





# The Bereavement Pathways Project: 'Bridging the Gap'



between the time when patients die in the health care sector until they find bereavement support the community

Bereavement Services Association  
and

Cruse Bereavement Care

# Bereavement Pathways Project

## The Background

- Department of Health 3 year project
- Mapping the bereavement journey
- Researching how it works
- 'Bridging the gap' NHS acute hospitals and voluntary bereavement services
- Cruse and BSA in partnership

# Cruse Bereavement Care

Cruse is the biggest bereavement charity in the UK and it's for everyone; services include:

- One to one, face-to-face bereavement support and advice
- Telephone and email support
- Support groups
- Written information / literature
- Website information – [www.cruse.org.uk](http://www.cruse.org.uk)  
- [www.rd4u.org.uk](http://www.rd4u.org.uk)
- Training and consultancy services
- Awareness-raising and working with government on policies

# About Cruse

'Cruse Bereavement Care exists to promote the well-being of bereaved people, and to enable anyone bereaved by death to understand their grief and cope with their loss'

# Bereavement Services Association

- National network for professionals providing bereavement support services
- National forum for discussion and training, particularly in the NHS
- Contributes to the improvement of the quality of bereavement services nationally

[www.bsauk.org](http://www.bsauk.org)

# Key Aims for the project:

- To improve partnership working between the NHS and the voluntary sector
- To map existing service provision both sides of 'the gap'
- To establish clear pathways for bereaved relatives and friends
- To develop up to date information on NHS, Voluntary and Community Sector and Primary Care bereavement services

# Importance of good Bereavement Care

- May be a valuable early intervention
- May avert mental health problems including clinical depression and PTSD
- May avert physical illness
- May enable people to remain socially engaged and economically active
- May avert formal complaints
- It is a hallmark of a caring society

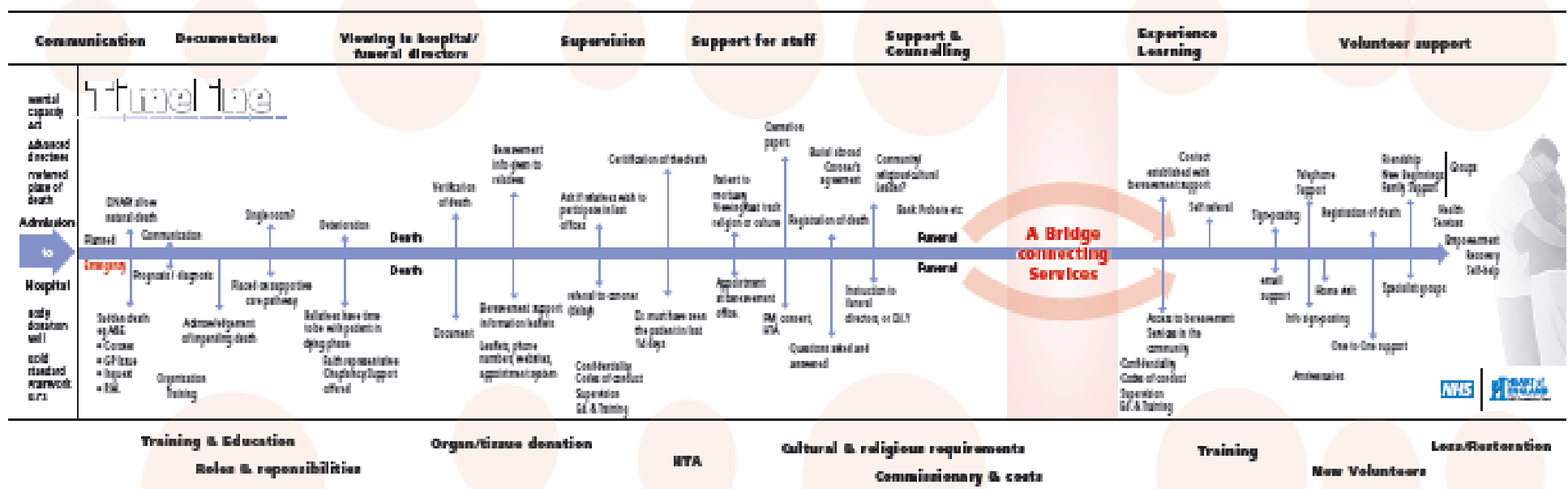
# Some background information

- 60% deaths occur in hospital
- 50% hospitals now have a formalised bereavement service
- Healthcare commission – 'spotlight on complaints'
- 60+ % ref to Cruse via GP/health professionals
- NICE and other national guidance

# Primary objective

To provide the right care, support and information to the right people, by the right people, at the right time

# Bereavement Pathway



(Good quality version available online at [www.cruse.org.uk](http://www.cruse.org.uk) – via front page link to Bereavement Pathways Project)

# Progress to date:

- Effective partnership and steering group established
- Two national stakeholder events B'ham / London
- Local networking days for fact-finding in Hertfordshire and Cornwall
- Pilot sites identified
- Bereavement Support Volunteers - local project in Birmingham hospitals
- Mapping of NHS & VCS services in Gloucestershire
- Research into why people seek help and how they find it
- Research into innovation and good practice
- National survey of NHS Bereavement services in acute hospital trusts

# Headlines from the 2008 NHS bereavement survey by the Project:

- 165 hospitals – 56 responded (32%)
- 81% designated bereavement service
- 64% Designated bereavement manager
- 40% Audit bereavement care
- 81% information on community services
- 8% bereavement assessment
- 28% follow up

Key finding: Poor assessment, little follow up, little follow through

# A Pilot: the Heart of England Foundation Trust, Birmingham

- 4,500 patient deaths each year
- Range of ages, causes, and end of life and bereavement expectations and requirements
- Centralised service with dedicated staff
- Information written and verbal
- Guidance on what happens next
- Open door policy

# But some gaps...

- No follow up
- No on going support
- No assessment
- No referral process
- Little joined up working with community voluntary sector

# The Birmingham pilot plan

- First national pilot site
- HEFT and Birmingham Cruse
- Bereavement Support Volunteers from the hospital trust
- In the bereavement offices across three hospitals
- 'At' and 'after' service
- Training and supervision
- Hospital volunteers; Cruse training and supervision

# Focusing on the 'Gap'

- Users' views
- How and why people 'bridge the gap'
- Questionnaire in bereavement booklets
- Complaints
- Meetings with bereaved relatives and friends
- Feedback from stakeholders and practitioners at networking events

# Cornwall – early proposals from the networking event

- A Bereavement Services Co-ordinator for Cornwall
  - Some good services across the community – need better links
  - Poor communication between / across organisations
  - Large rural county
  - Fluctuating seasonal population

# Some comments from bereaved people

- Staff should be trained in end of life care, including bereavement
- There is poor communication/information
- Need to use plain language for advice
- Need for care and compassion
- 'someone there to explain things rather than busy staff'
- Someone to sit, talk and listen
- Help in the hospital and help at home

# Challenges

- Sharing good practice and working across boundaries
- Infinitely variable circumstances
- Identifying and assessing those in need of help
- Resources and funding
- Identifying who are the bereaved
- Reliable and consistent minimum standards

# Some solutions

- Networking, sharing good practice, exchanging experiences
- Right information, right time, right people
- Opening up debate – breaking down taboo

# Potential Risks

## Caution

- Risk of fostering dependence
- Risk of disempowering the bereaved
- Risk of medicalising bereavement
- Risk of overwhelming VCS

However,

at present not identifying / assisting a small minority of bereaved who may benefit from appropriate intervention

# Remember:

'The experience around the time of death and afterwards can influence grieving and the longer term health of bereaved people'

**When A Patient Dies 2005**

# Dignity in death is important for bereavement:

*'How people die remains in the  
memory of those who live on'*

Dame Cicely Saunders Founder of the  
Modern Hospice Movement

