

# East Lancashire Prostate Cancer Support Group Newsletter



Volume3

Issue8

Date August 2014



## £1million boost for cancer care in East Lancashire

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10:54am Wednesday  
20th August 2014

By Lawrence Dunhill

CHARITY bosses have announced a new £1 million fund to boost cancer care in East Lancashire, in a bid to tackle some of the worst 'death rates' for the condition in England.

The Macmillan charity has teamed up with the NHS to launch a three-year improvement programme, which promises to involve all 90 doctors' surgeries in the area.

It comes after new figures revealed the number of premature cancer deaths in Burnley and Hyndburn were well above the national average between 2010 and 2012.

The under-75s cancer mortality rate for

Burnley was the second highest in the North West, at 205 per 100,000. Hyndburn's rate was 174 per 100,000, compared to the national average of 146 per 100,000.

The 'Cancer Service Redesign' for East Lancashire is among of the first of its kind, as only a handful of other 'hotspot' boroughs have so far received funding from the charity.

The cash will be spent on increasing cancer awareness and diagnosis among GPs, to ensure the disease is caught at an earlier stage in more cases.

It will also be focused on boosting screening rates and offering extra support to patients once their treatment has finished.

Jeremy Such, Macmil-

lan's development manager for Lancashire, said: "I'm very excited about this partnership and the project we're undertaking to transform cancer care in East Lancashire and Blackburn with Darwen.

"The project will provide better care and support for people affected by cancer at every stage, from the moment of diagnosis, through treatment and beyond.

"We want to improve outcomes for patients and deliver a better patient experience so that no one faces cancer alone."

- If you are affected by cancer and need information or support, call 0808 808 00 00 or visit [www.macmillan.org.uk](http://www.macmillan.org.uk)

## *Macmillan Pennine Lancashire Cancer Improvement Partnership*

This article follows on from the article on the front page.

The Introduction of associated support groups to the Blackburn with Darwen Council's Service User Focus Group was attended by representative members of our support group, (Dave Riley, Stuart Marshall, John Goulding, & Leon D Wright. Other Support groups were also in attendance providing a very good networking opportunity



The meeting was held at the Mercure Blackburn Dunkenhalgh Hotel & Spa , Blackburn Road, Clayton-le Moors. The meeting was very informative, covering the issues of social and community care to improve the patient experience in the treatment of their cancer

## *Macmillan Pennine Lancashire Cancer Improvement Partnership (MCIP)*

The Vision of the MCIP is to provide a comprehensive service redesign that enhances seamless and coordinated care pathways, embeds best practice within aspects of cancer care across Social, Primary, and Acute Care, and delivers better outcomes and a better experience for people affected by cancer in Pennine Lancashire

- Provision information & training of staff
- Access to physical activity
- Support primary care
- Holistic Needs Assessment
- Risk Stratification of patients.
- Care Planning.
- Use of Treatment Summary

Pages 5—8 Cover the Seminar Presentation on Wednesday 13th August 2014 it is a PowerPoint presentation which will be available to view on the [www.elpcsg.com](http://www.elpcsg.com) on the Service User Focus Group page.



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

## Contact Information

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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

### *B\*\*\*\*\*s to PCa*

We've had to learn a whole new lexicon  
New words and medical babble  
With such increased vocabulary  
We should be bloody great at Scrabble!

A new website for our ailments  
To help that constant toilet dash  
It's called bladder trouble dot co UK  
Forward slash, slash, slash, sla!

The Prostatectomy boys amongst us  
Still cross our legs and flinch  
The surgeon cuts away our prostate  
...And we lose that vital inch!

And the ladies all remember  
Those spontaneous, frantic humps  
Now it needs to be pre-ordered  
Using injections, pills and pumps!

But it has its compensations  
And it is why we're still a catch  
After taking you to heaven  
There's the bliss of no wet patch!

And the side effects of hormones  
Can play havoc with our bits  
Girl's you're not the only ones

Who will hear those words, 'nice tits!'  
We still keep hedonistic lifestyles  
But our demands have changed in tone  
It's no longer, 'pass the e tabs'  
It's, 'pass the abiraterone!'

Now ladies we salute you  
You stand by us every knock  
Your love is so unswerving  
You really are our rock!

But let's just restore some balance  
Keep our male egos all alive  
Why is it as a gender,  
You lot still can't bloody drive?!

Now no one chose to join this club  
It's just how our lives unfurled  
But, to steal the words of Carlsberg  
" Probably the best club in the world!"

So let's continue with our battle  
Fight this bastard all the way  
The tide it is a turning  
And we will win through one day!

So b\*\*\*\*\*s then to PCa  
Laugh at your Gleason score  
And pledge that everyone of us  
Will be back next year for more!

# Macmillan Pennine Lancashire Cancer Improvement Partnership

Service User Focus Group  
13<sup>th</sup> August 2014

## Vision

- A comprehensive service redesign that:
  - Embeds seamless and coordinated care pathways.
  - Embeds best practice within aspects of cancer care across Social, Primary and Acute Care.
  - Delivers better outcomes.
  - Delivers a better patient experience.
  - Is underpinned by service user involvement.



**Project Aims**

To provide a comprehensive service redesign which improves cancer care at all stages of a patient journey, which will:

- Enhance seamless and co-ordinated care pathways
- Embed best practice within aspects of cancer care
- Deliver better outcomes
- Deliver better patient experience

**Project Elements**

Dedicated workstreams:

- Social / Community Care
- Primary Care
- Acute Care

Underpinning Ethos:

- Service User Involvement



## Social/Community Care Work stream

- Provision of information for patients, carers and families in a range of community and primary care settings across Pennine Lancashire.
- Training for key primary and community staff to provide information.
- Provision of increased access to physical activity options and programmes
- Operation of Macmillan Solutions.





## Primary Care Work stream

- Primary Care Change Management Programme including:
  - Practice “Cancer Care Team”.
  - Cancer prevention and awareness.
  - Increased uptake of bowel screening.
  - Significant Event Analysis on emergency cancer presentations.
  - Implementation of a standardised, quality 2 week wait referral system.
  - Practice Nurse Training – CCR, IP’s.

## Acute Work stream

- The implementation of key tools and best practice, as detailed in the Recovery Package, across identified tumour sites:

- HNA, Care Planning, IP’s
- Risk Stratification
- Use of Treatment Summaries
- Changes to support and FU
- Development of a rapid re-access service



# Service User Involvement



- Consultation with service users to influence content of project.
- Engagement with ethnic minority and other less heard groups.
- Enabling people from PL to have an active voice in development of cancer services.
- Collaborative working between health professionals and patients to develop patient led cancer services.
- National policies implemented with input from people affected by cancer.

  
*Blackburn with Darwen  
Clinical Commissioning Group*

**Lancashire**  
County Council 

East Lancashire Hospitals   
NHS Trust



  
*East Lancashire  
Clinical Commissioning Group*

## What do you see as your role?

## *A charity says a decision by the NHS in England to reject a drug for men with prostate cancer is a "fiasco". (BBC News Health Nick Triggle)*

Abiraterone is already given to patients at the end-of-life after chemotherapy as it gives patients an extra few months.

But the National Institute for Health and Care Excellence said it was not cost-effective to offer it earlier.

It said while the drug improved quality of life, it was unclear whether it had the same impact on life expectancy.

This was due to problems with the research data, NICE said, claiming the trial was finished early - something disputed by the drug's makers Janssen.

### ***'Vital opportunity'***

Instead, patients will have to rely on their doctors applying to the Cancer Drugs Fund, a special pot set aside for cancer drugs not routinely available on the NHS.

Some 3,000 patients have done this in the last year, but that fund is due to end in 2016.

Owen Sharp, chief executive of Prostate Cancer UK, the largest men's health charity, said the whole process was "a fiasco".

He criticised NICE's inflexibility and the drug company's results-gathering process, saying: "This decision is a kick in the teeth for men with advanced prostate cancer.

"For many this presented a vital opportunity for extra time with loved ones and a chance to delay chemotherapy and the debilitating side-effects which come with it."

The decision comes just a week after **NICE rejected a breast cancer drug called Kad-cyla** - again leaving the Cancer Drugs Fund as the only option for patients.

The drug normally costs £3,000 a month, but is given to the NHS for a discounted price after negotiations two years ago when the ruling on its use after chemotherapy was reached.

### ***'Very disappointed'***

At the time it was hailed as a real breakthrough for patients with aggressive prostate cancer.

NICE chief executive Sir Andrew Dillon said he was disappointed not to be able to recommend abiraterone for use before chemotherapy.

He told BBC Radio 4's Today programme that pharmaceutical firms had to "balance their desire to make a profit" with the reality that the NHS had to meet all its needs.

"If we don't put in place arrangements to require drug companies... to look critically at what they are asking the NHS to pay, it will simply be a question of offering the keys to the safe and we can't do that," Sir Andrew said.

As well as the dispute about the way the research was conducted, this ruling has caused controversy because of the way NICE carried out the assessment.

When it assessed the drug for use after chemotherapy in 2012, NICE adopted its end-of-life criteria, which means it is willing to pay more.

For the latest assessment, it was judged to be a standard treatment.

The final guidance is expected later in the year, but major changes at this stage are considered unlikely.

While it will apply to England, the other UK nations also consider NICE's findings.

Janssen medical director Dr Peter Barnes said the firm was "very disappointed" and would appeal against the decision.

15/08/2014