

# Prostate Cancer UK's current campaigns

Tackle Annual Meeting – 13 June 2017



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CANCER UK**

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# Strategy

Prostate Cancer UK introduced a new strategy in early 2016 to tame prostate cancer and reduce the impact diagnosis and treatment has on an individual.

We are focused on four big changes to achieve this ambition:

- 1. Better Diagnosis
- 2. Better Treatments
- 3. Better Prevention
- 4. **Better Support**



# Improving treatment and support for men suffering from Erectile Dysfunction (ED)



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## Our aim is to:

Ensure all prostate cancer patients receive:  
standardised, up-to-date ED care and support, providing an individual with a choice of support services regardless of where they live in the UK.

# Campaign aims and objectives

- ED national guidance to be updated so men can access the treatments they need (return to pre-treatment baseline function)
- All men have access to the following 5 ED services/support
  - PDE5-i (Daily low Cialis)
  - VED
  - ED Clinic
  - Psychosexual services
  - Counselling
- Men are empowered to campaign to improve services locally
- HCPs/commissioners recognise and priorities the need for ED services to improve the quality of life of prostate cancer patients
- HCPs/commissioners supported to improve ED services in their local area

# Where we are now

Of all men who have had treatment for prostate cancer:

- 76% have experienced erectile dysfunction
- 30% say their ED treatment met their needs
- 47% said it had an impact on relationships

(Prostate Cancer UK Survey 2012)



**No-one understands the impact of the side effects I have. No-one asks or helps. My life is destroyed.**



**To a certain extent I have come to accept that my sexual life is over. It seems a calmer and more peaceful option than the frustration of fighting for attention in the NHS.**



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# National Commissioning Guidelines

The current guidance on impotence prescribing - called the Health Services Circular on Impotence (HSC 1999/148) - was produced in 1999 and fails to provide current best practice for treating men with prostate

Piecemeal updates.

**We think this needs to change**





# Inequality in ED care & support

- Freedom of Information – 237 commissioners  
(Daily low Cialis, VED, ED Clinic, Psychosex, Counselling)
- Postcode lottery
- Compare with results of Cancer Patient Experience Survey
- Targeted local campaign
  - 23 areas that offer less than 3 ED services
  - Nearly ½ CCGs/Health Boards/Social Care Trusts couldn't confirm or did not offer an ED clinic
  - 92 couldn't confirm/did not offer Vacuum Erection Devices (VEDs)

# Empowering men

- Online campaign platform - Better Care
  - *Empowering men*
  - *Local campaigns*
  - *How does your local commissioner compare*
  - *Improved recognition of need*
  - *Up to date picture*

<https://bettercare.prostatecanceruk.org>



# Men and partners involved (so far)

Campaign Action	November 16	December 16	January 17	Totals
Visitors to website	5,882	1,226	481	<b>7,589</b>
Individuals who searched postcode	2500	382	130	<b>3,012</b>
Completed local action	397	48	12	<b>457</b>
Completed national action	58	14	8	<b>80</b>

# Support Health Care Professionals

- HP advisory group
- Campaign platform
- Bespoke erectile dysfunction masterclasses
- Primary Care Masterclasses
- Prostate Cancer UKs Specialist Nurse

# Improving access to Clinical Nurse Specialists (CNS)



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## Our call to action

Every man living with and beyond prostate cancer will have access to the expertise of a specialist nurse who effectively supports them at specific points in their treatment/care pathway

# Access to a CNS

Some of the key advantages of having access to a CNS:

- Having access to, and being provided with, written and verbal information
- Having a point of contact for support and answers to questions
- Signposting to appropriate and essential services
- Having results explained
- Being consulted about treatment options and making informed decisions
- Feeling emotionally supported

# Commissioned CNS research

The specialist nursing workforce caring for men with prostate cancer in UK Report 2014

- **Caseloads** – Administrative support requirements
- **Succession / Workforce planning** – Strategic workforce planning requirements
- **Provision of education / Workforce development** - not equitable, and heavily reliant on self-funding or pharma and charitable support to advance knowledge and skills
- **Multi Disciplinary Teams** – poor MDT functioning (the foundation of good cancer care)
- **Instability** – constant cycles of workforce reviews
- **Equality of access** – unequal distribution of specialist prostate cancer care across the geographical regions





# What we'll be doing

- Work with Governments, NHS, Cancer Alliances and other key stakeholders across the four nations, calling for decision makers to address gaps in urology
- Inspire the existing nursing workforce to specialise in prostate cancer and urology through promotion and our education bursaries
- Develop a urology career pathway with key stakeholders to help student nurses and nurses in adult health understand the opportunities working in urology



**When?**

**Project activities will run  
from May until October 2017.**

**Evaluate progress and  
review new data / intel to  
inform next steps to feed in  
to bigger picture**



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**Men United.**  
**Keeping friendships alive.**