

HUG MAGAZINE



June 2008

(issued bi-monthly)

A magazine for HAEMATOLOGY and ONCOLOGY patients, being treated in the Day Therapy Centre and Dove Ward or under review following treatment

This Magazine is produced and paid for by the HUG Group. If you could receive future editions by email or would like to make a contribution to the printing cost, contact Irene by telephone or email.



We would love to hear from you with your comments, suggestions or articles.

Contact

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

H.U.G. Swindon

Get-togethers have normally taken place in the Osprey Unit Education Room but until further notice we are meeting 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
on the Thursdays shown:

03 July 2008 – Seminar Room 5
07 August 2008 – Seminar Room 5
11 September 2008 - Seminar Room 5

NOTE: Not always the SECOND Thursday of the month in 2008

AIMS!

HUG aims to improve the environment for ALL 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, all 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.**

NEWS THAT MAY BE OF INTEREST

Life saving screening for bowel cancer is on the way

As you may have read in the press, by the end of 2009, all men and women in England aged between 60 and 69 will be offered bowel screening every two years. Screening can find early bowel cancers, before there are any symptoms.

The screening test is called a faecal occult blood (FOB) test. The FOB test doesn't actually detect cancer, but detects very small amounts of blood in the bowel motions, which can't usually be seen. Bowel cancers can sometimes bleed and this is why the screening test looks for blood. If necessary further tests would then be done to identify the source of the bleeding.

The FOB test can be done at home, following a letter inviting eligible persons to take part in the screening programme. If you agree you will then be sent a testing kit along with the instructions. The screening test involves collecting three separate samples of bowel motions, and spreading small samples on a test card. The kit will include full instructions, cardboard sticks to collect the samples, the test card and a specially made prepaid envelope to return the samples hygienically and securely. You would be sent a letter with the results of your test about two weeks after it has arrived at the laboratory. The results will also be copied to your GP. Most people (98%) will have a normal result.

You don't have to take part in the screening programme, but there are lots of benefits in doing so. Screening will pick up many bowel cancers early - when 9 out of 10 people will be cured - and screening can reduce the risk of dying from bowel cancer by 16% (1 in 6). So it's well worth ignoring any embarrassment if you are eligible for screening.

For more information obtain the Cancerbackup booklet "Bowel Cancer Screening" via their website at www.cancerbackup.org.uk or via the freephone helpline on 0808 800 1234.

Cancerbackup News, Spring 2008

Hospital Parking

Hospital parking charges in Northern Ireland have been scrapped for cancer patients. Macmillan Cancer Support says that "It's appalling that cancer patients in England will have to continue paying to park to receive treatment. Two of the biggest extra costs that cancer patients have to deal with are travelling to and from hospital for treatment, and parking at hospitals. We know that on average cancer patients make 53 visits to hospital during the course of their treatment, which costs them £325. This can leave cancer patients financially and emotionally drained at an already challenging time. Patients in England face a postcode lottery on hospital parking. The Government has issued guidance so that people travelling to hospital on a regular basis get free or reduced parking but we know that not all hospitals in England are not putting this into practice. Macmillan will now be calling on hospital trust boards up and down the country to end this cancer tax."

Macmillan website 21 May 08

News in brief

- Lymphoma Association Spring Newsletter includes articles on Cancer related fatigue and more information on the NICE guidance on Follicular Lymphoma treatments
- Details of companies providing travel insurers for cancer patients are on the Macmillan website at <http://share.macmillan.org.uk>. There are also reports of experiences from patients on a Discussion Forum, indicating (not surprisingly!) that obtaining travel insurance for the U.S.A. is particularly difficult.

Eating and Cancer Patients

The challenges faced by cancer patients with eating, healthily or otherwise, can vary greatly. Some encounter a lack of appetite, others develop a voracious one, food often tastes peculiar or swallowing or digesting can be tricky.

You probably know that leaflets on the subject of food are available from cancer charities. However, if you are affected by any of the above, you might be interested to know that a very useful list has been put together by Macmillan of what is available out there. This can be found on their web site at:

http://www.macmillan.org.uk/Get_Support/Find_information

by clicking on Find Information, Cancer Publications and searching for Food. Details are included about which organisation produces each leaflet and how to obtain a copy.

The leaflets cover such subjects as Current Dietary Advice, Soft and Liquidised Food, to Nutrition for Patients with Lymphoma or with Myeloma.

If you don't have access to a computer you can ask one of the volunteers at the Cancer Information Point in Osprey to obtain a list or order a particular booklet for you.

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Who said history is boring?!

Next time you are complaining about how much better things used to be, think about how they were in the 16th century.

Most people got married in June because they took their yearly bath in May and still smelled not too bad by June. However, to disguise any hint of a whiff of body odour, brides carried a bouquet of flowers: hence the custom today of carrying a bouquet when getting married.

Baths consisted of a big tub filled with hot water. The man of the house had the privilege of the nice clean water, then all the other sons and men, then the women and finally the children - last of all the babies. By then the water was so dirty you could actually lose someone in it - hence the saying, "Don't throw the baby out with the bath water."

Poor people could only afford dirt on the floor of their house: hence the saying "dirt poor". The wealthy had slate floors that would get slippery in the winter when wet, so they spread thresh (straw) on the floor to help keep their footing. As the winter wore on, they kept adding more thresh, which then started to escape through the door. A piece of wood called a "thresh hold" was placed at the entrance to stop it.

A clothes horse is the only sure thing to put your shirt on.



H.U.G. ★
fridge magnet
★ **fun**



Bearing things in mind can prove weighty

When women are depressed they eat or shop.
Men invade another country.



Laughter is the sun that drives winter from the human face



It's nice to be important, but more important to be nice.



It is better to be born lucky than rich.

Holiday Thoughts

The World Traveller

I wish I were one of those spunky women who dash off to Africa
With a cleverly packed overnight bag and a pith helmet
Without always thinking, Is there a dentist, and can I buy Kleenex,
And where will I find the name of a good dry cleaners.

I wish I were one of those spunky women who climb the Matterhorn,
And race Maseratis, and run barefoot through the Bois de Boulogne,
Without always thinking that I'll step on a rusty nail and need a tetanus shot.

I wish I were one of those spunky women who travel around the world on
freighters,
And fight in doomed revolutions, and sleep with some dark stranger in Algiers,
Without always thinking that the strangers will talk about me in New Jersey.

I wish I were one of those spunky women....
But as I sit here on this plane from Dulles to London,
With twenty pounds of overweight in aspirin, A heating pad and
Tums and Kaopectate, and throat spray and an extra pair of glasses
(Suppose the first pair breaks in a pub in Chelsea?),
Wondering whether the sitter's rejecting my children
And whether I'll go down in flames reading Time magazine,
Then it all seems a high price to pay
Just to be Spunky.

By Judith Viorst from
It's Hard to be Hip Over Thirty, Persephone Books)

During treatment and the recovery period, it is often planning future treats such as holidays which keep us going. We hope that you are going to be able to have that well deserved holiday, that you've been looking forward to for so long.

We feel sure that you won't be worrying about such minor matters as in the poem above! Being ill should have put things into perspective and shown that some things are just not worth bothering about.

The important things to remember

- **Base you plans on current clinical advice**
- **Make sure that you have adequate travel insurance cover, based on your medical condition. This may affect your choice of possible holiday locations. (Within the EU is easier)**
- **Protect yourself against the sun at all times**
- **Don't overdo things – you may still tire easily**
- **Above all, have a great time.**

Here is a Word-Fit with a difference. See if you can place the underlined words correctly into the grid.

Logical deductions

1. Carla is married to Edward, Tracy is married to Michael, Barbara is married to Robert and Stella is married to Steven. Who is married to Christopher - Rosemary or Stephanie and why?

2. ADVERB, CARBON, CHOICE, ERASED, SURVEY.

Which one of the following words belongs in the list above and why?

CRATER, INCOME, LATEST, LENGTH, SCENIC.

H.U.G. News – read all about it

Get-togethers were held on 10th April and 1st May 2008, with Coffee Mornings at the Blunsdon Arms twice between get-togethers.

1. Get-Togethers away from the Hospital

We meet for coffee and a spot of lunch for those who want it at least once a month. Contact Irene for forthcoming dates and times if you would prefer to get to know us away from the Hospital. We realise that some of you visit it quite often enough already!

2. Purchases or Donations for Dove and Day Therapy

We have recently made a donation to the Dove Ward Charitable Fund Account, partly made up of contributions from individual members and the remainder from the HUG Group funds, in memory of Jon Smith.

3. Recent Get-Togethers

Thanks to M and Y for distributing magazines, making teas and supplying biscuits at the April get-together while I was in sunnier climes.

Both April and May get-togethers were set aside for group discussions and socialising. No speakers had been scheduled for these occasions.

4. Fund-Raising

Our sales table outside the Town Hall at Wootton Bassett on Wednesday 30th April was not as successful as hoped, due to a very wet day. We raised around £20, and practically froze in the attempt.

Our next sales locations are likely to be at car boot sales, which don't need to be pre-booked so far in advance. That way we can pick our weather carefully.

5. Forthcoming Events

Our summer outing will be to Gloucester Docks. Since we shall travel by car, we have been able to pencil in two possible dates. These are 14th or 21st July and surely the sun will shine on one of those days. If not, there is still plenty to do indoors!

6. Response on Soup Suggestion to Catering

The GWH Catering Manager responded promptly to our suggestion about the possibility of providing home made soup for patients in Dove. He replied that he had already looked at this in-depth and, as much as they would like to supply fresh soup, it is impractical to do so for many reasons, especially the low numbers and the labour costs. A couple of years ago he also looked at making fresh soup for all GWH patients but the labour and food costs together came outside the budget.

Questions to ask after initial diagnosis

It can be really difficult to think straight when you are first given the diagnosis that you have cancer, even when you may have already suspected as much, as tests progressed. Hopefully your Consultant or Clinical Nurse Specialist will provide you with most of the information you want or need, but it can be useful to have a set of questions prepared. Of course, not all patients may wish to know the answers to all of these questions, but if you have a list to work with, then you are in a better position to decide which ones you feel you want to ask. Perhaps you might also want to write down the answers for future reference.

Some of things you might want to know soon after diagnosis are:

- Is there a choice of possible treatments?
- If so, which is the best for me and why?
- What are the immediate side effects of the treatment?
- How is the treatment administered?
- How does the treatment work?
- Are there lasting side effects?
- What if I don't want to have the recommended treatment? Do I have any other options?
- How likely am I to go into remission with the recommended treatment?
- How likely am I to go into remission with an alternative treatment?
- What is the current overall success rate for this treatment?
- What are my chances of a complete cure?
- What is meant by cancer stages and high and low grade cancers?
- What are primary and secondary cancers?
- What are the survival rates for my cancer type from different cancer stages?
- When will treatment start?
- How long will the treatment last?
- What is the view of the Trust if I have part of my treatment privately?
- Can the treatment increase my risk of developing another cancer type in future?
- What will happen if I choose not to have any treatment?
- What complimentary therapies are suitable and are there any that I should avoid during treatment?
- How much might this cost me in prescription, parking and travel expenses (particularly if part of your treatment will be at another hospital).

The sad loss of a member

We are very sorry to report the death of J S on 11th April, 2008. J and his wife M had been attending HUG get-togethers for around a year. You may not have known him by name, but he was easily recognisable as a tall man wearing a black baseball cap and with twinkling eyes behind his glasses.

J was particularly well known in the Highworth area, where he had lived all his life. Indeed he was a guitar teacher at schools in and around the town until quite recently, when ill-health forced him to stop working.

He was always cheerful despite the many health setbacks he had encountered and could tell amusing tales about his clinical experiences, with a sardonic sense of humour. Despite his own ill health, he was always keen to know about the progress of fellow patients. As an example, he and his brother-in-law gave up some of their time with their families on Christmas Day 2007, to come in and play carols in Dove Ward. This was because he knew, from personal experience over Christmas and New Year 2006, what it was like to spend the festive season in hospital, and worse still, part of it in London.

We extend our sincerest sympathies to M, son J, J's mother and other members of the family at home and abroad.

Foundation Trust Progress

The election of the Council of Governors is scheduled for July 2008. The Trust hopes to be awarded Foundation Trust status in December 2008, following review of the application by "Monitor", the independent regulator of NHS Foundation Trusts. More members are still needed. Ask for a form at the Hospital.

Changes to the GWH Smoking Policy

A new smoking policy to be implemented in August 2008 will only allow smokers to light up in designated smoking areas. Shelters will be provided for them to use.

Although the Trust is very aware of the dangers of smoking, they accept that people can be anxious or stressed coming into hospital or visiting people who are poorly and are therefore not imposing an outright ban on smoking.

Puzzle Answers

Word-Fit

Across: (From top) Chat, Perfect, Pale, Sniffle, Nose, Doctor, Better, Normal, Morning

Down: (Top Left to Right) Stethoscope, Nothing, Pleased, Check, Chart
(Bottom Left to Right) Mention, Runny, Examine, Worry

Logical Deduction

1. The third letter of each woman's name is the same as the fifth letter of each man's name, so Rosemary is married to Christopher.
2. The second and fourth letters of each of the first set of words are consecutive, so INCOME belongs in the list.

