

# Norfolk & Waveney Prostate Cancer Support Group

## NEWSLETTER

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### Little shop – big donation



*Chairman Noel Warner receives the giant cheque from (left to right) Ruth Wood, Jo Wightman, Joy Kirkcaldy, shop committee chairman Adrienne Capp and trustees chairman Christine Buchanan*

A tiny charity shop in Brundall has raised £10,000 for our group in just 18 months – and we will be adding it to the £10,000 we have already pledged to the Norfolk and Norwich University Hospital's targeted radiotherapy appeal (TRA).

The shop – the Cancer Community Chest – opened in Brundall in 1995 and moved to its present home the next year. And among those helping to present a large cheque to our chairman, Noel Warner, was a volunteer who has been working at the shop for one or two days a week since it opened, 85-year-old Ruth Wood.

Led by a committee of eight, chaired by our joint welfare officer, Adrienne Capp, and overseen by trustees chaired by Christine Buchanan, the shop is staffed by a team of 40 volunteers. It is open six days a week and has become a hub of the village. "Some people drop in almost every day just to have someone to chat to," says Christine.

People donating items for sale come in from far beyond Brundall. Goods that the shop is unable to sell or find room to store are passed on to other local charities.

Why did the Community Chest decide to make such a generous donation to our group and the TRA? "We had a talk from David Capp (our joint welfare officer) and felt that this new centre would benefit not only prostate cancer patients but other patients who would otherwise have to travel to London or Cambridge," says Christine.

### Do come for a chat

A headline in our April Newsletter said: "There's no need for you to fight alone." And on Monday, October 7th, there's an opportunity to share your thoughts and worries with some of us "old sweats" who have seen it all before.

It's one of our "Meet and Chat" evenings at the Big C centre at the Norfolk and Norwich University Hospital when group members who have experienced all or most of the available treatments for prostate cancer will be on hand to listen and discuss and perhaps point you in the right direction if you have a particular problem.

Come along to the Big C any time from 7pm onwards for a cup of something and a mardle.

### Our future nurses

Should you find yourself in one of Norfolk's main hospitals over the next year you might find yourself receiving attention from a "pre-nurse experience health care assistant". Twenty-seven would-be nurses will be taking part in a year-long pilot scheme when they will gain practical experience to ensure that nursing is right for them. They should be intending to apply for nurse training at university and will have had little or no previous experience of working with patients. Norfolk has been chosen as one of six areas across the country to pilot the scheme.

The hospital trusts taking part are the NNUH, James Paget, QEH and Norfolk Community Health & Care.

# Insuring for that sunshine holiday

We're being treated for prostate cancer but we still want to fly off for our sunshine holidays or to visit family in far-flung places. But will anyone insure us and, if so, at what cost and with what sneaky caveats in the (very) small print?

Wendy Marchant, Big C information lead nurse, offered us plenty of helpful advice when she spoke at our August open meeting at the James Paget Hospital. Travel insurance is frequently a big problem for anyone with cancer – and there are no set rules. Insurance companies seem to make up their own, she told us. The best advice: shop around. There are some companies who particularly market their products to cancer patients, for instance, Insureblue deals specifically with male cancers (and, being politically correct, Insurepink for women's cancers). Although these companies are often more sympathetic they are not necessarily any cheaper. Some men opt not to include cancer cover in their travel insurance to make it cheaper but this can be a risk.

Factors which might affect travel insurance cover include your age, other medical conditions, and destination. Long-haul trips can be considerably more expensive to cover. European destinations are often cheaper but there can be problems. You will need to carry a European Health Insurance Card (EHIC) – free of charge but watch where you find these online because there are some unscrupulous websites which are set up as a scam to charge for this service, Wendy warned. Even though you have an EHIC you may still be required to pay for treatment up front so it is a good idea to carry a card with adequate credit in case of emergencies. The money is refunded by the NHS on your return to the UK. A further warning: the EHIC does not cover repatriation, lost luggage, cancellations and other holiday events so it is important to take out travel insurance as well.

If your treatment was completed several years ago and you have no on-going health problems insurance is often cheaper but if you are on continuing treatment, such as hormone therapy, some insurers may charge more, so ask when getting a price. If there is more than one traveller in your party, some insurers will insist that everyone travelling is covered under the same policy so that if something happens to one of you the policy will cover repatriation for everyone in the party (or hotel stays if one person is admitted to hospital abroad).

Cruises are often chosen as a great holiday for people recovering from cancer but the insurance may not be cheap because, if something happens to you which requires urgent treatment, the cruise liner might need to divert to the nearest port or you might have to be taken off by helicopter.

For more information about travel insurance please pick up a copy of the Macmillan booklet "Getting Travel Insurance". If you really struggle to get insurance do ask a broker to research it for you or you can contact the insurance ombudsmen (info in the booklet).

Wendy said she had heard that many patients were so shocked to find that they had been refused travel insurance that they assumed their cancer was worse than their doctor had told them. "This is not true. Doctors and nurses do not withhold this kind of information and this is simply company policy made by the individual companies to protect them from losses. It bears no relationship at all to your cancer or state of health."

- *Wendy offered a number of helpful tips about coping with problems specific to men with prostate cancer when they are travelling – too many for this issue of the Newsletter, so watch out for them in the December issue. They're worth waiting for!*

## Some thoughts and reflections

*By our welfare team, David and Adrienne Capp*

In St Peter Mancroft in Norwich there was a sign in the Chantry Room saying: "There are no strangers here but there may be friends we haven't yet met."

When Adrienne and I first started coming to the group's open meetings at the N&N we found the talks interesting and informative but once we removed to the refreshment area everyone seemed to settle at tables to chat away and we looked around feeling a little lost. We knew David Wiseman from his work at Princes Street church so we sometimes talked to him but often we just went home.

It is for this reason that we decided to wear distinctive sashes and proclaim at every meeting that we wanted to meet everyone who was attending for the first time. It is working and we have been made most welcome by everyone we have spoken to.

Our aim now is to ask everyone to share in the task. We are constantly having new folk come along to our meetings, some newly diagnosed and some who were treated several years ago but, with a rising PSA, have returned to seek reassurance and support.

No one who is new to an organisation or meeting is going to take the initiative in starting a conversation, so it is up to us the regulars to look out for anyone sitting on their own and talk to them.

You don't have to wear a gold sash but we are a support group and just as we all appreciated someone talking to us and giving reassurance it would be lovely if everyone could be on the look-out for fresh faces.

We would like everyone to talk to someone they know and someone they don't know at every meeting. Perhaps they were strangers when they arrived but let's hope they will be friends whom we can support and encourage by the time they leave.

# From where I sit – Chairman Noel Warner's view

## On the home front

Our garden was open to the public in July as part of a village scheme and my wife Ann (one of our trustees) had grown and potted loads of plants for sale to the visitors.

Despite the fact that it was the Wimbledon men's tennis final and a Grand Prix on that day, she succeeded in raising a total of £252 for our charity.

A neighbour, Michael Marlow, who also opened his garden, raised £21 of this total. Ann, being a keen gardener, had taken up the offer by Professor Richard Mithen at our June meeting and obtained some of the Beneforté broccoli plugs from the Institute of Food Research. They all look very healthy but no heads to show yet.

The latest news is that broccoli is very good for arthritis sufferers because it helps reduce inflammation and cartilage damage.

## Some community!

As we report on page one, the most amazing donation so far is the £10,000 raised by the Cancer Community Chest in Brundall.

Our welfare team, Adrienne and David Capp, were instrumental in bringing this sum to us which in turn has been pledged to the TRA.

This tiny charity shop with a big heart sells books, DVDs, glassware, etc, so imagine the effort it took to raise so much. Like other volunteer workers in our communities, they deserve a big round of applause.

## Targeted radiotherapy appeal

The fund continues to grow –over £160,000 has already been raised. Events and other fund-raising campaigns are currently being organised. One such event is "An evening with Martin Bell" to be held at the Open venue in Norwich on Thursday, November 21, starting at 7.30pm. Tickets for what should be a fascinating talk by our patron cost £7.50 and can be obtained from the fund-raising department at the N&N, telephone 01603 287107, or from these websites: [www.open247.org.uk](http://www.open247.org.uk) or [fundraising@nuh.nhs.uk](mailto:fundraising@nuh.nhs.uk). Please support this event and maybe bring some friends along too.

## ... and you don't need to be 'good at art'

Philippa Champain, art therapist, told us at our August meeting at JPH Gorleston about a new Thursday morning art therapy group starting shortly at Big C Great Yarmouth, 33 Regent Street – a free group for anyone diagnosed with cancer at some point in their life. The aim is for a friendly and supportive group which welcomes new members.

Art therapy can help when it is hard to express and make sense of how you are feeling and may have difficulty talking to friends and loved ones about your fears and worries.

Being part of a group of others who share some of your experiences can be very supportive and help to reduce feelings of isolation.

"To dispel misconceptions," said Philippa, "it is important to stress what art therapy is not! People often imagine that they have to be 'good at art' to attend but this is not the case. You do not need to

## From the horse's mouth



Colin Peach, a 66-year-old prostate cancer patient from Middlesbrough, decided to start his own awareness campaign in a unique way – he bought a race horse and called it PROSTATE AWARENESS. It has run three times so far, coming 4th in its last race. Colin's father had prostate cancer but, like so many men, was reluctant to discuss it with anyone. Colin is the reverse and is a man on a mission. He feels that if he can save just one life by reinforcing the PSA message then it will have been worthwhile.

have any experience of using art materials and the aim of the group is not to produce a masterpiece! It can be surprising how soothing and relaxing using art materials can be.

The group usually starts with a quick catch-up to check how people are, then when everyone is ready they can choose which materials they would like to use. There is no pressure to produce something and sometimes people prefer to take their time for the first couple of weeks. The art therapist will always be there to offer help if needed.

If you want to know more about art therapy and whether it might be right for you, phone Philippa on 07582 710410 or you can speak to Lisa or Wendy at Big C Great Yarmouth on 01493 855297. There is also the possibility of a group for carers, so if you think you would be interested please phone and leave your details.

## Whatever turns them on (and off)

The University of East Anglia is 50 years old and has established a world-wide reputation for medical research. We have reported the work being done by Professor Colin Cooper – but his team is not the only one. What follows is an extract from a report by JO MALONE in a celebratory supplement by the Eastern Daily Press, reproduced by kind permission of the editor:

Genes which switch on – and off – could have the key to how severely a person will be affected by some cancers.

Researchers at UEA are working with genes that are key elements in breast and prostate cancer – and money raised for the Big C is helping.

Particular genes, when active, mean a tumour is less likely to spread. The scientists, led by Prof Dylan Edwards, head of the School of Biological Sciences at UEA, are trying to mimic this gene “switch-on”. He explains that each human cell turns on only a fraction of its genes. The rest are turned off (repressed) and it’s known that genes are turned on and off in different patterns.

The Big C support has led to further funding into this research, with UEA scientists working with others from Norwich Research Park and the Norfolk and Norwich University Hospital. The work also includes looking at how genes affect tumour behaviour.

“It’s a puzzle and there’s a lot to do. It’s discovering things that are going to be of benefit to the patient, delivering better tests and better treatments,” says Prof Edwards.

## Life-saving statins?

Men taking statins may be less likely to die from prostate cancer, an American study claims. Research based on 400 men with the disease and 400 without it showed that the anti-cholesterol drugs were associated with a 63% lower risk. It’s apparently not clear why but a possibility is that the drugs have an anti-inflammatory effect. [All very well unless you have a serious adverse reaction to statins, like me. Ed.]

## Nothing new, then

Probably because it involves an area of the anatomy that we didn’t mention in polite company, we tend to think of prostate cancer as a relatively new disease. Not a bit of it. A mummy unearthed in Egypt was found to have traces of PCa. That, says an academic, indicated that the disease was caused by genetics, not environmental factors, because there were no pollutants – and modified food hadn’t even been thought of.

## Dates for your Diary

Wed 2 Oct & 6 Nov. . . . 5.30-7pm  
**Radiotherapy Department**

*Open Evenings, Big C & Colney Centre, NNUH. Meet at Big C. Call 01603 288779 to book.*

Mon 7 Oct. . . . . . 7-9pm  
**“Meet & Chat” at Big C Centre, NNUH**

*An opportunity for newly diagnosed patients to chat with members who have already been through the same journey.*

Mon 2 Dec. . . . . . 7-9pm  
**Open Meeting at Benjamin Gooch Theatre, NNUH**

*Mr Witold Lukianski, Consultant Urologist, QEH King’s Lynn  
‘Advances in MRI Scanning for Initial Diagnosis of Prostate Cancer’*

## Not on your bike

To the more decrepit of us, this won’t apply. But researchers have found that strenuous cycling can raise PSA levels.

“Some doctors may be unaware that cycling can spuriously raise a man’s PSA levels and so refer their patient for further and unnecessary treatment – all because their cycling produced a false positive,” says consultant urologist Chris Eden.

So, next time you are due for a PSA test, don’t go by bike!

## How to Contact Us

### ■ Telephone the Specialist Nurses:

**Sallie, Wendy, Helen & Rachel**

Norfolk and Norwich University Hospital  
01603 289845

**Angie, Wendy & Simon**

James Paget Hospital  
01493 453510

**Sally, Clare & Anne-Marie**

Queen Elizabeth Hospital, King’s Lynn  
01553 613075

**Lizzie – Macmillan Info & Support Radiographer**

01603 289705

### ■ Help or Advice – Our Welfare Team:

**We have over 30 members available to help. There is probably one near you.**

For more information please call our Welfare Team, David and Adrienne Capp, on 01603 712601

■ **E-mail us:** Noel Warner, Chairman  
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