

# HUG MAGAZINE



**February 2009**

(issued bi-monthly)

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



HUG members enjoying Christmas Lunch 2008

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# H.U.G. Swindon Get-Togethers

We meet in the Academy (at the back of the Hospital), Room Number as shown.

Turn up at any time between  
10:00 am and 12:30 pm unless otherwise stated  
on the Thursdays shown:

**12<sup>th</sup> March 2009 – Seminar Room 1**

**19<sup>th</sup> April 2009 – Seminar Room 1**

**14<sup>th</sup> May 2009 – Seminar Room 7**

## AIMS

**HUG aims to improve the environment for patients of the Day Therapy Centre and Dove Unit or under review following treatment in these areas at the Great Western Hospital, Swindon by:**

- ❖ **Holding regular “get-togethers” where Haematology and Oncology patients and their relatives can make friends, share their views and experiences and receive information about hospital and other relevant services, in an informal atmosphere over refreshments.**
- ❖ **Producing the HUG Magazine, a light-hearted and informative bi-monthly publication and making it available in Dove Unit, the Day Therapy Centre and the Osprey Waiting Area.**
- ❖ **Pointing patients in the direction of specialist help available, as required.**
- ❖ **Following up on comments about Hospital Services and reporting back on progress made.**
- ❖ **Fund-raising to provide items for the benefit of patients, such as mugs, bookshelves, room redecoration, donation to Dove Ward Charitable funds, Christmas gifts and slippers for patients. Ideas are welcomed at any time for future projects.**
- ❖ **Maintaining a website to promote the group.**

### **Get-Togethers away from the Hospital**

**In addition to the get-togethers at the Hospital, as advertised above, we meet for coffee and a spot of lunch, for anyone who wants it, at least once a month. Contact Irene for the next location, date and time, if you would prefer to meet us, away from the Hospital. We are a small friendly group, who would make you very welcome.**

# INTERESTING MEDICAL NEWS

## **Smoking and Cancers**

A US study has provided further evidence that smoking increases the risk of death from cancers other than lung cancer. The majority of lung cancers are caused by smoking, but scientists have long known that tobacco contributes to a number of other forms of the disease.

The latest study, which is published in the journal BMC Cancer, provides further evidence for the link between smoking and deaths from cancer. Researchers at the University of California-Davis conducted an analysis of National Centre for Health Statistics data on men in Massachusetts.

When they looked at annual death rates from lung cancer and death rates from all other cancers between 1979 and 2003, they found that the two rates changed in tandem, with the strongest association among men between the ages of 30 and 74 years. Overall, smoking appears to have been linked to more than 70 per cent of cancer deaths in 2003 - far higher than the previous estimate of 34 per cent in 2001.

## **Obesity link to ovarian cancer**

Researchers have found that obesity can put older women at a much higher risk of ovarian cancer, according to a report in the journal Cancer. Studies showed that overweight women aged between 50 and 71 are 80% more likely to have the disease than those of a healthy weight. The same increase in risk level was not evident in women who had taken HRT. More than 6,000 a women a year are diagnosed with cancer of the ovaries.

## **NICE – Guidelines on End of Life Treatments**

New Guidelines on the appraisal of end of life treatments have been issued by NICE. Full details can be found on their website at:

<http://www.nice.org.uk/aboutnice/howwework/devnicetech/endoflifetreatments.jsp?domedia=1&mid=97621FDD-19B9-E0B5-D42E151303D26288>

NICE 02 January 2009

## **Free Prescriptions for cancer patients**

Thanks to campaigning by Macmillan, free prescriptions for cancer patients who are not currently exempt, will start from 1<sup>st</sup> April 2008.

Application forms can be obtained from GPs or Hospital Doctors, who also need to countersign. Applications for certificates received by 24<sup>th</sup> March will be processed in time to be used for 1<sup>st</sup> April. Patients who do not apply for their certificate in time will have any prescription charges they have paid since the 1<sup>st</sup> April refunded.

Exemption certificates last for 5 years (but can be reapplied for) and cover all prescriptions not just those relating to cancer.

For more information, go to the Department of Health website;

<http://www.dh.gov.uk/en/Healthcare/Medicinespharmacyandindustry/Reviewofprescriptioncharges/index.htm>

**H.U.G. SWINDON, HAEMATOLOGY/ONCOLOGY UNITED GROUP, G.W.H.**

WAS IT ALL WORTH IT???

By a GWH patient

During the last week of February '08 I received a telephone call from the hospital to say that I had Lymphoma Cancer and could I get to the hospital in the next hour. I explained it would be nearer 2 hours as I needed to tidy up a few ends at home, pack a bag and then a ¼ hour drive.

I arrived at the hospital with my husband both, of us still numb - not really taking it in. I was met with much kindness and consideration from all the staff - discussions began immediately about the problem which was a blockage (tumour) in the bowel. Whereas the barium enema had not shown up anything, it had just been extremely painful, I had almost been in shock (I have had a barium enema before with no problems) and it took me a few days to get over it, CT scans had shown the blockage immediately.

The scan showed the possibility of a perforation and the surgeon said he would be able to fit me in the following Thursday, in the meantime I was placed on tablets etc. The treatment was explained to me and there were pills to help with sickness, dosage according to problems. Overall everything was very reassuring - it was a cancer which could be cured.

I had the operation on my stomach as planned. The whole thing turned out to be much longer and more involved than expected. I then managed to get an infection in the wound - maybe from the operation as Bowel Operations are apparently prone to cause infections, but the infection could have been picked up in the ward. I had terrible diarrhoea. The doctors do their rounds and look at your wound in the morning but there was no immediate follow up to redress the wound which means it is open to all the bugs (one day it was 3-4 hours before it was redressed. (I had to ask). There are not enough staff to follow up as necessary. I went home one evening and returned the following day in a very unwell state with my stomach leaking "*gunge*" etc. and it smelt terrible. It was sorted and took over a month to heal. The operation had been successful in that the tumour was completely removed but it had meant losing some of the large bowel and some of the smaller bowel as well as the control valve. Nobody was aware this would be necessary when it all began....

When I was fit enough it was decided to start chemotherapy - there were to be 6 sessions - 3 weeks apart. I would spend one day every 3 weeks in a day bed having the treatment - it was scary the first time, as I did not have a clue as to what it entailed.

A canula was fitted into my arm. For the first session things are done slowly in case of reaction. It takes all day of course. Blood tests are taken all the way through the next 18 weeks, as it was very necessary to keep a check on everything. Everyone was kind and caring and you felt cared for. Staff could not have been kinder.

After the first session I felt quite well for a couple of days, although very tired. The pills given helped the nausea and overall I felt pleased, then Wham! Bam! Alacazam! I felt dreadful, nothing specific and the diarrhoea was non-stop. I could not get back to bed before I had to go again. The diarrhoea had been more or less continuous since the operation but was now worse and my weight was going down fast. One of the more painful things was the sore mouth ulcers, sores, etc. The mouth wash and morphine made eating possible - but I would never have supposed a sore mouth would make me feel so unwell and useless. I returned home and was well looked after by the community and district nurses on a daily basis, I went on to booster building drinks which are milky, which I enjoyed, but it got worse.

**H.U.G. SWINDON, HAEMATOLOGY/ONCOLOGY UNITED GROUP, G.W.H.**

I found myself so depressed and weepy (not my nature normally). My blood counts were low and overall I was very ill - this continued throughout the treatment - very tired, diarrhoea, depressed, weepy, could barely walk around the room, nothing helped - we tried delaying one treatment but that resulted in the same symptoms. I went back into hospital after every treatment for blood, potassium, magnesium and antibiotics (overall I would have happily died). I picked up various infections every time.

I discussed with other patients their reactions and found we were all very distressed at our weepiness and lack of get up and go - food was of no interest, television much the same - concentration\_very limited. I think, but for the Olympics I personally would have given up. I cried when U.K. won, I cried when U.K. lost and not just the UK team, but all the teams were quite amazing. None of us had realised how lowering and depressed the treatment would make us feel.

Every time I had treatment my health went further down hill. It went lower and could not creep back. It was decided by mutual consent not to have the 6<sup>th</sup> chemo session, which was 7 weeks ago. I now weigh 7 st. 4 lbs - I was 10 st. when it all started. I have been as low as 6 st 13 lbs. I am still picking up infections but generally feel better. An interesting factor has been the lines which have appeared on my finger and toe nails. There were 5 lines fairly evenly spaced, the session with the delay being slightly further apart than the others. It has made my nails soft and rubbery, one growing on top of the other, they are growing out. Strangely, another line has appeared. Whether this has anything to do with chemicals or whatever still in my system, not as definite as the first 5. Hopefully this will be the last.

The other side affect, although cannot be positive at my age, was being forgetful. I could not do a simple crossword, as could not think of words. This generally got worse. I have nearly always had complete recall in the past, so you can imagine my upset, but I am glad to say everything is improving in leaps and bounds, including my memory.

It will take at least another 6 months before I will feel like me and I still have the diarrhoea to be sorted and - if ever - maybe it never wil l- my life would be controlled by the bathroom. I can now put the washing in the machine and can cook the dinner - what the future holds is debatable. I know I am 75 but had hoped to finish my years fit and able so that I could still have had a good life. I have a lovely family and many friends.

This is not a complaint or moan -I feel the best treatment possible has been available to me but no one knows each person's physical reactions which are obviously different. The whole of the last 8 months has been traumatic, painful for self and family seeing my deterioration. I am now a hairless scarecrow. I have a National Health wig which is great fun, but trying hard to overcome ill health, find fun of life again (limited at the moment). Hopefully there will be a future. Although things are working their way through I wish I had known more about the side effects. Maybe, if I had known more would I have tried or fought harder, who knows.

I hope that these few words will help other patients to understand a little about what is happening to them.

And now that I am feeling better, I think it **was** worth it.

(We are pleased to report that M is feeling much better this week.)

**H.U.G. SWINDON, HAEMATOLOGY/ONCOLOGY UNITED GROUP, G.W.H.**

Tolerance is composed of nine parts apathy to one of brotherly love.



H.U.G. ★  
fridge magnet  
★ fun

No. 1

ALWAYS REMEMBER -  
YOU ARE UNIQUE;

JUST LIKE EVERYBODY  
ELSE!



You know you're past it  
when your knees buckle but  
your belt won't.

A fool and his money are  
fun to go out with.



Is reading in the loo  
multi-tasking?



If at first you do succeed,  
try not to look



astonished.

## What is Maggie's and What Happens There?

A small group of HUG members went recently to Maggie's Cancer Information Centre at the Churchill Hospital in Oxford, to find out a bit about the aims of the organisation and what specialist services are provided.

We received an extremely warm welcome with an immediate offer of refreshments, much appreciated, on a day when it had seemed doubtful at first whether we could make it through the snow at! Well, Maggie's is a drop-in centre for anyone affected by cancer and the warm welcome is an important part of the Charity's philosophy, as a first step towards providing a range of psychological and emotional care, to help them to cope with their circumstances.

When we warmed up sufficiently, we were provided with a brief history and details of future plans for Maggie's by the Community Fund Raising Coordinator. She explained that the Charity's first centre was the vision of Maggie Keswick Jencks, an author and garden designer, who had been diagnosed with breast cancer in 1988, at the age of 47. She continued with her normal life for five years after a mastectomy, but then the cancer returned with a vengeance, having spread to Maggie's liver, bones and bone marrow. She was given the news that she had only a short time to live and the unacceptable way in which the news was broken to her had a profound effect. Maggie lived for a further 18 months, more than a year longer than suggested, and it was during this defining time that she began to think through several key things which were to lead to the planning of the Edinburgh Cancer Caring Centre.

Maggie realised that she felt much better when she took an active role in her treatment. She was interested in diet, nutrition, supplements and boosting the immune system. She did not think that others should follow the same route necessarily, but knew that everybody could benefit from doing something for themselves, in whatever way they thought best. She realised that they would need reliable information and support in finding the best way for them, especially in view of the amount of bewildering information on cancer and its various treatments, both complementary and conventional.

Maggie talked to her medical team about the need for a small domestic haven where patients could rediscover 'the joy of living in the fear of dying.' That place was a small disused stable block opposite the oncology ward at the Western General Hospital in Edinburgh.

Maggie was married to Charles Jencks, an expert writer and designer in architecture, with an international reputation. They were soon making plans to build a permanent centre at the same hospital. Maggie died in July 1995, a year before the centre opened. Her husband called the building a 'Maggie's Centre' after his wife, whose warmth, determination and passion for life had left behind a lasting legacy.

Since then, the Charity has grown considerably, and there are now additional permanent Maggie's Centres in Glasgow, Dundee, Inverness, Kirkcaldy and London, interim centres in Oxford, South West Wales and Lanarkshire and planned centres in Nottingham, the North East and the Cotswolds. Each centre aims to be more like a cosy house, rather than a hospital, but are opened all on hospital sites, so that those affected can drop in when they are there for other purposes. Each of the permanent centres has been designed by a renowned architect, through friends and contacts of Charles Jencks, so each is a beautiful and unique building. The interim centres, like Oxford, are in temporary accommodation till funds can be raised locally to pay for permanent building. The Oxford design, from the renowned architects WilkinsonEyre, is for a stilted tree house, the shape of which will incorporate trees that are already on the site. It should certainly meet the brief of being "bright and welcoming and unusual enough to inspire people's imagination, curiosity and enthusiasm", from the sketches that we saw.

So, in line with Maggie's vision, it's not just tea and sympathy, as the temporary Centre at the Churchill in a porta-cabin, already provides general information and advice from professionals, close to the radiotherapy department and the new Cancer Centre. Help can be given, for example, to prepare patients for treatment, come to terms with living with cancer and bereavement support. Maggie's also run regular courses based on demand, such as those provided at Oxford:

- Drop-in relaxation Groups
- Stress management programme
- Mindfulness Meditation
- Support groups
- Living with Cancer
- Eating for Health
- Expressive Art and
- Look Good, Feel Better (provided by local beauticians)

It is hoped to run a yoga course soon and staff are open to suggestions for other talks or courses. HUG members thought it might be worthwhile to have one aimed specifically at those who have come to the end of their treatment and may be having difficulty in recovering and getting back to normal life.

Other specialist help is also available at Maggie's Oxford. One of the Macmillan/Oxford Citizens Advice Bureau Advisers, explained how she and her colleague are based at Maggie's and can offer benefits advice to callers on a drop in basis on Wednesday mornings or Thursday afternoons and by appointment at other times. She explained that NHS and Macmillan grants may be available to cancer patients and their families in certain circumstances, in addition to the range of Social Security benefits.

One to one appointments can also be made with a clinical psychologist, for anyone who might need counselling.

Apparently there are significant numbers of Great Western patients using the services at Maggie's Oxford centre, usually while they are on site at the Churchill for radiotherapy. Even more may be expected when the new Cancer Centre building opens very shortly.

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If you would be interested in a Look Good, Feel Better session, we are hoping book one for a group from the GWH, so do give contact us. It doesn't matter whether you are a HUG member and we could almost certainly help with transport. The session would have to be booked around 3 months' ahead, since there is a lot of demand. Look out for leaflets in Osprey Unit, giving more details.

If you are interested in making a donation to Maggie's Centre Oxford, who have a target of £3 million pounds to reach for the permanent centre at the Churchill, ring on 01865 225710 or send to Maggie's Oxford, Churchill Hospital, Old Road, Headington, Oxford OX3 7LJ.



# H.U.G. News – read all about it

Get-togethers were held at the Great Western on 11<sup>th</sup> December 2008 and 8<sup>th</sup> January 2009 in the Academy at the GWH, with Coffee Mornings at the Blunsdon Arms in between

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## **1. Recent Get-Togethers**

Christmas mince pies, cake and seasonal non-alcoholic drinks were supplied by members at the December Get-Together. Afterwards, we dispensed Christmas cake to staff and patients in Day Therapy and left some for staff on Dove Ward. Since meetings have been in the Academy, it is less likely for anyone to drop in and join us.

Our Christmas lunch was a successful event at the Toby Inn. It was great to see those who are not able to get to most get-togethers.

## **2. Donations**

We have received donations totalling £220 from relations of Debbie. Other donations from her friends and family were given to the Prospect Hospice.

## **3. Events**

As detailed earlier in this edition, some of us paid a visit to Maggie's Centre in Oxford, in early January.

We shall be discussing other events for this year at our February Get-Together.

## **4. Spending**

Having used up our stock of HUG "designer" teddies, we have bought some more, at a very good price. They are virtually identical to the previous order, the only difference being the lighter pink colour of the pads on the paws. This will allow us to continue to sell at the bargain price of just £2.50 each, and still make a profit for funds.

Magnifying glasses, for use by patients in Dove Ward, who find it difficult to read, with the light available have been received and will be delivered to Dove Ward at the end of the February Get-Together.

The gel bags (for chemo patients) and the wheeled stools (for nurses administering chemo) are next on the list, as soon as we get precise details of the requirements.

After trialling some different models, staff in Day Therapy have decided which they prefer. We understand that there are still some negotiations, before we go ahead with a purchase. These are not standard NHS issue but would help greatly to avoid back strain, when nurses are sitting by beds for extended period to inject chemo drugs.

## **Sponsored slim for HUG funds**

**HUG member Y has decided to lose weight on a sponsored slim, and hopes to be able to donate at least £1 to HUG funds for every one lb loss in weight, over the 8 weeks starting 1st February. She already has several sponsors who have committed to £1 per lb. If you would like to sponsor her, for even a small amount, contact us by email, contact details as below. Be warned, when she puts her mind to it, she can really shift some pounds!**



## **Look Good, Feel Better**

**Remember, if you would be interested in a session of skin-care and make-up ideas at Maggie's in Oxford, do contact Irene. She will try to make all the arrangements, including transport. You don't have to be a HUG regular to join in.**

## **Stem Cell Transplants by Donor**

**We are hoping to collect some more opinions from patients about their thoughts on stem cell transplants by donor at the Royal Free. If you would be prepared to provide some information, please give Irene a ring. She will explain why we are asking. There is no need to have had any previous involvement with the HUG Group.**

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A woman came home to find her husband in the kitchen, shaking frantically, almost in a dancing frenzy, with some kind of wire running from his waist towards the electric kettle. Intending to jolt him away from the deadly current, she whacked him with a handy plank of wood, breaking his arm in two places. That was when she discovered that he had been happily listening to his IPOD.

What do Eskimos get from sitting on the ice too long?  
Polaroids.

A man rushed into the doctor's office and shouted, "Doctor! I think I'm shrinking!"  
The doctor calmly responded, "Now, settle down; you'll just have to be a little patient."

Laughter is the closest distance between two people.  
Victor Borge