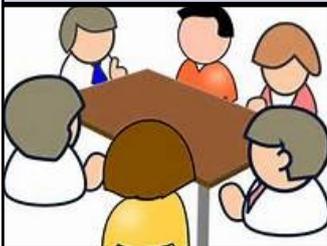




South Wales Cancer Network Patient Conference

OCTOBER 2014

' *Let's Talk About Cancer* '



INTRODUCTION

On 1st October almost 100 patients, carers, third sector organisations and health professionals attended the Third Patient Conference for the South Wales Cancer Network. It was held again at The Orangery, Margam Park.

Inside this Issue

Introduction	1
A GP Perspective– Challenge of Early Diagnosis	2
Awareness and Belief about Cancer	3
Neuroendocrine Tumours	5
Acute Oncology Project	8
Head and Neck Cancer	9

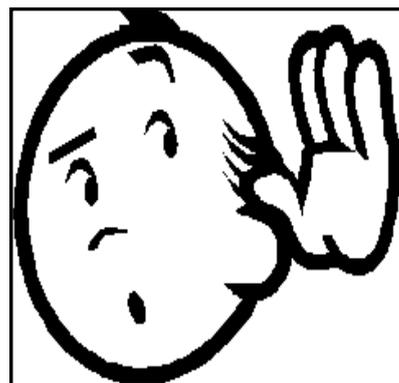
The title this year was 'Let's talk about cancer' and with a change of format from last year the day revolved around patient stories from those who had experienced a diagnosis of a rarer cancer.

The welcome was made by Mr Hywel Morgan , Director of the South Wales Cancer Network . He thanked the 15 organisations who were manning the display tables ; the organisations supporting patients and families across the region and thanks to all for what you do for others. He then thanked Macmillan Cancer Support for the grant which has enabled the conference to be held again this year.

The day was chaired by Lesley Radley, Chair of the Velindre Patient Liaison Group . Lesley explained that the format for this years conference was different to last years . The organising committee looked closely at the feedback from last years event and although feedback had been very positive , feedback from previous events has said there has not been enough time to ask questions. A Question and Answer panel closed the morning and afternoon sessions.

Lesley invited the attendees to use the lunch break to visit the display stands and to chat with fellow attendees.

Key Message: The Third SWCN Patient Conference has been developed using feedback from the previous conferences in 2013 and 2012.



A GP Perspective: The Challenge of Early Diagnosis

Dr Bridget Gwynne: General Practitioner & Lead Primary Care Clinician for South Wales Cancer Network & Primary Care advisor to Macmillan Cancer Support in Wales

Dr Gwynne talked about challenges faced by primary cancer to diagnose patients in a timely manner.

The Cancer story is improving; survival rates are improving; treatments are improving. Cancer is a political and medical priority. The challenge is ensuring an early diagnosis. Cancer survival rates in the UK and Wales are lower than the rest of Europe. Outcomes for patients are better they are diagnosed via a GP referral to outpatients rather than an emergency admission to hospital.

A GP has an average list of 2,000 patients with 8 new cancer patients diagnosed per year (50% will be the common cancers but 50% will be rarer ones). In areas of deprivation GP lists are higher and Practice sizes can add to the challenge for GPs. There is 1 GP for every 440 people in the UK; 1 GP to every 220 people in EU. To make an early diagnosis it is easier if people have 'classic' symptoms. Cancer is easier to diagnose if it is advanced but difficult in the early stages. Possible reasons why figures are poor in UK: Patients do not visit their GP early on with symptoms; GP does not think it is cancer and so patient not referred early enough; delays in the system.

GPs are the route into secondary care. NICE guidelines present a challenge as they are 10 years old and not yet caught up with challenges early diagnosis. It dictates routes and timings of referrals for patients presents with symptoms. New Guidelines are expected shortly.

An international benchmarking collaborative is comparing the UK to other countries: to see if cancer is measured in the same way; patients views; GPs views about the cancer patients' journey.

What is happening to try and change the situation?

- Screening – but this is very complicated as the test has to be good enough – in terms of misdiagnosis.
- National Early Diagnosis Initiative (NEDI UK) in England – worked with GP practices to identify if the practice could have made a diagnosis earlier, and in patient awareness. In Wales we are awaiting the outcomes to learn from this.



Lesley Radley, Chair of Velindre Patient Liaison Group

'Excellent conference. Also highlighted problem areas for patients accessing services'

'Excellent Day. Well done everyone. Much different to last year - interesting/informative - NETS great !

Patient stories very moving.

Thank you'

CONT'D

- Macmillan – developed risk tools on cancer diagnosis.

Wales will have a lung cancer campaign which has proven successful elsewhere.

There is a conflict between keeping people well in the community and the need to refer more people into secondary care for diagnosis in order to achieve earliest diagnosis. There has been some research into views of GPs, and how they react to diagnosis etc – results not yet available.

What might GPs do?

GPs should develop an orientation around cancer: have a positive attitude; 'think cancer' (I.e. ask the questions); be given greater access to tests; think earlier about cancer when in a consultation and have more active patient follow up; be clear in information given to patients and how it is conveyed to avoid misunderstanding; be more active in tests. Encourage practices to reflect on what they do – 'think cancer' process.

Key Message: The challenge for GPs is to ensure an early diagnosis of cancer for their patients and for patients to return to see their GP if symptoms persist.

Awareness and Beliefs about Cancer

Dr Kate Brain: Reader and Healthcare Communication & Quality Programme Lead, Cochrane Institute of Primary Care and Public Health, School of Medicine, Cardiff University

Dr Brain is participating in the International Benchmarking Partnership which began in 2010 – in which Healthcare professionals and researchers who make up the partnership are looking at why is cancer survival lower in the UK. The Focus is on low public awareness and negative beliefs. The 2011 data is not yet available.

What stops someone from going to the doctor if they have a symptom that may be cancer?

- lack of knowledge
- Other ailments e.g. IBS, menopause
- Negative beliefs e.g. Fear, fatalism
- Embarrassment
- Not wanting to waste GPs time
- Non-disclosure to family/friends



'Excellent conference and tremendously useful. Thank you'



CONT'D

An international survey was conducted, including the UK, looking at, amongst other things, survival rates. Most people surveyed gave a positive response (90%) but 50% thought cancer treatment was worse than cancer itself. Participants' educational background and links with +/- statements needs understanding.

Key points the survey highlighted were:

- Wasting GPs time is a large barrier in UK
- Embarrassment is big issue in UK – stiff upper lip mentality
- Most people surveyed have a positive outlook on cancer
- People surveyed felt cancer treatment is worse than the cancer itself
- An individual's educational background influences their beliefs; with more negative beliefs from people with lower educational attainment
- People from deprived areas are more worried and more fatalistic

Delays in seeking a cancer diagnosis may happen where no screening process is in place:

- Low awareness/ knowledge
- Patient mis-attributes symptoms as everyday complaint
- Negative beliefs, esp. fatalistic (more common in smokers and disadvantaged communities)
- Embarrassment
- Not wanting to seem neurotic/ waste GPs time
- Not having anyone to tell/ to legitimize concerns

Next Steps: There was little variation in knowledge across the countries involved – found that knowledge alone is not enough – there is a need to tackle beliefs and experiences. Strategies: 'Be clear on cancer' campaign already held in England; OVStat – symptom awareness tool leaflet; Tenovus Health Check

Key Message: there are several barriers that may put off someone from going to see their GP



'patient stories are fantastic. Keep doing these and maybe more of these. Length of sessions was good. Not too long and not too short. Keeps it interesting and flowing.'



NeuroEndocrine Tumours: An Overview

Dr Aled Rees: Consultant Endocrinologist

& Dr Mohid Khan: Consultant Gastroenterologist & General Physician

Cardiff & Vale University Health Board

Aled Rees:

Neuroendocrine Tumours (NETs) are a wide ranging group of tumours that can be found in several sites in the body, most commonly the gastrointestinal tract, the pancreas and the lung. Figures have doubled according to the newest research. NETS are now the second most common gastrointestinal cancer. NETs can show slow progression which impacts on the ability for early diagnosis.

The number of newly diagnosed NETs in Wales 2003 was 100 by 2012 it had risen to almost 200. How common are NETS = 5/100,000. These tumours can have effects on other areas of the body. A major increase in the number of new NET cases impacts on the NET team who in 2007 saw 67 patients and in 2014 are seeing 200.

Therapeutic options for the NET patients are complex and require individualised decision making by a range of clinicians. Clinical trials show positive impact.

In South Wales a survey of 43 NET patients was undertaken to see what the problems with the current service were. Challenges – delays in diagnosis (most common for 1-3 year process). Satisfaction rates will inform the next steps Problems that were highlighted included:

1. Delay in diagnosis due to difficulty in presentations – can take 1-3 years or longer.
2. Access to specialist care, key worker and info provision

Access to treatment

Suggestions for change:

Access to specialist nurse

Access to consultant

Dedicated clinic

GP and Nurse Education



'I just wanted to thank you for organising an informative and effective conference. It was inspiring to see how services can be effectively shaped by patients and to hear how much good services mean to the patients they benefit.'



CONT'D

The Way forward – Macmillan Cancer Support are funding a scoping project for 2 years together with a piece of work being undertaken by WHSCC (Welsh Health Specialised Services). These two pieces of work are in parallel.

Dr Mohid Khan:

Patients with endocrine tumours have very complex needs which need the input of a wide range of clinical specialties. The complexity and rarity of NETs require an MDT of specialists. Tumours are difficult to diagnose and therefore patients are usually late getting a diagnosis. NETs are usually diagnosed late due to the complexity/ causal symptoms. Cardiff and Vale have the right disciplines but not necessarily joined up. Cardiff and Vale do have most disciplines in the NET MDT team.

Key Message: NETs are a rare cancer with increasing incidence. The NET service in South Wales is currently being reviewed.

NEUROENDOCRINE TUMOURS : OUR STORY

– Sally Jenkins, Eleanor Jenkins and Yolande Mears

Sally's story by Eleanor Jenkins

Sally was unable to join us on the day of the conference as she was unwell. Her daughter Eleanor came along to tell us about Sally's story giving us the background to Sally's condition and timeline to diagnosis and treatment. Eleanor told us of the impact of Sally's diagnosis and the change of roles in the family to carers.

When Sally was diagnosed with her NET South Wales had poor support for NET patients and their carers after diagnosis and discharge. Sally found out about the Neuroendocrine Patient Foundation (a UK wide support Group).

Sally started a local (south Wales) group with Yolande – it now has 50 members and 2 branches. It gives mutual support to NET patients and highlighted the lack of services for NET patients. The group has campaigned vigorously to improve NET services across Wales meetings with AMs and the Health Minister.



'I thought that the patient stories were the most valuable part of the day. It's invaluable to hear about the way the NHS and cancer is viewed by patients'



'Excellent day, good speakers. Good to have focus on the rarer cancers i.e. NETS and head and neck.'

'Excellent conference with interesting and topical speakers.'

Excellent opportunity to network and gather information.'

Excellent venue and catering.'



CONT'D

The NET Service in South Wales is now under review. Thank you to charities who have helped and supported them – NPF, Macmillan, Maggie's, Tenovus. Thank you to health professionals (you know who you are).

Key Message: The moral is if you have unexplained symptoms keep going back to your GP; be polite but persistent but keep going back to the doctor. Do your research and gain support. Don't be fobbed off.

Yolande's Story :

Having had many GP appointments Yolande decided to undergo a self funded scan. This highlighted the fact that she had a NET. She did her research into treatment and found a NET service was available in Liverpool but GP said she couldn't access it. Yolande had already contacted the hospital in Liverpool and treatment was already being organised at Liverpool. She felt she'd won the lottery because she was able to go to Liverpool and have surgery. But her GP said that if surgery was available in Morriston she couldn't go to Liverpool – but consultant at Morriston said yes. Her surgery and all consequent treatment has been in Liverpool.

By accessing the treatment at Liverpool Royal Yolande is supported by NET CNS. There are inequalities in treatment between England and Wales. She strongly believes that access to treatment in England should be made to appropriate patients in Wales.

Key message: Please take responsibility for your own life by seeking the best treatment available and if necessary a second opinion. There is hope.

Contact Details for NET Patient Foundation :

<http://www.netpatientfoundation.org>



Acute Oncology Project

Gill Knight - Macmillan Chemotherapy & Acute Oncology Project Lead, South Wales Cancer Network

'really worthwhile day !

Excellent day - catering excellent

- more of the same next year please'

It is a two year Macmillan funded project. It started as a chemotherapy project and has developed into an acute oncology project. It has developed a strategy for Acute Oncology and Chemotherapy across South Wales. There is a steering group – from all sectors and organisations comprising professionals and patients across Wales.

Phase 1 – this was undertaken to understand the current position – I Visited every centre which delivers chemotherapy. Operational working was explored. Processes were investigated. Variations in practices were found. Some environments were not appropriate for service delivery. Investigations were measured against a gold standard.

I talked to patients; looked at systems and policies and follow ups etc. Patients had a vast variety of plans about what they would do if they got unwell – ranging from accessing the GP to the hospital. There is no standard tool for triage when patients call about issues. Some patients phone NHS Direct – but there were: there were no triggers into acute oncology – there are now

Model for improvement:

There is a plan for chemotherapy services and the associated services

Identified best first steps

Looked at what a 'gold standard' may look like

The project has 4 key work streams; found no standard tool for triaging unwell patients who ring in; now use the UKONS triage tool for help and Macmillan are working on a GP version

A data analyst looked at the data that was gathered – there were huge variances in practice across the health boards.

Key Message: A model for improvement, benefitting patients across South Wales.



'excellent conference with the best balance of contributors from health care professionals and patients'

My Story: Derek Ford

Derek told us of his experience at being diagnosed with Cancer at the base of his tongue. He had suffered from a sore throat for a few weeks and his GP had prescribed antibiotics. The pain worsened and he returned to see his GP and insisted on having a referral to see an ENT consultant. He was seen very quickly and had several tests. He described his visits to clinic as 'it felt a bit like being in the Mastermind Chair – everyone wanted to ask me questions'. Derek told us of his treatment and the after affects that still persist today. Despite all of this Derek now helps other head and neck cancer patients by talking to them about how he got through his treatment. He is also an active member of the Velindre Patient Liaison Group.

Key Message: Persist in getting a referral



'Good range of presentations. Good venue - lovely food'

Head and Neck Cancer MDT Service in Aneurin Bevan UHB

Jane Cox: Macmillan Clinical Nurse Specialist Head & Neck Oncology & Lucy Powell: Specialist Speech & language Therapist, Aneurin Bevan UHB

Jane and Lucy informed us of the Aneurin Bevan Head and Neck Support Team that they are part of. The team consists of a Head and Neck CNS (Jane); a speech and language therapist (Lucy); a dietician; a clinical psychologist x2; a surgeon and a benefits advisor. Prior to the setting up of the team patients, as Derek had mentioned in his talk, were overwhelmed with separate clinic visits to see various health professionals who were all asking the same questions of the patient. This has now been streamlined and the patients attend a pre-treatment head and neck clinic and are invited to attend both the 'Back on Track' Group and the 'Return to Eating Club' in order to have support from other patients and health professionals in their effort to deal with their diagnosis and treatment and its after affects.

Key Message: providing support at critical times throughout the patients' journey and improving their quality of life



'valuable conference. Well organised. Interesting presentations and good for networking'

We are on the web:

[http://
www.cancernetwork.wales.nhs.
uk](http://www.cancernetwork.wales.nhs.uk)

This newsletter has been produced by the South Wales Cancer Network if you wish to place an article in the newsletter please contact Eleri Girt via e-mail:

Eleri.girt@wales.nhs.uk

The network newsletters are available on the South Wales Cancer Network website :

<http://www.cancernetwork.wales.nhs.uk>

The conference organising committee would like to thank Macmillan Cancer Support for their generous grant which enabled us to hold the conference again this year.

Organisation of the 2015 patient conference will begin in early 2015. if you would like to take part as a speaker or have a display stand then please contact Eleri via email on **Eleri.girt@wales.nhs.uk** or phone 01792 530849

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