



Simon Stevens
Chief Executive
NHS England
PO Box 16738
Redditch B97 9PT

28 May 2015

Dear Mr Stevens,

We're writing as a coalition of 20 charities, health professionals and professional groups - led by Prostate Cancer UK - that work with people with a range of conditions for which erectile dysfunction treatments (ED) are funded on the NHS. We're concerned that the men we work with do not receive the support they need to cope with and recover from ED, and that much of this is due to prescribing guidance which is out of date and not fit for purpose.

As you'll know, ED treatments aren't normally funded on the NHS, but men with prostate cancer, diabetes, MS, Parkinson's disease, kidney disorders and other conditions are able to receive these treatments on the NHS. Access to them is regulated by the Department of Health's health services circular on impotence. While we understand from Prostate Cancer UK's previous correspondence that NHS England are not able to update this DH circular, we understand that any new guidance would need to come from NHS England and are therefore writing to ask that you work with us to develop new guidance to make sure men are able to access the ED treatments they need.

Prostate Cancer UK's research with men, health professionals and commissioners has found that although 76% of men who are treated for prostate cancer experience erectile dysfunction, only 30% say their ED treatment met their needs and that the current prescribing guidance is a main barrier that prevents men accessing proper treatment.

The guidance was originally produced by the DH in 1999 and since then has only received piecemeal updates such as one last year which removed generic Viagra from the guidance and opened it up for wider NHS prescribing. This was a welcome change, but it didn't go far enough. Although the guidance is meant to regulate the availability of all ED treatments, it doesn't name new treatments such as alprostadil, or non-drug treatments such as vacuum erection devices and we know from research with health professionals that commissioners have used this to justify decisions not to fund these important treatments. The guidance also places limits on the number of tablets men can access per month. For men with prostate cancer treatment-induced ED, this has a huge impact on their ability to recover due to the fact that a proper penile rehabilitation strategy relies on a man having sufficiently frequent erections (either drug or device assisted) in order to give him the best chance of returning to his pre-treatment baseline erectile function and reduce his reliance on drugs and other treatments in the longer term.

Men United. Keeping friendships alive.

Our clinical advisors also tell us that because the eligibility for ED treatments is restricted by disease and treatment groups, men who also have a treatment-induced physical cause for their ED resulting from a condition that is not specifically named are often denied treatment. This includes men who receive pelvic radiotherapy for a primary malignancy that is not named, men treated by radical radiotherapy or chemoradiotherapy for rectal or anal cancer or pelvic sarcomas and those having total body irradiation or systemic treatment for leukaemia or lymphoma, and men who are treated by androgen deprivation therapy for male breast cancer.

As I'm sure you can imagine erectile dysfunction has a huge impact on men and their relationships. Seventy eight per cent of men with treatment-induced erectile dysfunction, told Prostate Cancer UK that they found, or continue to find, it 'difficult' or 'very difficult' to deal with. More than half of these men said their erectile dysfunction had a negative impact on how they felt about themselves, citing depression, sadness, inadequacy, low self esteem and loss of masculinity. Forty seven per cent said that erectile dysfunction had negatively affected their relationship. And, polling by Relate found that, unfortunately, 91% of people with a long term health condition or disability were unaware that relationship support was available to them¹.

We'd very much like to work with you to produce new prescribing guidance for these treatments that provides commissioners with up to date and clinically effective information on the types of ED treatments they should be providing for men with relevant conditions. Prostate Cancer UK's research with commissioners has shown that 95% of Clinical Commissioning Groups still use the DH guidance. So, although it is out of date, we know that it informs commissioning decisions so developing new guidance that is up to date and fit for purpose is an important first step in ensuring men have access to the treatments they need, regardless of where they live. New guidance will be of real benefit to over two million men across the country.

We would be very grateful for your thoughts on this issue and how we can work together to address this situation. We'd be very happy to meet to discuss this further if that would be helpful. If you'd like to arrange a time to meet myself and other members of this coalition, I'd be grateful if you could contact Meaghan Kerr on 0203 310 7012 or by email to meaghan.kerr@prostatecanceruk.org.

Yours sincerely



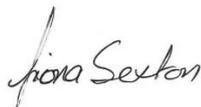
Owen Sharp
Chief Executive
Prostate Cancer UK

Please see overleaf for supporting organisations and health professionals

cc Bruce Warner, Deputy Chief Pharmaceutical Officer, NHS England
Stuart Merritt, Medicines, Pharmacy & Industry, Department of Health

¹ Relate (2015) Link Between Relationships and Health Ignored in the NHS (<http://is.gd/sBFZ9N>)

Supporting organisations and health professionals



Fiona Sexton
President
British Association of Urological Nurses (BAUN)



Dr Frank Chinegwundoh
Chairman
Cancer Black Care



Chris Booth FRCS
Clinical Director
CHAPS - The Men's Health Charity



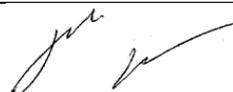
Bridget Turner
Director of Policy and Care Improvement
Diabetes UK



Nick Turkentine
Chief Operating Officer
James Whale Fund for Kidney Cancer



Tony Gavin
Director of Campaigning and Advocacy
Leukaemia CARE



Juliet Bouverie
Director of Services and Influencing
Macmillan Cancer Support



Martin Tod
Chief Executive
Men's Health Forum



R. Porta

Rebecca Porta
Chief Executive
Orchid Cancer Appeal

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FIGHTING MALE CANCER

Steve

Steve Ford
Chief Executive Officer
Parkinson's UK

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Keith Cass

Keith Cass
Founder
The Red Sock Campaign

The
redsock 
C A M P A I G N

Ruth Sutherland

Ruth Sutherland
Chief Executive Officer
Relate

relate
the relationship people

Amanda B Baxter

Amanda Baxter
Uro-oncology Clinical Nurse Specialist

Isabel White

Dr Isabel White
Clinical Research Fellow in Psychosexual Practice
The Royal Marsden NHS Foundation Trust

The **ROYAL MARSDEN**
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L. Grover

Lorraine Grover
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The Sexual Advice Association

 **Sexual Advice
Association**

R. Bartlett

Rowena Bartlett
Chief Executive

R. Wotton

Roger Wotton
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Tackle Prostate Cancer

tackle
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