

**Notes from group discussions and debates at the Bereavement Pathways Project Stakeholder Events
London on March 5 and Birmingham on February 12 2008**

From the Workshops

Guiding questions for the Pathway

1. What is a good death?
2. Is dying with dignity possible?
3. How can we ensure bereaved people have access to community services?
4. How can we work together to identify bereaved people in the greatest need?

Theme/ topic	Group A- Before death	Group B - At death	Group C - After death
1 What is a good death? How should different professional disciplines contribute to preparation for those who are to be bereaved?	Conflicting individual needs within the family when someone is dying Begin process early	Training and 'added value' of bereavement awareness Educate community to be informed Planning for the last moments - realistic and informed Environment, choices, pre-planning where possible Skills for breaking news, and training Policies informed from 'grass roots' Being there, identifying terminal stage Acute setting is busy - no time Expressions of grief vary Education for terminally ill children when dying Understand individual, culture, religion Best practice areas are the example	Concern for loved ones after a death, esp. people with special needs or bereavement needs Expectations around process - what we assume will happen: professional responsibility to give accurate and appropriate info Ditto viewing the body - how a body is laid out Applying classroom and life experiences and values
2 Is dying with dignity possible? What key improvements would delegates like to see for those close to the dying person?	Pressure on family members from person dying at home, esp. out of hours	Giving of bad news, and to whom Different needs in different families Not in isolation; individualised care Feedback from those using support agencies What was missing for people in bereavement	Information given 'at source', at time of death Brake Care Pack - locally developed info packs Best practice guide? Education around content and timing of offering information What would benefit our community?
3. How can we make sure that bereaved people have access to community bereavement	Identify most appropriate person/ key worker/ liaison/ facilitation	Recording the process not the content Use "When a patient dies" Practical/emotional issues combined, linked Who? Everyone? Who has info? Signposting Bereavement packs, mapping o community	

services?		<p>services</p> <p>Self-referral - booklet, form, offering element of self-assessment and helping clarify issues for bereaved</p> <p>Tighten and improve current practices</p> <p>Booklets on bereavement and signposting - where?</p> <p>Bereavement assessment by phone</p> <p>Enable people to proceed/cope</p> <p>Flexible, inclusive, co-ordinated</p> <p>No perfect system; people missing from the systems</p> <p>System for follow-up</p>	
4. How can we work together to identify those bereaved people in the greatest need?	<p>Evaluation of bereavement services needed</p> <p>Volunteers' work should be respected</p>	<p>On registration of death - all info available at that point</p> <p>Info needs to be local and personal</p> <p>Bereavement services - inform and follow-up</p> <p>Web-based info on wards and for GPs 24/7</p> <p>Local radio? Languages?</p> <p>Leave choices to families</p> <p>Shortage of community services</p> <p>Follow up service and evening service</p> <p>Educational/informative DVDs, eg on inquests, coroners</p>	<p>Research</p> <p>What is 'in need' (of additional support)</p> <p>Formal referral processes</p> <p>Use of assessment tools</p> <p>Push assessment back to primary care - GPs</p> <p>Assessment leading to medicalisation?</p> <p>Normalisation of death as a life event?</p> <p>How do we get emphasis</p>
Other topics arising			
Children	<p>Need for age-appropriate information/language</p> <p>Support for parents</p> <p>Children may be excluded from terminal phase</p> <p>To see the body or not?</p> <p>Children's needs - decisions/assumptions may be made for them</p>	<p>Cot deaths are a difficult issue</p>	<p>When to tell them - at diagnosis or later?</p> <p>How to give information</p> <p>Memory box - collecting life stories/memories - before or after diagnosis or end of life?</p> <p>Young carers - peer education/mentors</p> <p>Loss education for young people - general studies/life skills</p> <p>Recognising significant losses and how bereavement compounds other difficulties</p>
Community	<p>Education in the community</p>		<p>Talking to groups, taking info out to community</p> <p>Lack of knowledge of services</p>

			Perception of services and when to access them Access to self-help, incl internet resources Wide range of 'specialist' support available online
Mental health			Death in mental health hospitals Skills involved in coping with loss Access through different types of service
Thoughts and ideas	Don't over process the process Follow-up from bereavement services Pathway to continue later through the 'journey' University role to educate staff and students in training, esp as death is less common as an experience until later life		

Addressing “the bridge” between hospital and community services: Notes from the Workshop facilitated by Dawn Chaplin, Head of Bereavement Services at Heartlands Hospital, Birmingham, and Vice-chair of the Bereavement Services Association

- Assessing people in the immediate aftermath of a death – can we identify those who may be 'at risk' of difficulties during their bereavement?
- This can be very difficult especially after a sudden death – is it even possible at all at such a time?
- One person [Ros Butterfield Royal London & Barts] is piloting an assessment tool for ward staff to use to try and identify those who may be at risk of complicated grief. Needs education of ward staff for them to be able to use it and it requires them to engage with the patient whilst they are being cared for on the ward. Can be done through conversations while other care activities being done.
- There may be a problem with access to visitors if they live at a distance and visit only once or occasionally. How does one then map the family or assess people one never sees?
- [CMP] The genogram is an essential tool. In his experience most risk factors are pre-existing and known to the family and they can identify who will need help and support.
- A problem in the acute sector is how often people are unconscious when admitted and remain so through a very brief admission.
- [Ann Chalmers] We then have a 'tiny corridor of opportunity' at a time which is just a 'snapshot' of the overall family situation
- Who will do these assessments and how will they be trained?
- In an acute care setting the focus will always be on the patient, especially in an emergency attempting to save the life of the patient. This focus on the patient will be shared by the family but care of the family is important.
- Need to remember the number of agencies with whom the newly bereaved have to have contact. Many of these are during 'the bridge period, Families may find themselves in a twin track process – one dealing with practical issues, the other being their emotional journey.
- Do we/ should we routinely follow up the bereaved at 3 months/6 months? And offer a follow-up contact – give people the opportunity to ask further questions about the episode of care etc?
- Birmingham (Heartlands) considering use of Bereavement Advocates (title not yet settled) – under discussion as to whether paid or volunteers to complement role of bereavement office which by necessity is very practically/procedurally focused. Discussion followed about use of term advocacy – legal model or that envisaged when PALS first established – helping give a voice to those who find it difficult to speak for themselves.
- Discussion about complaints – why the bereaved complain – their experiences and that of the deceased may not have been different from others – but no compensation of recovery – need to seek justice. May be a distraction or a way of avoiding grieving – not letting go.

- We need the feedback of complaints and we need to hear the stories.
- How much is the need for support during bereavement generated by experiences (poor)?
- The context in which information is given is very important in terms of how it is received, both emotionally and retention of content of information.
- [Carol Page] Contact established by acute sector with local bereavement networks allows feedback in both directions and assures community organisations they can raise issues mentioned by clients to them.
- Concern expressed about the time taken for resolution of NHS complaints and the formality of the process especially the way letters are written. The importance of face to face meetings stressed as this allows human engagement.
- One trust had determined to have pro-active disclosure of information to families prior to an inquest – with a principle of ‘no surprises’ for the family at an inquest.
- In many hospices social workers play a bereavement advocate role.
- Remember some families want to plan ahead and obtain information prior to the death.
- Not all acute trusts have any kind of a bereavement service – some leave it to ward staff, others have it as part of the role of a general office/cashier.
- The importance of liaison with other professionals eg funeral directors.
- The importance of the role of GPs.
- Need to educate GPs – involves recognising the pressure on them and the possibility that they may be pressured to use psychological therapies as the default position for anyone presenting with sadness/depression/grief symptoms. Cruse would not cope if they became the referral pathway for everyone as struggling to meet current need.
- When we refer to a service how do we ascertain its quality/evaluate this? Do we have to get into the world of formal commissioning and SLAs if we are going to establish formal referral pathways?
- Do we check that people have acted on the information we have given them?
- Is this even appropriate – maybe just that one simple conversation and knowing that there is a source of help is enough? One episode of confidential listening may be all the support that someone needs.
- Some people may need support for decision-making at key moments
- There are risks for direct referrals from professionals (*can't remember what these were – maybe change of heart by bereaved person; perception of need by professional not shared by bereaved person*)
- [CMP] It is sometimes assumed that people have inner resources – but we do have expertise and should be sharing this and our knowledge of options/choices available to the bereaved
- Time line may expand over many years – one Cruse person had experience of supporting someone concerning a death 65 years earlier
- Problem of Cruse waiting lists – help may not be available at the time that people discover/express their need
- Lack of knowledge of services, variation in opening hours and type of service available
- Suggestion and general agreement that standards/ a ‘kite mark’ for bereavement services with a form of accreditation. How would this relate, could it tie in to funding/resource implications?
- Existing standards have been published – these could be shared – would need to be flexible enough to suit different types of service. To include issues of culture and faith sensitivities in support issues.
- Need to be aware that generic style services may not be helpful to people with a specific faith perspective – should generic services call in an expert or faith specific services be established?

Three summary points from workshop

- 1- learning gained from each other needs to continue (this has resource implications/need for training links etc)
- 2- need for an assessment tool and standardised follow-up protocols
- 3- need for shared standards

	From the plenary Q & As
The pathway	<p>Pathway could be boundless! Can't do everything! Can't be all things to everybody.</p> <p>End of life care is what, exactly?</p> <p>Have to be aware of roles and boundaries and facilitate the journey throughout</p> <p>Flexible pathway; dynamic pathway</p> <p>Has to be clear and plain</p> <p>Bridge should disappear</p> <p>Focus must shift from the NHS to the bereaved after death, and where the responsibility ends</p> <p>Supportive care around the bereaved</p> <p>We must not turn bereaved relatives into a patient</p> <p>But bereaved people may present to their GP at a cost to the NHS; that must be admitted and the need for a continuous bereavement support service recognised - it will make a saving.</p> <p>It is a balance about recognising serious consequences for some people, but that it is a normal experience for the majority of people.</p> <p>This would indicate a risk assessment for bereaved people - an interesting area for this project to think about.</p> <p>And this feeds back into the financing of services.</p> <p>Writing leaflets for people for guidance may not reach those most at need and most troubled, who may well be the one's who don't read them because they are too distressed.</p> <p>Information must be given in different ways, more than once.</p> <p>Everyone comes through the registry or the coroners so there will be an opportunity.</p> <p>Encourage and enable people to carry out some self-assessment</p> <p>Help them flag up their needs to self-refer and empower them to do so</p> <p>Aware of gaps in the community and requests for bereavement support so to improve this visit GP practices, help them set up a bereavement protocol to raise awareness and pick up on people needing help.</p> <p>Could develop a training programme with GP practices: eg four week follow up; local services in place;</p> <p>Produce guidelines, publicise them, share them</p> <p>Not a medical thing - but a time for people to value life and death, which is significant and a spiritual dimension, part of readjusting to life</p> <p>Pathway needs to cover psycho-social-spiritual needs</p> <p>Are we frightened of going into some of these areas?</p> <p>Listening to the client's language, admitting you don't always have the answers but sharing is valid</p> <p>You don't have to be religious to help people with their spirituality - it is about making sense of what is going on for someone</p> <p>Avenues for creativity and restoration?</p> <p>Timing and immediacy</p> <p>The grief story about how somebody died, giving bereaved people the truth and the picture to enable them begin grieving</p> <p>What do they need from us rather than what we can provide</p> <p>Sharing knowledge with people takes a high level of skill</p> <p>Open questions like: is there anything else I can do? Leave the door open</p> <p>Monitoring what's been done - important but rare</p> <p>Important people know they are not alone; others share their experiences</p> <p>People seem more open to asking for help</p> <p>Or do some people asking for help consider it a sign of failure?</p> <p>Men may express emotions through anger not tears - needs to be understood by the person on the receiving end</p>

	<p>Deaths and bereavements for elderly people - do we give these enough care? Just another older person, this is what they say of themselves.</p> <p>How do we promote bereavement care services?</p> <p>More successful at publicity locally - if we only had the money for publicity campaigns</p> <p>Cruse is not well known, death is not a popular subject - what can we do to improve that perception?</p> <p>Cruse service is a bit like the "stranger on the railway train"</p> <p>A one-stop shop, to know what is in your area? A single reference point with all resources open to you?</p> <p>To cover different deaths, different age groups?</p> <p>In terms of good patient and public involvement you would hope this was happening anyway</p> <p>Hospitals like hospices with wards for the dying? Not sure about that!</p> <p>Bereavement now higher on the agenda in the NHS</p> <p>Practical issues - go into the hospital as a wife and come out as a widow; lots to know and much to do</p>
A good death	<p>If you want someone at home, how do you ask, who do you ask if you want to find out more about a good death at home.</p> <p>A "yellow pages" for accessing information</p> <p>9-5 services not good enough - 24/7 and weekends essential to relieve people's stress. Many night-time and weekend deaths.</p> <p>No mortuaries, etc., tasks all left to A&E and dependent on quality/quantity of staff</p> <p>When somebody dies in A&E family should be registered as patients as a practical means of getting them into the system</p> <p>Perhaps there is a need for advocates?</p> <p>How do you find the care you need and want?</p> <p>Provide a room for end of life care, to be alone with family members - that means money</p> <p>What if you have people in bed with sores?</p> <p>It is hit and miss and it is not 9-5, Mon - Fri.</p> <p>A web-based service where people could turn to and get information or ask questions and get answers - that would be useful.</p> <p>Try the Princess Royal Trust for Carers, the Birmingham Trust for Carers - don't reinvent the wheel at any stage but signpost to the best help.</p> <p>Once people go home they feel left - no GP help, no hospital help and it is just the dying patient and the relatives/carers.</p> <p>Give families information as part of the discharge procedure</p> <p>Hospitals can give out packs</p> <p>Huge implications in mapping services, defining what we are mapping.</p> <p>How can hospitals learn from hospices where information before the death is better?</p> <p>For the end of life care vision to have meaning there's a need to differentiate between deaths that are difficult to prepare for and cope with and recognise deaths where one can prepare</p> <p>Emergency services have a role</p> <p>Some diagnoses are terminal, diseases that can only result in death - start from diagnosis</p> <p>The idea that technicalities of intensive care are more important than communicating with families must change.</p> <p>Professionals must assess the importance of what they are doing and find time for priorities, such as breaking bad news.</p> <p>Grieving people remember everything said to them at such times - any kind or helpful word will be remembered with gratitude always.</p> <p>Acknowledge the importance of this - that the psychological operation is as critical as surgery - and professionals will find time.</p> <p>Can volunteers be more involved at a different level rather than post-bereavement? Specifically trained to take someone through their journey rather than busy nurses?</p>

	<p>Discharge staff may be the appropriate people? There's a need to feed back things we hear through our practice. This comes back to boundaries and the roles and responsibilities. Along a journey there will be key areas of expertise and responsibility. Where people say it is not for me to do, they signpost you on. No dead ends!</p>
<p>Business case</p>	<p>Complaints often come from bereavement situations - hospices are much better: more resources, teams for a "good death"; not so easy in an acute hospital Face to face can be expensive and time-consuming</p> <p>Getting professionals involved and doctors involved and getting them to see the strengths and wins from attending bereavement groups and networks. Would CPD credits help here? Invite doctors to their own special separate meetings? Need to convince doctors that death isn't a failure but a common outcome in hospital.</p> <p>Savings to be made in terms of money, complaints, inquiries, investigations, etc. when things go wrong Information is important because anger leads to complaints, and anger may be justified, not just a grief reaction Investing time and information in helping people can save a lot Management of anger can be seen as a service and a business case and cost benefit. Sudden death is an important area. Training and resources will support the bridge Setting up information/support services is relatively cheap - a good selling point What things go wrong with enquiries and risk assessments - feedback and monitoring of complaints needed; positive feedback too and reasons why something worked well; look at the successful experiences.</p> <p>Child Bereavement Charity has funding for a resource pack for A&E units to address needs of children bereaved in these circumstances, and for intensive care when a parent or sibling dies and where children are concerned. Every A&E and ITU, and there is also training available.</p>