



Torbay Prostate Support Association

Serving men of all ages, and their partners, through a programme of support before, during and after diagnosis
Newsletter Spring 2014 Issue No.36

Chairman's Report January 2014

Dear All.

I trust all is well with everyone. There are one or two matters to report on, so hopefully I will try to bring you up to date. One of the projects we are bring about is the purchase of IMRT equipment. We are almost there and it should be insitu during February. Contributions and Donations towards this project costing up to £30.000 will be very welcome. A thank you to Torquay & Dartmouth Rotary Clubs and many thanks to all the individuals who have also been so generous. A more detailed report in layman's terms at our next talk. Family and friends at our last members meeting really enjoyed an excellent presentation by Fiona Ross MacMillan Dietician based at Torbay Hospital.

TPSA Members can you help

Phil Burr of the West Wales Prostate Cancer Support Group has asked if any of the of the TPSA members can help. "One of our members, John, is suffering long term incontinence, following prostatectomy in 2008. (obviously a very patient guy!) He is on a waiting list to have a male sling procedure. He would like to talk to someone who has followed this route. Unfortunately he doesn't have use of the internet. If there is anyone who can help and is willing to talk to John please let me know so that I can put you in touch. Please e-mail me on hilbwales123@btinternet.com or by calling 01559 363154."

The Torbay Police Choir together with the Cordettes Ladies Chorus

concert in aid of the TPSA on Saturday evening
12th July at Central Church Torquay.

NEXT TALK

Emma Meckiff BSC. Hons. Head of Pre Treatment Torbay Hospital

Intravenous Contrast and Planning of Prostate Cancer AT THE Redcliffe Hotel.Paignton Thursday 27th February
2014 1000 for 1030hrs EVERYONE WELCOME (Not Just Members Charity no. 1095734

New Hope for men with untreatable prostate cancer

Wonder drug set to extend survival time and improves quality of life for men with untreatable prostate

cancer **Enzalutamide (Xtandi)** is now available in England via the Cancer Drugs Fund A new drug for prostate cancer patients who have run out of treatment options has been licensed for use in the UK. It is now available in England via the Cancer Drugs Fund to men whose disease has become resistant to first-line hormonal treatments and has not responded well to chemotherapy. Early-stage prostate cancer can be treated but it is incurable if the disease spreads. Up to 30 per cent of men are not diagnosed until the disease has reached this stage, and 72 per cent of these will die within five years. Trials involving a number of sufferers with advanced cancer showed that Enzalutamide improved overall survival. Prostate cancer is fuelled by the male hormone testosterone. Enzalutamide works by targeting the male hormone receptors in the cancer cells, so blocking the effects of testosterone It is reported that Heather Payne, Consultant in Clinical Oncology at University College Hospital, London, says: 'Enzalutamide allows us to offer men another option which will extend their lifespan, and allow them to maintain a good quality of life for longer.' Although Enzalutamide is currently licensed for use only when other treatments have stopped working, it is also being trialled for use in earlier stages of the disease. she adds: 'It's not a cure but it slows down the progression of the disease. This drug gives huge hope to men with prostate cancer.' Enzalutamide, which is taken in capsules once daily, is now awaiting approval by the National Institute for Health and Clinical Excellence.

Why bone health is important if you are having hormone therapy

If you are unfortunate enough to be diagnosed with advanced prostate cancer, or your cancer has become advanced, the only treatment option available is Hormone Therapy. Although this will prolong your life, it will also cause osteoporosis, which in time can lead to Skeletal Related Events (SREs). It is therefore important to understand the particular problems surrounding advanced prostate cancer.

Why is bone health treated differently in prostate cancer?

In every other cancer, NICE has laid out a treatment pathway, which involves bone health with treatment with bisphosphonate drugs and latterly, Denosumab. These drugs help to limit the damage to your skeleton caused by hormone therapy, and therefore avoid SREs. Not so with prostate cancer, there is no pathway laid down by NICE involving bisphosphonates for bone health, so it is important that the patient knows about the issues involved.

So What are the treatments for my bone health

Bisphosphonates

There are many bisphosphonate drugs and many are taken orally, once a week on a particular day. They are taken first thing in the morning with a full glass of water, on an empty stomach. The patient has to be either sitting or standing in an upright position and must not eat or drink anything for at least 30 minutes after taking.

The standard bisphosphonate treatment is Zoledronic Acid, marketed as Zometa. This is given as a monthly infusion into the patient's arm and requires a visit to hospital. Blood tests have to be taken either on the day, or in the days immediately preceding the infusion.

Denosumab

Denosumab, marketed as Xgeva, is a new drug for bone health which has just been passed by NICE for all cancers, apart from prostate cancer. It works in a different way from bisphosphonates in that it is a fully human monoclonal antibody, which prevents bone destruction. Denosumab is given by a monthly injection given by your healthcare professional.

OK so what are the side effects of taking these treatments for my bone health?

All of these treatments are well tolerated, but as with all drugs, there can be side effects. The most serious of these is a condition called osteonecrosis of the jaw. The symptoms may include jaw pain, swelling, numbness, loose teeth, gum infection, or slow healing after injury or surgery involving the gums. In view of this, dental hygiene is of vital importance and

if the patient needs an extraction, then treatment must be stopped one month before dental work and until any damage to the gum and jaw are fully healed. To assist with this and nocturnal dry mouth there is a toothpaste called Duraphat 5000, which is available from your dentist on prescription.



So Why is bone health so important know

Both bisphosphonates and denosumab help to keep your skeleton healthy and prevent osteoporosis and skeletal related events. This is especially important when hormone therapy has failed and with the advent of new drugs like Abiraterone, many patients can look forward to an increasing lifespan and bone health is essential for quality of life.

They are available where I live

They are available in many parts of the country, but only your oncologist can tell you where.

How will advanced prostate cancer affect my family?

Men diagnosed with advanced prostate cancer will receive Hormone Therapy as their main treatment. As there is no curative treatment at the moment, this can be an on going cause of anxiety for the patient and his family

How will my treatment affect me?

Men who have advanced disease often feel better quite quickly, when they receive Hormone Therapy. The most common side effects initially are hot flushes and tiredness. As time goes on these settle down in most cases . Long term use of Hormone Therapy can cause Osteoporosis.

Will it affect my relationships?

Sadly, the other main effect of Hormone Therapy will be loss of libido and erectile dysfunction. There are treatments available which can give some help, but it is important to talk about these issues openly and honestly with partners and health professionals .

However, this is a life saving treatment and as with many drugs, side effects have to be weighed in the balance against no other treatment option .

Is it best to share my feelings?

Being diagnosed with a life threatening illness is both physically and psychologically challenging. Some men feel they cannot bring themselves to tell other people about their illness, but many find that by talking things through with their family and friends, but more particularly with fellow patients, can be helpful and informative.

Is there anyone locally to help me

Your local prostate cancer support group, is made up of prostate cancer patients who have experience of the disease in all its stages . There is a helpline which is available to patients and family members who may wish to talk through their issues. Wives and partners often struggle to come to terms with the diagnosis and find it helpful to talk to others who have had a similar experience.



Do I have to change my lifestyle or diet

Doctors recommend that exercise and a good balanced diet are important to maintain good general and mental health .

Will I be able to work?

This must be a personal decision, governed by age, the type of work and success of treatment.

Anger over NHS 'U-turn' on prostate cancer drugs

Enzalutamide (Xtandi)

Charities have accused the the National Institute for Health and Clinical Excellence (Nice) of “playing fast and loose” with the lives of those in the advanced stages of disease - dashing the hopes of thousands of men for whom it offered a last chance

Gift Aid declaration –for a single donation

Please treat the enclosed gift of £_____ as a Gift Aid donation. I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for the current tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities and Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for the current tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 25p of tax on every £1 that I have given. **Please forward completed forms and donations to Darrell Fulford (Treasurer) Corbyns, Ridgeway Road, Torquay TQ1 2HL**

Donor's details

First name & Surname _____

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