

## MID SUSSEX PROSTATE CANCER SUPPORT GROUP

### UROLOGY MACMILLAN TEAM PRESENTATION HELD ON 14 OCTOBER 2021

Brian Holden, Chair of the Support Group, welcomed members to the first face to face meeting with presentation for almost two years. He explained Health and Safety and Fire precautions and gave a rough timetable for the afternoon.

Brian then introduced Dan Rainsford-Holt and Anna Gochban, another member of the Macmillan Team in Brighton, who gave the following presentation:

#### PRESENTATION

To answer the question "Who are we and what do we do?", Dan explained the team and their roles.

The team consists of Dan Rainsford-Holt, Anna Gochban, Claire Mozd and Paul Walder. Paul is not a nurse but a support worker covering the areas the team covers and making sure things are run properly and on time. They are a very busy department.

Dan explained it is hoped that the team will soon have a new job filled, "Macmillan Urology Cancer Support Worker/Follow-up Coordinator", who will be involved in scans and blood tests etc. ensuring they're done on time.

Dan then outlined the urology-based cancers with which they work:  
Penile, Prostate, Testicular, Bladder and Kidney. The team actually cover a little bit of everything as follows:

- Liaison with GP
- Answering questions by phone or email
- Referring to other agencies eg, dieticians, finance people
- Chasing up scans or reports
- Supporting families when things get tough
- Helping with the embarrassing elements
- Nurse-led clinics in place of Doctor clinics
- Making clinical decisions
- Applying for grants or completing medical reports
- Applying for blue badges
- Reviewing people on the wards and advising junior staff
- Teaching - student nurses etc.

- They interact with patients and their families, doctors, nurses, care homes, hospitals, therapists, community teams, palliative care, Macmillan Horizon Centre, Dept of Work and Pensions, Leisure Centre staff, Pharmacists, exercise groups, dentists.

Dan stressed that if you are in any doubt, or if you're worried about anything, please speak to them on 01273 067800 or email [uhsussex.urologymacnurses@nhs.net](mailto:uhsussex.urologymacnurses@nhs.net)

There are so many ways to treat patients, and so many options to consider. Dan and the team are always there to talk things through, and offer advice.

He advised that men currently seem to be presenting later, and they are seeing situations which are a lot more complicated.

### **Initial Prostate Cancer Treatment and need for Further Treatment**

#### **Typical Questions the team encounter -**

- How long has it been there?
- Why do we treat and why do we wait?
- Why should I choose my own treatment?
- That isn't what my friend had
- How do I tell... my family, my friend etc?

Dan stressed this is your own personal story.

The facts are that prostate cancer is the most common cancer in men, more than 40,000 are diagnosed annually and more than 9,000 die each year. 1 in 8 men will get prostate cancer in their lifetime, with the most common age being over 50. Noted transwomen can develop prostate cancer.

#### **Treatment - Hormones vs surgery**

There is no right or wrong answer. If the cancer is a higher grade, it usually rules out surgery.

#### **Hormones side effects**

- breast development,
- hot flushes,
- mood changes,
- erectile dysfunction,
- fatigue,
- risk of incontinence,
- retrograde ejaculation (where it gets sucked up into the bladder giving cloudy urine)
- fertility issues

## Radiotherapy

- External beam vs brachytherapy
- Risk and benefits of both
- Side effects during and after treatment
- If you have radiotherapy first, it makes surgery later very difficult.
- Some like to have surgery first with radiotherapy as a backup.
- **MSCC** (Metastatic spinal cord compression) This is when cancer has spread from the prostate and moved near to the spine pressing on spinal cord.

## Chemotherapy

Docetaxel/Cabazitaxel - only given for advanced prostate cancers

### **Side effects:**

- sickness,
- fatigue
- sore mouth, hands and feet
- risk of infection
- bruising or bleeding
- loss of appetite/taste changes
- diarrhoea
- hair loss
- peripheral neuropathy
- conjunctivitis
- build up of fluid

## Other Treatment

- HIFU - only given for localised cancer
- Cryotherapy - only given for localised cancer and not available in Brighton
- Steroids - with the intention of shrinking the cancer
- Radium 223 - can be given for metastatic bone usually after Docetaxel
- Enzalutamide - blocks testosterone from reaching cancer cells. Has had some amazing effects so this is being used more and is more easily available, but very costly.
- Abiraterone - given with steroids, reduces amount of testosterone produced.

## Side Effects of Enzalutamide and Abiraterone

- hot flushes
- fatigue
- hypertension
- headaches
- restless legs
- muscle or bone pain
- skin changes

- mood changes
- difficulty concentrating
- osteoporosis
- sexual changes
- build up of fluid
- dizziness
- raised blood sugar
- raised cholesterol with Abiraterone.

Doses can be altered to allow benefits and reduce side effects, or maybe having short periods when you stop taking medication. If you're unsure about anything, please ring or email:

- Specialist Nurses team on 01273 067800 or uhsussex.urologymacnurses@nhs.net
- Consultant's secretary
- Chemotherapy team on 01273 696955 ext 64799
- or Research nurses if applicable.

Questions were then taken from members:

Brian asked why his Urologist reported his to be a smooth and benign prostate, following Digital Rectal Examination (DRE), when in fact his cancer was T3a Locally Advanced. Dan explained that a DRE could not feel all sides of the prostate and was not therefore a conclusive test. Dan had even brought along a device whereby members could feel for themselves what doctors might feel when examining by DRE!

Brian also asked how common was bowel incontinence following surgery, and Dan replied that it was very common, as well as urinary incontinence.

The wife of a new member asked whether there was any special nutrition advice for those with prostate cancer. It was agreed that everything in moderation was good advice. (We highly recommend watching a very good presentation by Penny Brohn available to watch on our website, if any member requires further advice.)

David, one of our newer members, mentioned to Dan and the group that he had been involved with Albion in the Community, including speaking with local leisure centre staff about the benefits of physical exercise for those with PC, and the difference it made for his personal treatment and recovery.

The meeting concluded with refreshments all round, whilst Dan and Anna mingled with members and guests who asked more personal questions. Members and guests also enjoyed catching up and chatting together.