

Breastfriends Cardiff and Vale Breast Cancer Support Group

May 2017

Breastfriends Abroad!



The world is becoming a very small place as Breastfriends Rosina Butler (left) and Jen Pascoe (right) discovered when they bumped into each other at their hotel pool in Tenerife.

See page 5

Who are we?

Breastfriends is a friendly support group for anyone who has had a diagnosis of breast cancer, whether it was last week, last month, last year or many years ago.

Breast cancer can be isolating and scary, but meeting others in a similar situation and sharing information and experiences can make a real difference.



Walk with us or talk with us

We meet once a month in Cardiff and once a month in Barry as well as meeting regularly for short walks in lovely surroundings. See back page for more details.

We know that walking into a room of strangers can be off putting, so please get in touch if you'd like a buddy for your first walk or meeting.

www.breastfriendscandv.org.uk

Osteoporosis

A huge thank you to Dr Jane Turton, Research Associate, Llandough Hospital, Cardiff for kindly agreeing to be the speaker at our February meeting. Jane has been a regular speaker at our meetings over the years and always generates a lot of interest. February was no exception.

All the information below has been taken from the National Osteoporosis Society web page - www.nos.org.uk

What is osteoporosis?

Osteoporosis occurs when the struts which make up the mesh-like structure within bones become thin, causing them to become fragile and break easily, often following a minor bump or fall. These broken bones are often referred to as 'fragility fractures'. The terms 'fracture' and 'broken bone' mean the same thing. Although fractures can occur in different parts of the body, the wrists, hips and spine are most commonly affected. It is these broken bones or fractures which can lead to the pain associated with osteoporosis. Spinal fractures can also cause loss of height and curvature of the spine.

Calcium

Calcium is vital for strong teeth and bones because it gives them strength and rigidity. Our bodies contain about 1kg of this important mineral, 99 per cent of which is found in our bones. Most people should be able to get enough calcium through healthy eating, without the need for additional supplements.

Vitamin D

You need vitamin D to help your body absorb calcium. Adequate vitamin D will also keep muscles strong and help prevent falls in older people. You can get vitamin D by the action of sunlight on your skin, from food and drink containing vitamin D naturally or added-in ('fortified') or from dietary supplements. You should try to get short periods (about 10 minutes) of sun exposure to your bare skin, once or twice a day, without sunscreen and taking care not to burn. Get outside between late March and the end of September when the sun's rays produce vitamin D.

To ensure you get enough, a UK government advisory committee have recommended that, in addition to sensible sunlight exposure, everyone over 1 year of age should get 10 micrograms (sometimes described as 10 µg) of vitamin D every day. (8.5 - 10 micrograms for all infants under 1 year). The government says most of us should get enough vitamin D from sunlight when we are outside in the summer, alongside foods that contain vitamin D but that in the winter months we rely on foods and supplements. 10 micrograms (µg) is equal to 400 International Units (IU).

Exercise and strong bones.

Another way your skeleton can grow stronger is if you do regular weight-bearing exercise. This is any kind of physical activity where you are supporting the weight of your own body, for example jogging, aerobics, tennis, dancing and brisk walking. If you have osteoporosis and are at high risk of breaking bones, you may need to be careful of vigorous, high impact exercise and forward bending (touching your toes).

Remember, it's important to stay active and find exercise you enjoy. Broken hips occur in older people when they are frail and more likely to fall. Exercises like swimming, gardening, golf and Tai Chi may help to maintain muscle strength, balance and co-ordination and reduce your risk of falling. See our booklet Exercise and osteoporosis for specific exercises.

Patient Experience at Velindre



‘Velindre is a very special place’. How many times have we heard those words, or even said them? So many of us who have been treated at Velindre have been overwhelmed by the friendly atmosphere of the hospital and the dedication of the staff.

Last year Velindre celebrated its 60th anniversary and at the heart of organising the celebrations was the Patient Experience Manager, Kate Hammond.



Kate, who came to what was a new role in Velindre 2 years ago, after 10 years working in Communications at the Welsh Blood Service, describes herself as ‘annoyingly optimistic and passionate about living the best life’, a philosophy she brings to her working life.

**Sut wnaethom ni
How did we do**



‘Our patients are so very important to us’ says Kate ‘and are at the heart of what we do. Their feedback is essential to helping us improve. Obviously, there are some things, such as car parking, that we can do little about at present although we can ensure that it is addressed in the building of the new hospital. However other issues may be dealt with on the spot and I

would urge your members and readers to let us know if there’s anything they’d like us to know about. Feedback can be face to face or anonymous and our comment boxes are dotted around the hospital to facilitate this’.

Velindre has a long standing well respected Patient Liaison Group and in recent months, Kate and members of the senior management team have been working with the group to produce its vision for the future. The patients and carers of Patient Liaison Group are just a small number of the many people who give their time to volunteer for Velindre , over 80 in total. In March, Kate (front) and Patient Advice and Liaison Support Officer, Daniel Payne (back), joined Michele Pengelly (right) and Ceri Harris (left) at the Patient Experience National Awards in Birmingham where the children’s book, Caring for my Family with Cancer, developed by Michele and Ceri, won the Communicating Effectively with Patients and their Families Award. Huge congratulations to Michele and Ceri for the work they’ve done and also to Kate who walked away with a special on the day award nominated by the MD of the Patient Experience Network.



If you’d like to know more about patient/carer involvement at Velindre, or share your story, please get in touch with Kate at kate.hammond@wales.nhs.uk She’d love to hear from you!

Sue Youngman



Well done to our very own Elaine Nicholas who was chosen as a runner up in the Boux Avenue Girl of a Kind competition run in conjunction with Breast Cancer Care. She won a £250 voucher to spend at Boux Avenue!

Elaine (left) was nominated by her best friend Jill Little (right).



Dates for Your Diary

Breast Cancer Care Cymru Dates

Moving Forward Courses

This free four week course (one morning per week) covers a range of topics to help you move forward after treatment. Expert speakers are happy to answer questions and there's time to share experiences with people in a similar situation to you.

Princess of Wales Hospital, Bridgend

10am - 12.30pm

Fridays 26 May - 16 June 2017

Llandough Hospital, Cardiff

10am - 1pm

Wednesdays 26 July - 16 August 2017

Booking is essential for the above Breast Cancer Care Cymru events.

Please call 0345 077 1894 or e-mail cym@breastcancercare.org.uk for more info.

Living with Secondary Breast Cancer has been designed to give you the opportunity to meet other people living with a secondary diagnosis and get relevant information and support.



In Cardiff there are regular (usually monthly) meet-ups where you can chat and share experiences with others with a secondary diagnosis. Topics include pain management, fatigue, benefits, and side effects sessions – we also welcome suggestions for topics you would like to cover.

If anyone is interested in the Living with Secondary Breast Cancer service they can contact Breast Cancer Care Cymru on 0845 077 1893 or email secondaryservices@breastcancercare.org.uk

19 May, 11am—3pm, Clinical Trials

16 June, 11am—3pm, Benefits and Financial advice

27 July, 11am—1pm, Meet up

18 August, 11am-1pm Meet up

15 September 11am—3pm, Physical Activity

Monday, 26 June 2017

7pm—9pm

Strawberry Tea & AGM

Guest speakers

**Dr Annabel Borley
Dr Helen Passat**



**The Canolfan Centre
Rhiwbina, Cardiff CF14 6LX**

All Welcome!

Please join us and bring a friend—we'd love to see you

Saturday, 9 September 2017

2pm—4pm

Late Summer Afternoon Tea

Tickets £10

to reserve, email info@breastfriendscandv.org.uk
(also available at Strawberry Tea)

If you are over 70..... Message from South East Wales Breast Screening Centre

'We will not invite you but you are still able to be screened if you wish. Please ask us for an appointment by getting in touch with your local Breast Test Wales screening centre. Screening is only available every three years'.

South East Wales Breast Screening Centre

18 Cathedral Road, Cardiff, CF11 9LJ. Telephone: (029) 2039 7222

Breastfriends Abroad (from page 1)

We say the World is a small place and getting smaller and that if we investigated hard there are allegedly only 5 degrees of separation....a TV actor also famously argues " there is no such thing as a coincidence..." well for Rosina Butler and her husband Derek, on holiday in Tenerife to celebrate their 45th Wedding Anniversary, this was a coincidence of note. At breakfast one morning, and not realising they had both travelled to Tenerife, on the same plane and the same coach transfer !! they met Cardiff Breastfriends member Jen Pascoe and her husband John.....coincidentally they had last met at a CRUK visit in October last year. Rosina is a member of Barry Breastfriendsimagine their surprise....



Equally surprising was that Rosina had discovered a self help group advertising at the hotel, AMATE, and that the Hotel were offering treatments with a portion of the fee going to support this group. AMATE started as an initiative by a group of women and men who had suffered and been affected by Breast Cancer. It now has over 600 members. Its stated main aim is to highlight the importance of early diagnosis and offers support and assistance to improve the quality of life of those impacted. It promotes self checking similar to our own TLC and lobbies what they class as National Health Institutions to improve the lives of sufferers. It apparently covers the whole of the Canaries Islands but is based in Santa Cruz de Tenerife. They support a Breast Cancer International Day on October 19th every year. It was good to hear there are other self help groups campaigning around the world where sufferers help each other and offer support and guidance. Just like we do here in Wales.....

Derek Butler

More Breastfriends Abroad

(and a lighthearted look at housework!)

Sue Youngman in Reykjavik, Iceland



Dust if you must, but wouldn't it be better,
To paint a picture or write a letter,
Bake a cake or plant a seed.
Ponder the difference between want and need?

Dust if you must, but there's not much time,
With rivers to swim and mountains to climb,
Music to hear and books to read,
Friends to cherish and a life to lead.

Dust if you must but the world's out there,
With the sun in your eyes and the wind in your hair,
A flutter of snow, a shower of rain,
This day will not come around again.

Dust if you must, but bear in mind,
Old age will come and it's not kind.
And when you go as go you must-
You, yourself will make more dust.

Rose Milligan

Gaynor Sinton in Vietnam



National Exercise Referral scheme (NERS)

NERS? NERS?..... Now I know what it is, I'm on it!

I have met such interesting and inspiring people. I also feel better and as Spring approaches I am more encouraged to get up and do more things. This is not the latest dating agency but a national referral scheme to get us more active - if we want to be, of course - and why not if it helps? Well done to the Welsh Government and participating leisure centres and GPs.

People with a range of conditions (knees, hips, hearts, backs the list goes on) are eligible and because the groups are a randomish mix everyone works at their own pace. Nobody mentions "the burn". It isn't relevant. The instructors I have been helped by are great - my lymphoedema sleeve was noticed and I was reminded (discretely) to remember it! I was impressed - they have been trained to deal with people like us. My fellow group members have taught me a lot about living and loving the life we have with good humour and steady perseverance.



The range of activities is what different leisure centres offer - but in special groups - so there is a really good choice, including Aqua if that floats your boat.

To register for the scheme talk to your Breast Care Nurse, or GP or get on the Macmillan Activity Promotion Programme (MAPP) - I went from MAPP .

You get a named person who helps you with progress over 16 weeks (£2 pounds per session). You can attend as many sessions as you like per week and if you leave for no good reason you have to wait 2 years before reregistering, which seems reasonable.

I recommend at least an inquiry about NERS.

Anne Donald

Walking (and talking) with Breastfriends

Inspired by the success of the Barry Breastfriends walking group which started in March 2015, we decided to trial one in Cardiff last year.



We chose Roath Park as our venue as the walk around the lake takes approximately 30 minutes (although coffee afterwards usually takes a lot longer!)

At first we walked every fortnight but that proved just a bit too complicated with everyone, including me as 'leader', wondering 'is it or isn't it this week?'. Also the number of lovely ladies turning up to walk soon made a weekly walk very worthwhile.

I asked one of our regulars if she could give me her thoughts about the walks and here's what she had to say:

'Enjoyable exercise in a lovely setting, a great group of people, of all ages, who care and with whom you can share any worries you may have and last, but not least, a lovely warm drink at the end of the walk. These were my thoughts when Sue asked me for something for the newsletter. Just in case you think it all sounds a bit serious I can assure you the conversations in the cafe have a happy combination of serious and downright hilarious!'

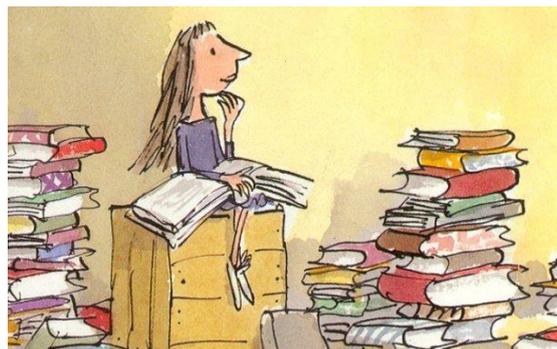
'You're sure of a warm welcome if you join our band of walkers. I started going, on my own last year and was made so welcome I've continued going'.

Please see page 8 for details of our Barry and Cardiff walks. **Sue Youngman**

Books I've read about Breast Cancer

Diary Entry: Monday 8th June 2009 *Long job interview process in morning. Meeting with specialist in afternoon. I have breast cancer. Bit of a shock. Didn't feel like going to Mum's for tea.*

I've always kept a diary right back to my school days in the 1970s. In the back of my diaries I always keep a list of books I've read. Mostly crime fiction but in 2009 I also read a number of books on the subject of breast cancer. I'd been warned not to go onto the Internet by my breast cancer support nurse who said I'd only scare myself witless so I went to my local library in search of enlightenment.



The first book was a paperback called '**My Mummy Wears a Wig**' by Michelle Williams-Huw. At the time Michelle worked the BBC in Cardiff and the book was all about her treatment and recovery. Not knowing anyone who had gone through the experience that I could talk to I found her book re-assuring and informative and not too 'heavy' a read.

In the book she mentioned '**The Breast Cancer Prevention and Recovery Diet**' by Suzannah Olivier. So I dashed out and bought it. This was a heavy read with tiny writing and a mind-boggling amount of dietary recommendations that leave you grasping for the biscuit tin and a glass of chardonnay. In one section she recommended that patients have a better chance of the disease not re-occurring if you are operated on early in the morning and just before a period as opposed to just after! Where do they get these ideas from? I soon discarded it even though it was recommended by a Mike Hudson, Consultant Surgeon, Breast Care Unit at Queen Elizabeth Hospital.

The next book from the library was called '**Lopsided: How Having Breast Cancer Can Be Really Distracting**' by Meredith Norton, an American. This book troubled me as she kept going to different specialists who all seemed to recommend different treatments and surgery. Should I have asked more questions? Or was this the American experience with health insurance and treatment costs becoming part of the whole cancer 'journey'.

The most useful book to come from the library was actually a collection of photographs taken by Lynne Redgrave's daughter. These photos showed one person's experience and I remember being amazed at how she continued to appear nightly on Broadway during her treatment. That was her way of coping. Everybody is different.

Lastly, I briefly remember trying to read a book that would have been at home in the Bridget Jones's Diary series – 'Bridget Jones Lollops Her Way Through Breast Cancer' or something along those lines. After about 20 pages the woman in the book started to irritate me with her quirky take on chemotherapy and I literally threw it out of the window barely missing the postman.

On reflection I have to say that all these books, and there are always plenty of them out there, did help me to understand what I was going through and that other people had experienced similar 'journeys' and had coped.

Everybody copes differently and has to find their own source of support. I'll always be grateful for a wonderful care nurse specialist who was always there if I needed advice and to Breast Cancer Care for providing its Moving Forward course where I met 11 wonderful people all going through the same thing as me.

Jane Shatford



What's on at Breastfriends

Join us at one of our meetings

Cardiff Meetings

Our Cardiff group meets on these dates from **1pm-3pm** at the **Margaret Whittaker Lounge, Rhiwbina, Cardiff, CF14 6LX** unless otherwise stated

Friday 12th May

Psychological support, Claire De Luca, Velindre

Friday 9th June

Jo Fowler, Choir leader, 'Sing with Us' Tenovus

Monday 26th June, 7pm—9pm

at Canolfan Centre, Rhiwbina, CF14 6LX

Strawberry Tea and AGM

Guest Speakers

Dr Annabel Borley and Dr Helen Passat

Friday 14th July

Lymphoedema and LVA

Elaine Nicholas shares her personal experience

****Please note there is no afternoon meeting in August**

Barry Meetings

Our Barry group meets on these dates from **2pm-4pm** at the **Mary Lennox Room, Barry Hospital, Colcot Road, Barry, CF62 8YH**

Friday 19th May

Coffee and Chat

Friday 16th June

Trekking after Breast Cancer
Elaine Nicholas and Sue Youngman

Friday 21st July

Reflections on my changing Body Image 7 years on
Breast Cancer Care model, Jane Shatford

Friday 18th August

Afternoon Tea at Whitmore + Jackson
Please contact Rosina on 01446 745269 for more information and to book

For more information on the Barry meetings please call Rosina on 01446 745269 or Linda on 01446 710516 / 07967 806073

Walk and talk with Breastfriends

We meet **every Tuesday (weather permitting)** for a short leisurely walk followed by coffee and maybe cake!

Barry walks alternate between Barry Island and the Knap and start at 10am or 10.30am depending on the time of year—Please contact Rosina on 01446 745269 or Linda on 01446 710516/07967 806073 for more info)

Cardiff Walks meet **by the lighthouse in Roath Park at 10.30 am** for a walk around the lake
(Please contact Sue on 07773 500525 for more info)



Contact Us

Phone: messages care of Breast Cancer Care Cymru on 0845 0771894

Please check our website for up-to-date information

Email: info@breastfriendscandv.org.uk

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