

## **The Bereavement Pathways Project - national survey**

### **Introduction**

In 2001, the Department of Health (DH) carried out a survey to ascertain the level of bereavement services being provided in NHS Trusts, with an 84% response rate.

In 2005, a second survey by the Department of Health sought to build on that information and had a 25% response rate. It focused on the extent of bereavement services, how they are staffed and how they fit into the overall provision of service across a Trust.

This work was part of a continuing initiative by DH to develop bereavement services in line with the Chief Medical Officer's recommendations on the retention of organs and tissues following post mortem examination.

### **Key messages from 2001 survey:**

- All Trusts provide some support to the bereaved in some form but the extent varies.
- More training in basic bereavement awareness and communication skills desirable.
- Need seen for national "guidelines" on provision of bereavement services.

### **Key messages from 2005 survey:**

- Over half of Trusts responding have a bereavement service in place with at least one member of staff and one dedicated room for the service. 12% of Trusts have a Specialist Bereavement Centre.
- Most Trusts now provide written information of some sort, e.g. to signpost other services in the voluntary sector/wider community.
- Training is now provided in the majority of Trusts, but the form and who receives it varies widely.
- One third of Trusts with a bereavement service in place deal with consent issues around organ donation or post mortem.
- Two thirds of Trusts provide one to one support and formal counselling for staff. Roughly half of Trusts provide one to one support for bereaved people and one third provides formal counselling for bereaved people.
- Although not widespread, a number of Trusts operate bereavement forums, groups or committees, some being multi-agency.

### **Key messages from 2008 survey:**

- Bereavement care is integrated into hospital structures in over two thirds of hospitals
- most hospitals provide information about bereavement support in the community
- The area of assessment needs further exploration
- Referral and follow up procedures are very patchy and need development

### **Context**

It is clear that a picture emerges about bereavement services in the NHS. Any attempt to interpret the results of these surveys is biased, and we recognise designer bias as well as interpreter bias. Designer bias in terms of the form, shape and content of the questionnaire for 2008, since the 2001 and 2005 were produced within the DH and the 2008 survey was produced by a bereavement practitioners' operative at the coalface in the NHS and as part of the Bereavement Care Pathway project (a joint venture between BSA and Cruse funded by the DH).

It is possible to provide a degree of comparison between the 2001, 2005 and 2008 surveys but inevitably there are restrictions due to the areas covered in those surveys and there was no attempt at the design stage of the 2008 survey to map on to or

replicate the 2001/2005 studies. The comparison figures that do emerge provide a helpful snapshot about bereavement services from which general trends and ideas can be drawn and deduced. It appears that a picture emerges of bereavement care becoming more of a structural entity within the NHS framework. In about 2/3rds of hospitals that development is quite advanced while the other third require further consolidation to allow for all hospitals to address bereavement needs adequately and consistently. The whole area of assessment, referral and follow up for support is much more underdeveloped and requires definition and development.

The 2008 project was clearly designed within the parameters of the bereavement care pathways project which the DH funded, enabling BSA and CRUSE to work on developing such a pathway. It is acknowledged that certain critical aspects needed to be included within the survey to enable collection of data around specific areas that may influence the direction of the project.

Finally it is recognised that in the last seven years the whole area of bereavement has become more acceptable within society, and politically the topic has received significant attention along with the accompanying resources. The DH guidance, 'When a patient dies: Advice on developing Bereavement services in the NHS' (2005) was published and has become the standard to measure services against. The Retained Organs Commission and its associated influences have impacted on NHS practices and procedures considerably in how the bereaved are handled and the associated issues of post mortem and tissue donation consent. The recent End of Life Strategy reinforces the importance of this whole arena.

The 2008 survey was sent to all acute NHS hospitals in England with a 32.12% response rate. The questionnaire was divided into seven sections with the first part collating data about the hospital, i.e. its name, size, how many sites and its specialities; in addition the profile of deaths was also sought.

Section two explored the area of post mortem examination; the first part asked how many deaths were referred to the Coroner each year, how inquests occurred and what support was available to people awaiting inquests. A very varied picture emerged, with 40% of respondents having only one inquest.

The second part focussed on hospital (consented) post mortems with a 54.7% response for up to 10 post mortems per year which shows the very low levels that have emerged consequent upon Retained Organs Commission. The largest single group of people seeking consent were the doctors (38.8%) with bereavement services requesting only 8.2% and mortuary staff 4.1%.

The training in obtaining consent to post mortem is very patchy with 44.4% claiming only in-house training and experience, while 22.2% had none and 20% suggesting that such training was part of doctors' general principles at induction.

The effectiveness of such training in seeking consent is only monitored in 33.3% of cases while the actual process of obtaining consent is only monitored in 45.7% of cases. These findings reflect that this whole area is in need of further development and exploration so that the factors that have hampered the levels of response to PMs within hospital are realigned to current needs. The public have responded to the matter with a major reaction against such consents. At the same time many teaching hospitals are aware of the impact this has had on training medical staff and are providing opportunities for clinicians to learn more of the pathology of diseases.

Section three focussed on the area of policies and procedures, and the picture given here was positive and encouraging. 55% stated that there was a bereavement policy in the hospital which had been ratified by the Board, this contrasts very clearly with only 27%

in 2005. The question about Standard Operating Procedures (SOP) relating to deaths gained 94.6% response with 91.1% stating there was an SOP relating to post mortem consent. This is an indication of the impact clinically of the Human Tissue Authority's work and the issues raised by the Retained Organs Commission., showing the transformation that has occurred.

A similar change is discerned with end of life pathways, with 78.4% having implemented the LCP and a further 19.6% having implemented a Trust specific end of life care pathway.

80.8% of hospitals said they have a designated bereavement service with 47.8% acknowledging that bereavement care is audited, which is a very positive picture and is evidence of a development from 2005 when only 67% had such a service. It is indicative of the structural integration that is evident for bereavement care.

Staffing since 2001 within bereavement has developed significantly with only 15% claiming to have full time staff in bereavement care at that time. That figures grows to 38% in 2005 and becomes 67% in 2008. There has clearly been a change in this area and hospitals have chosen to resource such a service and while the picture of how many staff are involved is more complex, nevertheless this initial finding shows significant progression.

Another very positive feature emerged with 70.2% claiming that there was a regular forum for the discussion of bereavement matters within the hospital. This again shows a clear development of practice as 2001 data records only 10% as having such a forum and in 2005 the figure is 40%. Obviously this shows a growing level of collaboration and cooperation across the various sectors of the hospital life that are associated with the bereavement agenda.

The bereavement process in hospitals appears to have developed significantly over recent years with a greater profile evident. Several indicators as mentioned above have changed dramatically in that regard. Comparison with the 2001 survey shows the clearest evidence of such developments.

#### Assessment, referral and follow up (section five)

The topic of assessment in relation to bereavement support is a factor that needs further discussion since only 36.2% have an assessment procedure. The picture that emerges seems very sketchy and incomplete.

It is also recognised that 38.5% of relatives are routinely followed up, and 42.1% of those followed up are done so within six weeks of the death. This is an interesting insight especially since there has been a connection made between bereavement process and the complaints. In a recent report, The Healthcare Commission highlight that care surrounding the death of a patient is one of the most common themes (making up 54%) of complaints about hospitals. This whole area deserves significant attention so that relatives feel supported following a death. It is acknowledged that hospitals clearly see the need for people to have accurate information given to them before they leave about the facilities for bereavement care but find the whole agenda beyond that point unclear. There was a staggering 91.7% stated that they provide information about bereavement services in the community to relatives. It would appear that this is the dominant method of providing support to the relatives.

Referrals to other outside agencies are low and interestingly it was noted that some 41.7% of those referred would be by means of self-referral. This needs to be set alongside the whole dimension of assessment and the paucity of any tools or aids in that realm at present. It is difficult to discern the relevant factors in this arena and it must be that perhaps people have given little thought to the levels of support and follow up that are necessary and relevant.

In the 2001 findings some 18% claimed to do some degree of follow up with the bereaved and that figure changed in 2008 to 38%. This is significantly under developed in the light of the fact that 54% of complaints are linked with bereavement. There is also a need for some clarification of thought here because of the difference between 'follow up' and 'counselling'. Lack of clarity and differentiation abounds with the levels of need requiring some deciphering and ordering. Some current practitioners would work on a split of 85% of people needing basic care and support, with 10% needing some form of counselling for a period of time, while 5% require specialist help from mental health services. The fear for many provider units is the whole area of psycho-social-spiritual care which appears like an enormous area which might consume major resources. It is unclear how those needs might be met and is it the place of acute care providers to do that in any significant way? It is not that staff are unresponsive to the needs of people who are grieving but they are unclear about the degree or quantity of resources that should or could be made available to such people. It is a situation of the unknown and the unexplored being seen as difficult and therefore not addressed. There is a lack of clarity around the whole differentiation between counselling and pastoral care. The former being structured bounded and task focussed while the later is more informal, ad hoc and responsive to needs. (See Gordon Lynch)

Finally a question was posed about how far has the guidance "When a Patient Dies" (October 2005) been implemented. 23.4% said it had been fully implemented, while 70.2% noted it had been partially implemented.

### **Conclusions**

It would appear that bereavement care in the NHS has come a long way in the past decade. There are however still some hospitals that need to catch up with recent developments. Others hospitals have made progress and they need to carry through some aspects of follow up care that would impact people recently bereaved. There is a need for some clear definitions and demarcations in this sphere which will provide a measure of clarity and understanding. When pathways are provided with the relevant and appropriate parameters established then adequate resources can be applied to this dimension of care.

A bridge, as that suggested by the pathways project, between the Voluntary-Community-Faith Sectors and the NHS seems vital as a way of enabling bereavement care to be sustained and accessible for all in the community. It would also allow for a continuity of care to be provided and the seamless service between acute and community to be more clearly developed.

There appears to be a lack of assessment with little follow up or follow through in terms of how care for the bereaved is provided across a spectrum of responses.

In summary the study of 2001 provides a picture of bereavement care as a patchy service while 2005 study shows changes emerging. The 2008 study categorises areas of progress and those which require fuller consolidation. The whole area of assessment, referral and follow up needs significant development which may be the logical sequence to the structural changes which have been implemented over the past 5 years. The service needs now require for that consolidation to be developed and some definition given to the whole area of follow up and after care following a death.

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Cambridge August 2008

## **The Bereavement Pathways Project National Survey – findings**

### Section 1 – About the Trust

Neonatal deaths (0-2 years): 50.9% had between 1 and 40 neonatal deaths per year.

Child deaths (2-18 years): 45.3% had between 1 and 10 child deaths per year.

Adult deaths: 34% had 501-1500 adult deaths per year, with 34% having 1501-2500 deaths.

### Section 2 – Post mortem examinations

Coroner referrals: 24.5% referred up to 200 deaths to the coroner each year, while 43.4% referred 201-800 deaths.

Of all the deaths referred to the coroner, only one death per year resulted in an inquest in 40% of cases.

Hospital (consented) post mortems: 54.7% conducted between 1 and 10 post mortems each year. In 38.8% of cases, consent is obtained by a doctor.

When asked about what training in obtaining consent to post mortem is provided, 22.2% reported no training was provided, 20% trained doctors in general principles at induction, and 44.4% provided in-house training and experience.

Is effectiveness of training in seeking consent monitored? Yes 33.3% No 66.7%

Is the process of obtaining consent monitored? Yes 45.7% No 54.3%

### Section 3 – Policies and Procedures

Does the Trust have a Bereavement Policy ratified by the Board? Yes 54.9% No 45.1%

Is there a Standard Operating Procedure relating to death and the provision of bereavement support for specific areas in the Trust? Yes 94.6%

Is there a Standard Operating Procedure relating to post mortem consent:  
Yes 91.1% No 8.9%

Is there a Standard Operating Procedure relating to organ and tissue donation:  
Yes 84.8% No 15.2%

Has the Trust implemented any specific end of life care pathway?  
Trust-specific 19.6% LCP 78.4%

Is bereavement care in the Trust audited?  
Yes 47.8% No 52.2%

### Section 4 – Staffing and Service Issues

Does the Trust have a designated bereavement service?  
Yes 80.8% No 19.2%

Is there a bereavement manager/head of bereavement services?  
Yes 67.3% No 32.7%

Does the Trust have bereavement administrative officers?

Yes 78.9% No 18.4%

Are there volunteers?

Yes 27.8% No 72.2%

Is there a regular forum for discussion of bereavement matters?

Yes 70.2% No 29.8%

#### Section 5 – Assessment, referral and follow up

Is there an assessment procedure in place to identify people who may require bereavement support?

Yes 36.2% No 59.6%

17.4% of these assessments are carried out by a nurse.

17.4% of these assessments are carried out pre-death.

Is there a specific format used for the assessment?

Yes 21.7% No 78.3%

Are bereaved relatives routinely followed up?

Yes 38.5% No 61.5%

Follow up is performed by:

Card 10% Letter 15% Telephone 20% Combination of these 55%

In 37.3% of cases, follow up is done in the six week period following death.

Is information about bereavement services in the community supplied to bereaved relatives?

Yes 91.7% No 8.3%

Is there a referral process in place to refer relatives to voluntary support agencies?

Yes 39.6% No 60.4%

41.7% of these referrals are self-referrals.

#### Section 6 – When a patient dies

How well would you say that the advice document 'When a patient dies' has been implemented in the Trust?

Fully 23.4% Partially 70.2%