

HUG MAGAZINE



December 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



VIEW FROM OUR CANAL BOAT TRIP FROM DEVIZES
NO SEASONAL SCENE BUT IT MAY BE NEW YEAR WHEN YOU READ!
Happy Christmas and a Healthy New Year to all readers

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. We shall be meeting at the Blunsdon Arms pub, on Thamesdown Drive from 11am onwards on the second Monday of each month.

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

Contact us for more details.

Known dates for 1st quarter of 2014 are the 2nd Mondays of months

13 January,

10 February and

10 March

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, on a regular basis. Dates known for 2014 are Tuesday 14th January, Tuesday 4th February, Thursday 22nd May, Monday 16th June, Tuesday 15th July, Tuesday 5th August, Thursday 18th September, between 9am and 4.30 pm.**

INTERESTING HEALTH-RELATED NEWS

Herceptin by injection

On September 24th, it was announced that NHS England had sanctioned a faster, more comfortable method for giving Trastuzumab (Herceptin) to breast cancer patients. A new sub-cutaneous (SC) form of the drug will be commissioned. Herceptin SC will primarily be used to treat women with early breast cancer who currently get the drug with chemotherapy before or after surgery.

Until now Herceptin has been delivered intravenously which means patients receive the drug by intravenous drip and each treatment takes between two and three hours. The revolutionary new sub cutaneous formulation Herceptin is given by an injection under the skin which takes just two to five minutes to administer. Patients will need to stay in hospital for around an hour and a half after the injection to be monitored. As well as being more comfortable for patients, it will save time for both them and highly trained cancer nurses.

The SC form of herceptin is also expected to save costs to the NHS as the drug is given as a fixed dose not dependent on patient size or weight, which should minimise waste and reduce overall drug costs. Refer to

<http://www.england.nhs.uk/2013/09/24/cancer-treatment-injctn/>

Anticipated benefits have already been mentioned by GWH Cancer Services!

Fatigue and exercise

The Autumn 2013 issue of Lymphoma matters Magazine contains an interesting article on cancer-related fatigue, in the form of questions put to the Christie NHA Foundation Trust Lead Occupational Therapist. Suggestions for exercises, which may help to overcome fatigue, were put together in conjunction with Manchester United Football Club. There is an exercise booklet and DVD, both available on line at

<http://www.christie.nhs.uk/the-foundation-trust/patient-information/patient-information-booklets/patient-information-videos/be-active-stay-active.aspx>

www.christie.nhs.uk/patients/booklets/video/default.aspx for the film, and

www.christie.nhs.uk/booklets/540.pdf for the accompanying booklet.

Selective Internal Radiation Therapy

Selective Internal Radiation Therapy (SIRT) directs large numbers of tiny radioactive beads into live tumours without harming surrounding tissue. The therapy is now being tested at 10 leading centres including Birmingham and Oxford on patients with liver tumours which are difficult to treat. It may be extended to patients with kidney and lung cancer. After the trial NHS England will decide whether it can be offered as a routine treatment.

For more information on the technique see:

www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Radiotherapy/SIRT.aspx

Will the Emergency Cancer Drug Fund meet demand?

The Cancer Drugs Fund was launched by the Conservative Government in 2011 and made some £200 million available per year. It will continue until the end of March 2016, following an extension announced in September 2013. From 2016 the Government plans to introduce a new way of setting prices for cancer drugs which aims to make more drugs routinely available in the NHS.

There is a national list of drugs available through the Fund. If a cancer patient meets the conditions for a drug that is on the list, he or she should be able to have it on the NHS in England. The Fund will also consider applications on behalf of individual patients for other drugs that are not on the list. This is usually to treat rare cancers. The list is updated on a regular basis and new drugs can be added to it.

The list includes information about which type of cancer the drug can be used for and under what circumstances. So it may also include information about the stage of disease and what other treatments you must have already had, or should not have had. This means that although a drug may be funded for one type of cancer, at a particular stage, funding may not be available for the same cancer at a different stage or for another type of cancer.

The patient's cancer specialist applies to the Cancer Drugs Fund. The application has to be supported by the lead cancer doctor at the relevant hospital Trust (the clinical cancer lead). Patients or their families are not allowed to apply direct.

Initially it was reported that the fund was being under-used in some parts of the country, but the number of applications doubled between 2011 and 2012. It has now been reported that there may be a shortfall of some £120m next year. This has led to concerns that there may be a level of rationing introduced, with some currently available drugs being removed from the list.

The only alternative would appear to be that the budget will need to increase. A Department of Health spokesman is reported as saying that no one will miss out on treatment that has already started.

But concerns exist for any patients who, in future, may need to start on one of the treatments recommended by their Consultants, but not approved by NICE. The hope is that the Government has amended this contingency fund provision once in extending it by two years and will be prepared to change the rules again, so that all cancer patients can receive the best new treatments for their condition.

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If crocodile skin makes a pair of shoes, what do you make from banana skins?

Slippers, of course!

How do you wash your hands?

Yes, of course we all know how to wash our hands. After all, we've been doing it since we were small children. BUT are we getting rid of lurking micro-organisms?

Hand hygiene is particularly important for cancer patients whose immune system has been compromised by treatment. Infections can be introduced because of poor hygiene, although there may also be internal causes, which would not cause a problem normally.

We make no apology for giving some guidance on thorough hand washing.

The following is guidance given to people who are preparing or handling food in commercial kitchens

1. Wet hands with water
2. Apply enough soap to cover all hand surfaces
3. Rub hands palm to palm
4. Rub backs with other palm
5. Rub palm to palm with fingers interlocked
6. Rub with backs of fingers to opposing palms with fingers interlocked
7. Rub each thumb clasped in opposite hand using rotational motion
8. Rub tips of fingers in opposite palm in a circular motion
9. Rub each wrist with the opposite hand
10. Rinse hands with water
11. Use elbow or single-use towel to turn off tap
12. Dry thoroughly with single-use towel

This should take 15-30 seconds

How often do you and I wash your hands as thoroughly as this? It should be every time.

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I fly through water. Some think I'm cute. I walk on cold land, in my best suit. What am I?

A penguin, of course

End of Life Planning

This may not be the most cheerful topic but it is one that is possibly best considered at the start of a new year, which is when most readers will see the HUG Magazine. Decisions are ideally made before you become infirm, but many of us put off thinking about them. Family and friends are better equipped to deal with our wishes, if they know what they are.

Here are a number of areas that need to be considered.

Set Down an Advance Statement

An advance statement is a written statement that conveys your preferences, wishes, beliefs and values regarding your future care. The aim is to provide a guide to anyone who might have to make decisions in your best interest if you have lost the capacity to make decisions or to communicate them.

Make a Will

Be sure that your wishes regarding legacies, distribution of assets and even items of sentimental value are clear, to avoid stress for your family.

Appoint a Lasting Power of Attorney

If you wish, you can officially appoint someone you trust to make decisions for you. This is called making a lasting power of attorney (LPA). It enables you to give another person the right to make decisions about your care and welfare. You can also appoint an attorney to decide on financial and property matters. The Office of the Public Guardian has guidance for people who want to make a lasting power of attorney at:

<http://www.nhs.uk/Planners/end-of-life-care/Pages/lasting-power-of-attorney.aspx>

It is very much more difficult for your family to set up a Lasting Power of Attorney if you are unable to authorise the decision, so organising it before it becomes necessary is definitely advisable.

The information above has been summarised from advice given by the NHS in an End of Life Care Guide at

www.nhs.uk/Planners/end-of-life-care/Pages/End-of-life-care.aspx

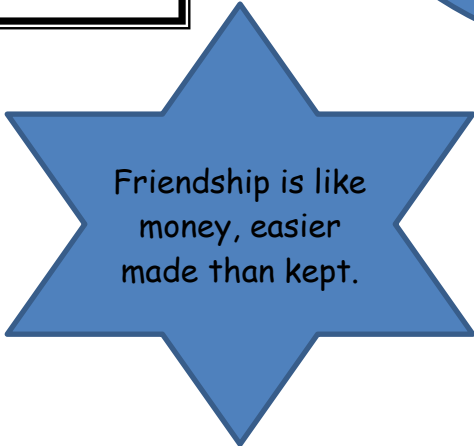
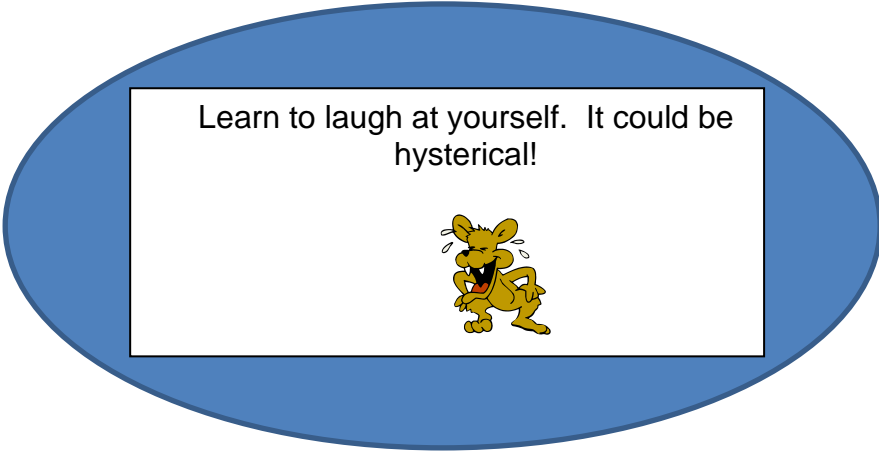
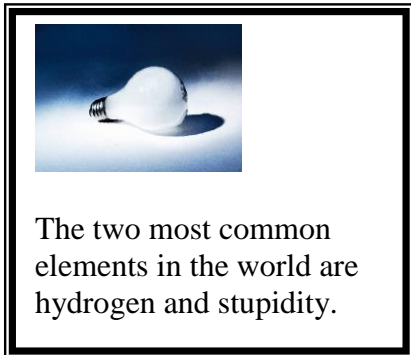
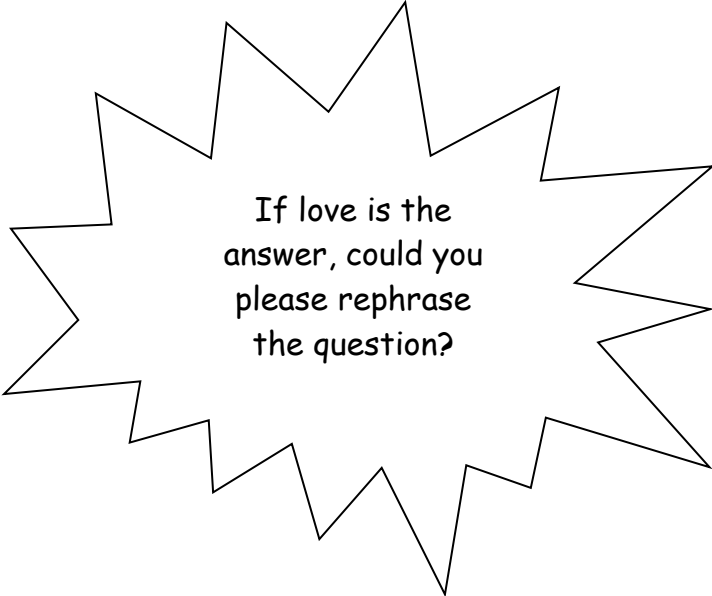
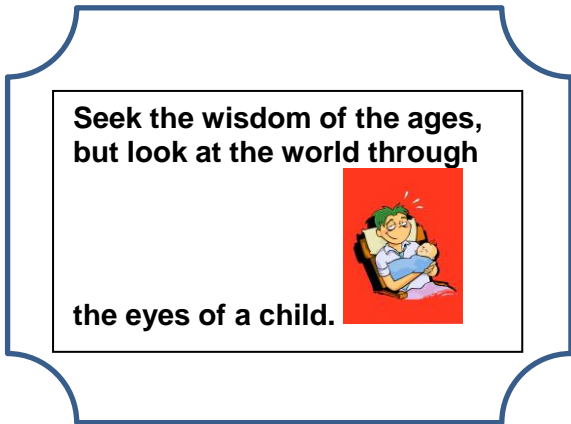
This web page includes links to other useful web pages, including charities that may be able to offer advice. If you don't know where to start, this might be a good place to try.

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What do you call a row of men waiting for a haircut?
A barbercue, of course!



Fridge magnets



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 at home to sell in the meantime.

1. Get-Togethers

It is our current intention to meet on the second Monday of each month at the Blunsdon Arms pub, on Thamesdown Drive, for coffee or tea from 11am onwards, throughout 2014. A lunch afterwards is optional.

Further additional dates and locations will be arranged on a month by month basis in the meantime.

We shall hold a post-Christmas special in January, when it is easier to get everybody together. A number of suggestions have been made, but agreement has not been reached in time for this issue of the Magazine.

Contact us for details of the date, time and place.

2. Income and Expenditure

Our sales of craft items, jewellery, cards and pottery behind the atrium in the Great Western have remained successful, with a number of staff customers who keep coming back! Baby knits have been particularly popular recently and we have a number of keen knitters who are not group members helping us to keep up with demand. A total of £265.95 was raised there between September and November. A further £88.47 was raised by direct individual sales and attendance at the Christ Church Christmas Fair.

Although we don't have so many dates scheduled at the hospital for next year, we hope to continue to raise funds for the benefit of cancer patients at the GWH.

3. Activities

HUG members assisted at the Macmillan Coffee Morning in Lambourn at the end of September, when a total of £577.60 was raised in just 2 hours. Thanks to members and friends who helped on the day.

Our boat trip, on the Kennet & Avon Canal from Devizes just two days later was a lovely relaxing affair, preceded by lunch. We were fortunate enough to pick the only good day of the week and the sun shone on us.

Going on a Sunday also allowed some friends that we don't see so often to join us and catch up with everyone's news.

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Chemo Cookery Club

We have just heard about this on BBCi's South Today programme.

More than 150 recipes have been devised by the wife of a colon cancer patient and produced as a book called the Chemo Cookery Club Making Food Special. It was launched in April 2012 and is said to have become Amazon's best selling cancer cookery book. It can be purchased as either a paperbook or an ebook.

The book is described as "helping to make everyday food a positive part of life for cancer sufferers and their carers. With tempting treats and healthy food ideas, the emphasis is on the nutritional values that can make a difference. Penny Ericson, experienced cook and carer, celebrates everyday meals and how they contribute to wellness, both physically and emotionally. If you're struggling with loss of appetite, wondering how to get more iron into your diet, wanting to relieve 'metal mouth' or dismayed that the foods you used to love now seem boring and tasteless as a result of treatment, Penny can help. Nutritional information and recipe analysis has been contributed by leading cancer research dietician Barbara Parry MSc PD."

Find it at www.chemocookeryclub.com/ or on Amazon, currently from £7.24 upwards (postage extra) or £10.99 from the Club .

A second book Around the Kitchen Table is not available to buy but can be downloaded free. It has also been produced by Penny, with the same expert help. You do have to register your email address and become a member of the club to benefit. You will be sent an activation password to access the download and see the members only section of the website. The recipes do look really appetising and a little bit different, but we haven't tested any of them out yet.

If you are interested, why not try the free download before you consider the pay option at:

<http://chemocookeryclub.com/index.php/around-the-kitchen-table-pcm>

Macmillan Skype buddy service

A new Macmillan service has recently started via Skype to provide emotional support to people affected by cancer. Skype allow voice and video calls (requires a web cam) via a computer or smart phone to anyone else who is registered with the service. Use of MacmillanSkype would also require users to have an email address.

To date 24 volunteer buddies have been trained to listen and talk about their own cancer experience.

If you would like to help Macmillan to deliver this new support service or know someone who could benefit from using the service, get in touch with the Skype team at support@skype-macmillan.com.

If you have never used Skype before and feel unsure about using the service, there are two links which can help you to get acquainted:

<http://www.bucks.edu/media/bcccmcdialibrary/pdf/tlc/facstaff/skype.pdf>

<http://www.saga.co.uk/money/best-deals/skype-10-steps-on-how-to-make-a-free-skype-video-call-and-m.aspx>

We do have the software, but so far haven't got to grips with Skyping, so this may be just what we need, whether we use the service or not.

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 was taken into account for the planning of the next course, which started at the end of November. Comments we've heard so far on the second course delivery have been positive.

Look out for poster in Day Therapy advertising the next one, or ask your Clinical Nurse Specialist if you are interested.

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Why are brides unlucky? Well, they never marry the best man.

Which is the most difficult train to catch?
They are all about the same to you if you let them start first.

