

HUG MAGAZINE



October 2009

(issued on 2nd Thursday of alternate months)

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



The winning HUG "Murder Mystery" team

Email: hugswindon@btinternet.com

**** Website****: www.hugswindon.co.uk

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:

12th November 2009 – Seminar Room 1
10th December 2009 – Seminar Room 7 (10:00 – 11:30)
January 2010 – Location TBA

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, which is available in Dove Unit, the Day Therapy Centre, the Osprey Waiting Area and Wren Ward or provided direct to HUG members.**
- ❖ **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 and distributing leaflets 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 us for the next location, date and time, if you would prefer to meet us, away from the GWH. We are a small friendly group, who would make you very welcome.

INTERESTING HEALTH-RELATED NEWS

Honey to boost white blood cell count?

Life Mel is a honey produced in Israel by honey bees fed on a specially formulated diet which includes selected herbs such as Siberian Ginseng, Echinacea and Uncaria Tomentosa. The chosen bees' diet is based on around 30 years of research.

A report published recently in the journal Medical Oncology indicated that eating half a teaspoonful (5g) of this honey twice a day in the morning and evening on an empty stomach this honey can boost the white blood cell count when taken before, during and after chemotherapy sessions.

At £37.50 for 120g, enough for a 12 day supply, the honey is not cheap. It is not suitable for diabetics, anyone with an allergy to bee products, small children or pregnant and breast-feeding women.

New Radiotherapy Machine

The new *RapidArc* radiotherapy machine can follow the contours of a tumour and deliver radiation in a complete circle to target it from all directions. Sophisticated computer technology allows exactly the right dose to be given to patients to the precise location where it is required. This will help to prevent radiation damage. At the moment there is just one of these machines in use at the Clatterbridge NHS Centre for Oncology in the Wirral. However the Government recently made £200 million available for local health authorities to spend on improving radiotherapy treatment.

Daily Mail 29 September 2009

Carers Emergency Card Scheme

Emergency cards are now available in the Swindon area for carers and those they care for, so that anyone finding the card can ensure that appropriate help is provided, if the holder is taken ill or is involved in an accident. Carers register by completing a form which sets out what they would want to happen in the case of an accident or sudden illness. One version states "Attention: I rely on someone for my care." and the other "Attention: I look after someone who depends on me." Both give an emergency 24-hour contact telephone number for the Clover Centre, which is coordinating the scheme. For more information about the scheme contact Swindon Carers Centre, 1 Wood Street, Swindon, SN1 4AN, telephone 01793 531133.

The EPIC study

Cancer Research UK is co-funding the UK arm of a massive study called EPIC, the European Prospective Investigation of Cancer. EPIC is a long-term study of more than 500,000 people in ten European countries. This includes around 90,000 British men and women, of whom about 30,000 will be vegetarians, recruited by Cancer Research UK groups in Oxford and Cambridge.

Many previous studies on diet and cancer have been flawed because they were too small, focused on one population with limited variation in diet or did not measure dietary intakes accurately. This study hopes to do better with participants from so many countries, over at least 10 years, and will be the largest study of diet and health ever undertaken.

Cancer Research Newsletter 2009

A Visit from the Cancer Services Dietician

We were visited for part of the August get-together by AK, who has recently joined the GWH staff in a newly created role as a Dietician specifically for cancer patients. She is being funded initially for one year, after which time a case for continued funding to allow the post to continue will need to be put forward.

Development of the new service will pay particular attention to the following areas in the first instance:

- Lung, gastrointestinal, and rarer cancers (head & neck) where a large number of patients experience dietary difficulties.
- Provide a dietetic service to the Day Therapy Centre and Dove Unit, providing nutrition training and education for staff where required.
- Provide dietetic outpatient oncology clinics.
- Involvement in audits related to the service.
- Implementation of the Malnutrition Universal Screening Tool and nutritional care pathway for all oncology and haematology patients to aid earlier identification and treatment of those patients at risk of malnutrition.
- Build links with the Oxford Dietetic Service and Thames Valley Cancer Network to ensure handover and follow-up of patients takes place as required.
- Nutritional assessment, dietary support, and follow-up for patients undergoing stem cell transplants. In particular dietary advice for patients with very low neutrophil (white blood cell) levels and at serious risk of infection, including food poisoning, as a result of intensive chemotherapy, bone marrow and stem cell transplants.

Most current HUG members are, or have been at some point in their cancer journey, neutropenic (having a low blood cell count), and discussions centred on this area.

Consideration was given to updating patient advice available at the GWH for neutropenic patients. HUG had commented in the past to Linda Webb, Nutrition and Dietetic Services Manager, that some of the information available to patients and their families was confusing and it was not clear when it applied. Since A joined the team, there has been a review of what is currently on offer.

As a result, it was decided to make the Leukaemia Research Leaflet “Dietary advice for patients with neutropenia”, available at the GWH, rather than produce an in-house leaflet. This booklet is easy to read, differentiates clearly between levels of neutropenia and was felt to be the best available from a relevant charity. Using a leaflet from a large national charity will also make it easier to ensure that information provided is up to date in future.

Copies are being made available in Dove Ward and Day Therapy to those likely to be affected by neutropenia, but anyone interested can download a copy of this and other patient information leaflets on the Leukaemia Research web site from:

<http://www.lrf.org.uk/en/1/dispubaz.html>

Alternatively you can request by telephone on 020 7405 0101, or write to:

Leukaemia Research
43 Great Ormond Street
London WC1N 3JJ.

The leaflet includes useful ideas for snacks, if you are suffering from loss of appetite. A advised those of us receiving or recovering from recent chemotherapy to ask our Consultant for our neutrophil count from blood test results, so that we know whether the stringent or more lenient dietary advice applies.

She explained that a further leaflet is being considered for guidance on food brought to in-patients by friends and family.

A then brought us up to date on the availability of special menus for neutropenic patients. The Clean Diet (also known as the Neutropenic Diet) is available on all wards. There is also a Dove Unit Snack Box Menu which can be provided outside of normal meal times for patients who cannot manage larger meals. The White Menu consists of plainer foods and the Black Menu, previously known as Cordon Bleu, has been slimmed down to include only what is currently available.

HUG Members commented that the smell of foods heating on the wards can put patients with poor appetites off, since the mingled smell of different dishes permeates rooms. Unfortunately this is unlikely to change because of decisions taken over how meals would be provided when the GWH was commissioned.

A's visit closed with a discussion about some foods and drinks to avoid for anyone with neutropenia, which not all HUG members knew about. For example fizzy bottled water is OK but still bottled water is not and live yogurt should be avoided. It was felt that some long term patients can miss out on some items of current advice, since it is sometimes assumed that they already know.

We thanked A for her visit and update on the diet advice and menu choices now available for neutropenic patients.

My mind is like a parachute...



it functions only when open.

HUG ★
fridge magnet
★ fun

Insanity is hereditary. You get it from your children.



He who places head in sand, will get kicked in



the end!

You know you're past it when your idea of a night out is sitting on the patio.



Tick Tock, Tick Tock

Time you enjoyed wasting is not wasted time.

It's a Dog's Life
by Boris

I like dogs: German Shepherds, St Bernards, Huskies and Sniffers: I like them all, except of course for some such as lap dogs, corgis and poodles. I don't exactly hate them, but they are not of my ilk. Dogs and dog owners can be funny and this is what I mean.

An old lady was walking across the park when a great big dog, a Wolf Hound, came bounding across the grass and nearly knocked her over. She started to fend it off with her stick and finished up by almost fencing with it. Then she spied the owner, lead in hand, standing nearby under a tree. "Call it off! Call it off!" the old woman yelled. "I can't", shouted the owner. "Why not" yelled the lady. "Well," said the owner, "his name's Caesar."

A dog went into a Job Centre and said to the girl at the desk "I'd like a job." The girl was astonished to hear a talking dog, but said "I think I can suit you. Wait a minute and I'll be back."

The girl went off and after a few phone calls came back to the dog. "Yes," she said "I've got you a job. It's in a Circus."

"A Circus?" said the dog. "What does a circus want with a Bricklayer!"

A Japanese aircraft, carrying spare parts for cars, was flying over Tokyo, when the undercarriage cracked open, and all the spare parts went showering down onto the city below. This was one occasion when you really could say that it was raining Datsun cogs.....

A couple were invited to go to a party and the wife was worried about the fact that they had not been able to find a minder for the children. Her husband suggested "Perhaps we can always leave them with our new puppy. Remember the man we got it from said that it was a baby setter."

H.U.G. News – read all about it

Get-togethers were held at the Great Western on 13th August and 10th September 2009 in the Academy at the GWH, with social events at the Blunsdon Arms at the end of August and the beginning of October.

1. Recent Get-Togethers

Our polo shirts with a rainbow and HUG Support Group at the shoulder have been delivered and very nice they look too. We finally went with a pale blue colour, because the grey was not available in both men's and women's styles. We shall wear these when visiting Osprey and when we are out fund-raising, so that we are recognisable.

The GWH's first Dietician appointed specifically for cancer patients asked to join us at the August get-together. A report is included in this issue.

2. Events

The Murder Mystery Evening attended by members at the Wyvern Theatre in September, courtesy of the bequest from DB, turned out to be a fun evening. We were split into two teams, one of which turned out to be the overall winners, after working out "who done it" (well, one of us was more with it than the rest). A bottle of bubbly was awarded as the prize, as the photo on the front page shows. The other team came in last, although no wooden spoons were given, and yes, there were a few other teams present!

The Zurich Challenge Relaxation and Treatment day takes place just too late to report this time, but we'll tell you about it next time.

3. Donation and Fund-Raising

We have received a donation of £25 from D's Uncle. In addition two of us ran a sales table at the Lambourn Festival Gala Evening and a car-boot stall at the Lambourn Sports Club. These two events saw HUG funds benefit by £87.25 for very little effort, and reduced the collection of saleable items stored at Irene's.

4. Spending

HUG is contributing £500 to the cost of the recliner chairs and nurses' stools in Day Therapy by making a donation to the departmental Charitable Fund.

The gel bags purchased from HUG funds to test out the quality have proved to be explosive and therefore most unsuccessful. A different supplier will definitely be used for the next order. Apologies to staff who had to clear up the mess!

We are going to discuss whether to publicise the group with two sorts of personalised items to give away: thermometers (for patients at risk of neutropenia) and sea bands which may help to alleviate nausea during and after chemotherapy. The stock of thermometers given by a commercial company is now exhausted and supplies seem difficult to obtain, possibly because of the swine flu scare.

You are invited to a
Scarf tying demonstration
On Monday 19th October 2009
Between 2.00 and 4.00 pm
at the abc activity meeting

**Lawn Community Centre
Windsor Road
Swindon
SN3 1LA**

A HUG member will be demonstrating ways of wearing head scarves and how to feel confident and comfortable when using headwear during and following hair loss from treatments.

There will be an opportunity to try tying techniques, participate in the demonstration and join in discussions.

If you don't see information about this event in time, contact HUG to indicate an interest in a repeat event at a later date

Haematology CNS

We understand that a replacement has now been appointed for AK, (who has been promoted, as announced in our previous issue). She may not yet have started in her new post, working with JH.

Royal Free Stem Cell Transplants

The number of patients going for stem cell transplants to the Royal Free, London, is small, around 6 a year. HUG members who have been through this have provided feedback. The quality of clinical care is agreed to be second to none. However, patients have commented to us about a number of areas.

The matter was raised at a Cancer Services User Group Meeting and then discussed with Dr NB and JH. It was suggested that a list should be made of the points which included:

- **More information wanted in advance about arrangements at the RF, such as telephone, television, other services available**
- **The financial implications**
- **Hospital transport**
- **The quality of the food!**
- **The possibility for relatives to overnight**

The list was faxed on to the Royal Free Haematology team.

A meeting was subsequently held with the Royal Free Transplant Coordinator. She has promised to produce a new draft Patient Information Leaflet, collect information from patients referred to the RF for treatment from all locations, via a questionnaire and to request that a washing machine is installed in the ward.

There is an intention to provide accommodation for patients and visitors, with efforts being made by a new charity set up for this purpose (which is hoping to raise £8m). In the meantime permission has recently been granted for put-up beds so that overnight stays are possible for relatives, which had previously been stopped on H&S grounds.

Comments on transport and the food are being passed to the relevant RF departments.

Financial advice is available from a Macmillan Benefits Advisor is available either in Swindon or at the RF.

Consideration is being given to a questionnaire for these patients at the GWH also, to collect more information.

