

East Lancashire Prostate Cancer Support Group Newsletter



Volume 8

Issue 10

Date October 2019



Yet another successful PSA Testing Day at Southport

*Wednesday 9th Oct at the Southport Theatre & Conference Centre
244 Test Done*

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Next Meeting 7th November 2019



Cancer and work

The Presentation that follows was given to us at our October 2019 meeting

We offer advice to people affected by cancer to promote independence and to build self-esteem. Where required we will support cancer patients to return to work and also retain employment. This is supported by fully trained and experienced employment officers, throughout Lancashire and South Cumbria.

Cancer related patients may see work as providing some normality during a difficult time, or work may be a financial necessity. Sometimes people with cancer who wish to return to work struggle to do so, because of a lack of up to date knowledge from health professionals and employers. We can offer advice on how to access to holistic services in order to support ongoing wellbeing.

We can offer:

Support in work - advice on employment rights, workplace issues and return to work plans.

Support finding work - we can discuss your options to suit your abilities and interests including retraining if appropriate.

To access our service you can self-refer or a healthcare professional can make a referral (for example your GP, consultant, nurse, or charitable organisations offering cancer support).

Please refer by contacting us on:

Tel: 01772 537 468

Email: employment.services@lancashire.gov.uk

Well-being and Employment Service

Dawn Drury, Gary Marsden & Paul Morley



www.lancashire.gov.uk



Aims of the service

- The service is available to people of working age who are living with and beyond cancer, that are seeking to stay-in or return to work, or self-employment
- Clients can self refer to the service, or alternatively a health care professional with permission can refer on their behalf
- The service works on a tiered approach and provides clients with initial guidance and informational requests, through to extended mediated advocacy and support

www.lancashire.gov.uk



What we can offer...

- A person centred, holistic approach and emotional support
- Up-to date information and guidance on employment rights
- Help with **work related** benefits and financial concerns
- Assistance in applying for, and obtaining a new job, or pursuing educational and training opportunities
- Signposting to complementary health and well-being services

Initially, a listening ear

- Clients and carers are understandably distressed at cancer diagnosis – “a million thoughts all at once”
- Loneliness and isolation – disconnected from friends, work
- Anxious about the future and the journey back to work
- Depressed about the long term effects of treatment and general prognosis – on self and family

Professional emotional support - signposting

- Fast track referral via consultant or specialist nurse – counselling, CBT
- Local hospices – clinical hypnosis, CBT, psychotherapy, counselling, mindfulness
- Ongoing support from GP
- Talking therapies via local support services, Lancashire Women, Carers Link Lancashire, etc.

Guidance on employment rights

- Cancer classified as a Disability under the Equality Act 2010
- From the day of diagnosis – for life
- Entitled not to be treated less favorably

Types of discrimination:

- Direct – treated differently or worse than a comparator
- Indirect - a policy or practice that disadvantages you

Negotiating with an employer

- A life changing diagnosis; the best way for an employer to provide support
- Discussing key points in relation to health, well-being and work
- Obtaining advice from a GP or Occupational Health in relation to capabilities and/ or reasonable adjustments
- Taking the initiative – suggestions to avoid conflict and provide solutions

Requesting reasonable adjustments

- Taking time off work for appointments
- Alternative working hours or patterns, including a phased return to work
- Obtaining clarity in terms of policies and procedures – e.g. sickness or agreed absences
- Adjustments may depend on the resources of the employer?
- “Reasonable” lends itself to negotiation...

Financial guidance – work-related benefits

- **Universal Credit (UC):** When a client is employed, how much Universal Credit is awarded will depend on their current income or savings, etc.
- **News Style Employment Support Allowance (NESA):**
 - Group 1. Work-related activity group, regular interviews with a JCP work coach.
 - Group 2. Support group, no regular interviews, but may need to be attend re-assessment meeting.
- **Personal Independence Payment (PIP):** Help with some of the extra costs if a client has a long term ill-health or disability

Access to Work

- To get help a client must have a disability or health condition (physical or mental) that makes it hard for them to do parts of a job or get to and from work
- A grant to help cover the costs of practical support in the workplace, such as special equipment, adaptations or a support worker
- Assistance getting to, and from work

Permitted Work under ESA

- If a client undertakes 'permitted work' it will not usually affect their ESA. To be eligible both of the following must apply:
- Maximum earnings of up to £131.50 a week, (after tax).
- Work less than 16 hours a week
- There's no limit on how many weeks a client's permitted work can last
- There is no 'permitted work' under Universal Credit.

Applying for jobs

- Updating a clients CV – listing strengths and achievements
- Skills based CV, rather than Chronological?
- Gaps – explain reasons succinctly and clearly
- Openness – prepare clients to discuss any potential health issues or on-going treatment and side effects

Networking and community events

- Macmillan and Rosemere Events
- Health & Well-being Melas
- Community Nurse Specialist Forums
- Hospices & MDT meetings
- Local Cancer support groups



Feedback from clients...

- “I would recommend the service to anyone in similar circumstances” – SK, Burnley
- “This service has made a huge difference to me returning to work” – TD, Blackpool
- “Thank you very much yet again for your continual help and support - a fast and unfailingly obliging service to our complete satisfaction” – AB, Blackburn

*Thank-you!
and any questions?*



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From: Simon Lanyon [<mailto:info@tackleprostate.org>]
Sent: 06 September 2019 12:46
To: Darrell
Subject: [SPAM]Tackle General News

[View this email in your browser](#)



This email is being sent to all the member groups of Tackle Prostate Cancer and to you as our main contact for **Prostate Cancer Support (PCS) Group - Cheadle, Cheshire**. Please would you distribute it to your committee and members as you think fit.

6 Sep 2019

Dear Darrell

This email is to let you know about a couple of items of possible interest and also to ask you for **contributions to our newsletter** which will be published in November. If your group has held any events or done anything which you think would be of interest to our members, then please [email the editor](#) with your article and any high resolution pictures to illustrate it before the end of September.

Members may also be interested to get involved with the following:

1. Europa Uomo, who are the voice of prostate cancer patients in Europe and which Tackle is a member of, are conducting a **Quality of Life Survey** of men with prostate cancer. To take part, click [here](#) and select the 4th option down "Complete survey in English".
2. Prostate Cancer UK have been asked to assist INVOLVE with finding volunteers to join the Trial Management Group of the PATCH and RADICALS trials, as **patient representatives**. The role of the group is to monitor all aspects of the conduct and progress of the trial, to ensure that the protocol is adhered to and take appropriate action to safeguard participants and the quality of the trial itself. The role can be done from home and ideally volunteers will be able to commit to the full trial period. Details of the role and additional information [can be found here](#). If you are interested in applying, please email Sue Boyes at sue.boyes@prostatecanceruk.org.

Best wishes
Simon Lanyon

07977 144 020

Please do not unsubscribe from this list. You are receiving this email because you are our contact for communication between Tackle and Prostate Cancer Support (PCS) Group - Cheadle, Cheshire. If you unsubscribe, you will prevent others in your group from keeping up to date.

If you do opt out, there are some communications that we need to send which are essential to fulfil our obligation to you as a member; examples include membership-related mailings such as notice of our Annual General Meeting and our newsletters. You can find out more in our [Privacy Policy](#).

Stampede Trial Update

MRC Clinical Trials Unit at UCL about the STAMPEDE Trial 3rd Sept 2019.

Late last year the STAMPEDE trial published results from the radiotherapy comparison. This looked at whether adding radiotherapy to standard treatment for men whose disease has spread beyond the prostate can help men live longer. The results showed no difference overall, but that some men do benefit from having radiotherapy.

These findings mean that radiotherapy, in addition to hormone therapy and chemotherapy, should become the standard treatment for some men with advanced prostate cancer.

In this part of the STAMPEDE trial, more than 2,000 men with prostate cancer that had already spread beyond the prostate were randomly split into two groups:

- Group A received standard treatment (hormone therapy, plus docetaxel for those men who were recruited in 2016)

Group H received standard treatment (hormone therapy, plus docetaxel for those men who were recruited in 2016) plus radiotherapy to their prostate.

After three years of follow-up, the researchers found that overall, there was no difference in how long men in the two groups lived, on average.

But, for the sub-group of men whose disease had spread less ('low metastatic burden ') at the time of diagnosis, there was a significant benefit from radiotherapy. After 3 years, 81% of men with low metastatic burden in the radiotherapy group were still alive, compared to 73% of men in the standard treatment group. Radiotherapy also delayed the disease getting worse.

Radiotherapy did not help men whose disease had spread further at the time of diagnosis (high metastatic burden disease) to live longer.

The proportion of patients reporting having had severe side-effects was very similar between men who had standard treatment plus radiotherapy and those who had standard treatment alone.

Dr Chris Parker, lead researcher of the study and based at the Royal Marsden, said: “Our results show a powerful effect for certain men with advanced prostate cancer. These findings could and should change standard of care worldwide.

“ Until now, it was thought that there was no point in treating the prostate itself if the cancer had already spread because it would be like shutting the stable door after the horse has bolted. However, this study proves the benefit of prostate radiotherapy for these men. Unlike many new drugs for cancer, radiotherapy is a simple, relatively cheap treatment that is readily available in most parts of the world. ”

Further information

Lancet paper http://bit.ly/STAMPEDE_Lancet
Infographic summarising the results <http://bit.ly/STAMPEDEinfographic>
STAMPEDE website <http://www.stampedetrial.org/>

William Everett

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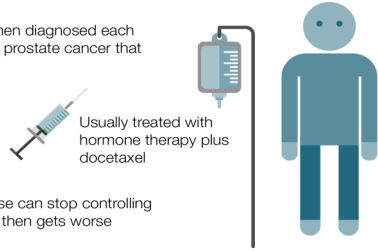
Work Hours: 0730 – 1730 (Mon – Thurs)



Smarter Studies. Global Impact. Better Health.

Radiotherapy for treating prostate cancer that has already spread

Around **7,000** men diagnosed each year in the UK with prostate cancer that has already spread



Usually treated with hormone therapy plus docetaxel

But, after time, these can stop controlling the disease, which then gets worse

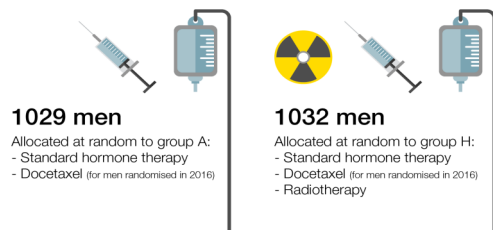
Radiotherapy and prostate cancer

Radiotherapy can help men whose disease hasn't spread live longer



But what about men whose disease has already spread?

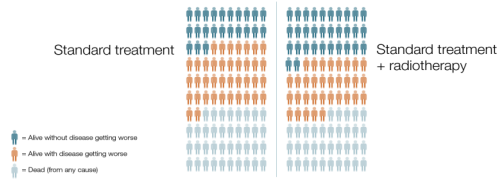
STAMPEDE compared:



STAMPEDE found:

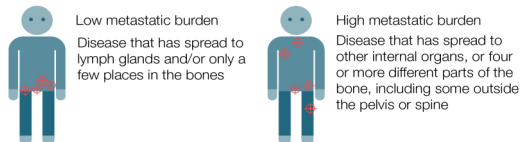
After 3 years...

No difference in how long the men in the two groups lived overall
But a difference in how long men lived without the disease getting worse



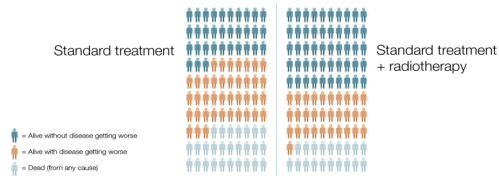
Evidence from other trials suggest men whose disease has not spread as much may benefit more from treatments like radiotherapy

What is metastatic burden?



Low metastatic burden: Results

Radiotherapy significantly improved how long men with low metastatic burden disease lived

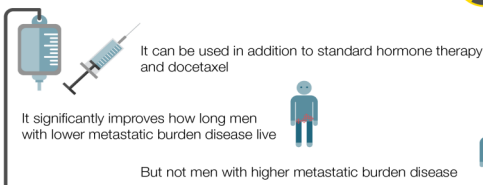


But not for men with high metastatic burden disease

Similar proportion of patients reported severe side-effects

Prostate radiotherapy for treating disease that has already spread

Radiotherapy is a widely-available, well-tolerated, low-cost treatment





Contact Information

Tel: 07548 033930
E Mail elpcsginfo@virginmedia.com

From Left to Right Hazel Goulding (Treasurer) Leon D Wright (IT Admin) Stuart Marshall (Secretary) Steve Laird (Vice Chairman) Dave Riley (Chairman)

We are a group of local people who know about prostate cancer. We are a friendly organisation dedicated to offering support to men who have had or who are experiencing the effects of this potentially life threatening disease.

The East Lanc's Prostate Cancer Support Group offers a place for free exchange of information and help for local men and their supporters (family and friends) who may be affected by this increasingly common form of male cancer.

At each meeting we strive to be a happy, supportive and upbeat group of people; encouraging open discussion on what can be a very difficult and perhaps for some an embarrassing subject. We have lively, informative, interactive, sharing and above all supportive meetings.

Prostate Cancer Research Centre Says Thank you for your Support after their presentation at our September Meeting

Thank you very much for your all your support on Thursday – it was really great to meet everyone. I hope the groups enjoyed the sessions and found them useful.

We've now collated the attached responses from the sessions. Please feel free to forward onto David and Stephen.

The next steps are for us to analyse the responses and categorise them into themes. We will then look at potential activities/solutions for each. From this, we should hopefully be able to start developing a robust patient-centred project. It would be great if we could discuss a potential partnership on this, once we know activities.

Additionally, we have received many stay in touch slips from group attendees, along with some positive and useful feedback, which is really great.

Thanks again and look forward to speaking soon.

Best wishes,

Peter Harrison

Trusts and Foundations Manager

0203 330 0749

Prostate Cancer Research Centre

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