

AIREDALE CANCER USER PARTNERSHIP GROUP

Minutes of the meeting held in the boardroom AGH

8th July 2008 12 noon to 2pm

Matters Arising:-

1. **Information Booklet** – There are fewer resources now so more space in the booklet. PS has negotiated with printer to have a flap for the index after showing to the Easy Reading Group. He has also secured funding from the PCT. There was discussion around the need for counselling (basic talking and listening skills) rather than psychology; there is no counselling resource in the Airedale area for cancer patients that we could include in the booklet. Problems picked up in HODU can be referred urgently to Sue Aitken in Clinical Psychology or if not urgent they recommend patients see their GP. It was suggested that the CNS Site Specific Nurse would be available for counselling. (Only one of the CNS's at AGH has not undertaken the Advanced Communication Skills course.) Some cancer sites at AGH don't have a CNS, so to put them in the information booklet might be misleading. Some patients felt anyway that the CNS was too busy and didn't like to bother them or that they were inappropriate.

Counselling is available at Bradford Cancer Support (BCS) for patients, carers and family members living in the Bradford & Airedale PCT and those accessing the local hospitals. Transport is not generally available to those who don't live locally or who do not meet the BCS criteria, but the voluntary transport service at Airedale General Hospital may be able to help with some transport requests.

2. **Managing the Stress of Cancer Booklet Update**

All changes now made. Next stage – MA, PS and JH to look at it. PS discussed having it on our website to download with sound (cost £300). Janet Duerden said she would write to the original author, J Brennan, for permission. Other languages were discussed but the Website is single language.

(MA informed group that the Yorkshire Cancer Network is currently developing a Patient Information Website that will be available in several languages.)

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3. **Airedale & Bradford UPG Website:** MA had tried to access but was unable to. Discovered that it now has an NHS domain (www.abcupg.nhs.uk). Apparently, it needs an £8 fee to stop it being an NHS site, but who pays it and to whom should the payment be sent?

Pam Whitaker/Nick Carter had finished training to input data onto website. General discussion about the site – who takes responsibility, someone else is the editor and allows the changes to 'go live' but no one seems to know who that is. MA to look into. PW and NC will try and get material on to website.

4. **Cancer and Nutrition by Lesley Conti.**

Lesley Conti has spent a lot of time looking into diet and cancer – in particular keeping the body in an alkaline state rather than an acidic state. She quoted Percy Westons book *Cancer, Cause and Cure* and highly recommended the book:

Back to the House of Health No. 2 author Shelley Redford Young. Woodland Publishing (USA) \$24.95 ISBN 1-58054-377-4 www.woodlandpublishing.com

(there is also **Back to the House of Health No. 1**)

Lesley's diet has been totally organic and vegetarian with the very occasional small amount of white fish. She also talked about essiac herbs. She advocates their use as support and *complementary* to mainstream treatments. There was a discussion about how interesting this was and how to inform other patients.

Some of the ideas to take this forward were

- a) 10 Key points in the info booklet
- b) 10 key points to be put on the UPG website.
- c) PD suggested to Lesley that she could write up her own experience which would be available to other patients in HODU.

5. **HODU** - Dr Crawford had sent out a leaflet for the user group to look at about the emergency care of patients with cancer and undergoing chemotherapy at AGH. There seems to be some misunderstanding about what patients are being told about the *pathway of care*. All patients are seen in Consent Clinic and given an explanation about this by CNS or Sister Askew. If the patient chooses to come AGH (which is an option in the *patient care pathway*) the CNS will go through the reasons why the patient might want to consider whether they'd want their treatment at AGH or BRI. The group felt that the leaflet was not worded very well. JH re-wrote it whilst a lengthy discussion took place. She read it out to the group and it was agreed. Everyone thought the leaflet should be in the pack of information given to the patients at the Consent Clinic. Dr Crawford to be consulted.

GH stated that the PCT are looking at the *patient pathway* and making sure that patients are not being disadvantaged in any way whilst on the *current pathway*. An (unspecified) audit is taking place both at BRI and AGH, but no Patient or Clinician Experience is being monitored. MA asked for Patient Experience Questionnaire to be included in audit. GH to look into this.

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Pat Dyminski had a copy of letter sent to Adam Cairns, Chief Executive AGH. It was from a patient who asked for it to be circulated within the group. It related to her experience when she attended BRI as an emergency patient. The letter highlighted some real concerns and we look forward to hearing the outcome.

6.

CLAN (Cancer Locality Area Network) meeting

(no hospital trust member from AGH present)

MA reported that nothing yet resolved about getting a facilitator for the group. GH explained that the commissioning was for Bradford, Airedale and Craven but not East Lancs. She felt that patient groups are important as they improve patient experience, which is very high on the agenda for the commissioners. This group is different from others, she said. Clerical support for the group acknowledged as needed. It was explained that it was the CLAN's prime objective to put an Information Centre on AGH site. It was thought that any personnel would have a dual role, information and facilitation. Details to be worked up for admin support to start with and MA needs to liaise with Helen Hirst at the PCT. Lesley Sterling-Baxter, Head of Patient Engagement, turned up to one of our meetings which, unfortunately, had been cancelled. We were unaware that she intended to come so were unable to let her know.

MA has since made contact and hopes to meet up with her in the near future.

7. Cancer Reform Strategy unable to discuss as no time left.

MA will attempt to write a short 'patients guide to the CRS' and circulate to members before next meeting.

Any Other Business

1. Future of the Group: Janet Duerden felt that the group would be easy to dismantle but very difficult to reconstitute. Meaningful discussion between patients and health professionals is a lever for change. She reminded the group of the long journey we had been on together so far and, despite some setbacks, that we had achieved quite a lot for patients. Support was offered from the B&E Bosom Friends who were at the meeting.
2. Pat Dyminski told the group she had contacted Mat Neligan (Director of Commissioning, Bradford & Airedale tPCT) about the review of the Oncology Patient Pathway Collaboration. The group asked that representatives from both the Bradford and Airedale User Groups be involved, as this didn't happen last time.
3. Janet Harrison informed the group that this would be her last meeting. Members thanked her for her support and commitment and wished her well in her retirement.

Next Meeting 16th September 2008 (1200-1400) Boardroom AGH
(agenda items to Marion smithallinson@btopenworld.com before 5th September)