

HUG MAGAZINE



February 2011

(issued on 2nd or 3rd Thursday of alternate months on meeting days)

For HAEMATOLOGY and ONCOLOGY patients, being treated in the Day Therapy Centre and Dove Ward or under review



Some of us at the Christmas lunch

Email: hugswindon@btinternet.com

H.U.G. Swindon Get-Togethers at the GWH

We meet in the Academy on the second Thursday of the month.

Turn up at any time between
All between 10:00 am and 12:30 pm

10 March 2011 – Seminar Room 5
14 April 2011– Seminar Room 6
12 May 2011 – Seminar Room 6

(The Academy can be reached from the front of the Hospital by going through the double doors at the back of the atrium, turning right and following the signs, which first appear at the end of the corridor. Alternatively park in the public car park at the back of the hospital, cross the road and walk back towards the entry road. The Academy entrance is about half way along, in the main building. The small parking area just outside the Academy is unfortunately for staff only.)

What do we do?

HUG offers tea, sympathy, sharing of ideas and information and much more, to patients and their families or carers, including:

- **Organising monthly get-togethers at the Hospital, Coffee Mornings (contact us for details of the next one) and Craft Sessions (refer to page 8) away from the Hospital**
- **Suggesting how and where to access professional help, where appropriate**
- **Attending Cancer Services User Involvement Meetings on behalf of patients and carers and discussing or raising and following up on issues of importance to them.**
- ✓ **Items currently under discussion include Complementary Therapies, End of Treatment Care Plans, Parking and Radiotherapy for Swindon**
- **Fund-raising to provide practical help with purchases including thermometers, travel bands, mugs, slippers and gel bags, when suggested by clinical staff, patients or carers.**

Maintaining a website and distributing leaflets to promote the group and advertise out activities.

Producing the HUG Magazine bi-monthly and making it available in Cancer Services areas, providing direct to members and posting on the website.

INTERESTING HEALTH-RELATED NEWS

National Cancer Patient Survey Report

This national report provides insights into the care experienced by cancer patients across England who were treated as day cases or inpatients during the first three months of 2010. 158 NHS Trusts providing cancer services identified patients and 67,713 patients chose to respond. The 2010 survey builds on a previous survey undertaken in 2000 involving over 65,000 cancer patients and a smaller survey undertaken in 2004 involving 4,300 patients. Importantly the 2010 survey is the first to involve patients with all types of cancer. It is also the first national survey in this country in which the word cancer has been explicitly used.

Each of the 158 NHS Trusts taking part in the survey have been provided with a bespoke report which enables them to compare their provision of cancer patient experience with other Trusts, and to drive quality improvements and better outcomes locally. Great Western Hospitals NHS Foundation Trust was included in the survey. Refer to the link below for more information, or simply search for DH_122516:

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_122516

Improving Outcomes: A Strategy for Cancer

This UK Department of Health document was published on 13th January 2011. The intention is to detail cancer targets to help the reformed National Health Service to deliver cancer outcomes that are amongst the best in the world. Although significant improvements have been made in recent years, there is still a gap in survival and mortality rates compared to the European average. This is believed to be due to later diagnosis and specific capacity limitations. The coalition Government wants to deliver improved outcomes, by tackling preventable incidence, earlier diagnosis and by improving the quality and efficiency of cancer care services. The strategy sets out how this can be done, linked to a new Outcomes Framework, with the aim of increasing survivorship by 5,000 per year every year by 2014/2015. You can find it on the following path or do a search on DH_123371:

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123371

Breast cancer incidence

Breast cancer statistics released on 4th February 2011 show an increase in the number of women diagnosed each year, rising from around 45,500 to 47,700, increasing the lifetime risk to one in eight. Part of this can be attributed to an ageing population (age being the biggest risk for developing breast cancer), increased awareness of breast cancer symptoms and the success of the NHS screening programme. More research is needed to examine the role factors such as lifestyle and diet play in these figures.

It remains crucial that women are breast aware throughout their lives and those aged 50 and over attend their routine NHS screening appointments, as early diagnosis will increase the chances of long-term survival.”

Excerpt from press release by Pamela Goldberg, Chief Executive, Breast Cancer Campaign

(Last time we reported on the Open Day at the Penny Brohn Cancer Care Centre in Bristol. We now follow up with two articles from patients who have been on courses there. The Centre is now a Charity which does not charge, although donations are welcomed. Our sincere thanks to them for the following articles.)

Penny Brohn Experience

By: JF

I first heard about the Penny Brohn centre in Bristol five years ago when an information pack unexpectedly popped through my letterbox. My sister had heard about the centre from a friend and kindly ordered the information pack for me. Its arrival coincided with the beginning of my first chemotherapy session. At that time I was so consumed with trying to make sense of my diagnosis and the enormous volume of clinical language my life had become that it got put to one side.

Over the next couple of years I picked up the brochures a number of times with the intention of contacting the centre but life took over again. In addition eight rounds of chemotherapy and monthly hospital admissions had left me jaded. If I'm honest I was so fed up with talking about cancer and being around 'cancer' I wanted a break; I wanted to feel 'normal' again. I thought the centre was 'all about cancer' - that I was later to discover was a very flawed judgement on my part. Three years into my journey a close friend of mine visited the centre on an open day and reported how lovely it was. On this recommendation I went ahead and booked the three day residential course.

I arrived at tea time on the first day and any nerves I had (and I had them) were alleviated instantly. As I walked through the doors there was someone waiting for me. Everything was organised so professionally and calmly. I found myself chaperoned to my bedroom, which was beautiful, given time to settle and then collected for the evening meal to meet everyone else on the course.

Over the next three days there were a great deal of new experiences to enjoy. We were guided through meditation, which I really loved. We had the opportunity to have individual consultations with the doctor, nutritionist and psychotherapist. I had a session with the healer which was a lovely experience. On reflection we managed to do rather a lot. However, if you were particularly tired or needing alone time the practitioners would do the consultation in your room if you so wished.

The food, building and grounds were breath-taking and you had the opportunity to stroll around the gardens at your leisure.

The highlight for me was the evening spent with one of the co-founders, Pat Pilkington. It was so humbling to hear how the centre was formed as well as sharing Penny Brohn's journey with one of her close friends.

I would highly recommend anyone to attend the centre, not just if you are affected by cancer. You will be welcomed with open arms. I continue to use the centres facilities and am hoping to attend the five day residential course later in the year. I am very grateful for the centre and the vital work they do. My experience was personally life changing.

Penny Brohn Experience 2

By: SH

I first heard about Penny Brohn Centre four years ago when I was undergoing treatment but at that time it was a very expensive option. A couple of years later I went on a one-day introductory course with women from the Breakaway breast cancer support group. The day was a perfect introduction to the work of the centre and so I was thrilled when I found out last year that the courses were now being offered free.

I undertook a five day retreat last August and it was an enlightening way to review and reflect on my cancer journey and to look at ways of staying well and to coming to terms with the diagnosis. Four years on from initial diagnosis I was not consumed with fear but there was fear none the less, fear of the disease returning.

Over the five days a number of personal one to one appointments were set up for each person to attend. These included consultations with a doctor, a nutritionist, a healer, a psychotherapist and a bodywork session, which for me was a massage, but could be shiatsu or acupuncture. Each morning before breakfast there was the opportunity to attend a stretching class. After breakfast the day's activities would begin, interspersed with time spent on developing meditation skills, something I had never done and I was surprised that the meditation moments made you feel so at peace with yourself.

Throughout the day there were also different group activities, from nutrition talks, art therapy and group discussions. The centre promotes an integrated medical approach to maintaining health. No one is ever discouraged from following conventional medicine but emphasis is also placed on the person developing a healthy lifestyle to support his or her own recovery. The food at the centre is outstanding and the chefs work hard at creating some of the most imaginative food I had ever tasted. Food is based on the whole food plant based approach, however small amounts of fish and meat are available but they really are very small amounts! Dairy accounts for organic butter at breakfast and sugar is replaced with honey or agave syrup.

If you are not used to this approach it can seem quite daunting on the first day but everyone in my group marvelled at the taste of everything presented to us. The food is continuous throughout the day with stops for snacks and juices and as many herbal teas as you wish. The emphasis is on keeping yourself well nourished so that the body can work to its best. The doctor and nutritionist gave me time to explore different approaches to maintaining health and address some ongoing problems from the treatment.

The psychotherapist helped me to clarify some of my thinking about the disease. This was a very emotional session as like so many people I had kept my feelings to myself. The masseur was able to work on the treatment site and for the first time in four years I was able to lift my arm above my head and without pain. The healing session was unlike anything I had ever experienced and I was shocked when she explained that the person doing the healing is you! She was just the facilitator.

The five days went very quickly. It was a very emotional and humbling experience but everyone who attended had a lot of fun. The last evening was spent drinking wine and dancing under the instruction of a dance teacher! I came away not only with instructions about how to care for myself physically but how to be kind to myself, acceptance of the journey and of being involved and enjoying today.



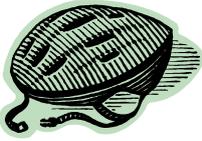
HUG ★
fridge magnet
★ fun

If you're going to be late, then be really late: make it an hour and enjoy your breakfast.



Our hopes are but memories reversed.

Hope sees the invisible, feels the intangible and achieves the impossible.



"I take nothing for granted. I now have only good days, or great days."

Lance Armstrong

You know you're living in the 21st century when you haven't played solitaire with real cards in years.



Laughter is the nearest we ever get, or should get, to sainthood. It's the state of grace that saves most of us from contempt.

John Osborne

My New Hair: Patient Information Resource

A very useful information leaflet called "My New Hair" is included on the Trevor Sorbie charity My New Hair website at www.mynewhair.org. The leaflet can be found under the tab "Advice and Support", and has been produced in conjunction with the Department of Health. It can be downloaded for reference.

Alternatively if you do not have internet access, you can ask for help at the Cancer Services Information Point or at your local library.

It contains a number of different topics:

- separate sections on hair loss through chemotherapy, radiotherapy and hormone treatment
- emotional support
- description of ways to reduce or prevent hair loss
- the choice of wigs and wig bases available
- what might be offered on the NHS
- considerations when selecting a wig
- information on how wigs can be styled for the individual
- suggestions for alternatives to wigs
- the options for men and children and different ethnic groups
- advice for those with thinning and patchy hair and methods of disguise
- links to other websites such as Cancer Research and Macmillan for more information

The website lists wig suppliers and hairdressers trained in hair loss issues, and includes a section for professionals who wish to become involved in the charity. Overall, the booklet and website have improved since we first took a look.

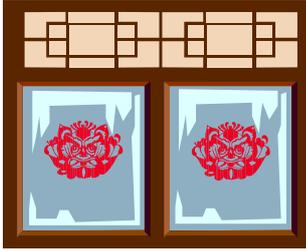
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Having a Bad Day? Well, it could be worse!

The average cost of rehabilitating a seal after the Exxon Valdez Oil spill in Alaska was said to be \$80,000.00. At a special ceremony, two of the most expensively saved animals were being released back into the wild amid cheers and applause from onlookers.

A minute later, in full view, a killer whale ate them both (reputedly!).

H.U.G. Support Group

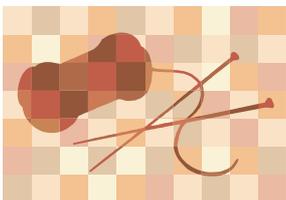


Craft Sessions at Haydon Court Haydon Wick (behind Morrisons Supermarket)

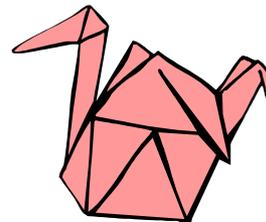
On Monday 21st February

And then on the 3rd Monday of each month
Between 2pm and 4pm

Join us to work on your own projects
or one of ours!



..... or just come along for a chat!



H.U.G. News – read all about it

Get-togethers were held in the Academy at the Great Western Hospital on 16th December 2010 and 13th January 2011, with a coffee morning at the Blunsdon Arms at the end of November.

1. Recent Get-Togethers

At the December get-together we held a social where we had nibbles and soft drinks which were greatly enjoyed by those present. We advertised this session as a “Drop-In”, but attendance was poor, with a number of regulars unable to attend because of appointments or one of the pre-Christmas bugs around.

In January we finalised plans for buying craft supplies and looked at the annual accounts for the group. These showed a healthy financial position. Ideas were also collected for the End of Treatment Care Plan Workshop organised by the Thames Valley Cancer Services User Involvement Group. A representative attended on the group’s behalf.

The next step in the possible provision of complementary therapies will be discussed at the next Swindon Cancer Services User Involvement Meeting, which takes place just as this Magazine issue is distributed.

2. Donations

No fundraising was carried out over the Christmas period after the November Christ Church Christmas Market. However, we have received a very generous donation from the Rotary Club of Swindon, to be used to buy craft materials and pay the initial rent on the common room at Haydon Court. We also received a further donation of £160 from friends of a patient.

3. Spending

M and I have been shopping for a selection of materials to get us started on card making at the first craft session. We’ll do more shopping once we know what everyone would prefer to make.

We have also placed an order for a further batch of thermometers to be given to patients who are at risk of neutropenia, following a request from the Haematology Nurse Specialists. They tell us that the existing batch has been used and that they have been much appreciated by patients. As before these will have “HUG Swindon” printed on them, as a way of advertising the group.

4. Activities

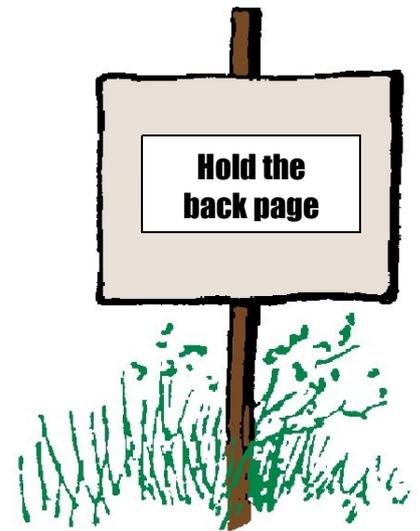
For our late Christmas lunch we went to the Blunsdon House Hotel, and were able to take advantage of a very favourable special offer price for a delicious array of dishes. There is something to be said for leaving the celebration lunch till after Christmas, when we are less busy and the prices come down.

Thanks to D for photographs of us enjoying lunch. One appears on the front page and the others will be put onto the web site.

Care about your hair?

We have mentioned the charity My New Hair which has been offering practical help and advice at Trevor Sorbie and other trained salons, to those who have lost their hair. Unfortunately there is still not a salon in Swindon listed so far. Refer to Page 6 for details of other information which is included there.

Meanwhile, Toni and Guy salons, working with Macmillan, are also offering specialist advice and support on hair care for people affected by cancer. Even better, their Swindon salon at 27 The Parade, SN1 1BB is offering this service.



Boots Cancer Information Points

Look out for Macmillan Cancer Information Points which are appearing in Boots Stores in High Street locations.

Leukaemia Care

This charity provides a 24 hour care line on 0800 1696680, on a Freephone number. They also have a volunteer network throughout the UK, to ensure that there is local support wherever a patient and their family live.

They are involved with patient advocacy, to help improve the outlook, treatment and quality of life for anyone who has been affected by blood cancers.

In addition Leukaemia CARE can provide discretionary financial assistance to patients and carers in need. This can include travel costs to and from hospital for family members, payment of utility bills, food vouchers, or help with the purchase of essential household items. They also provide a signposting service to other charities and organisations which may be able to offer additional assistance.

Prospect Hospice

We hear via Voluntary Action Swindon that Prospect Hospice chief executive Angela Jordan is encouraging smaller voluntary organisations to take advantage of some of their excellent new facilities - for meetings or events. "We have a fabulous building for patients, staff and volunteers and I feel strongly that others should be able to use the facilities whenever we can make them available. Our new cafe space, aptly named 'Heart of the Hospice', opens early in 2011 and I do hope other local organisations and members of our community will pop in."

Local organisations wishing to enquire about using any of Prospect's facilities should call Siobhain Acott on 01793 816119 (Mon-Thursday) or visit the website at <http://www.prospect-hospice.net/>.