

HUG MAGAZINE



June 2015

(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



Launching the radiotherapy equipment appeal – see Page 5

Email: hugswindon@btinternet.com

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HUG Get-togethers

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

Further get-togethers and venues are often arranged on a month by month basis on dates to suit attendees. Contact us for more details.

Agreed dates for the third quarter of 2015 are as follows:

13th July 2015

10th August 2015 and

14th September 2015

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
- Representing patients and carers on Cancer Services User Involvement teams, discussing or raising and following up on issues of importance to them
 - ✓ Items currently ongoing include radiotherapy for Swindon, home delivery of chemotherapy, end of treatment care
- Fund-raising to provide practical help with purchases which have included 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.
- Running a stall behind the atrium at the hospital. These will normally be held on the first Thursday of each month in 2015 with the following exceptions, due to holiday arrangements:

Friday 11th September and Thursday 22nd October

INTERESTING HEALTH-RELATED NEWS

Pregnancy testing for men as a diagnostic tool for testicular cancer

Pregnancy tests are increasingly used to diagnose, or rule out, testicular cancer. They are considered reliable because the same proteins are detected in the urine of testicular cancer patients and of pregnant women. This has recently been publicised in a number of UK newspapers after a boy with a tumour was referred to the Teenage Cancer Trust to investigate the exact nature of his problem and received a pregnancy test.

The Teenage Cancer Trust said pregnancy tests had been used to diagnose testicular cancer for around six years.

Ovarian Cancer test

UK researchers have developed a new, improved method of detecting ovarian cancer, which looks at changes over time in the levels of a protein called CA125 in a woman's blood and calculates whether she needs further tests (such as an ultrasound scan), based on her personal risk level.

In a study, published in the *Journal of Clinical Oncology*, the new method detected eight out of 10 women who have the disease. This was a big improvement on previous methods. Symptoms of ovarian cancer are not easy to spot in the early stages.

Although it is known that early diagnosis greatly improves the outcome for patients, it is not yet clear whether this method of monitoring CA125 levels over time translates into saving more lives. Further results are to be published in the autumn.

It seems likely that a national screening programme would be necessary to identify affected women at a much earlier stage, when they are still symptom free. More evidence of the benefits are needed before this could be considered.

Cancer Research <http://scienceblog.cancerresearchuk.org/2015/05/05/>

Dramatic results for early trials using combined monoclonal antibodies

Results of early trials of a skin cancer therapy on 142 patients have produced dramatic results. 72 of the patients were given a combination of immune-system boosting Nivolumab and Ipilimumab and the others were given one of these drugs plus a placebo. In 61% of those patients given the combination of both drugs, their tumours shrank over a 12 month period.

Another trial involving 950 patients with advanced skin cancer using the same drugs showed that 60% of tumours had shrunk or been brought under control. Results of trials using the combination therapy on patients with advanced lung or skin cancer were also presented at the American Society of Clinical Oncology meeting in Chicago, at the end of May, 2015.

Professor Peter Johnson, head of cancer medicine at Southampton University and director of medical oncology at Cancer Research UK announced that the results were far better than expected. The treatment worked in a higher proportion of patients and was effective.

<http://am.asco.org/>

Electronic NHS Patient Records

The NHS is continuing with the implementation of a system known as the **Summary Care Record (SCR)**, and comprising a series of software applications which bring together key clinical and administrative data in a central database controlled by the Department of Health.

Patient confidentiality is said to be safeguarded through the strongest national and international security measures for handling electronic information. Access to a patient's electronic record is only possible via a smartcard (which is like a chip and pin bank card) and a clinical relationship with the patient. Each time a patient's information is accessed, an electronic record of this access is made. This means that misuse of a smartcard and by whom would be recorded.

There are a number of ways in which use of the SCR is said by the NHS to improve the quality of patient care:

- Improving Patient Safety - supporting safer and more informed prescribing by providing timely access to accurate information. Key clinical information would be more legible and accurate.
- Improving the Efficiency of Patient Care - reducing the time, effort and resources required to obtain this information from the patient's GP practice. The record would be available instantly wherever and whenever it was needed
- Improving the Effectiveness of Patient Care - supporting the delivery of appropriate care to patients
- Improving Patient Experience - reducing the requirement on the patient to recall/repeat their medication information and supporting people with difficulties communicating

Large numbers of GP practices across the south of England have already implemented SCRs. (Refer to the map at <http://systems.hscic.gov.uk/scr/deploy?data=Y57> for an up to date list)

The British Medical Association has produced guidance for members on confidentiality issues.

<http://bma.org.uk/practical-support-at-work/ethics/confidentiality-and-health-records>

Despite all the assurances, a group of Doctors have recently asked for implementation to be put on hold until it is clearer that data protection issues have been fully addressed. They are concerned that too many people will be able to access records. Anyone with the appropriate NHS smartcard, including students, can access records. They also expressed concern about whether data would be available and secure, if patients were overseas.

Most of us have received letters, which explained that we needed to opt out if we did not want our medical records to appear on the database. Did you decide to opt out and make the effort to advise your GP accordingly?

If U.S. Government records can be accessed by hackers, how happy are we that our medical records will be safe?

Fund-raising for Radiotherapy

A sizeable crowd of patients, staff and local supporters gathered at the Great Western Hospital on 28th May to celebrate the launch of the appeal to raise £2.9 million over two years to buy the equipment for a dedicated radiotherapy centre. The treatment will be provided by Oxford University Hospitals Trust (OUH). While the expansion of the OUH service is subject to a final approval process, the planning stages are well advanced and it is envisaged that treatment could be available locally by the end of 2017.

Our photograph on the front page of this edition shows some of the crowd, with their balloons at the ready for take-off. The 284 balloons represented the average number of people diagnosed with cancer each month at the Hospital. The appeal was launched by Brighter Futures, the fundraising arm of the Great Western Hospitals NHS Foundation Trust.

Last year, 700 patients were forced to make daily 70-mile round trips to Oxford's Churchill Hospital, with the average treatment time taking between four and seven weeks. On average GWH patients travel up to 40 times for their treatment.

GWH Trust medical director Dr Guy Rooney said: "Think of how many people are driving every day to get lifesaving treatment. We have even heard sadly that people are giving up on treatment because they cannot do the drive. This new centre can change everything.

Jennifer Green, Brighter Future's head of fundraising, thanked everyone for coming and making a fantastic success of the launch. She added that many fundraising events have been planned and that they would love for people to come and support them.

Events for which dates have been advertised are as follows:

- **A Tea Party on 3rd July** or another date to suit the organiser/s: A Wimbledon theme is suggested. Tea Party Packs are available on application.
- **Sky-Diving on 19th July:** Contact Go Skydive on 01722 212069 or email holly@goskydive.com and see the GoSkydive website (www.goskydive.com/brighter-futures) for full details.
- **Cycle Ride on 20th September:** You can register online at Entry Central: Ride for Radiotherapy (www.entrycentral.com/rideforradiotherapy).

Telephone the Fundraising Team on 01793 605631 or email them at fundraising@gwh.nhs.uk. They can provide details of how to make personal donations, via the Brighter Futures, Just Giving and Virgin Money Giving web sites, by cheque or by telephone.

(Brighter Futures is a Registered Charity (1050892) which raises funds for Great Western Hospital and community health services across Wiltshire. The website is at <http://www.brighterfuturesgwh.nhs.uk/>)

The recent Parliamentary and Health Service Ombudsman's Dying without Dignity report found 'tragic' cases of patients spending their last days in 'unnecessary pain'. The report found too many instances of poor communication leading to families losing the chance to say goodbye to their loved ones, along with insufficient pain management and inadequate out-of-hours services.

Every year, approximately half a million people die in England and for three-quarters of them, death is not sudden but is expected, the report said. Many of these people may benefit from end of life or palliative care, with much that can be done to improve the last months of around 355,000 people's lives.

The ombudsman, who makes final decisions on complaints about the NHS in England, looked at investigations it had completed from GP practices to hospitals and mental health trusts, to identify the issues it sees the most often.

It found "tragic" cases where people's suffering could have been avoided or lessened with the right care and treatment as they approached the end of their lives. Ombudsman Julie Mellor said the NHS should consider the report to help prevent similar cases from happening again.

She said, "This report highlights the impact on patients and their loved ones, when the care and treatment of people nearing the end of their lives, falls short. Our investigations have found that patients have spent their last days in unnecessary pain, people have wrongly been denied their wish to die at home and that poor communication between NHS staff and families has meant that people were unable to say goodbye to their loved ones."

We are fortunate to have the Prospect Hospice so close to the Great Western. Palliative care personnel at the two sites work closely together.

A great deal of time and effort has gone into the organisation of end of life care at the hospital and hospice. Topics such as holistic care, resuscitation wishes and involving families at every stage have been discussed and agreement reached.

Ideally everyone who wanted to would be able to spend their last days at the Prospect, where they could benefit from the added privacy and the peaceful surroundings, as well as the level of care there.

The situation with home care may be somewhat less satisfactory. Swindon is on the edge of Wiltshire and three other local authority areas are close by. Each of these makes their own decisions about the level of funding and the way they choose to spend it at the moment. New care funding requirements will be implemented next year, based on legislation already available in The Care Act 2014. There are concerns about how councils will pay for the changes.

At a very upsetting time, it may be difficult for families to voice any concerns or worries about the care that a seriously ill relative is receiving, but it is important that they do so. Understanding what is happening and why is vital, and insisting on changes to the care package, if necessary.

Agency Staff fees in the NHS

NHS spending on agency nurses and staff has spiralled to more than £5.5bn over the past four years and is continuing to rise. According to the latest figures from the Royal College of Nursing, there were 7,000 fewer qualified nurses in August 2013 compared with May 2010, excluding health visitors, school nurses and midwives. Government Ministers have been accused of “truly incompetent planning”.

In the last year of the Labour government, NHS foundation trusts spent £734m. In 2013-14 that had doubled to £1.3bn. Trusts are now facing what Monitor, the NHS regulator, calls “unprecedented financial pressure” due to their reliance on expensive agency staff.

Reliance on agencies – at a cost of up to £1,800 per day per nurse – comes as the number of nurse training places in England has been cut. At the same time there has been growing demand on hospitals and a rapid attempt by hospital bosses to take on more nursing staff to improve patient safety in the wake of the Mid Staffordshire care scandal.

Agencies charge significantly more per shift for their staff than the equivalent cost of a full-time NHS nurse or doctor, and health bosses have been criticised by regulators for failing to plan their workforce needs more efficiently. Agencies can also offer more flexible working, for example to staff with childcare commitments, who may wish to work part-time.

(Sources of information: Recent articles in the Guardian, the Independent and the Daily Mail)

It is not known how much the GW Foundation Trust is currently spending on agency staff. It is known however that they have tried hard to recruit additional permanent nurses.

The Trust Report & Accounts for 2013-2014 state that there were 100 more nursing and midwifery staff at the end of the year than at the end of the previous year. However, recruiting was regarded as challenging, with 285 vacancies, 6.07% of staffing levels.

A total of 70 vacancies had been filled by recruiting in Ireland, Spain and Portugal and work continues with local universities to identify and train future staff.

The Trust is doing what it can in what is a difficult situation nationally, and with the possibility of more Government funding cuts to come.

Fridge magnets

Is it a good or bad thing if your vacuum cleaner really sucks?



Every crowd has a silver lining is the pickpocket's creed!



Try to avoid looking forward or backward and try to keep looking up.



I know I've had far too many Birthdays, but I really would like some more.



A real woman could do it all by herself, but a real man

wouldn't  let her.

A day without sunshine is like...night.



H.U.G. News – read all about it

- Get-togethers are usually held at the Blunsdon Arms pub, as regular coffee mornings and lunches.
- Occasional group craft sessions are arranged for those who are interested, as new sales stock is required.
- Those of us with the time and the urge are still making items individually at home to sell.

1. Get-Togethers

Get-togethers are taking place on the second Monday of each month. Further additional dates and outings are arranged on a month by month basis depending on members' availability and willingness.

Contact us to find out what has been arranged.

2. Income and Expenditure

Sales on our stalls at the GWH have continued to be extremely buoyant since we have been more visible in the reception area. Everyone entering or leaving the main building is able to see us. We have made sales worth nearly £750 for just 4 months this year. (There was no stall in January and the June one is just too late for the Magazine printers.)

A big thanks is due to the friends who knit and crochet for us. Without them, it would not be possible to raise this amount of money.

We have already booked a stall at the Dragon Boat Race on the last Sunday in June and even the Commonweal School Christmas Market.

We are donating all our profits to the radiotherapy linear accelerator fund.

3. Activities

Our visit to Littlecote House and Hungerford will take place in July, on a date to hopefully take advantage of some better weather.

We are also considering a trip on the Swindon & Cricklade Railway as a second outing before the autumn.

Additional CNS for the Haematology team

We heard just too late to include in the last issue of the HUG Magazine, that VJ has become a Macmillan Clinical Nurse Specialist in the Haematology team at the GWH. Vicky is well known to patients of the Day Therapy Centre or Dove Ward, where she has been Senior Sister for a number of years. Her colleagues tell us that they are delighted with this appointment, which will allow each patient to have more of their time and allow them to set up new initiatives. Her experience of haematology will be invaluable to patients.



WI-FI

Wi-Fi is now available for patients, visitors and staff at the GWH! This will be most useful for anyone trying to work from the hospital. It will also allow cheaper mobile phone connection, where use is allowed.

Intra-Operative Radiotherapy for breast cancer patients has started

In the middle of March, the Great Western Hospital in Swindon became the first NHS hospital in the south west to begin treating breast cancer patients with new intra-operative radiotherapy.

As mentioned in previous issues of the HUG Magazine, when fund-raising was under way, this new treatment works by giving patients a single dose of radiotherapy while they are still in the operating theatre. This means that following surgery patients will not have to travel to either Bath or Oxford to receive radiotherapy.

Other advantages include patients experiencing less pain and sensitivity, a reduced risk of infection and quicker recovery times.

Fund-raising manager Jennifer Green said "It costs £150,000 to offer this treatment for one year. We originally set out to raise £75,000, with the other £75,000 being provided upfront by Brighter Futures. The people of Swindon and Wiltshire smashed the target and, at the last count, we had raised around £110,000. This is fantastic as it means that more of the cost is covered by the community contribution and that Brighter Futures can invest more funds into other worthy projects."

Health Talks

Unfortunately we didn't know in time about the talk on breast cancer, held on 3rd June. Talks for the remainder of the year are as follows:

7 October 2015	6.30pm	Dementia
2 December 2015	6.30pm	Migraines

All Health Talks will take place from 6.30pm-7.30pm, in Lecture Hall 1, The Academy, Lower Ground Floor, Great Western Hospital. Light refreshments will be available from 6.00pm.