

Acute Services Review

You will be aware of the 'acute services review' currently being undertaken on the Island. In brief terms this is likely to lead to some services being moved away from the Island to mainland hospitals. A consultation process is well under way. We were invited to be a part of that process, indeed a morning was dedicated by the review team to hearing our views. We had already canvassed the membership through the Newsletter and during a Support Group meeting (September) and so together with the 5 members who attended we were in a good position to input. It would be fair to say that much can be learned from individual anecdotes relating the experience we have as individuals. BUT so much more can be learned when these anecdotes become trends. We therefore tried to focus our feedback on drawing

attention to the 'trends' we have observed, giving of course examples. As they say on TV 'in no particular order' we drew attention to (a) the tendency for many healthcare professionals to not see the whole person and only think in terms of specialisms. This can lead to unsafe practice whereby other significant issues are not picked up or not communicated. (b) poor pain management and (c) defensive attitudes to criticism. In many respects from a Prostate Cancer perspective most changes will not affect us as key services such as Radiotherapy and Surgery are already contracted out to mainland hospitals and in particular the Queen Alexandra hospital in Portsmouth but for other serious conditions there may well be significant change. As it stands at the moment though no changes have been agreed.

A View from the Chair

As the year comes to a conclusion it is customary to reflect on the successes and failures. Its a year when inevitably some of our members have died and our thoughts go out to those who were closest to them and who now face a Christmas without them. It is salutary for all of us recovering from Prostate Cancer to reflect that nationally the statistics are that 16% of us will not survive 10 years. Its a fact and annually we reflect on those friends of ours who fell into this category. The Group has succeeded in delivering a long treasured aim to have an Island-wide campaign for raising awareness. The success of this can in part be measured by the numbers now taking up the option of a PSA test. This has lead to increasing numbers of positive diagnoses. Of course the earlier the diagnosis the more positive the prognosis. Financially the group is going from strength to strength and we have been able to fund the raising awareness campaign as well as contribute to prostate cancer research. The Support Group meetings are well attended and new members are increasingly finding their way to us. The Befriending scheme in the hospital is not as well 'manned' in terms of volunteers as in

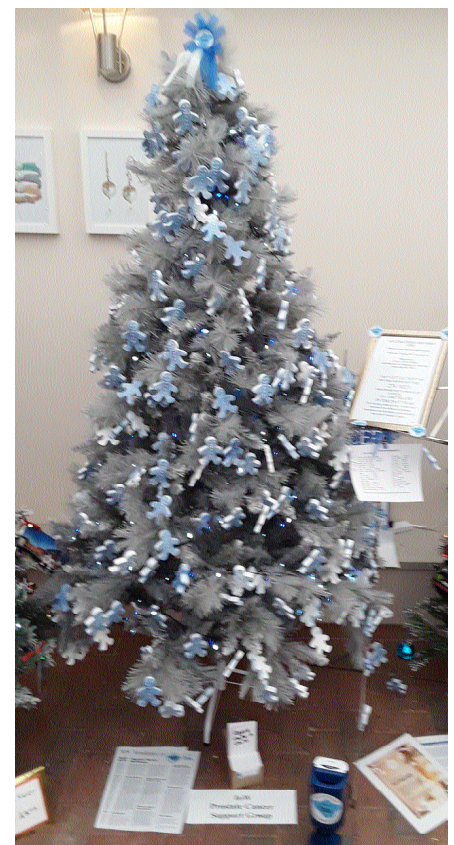
past years and could benefit from new 'blood'. On the positive side we are responding well to the need to offer support individually in the community. This is no place for a detailed analysis but I would like to thank all of our Trustees for their hard work on our behalf. In addition I would like to thank the numerous volunteers who keep the group going and effectively at that. Thank you one and all.

New Year's Day Dip

The Cancer Nurses under the leadership of Ann Snow are undertaking the New Year's Day Dip at Small Hope Beach, Shanklin at 1pm but congregating from 12noon. They are raising funds for the Wessex Cancer Centre 'Daisy Bus'. So a cause close to the heart of all of us. Why not pop along to support and encourage them. We are sure they will welcome your support. If its cold there is a very good cafe close by with a beautiful log burner!

Prostate Cancer Christmas Tree

This year, thanks in no small part to Roz and Mike Dennison, we were fortunate to be allocated a place in the annual Christmas Tree extravaganza which started in Brightstone and has become so big that it has spread to many venues in the locality. Our tree has a Prostate Cancer focus as you can see from the adjacent photograph. The tree has a key message in the 274 'little men' with which it is decorated. Mike painstakingly made each one from plaster of paris. Each one of these figures represents one of the 274 men diagnosed last year on the Island with Prostate Cancer. Roz and Mike have also managed to organise sponsorship of these 'little men' at £2 per 'person' raising over £300 so far. So if you want to add a different dimension to the meaning of Christmas why not pay the 'Wight Pearl' a visit as you will find our tree there, along with scores of other entries.



Humour

I understand October's contribution from a mainland support group did not go down well with everyone, it was rather dark we have to admit. Anyway this month we came across a health tip, probably from the USA – 'If you can't afford a doctor, go to an airport – you'll get a free x-ray and a breast examination and; if you mention Al Qaeda you'll get a free colonoscopy.'

Hot Flashes – a Potential New Treatment

In the USA a small pilot study (Rich et al) is indicating that intermittent auricular acupuncture may reduce the intensity and frequency of hot flashes resulting from ADT (hormone therapy). The frequency of the acupuncture was every other week for 6 weeks. The intention in the USA is to follow up this research with a more extensive study.

Your Personal Data

We have as an organisation long considered the need to protect your data as best we can and in so doing we have complied with the data protection act (DPA). Consequently you will have noted the entry at the bottom of correspondence giving you the right not to receive correspondence from us. If a member decides not to receive information from us then we will at their request delete their contact details from our database. We have just heard that the DPA is to be replaced in April by the GDPR in other words the General Data Protection Regulation. This should mean relatively little change to our practice but your Trustees will be reviewing the implications in order to see what change if any needs to be made.

The Daisy Bus

By now there can be few people on the Island who are not aware of the outcomes from our involvement in negotiating for a future for the Portsmouth Daisy Bus. As it stands we are expecting another meeting to be convened at the Hovercraft (boardroom) in the New Year. The object of this meeting will be to arrive at a more permanent solution to its continued funding. We are committed to playing our part in this future and will do our best to ensure that patients come first in the deliberations. Watch this space for further information as and when we get it.



“Lose some weight, quit smoking, move around more and eat the carrot.”

Vitamin C – Good or Bad?

Many of us use vitamin C in tablet or capsule form on a daily basis, in some part of the world it is also used intravenously. I guess we all do so in the hope it fends off colds etc, even though there is not a great deal of evidence that it does in these formats. In fact emerging evidence indicates that in larger dosages it can increase the risk of kidney stones. According to North American research it

(intravenous) can also cause false results in the Bowel Cancer test. A recent study from the Copenhagen University Hospital found that it could in fact stimulate tumour growth! All of this may be academic as I guess not many of us receive vitamin C intravenously and quite what it means for us who include it in our morning cocktail of pills is another matter, but it makes you think!

Changes to the Group's Priorities

As a group we have nine priorities and these have been set by you our membership and they are reviewed on an annual basis. Our sixth priority is to "MAINTAIN A ROLE IN LIAISING WITH HEALTH COMMISSIONERS TO IMPROVE TREATMENT AND ADVISE NHS ON TREATMENT PATHWAYS: Provide a link to Health Commissioners mainly through attending Long Term Care Conditions Group. Maintain accuracy of information contained in the treatment pathways and our leaflets. Provide an advocacy role for individuals dealing with Health organisations". You will see here mention of the Long Term Care Conditions Group (LTCG). This is chaired by the Commissioning Group (CCG). During the issues over the Daisy Bus we

were extremely disappointed that the CCG did not use this forum to alert us to the emerging risk to the Daisy Bus. They were informed in September by the Wessex Cancer Trust that without funding it would be withdrawn. A LTCG meeting took place in October at which we were present and no mention was made of the risk, nor was it included in the November meeting agenda. We are as a result seriously considering whether we can continue to be members of this group. The Trustees will be discussing this issue in the near future and we will make a considered decision. If you have views on the issue we would welcome them. You can communicate them to our chairman, Dave Kiely on davekielyiow@aol.com or by telephoning 407662.