

HUG MAGAZINE



August 2009

(issued bi-monthly)

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



A few of us enjoying lunch and a natter at the pub

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

H.U.G. Swindon Get-Togethers

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

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

10th September 2009 – Seminar Room 1

8th October 2009 – Seminar Room 7

12th November 2009 – Seminar Room 1

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 the Osprey Waiting Area and Wren Ward.**
- ❖ **Pointing patients in the direction of specialist help, 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. We have provided mugs, bookshelves, room redecoration materials, purchased Christmas gifts, magnifying glasses and slippers for patients and donated to Dove Ward Charitable funds,. 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, in another environment. We are a small friendly group, who would make you very welcome.

INTERESTING NEWS

New Book on Breast Cancer Patient Experiences

Details have been sent to us of a new book: *Hearing the Stream, A Survivor's Journey into the Sisterhood of Breast Cancer*. The foreword of the book is written by Dr. Jodi Chambers, a prominent breast cancer surgeon in Denver, and the back cover testimonial is written by Dr. Tim Byers, Interim Director of the University of Colorado Cancer Center. The author writes based on her own and her grandmother's experiences of breast cancer. We have not read the book and are therefore providing information only, rather than making a recommendation.

The book is available online at www.ellexpress.citymax.com or through Border Books.

Mobile phone number national directory

You may have read press reports about the telephone directory that is being made available of mobile phone numbers by the directory enquiry service 118800. This will contain the number of anyone who does not register that they wish to opt out. HUG member Mary told us about how to go about this on www.118800.co.uk/removeme/remove-me.html. We have now discovered that there have been so many ex-directory requests that the service has been suspended. You cannot now make an ex-directory request by telephone, text or on the website, until the service resumes. There is no indication of when that will be or details of how to request being ex-directory by text or telephone.

We hope to provide the information in our next edition.

Effectiveness of Radiotherapy/Chemotherapy improved by increasing Oxygen to tumours

Oxford University scientists have found that slightly increasing the supply of oxygen to cancerous tumours strengthens blood vessels in cancer cells, making radiotherapy and chemotherapy more effective. Details have been reported by Professor Gillies McKenna, Director of the Gray Institute for Radiation Oncology & Biology, jointly funded by Cancer Research UK and Oxford University in the journal *Cancer Today*. Tests have been carried out on various carcinomas in mice, with four drugs which are in clinical use or under development. An early trial on patients with pancreatic cancer has also proved positive. Clinicians intend to start trials later this year for patients with lung, cervical and rectal cancers.

The Telegraph 01 August 2009

Dioxins in plastics and the link with cancers

You may have read recent "e-rumours" about a possible link between cancer and the dioxins in plastics. An e-report received by Irene recently goes a bit further with specific suggestions such as:

- Do not drink water from a plastic bottle that has been left in a warm car or frozen.
- Do not heat foods, particularly those containing fat, in plastic containers in the microwave. Remove ready meals from their containers and place in glass instead for heating.
- Do not use cling film to cover foods for microwaving. Instead use a paper towel.
- Do not buy fast food in polystyrene containers.

The Doctor quoted was Dr. Edward Fujimoto, the Manager of the Wellness and Lifestyle Medicine Department at Castle Medical Center in Hawaii. However, it is understood that he has not come up with any research that proves his theories.

So you can make up your own mind whether you want to make some fairly simple changes to use of plastic containers, just in case!

Five Years on by I.B.

Amazingly, five years have now flashed by since I completed a course of six chemotherapy sessions for non-Hodgkin's Lymphoma. I don't want to make a big thing of it, given that some other patients are not so fortunate. However, I do feel that I should say something, to encourage those patients who have been told that they should make a full recovery.

I had developed some swelling in my neck, which my GP thought was "probably nothing", but it ought to be checked out just in case. I had an ENT appointment two weeks later. The diagnostic period was perhaps the most difficult, with scans, two needle biopsies and then a surgical biopsy, for which results are not immediately available. I first visited the GWH in mid-December 2003, but did not start treatment till the beginning of March, 2004. That did seem like a very long time, but target times from referral to treatment have now been reduced.

My way of coping was to keep as busy as possible generally and to find out as much as I could about neck swelling. One of my sons is a physiologist and both he and I independently came up with the same diagnosis of NHL before the biopsy results confirmed it. I actually received my final diagnosis at the Radcliffe Infirmary (a long story!) and probably surprised the assembled team of clinicians, Macmillan nurse and clinician nurse specialist by calmly saying "Oh yes, that's what I thought it was!"

Plenty of information was provided about the likely side-effects of treatment with R-CHOP, and I chose to find out more for myself about the treatment and its effects by researching further on the internet. This may or may not appeal to other patients. If you choose not to know too much, then that's fine too. Experiences of side-effects during chemotherapy treatment vary greatly, but clinicians have a good idea of how individual patients will be affected, based on their health at the start and how they react to the first chemo session.

Losing my hair seemed like a small price to pay for future good health, and once the messy fall-out was over, it did not bother me at all. In fact I found that I sometimes forgot I was bald, giving one or two people calling at the house a bit of a shock, when I opened the door. Starting treatment in March 2004 meant that it was getting warmer over the period when I had no hair, so I often found it more comfortable to wear a scarf or a turban than the wig I had chosen and at home I went without any head covering. Also the wig suddenly gave me "big hair", which I've never had in my life, and felt a bit strange.

Another effect of treatment was that my neutrophil count became very low midway between treatments, which meant taking antibiotics for a week each time, to reduce the possibility of infection. I got mouth ulcers, as a result, although using the mouth wash provided did help. I was lucky enough not to be, or even feel, sick as a result of the chemo sessions, with the help of the preventative medication.

Far from losing my appetite, I felt the urge to eat more than usual. This was probably a result of the steroids, which also had me gardening at 6 o'clock in the morning when I couldn't sleep and before the sun came out. I developed an overwhelming desire for sweet things, which I don't normally eat much of. It is definitely better just to eat whatever you feel that you can face at this time.

In general the steroids make patients hyper-active and definitely affect concentration levels. Towards the end of the course of 6 treatments I was rather less energetic, however, and needed a sleep for a couple of hours every afternoon. Also after sessions 5 and 6, constipation meant that I had to up the fibre in my diet, but without the wholemeal bread that I normally eat. It tasted disgusting, as did tea, my usual reviver. So prunes and liver salts became the order of the day!

The final chemo session is clearly the main objective for all of us, but it is important to remember that feeling better may still be some time away, with a good prognosis. It was really about 6 months before I felt that my energy level was back to normal. Losing my hair hadn't bothered me too much, but getting it back did seem to be an infuriatingly slow process.

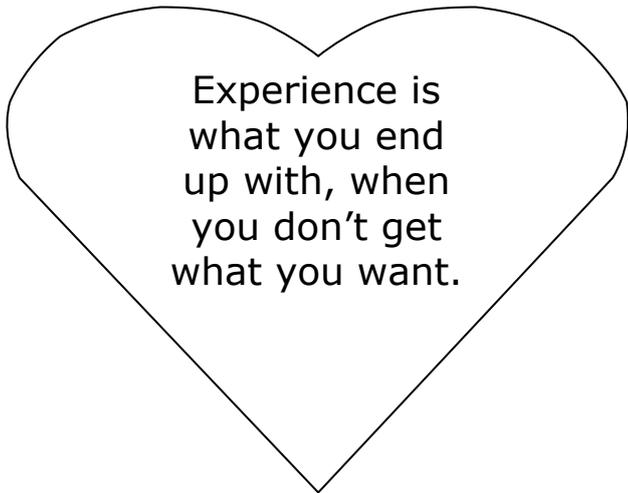
There is also something of a void in your life, at a time when you may be having trouble accepting that you really are better. Suddenly you are having much less attention and visiting the hospital much less frequently. It can be difficult to accept that you really don't need to be monitored to the same extent. I found myself checking for lumps many, many times a day for a long time and probably imagining that I had another problem, although clinical staff didn't even suggest that, when I contacted them. One of my coping mechanisms was to join HUG and get involved in fund-raising, to give something back as a thank you for the medical care I had received. It was also useful to discuss both side effects and emotions with other patients, who had had similar experiences.

Five years on, there are still one or two effects from treatment. I am fair skinned anyway, but just a few minutes of sun on unprotected skin can now bring me out in a rash, and I have to use a really high SPF sun screen and cover up well.

One unexpected effect has been that only my face "glows" when I'm hot. It can be a little embarrassing when it drips, but may be partly due to the layer of high factor sun screen melting. On the other hand, I now have only a rare need for deodorant and my once sweaty feet are not so any more. I haven't read about this effect anywhere.

Only a few kinks of the curls that arrived with my hair re-growth remained with me, and the apparent initial thickness was short-lived. My hair has definitely become thinner over the last 5 years. In my case, this is an inherited tendency, but other patients have reported thinning hair and sometimes a complete colour change as a result of chemotherapy.

It does make me appreciate life more and realise the importance of doing things now!



HUG ★ fridge magnet ★ mottos

Better a wealth of love
than a love of wealth

**The man who has planted a garden
feels that he has done something for
the good of the world.**

Charles Dudley Warner



Laughter is the sensation of feeling
good all over and showing it principally
in one place.

Josh Billings



In the practice of tolerance one's enemy
is the best teacher.



Dealing with loss of appetite

Maintaining a healthy weight and providing the body with suitable nutrition is important for cancer patients, as for many other medical conditions. Loss of appetite is a common side effect. Family and friends may be at their wits' end trying to come up with snacks and meals that appeal and will raise a patient's energy level. Even the smell of food cooking can be a turn-off as a result of nausea. Chewing and swallowing can be difficult because of mouth ulcers. There are many helpful hints around, including the following:

- Eat whatever you fancy, whenever you fancy it
- Frequent small snacks may be more appealing than larger meals
- If you are losing weight, aim for higher calorie meals than normal. Add cream to sauces and eat more starchy foods, for example.
- It may help to avoid hot food and eat cold or cool snacks, especially if you have a sore mouth.
- It may be advisable to avoid spicy foods, but some patients find that strong flavours are actually more appealing
- Take advantage of the help from websites, patient leaflets and hospital dieticians
- Use nutritional supplements if you really are not eating very much

There are helpful dietary advice leaflets available from charities including CLL Support Association, Leukaemia Research and the Lymphoma Association. A good place to start might be the Macmillan website, which lists 59 booklets that are available on food related issues from a variety of organisations, including themselves. (Search under Get Support and Publication for "Diet" at www.macmillan.org.uk)

The Penny Brohn Cancer Care in Bristol runs regular courses on nutrition and cooking, which one or two patients are known to have found useful.

We recently heard that the Rarer Cancers Forum had produced a Cancer and Nutrition DVD, with help from Macmillan and Cancerbackup, and educational grants from Nutricia and Pfizer. The DVD can be obtained from nutritionincancer.co.uk and contains advice from cancer care professionals, as well as ideas for food. The website also contains hints and tips, useful recipes (not all using Nutricia products) and has an "Ask the expert" section, for putting nutritional questions to healthcare professionals.

A couple of pet jokes to cheer you up

(Thanks to Ron for the following and the promise of more jokes for future issues.)

An old lady wanted a companion, and decided that a parrot would be the ideal solution for her. She went into a Pet Shop to buy one.

“Sorry,” said the shopkeeper “we have puppies and kittens, rabbits and gerbils, mice and snakes, but I sold my last parrot yesterday.”

The lady was upset as she had set her heart on a parrot. However the keeper did say “There are some Auction Rooms around the corner, and sometimes they have parrots for sale. You should get one for around £30.”

The lady made haste to the Auction and there, as lot 52, was a lovely red, blue and green parrot, just what she wanted! The bidding started at £25, and quickly rose to £35, then £45, £55 and £60, but the lady was very determined to have the bird and eventually bought it for £98.

When the Auction was over, the lady went up to the desk and paid for the parrot. “By the way,” she asked the young girl there, “does the parrot talk?” “Talk?” said the young girl, “Talk? Who do you think was bidding against you?”

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A young man was walking along a street when he passed a Pet Shop. In the window was a small black and white kitten, but what was strange was that it was drinking milk from an elaborate saucer. The young man immediately recognised the saucer as being a rare antique worth several thousand pounds.

He thought he could not make an offer for the saucer as the shop owner might be suspicious, so he decided to buy the kitten and ask the owner to include the saucer as well, as the kitten liked it so much.

“I can’t do that.” said the shop keeper. “That’s my lucky saucer.” “What do you mean by “Lucky Saucer?” asked the young man? “Well,” said the shopkeeper, “since it has been in the window, I have sold 6 kittens and 2 puppies this week already.”

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Plus some reasons why men are never depressed!

- ◆ You can never get pregnant.
- ◆ Car mechanics tell you the truth.
- ◆ Phone conversations are over in 30 seconds flat.
- ◆ New shoes don't cut, blister, or squash your feet.
- ◆ Wrinkles add character.
- ◆ You can wear the same hairstyle for years, or even decades.
- ◆ A week’s holiday requires only one suitcase.

H.U.G. News – read all about it

Get-togethers were held at the Great Western on 11th June and 9th July 2009 in the Academy at the GWH, with Coffee Mornings at the Blunsdon Arms at the end of June and early August (because of our availability).

1. Recent Get-Togethers

We reached consensus on the design and colour of HUG polo shirts and the order has been placed. These will make it easier to recognise us both at the Hospital and when we are fund-raising. Thank you to the Ward family for the idea. They will be blue with a rainbow design and the group name at the top left. Look out for us in Osprey and Dove from the end of August onwards.

2. Events to come

We have now made arrangements to join a Murder Mystery Evening at the Wyvern Theatre, using the gift from former HUG member Debbie Bird. This will be on 19th September.

We are also organising a picnic day out, Bradford-on-Avon, early in September. The exact date will be decided at the last minute, to beat the weather. Everyone will contribute something for the food, to provide plenty of variety.

Our Relaxation Day, courtesy of Zurich Challenge, will take place on Monday 5th October. We are going to the new Four Pillars Hotel, near Cirencester, where everyone will be able to have their choice (subject to medical agreement) of 2 therapy sessions and use of the spa facilities, plus refreshments. The Zurich team is raising the funds to make it happen with a raffle, a departmental picnic and even renting out parking spaces during staff holidays. This should be a great day out, as part of a wonderful Zurich scheme.

3. Fund-raising

A recent car boot sale at Dauntsey raised nearly £40 for HUG funds. Attendance at a local fair and another car boot sale is planned for August.

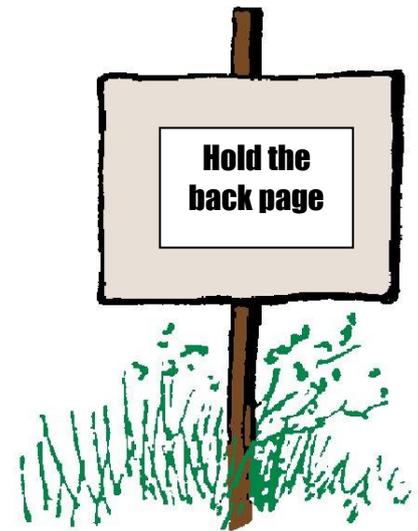
4. Spending

We have purchased a dozen gel packs for use in Day Therapy and Dove Ward and are awaiting feedback on the quality after a few uses.

The purchase of kettles for Dove has been shelved because of health and safety issues. New suggestions for HUG spending include a Wii Fit for Dove patients, thermometers for new patients, a contribution towards the cost of new equipment for Day Therapy. We hope to reach agreement on the next spend at the August meeting.

Go the Extra Smile campaign

We promised to find out the cost of this GWH NHS Foundation Trust campaign, following discussions at HUG about whether it was a good use of resources. We have now found out that it has cost just £2,000 to date and is being regarded as a great success by the Director of Nursing. The campaign started because of complaints from patients that some staff were not welcoming and friendly enough. Staff at all levels, and particularly new starts, are being encouraged to come up with ideas for improvements, as well as comments and suggestions from patients and visitors being taken into account.



Peer Review Internal Validation Process

Two of us from HUG have joined representatives of other local support groups to participate in the above process. The aim is for a team made up of Cancer Services personnel, clinicians from another area of Cancer Services and a "User" patient or carer to review how another area of Cancer Services is meeting the national targets, specific to their specialisation. This year the internal validation will mean that reviewers are looking at a number of areas, including the Multi-Disciplinary Teams for Gynaecology, Lung, Skin and Urology.

A team of external reviewers, also including a patient or carer, will monitor performance against the targets on a 5 year cycle. We haven't committed ourselves to that so far, but one of us has been on the first day of training, including finding out more about what it would involve. Do contact us if you would like to know more.

Foundation Trust Constituency Meetings

The Wiltshire Constituency Annual Meeting was held in early July at Wootton Bassett. The idea was for Foundation Trust members to raise general issues related to the Trust, although our HUG attendee felt that most matters raised were of a more personal nature.

The meeting was scheduled for 4pm, and it was therefore not surprising that most of the attendees, who numbered around 30, were senior citizens. A more representative audience might be obtained at an evening meeting.

Promotions and new clinical staff for Cancer Services

Congratulations to AK on her promotion from Haematology Clinical Nurse Specialist to a full-time position as Lead Cancer Nurse, replacing SB, who is standing down. LM will be the full-time Lead Chemotherapy Nurse. A Cancer Clinical Psychologist, a Cancer-Specific Dietician and a Cancer Research Nurse have been recruited and may have already started by the time of issue of this magazine. Five days a week cover by an Oncology Doctor and the recruitment of a Consultant Paediatric Oncologist are also planned.