 vaccine has arrived on the Island and there are 3 sites where it will be distributed. If you qualify for the first cohort expect a letter from your GP inviting you to attend. Proposed sites are Westridge Centre, Ryde; West Wight Sports and Community Centre, Freshwater; Carisbrooke Health Centre.

We would like to welcome Graham Dooley as a Trustee, after he

expressed his wishes to help out and attended our last meeting. There is still a space for anyone else who would be interested in helping to run the Support Group.

With the quality of the Speakers we have been able to invite to our members' meetings, we have again been asked by other groups if they can attend our meetings. The Trustees feel that all Support Groups especially small ones, should be invited to join us.

2021 will be the 10th Anniversary of the Support Group's formation and so we intend to mark this with a special event. Any ideas, please pass these on to any of the Trustees, or email iwpcsg@gmail.com

Finally Ryde Lions had informed the Group that they would be putting a report into the County Press of their support work during 2020 and this would include PSA testing.

## Website/facebook

If you have been to our Facebook Group site recently you will have seen that Tony Wheatley, our Vice Chairman, has updated the front page. He and Norman Harris have also been working on our Website, including putting details of how to donate to the Group. The link to Peter Hunt's Muchloved memorial site will be there until the end of the year, when it will be deleted.

There are plans afoot for more revision to the website in the near future as we endeavour to maintain the high standard we have set ourselves for our site.

We are also working on the Facebook page with reference to Charity recognition, so that donations will be able to be made directly using the page.

Again our thanks to Norman and Tony for all the hard work they have put into our social media site this year.

## Zoom Christmas Special

I must thank firstly, our new Social Secretary, Pam Blayney, for arranging to have John Hannam as our Christmas Speaker. Although this was John's first-time using Zoom, his sheer professionalism shone through and his hour presentation appeared to be over too quickly. What an amazing array of stars he has interviewed, and I loved his honesty about those who were really kind and helpful, despite their stature and those who were not. I received so many email messages from across the country from supporters

who had watched the presentation, just fantastic. And John was game to enter our Quiz afterwards, about the Isle of Wight, what a lovely man. John showed us his latest book "More Wight Connections", the fourth in his series of interviews with celebrities.

*To the 60+ people who attended I know you enjoyed it and Pam and I made a fruit basket presentation later that week as a thank you for the time John had spent preparing and presenting his talk. We will have to work hard to better that at our AGM in April.*



## Future Events

### 16th January 2021

Ladies' Zoom meeting at 2pm.

### 28th January

Members' Zoom meeting at 2pm. Speaker Sarah Gray, Tackle's new National Support and Development Manager, talking about "How you can help Tackle and Tackle can help you."

### 25th February

Members' Zoom meeting at 2pm. Speaker Tony Collier, talking about the importance of movement and exercise both to help treatment and well-being.

## Quote – Unquote

If your plan A doesn't work, remember the alphabet has 25 other letters.

Failure doesn't mean it's all over, it means try again with Experience.

The most certain way to succeed is always to try just one more time.

Fall down seven times, stand up eight.

Your dream doesn't have an expiration date, so take a deep breath and try again.

Stop keeping track of the mistakes you've made – it's time to forgive yourself.

If God closes a door and a window, consider the fact that it might be time to build a whole new house.



## Quick Quiz

Happy Christmas to everyone who reads this Newsletter and a Covid-free New Year. So again a chance to win one of our membership ceramic clip-on badges, just answer our festive quiz and send your answer on an email with your name to iwpcsg@gmail.com or call 07568245124.

How many reindeer pull Santa's sleigh, including Rudolph?

## Zoom Meeting with Prostate Cancer UK

PCUK held their Christmas support group leaders' meeting in which 30+ leaders, suitably attired in Christmas jumpers, hats and backgrounds, took part. There was some business to clear, in particular the concern that diagnoses had dropped this year, fundraising had also suffered and if there were any statistics to illustrate these problems then could the group leaders pass it on to Sue at PCUK. I have to say that the Quiz set by PCUK,

despite being told how easy it was, was in fact really difficult! Still, it was good speaking to the breakout groups, all were concerned about the dropping of numbers coming to Zoom meetings and trying to maintain enthusiasm. It was decided that the next meeting would be dedicated to trying to solve this conundrum, with shared ideas. It closed with best wishes to all and a cartoon created by one of the leaders with a Christmas theme.

## Pause for Thought

Some of you might know that I been having problems recently with my palliative treatment which resulted in an MRI and an early appointment with my Consultant. The result of this led to an increase in the treatment I am receiving with the added side issues. There was a miscommunication between my Consultant at QA Hospital and my GP's surgery, so that my latest prescription did not have the increased dosage for my treatment. I contacted my GP's surgery and asked for an appointment to see my doctor, but the receptionist wanted to know why I needed the appointment. I carefully explained my situation, that without the increased dosage I would be in considerable difficulties. She informed me that the doctor could not help me and I should contact my Consultant. I said I had phoned twice and had no reply and as QAH's Covid situation was becoming difficult, expected he had been seconded to help as he had last April. Still she refused to give me an appointment, offering a phone appointment with a pharmacist to explain why I could not have a change to my prescription. I again asked for the doctor and was told he could not help me and I must keep on trying at QAH. Finally after almost begging for an appointment, I was offered a telephone appointment with a doctor a day later.

I wonder if that woman understood the anxiety and stress one has living with advanced cancer, and why she needed to make it so difficult for me to obtain an appointment. As the quote goes, "if at first you don't succeed, try..."

## Fundraising

The final figure for Peter Hunt's MuchLoved site looks like £1400, but the site will not close until the end of the year. We are very grateful to Helen Hunt for setting this up.

The sponsored weight loss donation has been delivered and was a very healthy £335. Many thanks to all the sponsors supporting our member's efforts.

We have also received donations from other members this month, all of which will go towards the planned PSA event in April, to be held at Cowes. To all who have organised events and made donations to the Group this year, our thanks and be assured that the money has saved men's lives.

