

HUG MAGAZINE



February 2010

(issued on the second Thursday of alternate months)

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



Some members at the Christmas lunch 2009

Email: hugswindon@btinternet.com

Website: www.hugswindon.co.uk

H.U.G. Swindon Get-Togethers

We meet in the Academy (at the back of the Hospital), Room Number as shown on the second Thursday of the month.

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

11 March 2010 – Seminar Room 4
15 April 2010 – Seminar Room 4
13 May 2010 – Seminar Room 4

AIMS

HUG aims to improve the environment for 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, in an informal atmosphere over refreshments.**
- ❖ **Producing the HUG Magazine, a light-hearted and informative bi-monthly publication, which is available in Dove Unit, the Day Therapy Centre, the Osprey Waiting Area and Wren Ward or provided direct to HUG members.**
- ❖ **Pointing patients in the direction of specialist help, 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. We have provided mugs, bookshelves, room redecoration materials, purchased Christmas gifts, magnifying glasses, slippers and gel bags for patients and donated to Dove Ward Charitable Funds. Ideas are welcomed for future projects.**
- ❖ **Maintaining a website and distributing leaflets to promote the group.**

Get-Togethers away from the Hospital

In addition to the get-togethers at the Hospital, as advertised above, we meet for coffee and a spot of lunch, for anyone who wants it, at least once a month. Contact us for the next location, date and time, if you would prefer to meet us, away from the GWH. We are a small friendly group, who would make you very welcome.

INTERESTING HEALTH-RELATED NEWS

Lymphoma among young people

The Lymphoma Association has launched an exciting campaign to raise awareness of lymphoma among young people in January 2010. Lymphoma is the most common cancer among 15-30 year olds. To help make them aware of the symptoms of the disease, they have created a simple acronym PITS - which stands for **P**ersistent lumps, **I**tching, **T**iredness and **S**weating.

In order to get the message out there, there is a website area where you can find out about the signs and symptoms of the disease and read personal experiences submitted by people who have been diagnosed with lymphoma.

You can Email pitfart@lymphomas.org.uk or call 01296 619424 to request a PITS pack, which contains leaflets, stickers, t-shirts and posters that you can distribute and display to raise awareness of the campaign.

Chemo hats

While looking for knitted hat patterns on the internet, one of our members found that there are lots of patterns out there for "Chemo hats". Most of these are made of cotton with a touch of lycra and some of them were really nice. You can find them on a Google search.

Leukaemia Research name change

The organisation has recently changed its name to Leukaemia and Lymphoma Research. Their life-saving research is focussed on finding causes, improving diagnosis and treatments, and running groundbreaking clinical trials for blood cancer patients. The change of name is designed to better reflect the area of interests, which covers all blood cancers including leukaemia, lymphoma and myeloma affecting people of all ages. The website address has been changed accordingly to

<http://www.llresearch.org.uk/en/1/home.html>

Super foods

We are often reading articles about the anti-oxidant properties of super foods such broccoli, blueberries, sweet potatoes and avocados. Nutritionists claim these antioxidants can lengthen your life by cutting the risk of heart disease and cancer, but not it appears that we can have too much of a good thing.

Researchers from Kansas State University in the U.S.A., have tested animals with different doses of antioxidants. Those that were given high levels showed impaired muscle function, reported the study published in the Journal of Applied Physiology. It is suggested that too many antioxidants could tilt the balance and make it harder for the elderly to breathe and stop them from doing the exercise that could help them stay fit.

Refer to: <http://www.dailymail.co.uk/health/article-1246542/Eating-superfoods-harm-health-overdosing-antioxidants.html#ixzz0dzejjILU>

A Patient's Tale: Living with Non-Hodgkin's Lymphoma

As reported on the back page, three of our members recently gave a talk to nursing students at Oxford Brookes University Ferndale Campus. A summary has been produced for the HUG Magazine of one of these talks. D has previously written about his experiences of a stem cell transplant of his own stem cells.

D first had a symptom in September 1999 when he developed a painless lump at his left shoulder. When there was no change after 3 months, he visited his GP. This visit led to surgical removal and a biopsy in February 2000. Non-Hodgkin's Lymphoma was diagnosed and he was referred to a consultant Haematologist. He had radiotherapy on the site to kill any remaining cancerous cells.

He first relapsed in April 2002 when he noticed a lump, again painless, at the right side of his neck. Diagnosis and treatment were carried out as before.

In October 2004 he noticed 2 lumps, in his right arm pit and at his right elbow. On this occasion following surgical removal of the armpit node and a biopsy, a return of the cancerous cells was confirmed. This time he received chemotherapy as an outpatient, in 6 sessions, with 3 weeks between them. He found that he tolerated the chemotherapy well, with few side effects. His appetite was reduced and he suffered from fatigue.

D's third relapse came rather more quickly. In June 2005 he developed back pain which increased in intensity until late August. He suffered from instability when walking, and his left leg would drag. Late September emergency admission to hospital paralysed from waist down. An MRI scan revealed spinal cord compression by tumour. He received steroids and radiotherapy to relieve pressure. This was followed by chemotherapy, again as an outpatient with the same regime as before, starting in November. In December he had to be admitted to hospital with blood clots on his lungs.

This time the chemo mix was stronger and there were more side effects, with hair loss and constipation, in addition to a reduced appetite and fatigue. He needed some physiotherapy to help walking and mobility.

A scan in March 2006 revealed that D had developed further tumours at other sites, and an intrathecal chemotherapy regime was tried, with chemo injected into the fluid around the spinal cord. Unfortunately this was unsuccessful.

In July 2006 it was suspected that a chest infection might turn out to be TB, but he tested clear. It was at this stage that a stem cell transplant was advised.

In August 2006 he started to receive chemotherapy and steroid treatment prior to stem cell harvest at John Radcliffe hospital. Then in August he went to the Royal Brompton Hospital lung biopsy and endoscopy because of continued chest problems. These had to be cleared up before the stem cell transplant could take place.

Following further intensive chemo he had his stem cell transplant in April 2007. The side effects from the chemotherapy were dreadful, but he was still able to be released from hospital in May 2007. Amazingly, he returned to work full-time in July 2007, paired with a colleague initially.

D continues to have regular monitoring, currently on a 3 monthly basis and is only using 1 medication. There have been some side effects of the various drug and treatment regimes: tinnitus, nerve damage below compression point, reduced immune system efficacy.

Some things didn't go as well as they might have during his treatments.

- Inter agency communications which meant that the same medical history had to be repeated several times.
- Access to treatments before the emergency stage.
- Processes that seemed to obstruct rather than progress, for example at one point he had two treatments rather than three because trained staff were not available.
- Horrendous bureaucracy when dealing with social services, voluntary agencies and hospice services, when his attention span was short.

On the other hand some things went very well.

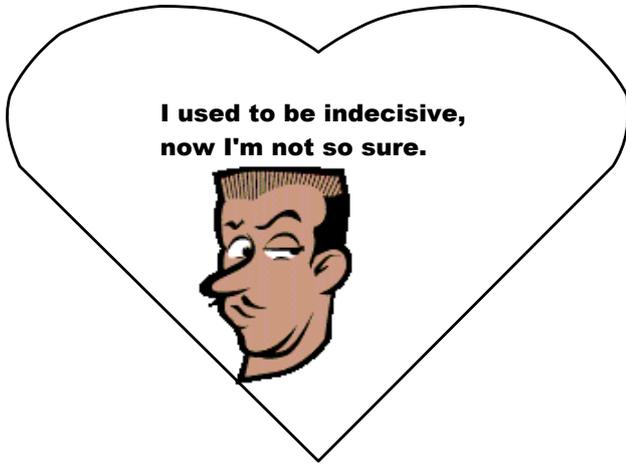
- Treatment at the emergency stage.
- The involvement of many agencies: health, social, voluntary and hospice services.
- His support circle of family, friends, employer and support groups.

D is now keeping well and would like to thank the clinical staff in the Haematology department at the Great Western who have cared for him.

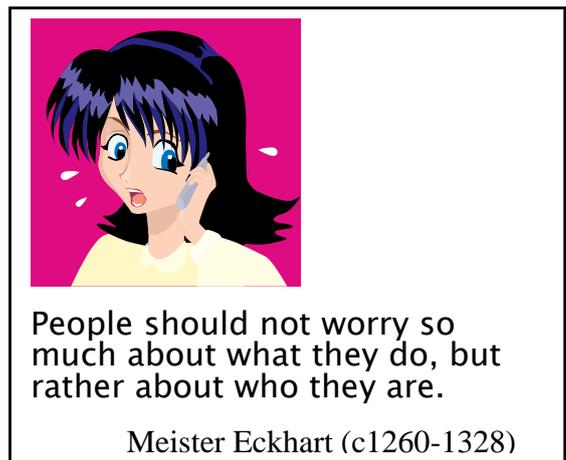
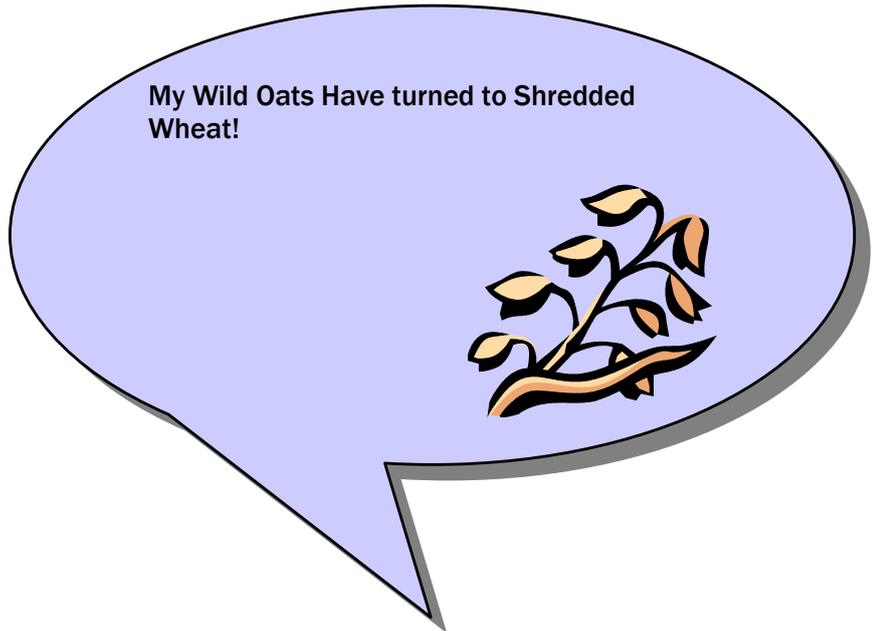
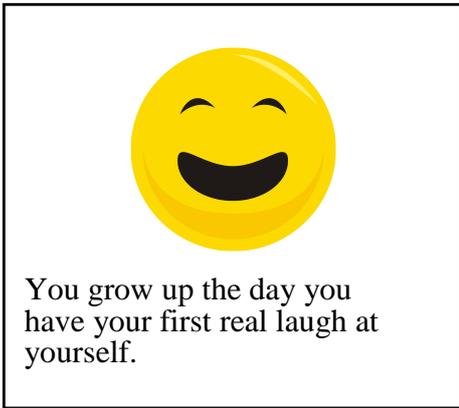
Although the initial diagnosis was a hammer blow, he felt that his family had suffered more than he did because he was the centre the attention during relapses. He found it helpful to find out as much as he could about his condition and treatment regimes when he had setbacks, using the internet and other information sources to collect data. The empathy of other patients also helped him to understand his condition.

This is of course the experience of one patient and we would stress that it may be entirely different from that of another patient with the same condition, and treatments have changed since D was first diagnosed.

We wish D the very best of health for a long time to come.



HUG ★
fridge magnet
★ fun



In Praise of Avocados

The Hass avocado (*Persea americana* Mill.) is a great American success story. A California mailman named Rudolph Hass discovered this cultivar, which turns purplish-black upon ripening, and patented the tree in 1935. Every Hass avocado tree in existence is derived from a single tree that Hass planted in La Habra Heights. (The tree was finally cut down in 2002.) While Hass avocados today constitute a billion dollar business, Hass himself made only \$5,000 from his patent.

Hass avocados are often shunned by the health conscious because of their high fat content. But most of the fat in question is mono-saturated, and thus is similar to olive oil. Other than its potential for adding poundage, avocados are a great source of nutrients, such as potassium and fibre. They have an abundance of vitamin C, vitamin E, vitamin K and folic acid. Hass avocados contain the highest content of lutein among all commonly eaten fruits, as well as other carotenoids such as zeaxanthin, alpha-carotene, and beta-carotene.

In the past few years, there has been a steady stream of research on the anti-cancer potential of avocados. Scientists at Ohio State University (OSU) found that an extract of Hass avocado selectively induced apoptosis in cancer but not normal, human oral epithelial cell lines. Apoptosis is the most common form of programmed cell death (PCD) and is the way that most drugs actually kill cancer cells.

OSU scientists believe that consuming avocados may help prevent oral cancer (Ding 2009). "As far as we know, this is the first study of avocados and oral cancer," said Dr. Steven M. Ambrosio of Ohio State. "We think these phytochemicals either stop the growth of precancerous cells in the body or they kill the precancerous cells without affecting normal cells. Our study focuses on oral cancer, but the findings might have implications for other types of cancer" (Science News 2007).

Another promising study from the University of California, Los Angeles (UCLA) showed that an extract of avocado inhibit the growth of both androgen-dependent and androgen-independent prostate cancer cell lines in the laboratory. This caught the attention of many patients, since there are few treatments that will work on prostate cancer that is no longer responding to hormone therapy. The mechanism of action was an arrest of the cell cycle accompanied by increased expression of the p27 protein. P27 helps regulate the normal cell cycle.

Many colourful fruits and vegetables also contain carotenoids. But UCLA scientists speculate that it is precisely because of the high monosaturated fat content that the carotenoids in avocado are absorbed into the bloodstream, "where in combination with other diet-derived phytochemicals they may contribute to the significant cancer risk reduction associated with a diet of fruits and vegetables" (Lu 2005).

So, yes, avocados can be fattening, but the mono-saturated oil in this case may be serving a very good purpose. Depending on your weight, adding avocados to the diet could be an excellent idea.

In addition, avocados are considered to be among the foods that have the least amount of pesticide residues. They therefore made the "Clean 15" list of the

Environmental Working Group. Fewer than 10 percent of avocado samples had detectable pesticides, and fewer than one percent had more than one pesticide residue (Minton 2009).

--Ralph W. Moss, Ph.D.

References:

Anonymous. Avocados may help prevent oral cancer, study shows. ScienceDaily, Sep. 5, 2007.

Ding H, Han C, Guo D, et al. Selective induction of apoptosis of human oral cancer cell lines by avocado extracts via a ROS-mediated mechanism. Nutr Cancer. 2009;61:348- 356.

Lu Q, Arteaga JR, Zhang Q, et al. Inhibition of prostate cancer cell growth by an avocado extract: role of lipid-soluble bioactive substances. J. Nutr. Biochem. 2005;16:23-30.

Minton, Barbara L. Research reveals which conventional produce can be safely eaten. Naturalnews. com, June 23, 2009.

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Just room for some unintentional patient notes jokes!

The patient has no previous history of suicides.

Patient has left her white blood cells at another hospital.

Patient's medical history has been remarkably insignificant with only a 40 pound weight gain in the past three days.

Patient has chest pain if she lies on her left side for over a year.

On the second day the knee was better and on the third day it disappeared.

The patient is tearful and crying constantly. She also appears to be depressed.

Patient had waffles for breakfast and anorexia for lunch.

She is numb from her toes down.

While in ER, she was examined, x-rated and sent home.

His skin was moist and dry.

H.U.G. News – read all about it

Get-togethers were held at the Great Western on 10th December 2009 and 12th January 2010 in the Academy at the GWH, with social events at the Blunsdon Arms in early and late January.

1. Recent Get-Togethers

The December meeting was a short one, because of lack of room availability. M supplied some mince pies and I brought some tablet (Scottish fudge) and truffles, which were all much enjoyed.

In January numbers were limited because of the weather conditions, but we worked our way through the Cancer Myths Quiz, from the Cancer Action Newsletter. Some of the correct answers were really surprising!

2. Events

Five of us were involved in offering Christmas biscuits, truffles and cakes in the Osprey waiting area and the Day Therapy Centre on 8th or 10th December. These seemed to be greatly appreciated and enjoyed by both staff and patients. Leaflets advertising the group were given out to anyone interested. Many thanks to our bakers for the goodies provided.

Our Christmas lunch at the Toby Inn was most enjoyable, with a wide choice of main course meat, poultry and vegetables plus starters and puddings for a really reasonable price. We provided our own crackers and “Secret Santa” present for the name each of us had drawn in advance. Unfortunately two members were unwell and therefore unable to attend. Coffee morning numbers were also down in January, because of the weather.

3. Fund-Raising/Donations

There has been no fund-raising over the holiday period. We have however, received two donations. The first was for £50 from the sister of a patient and would like to thank her very much via the Magazine, since we do not have contact details. The second, from the family of Jon Smith, was for £336.92. Some sales of hand-made Christmas cards were also made.

4. Spending

A batch of thermometers, personalised with “HUG Support Group” has now been obtained by the group, following clinical approval of a sample. They are being provided to the Cancer Services Clinical Nurse Specialists, to give away to patients at risk of neutropenia. A raised temperature is often the first sign that a patient has developed an infection.

Our next project is to provide sea bands, which are said to help to alleviate nausea during and after chemotherapy. We are going to have to sew labels on these to promote the HUG group, but we already have some volunteers to do that.

There is no further news on the possibility of providing complimentary therapies for patients in Day Therapy and Dove. This will be further discussed at the Cancer Services User Involvement Group later in February.

Presentations to Student Nurses

HUG was asked recently if any of our haematology patients would be prepared to talk to some second year Oxford Brookes University student nurses about their experiences. We were delighted to find that not one, but three, members were keen to do so. The talks were given on 2nd February and have provided some possible material for the magazine. A summary of one of the talks appears in this issue.



Hospital Food

The Conservative Party's comments in the national press regarding the higher number of patients leaving hospital with malnutrition, compared to those being admitted, was reported in the Swindon Evening Advertiser in late January. The Director of Nursing, S R, responded on behalf of the GWH, explaining that health issues may mean that patients are unable to eat. She pointed out that help is available from volunteers when patients are unable to feed themselves and clarified the "red tray" system used for patients whose food intake is being monitored.

The Advertiser was apparently also inundated with calls from former patients in defence of the catering, the selection and amount of food available and the help provided.

If you have any different experiences do let us know, either by telephone or via email.

Support available from Macmillan

L from Cancer Services has provided us with details of the launch of Macmillan's new free phone service, which brings together their CancerLine, benefits helpline, cancer information nurse helpline and Youthline under a single freephone number, which is:

0808 808 0000.

Calls can be taken on this number, from Monday to Friday at any time between 9 am and 8 pm.