

New treatment struck off CDF

A new treatment for men with advanced (metastatic) prostate cancer has been struck off the Cancer Drugs Fund (CDF) list in the latest ruling by the NHS. Even before its final appraisal is completed, probably in January, Radium-223 (Xofigo) will be removed from the list in November.

The good news is that in the latest round of delisting two other life-prolonging drugs, Abiraterone (Zytiga) and Enzalutamide (Xtandi), have survived the cull but still with the proviso that men who have had one cannot then have the other. In the previous round a chemotherapy drug, Cabazitaxel (Jevtana), which was deleted in January, was restored to the list.

Radium-223 can prevent symptoms of bone disease such as fractures and also reduce bone pain while extending life. But the NHS believes that it is not cost-effective. However, it will be a matter of relief to men who have already started the treatment that it will continue for as long as their doctors feel is necessary. If your doctor, decides that you should receive this treatment within two months of NHS England announcing its decision, you will still be able to have the treatment and continue with it as long as it is needed.

Commenting on the latest rulings, Prostate Cancer UK says: "We know that the CDF is overspent, which is why NHS England needs to cut back on the drugs it funds. We also know that the current situation is unsustainable. But we really don't think that patients should be bearing the brunt of a broken system. So, while NHS

England and the National Institute for Health and Care Excellence (NICE) establish a more sustainable way of funding cancer drugs, we will fight to make sure that men don't fall through a gap in the system. Meanwhile, we urge pharmaceutical companies to make sure that their drugs are affordable."

PCUK is fully involved with the appraisal process and doing everything it can to make sure that NICE makes the right decision.

Chief Executive Owen Sharp said: "It will be a relief to many men that two very important new prostate cancer treatments have been kept on the fund. However, this is not a long-term solution. Pharmaceutical companies must now do whatever is necessary to ensure these treatments are made routinely available as soon as possible.

"It is disappointing that Radium-223 has been removed from the Fund while it is still waiting for a final appraisal decision from NICE, and we want to see arrangements put in place so that no man who needs this drug misses out on access in the interim. It is baffling that this process is happening at all before ongoing discussions about reform of the Fund have reached a conclusion.

"It highlights once again that all parties involved in drug appraisal and access need to be doing more and working faster to ensure we have a streamlined system which works for patients. This includes the pharmaceutical companies working as hard as possible to produce reductions in price."

We have discovered a treasure(r)

No, it's not a typo – Andrew Hadley has stepped into the breach to take over as our treasurer following the resignation of Dave Kirkham, and his background suggests that he will be a very valuable asset to our support group.

Andrew is a Rotarian and worked for Macmillan Cancer Support as a fund-raiser. He has the distinction of receiving a Lifetime Achievement Award, having been involved in raising half a million pounds for them.

He has managed many other fund-raising events and has plans to introduce some to help fill our coffers. The timing could not be better because I hear on the grapevine that the James Paget University Hospital is in need of some equipment but is unable to get capital approval.

I hope you will join me in giving Andrew a very warm welcome.

Noel Warner, chairman



Who's this good-looking young corporal manning the radio while on National Service with the Suffolk Regiment back in 1959? Turn to page 2 to find out.

How a young soldier 'reported' the end of an era

Our patron Martin Bell achieved fame as a BBC war reporter and Independent MP but before he became a "household name" he served as a soldier in Cyprus between 1957 and 1959. In a chocolate box in his attic many years later he found more than 100 letters that he had sent home to his family. He was not a journalist then, but the letters are war reports of a sort, impressions of what it was like to be a conscript on active service during the EOKA rebellion against British rule.

They describe road blocks and cordons and searches, murders and explosions and riots – and a strategy of armed repression that ultimately failed. The reality of the failure dawned on the young soldier only at the end, as he burned his intelligence files in perforated oil drums while the EOKA fighters were being feted as heroes in the streets of Nicosia. "It seemed," he wrote, "like a bonfire of the policies".

From this beginning he has written *The End of Empire*. What started as a personal reminiscence then turned into a narrative of the passing of the Suffolk Regiment, one of the British Army's great regiments of the line.

One of its officers, Lieutenant Colonel Arthur Campbell, who was also an established author, was commissioned by one Governor of Cyprus to write a book about the campaign, *Flaming Cassock*, which was then suppressed by the next Governor.

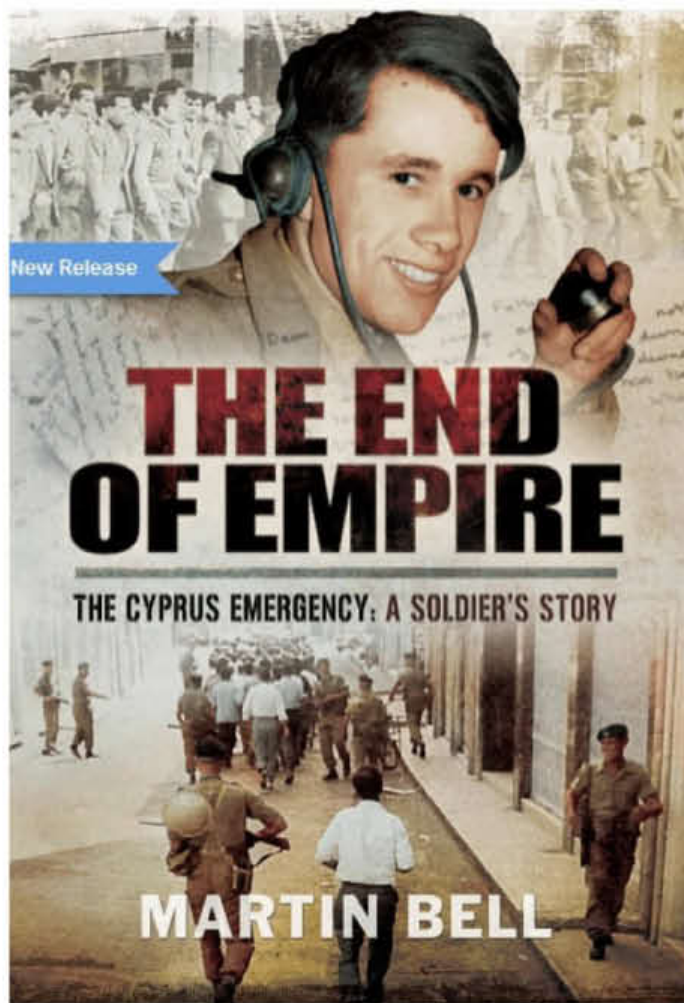
Martin Bell used the Freedom of Information Act to rescue it from oblivion. He calls it "buried treasure". He also uncovered an inch-thick file of documents about its suppression.

The true story of the insurgency and the campaign to defeat it can only now be told. *The End of Empire* draws on former Top Secret documents that have been declassified within the past two years. These include a 400- page memorandum by Field Marshal Sir John Harding, Governor of Cyprus from 1955 to 1957; and the file on Operation Matchbox, a round-up of EOKA supporters which went ahead in 1958 despite being opposed by Harding's successor, Sir Hugh Foot.

The former corporal in the Suffolk Regiment concludes that operationally the island was run not by the Governor but by a military junta. The Army commanders were looking for the knockout blow that would deliver victory; but their tactics served only to strengthen support for their enemy.

The End of Empire is a powerful and personal account of the violent process of decolonisation; of the character of the British Army at the time; of its codes of conduct, speech and dress; of the impact of National Service on young men who were not much more than "kids in uniform"; and of the ultimate futility of the use of force in wars among the people. "We were left at the last parade wondering what it had all been for: such great expectations and yet so little to show for them. It had not occurred to me – and did not, until the end – that it was all for nothing."

The book is written from an Other Ranks' perspective. No disrespect is intended, except where it is, to the Regiment's gallant and distinguished officers. Despite the campaign's failure, and a falling out with the Regimental Sergeant Major, Martin Bell concludes that much of his National Service was "on the sunny side of tolerable"; that his two years in the Suffolk Regiment were the best education he ever had; "and we who served can be proud that we served – the last who ever did – in the 12th of Foot."



Jill's generous gesture

When Jill Siely retired after 40 years at the Haven Veterinary Surgery in Great Yarmouth, grateful clients contributed £80 for a farewell gift for her. But Jill had other ideas.

Husband George had had surgery for prostate cancer and Jill decided that the money should be donated to our group – and it didn't stop there. She and George held a party at their home at Happisburgh for 150 relatives, friends and colleagues who were given the option of adding to the donation to the group. The lady who made a cake refused payment but invited George to make a donation and he added £100 to the kitty.

"All in all, thanks to the fantastic generosity of my friends the sum total was £1370," writes Jill. "George and I will always be eternally grateful for the support we received following his diagnosis and subsequent surgery and will remain staunch supporters of the support group."

And we in turn are most grateful to Jill for her splendid gesture.

In recent months we have received a number of other donations for which we are very grateful: K.A Bell, £60; TR & VJ Colby, £300; Chapelfield Road Methodist Church, £20; Costessey Park Golf Club, £210; Vale Probus Club, £86.50; A. Egerton-Smith, £100; Loddon Players, £370.

■ If you wish to make a donation or a bequest to the group, you can do so via our website page www.prostatesupport.org.uk and click the link to www.mydonate.com.

When Mr and Mrs answered the call

By David Capp

"We need a new Welfare Officer." Three years ago, along with many others, my wife and I sat at the annual meeting of the group when the plea went out.

A hurried, whispered conversation ensued before I tentatively stood and offered not only myself but also my wife to take on the task. No-one else seemed keen, so it came to pass that our group had its first husband and wife welfare team.

From the very start, our hunch that the support group needed someone in whom the wives and partners could confide proved correct.

We decided to be proactive and high profile, so we wear a gold sash at every meeting to ensure that we are instantly recognisable. We make public announcements at every meeting urging anyone who is new to the group to come and talk to us before they leave and nearly all of them do.

It has worked and by our taking the lead those who feel a little diffident or reluctant to talk become emboldened, the ice is broken and meaningful conversations ensue. A very pleasing knock-on effect has been that many more members are now seeking out others to talk to, share experiences and offer support.

Our Meet and Chat meetings are particularly rewarding. It is very encouraging that virtually everyone now sees it as their duty to talk to as many people as possible and to introduce sufferers to those who have had or who are about to undergo specific forms of treatment. Official booklets and pamphlets are very informative and helpful but they do not cover every eventuality. The end result is often a feeling of despair and helplessness when contemplating all the things that might go wrong and all the possible side-effects.

To meet and chat to a room full of men who have all had various forms of treatment and are both surviving and thriving, often ten-plus years after diagnosis, is very reassuring. We often see someone who arrived looking anxious and worried leaving at the end of the meeting saying how much better and confident they feel.

As many of you know, we don't have a computer, so no-one can contact us by e-mail or text. This means they have to speak to us on the telephone. I feel this is a huge advantage for it is a human voice and human contact that is important when under stress.



Our role is not particularly onerous but it is very rewarding and we do appreciate the help and support that everyone offers. I am so pleased that we said "Yes" for through our work we have made lots of new friends and met so many interesting people.

...and Adrienne adds:

I agreed to join David as welfare officer when, sitting at the AGM, I thought: "It's all about the men. What about the others involved because prostate cancer affects many more than the sufferer."

Having gone through coping with silences, mood swings and aggression from my own husband, I knew we supporters also needed to talk to each other.

Small beginnings have grown and from a quiet one-to-one at our Meet and Chats we "supporters" have our own corner. This is where we too can share our experiences, seek solutions and see that we also are not alone on the prostate cancer journey.

Breakthrough could save more lives

Scientists at Cambridge have found that there are five different types of prostate cancer – and the discovery could transform the treatment of the disease.

By studying the DNA of tissue samples from 250 men, researchers at the Cancer Research UK Cambridge Institute and Addenbrooke's Hospital showed that prostate cancer can be split into five main forms, each with distinctive characteristics.

The breakthrough can allow doctors to distinguish between slow-growing and fast-growing variants, the "Holy grail" of diagnosis.

Two of the main types have the worst prognosis and are a sign that a man has the more dangerous "tiger" form. Two more signal the "pussycat" version and the fifth lies in between in terms of severity. Importantly, the genetic analysis is more accurate than the existing methods for determining how serious the cancer is.

Professor Malcolm Mason, Cancer Research UK's prostate cancer expert, says: "The challenge in treating prostate cancer is that it can either behave like a pussycat – growing slowly and unlikely to cause problems in a man's lifetime – or a tiger, spreading aggressively and requiring urgent treatment. But at the moment we have no reliable way to distinguish them.

"This research could be game-changing and could give us better information to guide each man's treatment, even helping us to choose between treatments for men with aggressive cancers. This could mean more effective treatment, helping save more lives and improving the quality of life for thousands."

To test or not to test

It's more than three years since the last of our four mass PSA testing sessions. Should we run more? Ray Cossey, former group chairman and now chairman of our trustees, who was the driving force behind the series of tests, sets out the pros and cons. But what do you think? We would welcome the views of our members, either in confidence or for publication.



During the four years I was chairman of our support group I initiated, with the support of the committee, a series of mass PSA testing sessions held in Norwich, Great Yarmouth, Fakenham and Thetford.

During these events we tested well over 800 men and, on average, found that 3% of them had prostate cancer of which they were totally unaware. It is most unlikely that many of them would have had their cancers detected without their having attended one of our mass testing sessions.

There are critics of PSA testing even within our own membership and I respect their views, even though they are diversely opposed to my own. I am the first to agree that the PSA test is not perfect, far from it. It is readily accepted, throughout the medical profession, that this particular test can produce both

false-positive and false-negative results. Consequently, it can give unreal reassurance for some and cause some unnecessary concern for others.

No one pretends that the PSA test is a true diagnostic tool; it is not. All it does is give a pointer to there, perhaps, being something amiss with a prostate. To my knowledge, no man has ever been subjected to treatment for prostate cancer based solely on the result of a PSA test. What it does, however, is to get your GP, or more likely a urology-consultant, to investigate further.

Another argument, often stated against PSA testing, is that it might lead to a patient being given treatment, or even radical surgery, unnecessarily. Being on the receiving end of the latter I cannot, hand-on-heart, swear that my radical prostatectomy was necessary; I simply do not know and I guess that may well go for many of us.

For my part, I think it better to have received, possibly, unnecessary treatment than to have received no treatment at all. Do those who are adamantly against PSA testing wish us to play what, to my thinking, is a game of "prostate cancer roulette"?

All over the world prostate cancer researchers, including those at the world-renowned science- research park at Colney, Norwich, are searching for the 'holy grail', which is a test which can determine whether a prostate cancer is a "pussy cat" or a "tiger". I have no doubt that one day, in the not too distant future, they will.

Dates for your Diary

Saturday 26 September. . . 11am-1pm

"Meet & Chat" at Louise Hamilton Centre, James Paget Hospital Gorleston-on-Sea, NR31 6LA

Monday 5 October. 7-9pm

"Meet & Chat" at Big C Centre, NNUH Opportunities for newly diagnosed patients to chat with members who have already been through the same journey.

Wed 7 Oct and 4 Nov. 5.30-7pm

Radiotherapy Department

Open Evenings, Big C & Colney Centre, NNUH. Meet at Big C.

Call 01603 288779 to book.

When that day comes, unnecessary treatment will be a thing of the past.

At the moment, despite all its perceived shortcomings, the PSA test is the best pre-diagnosis test we have. One day they will discover a totally reliable test to replace the PSA test, but it is not available now. One thing I can say, with total conviction, is that there are men who, as a direct result of having attended one of our four mass PSA testing sessions, have had life-saving treatment for their prostate cancer, which they were unaware that they had.

■ The East Suffolk Support Group held their fourth PSA test event in Ipswich in April – and rather to their embarrassment 447 men turned up. They were expecting 250-300! Twenty of the men have since received "red letters" advising them that their result was "abnormal" and they should see their doctor in the near future. A further 20 received "amber letters" with the advice that they should discuss their (slightly above normal) result with their GP.

How to Contact Us

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Sally, Clare & Anne-Marie

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Lizzie, Macmillan Info & Support Radiographer

01603 289705

■ Help or Advice – Our Welfare Team:

We have over 30 members available to help.

There is probably one near you.

For more information please call our Welfare Team, David and Adrienne Capp, on 01603 712601

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■ Visit our website:

www.prostatesupport.org.uk