

NEDPSA

North & East Devon
Prostate Support Assn

Newsletter

ISSUE No 27

AUGUST 2010



PAUL GODFREY RAISED £562 BY RUNNING THE GREAT WEST RUN

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What has been going on!

It has been a busy couple of months for the happy band of people who always step forward when there is work to do for the Association.

Apart from the regular routine of Association and Area Group meetings we have been manning stands at the Beer Music Festival, the Festival 4 run for Prostate Cancer Research and the North Devon Show; collecting for a couple of days outside Sainsbury's Pinhoe; shaking our buckets for the Chestnut Appeal at the Devon County Show; and - highlight of the year - the Honiton Cream Tea Garden Party.

The Cream Teas boosted our coffers by £800 and on top of that Brian's son, Paul, did the Great West Run on our behalf collecting a further £562. Douglas Mounce from Radio Devon was invited along to perform the official opening of the Garden Party and such exposure is invaluable in our efforts to create awareness. The event was also covered in the Local Midweek Herald and led to an invitation to take part in the Annual Honiton Charter Day celebrations.

MOVING INTO CYBERSPACE

At our AGM in April, Roy Quastel our Treasurer, commented on the high cost of posting out (a) each edition of this newsletter and (b) the notices of our Association meetings.

Inevitably discussion turned to the use of e mails as an alternative but this met with some cynicism. Undeterred we thought that we could offer it as an option and in that way everyone will be happy.

So..... if you prefer or would like to try the e mail option just drop a line to Tony Lowe (lowe.tony@yahoo.co.uk) and you can have either (a) or (b); or both sent by e mail. In addition to saving postage and paper you may well be saving the planet.



INTRODUCING YOUR VICE CHAIRMAN

Brian Godfrey

Brian is Devon through and through, having been born on Crossfield Farm in 1944 about a mile from his present home. When he was about 10 years old the family moved to Skinners Ash Farm at Fenny Bridges and Brian did all his schooling in Broadhembury but sadly the school is no longer there.

A keen cricketer in his youth Brian can claim the wicket of Ian Botham in a Testimonial match for Brian Close and an impressive 8 wickets for 8 runs playing in another memorable match for Feniton, his local team. He married Jill in 1966 and they have 3 children, a twin boy and girl, and another brother.

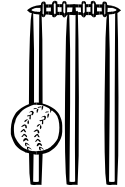
He was for a long time involved with the Red Cross and became a Trustee for the Devon and Dorset Ambulance. In that capacity he and Jill were invited to a tea party at Buckingham Palace where they were introduced to the Queen. On being informed that they were farming in Devon she was curious to find out if they had been bothered by any of the outbreaks of crop circles that were common at the time.

He took over running of the farm when his father retired and in 1990 they sold the herd and went into the holiday trade and developed it with 2 holiday-let barns, a B & B, shop, tea room, camping and caravan site and an open farm.

In 2007 he moved into Manna House in Honiton which he runs as a B&B with Jill and they have invested a lot of time and effort transforming its grounds into a peaceful haven with allotments. Diagnosed with prostate cancer that year he has had both surgery and radiotherapy and says that gardening has been a great help in getting back to normal.

Always very much involved in community affairs he was Chairman of the Feniton Scout Group and is currently Chairman of the Feniton Flower Show. With that wealth of experience we are very happy that he has taken up the post of Vice Chairman in our Association.

Perhaps we should also mention that he raised just on £800 for the Association last month at his Cream Tea Garden Party!



THE DEVON COUNTY SHOW



The Chestnut Appeal was adopted by the Devon County Show as their Charity of the Year and about 20 of our members pitched in to help out manning their stand and, decked out in our Tee shirts and Rosettes, we were let loose on the general public soliciting pennies and ha'pennies.

The total amount raised was £9 217 from a variety of sources and this enabled them to meet their target of £35 000 for the purchase of two head cameras for use in the operating theatres at Derriford and Wonford.

As agreed by members at our AGM we, as an Association, had donated £2 000 towards this.

Above we can see Mervyn Reed, Roy Quastel and David Beard ready for action whilst on the right we can see the Stand itself, where on display was a head camera of the type to be purchased.

The Austin A30 Convertible parked in front of the stand was part of the display though quite what it meant to represent was not clear.



Space has been a problem with this edition of the newsletter and so reports from Sidmouth and Honiton Group Meetings had to be abandoned.

Sufficient to say that the Royal York & Faulkner Hotel and the Three Tuns at Silverton are still doing a roaring business

PROSTATE PARTNERS

Who takes care of the carer while the carer is taking care?

One carer's frank and open perspective

I'm not a medical professional or a nurse or a saint - I just care.

It is often the partner of a man encountering prostate problems who encourages him to seek medical advice. Disturbed sleep and urinary symptoms can be first signs that 'something is wrong'.

Fear and panic can flood in when you hear the words *it's Cancer*. Fear of having to nurse, fear of death, fear of the changes you will have to make. Anger, because this is not what you signed up for. Anger at the prospect of financial changes due to time off work, medication and treatment. Then guilt because you realise it is not what he wanted either. All of these reactions are normal. The mood swings, uncertainty, anger and the *why me* syndrome that can happen during this period of diagnosis will often disrupt the calm and normal running of the domestic scene. Few people realise that the partner is experiencing similar emotional symptoms to the man, whilst trying to keep an optimistic outlook and adopt a supportive role.

Things you might do:

Offer your support, go with him to his appointments if he wants. If he prefers to go alone, be there with him, mentally and spiritually.

If you go to the consultations, be the **note taker** and the **listening ears**. Write down the *medi-speak* so that you can look it up later. The person being diagnosed has his own agenda and may not want to hear the details or the stark truth.

You can **Ask questions** - and if the answer is not clear **ask again**. **Ask** pointed questions. **Ask** embarrassing questions.

If you and your partner are not comfortable with the treatment plan or the doctor, encourage your partner to ask the GP for a second opinion. Discuss with the Doctor and your partner all the ramifications of

If he goes to the Doctor alone, **listen attentively** on his return. You may need to go with him to a future appointment to get things clarified. **Read** as much as you can about his and your particular problems, search the internet. Remember there is a **wealth of formal and informal help** that's on hand locally, usually at the end of the telephone line or at your local support group.

During Treatment the waiting time can become unbearable unless you busy yourself and get him involved in 'stuff.'

Things you might try to help your partner:

Think about changing the general diet or methods of cooking and eating. Include food or drinks that the experts say could help - pure pomegranate juice, pure tomato juice, tomatoes cooked in olive oil, soya milk etc.

Let him experiment with complementary therapies that **do not intrude** on regular treatments. For example, relaxation or aroma therapy, massage, yoga or meditation. These things are a positive move that often results in a feel good factor, even if they are not cures but always check it out with the Doctor first.

Encourage him to embark on exercises or routines that can be followed to strengthen muscles, mood and spirits.

Things you might try for yourself:

Keep your sense of humour as much as you can or as much as you dare to! **Men's ailments are always so much worse than women's!!** Fear of not being able to achieve and maintain an erection will often make your man feel less of one, and his defences will not even allow him to cuddle, stroke or hold you. This can be very hurtful but you've got two arms two lips and a sex drive, so read the magazines and try some of the moves! The worst that can happen is that he'll tell you to get lost. That's not unusual; in any long term partnership so try again tomorrow - or next week.

Try to let people help if they offer. Perhaps let them drive you to or from hospital, or the hairdressers, the shops or to have coffee and a chat with friends. Talk about mundane matters to ease the continual stress of coping - or not coping. Continue with as much of your social life as possible. Depression can become a problem. Two depressed partners can cause untold misery. Get help if or when you think you

need it.

You must ensure that you both get some good quality rest and sleep, but it is not the best time in the scene for you to suggest separate beds OR to get cranky if he says he would appreciate sleeping alone. You have feet and can always walk to the next bedroom for that very important goodnight or good morning cuddle, canoodle or aroma therapy massage! *Yes! Him to give you the treatment!* Some medication may assist any extended lack of sleep. Remember to look after yourself as well. You still have your own needs.

Things you might try together:

A man with problems with his plumbing can still take the rubbish out, can still cut the grass or clean the windows and has not usually gone soft in the head. You can do a cross-word or two, take short walks together, have a visit to the movies, go on a shopping trip, or have supper with family and friends. All these may well be a distraction - an outlet for chat and may restore a few hours **normality** which is, at times, hard to achieve. Give family, relations. Workmates and friends some updates and information about you situations so that they can understand any changes in his or your routines, attitudes or behaviour.

Now is a good time to ensure that your relatives and friends check their prostate health to avoid being in your partner's situation at a later date.

Slow recovery or setback:

Truthful optimism, positive thought, meditation, prayer, any form of exercise and the support of family and friends are all useful tools to rally flagging spirits. When all else fails to help, go to the beach, the garden or the park, scream loud and long, have a really good weep, and go back to start with your head held high. Hope is positive and help is available for carers.

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EXETER GOES TO THE SEA SIDE.

On the 16th June 14 members of the Exeter group went to Sidmouth and met at the Westcliffe Hotel for coffee and a social gathering.

After excellent service at the hotel for coffee and biscuits a few members stayed put in the very comfortable lounge of the hotel whilst a few more visited nearby picturesque gardens. Two others had the energy and went for a walk down along the seafront whilst two of us men-folk were compulsorily dragged around the bustling town centre shopping by our wives.

A couple of hours later we all met up again back at the hotel where various meals from a wide bar meal menu were thoroughly enjoyed by all. Everyone contributed fun and conversation to the day and it really was a fantastic atmosphere with plenty of humorous interaction and banter.

The day was organised by **Tony and Val Hanson** who both used all their influence to ensure we had a gloriously sunny day. We are sure we speak for everyone attending that sincere thanks and a very big **well done** are due to Tony and Val and it is hoped more such days can be held in the future with more members and guests attending to enjoy a great day.

The next meeting/coffee morning for the group will be at 39 Clyst Valley Road on Thursday September 9th at 10:30 am. All are welcome.

Graham & Joyce Sluman. Mike & Moyra Pulman.

THE LADIES GROUP

Our next meeting will be on **Wednesday, 18 August** when we will catch the ferry from Topsham to the Turf Hotel, at the end of the Exeter Ship Canal, for lunch.

This is a repeat, by popular demand, of last year's very enjoyable outing.

Why not join us? Please contact Dinah on **01392 - 876001**

NEWS FROM TORRIDGE

Due to various commitments and medical appointments, the attendance at our meeting on 13 May was limited to five people. A bit of a "comedown" from the turnout for our previous meeting which was a "guest speaker" event attended by about thirty five people.

Our next "get together" will be as guests of the Barnstaple group. A gentleman who has undergone Tomo-Therapy will be relating his experiences and we are considering the following themes for our autumn meeting:-

1. Lunch at the "Merry Harriers". (Popular on a previous visit)
2. Sunday Lunch at "Uncle Bill's", Hartland.
3. Guest Speaker.

Any further inputs from members would be appreciated.

Changing tack completely, I attended the recent very informative briefing by John McGrath in which he described the very sensible "Centres of Excellence" concept.

However, I recently became aware of a case in which a consultant had recommended a procedure for a patient that could only be done outside of the patient's area and the PCT refused funding without any reference to the recommending specialist.

It would obviously require a consultation to ascertain whether or not the patient's condition was compatible with the procedure and, of course, whether the patient wanted to undergo the treatment but the creation of "Centres of Excellence" has got to be the way forward.

However, it must be very frustrating for everybody if the parochial postcode gnomes prevent the system being used!!!

CONTROVERSIAL? I hope so.

Ron Cave

Did you know.....Across the whole of the UK women with breast cancer and men with Prostate cancer were most likely to survive for at least 10 years but, for all cancers, Dorset has the highest proportion of 10 year cancer survivors. Must be all that fresh air!

Wanted - Personal Experiences



As all of our members should be aware, we have a comprehensive list of members who are willing to talk about their experiences with prostate cancer and the types of treatment they have received. This is a vital NEDPSA resource, which not only reassures the newly-diagnosed patient but also gives a personal view of what to expect.

Unfortunately, there is very little information about follow-up treatments, especially for those who may have suffered surgical complications, and because of the wide geographical spread of our membership it's difficult to find out about such things by word of mouth.

In an attempt to fill this gap, the newsletter will be including a Message Board feature in future editions, so that members can ask for feedback on points of interest. If you would like to appeal for any particular help, advice or suggestions, please contact the editor.

Tony Lowe has volunteered to act as an intermediary if anyone does not want his medical problems advertised all over. In that way we will not publish your contact details but any respondents will be directed to Tony so that he can match them up with the person seeking advice.

If anyone has experience of peri-urethral collagen injections, the male sling or similar treatments, please get in touch. Tony Lowe, 01598 740331 – lowe.tony@yahoo.co.uk



Whilst we are at it, if there is anything else that you would like to write in about, complaints, suggestions or similar, then we will be very happy to hear from you.

A GHOSTLY TOUR

Trip steps, spiral staircases, hidden rooms and ghostly tales did little to deter the Barnstaple group from enjoying a fascinating tour of Chambercombe Manor recently.

Tucked away in one of the more remote corners of Ilfracombe (yes, they do exist) Chambercombe Manor is something of a hidden gem. Dating from 11th century it has a fascinating history, which is kept alive by a willing band of volunteers, who not only maintain the property but lead guided tours.



Twenty members of our group listened intently as a witty and informative guide led us through the property via a labyrinth of rooms, stairways and passages. After such an 'exhausting' tour it seemed appropriate that we replenish our energy with an excellent cream tea at the Manor's tearooms. A gentle stroll through the Manor's delightful gardens helped the digestive systems and completed a most enjoyable day.

The next group meeting will be a slightly more formal affair! Allan Grimsley has kindly agreed to come and talks to us about his PSA rollercoaster, the Pfeiffer Protocol and Tomotherapy. We're very much looking forward to hearing about his experiences. The meeting will be held at our usual venue in Fremington Parish Hall on Thursday 19th August at 10.00

Tony Lowe

01598 740331

On the right we can see the Group relaxing outside the Tea Rooms after the tour whilst above is the Chambercombe Coat of Arms.



Association Meeting – July

Jane Billing got us underway with recent developments at the RD & E and in particular the introduction and development of the "Enhanced Recovery Programme." This is all about improving the patient experience, its outcomes and speed of recovery after surgery. This clearly will be of enormous benefit to both patients and the hospital.

The programme focuses on making sure that patients are active participants in their own recovery and is being rolled out through the NHS nationally. Importantly, it is clinician driven as opposed to being imposed by admin which means that all the changes are being introduced for all the right reasons.

There are 4 stages to be considered. First of all the pre admission assessment; followed by steps to reduce the physical stress of the operation itself; immediate post-op care; and finally early mobilisation. Jane gave examples where open radical prostatectomies which previously required a 5 - 7 day stay in hospital are now turned around in as little as 2 days.

She also gave details of some of practical procedures used to achieve this including a reduction of the use of morphine for pain relief; elimination of drains and tubes for feeding; and some more bizarre examples such as pre-op carbo loading and the use of chewing gum to speed up recovery of the digestive system!

Patients would also be given leaflets explaining what would be happening to them during their stay. The first would be a general information sheet about the procedure but the second one would give a detailed programme of what the patient would be doing on a day by day basis during his stay.

The RD & E were amongst the leaders in the implementation of this programme, thanks to the efforts of John McGrath who was also instrumental in establishing a Research Area at Wonford and some trials had already started with more in the pipeline.

Mr Crundwell would shortly be taking on laparoscopic (keyhole) prostatectomies at Wonford and she was also pleased to say that the Headlight camera, purchased by the Chestnut Appeal and to which we had also contributed, had been delivered that very day.

On our return from coffee, Paul Bennett of the Prostate Cancer Research Centre gave us an insight into the working of the Centre. It was started in 1989 in St. Paul's Hospital and shortly afterwards moved to its current site in Riding House Street as part of the University College London (UCL).

Paul is the Fund Raising and Communications Director responsible to the Executive Director and we were pleased to hear that the Charity itself is run on a shoe string with only 2 other members of staff, one lady in charge of administration and another looking after events and publicity.

The research is carried out in the laboratories of the University College London (UCL) by a small group of scientists who are currently looking at two particular areas - **stem cells** and the **invasion and spread of the disease**.

It is thought that cancer often starts in a stem cell but much of the therapy that is used to treat cancer kills lots of the cancer cells, but tends to spare the cancer stem cells. So if we could target and kill the cancer stem cells, there is the possibility of curing the cancer. Finding the stem cells though is a little tricky. The average prostate gland weighs approximately 7 grams and 1 gram contains about 1 billion cells. Of that billion a mere 100 to 1000 are stem cells! A new incubator with a built in microscope recently acquired enables them to study the development of these stem cells more easily.

The second area focuses on how and why the cancer spreads from the prostate. Whilst confined to the prostate it can be cured with surgery or radiotherapy, but once it has spread beyond the prostate it is hard to treat. This research will assist in the development of treatment to delay or prevent the spread. In this context he pointed out that there had been no improvement over the last 20 years in the survival rate for men with locally advanced cancer.

He explained also how they worked with other Charities under the umbrella of the *Prostate Cancer Charter for Action* in order to avoid unnecessary overlapping of the functions and services provided

Paul was impressed by the number of ladies we had at the meeting as he the Charity recognizes their importance in its work and has recently launched a 'My Man' Campaign to highlight this and to encourage even more involvement with the Ladies.

DATES FOR YOUR DIARY

Wednesday 4 August - at the North Devon Show - a Chestnut Appeal Stand manned by local NEDPSA volunteers.

Wednesday 18 August - Ladies Group outing on the Topsham Ferry - for details phone Dinah Quastel on 01392 876001

Thursday 19 August - Barnstaple Group meeting at Fremington Parish Hall for "A conversation with Allan Grimsley" at 10.00am.

Thursday 9 September - Exeter Group meets at 39 Clyst Valley Road at 10.30 am. Tel Tony Hanson 01392 874254 for more details.

Wednesday 15 September - Tiverton/Cullompton/Honiton Lunch at the THREE TUNS, Silverton at 12.30 pm. Please phone Ken or Sylvia Trow on 01392 841603 to let them know you are coming.

Monday 20 September - The Sidmouth Group will meet at the Royal York & Faulkner Hotel. Further details from David or Jennifer Jannaway (01395 567159).

Thursday 7 October - The Budleigh Exmouth group will be holding a Collection Day at the Tesco Store, Exmouth

Tuesday 12 October - Budleigh Salterton & Exmouth Group Meeting at Tidwell Manor 2.30 pm. Tel David Warner (01395 442707) for further information.

Thursday 21 October - Association Meeting. ISCA Centre 10.00 am. Speaker- Graham Fulford of the Fulford Foundation.



SCENES FROM THE HONITON CREAM TEA

Held at Manna House, courtesy of
Brian and Jill Godfrey.

