



Bath and North East Somerset End of Life Care

Stakeholder Meeting Notes

**Neurological Commissioning Support
Bath and North East Somerset (BANES) Stakeholder Meeting**

**Notes of a meeting held at
The Francis Mercure Hotel
Bath BA1 2HH
on**

Friday 18th July 2008 9.00am – 12.45pm

In attendance:

Focus Group Members:

Julian Bewick
Barbara Chard
Daphne Cox
Nicola Dent
Erica Jones
Wayne Jones

BANES PCT representatives:

Corinne Edwards (Commissioner)
Sue Eskin
Elizabeth Murray
Wendy Pepper
Roni Ross
Sue Townley
Carrie Wedgewood

NCS national and local staff:

Martyn Yeats (Project Manager)
Hilary Fairfield
Val Buxton
Neil Smart
Chris Bennett
Andrew Kemp
Esther O'Brien
Charlotte Rees

Other attendees:

Jo Black (National Council for
Palliative Care)
Peter Sanders (MSS Regional
Chair)
Matthew Trainer (MS Society
Communications)

Welcome	MY welcomed everyone and gave a brief PowerPoint overview of the BANES Project.	Appendix 1
End of Life Care in BANES	The Service User & Carer Experience MS outlined her own background and gave an overview of the End of Life project, explaining the process taken, amendments made, and highlighting areas of the report that she felt particularly important.	Appendix 2
Comments and Thoughts	Discussion was opened up to the floor. It was established that everyone had been very pleased with the report. Feedback was given concerning thoughts arising from the report, alterations that could be made to the interviewing process, and ways forward for the project.	Appendix 3
End of Life Care in BANES	Commissioning CE made the following key points: <ul style="list-style-type: none">• Local Authority, Health and Social Care and Housing are now integrated with the PCT which should aid in swift development of services.• The report will be circulated to the End of Life Care Strategy Group where funding has already been set aside for progress to be made. It will also be circulated to the PCT Executive Group, the Practice-based Commissioning Consortium Board and the Health and Wellbeing Partnership Board (PCT and LA partnership). <p>Questions were then put to CE from the floor, which the group as a whole contributed to where necessary.</p>	
Small Group Discussion	Small break-out groups, each comprised of a mix of professionals and service users, discussed further those things previously raised, considering ways forward, issues to prioritise, and adding any additional	Appendix 4

comments they felt were necessary. Key points were noted on flipcharts.

Feedback

Each small group fed back to the room three key points they had identified as being most important to their conversation, and therefore most necessary to be noted.

Appendix 5

Next Steps and Close

MY felt that 'next steps' had been covered extensively throughout the meeting's discussions, and particularly during the small group and feedback exercise.

MY thanked all those who attended, with special thanks to Marie Seaton for creating the report, and the service users for their attendance and contribution.

Appendix 1

Key points from Marie Seaton's overview:

- This report could not have come at a more auspicious time with the government launching an End of Life Care Strategy.
- There was a common opinion amongst those interviewed that cancer patients often have the upper hand in End of Life Care, whilst those with a long-term neurological condition are left with, what they feel to be, a lack of available facilities.
- The original brief to interview nine carers and nine service users was quickly adapted to a prominently service-user base, whilst the focus group setting was altered to individual interviews, which ultimately resulted in a broader spectrum of findings.
- Those being interviewed were self-selected (with the exception of those with Motor Neurone Disease due to the nature of the condition), and although not so advanced in their conditions to be considered in the 'end of life' bracket, contributions of their future wishes were no less important.
- Discussions were wide, and much was expressed, from abhorrence at institutional care, including fear of a lack of understanding from staff and anxiety over the numbers of people per room, to a concern that their wishes would not be acknowledged or correctly interpreted at a later date.
- This concern for communication – not being listened to or being misunderstood – was a key finding of the report.
- Other findings included a lack of knowledge as to available services; a common question was 'Do I have a right to be cared for at home?' The day to day realities of household help and home care were not fully understood because of a lack in ready information.
- A high regard was expressed for Dorothy House Hospice, who 'live their values' and pay attention to their patients, not imposing upon the patient what it is thought they should want, but rather listening to the patient themselves.
- Questions concerning professional practice and roles of professionals were met with mixed reactions. Some

professionals were considered 'excellent'; sensitive and understanding, allowing their patients time to express themselves. Others, however, were said to be 'appalling'; arrogant and patronising, failing to listen and seeing only symptoms, not a person.

- A person-centred approach, then, is called for by the report. There seems to be a problem with people grasping the necessary difference between compassion and protocol. Steps need to be taken to stop procedure from taking precedence over people's individual wishes.
- A bi-product of the focus groups was an exchange of information between members, a chance to discuss available services and share knowledge of them. Equally, many found it a liberating experience, able to be frank about death – breaking the taboo and opening up a space for honesty. It was found that professionals are generally unwilling to discuss end of life, or the nature of the long-term neurological conditions themselves, due to uncertainty.
- A strong finding of the report was the devotion and commitment of carers. Financial burdens, emotional fatigue and exhaustion were all common problems for carers fighting to ensure that the person they cared for remained unaware of these pressures lest they felt responsible. The report makes it clear that carers need far more support than is currently offered, and that knowledge of available support must be widely spread.
- It was found that access to services was, although not particularly a 'postcode lottery', largely due to the patient's General Practitioner. The GP was shown to be a gatekeeper to support and services, the patient's access to both being strongly dependant on their GP.
- Another key find was the problem of public transport in rural areas. For example, some people are forced to rely solely on taxis as a source of transport, often finding that their request for an accessible taxi has gone astray, and that they are, in essence, stranded at home. The report states how essential it is that rural areas are given the transportation services that are needed.
- The report finds that people are overwhelmingly in favour of Advanced Care Planning, but that this planning should not be

imposed on them; they have a right to choose when to make these key choices.

- Such choices are complex, as is the implementation of them – some people may make choices that professionals would neither recommend, nor advocate. Key to the study was, essentially, the understanding that people facing the end of life need to be listened to; this includes whether or not professionals agree with their expressed wishes.

Appendix 2



'End of Life Care' Stakeholder Conference 18 July 2008



What is important about this project?



- Active engagement of people affected by long-term neurological conditions
- Third sector involvement in the commissioning of services
- A cross-neurological focus
- Utilising & developing partners' skills and knowledge base
- Outward knowledge dissemination



What we did



- Discussions with PCT Commissioners
- Stakeholder Event 9 January 2008
- Agreed to look at the real life experiences of people with a long term neurological condition
- Appointed a Consultant to undertake the work
- Local Steering Group



Today



- Service User Focus
- Consultant's Draft Report
- Initial views of the Commissioners
- Small Groups to comment.
- Work will inform future BANES commissioning intentions and investment decisions in End of Life services



Appendix 3

Information availability:

- Information is key – a common theme is that no-one knows where that information can be found (AK)
- There is something problematic to identify between what we think should be the case and what actually is
- The cost of care in the home is very expensive and there is no financial help offered. Could something be set up, or information made available for how to seek aid with this? (DS)

Compassion vs professionalism:

- You can't teach people compassion – personnel must be chosen for their compassion or be aware that they need to change (RR)
- There is a challenge for health professionals in 'being' rather than 'doing' – not something that can easily be taught
- In providing end of life care, people need courage to 'be' and to 'do' simultaneously; to behave naturally. (MS)

Problematic definition:

- The definition of 'end of life' is problematic and not an appropriate term for people to accept – it requires a different approach to people with malignant conditions. 'Palliative care', or 'appropriate care for people with neurological conditions' are more appropriate terms. (DS)
- It's difficult to talk of 'death' within hospices; various euphemisms are used – how can we know what language is acceptable? (HF)

How did it feel to take part in the interview?

- It was helpful to discuss the issues, to be listened to. It didn't faze me to consider what would be needed at the end of life – it's necessary to be sensible about it. (ND)
- It was refreshing to able to talk to those with similar views when talking with strangers in a focus group. I was surprised to find that it had been stressful.
- I'm very interested in having a revised plan while we're all 'compos mentis'

Death as taboo and issues surrounding it:

- The English have a problem discussing death and sex – no-one talks about death.
- It is not always the neurological condition which causes the end of life. It is important to 'go with them on what they want' regardless of whether you would professionally recommend it.
- How can the findings of the report be transferred to develop or change services? (JB)
- People used to having views and expressing them find it difficult to comprehend what it must be like not to be able to make your wishes known. It is the task of the carers to understand, and professionals to be sensitive to those who don't know what they want or are unable to express what they want. People must become aware of what is wanted and fill the gap for what is needed.
- Life can change within family relationships. Too much focus is placed on dying at home in a happy family which isn't necessarily the case. There's nothing worse than having a partner who cannot cope with your condition – some people split up. There are a lot of different experiences of death – for me, dying in a hospice is the other option. (JQ)
- In the same way that people devise a 'birth plan' over the nine months of their pregnancy, a 'death plan' should be considered – as an indication that an important process has occurred. (ND)
- Family members don't want to have to talk about death – it is important to be aware that some people are able to talk about it and others are not. (JQ)

What could we have done better?

- One member of a focus group became very distressed – it would have been useful to have a trained bereavement (or other) counsellor available, both within the session and to talk with afterwards.
- Questions being asked could be circulated ahead of the meeting itself, to enable people to prepare, and to be aware of why they are being seen and what will be required of them. (MS citing JB)

Next steps:

- Something needs to be set up for end of life to be discussed more openly and frequently. Is there potential for an ongoing group where death can be discussed (with a GP? With other service users?). (JB)
- It's very difficult to talk to people with MND about 'end of life' due to the rapid deterioration the disease causes; fourteen months. (HF)
- If a birthing plan takes nine months, then a death plan can be done in fourteen. (RR)
- It's important to 'get death out into the open'
- There are two certain things in life – birth and death – how do we die?

Appendix 4

People brought very powerful information forward – how can we keep them informed of developments? (AK)

- CE agreed that feedback was essential and that to understand what was changing as a result of the project, a mechanism must be put in place for feeding back.

Aside from who the project will be circulated to as a step forward, what will the hard outcomes be? How can we demonstrate what has changed? (HF)

- CE stated that what the outcomes are and how they are measured will be informed by the meeting taking place.

All information is going straight out to nurses teams to be implemented – how will a change in their services be monitored? (RR)

- CE suggested that carers would be the best judge of whether changes take place within nursing. Some of the report's findings have been impacting service development for a while – the report is tangible and carries weight, giving confidence to these priorities already in place, enabling them to continue.

Circulating the project's findings is great initially, but real progress is made through involving people in an ongoing way – how can this be done? (JB)

- CE highlighted that this process can be replicated in a number of ways, through National Policy, Local Policy and the Strategic Health Authority. CE pointed out that of the objectives recently delivered to the PCT, one which is expected to be implemented by March 2009 is End of Life Care – it is a priority, and this project has given reality to it.

How can the information gathered influence care in residential settings through PCT structures? (NS)

- CE reiterated the partnering of the PCT with the LA etc and explained that this should enable the swift movement of information from one area to another, culminating in action across the board.

- MY added that the merger of these organisations is highly significant, pointing out that the information from the project could filter into conduct in care homes and other aspects of social care.

In terms of the group of people gathered, would it be possible to maintain a group of people to keep the dialogue going regarding end of life. (MY)

- JQ agreed that a user group would be helpful, breaking barriers and creating a safe environment to discuss these issues.
- HF wondered if a similar group could be used as a sounding board for the PCT, whilst providing therapeutic value for those involved – information sharing, discussion of wishes, etc.
- JQ thought that carers should be aware of this group too, and potentially be required to attend a certain number of times.
- JB suggested that small groups would be necessary in order to avoid large anonymous gatherings.
- MS pointed out that two different groups are needed here – A service development feedback group, and a therapeutic discussion group
- ND queried what is available within other organisations, for other chronic illness sufferers, and suggested looking to them for a code of best practice.

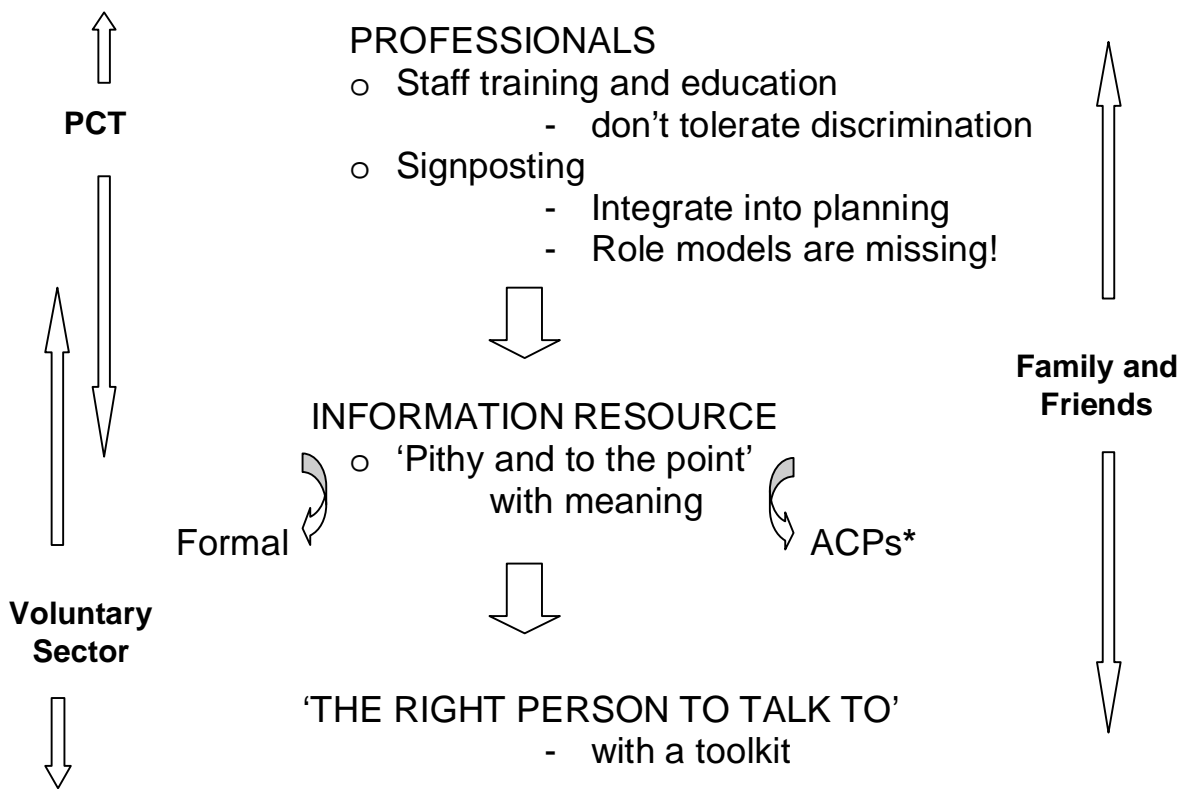
Appendix 5

Blue Group (facilitated by Neil Smart)

- Resources
 - Those who are living with a Long Term Neurological Condition (LTNC) should be involved in the long term for thoughts / comments / ideas etc. Reference Group (partnership; service development)
- BANES Finances
 - Plans / funds are available for service development – opportunity!
- Statutory / Voluntary Working
 - Successful partnership
 - On-going dialogue / discussion
 - Other issues, eg transport, other support services, etc
- Flexibility
 - Need to vary planning; learning exercise - how will we learn / take forward focus groups / interviews 1:1?
 - Continue learning about end of life
 - Develop concept to look at other services
 - PCT to look at priorities – be prepared to re-focus
- Education
 - Develop a strategy for staff training / development on LTNC
 - Consider special interest groups
 - Basic training
 - Specialist knowledge
 - Dignity / respect / care / support
 - Staff recruitment
 - how to identify
 - quality / empathy
 - values
 - personal skills
 - Service users / involvement
- Sharing
 - Issues / ideas we have learnt can be shared in other areas
 - How the process worked
- Joint Neurological Group Meetings on practical issues

- Enduring power of attorney
- Financial / legal
- ↻ Treatment
- ↻ Advanced Decision to Refuse Treatment (ADRT)

Green Group (facilitated by Matthew Trainer)



*ACP = Advanced Care Plans

- Information & access to services
 - 10 minutes is too short!
 - When to talk about end of life?
 - When is appropriate?
 - Very difficult with accelerated conditions

- Should be included in training
 - Role for carers?
 - Time is limited
 - Purposeful use
 - Tasks – not caring?
 - Outcome-led planning needed
- } Linked with professional staff
- Very personal – trust and respect is needed
- Communication
 - Professional staff
 - Time?
 - Ongoing help?
 - ‘Can you teach compassion?’
 - Bad news broken badly
 - Impact on carer
 - Continual learning from people
- } commissioning
- Non-professional support group
 - Appropriate people to talk to
 - Specialist nurses
 - Facilitate contract
- Personal
 - Taking away learning from the conversation
 - Influencing service development
 - Training & education
 - Advanced Care Planning
 - Documentation!
 - Training
 - If not compassion, then understanding
 - User involvement
 - End of Life Care strategy group – time to set up an advisory group of users
 - Information
 - What services are out there?
 - Website – integrated model

Black Group (facilitated by Val Buxton)

Dignity and personalisation:

- Training from Dorothy House
- Regular customer satisfaction surveys covering key issues
 - Acting on feedback
 - Designed by service users
 - Administered by service users
- Issues from report apply beyond End of Life Care – communication is a major factor determining quality of overall care
- Need for staff and users to gather for ongoing dialogue
- Fragmentation is a key problem
 - eg no meetings with GP and District Nurse (who knows what key issues are)
 - GPs need to be part of the partnership of care – hierarchies still exist which impact on service users
- Access to aids and adaptations is problematic
 - Eg access to wheelchairs – lack of equipment and lack of staff (need to put money into service)
 - Need for timed appointments

What:

- Power of user accounts needs to be shared with staff directly involved
- Replicate event with Neurological Rehabilitation Team, nurses, GPs, etc
- Share the fact that people are willing to talk about these issues
- Difficulties with staff involvement in End of Life Care Plan
 - GPs should be highly involved in the planning, yet there may not be ongoing contact between GP and service user
 - Patient organisations could be more involved in providing support
- Need to be able to revise the End of Life Care Plan over time
 - Need for choice in this, too!
- Need for more information on Advanced Care Planning / thought about how to offer choice and support, and how to communicate

- Equipment can make a key difference for someone's quality of life

Information:

- Information prescriptions – the right information at the right time
- The challenges of getting the right information in the right form and volume to the GP
- Consider the GP's role as 'gatekeeper' to information
 - There are concerns about their ability to act as gatekeepers if they do not know enough
- Consider the strengths and limitations of internet information
- Where would the one main point of information lie?
 - A role for patient organisations?
 - How do we ensure that people know about it?
 - Information needs to be available at all health outlets
 - Issues concerning the regularity of contact with specialists – a need for regular reviews and greater capacity
 - PCT are looking at specialist nurse capacity
- Needs to be a movement towards people being able to refer themselves back to be seen
- Everyone needs a care plan!

Red Group (facilitated by Chris Bennett)

- Take discussions out into other neurological conditions
- Involve people and views from across the spectrum of experience of these conditions
 - Need the widest possible range of views
- The project needs to explore learning about how we approach discussions concerning Advanced Care Planning for neurological conditions
- Concern about terminology

- 'Palliative Care' and 'Advanced Care Planning', rather than 'End of Life' – 'End of Life' is a misleading way of describing palliative care and can be difficult to hear
- Need to bring information and discussion about Palliative Care / End of Life / Advanced Care Planning / Living Will to existing support groups and branches
- Need information concerning End of Life Care to be made available widely as part of a suite of information provided about the condition
- Continue discussions with the Hospice Movement about care pathways for people with neurological conditions
 - Do we need specific care settings?
 - Is it specialised in its own right?
 - Could project group work filter in here?
- Consider the possibility of a service user / carer reference group for BANES End of Life Project
 - People bring a range of experience which is by no means confined to the condition they have
 - Strategy group and South West Strategic Health Authority (SWSHA) Consultation
 - How can this be done appropriately?
- How can discussions from this project be translated into personal experiences of Health and Social Care services?
- Need to raise awareness of End of Life Care and tell its stories
 - Break the taboo of death and dying
 - Look at this within the wider public and community and find out what people want to know
 - Need to try to bring pressure from the public to improve services – it is not just those with a neurological condition who need these services – death is a part of humanity – Mark Twain lyrics 'Nobody Gets out Alive' are poignant