

PHAROS

A beacon of hope in the darkness

Newsletter of the Reading Prostate Cancer Support Group (RPCSG)

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Website: www.rpcsg.org.uk

THE AUGUST MEETING.

The August meeting was held using Zoom and featured a talk by Lorraine Grover. The meeting was well attended by 17 RPCSG members and 12 participants from other prostate support groups. The talk by Lorraine was very interesting, with many accounts of Lorraine's experiences.

Lorraine introduced herself as previously being an Accident & Emergency sister and is now a Psychosexual Nurse Specialist (A combination of being a Clinical Nurse Specialist in Erectile Dysfunction as well as a sex therapist). She has 27 years expertise managing sexual issues for people who are diagnosed with prostate cancer. She works in the private sector and does much work for charities.

Lorraine described the impact of cancer on sex, intimacy and relationships and said that age and relationships are no barriers to addressing sexuality with patients. The organisation NICE (National Institute for Health and Care Excellence) has issued some guidelines in their document NG131 concerning prostate cancer. These include:

- Healthcare professionals should ensure that people and their partners have early and ongoing access to specialist psychosexual and ED (erectile dysfunction) services.
- Patients and their partners or carers should have the opportunity to talk to a healthcare professional qualified and experienced in dealing with psychosexual issues at any stage of their treatment.

NICE has also issued Quality Standards that were updated in May 2019 and say that:

- People with adverse effects of prostate cancer treatment are referred to specialist services.
- The specialist services include erectile dysfunction services, continence services and psychosexual counselling.

PCUK (Prostate Cancer UK) found that 76% of men treated for prostate cancer experience ED but just 30% of those men received the support that met their needs. Lorraine found that in cases of men having radical prostatectomy 98% had an impact on their sexual function.

PCUK recommends early intervention and a choice of five treatment options:

- Appropriate choice of medication including a daily low dose of tadalafil
- Vacuum pumps
- Access to an ED clinic
- Access to a psychosexual clinic
- Counselling.

Lorraine discussed ED and the lifestyle factors that can affect it adversely:

Alcohol
Drug and substance abuse
Smoking
Obesity

There are several possible physical causes of ED:

Diabetes

Vascular disease

CHD (Coronary Heart Disease)

Pelvic surgery

Peyronie's disease

Psychogenic factors can also contribute to ED such as Anxiety, Relationships, Depression and Stress.

Some risk factors in both ED and coronary heart disease are smoking, high blood pressure, cholesterol level and diabetes.

Lorraine said that there is a small artery for the penis and that ED can be a marker for other issues. If diabetes and hyperlipidemia are not controlled then heart problems can occur maybe 3 to 5 years after the onset of ED.

Lorraine talked about treating ED following prostate cancer treatments. There are two booklets on this subject that are available from PCUK titled 'Treating Erectile Dysfunction after surgery for pelvic cancers' and 'Treating Erectile Dysfunction after radical radiotherapy and androgen deprivation therapy (ADT) for prostate cancer'. She then described the effects of treatment on sexuality, which are:

- Fatigue, sleep patterns and arousal difficulties
- Nerves can be affected by surgery that impact on erections, penile size and lack of ejaculate
- Radiotherapy can cause a gradual onset of symptoms such as bowel disturbance and reduced sensation.
- Chemotherapy has temporary effects such as tiredness, lower sex drive, hair loss and mood swings.
- Hormonal changes such as hot flushes and changes in body image. Testosterone deficiency can cause lack of desire and erectile function, lack of strength and vigour, and decreased muscle mass and bone density.

Treatments for ED were described. These are:

- Lifestyle changes; as mentioned these are stop smoking and keep a healthy weight
- Vacuum devices produce an erection either for exercising the penile muscles or for maintaining an erection by the use of constriction bands.
- Intraurethral pellets (known as MUSE) that is a small pellet introduced into the urethra close to the tip of the penis.
- Injections. These are quick, painless using fine needles and very effective. The correct dose has to be established and this will be done with professional guidance.
- Tablets such as Viagra. Other brands are Cialis, Levitra and Spedra.

There are also psychosexual techniques that feature:

- Dispel myths and misconceptions
- Set expectations
- Self-focus
- Intimacy – set targets
- Communication, talk and touching
- Tasks
- In the privacy of the home.

Lorraine finished by showing a reading list that included:

Macmillan and PCUK leaflets
The New Male Sexuality. Zilbergeld 1999
Healthy Sex. Miriam Stoppard 1998
For women only. Berman and Berman 2001
Intimacy and sexuality for cancer patients . Brandenburg, Grover and Quinn 2010 (Sexual Advice Association).

And three websites:

<http://www.sexualadviceassociation.co.uk>

<http://www.macmillan.org.uk>

<http://www.prostatecanceruk.org>

There were then some questions from the participants and Lorraine was thanked for her presentation. The committee has made a gift of appreciation to Lorraine as well as donations to the charities Bloodwise and the Sexual Advice Association.

Anyone wanting more information can visit Lorraine's website <http://www.lorrainegrover.com>. Details of contacting Lorraine are in that website.

NEXT RPCSG ZOOM MEETING - 3rd September 2021

The next group meeting will be held by Zoom **on Friday 3rd September** that will feature a talk by Jo Hand who is a research nurse at the Royal Berkshire Hospital who will talk about research at the RBH.

A link for this meeting was sent to all members on the 29th August 2021.

RPCSG WALKS

We held an enjoyable walk in August starting at the Tyle Mill bridge on a walk of 5 miles with 10 members participating.

The next RPCSG walk will be on the 14th September that will start in Ramsbury at 10:30 a.m. Details and directions will be sent to members nearer to the date.

COFFEE MORNINGS

In August an enjoyable coffee morning was held at the Cunning Man in Burghfield.

The September coffee morning will be on the 21st September again at The Cunning Man in Burghfield from 11:15 a.m. Directions will be sent to members nearer to the date.

Some photographs during the August walk and coffee morning:



Refreshment stop at The Butt Inn

Coffee morning at The Cunning Man

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DISCLAIMER

This newsletter does not offer medical advice. Nothing contained in the newsletter is intended to constitute professional advice for medical diagnosis or treatment or to advocate or recommend the purchase of any product or use of any service or guarantee the credentials or appropriateness of any health care provider. Members are strongly advised to consult with an appropriate professional for specific advice tailored to their situation.

This newsletter may refer to named providers and their products or services, and such reference expresses no inference upon any aspect of any provider's business, services or products, and expresses no recommendation or preference for any such products or services.

DATES FOR YOUR DIARY.

Friday 3rd September 2021 is an RPCSG Zoom meeting with a talk by Jo Hand, research nurse at RBH.

Saturday 4th September is our awareness day in Broad Street.

Tuesday 14th September 2021 is an RPCSG walk starting in Ramsbury.

Tuesday 21st September is a coffee morning at The Cunning Man.

Friday 1st October 2021 is an RPCSG Zoom meeting with a talk on nutrition by Nicky Robinson.