My main problems were:

- Tender mouth. I bought a child's soft toothbrush and used my grandson's strawberry flavoured toothpaste. I left my partial denture out for long periods during the day as well as at night.
- Dry, sore lips. A little Vaseline was very effective.
- Constipation. My digestive system seemed to grind to a halt very soon after each treatment. The steroids made me feel (and look) bloated but also stimulated my appetite so I continued eating. I was prescribed some laxatives (Lactulose and Fybogel) but to some extent it was a waiting game.
- Blood in my urine. I think this was made worse by the WARFARIN (anticoagulant) which I take. If you have to have your INR monitored be sure to have it checked frequently. Chemo sent mine haywire.
- Infections. This is a potentially serious hazard so you are given advice in your pre-assessment about the precautions you need to take such as keeping clear of anyone with an infectious illness (and avoiding crowded places, just in case), avoiding certain foods, taking your temperature daily and avoiding PARACETAMOL if possible (this keeps your temperature down, so might hide the early signs of infection).
- Tiredness. About two days after each session I would feel tired, weary and slightly achy. Generally a bit rough in a non-specific way.
- Peripheral Neuropathy. Tingling and numbness in toes and finger. This only started after my 7th session, not following a three week cycle but slowly getting more evident after each treatment.
- Hair loss. This was a bit patchy so I just had mine cut grade 1 all over.
- Bad taste. No I didn't start wearing clashing colours! The taste of tea, coffee and many more of my favourites was ruined.
- Heartburn. I started getting this very frequently. Doctor prescribed me some OMEPRAZOLE and the heartburn stopped abruptly after I took the first capsule!

There are other possible side effects which, thankfully, I didn't get, but that was my experience.

Thinking back, it is the positive things which come to mind. The benefit in terms of setting back the progression of my cancer. The professionalism and friendliness of all the staff on the whole of the Deansley unit. The time I spent on the Snowdrop suite actually receiving was made pleasant and became a part of my routine that I actually missed when I finished.

Would I have it again? Definitely. You might think that is easy to say because it is a hypothetical question. DOCETAXEL is apparently only licensed for a single course of 10 sessions. What I can say though is that at the time, when discussing my side effects with doctors and nurses, my biggest fear was that they would stop my treatment.

"Wishing you all a very happy new year for 2011 from Clare, Jenny, Helen and everyone in Urology"

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The Royal Wolverhampton Hospitals NHS
NHS Trust

Wolverhampton Prostate Cancer Support Group

Newsletter December 2010

Welcome to the latest newsletter for the Wolverhampton Prostate Cancer Support Group. Meetings will continue for 2011 at the regular time of 1.30pm to 3.30pm at the Community Centre, Marsh Lane,Wolverhampton. Please be aware that the community centre is being rebuilt at present so we have moved to the building opposite. Thank you to everyone who continues to support the group and attends the meetings. Please continue to contribute to the raffles, we rely on monies raised to fund the meetings.

New Programme for 2011

Here is the new programme for the next year's meetings. If there are any subjects of particular interest to you that do not appear on the programme then please let Clare Waymont or Alan Morris know.

Monday 24th January 2011 –RAFFLE
Diet and Prostate Cancer
(Ann Malone – Health evolution)

Monday 21st March 2011
Radiological Staging of Prostate Cancer
(Mike Collins – Consultant Radiologist)

Monday 16th May 2011 - RAFFLE
Topic to be confirmed
(Mr Cooke - Consultant Urologist)

Monday 11th July 2011
PSA and Prostate Markers
(Jane Boddy – Consultant Urologist)

Monday 5th September 2011 – RAFFLE
Topic to be confirmed
(Brian Waymont – Consultant Urologist)

Monday 31st October 2011
Treatment for Advanced Prostate Cancer
(Richard Gledhill – Prostate Cancer Specialist Nurse

Monday 12th December 2011 – RAFFLE
A Pathologist's perspective of Prostate Cancer
(Uttara Karnik – Consultant Histopathologist)

Welcome to New Consultant

Miss Jane Boddy, Consultant Urological Surgeon, joined the urology team at the Royal Wolverhampton NHS Trust on the 1st November 2010. Miss Boddy graduated from the University College London Medical School in 1998. From here she went on to complete her Basic Surgical Training at the Queens Medical Centre, Nottingham.

Having identified her interest in urology she obtained a Research Registrar post at the Royal Berkshire Hospital, Reading where she spent two and a half years researching into new diagnostic and prognostic markers for prostate cancer, working in collaboration with the Cancer Research UK group in Oxford. During this time she presented her work at numerous national and international meetings and much of it has been published in recognized journals.

Having been successfully awarded a Doctorate of Medicine Degree by the University of London for her research she went on to take up a Specialist Registrar Training position in the West Midlands.

During this 6 year training scheme Miss Boddy worked at many of the large teaching hospitals within the region and gained a broad range of urology experience with an emphasis on the diagnosis and management of urological cancers.

Miss Boddy continues to have a primary interest in the care of patients with cancer, and in particular prostate cancer and has recently written a book chapter covering the management of this disease to help trainee urology registrar who are taking their FRCS exams.

Miss Boddy hopes to continue her work in this area and help further develop the services for this disease in the Wolverhampton area. Miss Boddy writes,' I am looking forward to becoming an active member of the urology team and hope to help those patients and their families affected by cancer and work with them to ensure we provide the best care possible'.

Behind the scenes

The urology waiting list personnel are responsible for organising procedures and operations once you have been placed on the waiting list. They liaise with your consultants and make all the necessary, behind the scenes arrangements to try and make your experience as stress free as possible. As with lots of staff behind the scenes the department could not function efficiently without Heather, Jayne and Nina and I would like to say a huge thank you to them for all their hard work.

The Prostate Cancer Charity comments on UK National Screening Committee decision against prostate cancer screening

The Prostate Cancer Charity comments on the latest announcement by the UK National Screening Committee not to recommend the development of a screening programme for prostate cancer using the PSA blood test.

John Neate, Chief Executive of The Prostate Cancer Charity, explains: "Although this decision is not a surprise, the announcement from the UK National Screening Committee today is extremely disappointing. While the evidence points to the potential risk of over diagnosis and over treatment through large scale PSA testing, we also know that for some men with aggressive prostate cancer, but no symptoms, the PSA test will be the only early indicator of the cancer at a time when effective treatment can be offered. This makes it essential that all eligible men* are made aware of the test and enabled to make a personal choice about whether it is right for them.

"We believe that a critical opportunity to fully address the inequities faced by men seeking access to the PSA test has been missed. We know that 70 per cent of men over 50 are unaware of the test's existence or their right to request one from their GP. We also know that this roadblock in accessing the test widens even further for those men from less affluent backgrounds. This is a completely unacceptable state of affairs.

"Although we will always seek to work constructively with Government, the status quo cannot continue. It is a regrettable that this announcement has been made in isolation by the UK National Screening Committee and that a key opportunity to reflect on the wider issues surrounding awareness of prostate cancer and the PSA test was not grasped. This could have been a breakthrough moment for Government to give a firm steer on this critical health issue.

"We will ensure that PSA testing for eligible men is not simply returned to the back-burner and will over the coming months be launching a vigorous and constructive campaign to break this impasse."

We are Sailing!

In April 2010 a group of staff from the urology department were lucky enough to take part in the BRAUN 2010 NHS Regatta. Clare, Jenny and Helen were amongst the crew who took part in a weekend of racing between Portsmouth and Cowes in the Isle of Wight. None of the crew had ever sailed before and with just the direction of our skipper we managed not to sink the yacht and more importantly we didn't finish last! It was an amazing experience and one which we would all hope to repeat again in the future.

Current Prostate Cancer Research and Clinical Trials

(Taken from Cancer Research UK Website)

Surgery

A trial called LopeRA is comparing three operations for prostate cancer. It is comparing open surgery, keyhole (laparoscopic) surgery and robot assisted surgery for prostate cancer that has not spread. Doctors usually remove localised prostate cancer with surgery. There are several ways to do this, and no one is quite sure yet which one is best.
Open surgery is when the surgeon makes a cut in the abdomen, or between the testicles and back passage, to remove the prostate. Laparoscopic surgery is when the surgeon makes several smaller cuts and puts surgical instruments and a camera through these small holes. The surgeon uses these to look inside, find and remove the prostate. Robot assisted surgery is similar to laparoscopic surgery. But the surgeon controls the instruments and camera using a machine (robot). It is sometimes called da Vinci surgery. Some of the aims of the trial include how long you stay in hospital, the side effects, and to see if the cancer comes back after surgery.

Radiotherapy

Changing the external radiotherapy dose

Researchers are looking at different ways of giving the total dose of radiotherapy for men with prostate cancer. The CHHIP trial aims to find out if giving a higher dose of radiotherapy per session (fraction), but fewer fractions, works as well as standard radiotherapy. The researchers also want to find out what the side effects are. All men on this trial will have IMRT.

Combining internal and external radiotherapy

An NHS trial is looking at combining internal radiotherapy (brachytherapy) and external radiotherapy. This trial finished recruiting patients in August 2005. Initial results were released in 2007. The researchers found that a combination of external and internal radiotherapy was useful for treating localised prostate cancer. Combined treatment seemed to give a lower chance of the cancer coming back, a better quality of life and fewer rectal side effects. The trial team are still following the progress of the men who took part. They plan to do a further analysis in late 2010.

Radiotherapy after surgery

At the moment, many men who have removal of the prostate gland (radical prostatectomy) for early prostate cancer will not have any further treatment unless their PSA level rises. The RADICALS trial is looking into whether it would be better to give all men radiotherapy after radical prostatectomy, whatever their PSA level. It is also investigating whether having hormone therapy as well works better than radiotherapy on its own for this stage of prostate cancer, and if so, how long you should take it for

Finding out about radiotherapy side effects

A study called PRECIOUS is looking into how doctors and nurses collect information about the side effects of radiotherapy for prostate cancer. Researchers have developed a questionnaire which people answer on a computer. They want to test the questionnaire to find out how good it is at helping doctors understand and treat the side effects. This study is now closed and we are waiting for the results.

Radionuclide radiotherapy for bone metastases

In Belfast, there was a small trial of internal radiotherapy for men whose prostate cancer had spread to the bones, and was no longer responding to hormone treatment. Men in the trial had docetaxel chemotherapy, steroids, and rhenium-186. Rhenium-186 is a radioactive substance which doctors think will target the cancer cells in the bone, and stop them growing. This is called radionuclide treatment and is a kind of internal radiotherapy. The trial has now closed and we are waiting for the results.

Finding out how radiotherapy affects the immune system

The Prostate Radiotherapy Pneumovax Study (PRP) is a small study looking at how radiotherapy affects the immune system of men with early prostate cancer. Men with prostate cancer on this study have already started hormone therapy. Researchers take blood tests from some men before they have radiotherapy and from some men before, during and after radiotherapy. All the men on the trial have vaccinations against a particular type of pneumonia at different stages of their treatment. Blood tests aim to show how the immune system responds to the vaccine before or after radiotherapy. The researchers hope that the results from this study will help them to develop a cancer vaccine to treat prostate cancer. This trial has closed and we are waiting for the results.

New hormone therapies

Doctors are continuously looking for new hormone therapies to treat prostate cancer. Many of the current hormone drugs cause a rise in testosterone when they are first taken. So prostate cancer symptoms tend to get worse before they improve. A drug called abarelix does not seem to do this. Research so far shows that abarelix works more quickly on prostate cancer and does not seem to cause the initial rise in testosterone levels that other standard hormone drugs do. Similar drugs are also being tested, including degarelix, ganirelix and cetrorelix. Degarelix is now licensed in the European Union for treating advanced prostate cancer. In Jan 2010, the All Wales Medicines Strategy Group (AWMSG) did not recommend it for use on the NHS in Wales. They said it is not cost effective.

The AFFIRM trial is testing a new hormone therapy drug called MDV3100 for prostate cancer that is getting worse despite hormone therapy and chemotherapy. MDV3100 blocks the receptors that testosterone uses to get into prostate cancer cells. It is a type of hormone therapy called an androgen receptor antagonist. This trial aims to see if MDV3100 helps men with prostate cancer to live longer.

In 2003 a small pilot study looked at hormone replacement therapy (HRT) patches to treat men with advanced prostate cancer. The researchers reported that all the men in the study who were treated with HRT patches felt that they had an improvement in their quality of life. But this was only one small study. Larger, randomised, controlled clinical trials are needed before we know more about the side effects men get when treated with hormone patches. The PATCH trial is comparing oestrogen patches with standard hormone treatment to see if they work as well.

Early trials of a hormone therapy called abiraterone have shown some promising results. A phase 3 trial called COU-AA-302 aims to find out how well the combination of abiraterone and the steroid prednisolone works for men with advanced prostate cancer. Abiraterone acetate stops an enzyme in your body called CYP17 from working. If CYP17 can't work, your body cannot make testosterone. The trial is for men who have had hormone therapy, but not chemotherapy. This trial has finished recruiting patients, but the results are not known yet.

Chemotherapy: by Robert Cox

'my biggest fear was that they would stop my treatment.'

Prostate Specific Antigen (PSA) seems to be the blood test which is used to measure the effectiveness of prostate cancer treatments. A substantial rise in PSA, despite continuing treatment, may mean that the disease has become hormone refractory. If the disease is already advanced, this may indicate that chemotherapy could be useful.

When I was told that my PSA had risen to levels where I needed a referral to an oncologist for possible chemotherapy I was, to say the least, apprehensive. Now, a year later, I can tell a happier story than the one I had conjured up in my mind. Perhaps I can share that story with you in the hope that if chemo ever becomes a possible part of your treatment, your reactions will not be the result of inaccurate and outdated preconceptions.

Of course I am not going to tell you that I had no side effects with my chemo. I had several. Even some potentially serious problems.

No, what I can say is that if,12 months ago, I knew what I know now, I would not hesitate to have that chemo.

My diagnosis was given to me in January 2009. I had gone to my G.P. with back pain – pain which seemed to be spreading around my upper body. Almost as an afterthought I mentioned my waterworks; slow urine flow and over frequent visits to the toilet at night. My Doctor sent me for an X-ray and a blood test (PSA). 'Come back and see me in two weeks for the results' he said. A week later, however, I was beckoned to an outpatient appointment at New Cross Urology department, when hormone treatment for prostate cancer was started. A subsequent bone scan confirmed that the prostate cancer was advanced and had already spread to my shoulder blades, vertebrae and several ribs. Hence the pain.

My PSA came down from a high of 779 to 9.6. However, before the end of that year my PSA was unstable again, hence the referral to oncology and the chemo which started in March 2010.

The cytotoxic drug I was given was DOCETAXEL, often referred to by the brand name of TAXOTERE. I had the usual course of 10 treatments given intravenously at intervals of three weeks. The total duration of treatment being a little over 6 months.

Steroids and anti-sickness medications were given around the time of my chemo and I am happy to report that the anti-sickness medication was particularly effective. I was told that if I experienced any nausea or vomiting I could ask for higher doses, but this was not necessary. The nausea or vomiting I had dreaded so much was not a problem. ▶