

British Association of Neuroscience Nurses

HEADLINES

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REPORT ON BANN CONFERENCE IN BIRMINGHAM OCTOBER 2007

Firstly I would like to congratulate the team in Birmingham for organising such a successful conference.

The Copthorne Hotel was ideally placed for a 'little shopping', a drink and a curry, and a stroll along the canal.

The programme was packed with interesting topics and workshops. The final programme can be viewed on the web, www.bann.org.uk

The sessions were Chaired by Sue Gray, Matron, Professor Sir George Castledine and Mr Carl Meyer. The programme can be viewed on the website and a copy of the abstracts are available on request.

I particularly enjoyed the presentations on Palliative Care in Huntingdon's Chorea, Advancing Nursing Practice, the Brain Tumour morning and the multidisciplinary approach to separating twins who were joined at the head.

I was volunteered by my colleagues in Edinburgh to help out with the Brain Empathy Workshop which generated much discussion. I thoroughly enjoyed it and have included some photographs.

Should you wish to comment on any aspect of the conference please send me your letters and they will be published in the next edition of Headlines in the Summer 2008.

At the BANN AGM there were some changes to the Board. Elizabeth Preston stood down as President after many years of service to BANN. Anne Preece is now our new President. I'm sure you would all join me in thanking Liz for her hard work and wishing Anne well in her new position.

The vacant post of secretary has been taken on by Julie Neal, we welcome her on board.

The committee members are:

Anne Preece—Presidnet

Shanne McNamara—Vice Pres

Dee Cope—Treasurer

Cath Waterhouse-EANN/RCN

Kate McArdle-WFNN

Mary Braine

Julie Neal

Jenny McCambridge

Neal Cook

Andrew Carter

Many thanks to Carole Forde-Johnston and Judy Withers for their hard work on the BANN Board for many years.



Neliss Baxter at the brain empathy workshop



Getting together at the conference



Brain empathy workshop

Kate McArdle Reflects on Relocation of Oxford's Neurosciences Intensive Care Unit.

When I moved to Oxford in 1991 talk of a new hospital ebbed and flowed but it was not until early this decade that it became a reality. From the beginning I became involved through meetings, visiting other units, reading Health Building Notes and measuring our existing unit.

In Birmingham the BANN conference started with a presentation from the Queen Elizabeth hospitals Chief Executive. This was interesting, informative, exciting and lively but caused me some concern. Therefore I felt stimulated to write this open reflection. Relocation even to a new and purposely designed building is daunting and can present many “hidden” challenges and problems which may impact on care and established methods of practice.

We were given a “footprint” size for our new unit and the first challenge was to fit everything in. To make more space in one area we had to consider reducing space elsewhere such as the bed areas or office sizes. In fact we felt we just needed more space and a bigger footprint but this was not possible financially.

A hospital wide exercise agreed everyone's clinical priorities and adjacencies. The result being Theatres, Neuro Radiology and ICU on the same floor – marvellous – our transfers are really speedy now with very few corners to negotiate.

Meetings were a priority. We ensured that someone who could make decisions and speak up should represent the unit at every meeting. This was reinforced when we realised if we could not send anyone the meeting was held without clinical input which we felt was not acceptable but we were the ones who had to compromise by changing our timetables to suit relocation. This was often at very short notice especially when equipment was to be reviewed and selected. We probably managed 99% attendance. We also found that taking notes was essential for our own records as we soon realised there was never enough time to consider every point at a meeting and then items could easily slip off the agenda.

Our main achievements are:

- Big windows for daylight, what a joy this is for staff, patients and relatives especially as great views were added free of charge.
- Bed spaces which are flexible for level 2/3 patients.
- A store room which did not reduce in size in spite of great pressure to utilise this space for other uses. I am glad we resisted the pressure as it is pretty full already.

We feel that the new unit is excellent; however several areas are still unresolved or could have been done better such as:

- Carpets in rooms though not requested or agreed. Changing them was not a priority due to the cost
- The pendants at each bedside were challenging to fit out as this is one of those items that you need to use first to know what you want on them
- What you are promised may not be what you get

- Our new build has four isolation rooms. We had one in our old unit. We decided to open two immediately. However we found that the sound proofing is excellent therefore you quickly become isolated once in there with the door closed. The alarm system is there but not very easily accessed. The doors windows are smaller than anticipated and the window screening further reduces the visibility. We had our first critical incident within our first few weeks.

The Neuro ward also have many concerns over visibility due to similar issues with their layout; therefore I was intrigued and concerned when the chief executive in Birmingham was suggesting that ward and isolation room doors would be kept closed in their new hospital. I would certainly recommend a risk assessment for the Neuro wards.

We discussed the move endlessly and we found a “table top virtual move” focussed everyone’s minds. We were very fortunate to have access to and an offer from RAF staff to transfer our patients. Our clinical director chose to lead the patients move and everything went very smoothly. I elected to organise the move for staff, equipment and stores.

My learning points here are:

- Deliveries arriving late in the day particularly the main move day meant staff were very tired
- Training days for all staff allowed them to see the unit however bed spaces were not set up properly, therefore unreal for actual training. These days did keep staff motivated and excited for the move
- A notebook in coffee room was suggested by one of the senior staff nurses. This proved very useful to get staff talking/asking questions and airing issues and concerns as well as making suggestions for the new unit.

We also held regular sessions to go over plans and layout which was another way to involve staff. All staff faced the move upbeat, excitedly anxious though this was more about parking and travel than new equipment and ways of working!

We found it useful to look at changing our existing practice as this made us receptive to change prior to the move. I now find everyone is more flexible and motivated following the move. In the summer I returned from holidays and loads of activities/audits/questionnaires etc were being done and initiated by all levels of staff.

Once we moved we had little time to settle in prior to expanding the unit. This huge challenge has been successful as we have opened more beds over the summer.

What would I do different?

- I would look at working practices following relocation. Moving to an established hospital meant changing to their ways of working. Often we only found out we needed to change when things didn’t happen...

What would I do the same or recommend to others?

- Definitely invite the RAF to transfer the patients they were fantastic.
- Talk to all staff about relocation constantly.
- Go to every meeting no matter how inconvenient.

Would I do it again? Maybe - but only with the same fantastic team for support. They all did really well

We love having visitors to show of our new unit and if I can offer you handy hints or even a survival guide please do contact me.

Kate.mcardle@orh.nhs.uk

REPORT OF A STUDY DAY IN EDINBURGH FOR HEALTH CARE PROFESSIONALS

A study day was held during the *International Brain Tumour Awareness Week* on the 26th October at the Western General Hospital in Edinburgh. The title of the day was 'Towards Improving the Management of People with Brain Tumours'.

We were fortunate in having excellent invited speakers with; Dr Antonio Omuro from Paris speaking on imaging and diagnosis, Professor Whittle from Edinburgh on improving surgical outcome, Dr Alan James from Glasgow on improvements in oncology treatments and finally Andrew Anderson from Maggie's Centre Edinburgh on holistic care. All of the sessions received excellent evaluation.

Doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, social workers, therapy radiographers, dieticians and medical students attended the day. It was truly a multidisciplinary day with plenty of time for networking with our colleagues.

This, following a successful session at the BANN conference this year has really put the care of people with brain tumours on the map.

Shanne McNamara

Clare Sweasey Tells Us About Working in Kyeeya, Uganda

I am a staff nurse currently working in Neuro ICU in Oxford. During my annual leave and in my spare time I work alongside a charity, Christian Relief Uganda (CRU), where I am working as a project manager and raising money to build a health centre in a rural area of Uganda called Kyeeya. At present Kyeeya does not have any health services so the population of about 2000 people have to travel about 10km to the nearest clinic. The roads are appalling with high rainfall making them very dangerous, there are no public buses running in this area, so for a patient to get to the clinic they would have to ride on the back of a push bike or a motorcycle and if they can't afford that then they have to walk. Therefore this area has a very high mortality rate.

On my first trip to Uganda I met a lady who had just walked 2km to the nearest clinic. She was in labour and was on her own, half way there she had given birth to her baby, cut the umbilical cord and then walked the rest of the way. Fortunately they were both healthy. This was one of the reasons I decided to raise money for the clinic in Kyeeya, this lady had walked 2km the ladies of Kyeeya were walking 10km!

This is my 3rd year of visiting Uganda and progress is going well. The outpatient department is complete and we are now building the staffing quarters. Once this is complete we will hand the clinic over to the government and they will staff and fund it.

Therefore the local people will receive free health care. I have drawn up a contract with the local government and I will continue to visit the area to make sure that the health centre is running efficiently.

One way that I am raising the money for the clinic is to buy jewellery in Uganda and then bring it to the UK to sell; all the profit goes towards the clinic. On my last trip I was invited to a village to meet the ladies who make some of the jewellery. It was one of the most moving and emotional trips that I have been on. There are about 25 ladies who have started a ladies group, they have learnt and perfected the technique of making paper necklaces. They now make them to a very high standard. Some of these ladies were so poor that they couldn't even afford to send their children to school (all that they required was paper, pens and a bag of maize!). One lady has just started sending her son to school and he has already gone up a class, as he is so intelligent, he nearly missed out on an education. Another lady, Christine, was born deaf, she has never been educated and has never learnt how to do sign language, however the ladies look after her and they've managed to create their own sign language so that she has also learnt how to make the necklace. The women danced and sung to us, they are so excited that the people in the UK are buying their jewellery and enabling them to make their own money and not rely on handouts.

If anyone would like further information on this project or would like to buy some of these necklaces, please contact me, Clare Sweasey at cswease@hotmail.com.



The ladies group

The clinic

The road to the clinic





The World Federation of
WFNN | Neuroscience Nurses

Agnes Marshall Research Grant Award

The Agnes Marshall Research Grant Award is named in honor of Agnes Marshall, founder of the World Federation of Neuroscience Nurses (WFNN).

The purpose of this award is to foster neuroscience nursing research and advance the scientific base of neuroscience nursing.

The WFNN offers you the opportunity to submit an application for the Agnes Marshall Research Grant Award.

Criteria:

1. The principle investigator must be a registered nurse and current member of the WFNN.
2. Members of the WFNN Scientific Committee may not apply for, or benefit from, funding.
3. The research project must be pertinent to neuroscience nursing.
4. The application must be submitted prior to initiation of data collection.
5. The principle investigator must sign an agreement with the WFNN.
6. The principle investigator must assume responsibility for the conduct of the research.

Amount of Research Grant:

Total maximum amount of award(s): US\$4,000.

Procedure:

1. Applications submitted to the Chair, WFNN Scientific Committee, on the official WFNN application forms, to be received no later than **November 1, 2008**.
2. Award presented at the WFNN Congress, Toronto, Canada 2009.
3. Completed research to be presented at the WFNN Congress in 2013.

Deadline for applications for the 2009 Award is **November 1, 2008!**

Application forms and instructions are available from the WFNN website: www.wfnn.nu

For further information, contact your WFNN representative through your WFNN Membership Association, or send an email to:

Vicki Evans
Chair, WFNN Scientific Committee
E-mail: vevans@nscchahs.health.nsw.gov.au

Communication access to services – everyone’s responsibility

By Susie Parr, Connect – the communication disability network

We all want to make our service as accessible as possible. Currently in the UK, there is concrete evidence of public service compliance with the Disability Discrimination Act as doorways are widened, ramps built and lifts installed. These are the tangible aspects of access. But people with communication disabilities encounter different types of barriers in using hospital and health services.

People with aphasia, developmental language delay, learning disabilities dyslexia and other communication disabilities struggle to engage with service information that is inaccessible. They are often unable to play an equal part in decisions or even simple discussion, because talking, understanding and reading are impaired. Difficulty with writing means that applications, queries and complaints are often not even attempted. ‘*You’re lost*’, as one person with aphasia put it.

Evidence suggests that many over-stretched service providers don’t know how to manage people with communication disability and lack the skills, confidence and time to engage with these patients (Mencap 2004; Law et al., 2007; Parr, 2007). Even highly qualified and experienced nurses and therapists can find the demands of communicating complex information about conditions and treatments overwhelming. Service providers often feel they should leave the job of communication to the speech and language therapist, with the risk that these patients become marginalized and excluded.

Connect (the communication disability network) is remedying this with **Making communication access a reality**, a ‘tools and training’ package. This pioneering resource equips delegates to train service providers in their setting, giving them the practical skills to ensure that people with communication disabilities can get the best out of their services. The package includes two days training and a ‘toolkit’ to take away – all the resources needed to cascade training out to colleagues and team members.

Developed in conjunction with people who have aphasia, the communication access training was trialled in 2006-2007 in a range of care settings. ‘*Will make a huge difference*’ said one stroke ward sister. ‘*Inspirational*’ said an OT. For everyone, the potential is enormous: to focus service providers on a neglected aspect of access, enable sustainable transmission of skills, raise confidence and promote equity for an excluded group.

The Toolkit (which includes training manual, workbooks, CD Rom and DVD) draws on the experiences, recommendations, stories and ideas of people with aphasia and creates a structured, yet flexible programme of learning for service providers. This is relevant to patients with a wide range of communication difficulties, including people with learning disabilities

The Toolkit equips trainers and managers within different health and social care settings to conduct the communication access training with local service providers. Trainees teach, support and inspire each other so that the good ideas become sustainable. The Toolkit provides suggestions for auditing communication access, ensuring that high standards are monitored and maintained after the training ends and patients with little or no English.

Caption: people with aphasia discussing the content of the toolkit



Following her stroke, Basia wanted to discuss with her consultant the severe pain she was experiencing. Basia has aphasia, and at the time of her appointment was finding it difficult to take in information, especially when she was tired or apprehensive. In addition, she knew what she wanted to ask about, but could not find the words she wanted. Sometimes the wrong word came out. When the consultant realised there were communication problems, he was not sure what to do. He talked very quickly and used quite a lot of jargon in his explanations. He knew Basia couldn't speak and didn't know how to help her. Usually, he would ask patients if they had any questions, but he didn't think there was any point with Basia. He told her he would phone her husband. Basia was furious: *'Wanted to throttle him, actually.'*



The Toolkit is founded on the premise that good communication access is beneficial, not just for people with communication disability, but for everyone. In keeping with this, the training involves clear, accessible and engaging teaching materials and activities so that every trainee, no matter what their background, experience or qualification, can become involved. When the communication access training was trialled a wide range of service

providers was trained: specialist nurses, dieticians, therapists, GPs, receptionists, social workers, domestic workers and volunteers.

Domestic workers are particularly important as administrative and auxiliary staff often have as much day-to-day contact with patients as clinicians. If all service providers can promote communication access, service users' experience will be dramatically enhanced. And the training is welcomed by all, even by highly experienced and qualified clinicians:

Having had the tuition about how to help me in the consultations, it felt to me so radically different, made me feel much more at ease so that I felt it wasn't only helpful for the patient it was helpful for me as the doctor and made me enjoy the consultation much more than I would have done normally. I'm thinking about patients I could use the techniques with and make the consultations much more meaningful and therefore much more satisfying for me and make my job more enjoyable.' (GP)

Some service organisers and managers, having received communication access training, have been inspired to take a fresh look at the accessibility of what they offer. Documents and practices that are normally taken for granted can be re-visited and refreshed, to everyone's benefit. Drawing on the skills of people with aphasia, Connect is now offering a consultancy service providing advice, audits and support on communication access on the ward, in units and other service settings. One manager who used this service commented:

'Objective, encouraging and constructive advice. It is much easier to implement changes when workable solutions are suggested to address the problems identified, and this you did.'

Ultimately, Connect's vision is for communication access training to have an impact across all public services and to become as much a part of induction as Health and Safety. After all, communication is everyone's responsibility. Why not start with your service? You can play your part in making a difference to patients with communication disability.

References

Mencap (2004) 'Treat me right campaign' www.mencap.org.uk/html/treat_me_right/report (accessed 22/11/07)

Law,J., van der Gaag,A., Hardcastle,B., Beck,J., MacGregor,A., Plunkett,C. (2007) Communication support needs: a review of the literature. Edinburgh, Scottish Executive Social Research.

Parr,S. (2007) Living with severe aphasia: tracking social exclusion. (Aphasiology, 21 (1), 98-23.

Making communication access a reality (a two-day training package including toolkit) next takes place on 10th -11th March 2008.

For information or for consultancy please visit www.ukconnect.org telephone 020 7367 0846 or email events@ukconnect.org

EDITORS COMMENTS

2008 is approaching and I would like to wish all BANN members the best for next year. The next edition of Headlines will be in the summer. Please send me your comments and letters by the middle of May. Remember there is a £20 book token for good articles.

The next BANN conference is to be held in Leeds from 31st October to the 2nd November 2008.

Put the date in your (new) diaries!

The BANN application form for new members is available on the web, encourage your colleagues to join.

With very best wishes for Christmas and the new year.