

**Winter  
2015**



# South Wales Cancer Network Newsletter



## Summary of SWCN Patient Conference September 30<sup>th</sup> 2015

The fourth annual conference was attended by approximately 85 patients, carers, health professionals and third sector organisations at The Orangery, Margam Park on 30<sup>th</sup> September 2015.

We were also able to welcome the Tenovus Bridgend and Swansea Sing with Us choir who entertained us beautifully during lunch.

The presentations from the day were varied:

**The challenges of a cancer diagnosis in someone with a learning disability by Tracey Lloyd and Wendy**

**Thyroid cancer – My Story by Cy Davies**

**Thyroid Cancer by Dr Laura Moss**

**Thyroid Cancer Support Group Wales by Helen Hoborough**

**National Macmillan Thyroid Cancer Clinical Nurse Specialist by Ingrid Haupt-schott**

**The Cancer Key Worker- the Good, the Bad and the Ugly by Elizabeth Coveney**

**Macmillan Chemotherapy & Acute Oncology Project Phase 2 – overview by Abby Stevens**

**An Update on NET Services in South Wales by Sally Jenkins**

**Making a difference by Maria Parry and Eleri Girt**

**University collaborations and partnerships by Dr Sally Anstey**

Cont'd

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## **Working together with patients, families health care professionals and the public -the role of the Macmillan Skin Cancer Clinical Nurse Specialist (CNS) by Sharon Hulley**

We would like to thank Macmillan Cancer Support for funding the conference through a Learning and Development Grant. A big thank you to the Conference Organising Team for all their hard work. And finally a big thank you to all the presenters and all the Organisations who had table displays (there were 15) and to everyone who attended and continues to support the conference.

### **Eleri Girt**



'So good to hear from passionate speakers, health professionals who have the patients as their focus – inspiring!'

'Excellent and valuable event. The choir were brilliant!'

'Excellent conference. Thank you met some very interesting people again. Such a worthwhile day.'

## **Macmillan Information and Support Service in Blaenau Gwent Libraries**

The Macmillan Cancer Support and Information Service based in Blaenau Gwent Libraries is now back up and running again after appointing a new post holder.

The service provides a one stop information and support facility for anyone affected by cancer, patients, families, carers at any stage of a cancer journey in an informal, confidential environment by a Macmillan Professional.

Anyone affected by cancer can access:

- Information on the many aspects of cancer
- Signposting for financial support
- Information on local organisations
- Emotional support and someone to talk to

For more information either pop into one of Blaenau Gwent's Libraries or telephone 01495 355857

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**Scott Price**



**Jane's Corner**  
**Being Realistic**



Let's be pleased about what we can do, and be realistic about what we can't do. For instance, my days of deep cleaning the house are over, I concentrate on the kitchen and bath rooms, and laugh at the dust bunnies. I have a friend who deals with the dust, not that it does any harm. And in turn she gets my grateful thanks.

It is a different story if my medical well being depends on something I just can't do. So far, I have been lucky. I have managed to take the tablets, go to the hospital on time, and co-operate with samples.

Let's look at Brenda. (Names have been changed here). Brenda is 93 and has a collection of problems. One of which is her blood pressure. To check that the medication is working correctly, Brenda's GP asks her to take her own blood pressure every day for a week. Brenda gladly agrees. Unfortunately, Brenda's kind friends who normally take her blood pressure are on holiday. she does not like to admit it is too complicated and uncomfortable to do on her own. The surgery seems to think she should be able to do it so she agrees with them, but she won't ask others for help.

Because Brenda is so eager to please the doctors, she doesn't think the matter through. There is no way that she can take her own blood pressure and go back in a week as she has agreed.

In Brenda's case, there will be a solution because her daughter knows about the situation. They will postpone the reading for a few weeks and then report back. The problem is ongoing, and in this case the surgery have been asked and agreed to the solution.

But- if you, or I, or Brenda can't comply with a request, we could be putting ourselves at risk.

If you don't understand what the doctor or nurse is telling you, tell them. Ask them to make it clear and go on until you do understand. Nurses know that people frequently don't understand medical terms. Then tell the medic what it is you understand- to be sure you are correct.

If you don't know how to do something, or just can't do it, say so. Ask for a way around the problem. If you can't do it or understand it you can be quite sure that lots of others can't either. These other people will routinely get help to overcome the problem, it's not just you.

**Never be afraid to ask - what do you expect me to do?**

Lots of people write lists to remember things. Lots of people set alarms to remind them to take important tablets. Lots of people have a check list around to remind them to take a tablet or not - and there are other ways to sort this out. The pharmacist can help, they already have lots of solutions, you won't be the first with this problem. Don't struggle with things yourself, ask for help.

Live the best life you can.

**Jane Barnard**

**Cancer Awareness Dates 2015**

**January**

Cervical Cancer

**February**

World Cancer Day

**March**

Prostate Cancer

Ovarian Cancer

Brain cancer

**April**

Bowel Cancer

Orchid Male

Cancer awareness

**June**

Carers week.

Myeloma week

**July**

Mesothelioma Day

**September**

Thyroid Cancer week

Lymphatic Cancer week

**October**

Breast Cancer

**November**

Mouth Cancer

Lung Cancer

NET Cancers

**December**

Childhood Cancer Awareness Week

## Wales Cancer Research Centre

On Wednesday 21<sup>st</sup> of October, the **Wales Cancer Research Centre** held its official launch event at the SWALEC Stadium in Cardiff.

Nearly 200 people came through the doors for a series of talks and workshops exploring the WCRC's work and ambitions. The day started with a keynote speech from Ian Tannock, Emeritus Professor of Medical Oncology from Toronto. Prof Tannock set the global scene for research from bench to bedside, and established how the WCRC fits into the international picture.

A highlight of the day for many was a patient voices panel. Dawn Fisher, Alan Buckle and Ceri Hopkins all shared their experiences of being on a clinical trial. They talked about the challenges they faced, the misconceptions many people have and their gratitude for the care they've received.

The deputy minister for health, Vaughan Gething, gave an official launch address, highlighting the opportunities for Welsh research to shine on the world stage. Other talks and workshops came from WCRC researchers, detailing their plans and past successes.

During coffee breaks, delegates were asked to contribute to a piece of artwork (see photo). Each of the threads represents an individual involved in cancer research, and the woven pattern symbolises our strength when we work together.

The launch was a great success, and the WCRC hopes to repeat a similar event next year to share their progress. For more information about their work, please visit [www.walescancerpartnership.com/wcrc](http://www.walescancerpartnership.com/wcrc), follow them on twitter @theWCRC or like them on Facebook at [www.facebook.com/theWCRC](http://www.facebook.com/theWCRC)

### Jodie Burnham



## Look Good Feel Better

### Facing Cancer with Confidence

Finding out you have cancer can be traumatic and daunting and the added stress of the appearance related side-effects can feel overwhelming. This can have serious consequences on self-esteem and confidence during what is already a difficult time but there are ways that you can use what you already have in your make-up to combat these changes.

Cancer support charity, Look Good Feel Better was formed in the UK 21 years ago by the beauty industry to support women living with cancer, through their free confidence boosting skincare and make-up Workshops and Masterclasses. The two-hour sessions are led by trained beauty volunteers, who share tips and techniques to help with eyebrow and eyelash loss and changes to the skin and are available in more than 80 hospital locations and cancer support centres across the country.

Workshops are currently held at Velindre Hospital, Cardiff and Singleton Hospital, Swansea. There are also regular Masterclasses held in partnership with Marks & Spencer's in Haverfordwest.

For those that cannot attend a Workshop or Masterclass, Look Good Feel Better has created 'The Confidence Kit'. A DVD and booklet that provides an at-home version of the sessions. Filmed with International make-up artist, Caroline Barnes and renowned hairdresser Charles Worthington the kit provides all of the information you need to help combat the visible side effects of cancer treatment. It includes tips and advice on skincare, make-up, wig styling and selection, haircare, headwear and information on how to look after your nails.

### Skincare and make-up tips

Skin will often be much drier during treatment so it's a good idea to use a gentle cream cleanser, followed by a rich moisturiser to allow the skin to absorb and benefit. Make sure you use gentle products suitable for sensitive skin.

Eyeliner can help to define and shade the eyes, creating the appearance of eyelashes that may have been lost through treatment. Using an eye pencil, roll the tip on the back of your hand to soften before applying. Start at the outer corner of the eye and work slowly to the halfway point on both the bottom and the top eyelid. You may want to use a cotton bud to blend the line, giving a softer effect.

Nails are ten times more absorbent than skin. They need extra care and protection when going through treatment so it's a good idea to carry a hand cream with you and make sure you apply it every time you wash your hands and before you go to bed.

*"It's not just about a bit of make-up, it's not vanity, - it's about control. It gives women the strength to fight this horrible disease."* LGFB Beneficiary

Information on Workshop and Masterclass locations, self-help videos and additional information can be found at [www.lgfb.co.uk](http://www.lgfb.co.uk)

**Shannan Walls**

## Macmillan Activity Promotion Programme (MAPP)

### **What is the Macmillan Activity Promotion Programme (MAPP)?**

MAPP is a FREE 6 week group physical activity programme run by a team of specialist oncology physiotherapists which aims to improve your level of physical activity. You may be at any stage of your cancer journey from diagnosis through to recovery or palliative care. If you want to be more active we will do what we can to help you. Each session consists of a 45 minute "well-being" discussion on six different topics and then you will complete a 30 minute physical activity session.

The physical activity session will be tailored to your individual needs and will vary on a weekly basis. At the end of the course we hope you will feel more confident about physical activity and that you will carry on using local services or doing activities on your own. During the course we will help you to identify activities that you might like to continue after the course has ended and discuss the wide range of opportunities available to you.

### **How do I access MAPP?**

**It's as easy as 1, 2, 3!!**

**Contact us** - If you are interested in MAPP the first thing to do is speak to the MAPP team by calling (02920) 615888 (ext 6340 – physiotherapy) or by emailing [MAPP@wales.nhs.uk](mailto:MAPP@wales.nhs.uk). We will then send you a patient self-referral form. Alternatively, you can download the referral form from the Velindre website – visit <http://nww.velindrecc.wales.nhs.uk/document/368726>

**Book an initial assessment** - When we receive this referral form we will contact you with a date for an initial assessment. Your assessment will take place at Velindre Cancer Centre, Whitchurch. This assessment will be completed by a physiotherapist and will establish if MAPP is the best option to help you become more active.

**Decide on a start date** – Following your initial assessment, if you are happy to start MAPP we will enroll you on a class within your local area for you to attend (subject to availability).

### **What our patients have said...**

Take a look at what some of our previous patients have said about the programme:

***"It has been good to be with a like-minded group of people and supported by very professional staff."***

***"The weekly sessions were a great encouragement and motivator. I feel more positive and energetic."***

***"MAPP has helped me feel I am moving on. I've made progress with my exercising and have felt safe."***

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# MACMILLAN ACTIVITY PROMOTION PROGRAMME

**Did you know that there are great benefits to being more physically active?**

**Have you been affected by Cancer?**

**Do you live in South East Wales?**

Run by physiotherapists, this is a 6 week programme for people living with a cancer diagnosis who want to get more active.

We will support you to make long term changes and help you to look at the different options available to you.

If you are interested please speak to your GP or contact the MAPP team on  02920 615888 extension 6340 or  [mapp@wales.nhs.uk](mailto:mapp@wales.nhs.uk)



## **The Patients Voice at the Heart of the Hospital**

### **Who are we?**

A mixture of **Velindre Cancer Centre** patients, carers, management and staff who work together to improve the lives of patients and carers.

### **What do we do?**

Patient Information Bags – over 11,000 produced since Jan '04.

Provide the patients view on a wide variety of subjects from Transport to Catering to Dignity.

Help out at Radiotherapy Open Evenings.

Help with annual audits at the Hospital.

Discuss all your comments, suggestions and opinions.

**For Further Details Email: [plg@wales.nhs.uk](mailto:plg@wales.nhs.uk)**

**or ring Helen Davies on 029 20 316278**

## **WE ARE ON THE WEB:**

**[www.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](mailto:Eleri.girt@wales.nhs.uk)

The network newsletters are available on the South Wales Cancer Network website : <http://www.cancernetwork.wales.nhs.uk>