

NOTES OF BRADFORD USER PARTNERSHIP GROUP MEETING
18^h May 2007, 11.30am to 1.30pm

Present: Sue Hodgson; Linda McAlroy (Chair); Peter Sale; Stanley Shepherd, Colin Sloane, David Woodhall (vice chair), Sheena Firth, Barbara Roberts, David Bland, Alice Brown, Lillabet Czyzewska, Rod Dailey, Moira Dailey.

Apologies for Absence were received from Margaret Dalgety, Marjorie Long, Rene Hoyle, Anne Raine, Reva Tray.

Members spoke about Brenda Leach and Harold Long who recently passed away, Linda McAlroy (Chair) sent a message of condolence to Brenda's husband Jed and son Daniel. A letter was also sent to Marjorie Long, Harold's Wife, Marjorie has contacted Colin and wishes to stay involved in the group. The group formerly acknowledged the contributions of both Brenda and Harold.

Sad news was also received this week about the passing away of Michelle Angelo Petrone, an artist who some members knew from the National Conference. Michelle had also been involved with Bradford Cancer Support in the past.

Minutes of the meeting on 25th April were approved.

Website www.abcupg.org.uk – Colin was going to demonstrate the web site to members but unfortunately the internet connection at the centre was not working so the demo could not be done. Colin explained to the group a little about the site. Some group members had already visited the site and given feedback. The feedback so far has been very positive. Colin explained that there have been a few problems with the package we are using at the moment and therefore we are going to change to the same package that the hospital Trust uses. This is a far better package and much easier to use for those who are training to update the website.

YCN Local User Groups get-together – Colin reminded the group about this event which is being organised to try to get all local user groups together. It will be held on 24th May, 10 a.m. to 4 p.m. at Chevin Park Hotel, Otley. The Chair and up to six members of each group to meet together to exchange ideas. Sue Hodgson, Jane Margerum, Barbara Roberts, Alice Brown, Linda McAlroy, Lillabet Czyzewska and Colin will attend.

Reports and Feedback

Marie Currie project steering group

David Bland and Barbara Roberts have attended two of these meetings and feel they have been very positive. The hospice is keen to re-assess the whole of their services to look at where the service may be improved. David and Barbara have been very pleased with the way they have been included in these discussions. Minutes are being produced from these meetings and Barbara and David have agreed to share them with this group. Peter raised the issue around the difficulties faced by those cancer patients who live alone and what happens to them when they are discharged from the hospice. They surely face much more difficulty if they have no one to help them at home. David and Barbara said that this issue is also being discussed at these meetings and they will ensure this very important issue stays on the agenda. It was felt that some services in the community such as Home Help services are often under-resourced and therefore do not provide as comprehensive a service as they perhaps should do. Colin informed the group about the 'Older Peoples Focus Group' which is run by City of Bradford Metropolitan District Council, issues relating to home help provided through social services can be fed into this group. They have a meeting on the 27th June at The Kings Hall & Winter Gardens, Ilkley at 11am. A couple of members from this group could go along or we could put a paper together to present to the Focus group. Colin will liaise with Linda McAlroy.

West Yorkshire Universities Service User Involvement Project – 6 members of the group attended this project. Workshops took place on three Thursdays and one Friday. Participants were from various places and with different illnesses as well as cancer patients and carers. The aim of the project is to get service users involved in the training of future Health Professionals, particularly around communication skills. Everybody felt that it was worthwhile attending. Jools Symonds (Project Co-ordinator) will attend our next evening meeting on 27th June to feedback about the project.

Information sub-group of Yorkshire Cancer Network – Pete had attended this meeting and reported that the group are currently looking at the roll out across the Network of the NICE Improving Outcomes Guidance for Supportive and Palliative Care for Adults with Cancer. Pete suggested that it would be useful for this group to have copies of the guidance as most cancer service providers are using the guidance as a benchmark for cancer services. Colin will order copies for the members.

Yorkshire Cancer Research Network Haematology Study Day

Lillabet was a speaker at this event, speaking about her own experience of being on a Haematology clinical trial. The delegates were predominantly health professionals and many of them thanked Lillabet for her excellent talk. A report will be produced from the day and Lillabet will share this with the group.

A.O.B.

There was some concern expressed at the very low attendance level of health professionals at the User Partnership group. Since becoming a User Partnership Group there has been a notable low attendance of health professionals at the meetings. It was recognised that many health professionals are very busy and find it difficult to get to meetings, however, it was also noted that the group went through a very difficult time when changing to a partnership group and to operate as a true partnership, we need to have good representation from health professionals as well as cancer patients and carers. Now that we have a place on the Cancer Local Area Network (CLAN) group, it was suggested that this is brought up at their next meeting. The Chair will also write to Rose Stephens (Deputy Director and head of Nursing, Bradford Teaching Hospitals Foundation Trust), particularly regarding the replacement of a Lead Cancer Nurse, which has not yet happened. There was also a suggestion to hold the Partnership Group meetings within the hospital, perhaps a room in Field House. This may make it easier for some health professionals to attend; Colin will explore this idea further.

Next meeting = Wednesday 27th June, 6.30 p.m. to 8.00 p.m. (Evening Meeting)