

Findings from the Bereavement Pathways Project networking event held in Cornwall, 9 December 2008

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| What we do | Provide breaks for bereaved families Offer one week/short breaks for bereaved at cottages at Marazion The project is open to families from all over the country (national charity), plus Cornwall | Sandrose Project |
| | Currently looking at support at time of death and after; listen, answer questions, give information | Glencoe Nursing Home |
| | Support for parents after losing a baby in pregnancy with befriending, telephone, annual baby loss event, focus groups, children's gardens of remembrance at county's two crematoria, public awareness, listening ear even years later | Forget me not |
| | Pre and post bereavement care with 20 volunteers; telephone and one to one support, group work, letters, anniversary cards, staff training/workshops, volunteer training, ongoing training; post-death information; literature; family support team | Cornwall Hospice Care |
| | Listen and let callers cry and talk about their loved ones | Samaritans |
| | Working with families to design a ceremony that they want, including working with them on text, etc. | Humanist celebrant |
| | Team of volunteers signposting pre and post bereaved adults; initial training, on-going workshops and supervision under our BS Team Co-ordinator, who is employed by the Hospice. Clients initially referred by nursing staff. Telephone contact and group support helpful. | Mount Edgecumbe Hospice |
| | Emotional support and practical help and info for family and friends of victims of homicide in Cornwall, from immediately following the incident for as long as needed; also support for bereaved through legal processes and courts. Trained volunteers with professional experience. Aim is to listen and signpost | Victim Support |
| | Children's bereavement service for the county (300 referrals March 06-07) for children 4-18 and parents/carers. Limited pre-bereavement support; post-bereavement 1:1 plus groups; website, helpline, library, publications; family handbooks. Teenagers' group held monthly in Redruth. Training for professionals, community groups, parents, volunteers in "Childhood Loss and Grief" to Levels 2 and 2. Work with emergency planning. Social activities; member of Child Bereavement Network to effect change nationally; supporting funeral directors countywide. | Penhaligon's Friends |
| | Royal Cornwall Hospital and West Cornwall Hospital - bereavement service providing admin and emotional support and advice to relatives and friends of patients who have died at either of the two hospitals; a full bereavement and viewing service with trained staff; refer on to other agencies; advice and support on all aspects of after-death care for those bereaved by our hospital patient deaths. | Bereavement Care Co-ordinator, RCHT |
| | Bereavement counsellor providing service for those bereaved by patients who have died of cancer | Specialist |

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| | | Palliative Care |
| | Helpline, befriending, leaflets, there to help extend services | Foundation for Study of Infant Deaths |
| | Bereavement counselling and support for those bereaved by suicide; group in Truro | Independent bereavement counsellor |
| | Domiciliary care support to people in their own homes. Six internal agencies across the county; anyone over 18 supported with personal care, relief care, all client groups and disabilities; currently support bereaved carers in a very minimal way. When cared for person dies, provision usually ceases so carer loses link with services and staff who have become familiar with them. Training limited to loss and bereavement via inhouse training department. | Cornwall County Council |
| | Support for parents who have lost a baby in pregnancy - telephone, groups, one to one (repeated I think) | Forget me not |
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| What works | Macmillan and hospice run support groups for 6-8 weeks | |
| | Pre-bereavement for families, patients and carers as well as post-bereavement | |
| | Help for children pre and post-bereavement | |
| | Assessment by professional, pre and/or post-bereavement | |
| | Volunteer support workers in hospice pre and post-bereavement | |
| | Support for children in Cornwall | |
| | Support given when patients seen by hospices and by Cruse when available | |
| | Spiritual support , eg service in chapel every few months for relatives recently bereaved | |
| | Training staff to provide help and support to clients and their families whilst receiving care | |
| | OASIS (counselling service) | |
| | Buddying system (St John's) | |
| | Sitting, listening, talking | |
| | Giving people an opportunity to express themselves (light a candle, put a message on a commemorative tree, collect together good memories, etc) | |
| | Understanding what the funeral directors do | |
| | Practical information - what's needed written down, eg phone numbers, what is required to do, etc. | |
| | Funeral arranges give/provide written information; providing all info/references needed | |
| | Advising people that how they feel is normal | |
| | Talking, smiling, being there | |

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| | Understanding funeral choices available - service, music, poetry, etc. | |
| | Cruse, Penhaligon's Friends, hospital chaplains and vicars, helpful registrar's office, funeral directors | |
| | Liverpool Care Pathway for expected deaths | |
| | Access to Macmillan team counsellors | |
| | Macmillan nurse follow-up at 6-8 weeks | |
| | Bereavement booklets | |
| | Independent funeral advice at Penmount Crematorium | |
| | Referral to Cruse, SANDS, Forget-me-not, Penhaligon's Friends, etc. | |
| | Memorial advice | |
| | Staff available just to talk to and listen | |
| | Useful literature offered | |
| | Two private interview rooms | |
| | Awareness of good work/practice going on | |
| | Good supporting and training in existing organisations and for the volunteers | |
| | Penhaligon's Friends unique to Cornwall | |
| | Treliske has a dedicated bereavement team | |
| | Cornwall is open to innovation and change! | |
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| What doesn't work | Bereavement support is tokenistic in NHS as no on-going care supplied or offered | |
| | No bereavement support except for one visit or phone call post-death; left to GP thereafter | |
| | Lack of knowledge and knowing what services are available | |
| | Inadequate training for GPs and practice counsellors in bereavement awareness, particularly with children | |
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| What's missing | Counselling, especially for those with complicated grief - more counsellors needed | |
| | Bereavement services often not supported by statutory agencies | |
| | Education for providers | |
| | A co-ordinated service; good information; what's available | |
| | Good information on grief | |
| | A bereavement pathway with easily accessed info on support given to the bereaved | |
| | Pre-bereavement care for whole families | |
| | 3-tier approach; NICE guidelines | |
| | Little support for those bereaved by traumatic death - accidents, suicide, murder | |

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| | On-going support | |
| | Library service providing easy access to up to date books on grief | |
| | Guidelines for good practice and services for adults bereaved | |
| | Networking | |
| | Bereavement care and counselling for families | |
| | Clear information for bereaved families and what support is available | |
| | Clearer information for support for bereaved children | |
| | Continuing aftercare with contact, phone, coffee, card, invitation to remember, and other opportunities | |
| | More overt information about funeral services and options, eg humanist, christian, gravestone, cremation, woodland, etc. | |
| | Bereavement groups at GP surgeries | |
| | Remembrance services at Christmas | |
| | Permission to be a non-christian at time of death when all around you expect C of E committal. | |
| | Better communication about bereavement, that it is not “catching” and it is safe to mix with bereaved people | |
| | Training | |
| | Identification of skills required | |
| | Assessing/reviewing skills and good practice | |
| | Correct signposting and “open places” - eg drop-in for tea coffee and chat (funeral directors?) | |
| | Need to manage the “space” between having family and support and after it’s all over | |
| | Co-ordinated Countywide bereavement service | |
| | Clarity about provision at time of bereavement and signposting to the most appropriate organisation/service | |
| | Joined up signposting, eg. funeral directors, GPs, professionals, support groups, churches | |
| | Old-fashioned community | |
| | Breaking down barriers and preconceived ideas about death, hospices, church, religion, etc. | |
| | Better trained clergy at funerals | |
| | National advert: bereavement is not infections! to break down barriers | |
| | Follow-up beyond death | |
| | Training for hospital staff | |
| | Co-ordination between services | |
| | GP follow-up | |
| | Help and support during time between death and coroner inquest | |
| | Funding and resources | |
| | Information on who does what and clear signposting | |

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| | Just who are the bereaved? Including staff and care workers? | |
| | Funding across the board | |
| | Equitable provision of services across the county | |
| | GP involvement and training | |
| | Medical training in general | |
| | Holiday-makers / retired people left without support | |
| | Recognition that Cornwall is a deprived county - nowhere to ask for financial help with funeral, headstones, etc | |
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| What's needed | Equity of service, whenever and wherever the death occurs from whatever cause | |
| | Equity of service for many who don't access hospice care or die at home | |
| | Support and guidance from staff for patients in non-hospice settings/care | |
| | Pathway to offer bereavement support | |
| | More written, oral and online support for bereaved people | |
| | Up to date electronic information on bereavement, support, services, local and national | |
| | Better training for volunteers and professionals to be informed on available services | |
| | Clearer understanding by referral agencies about services so families can benefit at right time and with right support | |
| | More support for families with S&TD | |
| | Communication | |
| | Education | |
| | Access to services | |
| | Designated phone line and co-ordinated service | |
| | More contact with others who offer support | |
| | Sharing of resources regarding spiritual support and a "community chaplain" that community staff can call on | |
| | Provision of facilities for bereavement support in an emergency, ie humanitarian assistance centre | |
| | Do not choose to protect me from further grief - ask me and let me choose for myself | |
| | Gold Standard Framework for care homes and advanced care plans | |
| | The spiritual and emotional at end of life as well as the clinical and the medical | |
| | Talking to people and asking what they want | |
| | Helping families and individuals, including children and grandchildren | |
| | Give families a support pack - signposting, leaflets | |

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| | Advanced care planning | |
| | Gold Standard Framework | |
| | GPs focused on practical issues | |
| | Closer links in primary care with family and friends | |
| | Training for GPs in bereavement process and signposting | |
| | Space/rooms for privacy | |
| | Standard of follow-up to be equitable | |
| | Better co-ordination/communication between agencies | |
| | More information (social services/CAB) on benefits, council tax advice, etc. | |
| | QOF points for bereavement | |
| | Access to high level counselling (eg Macmillan counsellors to wider population) | |
| | Practice manager key role - contact after death and packs for bereaved people with info and contacts | |
| | Improved staff training, particularly junior doctors | |
| | A care pathway for unexpected deaths standard across Cornwall | |
| | Reducing waiting lists - more immediate responses | |
| | Pre and post-death support in hospitals - training, staff confidence, staff competence | |
| | Ward-based information packs (eg, availability of a humanist chaplain) | |
| | NHS - evidence of support and how it is done | |
| | Info in schools - for staff to offer support in familiar setting | |
| | Differentiate between various bereavements - at home, in hospital, S&TD, etc. | |
| | Different pathways for different types of death | |
| | Patient and carer support at diagnosis | |
| | Education - for children and others, that death is part of the life cycle | |
| | Awareness training for care staff in homes and community to give them confidence and to do what's needed | |
| | Bereavement support volunteers in the community at end of life | |
| | Centralised co-ordination | |
| | Market-place meetings regularly (like the Bereavement Awareness Day held in Hertfordshire) | |
| | Avoid duplication of services | |
| | Dealing with practical issues in the hospital - parking, communication. little things that complicate life and grief | |
| | Pre-bereavement support to prevent isolation - not necessarily long-term | |
| | Information points in one stop shops and hospitals | |
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| Good practice & innovation | The Samaritans | |
| | The integrated discharge model | |
| | Buddying system and membership support system | |
| | Support for people in their own homes, their safe space, where appropriate - only three specialists in County | |
| | Funeral directors and crematoria providing assistance and support | |
| | See what works well | |
| | Wolverhampton one stop shop facility for the bereaved | |
| | Co-ordinated services in Bromley | |
| | Charter for the Bereaved | |
| | Rights for the bereaved | |
| | Institute of Cemetary and Crematorium Managers (www.iccm.org.uk) | |
| | Why not run co-ordinated bereavement services on the model of integrated discharges, where it works? | |
| | Identified post to co-ordinate, facilitate, hold info, communicate.... | |
| | Peninsula Cancer Network - database and flow chart of where to go for end of life services http://www.peninsulacancernetwork.org.uk Information pathway online - could be developed further | |
| | Plymouth Mustard Tree for mental handicap and special needs | |
| | Penhaligon's Friends leaflets | |
| | Database - timeline of services online | |
| | 2006 Bereavement Project Report for Cornwall informative and comprehensive | |
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| And....plenary | Keep the momentum going! | |
| | Bereavement Support Volunteers into RCHT, community hospitals (14) and GP surgeries with training (as Birmingham model) | |
| | Good online database needed: statutory services, CVS, pathways, flowchart - local and national and updated | |
| | Co-ordinator for services across the county (including database) - joint funded and independent | |
| | Use info points and libraries | |
| | Co-ordinate leaflets and have one pathway and a paper directory alongside | |
| | Package for professionals - with info about spiritual care | |
| | Pre and post-bereavement care out of hospital as well as in hospital, especially for at home and in homes | |
| | Peninsula Cancer Care pathway template | |
| | Training and info on managing bereavement widely available and support for those doing the work | |

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| | GSF - advance care programme - End of Life group | |
| | GP followup at six weeks and offer services if needed | |
| | Despite many and varied good services, communications are poor - improve them! | |
| | Build on work in schools - inset days, SEAL and PHSE, embedding bereavement in life | |
| | Attempt to secure a co-ordinator for bereavement services/provision across the County failed before - business plan needed for funding for the role: a Bereavement Services Co-ordinator for Cornwall | |
| | Can BPP help lever this into action? | |
| | NICE guidelines - not just cancer but every death | |
| | Evidence from pilot role for permanent role | |