

Autumn & Winter 2014



South Wales Cancer Network Newsletter

Welcome to the Autumn and Winter Edition of our Newsletter

Macmillan Worlds Biggest Coffee Morning

On Friday September 26th staff from the South Wales Cancer Network joined thousands of others across the UK in holding a Coffee morning and cake sale in aid of the Macmillan Worlds Biggest Coffee Morning. In addition Sheila James and Lisa Williams did the Gower MacMarathon and in total we raised a magnificent Grand Total of £1,913.50. A huge thanks to all who supported the event by either donating cakes or raffle prizes and to those who bought the cakes.



Special points of interest:

- Maggie's Swansea
- Shine Support Group
- Open Wide—Cwm Taf UHB
- SWCN Patient Conference



Time



You took the time
To listen
You took the time
To understand



You took the time
When it was scarce
You took the time
To help me take command

You took the time
When I was scared
You took the time
When I was lost

You took the time
When I needed it
You took the time
It helped me think
You took the time
When time was all

I needed

By Malachy O Donnell



Inside this issue:

SWCN Macmillan Coffee Morning	1
A Poem	1
Maggie's Centre Swansea	2
Jane's Corner—Eating Well	5
Open Wide	5
Shine—Cancer Support Group Cardiff	8
2014 Patient Conference roundup	9



Maggie's Cancer Caring Centre, South West Wales, Swansea - Maggie's South West Wales can be found in the grounds of Singleton Hospital, Swansea.

What happens in a Maggie's Centre?

Maggie's offers free professional practical, emotional and social support for people with cancer and their families and friends including to those bereaved.

Emotional support might be one to one counselling, a group session with people in a similar situation, stress relieving workshops, or something like art therapy or supportive walking that might help to you understand what you're feeling.

Some examples of the practical support on offer includes benefits advice; nutrition work shops, Tai Chi, relaxation or restorative yoga classes; **Talking heads** for people who may lose their hair and **Where Now?** a 6 week course for those who have completed treatment.

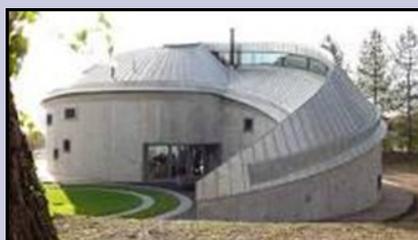
Social support comes from the community spirit in our Centres and the friendships that are formed over our kitchen table. But even just a cup of tea with someone who understands what you're going through without you having to explain can be a huge relief.

Who was Maggie?

Maggie Keswick Jencks was a landscape architect and writer who lived with advanced cancer for two years. During that time she used her knowledge and experience to create a blueprint for a new type of care. Care that gave people information to become active participants in their own treatment; care that recognised the importance of comforting spaces when people are feeling vulnerable; and care that never allowed people to "lose the joy of living in the fear of dying" as she put it. Maggie died in 1995 but her ideas live on today in the Centres that bear her name.

Who is Maggie's for?

Maggie's is for people with cancer and their families and friends: young or old, male or female, rich or poor, local or otherwise. It doesn't matter what type of cancer you've got, what stage it's at, or whether it was you that received the diagnosis or somebody close to you. If cancer has affected your life in any way, you're welcome at Maggie's. This year alone, 10,000 visitors have been welcomed here at Swansea. We cover a population of 900,000 from Bridgend to Pembroke and up to Mid Wales. We are the first Maggie's Centre in Wales although there are 18 Maggie's centre across the UK, the next is planned at Cardiff.



The Maggie's Building itself

Great design and architecture is vital to the care Maggie's offers. The building is special and delivers a calm and uplifting environment that make such a positive difference to people with cancer and to the people who work in our Centres.

Evidence shows that an uplifting environment can reduce stress and anxiety. Maggie's Centres are intended to feel more like a home than a hospital and designed to make people feel safe, valued and comfortable in an atmosphere that stimulates their imagination and lifts their spirits.

Does it actually make a difference?

Yes, Maggie's programme of support has been proven to improve the physical and emotional wellbeing of people with cancer and their families and friends. 99% find support that we provide helpful. The Department of Health has described our work as an example of best practice in the Cancer Reform Strategy in 2007 and the National Cancer Survivorship Initiative report in 2013. Maggie's unique approach to cancer care was also acknowledged by the NHS Cancer Plan in 2000 and the NICE report 2004. We review the programme of support regularly to be sure that it stays at that standard, through visitor feedback, an annual audit, internal audits of two Centres and a three-yearly external review carried out by international cancer experts

Our Professional Advisory Board of leading cancer specialists offers independent advice on the quality and delivery of the support we offer.

How much does it cost to visit?

Nothing. There is no cost for any of our services we are a cancer caring charity.

What can I expect the first time I visit a Maggie's Centre?

We always keep an eye out for first time visitors to make sure they're made to feel welcome. We listen to you over a cup of tea and help you decide what you'd like to get out of visiting Maggie's. We will suggest parts of the programme that might interest you, but the decision will be entirely up to you – you can get involved with as much or as little as you like.

Do I need an appointment or a referral?

No - Maggie's operates on a "drop in" basis, so you can pop in whenever you like Monday to Friday 0900-17:00. Some parts of the programme take place at certain times and may require an appointment or booking, but our doors are open – just come in.

I'm worried Maggie's will be full of sick people and doom and gloom.

Maggie's is for people at all stages of cancer with all types of cancer, so there's a real diversity among our visitors. There is place for quiet reflection and sad moments, but you'd be surprised what a positive uplifting environment there is in our Centres and how much laughter emanates from the kitchen table!



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>



Maggie's Swansea Cont'd

What if I don't want to talk to other people with cancer?

There are lots of quiet corners in every Maggie's Centre where you can retreat with a book or a newspaper. And even sitting at the kitchen table, people are very respectful of those who don't want to talk. Everyone is going through the same thing, so there's a lot that can be left unsaid.

Is Maggie's a hospice?

No, Maggie's is not a hospice – it's there for people with cancer and their families and friends at any stage of cancer and the support we offer is not residential. There are no beds at Maggie's so you can't stay overnight (although there are a few corners that are so quiet and cosy that people have been known to catch forty winks!). Maggie's Centres are open weekdays from 9am to 5pm or 24/7 online at

www.maggiescentres.org/onlinecentre

Is Maggie's part of the NHS?

No. Maggie's is not part of the NHS – we are an independent charity.

Maggie's Centres are built in the grounds of NHS hospitals at the invitation of the local trust; our programme of support is developed with the input of leading clinicians to complement medical treatment; and 50% of all people who come to Maggie's are directed to us by hospital staff, so our relationship with the NHS is very important.

By

Sarah Hughes Centre Manager Maggie's Swansea

To view our programme or to find out more follow links below :

Maggie's web link www.maggiescentres.org/swansea

Maggie's Facebook link www.facebook.com/maggiessouthwestwales

Maggie's twitter@maggiesswwales

Maggie's SWW, phone number 01792 200 000

sarah.hughes@maggiescentres.org



Jane's Corner



Cancer Awareness Dates 2014

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

Eating well

It can be difficult eating well when you are having cancer treatment. If your mouth is sore, or you have any other problems, ask for medical help. If you are seeing your clinic every month, then take a list of what you want to ask. And don't forget that you can always ring up the clinic, or your GP for advice.

Most important is to get enough to drink. One cup of tea a day is not enough! Drinking water is good for you. Even if you have been sick, you might be able to sip lukewarm water. If you are nauseous, you might not be able to drink a whole mug at once like you used to.

Try and keep a record of what you are able to eat. Ideally, we need protein, vitamins, minerals, fat and carbohydrates daily. You might not be able to eat all that. Eat protein (scrambled eggs can be good) if you are able. But if all you can 'eat' is a sugary drink, then do that, and ask for help from your GP.

If you are being sick, tell both your doctors and your dentist. Your dentist can advise you on how to look after your teeth.

There will probably be times in the 4 weekly treatment cycle when you can eat better than others, just make the medics aware of what is going on.

By Jane Barnard

'Open Wide': Can exercises given before Radiotherapy for some cancers of the Head and Neck reduce the risk of problems with jaw opening and is this kind of therapy practical and acceptable to patients?

What is Trismus?

In our role as Speech and Language Therapists working within the Head and Neck Cancer MDT we come across many patients who experience '**Trismus**'. Trismus can be defined as a reduction in mouth opening less than 35 mm. Significant trismus is mouth opening below 20 mm.

Tumours in the mouth, back of the throat, base of tongue, salivary glands and the upper and lower jaw may require Chemo-Radiotherapy or Radiotherapy to be delivered to areas including the jaw joints and muscles; this can sometimes cause damage and scarring to these tissues which can lead to Trismus.

Cont'd from p5

Not being able to open your mouth enough can lead to poor oral hygiene, dental caries, difficulties with intubation, problems with speech, swallowing difficulties/reduced nutritional status as well as emotional distress and reduced Quality of Life.



Incidence appears to be 25.4% post radiotherapy and 30.7% for Chemo-Radiotherapy (*Bensadoun et al 2010). It is most likely to occur nine weeks post Radiotherapy treatment but onset can be up to 24 months post treatment (Bensadoun et al 2010) – it is a progressive symptom with a risk of mouth opening reducing over time.

Anecdotally as Speech and Language Therapists working within the Head and Neck Cancer MDT we frequently meet patients suffering Trismus as a result of their radiotherapy treatment. The functional impact of Trismus can be devastating for the patient:

"I find not being able to open my mouth very frustrating. Communication can be difficult especially with those who do not know me although it can still be difficult with immediate family. I am unable to eat and not being able to eat meals with my family mean that Birthdays, Christmas, holidays and parties I tend not to join in anymore. I go to my local but for most of the time I sit alone and PEG feed due to the communication difficulty and embarrassment"

The project:

If people develop problems with opening their mouth after they have finished their Cancer treatment the usual therapy offered is a programme of exercises using a jaw stretching device called a 'TheraBite'.



TheraBite – Platon Medical

It has been suggested that the use of 'TheraBite' may be beneficial before Radiotherapy treatment has started.

Aims:

There are 2 main aims of this small, single centre, non-randomised study:

To examine the acceptability to patients of the use of a 'TheraBite' before and during their Radiotherapy treatment instead of after and to determine whether this intervention is acceptable and feasible in a NHS Setting in South Wales.

To assess the feasibility of a larger multi-centre randomised control trial to test the hypothesis that providing pre-emptive Trismus exercises mitigates the reduction in mouth opening sometimes caused by radiotherapy to the jaw joints and muscles.

How will the findings of this study ultimately benefit people affected by cancer?

We hope our results will go towards

Reducing the incidence of Trismus among the head and neck cancer population.

Reducing symptoms as a result of Trismus such as poor oral hygiene, caries, communication impairment, swallow impairment

Improving the awareness of patients, carers and health care professionals regarding the risk of Trismus and the need for timely intervention

The project has been funded by Tenovus for 18 months. We hope to recruit 20 participants from our Head and Neck Cancer Combined Clinic in the Royal Glamorgan Hospital. Each participant will be provided with a TheraBite device and followed up monthly for a period of six months. We hope that the results will prove positive and enable us to provide this already proven treatment as a preventative measure to those at risk of developing this debilitating condition.



**Bensadoun R et al. A systematic review of Trismus induced by cancer therapies in head and neck cancer patients. Support Care cancer 20010; 18 1033-1038*

Contact details:

Project Lead: Kerry Davies, Highly Specialist Speech and Language Therapist
Kerry.davies2@wales.nhs.uk

Royal Glamorgan Hospital, 01443 443287

Chief Investigator: Menna Payne, Macmillan Clinical Lead Speech and Language Therapist
Menna.payne@wales.nhs.uk

Shine – Cancer Support

A charity that aims to support young adults who are living with a cancer diagnosis has launched a network in Cardiff.



Shine Cancer Support is the only charity in the UK that is working to ensure that people diagnosed with cancer in their 20s, 30s or 40s have access to the information and support that they need, in a way that suits their lifestyles. Shine is working to build a community of younger adults with cancer and ensure that all young adults can access a peer network both online and in person.

Being diagnosed with cancer is a daunting experience and Shine gives younger adults the chance to build friendships with people who are in a similar situation through meet ups that are suited to their lifestyle . These include beach/country walks, evening drinks, lunches and days out. In addition, Shine's closed Facebook group gives members the opportunity to introduce themselves, interact with people prior to meet ups, and get to know others online if they do not live near a Shine network.

Rhian Jenkins, a coordinator of the fledgling Cardiff group said: 'Shortly after joining Shine's online community I found myself visiting the Bristol network for a coffee. I walked into the venue and the next three hours were a whirlwind of exchanging ideas and chatter. Before attending a meet up I was worried that I wouldn't have much to say or that I would find that they really weren't suited to me, But they turned out to be a wonderful and uplifting experience. When Lucy and I met through Shine and began talking we realised that there was a desperate need for a network in Cardiff '

Lucy Burgess, fellow Cardiff Coordinator said: 'I found that many of the other patients I met during treatment were considerably older than me and that many of the support groups were cancer specific or aimed at teenagers. After joining Shine's online community I saw the benefit of having access to support from people who share an understanding of what it means to be a cancer patient at a time in your life when many of your peers have no experience of cancer and might find it difficult to offer you support.'



Shine Cardiff holds twice monthly meet ups and welcomes those at any stage of any cancer diagnosis. If you would like to be added to our mailing list or would like to receive any materials to pass onto patients please email : cardiff@shinecancersupport.org.uk

<http://www.shinecancersupport.co.uk/Pages/default.aspx>

South Wales Cancer Network Patient Conference



On 1st October 2014 almost 100 patients, carers, third sector organisations and health professionals attended the third Patient Conference for the South Wales Cancer Network, at The Orangery, Margam Park.



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 the diagnosis of a rarer cancer.

The welcome was made by 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 the format for this year's conference was different to last years. The organising committee had looked closely at the feedback from last year's event and, although feedback had been very positive, it was felt there was not sufficient 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. There were a variety of presentations throughout the day which included:

The Challenge of Early diagnosis

Dr Bridget Gwynne: *General Practitioner & Lead Primary Care Clinician for South Wales Cancer Network*

Awareness and Beliefs about Cancer

Kate Brain: *Senior Lecturer in Healthcare and Communication Quality Programme Lead, Cochrane Institute of Primary Care and Public Health, School of Medicine, Cardiff University*

Neuro Endocrine Tumours

Dr Aled Rees: *Consultant Endocrinologist Cardiff & Vale University Health Board and*

Dr Mohid Khan: *Consultant Gastroenterologist & General Physician Cardiff & Vale University Health Board*

Eleanor Jenkins (on behalf of Sally Jenkins) and Yolande Mears: *Patient representatives*

Acute Oncology Project

Gillian Knight: *Macmillan Chemotherapy & Acute Oncology Project Lead, South Wales Cancer Network*

Head and Neck Cancer

Derek Ford: *Patient Representative and Vice Chair Velindre PLG*

Jane Cox: *Macmillan Clinical Nurse Specialist Head & Neck Oncology, and*

Lucy Powell : *Specialist Speech and Language Therapist, Aneurin Bevan UHB*

Many thanks to Macmillan Cancer Support for the awarding of the grant that enabled us to hold the conference.





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

or ring Helen Davies on 029 20 316278

WE ARE ON THE WEB:

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

www.cancernetwork.wales.nhs.uk



**GIG
CYMRU
NHS
WALES**

Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board

South West Wales Cancer Centre Patient Forum

DO YOU HAVE OR HAVE YOU HAD CANCER?

We are setting up a South West Wales Cancer Centre Patient Forum and we are looking for patients and carers to join the group

If you would be interested in getting involved then please come along to our meeting

If you are interested in joining the Forum then please contact:

Mandy Town

Specialty Manager - Cancer Services

Abertawe Bro Morgannwg University Health Board

Tel: (01792) 205666 Ext 8389

Email: mandy.town@wales.nhs.uk