

HUG MAGAZINE



3rd Quarter 2013

(issued during the last month of each quarter)

For HAEMATOLOGY and ONCOLOGY patients, their families and friends being treated in Cancer Services areas or under review



SELECTION OF OUR CHEMO HATS

Email: hugswindon@btinternet.com

**** Website address (note change): www.hugswindon.org.uk

HUG Get-togethers

We have suspended meetings at the hospital in favour of coffee mornings at other locations. Dates for the meetings fixed for the rest of 2013 are as follows:

**Monday 14th October
Thursday 21st November
Monday 9th December**

All of the above will be at the Blunsdon Arms pub, on Thamesdown Drive from 11am onwards.

Further get-togethers and venues will be arranged on a month by month basis on dates to suit attendees.

Contact us for more details.

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 Coffee Mornings and Craft Sessions (as new stock for sale is required)**
- **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 End of Treatment Care, Car Parking and Bus Access, Palliative Care and Radiotherapy for Swindon**
- **Fund-raising to provide practical help with purchases including thermometers, travel bands, mugs, slippers, gel bags and heat pads, when suggested by clinical staff, patients or carers.**
 - ✓ **Items for sale at any time: chemo hats made of a silk/wool mix in a choice of colours and styles and our personalised mugs and teddy bears. Contact us for more details.**
- **Maintaining a website and making leaflets available to promote the group and advertise our activities**
- **Producing the HUG Magazine quarterly and leaving copies in Cancer Services areas, providing direct to members and posting on the website.**
- **We have a stall behind the atrium at the hospital, around once a month. Dates for the remainder of 2013 are Tuesday 15th October, Monday 11th November and Tuesday 17th December, between 9am and 4.30 pm.**

INTERESTING HEALTH-RELATED NEWS

Use of Talcum powder and Ovarian Cancer

A recent review has been carried out on a number of previous studies to try to agree whether there is a connection between the use of talcum powder in the genital area and ovarian cancer. Researchers at Brigham and Women's Hospital in Boston, U.S.A. pooled data from eight separate studies and concluded that there is an increase in risk.

Annwen Jones, Chief Executive of Target Ovarian Cancer states that the organisation generally advises against the use of talc on intimate body parts, but stresses that the additional risk is small.

For more details refer to

<http://www.targetovariancancer.org.uk/news.asp?section=29&itemid=2190&search=>

(June 2013)

NICE Guidance on Familial Breast Cancer

The final NICE (National Institute for Health and Care Excellence) guidance on genetic testing and surveillance of people at risk of familial breast cancer and treatment strategies was released at the end of June 2013.

For more details refer to <http://guidance.nice.org.uk/CG164>

Alternative test to detect cervical cancer

Testing women for the human papillomavirus (HPV) first, instead of using the traditional cervical screening test to detect abnormal cells in the cervix, could prevent around 600 cases of cervical cancer a year in England.

These results from Cancer Research UK were presented at Public Health England's National Cancer Intelligence Network annual conference in Brighton and published in the Journal of Medical Screening.

Cancer Research UK scientists, based at Queen Mary, University of London, identified more than 8,750 women with cervical cancer and looked back at their screening records. They found almost 40 per cent had a negative cytology test result – the existing cervical screening test – within six years of their diagnosis.

They then used these data to predict how many more cases of cervical cancer could have been prevented if HPV testing had been used as primary screening test instead of the cytology test.

For more details see <http://www.cancerresearchuk.org/cancer-info/news/archive/pressrelease/2013-06-14-HPV-testing-could-cut-cervical-cancers-by-third>

Liverpool Care Pathway

Over a year ago, we requested an explanation of how palliative care was being organised and implemented for terminally ill patients at the Great Western Foundation Trust, via the Cancer Services User Involvement Group. It took a long time to agree a mutually suitable date, but a meeting of the group took place at the Prospect Hospice in mid July, 2013, with the Palliative Clinical Nurse Specialists Team Lead. It was confirmed that the system in use is based on the Liverpool Care Pathway (LCP).

This pathway has received a lot of bad, and in some cases almost hysterical press reports, but at the time of first asking about palliative care, we had not actually heard the term used. It was just days after the meeting took place that the government-commissioned review concluded that the LCP should be abolished, based on wrong interpretation of guidance by staff. It is to be replaced by more flexible care pathways, designed for individual patients. Until these are agreed and implemented, the LCP will continue to be used in the GWH Foundation Trust, at the Prospect Hospice and local care in the community for terminally ill patients.

We don't think that there is any need to panic, however, if it is suggested that a relative of yours should be put onto the LCP. Guidance is provided, but there are options, choices and the possibility of changing the pathway route. Many of the issues raised in press reports have been related to families not having the care explained to them, staff not being sufficiently well trained or experienced and the care not being reviewed frequently enough to check whether needs have changed. Introduction of the LCP in individual cases requires:

- An initial detailed joint assessment by a doctor and nurse.
- A multi-disciplinary team (MDT) assessment of the patient's condition and needs
- Discussion of the proposed care with the closest relatives or carer, and the provision of an information sheet, which includes contact details for palliative care nurses.
- Second opinions are sought when there is doubt about the most suitable care regime.
- Regular documented assessment of the patient by senior clinical personnel and a full MDT reassessment every 3 days.
- Review and possible changes in the care regime if certain criteria apply. For example, improved consciousness level or oral intake.
- Continued communication with relatives or carers throughout the palliative care is regarded as of paramount importance.
- Review of care if concerns are expressed about the management plan by the patient, relative or carer or any MDT team member.
- Pain control and nausea and vomiting avoidance medication.

We asked questions about staff ratios for those terminally ill patients who are not in Dove Ward, where there are just 10 single rooms. Privacy may also be an issue for those patients. It is accepted nationally that the best care for the terminally ill is provided in a hospice, and that the same conditions of privacy for the patient and family and level of care cannot always be provided in an acute hospital or care home. New guidance is intended to expand on the hospice model.

The website www.dyingmatters.org contains useful advice, information, ideas for planning ahead and provides links to local services.

Odds and Ends

Travel Insurance

It's been some time since we made any suggestions on ways to obtain suitable travel insurance if you have a medical condition.

One route that has recently come to our attention has been launched by the website Moneysupermarket.com, with the aim of simplifying the chore of obtaining suitable cover. The advantage is that you can compare what is on offer, without having to visit the websites of individual companies, or spend ages on the telephone calling them.

We would be very interested to hear how helpful this section of the website is.

Macmillan Exercise DVD

Macmillan has produced a Get active, feel good exercise DVD. It features an exercise programme designed specifically for people living with or after cancer. All the exercise can be done easily at home.

There are four sections, in each of which exercises can be performed at different levels:

- Mobility and pulse raising
- Cardiovascular
- Muscular strength and endurance
- Flexibility, balance and cool down

Free copies are available from Boots pharmacies or if out of stock you can order from the Macmillan website or by telephone:

www.be.macmillan.org.uk or call 0808 808 00 00

Prospect Hospice Wins Grant for Family Lodges

The Department of Health has provided a grant to the Prospect Hospice to fund the construction of accommodation lodges for patients' families during their loved one's stay in the in-patient unit.

The grant will not cover the full cost of the new lodges, but a legacy from the will of a local well-wisher will allow the completion of the building work. It is hoped that these will be opened in spring 2014.

This will be a valuable additional asset for the Prospect and donations are always welcomed. You can find out more about how to donate by calling 01793 813355.

National Cancer Peer Review

We wonder how many patients actually know how to find the National Cancer Peer Review directory of NHS cancer services across England. Well, here is the answer, at least for those who have access to a computer!

Go to www.mycancertreatment.nhs.uk

This website contains the information you need to be able to locate and compare NHS cancer services. By using the 'Find Your Treatment' search tool you can easily search for information on NHS cancer services by postcode, hospital or cancer type.

For each service you can access detailed reports that explain the quality of the service provided by the hospital or cancer service. In theory, this can empower you with the knowledge to make an informed decision when choosing where you would like to be treated. In practice, most of us just want top quality treatment at our local hospital.

This information is brought to you by the National Cancer Peer Review Programme, hosted by the NHS, who monitor NHS care performance quality, with entries to the database made by the hospitals themselves initially. So how does it work?

Self – Assessment: The service self-assesses against the national measures for the relevant cancer service and rates percentage compliance level. A summary report is produced by teams to provide an overview of the service.

Internal Validation: Every third year the trust is required to 'validate' the accuracy of the self-assessments. Comments are made against the self-assessment report and additional concerns added if necessary. Compliance with the measures is also reviewed and percentage scores adjusted accordingly.

External Verification: External verification is carried out following inspection by the National Cancer Peer Review team and provides a further check on self-assessment and accuracy of internal validation.

Peer Review: Visits are undertaken by external teams (of 4-6 people) that may include doctors, nurses, allied health professionals e.g. physiotherapists, occupational therapists and dieticians as well as patients/carers and managers who are all specialists in, or have experience of, a particular area of cancer care. These visits are made to teams based on specific criteria, such as immediate risks identified and not resolved. Again a report is written.

A recent improvement to the website means that it is now possible for hospital trusts to include an update of corrective actions taken, following the reporting of any serious concerns and immediate risks.

Car Parking

Obviously we cannot claim that changes are all down to HUG member comments at Cancer Services User Involvement Group Meetings, but we like to think that we have played a part in the process, particularly on behalf of people with disabilities. Of course the parking situation has also been raised by other patients and visitors, and also by staff members.

In September contractors begin work on the next phase of car park expansion. This follows the work over Easter to enlarge the gravel car park. When this phase is completed, there will be around 230 more parking spaces than before Easter 2013. The start of the work followed a successful planning application to the Swindon Borough Council and means that some of the pressure experienced over the winter months will be eased. The work will also include better lighting, landscaping, and some signage improvements.

As a result of the changes to the staff car park there will be some adjustments to the Brunel Treatment Centre car park. Around 40 visitor spaces will be created there, so that more disabled parking can be provided at the front of the hospital.

It is hoped to replace the existing Commonhead bicycle store and changing rooms, with (hopefully) bigger and better facilities. It should be noted that this is still subject to planning permission, however.

Boots Pharmacy coming to the GWH

The Trust has teamed up with high street chain Boots to provide outpatient pharmacy services. The new pharmacy was due to open Wednesday 4th September. It is located in the Clover Centre with easy access from the main building.

The new partnership means outpatients with prescriptions will experience shorter waiting times. The pharmacy will also offer services such as a counselling room for patients to speak with a pharmacist in private and will sell a range of typical Boots goods including lunchtime meal deals.

Inpatient pharmacy services will continue as normal. As Boots will be providing outpatient pharmacy services from September, the Trust Pharmacy Team will have more time to spend on directly supporting patients and staff on the wards. It is hoped that the turnaround time for discharge prescriptions will also improve.

Refurbishment of the GWH Emergency Department

From the 14th August building work began to transform the Emergency Department at the GWH. The new design will include a dedicated children's unit and the whole department will be refurbished and given a new layout, creating a more pleasant, modern and comfortable environment. Building work is expected to end in October 2013 (the refurbishment will pause for the busy winter period and then recommence again in 2014). The department will remain open a normal throughout the building programme.

Have you ever wondered why...
'abbreviated' is such a long word??

Fridge magnets



I couldn't care less about apathy.

DESSERT: The reason for eating a meal?



You know you're past it when your secrets are safe with your friends – because they can't remember them either.



Now and then there is a person who is so unlucky that he runs into accidents which started to happen to somebody else.



My definition of an intellectual is someone who can listen to the William Tell Overture without thinking of the Lone Ranger.'

Billy Connolly

Football would become an even better game if someone could invent a ball that kicks back.



H.U.G. News – read all about it

- Get-togethers took place regularly at the Great Western Hospital until August, but have now been suspended
- Coffee mornings and lunches have continued between GWH meetings.
- Group craft sessions have not re-started, but we intend to recommence when our stocks are running low. We are still making items to sell at our homes in the meantime.

1. Get-Togethers

We have decided to suspend GWH get-togethers, where attendances continue to be really low. It is something of a vicious circle, that we cannot justify inviting speakers along, but they would possibly attract more attendees. Some members think that patients and carers do not want to be at the hospital any more than they have to and they do have a point.

We have advertised dates for one get-together a month away from the hospital until the end of the year on page two of this issue. Further meetings will be arranged depending on the availability of members. Contact us if you would like to know the venue and date of any of these.

2. Income and Expenditure

Our sales in the atrium in the Great Western for June, July and August raised a total of £378.40. We have some new stock of hand-painted Mexican pottery birds, which would make lovely presents. From September onwards, we shall be bringing our stock of Christmas cards, tree decorations and other present items. We shall also be selling cakes and preserves, depending on our stock at the time.

3. Activities

We are going on another boat trip, on the Kennet & Avon Canal from Devizes on Sunday 29th September. An optional lunch will precede the trip, with refreshments also available on board.

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Look Good, Feel Better

Look Good, Feel Better Sessions are planned on 22nd October and 19th November for the ladies. Help is available from trainee beauticians to cleanse and apply make-up to make the best of your appearance. Do think about attending a session for a real pick up.

If you would like to attend please speak to a member of your health care team for an application form or contact:

Cancer Services
01793 646152

Or

01793 605859

(Telephone Monday to Friday 1pm – 4pm)

Mobile Chemotherapy HOPE bus latest

One of our HUG members had the opportunity to have her treatment in the mobile unit outside the GWH. She was very happy with the experience.

She commented particularly on the shorter waiting time, the friendliness and helpfulness of the staff and the intimate atmosphere which enabled patients to chat more easily during their treatment sessions.

We understand that there have been some difficulties with power supplies at Savernake, but patients who might have been treated there have used the unit at the GWH instead.

A service for Malmesbury is going ahead as planned.

Penny Brohn update

The first local delivery of the Penny Brohn Cancer Care Living Well programme took place in July in Swindon.

Feedback was collected from attendees and will be taken into account for the planning of the next course.

HUG attendees thought that the content of the course, as presented on this first occasion, would be of most benefit to patients at an early stage of diagnosis and treatment.

Do not Resuscitate

Staff and a HUG representative met with the Resuscitation Service Manager in August to review the current policy, patient information, patient communication, and the legal aspects of Do Not Resuscitate (DNR) within clinical settings.

Key questions were the need to repeatedly raise the discussion of DNR with patients and family including sensitivity and timeliness of communication, and the need for ongoing review of DNR status.

It was confirmed during the meeting that the Trust policy clearly indicates that DNR is not age related and is a clinical decision.

The Resuscitation Team are currently reviewing the GWH and Community DNR –CPR Policy. The team are also in discussions to include a universal form which will remain with the patient (in hospital and community) providing information about the patient's DNR status. This development will require wider clinical consultation.

