

HUG MAGAZINE



April 2012

(issued on 2nd or 3rd Thursday of alternate months on meeting days)

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



Email: hugswindon@btinternet.com

Website: www.hugswindon.co.uk

H.U.G. Swindon Get-Togethers at the GWH

We meet in the Academy on the second Thursday of the month.

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

17 May 2012	- Seminar Room 5
14 June 2012	- Seminar Room 5
12 July 2012	- Seminar Room 5

(The Academy is reached from the front of the Hospital through the double doors at the back of the atrium, going right and following the signs, which first appear at the end of the corridor. If you are eligible, you can use the disabled car parking spaces at the back of the hospital, cross the road and head back towards the entry road. The Academy entrance is about half way along, in the main building. The small parking area just outside the Academy is for staff.)

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 monthly get-togethers at the Hospital, Coffee Mornings (contact us for details of the next one, usually around the end of each month) and Craft Sessions (on the 2nd Monday of the month) away from the Hospital**
- **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 Complementary Therapies, End of Treatment 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.**

Maintaining a website and making leaflets available to promote the group and advertise our activities.

Producing the HUG Magazine bi-monthly and leaving copies in Cancer Services areas, providing direct to members and posting on the website.

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.

INTERESTING HEALTH-RELATED NEWS

Tamoxifen as a preventative for breast cancer

A trial is being carried out at the Genesis Prevention Centre using tamoxifen on women whose family history indicates an increased risk of developing breast cancer in the future. The normal use of the drug is as a follow up to breast cancer treatment, which can involve surgery, radiotherapy and chemotherapy. It works by blocking the update of the hormone oestrogen by cancer cells, stopping them multiplying. Although approved by the U.S. FDA for this use, tamoxifen has not been licenced in the UK as a preventative drug, because of concerns about the possible side-effects, such as hot flushes, mood changes and joint pain.

Daily Mail 20 March 2012

Breast cancer screening review

A review of the breast cancer screening programme has been announced by the cancer czar Sir Mike Richards, amid fears that it may do more harm than good. The leaflet regarding the screening programme is being re-written, Researchers from the Nordic Cochrane Centre have claimed that screening does not save lives and that a third of the tumours detected may be harmless, with treatment unnecessary, following their review of data from breast cancer trials.

The Guardian, 23 January 2012

Cure for many viruses may be on the way

The Massachusetts Institute of Technology may have found a cure for many viruses, with a drug known by the acronym DRACO. The scientists there have exploited natural defences against infection with a process which causes diseased cells to kill themselves. In preliminary testing, the drug proved effective against 15 different viruses -- including H1N1 flu -- but was nontoxic in 11 types of mammalian cells.

Experts in the UK have warned that it will require years of testing before the breakthrough is considered safe enough to test in people, because it works in such an unusual way.

Read more: http://articles.businessinsider.com/2011-08-18/news/30077165_1_cells-h1n1-viruses#ixzz1rSMfzvoU

ISO 14155:2011 Standard for Conducting Medical Device Clinical Trials

This update to the requirements for clinical trials in medical devices for human subjects focused on safety evaluation and reporting requirements for medical devices as well as risk management to determine safety by the manufacturer as part of the product lifecycle process. The responsibilities of the sponsor (manufacturer) have been expanded, informed consent for vulnerable subjects is now required and the requirements of study monitoring have been elaborated. It will be adopted at EU level and lead to more standardisation and hopefully reduce future issues with joint-replacements, breast enhancement etc. over time.

ISO 14155:2011 01 Feb 2011

Help from families for sick relatives in hospital

The Quality Care Commission checks all hospitals in England to ensure they are meeting government standards, and shares findings with the public. They have recently reported that half of our hospitals fail the elderly. For details of the standards that are expected, refer to

<http://www.cqc.org.uk/public/what-are-standards/government-standards>.

We have all heard or seen regular reports of frail patients left unwashed, or without clean bed linen, or without food or drink, because they are unable to manage to help themselves. Government standards in summary specify that:

- Your personal needs are assessed to make sure that you get care that is safe and supports your rights.
- You will get the food and drink you need to meet your dietary needs.
- You will get safe and co-ordinated care when more than one care provider is involved or if you are moved between services.

The Royal College of Nursing chief executive Dr Peter Carter thinks that relatives should help out busy nursing staff with basic personal hygiene and mealtime care for their family members. It is accepted that it may take a long time to feed some very poorly patients and that it may not be possible for staff to cope with several such patients in a single ward. Help with feeding and washing from relatives would free up nursing staff for more specialised care duties and patients would benefit from more close contact with their families. It is also possible that some patients might be more cooperative with someone they know well, if they are confused. His view is upheld by a recent survey into hospital feeding by the Patient and Client Council, the public's voice on health in Northern Ireland. They found that many older people would welcome family help on the wards at meal times.

On the other hand, some patients may have no relatives, none who live close enough to the hospital to be able to help, or not have any family members who are available at meal times during the day because of work commitments. Some hospitals, including the Great Western, are getting around this by using volunteers to help with feeding. These volunteers should have received some training to enable them to monitor a patient's food intake level and possibly changes in their general condition.

Concerns related to relatives and friends helping with some personal care provision include health and safety issues if a patient chokes while eating or slips on the way to the bathroom. Who would then be responsible?

There are also worries in some quarter that once families do more to help their ailing relative, then they could be asked to perform more personal care, like washing bedding, in order to save money. Much might be said on both sides!

Welfare Reform 2013

[Thank you to SW, Macmillan Benefits Advisor at the Citizens Advice Bureau, Swindon for this text]

Proposed introduction date: 01 October 2012

Who will be affected? People from working age 18 to retirement age.

What is the proposal? All means tested benefits will be amalgamated into Universal Credits. This means that Employment Support Allowance (Incapacity Benefit), Jobseekers Allowance (Incapacity Benefit) Housing Benefits, Working and Child Tax Credits will all be affected.

Both members of a couple will need to be claimants and sign the "CLAIMANT COMMITMENT". Once Universal Credit is introduced, Pension Credit will be amended so that BOTH members of a couple need to be of a qualifying age.

Entitlement to the Carer amount of pension credit will not be dependent on an underlying entitlement to Carers Allowance; however carers will need to prove regular and substantial caring responsibilities.

Restrictions: No one will receive both disability premium and carer premium in the same award.

Benefit cap proposal: £350 for single claimant; £500 for others.

Capital and Income: Lower Limit £6000 and Upper limit £16,000 (NB no limit for Tax Credit capital)

There are no current plans for Council Tax Benefit, which will be abolished and replaced by local rebate schemes instead.

The Discretionary Social Fund will be abolished and applications will be transferred to local authorities.

Social Housing Tenants: Payment will be restricted if a claimant has more bedrooms than needed. The percentage reduction will be based on number of excess bedrooms.

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According to the Macmillan website:

- Some people with cancer will lose critical financial support after only one year.
- People with cancer getting the same drug, but administered in different ways, are being treated differently in the benefits system.
- People with cancer will have to wait six months before they can apply for the new Disability Living Allowance.



HUG ★
Fridge magnet
 ★ fun

Don't drown the man
 who taught you to
 swim.

April hath put a spirit of
 youth in everything
Shakespeare





The great question... Which I have not
 been able to answer...is, "What does a
 woman want?" - Freud

And to give some balance!

Men are like bobble hats. The
 good ones just nod at everything
 you say.

Hard work has a
 future payoff.
 Laziness pays off



NOW!

Count your age with friends
 but not with years.



Clinical Commissioning Groups

With the disappearance of Primary Care Trusts, they will be replaced by Clinical Commissioning Groups (CCGs) of GPs. These groups will take responsibility for spending around £60bn of NHS funds. At the same time more NHS services will be subject to competition from the private sector. There is expected to be a smaller number of managers and a reduced level of bureaucracy.

Initially there was a very positive response to proposals from the coalition Government, but further consideration has led to the need for a number of amendments.

Where compromises have been made:

- * NHS professionals such as hospital consultants and nurses given greater say in spending
- * Competition limited to quality not price
- * More managers to look into perceived risks
- * All providers to be assessed for their suitability to run services.

The shape of things to come:

- * CCGs decide on care for patients, advise them where to go for treatment and pay the bills
- * Some of the day-to-day control of the NHS passes to the new NHS Commissioning Board, which will manage the CCGs at a national and local level
- * Responsibility for public health issues like obesity, smoking and alcohol abuse is handed to local councils
- * All hospitals become foundation trusts and compete for treatment contracts from CCGs
- * The cap on how much hospitals can earn from private patients rises from as little as 1.5% to 49%.

It was reported in early April on the BBC news that GPs are now less in favour of the changes than when the proposals were first announced. There are fears that they will be forced to commission with less funds.

The Guardian reported on April 3rd that National Voices, a coalition of health and social care charities, has found it impossible, during the last year, to gauge accurately how the Health and Social Care Act's provisions will affect direct patient care and treatment. Because the act rewires structures and concentrates on commissioning, it does little that directly addresses the provision of care.

It is therefore possible that care provision for some healthcare needs could be patchy across the country.

Bowel Cancer Awareness

It's bowel cancer awareness month and Cancer Research has produced a video to help people recognise the symptoms. You can find it at:

http://info.cancerresearchuk.org/spotcancerearly/cancersymptomvideos/spotbo welcancerearly/?utm_campaign=DG_TogetherApr12_Std&utm_content=26585681287&utm_medium=email&utm_source=Emailvision

(Whew!....or it might be easier just to go to the Cancer Research website and search for it!)

There is also a summary of the signs to look out for as follows:

Look out for:

- bleeding from the back passage without a reason
- a persistent change in your bowel habit towards looser or more frequent bowel motions
- bloating, swelling, pain or an unexplained lump in the tummy
- tiredness or looking pale

If you have any of these symptoms for more than 3 or so weeks, you should make an appointment to see your GP. Most of these symptoms won't be due to bowel cancer but it's better to be on the safe side.

If they are signs of bowel cancer, the earlier they are picked up, the greater the chance of successful treatment. If you notice any of these symptoms, get them checked out.

The biggest single risk factor is age. More than 85 out of 100 bowel cancers (85%) are diagnosed in people aged 60 or over. So the risk increases as you get older.

If you think you have a strong family history of bowel cancer, see your GP. If your doctor agrees, they will probably refer you to a specialist genetics service. They will look into your background closely by talking through your family history and asking detailed questions about your families' health and illnesses. You may have blood tests as part of this investigation. If it is agreed that you are at high risk you will have regular screening tests.

Growths in the bowel, called polyps or adenomas, are not cancerous. But they can develop into cancer over a long period of time. The bowel screening programmes in England, Wales, Scotland and Northern Ireland aim to find and remove polyps in the general population before they become cancerous.

Ulcerative colitis and Crohn's disease are chronic bowel diseases causing inflammation in the bowel. Having very severe ulcerative colitis or Crohn's disease for many years increases your risk of bowel cancer.

People with diabetes also have an increased risk of bowel cancer. The reason for this is currently unknown and scientists are looking into it.

H.U.G. News – read all about it

Get-togethers were held in the Academy at the Great Western Hospital in the middle of February and March.

Coffee mornings continued at the Blunsdon Arms early in March and April.

Dates were arranged according to the availability of members.

- A craft session took place at the end of February.

1. Get-Togethers

Two members did an excellent job of running the March meeting at the hospital, while Irene was on holiday. They were pleased to welcome two new attendees whom we hope to see again soon.

2. Income and Expenditure

We have decided to try making a few sales of stock through Ebay, on a trial basis, starting with our chemo hats and other donated items. We'll let you know next time how this goes.

Out talks to student nurses at Oxford Brookes University have now contributed to funds to the tune of around £31, since both speakers donated their payment. This year we just gave short talks, to supplement what the Haematology Clinical Nurse Specialists had to say. What a pity that the payment was still liable to personal tax!

Our hospital sales table on 5th March 2012, was less successful than the December one, although that is not surprising at a time of year when less people are looking for presents. We raised £44 this time.

We have bought a few more craft items which we needed to build up a stock of Get Well Cards. It also seemed like a good idea to buy some postage stamps ahead of the price increase, since a few people do receive copies of the magazine by post.

In addition we have invested in some updated advertising leaflets for the group, which will be available on the Cancer Services Information Point in Osprey and given to new patients with their information packs.

3. Other Activities

The Outing to Evesham Country Park, sponsored and organised by Day Therapy volunteer JY, will have taken place by the time you read this. We shall update you on how it went in the next issue of the HUG Magazine.

Curing a Cough

The owner of a Chemist's arrives at work to find a man leaning heavily against a wall. He goes inside and asks his assistant what's up.

"He wanted something for his cough, but I couldn't find any cough syrup," the assistant explains. "So I gave him a laxative and told him to take it all at once."

"Laxatives won't cure a cough, you idiot," the owner shouts angrily.

"Sure it will," the clerk says, pointing at the man leaning on the wall. "Look at him. He's afraid to cough."

Survival Guide

A Survival Guide, an information booklet for living with and after cancer, is now available to cancer patients, thanks to sponsorship from Macmillan Cancer Support. The booklet gives links to organisations under a series of headings, such as Self-management, Looking after your health, Emotions, Relationships and communication and many more. It lists both local and national organisations for help and advice. A link to an electronic version will be given to patients who have computer access.



BrowseAloud

BrowseAloud is a piece of software that reads web pages aloud for people who find it difficult to read online. This includes people with dyslexia or mild visual impairments and those who do not speak English as their first language.

Once the software is installed on your computer, you can choose to listen to the content of web pages and files such as PDF documents on the Great Western Hospital and other BrowseAloud-enabled sites. The software, which is free to use, is available on the website at

http://www.browsealoud.com/page.asp?pg_id=80004

Once you have downloaded the software, the BrowseAloud icon will appear in the bottom right-hand corner of your screen. When you move your cursor over text, the relevant sentence is spoken aloud. You can choose to listen to selected sections of text or the entire page from where your cursor is pointed. There is also an option to see the words that are being spoken in large text at the top of the screen.

To customize your BrowseAloud settings, simply double click on the icon, once it is installed on your computer to view options for speech and appearance.

Trials of hands-free drink system

A hands-free drinks system, called a Hydrant is being used to help patients to access fluids unassisted at all times. It enables them to drink without having to reach for or hold their drink. Staff can accurately measure how much fluid the patient is taking in and it also benefits patients on fluid restrictions as staff can see at a glance what has been consumed. The Hydrant can be attached to a patient's bed so that it need never be out of a reach.

The device, invented by the owner of Hydrate for Health, has been trialled on Jupiter Ward for a few months as part of the Productive Ward scheme, which aims to improve efficiency throughout the Trust. The inventor came up with the idea after injuring his back and being unable to reach drinks for himself.