



Bereavement Pathways Project

Bereavement Pathways in the Community Consultation Paper



This paper is intended as information and consultation for services providing bereavement care in the community.

The Bereavement Pathways Project is a 3 year Department of Health funded joint initiative from Cruse and the Bereavement Services Association. It started in April 2007.

Project objectives

- To establish a key partnership between the NHS and the voluntary sector by linking hospital-based services, particularly those in acute trusts, with those based in the community which provide a range of services, including longer term support for bereaved people.
- To increase access to services for bereaved people - however a death occurred, whoever they are and wherever they died.

Background

The key Department of Health advice document "[When a Patient Dies](#)", has contributed significantly to the development of bereavement services within the NHS by highlighting areas of good practice, and it is anticipated that the development of an effective bereavement pathway will illustrate additional good practice within the voluntary sector. This may lead to additional recommendations to support closer and more effective working across all sectors; thereby providing both an overview of the current awareness of guidance in the NHS and community bereavement services, providing an evaluation of the impact and implementation of those guidelines across all sectors, and enabling further demonstration of good practice to be highlighted, and possibly incorporated, in any future Department of Health advice.

By "bereavement care in the community", we mean bereavement services (information, advice, support or counselling) provided by voluntary organisations, faith groups, hospices, and statutory health and social care providers, outside a hospital setting.

Policy Background

The project has started during a period when a number of key developments for bereaved people are under way, notably recent work on the Department of Health End of Life Care Strategy, which encompasses bereavement care. Although the finalisation of the Strategy has been delayed, it has resulted in a request to Strategic Health Authorities that they set out *their vision for a world class service across eight areas of care. One of these is end of life care ...*¹

Other current key policy processes with potential for improving bereavement care include Coroner reform, the revision of procedures for death registration, and the Department for Work and Pensions *Tell us Once* Project.

¹ Letter from Mike Richards, National Cancer Director, 5 October, 2007.

Proposed Essential Features of a Community Bereavement Care Pathway

- 1. The Pathway should contribute, with the care provided by NHS Hospital Trusts, Hospices and Care Homes to the support and development of the following for bereaved people:**
 - Information about the death and the surrounding circumstances
 - Information about bereavement reactions, to support their understanding of what is happening to them
 - Information about the official processes surrounding death and support (if required) in dealing with them
 - Support in meeting the requirements of religion, culture, community or personal beliefs
 - Support with any individual needs which influence access to help
 - Emotional support
 - Bereavement counselling if required
 - Helpline support
 - On-line support and information
 - Consistent service standards across agencies
 - Referral and information systems to facilitate the provision of support across geographical distance and boundaries
 - Appropriate assessment and access to clinical services if required

- 2. The Pathway should be relevant to all bereavement services provided in the community, whether the provider is located in the voluntary or statutory sector.**

- 3. The Pathway must be flexible enough to accommodate a wide range of needs, and must support the clear identification of responsibilities for the care of bereaved people.**

The range of needs to which community-based bereavement services may need to respond is wide. The mix is individual in each case, and will be affected by the bereaved person's personal circumstances, including gender, ethnicity, sexuality, family, and social network. The mode of death giving rise to the bereavement, the response of others, and dealings with official agencies, will also be significant. Bereavement services need to be able to respond to needs already identified during an End of Life Care Pathway, as well as to those which arise unexpectedly. For some bereavements, services will need to be able to respond to clients who have had no opportunity to prepare; for example, those bereaved by:

- Unexpected death from natural causes
- Death on the road
- Suicide
- Murder and manslaughter
- Work-related deaths
- Events involving multiple deaths – natural disasters, acts of terrorism, crashes or accidents, pandemics²

² As all statutory and many voluntary community agencies are already involved in extensive planning for terrorism and pandemics, it is not proposed that the project will focus on the dedicated response to these events, although there will be similarities in the need for inter-agency co-operation, and learning which can be applied.

Some bereavements may be particularly complex, including those where, for whatever reason, the griever is disenfranchised because a significant relationship has not been recognised by others. Often, it is the case that a key skill for those providing bereavement support in the community is the ability to “work with the bereaved stranger”; a person in crisis walks through the door, and support has to be provided with of no knowledge of how s/he previously functioned. This may occur even in hospice-based bereavement services, as family members needing bereavement support may not always identify themselves before the death.

4. Building links

The project partnership has been formed because of the large number of deaths which occur in hospital settings. *When a Patient Dies*³ acknowledges that some Trusts offer follow-up contact to bereaved people, although it also warns of the need to be sure that adequate resources are in place, before doing this. This is one reason why links with community bereavement services are particularly important.

The same document advises Trusts to compile and keep up to date a directory of bereavement services in their area, a task now supported by the publication of the *Directory of Bereavement Services in the UK*.⁴ It is clear that national as well as local information is required – for example, adults whose parent has died comprise a third of the longer term caseload of Cruse Bereavement Care; many of these people will not live in the area of the Trust where the death occurred.

Bereaved children and young people

The Bereavement Pathways project is funded under the Adult Mental Health funding stream. However, it would not be appropriate for any Care Pathway to ignore the needs of children and young people – through Cruse membership of the Childhood Bereavement Network, and through the comments of local practitioners dealing with both client groups, we aim to ensure that this aspect is appropriately covered and /or the relevant links made. These will also be fostered through relevant established local bereavement forums.

5. The Role of Community Bereavement Organisations in Developing the Pathway

Cruse and the BSA are conscious that in asking anyone for their contribution to the project, we may be asking for work to be done by very hard pressed people, some of whom are volunteers. We hope that community bereavement organisations will find it worthwhile to contribute.

As the project progresses, we will be building a library of relevant protocols and other materials; one purpose of this consultation is to ask colleagues whether there are any which have been found to be particularly useful, and we hope you will be able to help us.

³ Department of Health, October 2005

⁴ Obtainable from ris.org.uk, and published by Cruse Bereavement Care, Help the Hospices and Resource Information Service, 2007.

We would be very interested in comments from community bereavement services on any aspects of the project, and particularly, at this stage, in the following:

- Does your service agree with the proposed essential features of a community bereavement care pathway?

Response:

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- Comments on the issue of standards in community bereavement care

Response:

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- Examples of good liaison between a community bereavement service and the NHS

Response:

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- Comments on referral procedures – e.g., whether services take consented third-party referrals, or self-referrals only; comments on how well the system works, etc.

Response:

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- Suggestions as to how we may all work together to make it easier for bereaved people to seek help when they want to do so – soon after the death, or later

Response:

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- Comments about your experience of using risk assessment procedures, especially any which you have found particularly useful in working with bereaved people who have not been involved in pre-bereavement planning of services

Response:

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- The role and benefits of established local bereavement forums

Response:

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- The role of the GP, to whom many bereaved people turn for help

Response:

Anne Viney
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Cruse Bereavement Care
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