

Bereavement Care for Older People

Guidelines for Practice

Version 1

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Guidelines for bereavement care for older people

This document contains guidance for healthcare staff on providing bereavement care for older people. It is the outcome of a research study carried out by the author on bereavement and bereavement care for older people and how services currently provided could be enhanced. The guidelines have been designed for the use of healthcare staff in general practice, community nursing, hospital wards, and care homes for older people. All staff who, from time to time, care for bereaved relatives in the course of their work can use the guidelines. This includes trained and untrained nurses and carers, doctors, allied healthcare staff like occupational therapists, chaplains, reception or administrative staff. The document is presented in two parts:

PART A. Development of the guidelines;

PART B. Guidelines for bereavement care for older people.

BACKGROUND

Bereavement is experienced by everyone and when the person who has died is a close family member or friend it can have particularly distressing effects and lead to physical and mental health changes, and social readjustment (1). For most people those closest are the greatest source of pleasure, and consequently their loss is the greatest source of pain (2). People react to bereavement in diverse ways, and while the majority experience short grief reactions and remain stable or resilient during their journey through bereavement, some experience more long term grief effects and recover slowly during the first 1-2 years. Others (10-15%) suffer distress and depression in the long term (3).

Loss of a spouse or partner is a usual experience for older adults. In 2009 in Scotland 42,832 people aged 65 years of age or more died (4). Consequently many of these deaths would have left spouses and partners, other family members and friends bereaved. More specifically, a larger number of older women than men in western societies become bereaved of a spouse or partner due to common diseases affecting men at a younger age (5).

Across the life span older people are most likely to suffer bereavement, and many may even be multiply bereaved. However, support for older people in the time leading up to a loss, at the time of loss, and in the days, weeks and months afterwards is inconsistently provided within healthcare services (6). Bereavement care services are traditionally well developed in palliative care but there is little

evidence of replication in generic healthcare settings where deaths are more likely to occur (7). In addition, previous research has identified a lack of clarity about care provided to the bereaved in general hospital wards, care homes and in community settings, and that there is no particular provision for older people (6). The guidelines presented in this document have been developed to holistically reflect bereavement experiences and needs of older people. It considers bereavement in the context of care provided by healthcare staff in hospital wards, general practices and community nursing, and care homes. Through contact with relatives of patients in the time leading up to a death, healthcare staff are ideally placed to ensure that older people set out on their bereavement journey with appropriate information and support to help them adapt.

PART A

DEVELOPMENT OF THE GUIDELINES

Developments in bereavement care services should reflect and respond to the needs of bereaved older people and difficulties they may face when bereaved. The initial phase of developing the guidelines included a literature review and an interview study to explore older people's experiences of bereavement, and healthcare staffs' experiences of providing bereavement care. In addition, the interview study went on to examine what is currently done for bereaved older people, people's perceptions of gaps in service provision, and how gaps could be addressed. Interviews took place with members of staff in general practices, hospital wards, and care homes and a sample of bereaved older people. The findings, outlined below, were used to inform the development of the guidelines.

1. Literature review: Previous research about bereavement and older people

Searches were made of the main health and social science databases for research relevant to bereavement and older people. Four main themes identifying older people's experiences of bereavement were identified in the available literature:

1. physical effects;
2. psychosocial effects (including loneliness);
3. changed relationships with self and others;
4. continuing bonds with the deceased.

1.1 Physical effects

Bereavement and loss of a spouse or partner in particular, often takes place at a time when an older person has the increased likelihood of suffering from health problems that may be chronic in nature (8). High morbidity and mortality rates for all causes following loss of a spouse have been identified, particularly in the newly bereaved.

Those with more symptoms before bereavement have highest mortality (9), though trends suggest that older widowed people are at less risk of death than younger widow(er)s (1). Additionally, increased risk of sleep disruption, and increased tobacco and alcohol use have been identified in the early months following bereavement in all adults and early mortality may be a consequence (10).

A recent study of mortality in widowed older people has identified older age, male sex, low level of physical functioning, and expressing relief at the death of the spouse as factors that may increase risk of mortality (11). Decreased risk was found in those who were physically active, and those who did not express relief after the spouse's death. However, risk factors for mortality after bereavement that were apparent up to six months were found to reduce in the longer term.

Studying older women, Grimby et al (12) found that widows spent less time walking in the first year of widowhood than married women. However, the amount they walked increased in the 5 years post bereavement. Reduced physical health and social isolation in the short term may be barriers to widowed women taking part in physical activity. In the long term, lower levels of activity led to worsening health and inability to exercise. Most, however, will regain a certain level of activity as time since bereavement lengthens and social involvement increases.

1.2 Psychosocial effects (including loneliness)

Coping with a loss can result in an older person having increased mental health symptoms, including depression. In older people, in general, depression has been found to be worst in those with poorer physical health (13,14), and who have had a recent bereavement (13). Intensively caring for the deceased person in the period leading up to the death may also lead to increased incidence of depression (14,15). In addition, symptoms of traumatic response have been identified in bereaved older people, in which feelings of numbness, helplessness, being unable to express needs, and fears of illness or death for themselves are reported (16).

The studies reviewed highlight diversity in the process of adjustment to bereavement in older people. In general, grief reactions become less acute as time progresses and mental health symptoms abate. In addition, older people may be more resilient than other age groups and more likely to resolve their regrets leading to better mental health outcomes (17).

Loneliness may be a dominant emotion experienced by older people, particularly those bereaved of a spouse or partner, and is frequently highlighted in the bereavement literature. Studies of older widows and widowers find social isolation and loneliness to be key themes (18-21). Loneliness has also been identified as affecting bereaved older widows and widowers socially and/or emotionally. A range of factors affect social loneliness including poor physical or mental health; and attaching less importance to contact with others. Predictive factors for emotional loneliness include having been unable to anticipate the death; and poor physical health (22).

Loneliness may also be heightened by reminders of the dead spouse or partner, anniversaries of the death, having to learn to do tasks previously carried out by the partner, and socialising as a single person (23). In addition, loss of a life partner in particular often means that the bereaved are also at risk of losing their place in their social network (24). The research underlines the need to understand coping strategies in widows and widowers and how this influences their support needs. Providing meaningful support consequently challenges the wider social network and health and social care service providers. There may be a need for healthcare providers to maintain a link through follow up or regular surveillance of recently bereaved older people.

1.3 Changed relationship with self and others

Following bereavement, relationships between family members, friends and others often change to accommodate the loss and those who have suffered most from the loss. The bereaved continue to include the dead person in their lives in a variety of ways that may, or may not, let them make changes in their home and social lives. Key to successful adaptation to bereavement is the development of a story about the deceased and their death that allows the bereaved to cope with their own changed identity, and changes in their relationships with others (25). In addition, investment in new relationships and in making changes to existing relationships by the bereaved themselves and those around them are necessary to find meaning in the death and in continued life. Relationships and roles often change within families for each other's benefit, and common interests and support may be found with friends (26).

1.4 Continuation of the bond with the deceased

In the past bereavement care was aimed at helping the bereaved to break bonds with the deceased. However, current knowledge indicates that maintaining a bond can facilitate adjustment (27). Studies of bereaved older people have commonly found that people take comfort in memories of their spouse or partner, and cope by managing reminders of the loss and maintaining a continued relationship (19,20). In her study of the challenges of sustaining a meaningful life as a widowed spouse or partner, Hockey et al (27) found that the influence of the dead spouse or partner lies within the home and the places formerly visited as a couple, and is key to how widows use and adapt the same familiar spaces. In addition, Costello and Kendrick (18) and Costello (28) found that forming a story of the death of the spouse or partner, and having dialogue with the deceased was part of widows' coping strategies. Talking with bereaved older people about the deceased and allowing them to tell stories about their life and death may help them to integrate the dead person in their ongoing life. Staff can also reassure the relative that it is normal to feel the presence of the dead person as they go about their daily activities.

2. The interview study

Interview participants were:

6 bereaved older people

13 hospital staff (ward sisters, trained and untrained nurses, doctor, administrator, chaplain)

10 care home staff (home manager, trained nurses, untrained care staff)

9 general practice staff (GPs, district nurses, community nurses)

1 other (voluntary sector)

Findings

2.1 Bereavement care depends on an established relationship

Bereavement care is dependent on an ongoing relationship between healthcare staff and a patient's or resident's family. The relationship develops from the time that the patient or resident first comes into the care of staff. At the end of life the established relationship facilitates preparation of the relatives for bereavement, support at the time of the death, and for some, support in the days and weeks afterwards. While the relationship exists it can be intense in nature, though there is an understanding between staff and relatives that it will end at some point after the death.

Relatives in the study also suggested that bereavement care would only be helpful if the member of staff was known to the patient and relative. The ongoing relationship with a GP was seen as a suitable basis for follow up, however, GPs are variable in their practice. Supportive relationships do not happen universally and only one widow in the study described such a relationship. Other experiences were of dissatisfying contacts and poor communication. In addition, sudden death means reduced opportunities for relationships to develop.

2.2 Preparation for the end of the relative's life may not equate to preparedness for bereavement

Preparing the patient's relatives for the loss is seen as part of healthcare staffs' role in the lead up to a death. However, the preparation process is multifaceted and may not mean that relatives are ready for the death or bereavement. Difficulties of communicating effectively about death and bereavement, and relatives' denial of the reality of the situation were identified as barriers. In addition, facilitating preparation depends on the staff recognising that the patient is in the end stages.

Relatives in the study described only getting information if they asked questions of medical staff, being told bits of information by different healthcare staff, and staff putting a positive spin on the situation. However, relatives may also be unwilling to enter discussion of death and bereavement and wish the focus to be on the dying person. Staff may judge the appropriate level of information to give on an individual basis. However, staff and relatives believed that no matter how much preparation there has been for the death it may still come as a shock.

2.3 The Open Door to bereavement care is only slightly ajar

Theme 1 identified that the death of the patient in general signifies the ending of the relationship between staff and family. However, staff described taking steps to ensure that bereaved relatives have information and a means of reaching back into services. Various strategies are employed to provide an 'Open Door': inviting further contact; opportunistic support; information provision; handing on; and relying on the family to support. All five demand little staff engagement in terms of time and resources and are convenient ways to validate further contact. However, barriers to accessing the 'Open Door' are apparent.

i) Inviting follow up contact

Relatives are usually given contact details for the service to enable the bereaved to reach back in for further information. The type of support offered by hospital staff through this open invitation is, in general, about clarification of events that led to the death. However, there was little experience of anyone making contact after a death, so no knowledge of relatives' support needs from which to draw.

ii) Opportunistic support

Informal meetings after the death between staff and relatives provide opportunities to see how bereaved older people are getting on. These types of encounters often take place in public places. Staff use these encounters to share sympathies or reminisce about the patient or resident, though no therapeutic value is attached. Contact with bereaved relatives could also be opportunistic on the part of the GP and bereavement concerns may arise unexpectedly and sometimes a long time after the death.

iii) Information provision

Staff in wards and homes routinely provide oral and written information about administration procedures that take place after a death. Other types of information,

for example, about how bereavement affects the individual, and support organisations may also be useful. Giving information reassured staff that relatives had something to refer to if they had a need. However, relatives in the study indicated that though they had the information they may not find it accessible or useful.

iv) Handing on

Health centres are routinely notified of deaths in hospitals and homes and responsibility for relatives is therefore handed over. However, there was no clear idea of whether or not follow up takes place. In addition, practitioners were unaware of any communication, or did not themselves communicate concerns about bereaved relatives to other services. Being located within a hospital or nursing home was a particular barrier to communication or contact with, for example, community services. When relatives known to practice staff are followed up in bereavement some communication may take place, and GPs may go on to refer bereaved older people to other services. However, it is more usual to suggest voluntary sector or counselling services to relatives and leave them to decide whether or not to make contact. Communication links regarding bereaved older people are undefined and there is a risk that people with problematic grieving remain unidentified.

v) Relying on the family to support

Relatives in the study described their families as their main support network and experienced variable follow up support from healthcare staff. In addition, healthcare staff generally believe that families will support each other. However, concern was expressed by staff for those older people who have no family left, or live at a distance from their relatives. Even though there was awareness that someone was coping alone, hospital ward and care home staff stopped short of notifying the general practice of the situation.

PART B

GUIDELINES FOR BEREAVEMENT CARE FOR OLDER PEOPLE

The findings outlined above directed development of the structure and content of the guidelines. In addition, interviewees suggestions for elements that could be included fed into the process. To ensure a complete approach to bereavement care for older people was given in the guidelines, items from current bereavement research, bereavement theories, and other guidelines, for example, in palliative care were identified and included.

The layout of the guidelines

The guidelines are arranged in four main sections:

1. pre bereavement preparation;
2. bereavement care at the time of the death;
3. bereavement follow up;
4. bereavement support resources.

Sections in the guidelines are subdivided to lead the reader through the bereavement journey with an older person. Each subsection gives an overall recommendation or goal for care. The recommendation is provided in detail as a recommendation statement, and supported by the rationale, or reasons why the recommendation is given. The actions for healthcare staff to follow are given as criteria for care. The different actions are listed in an order that leads the reader through the process of caring for a bereaved older person. However, the order should not be prescriptive and the timing of actions made flexible to the bereaved older person's needs. Practitioners should identify from the list, and carry out the activities that may be helpful for the individual bereaved older person. Evidence supporting the use of some items included in the guidelines can also be found in previous research studies and are referenced in the guidelines. In addition, quotations from interviews are provided following each recommendation to validate the inclusion of some criteria in the guidelines.

Intended outcomes of using the guidelines

1. For bereaved older people

They are cared for consistently whatever the circumstances or care setting;
Their support needs are identified and addressed appropriately (29,30);
Care received is experienced as compassionate and supportive;
Where there are follow up needs, links with services that can provide support are established (31);
They are supported to be independent (32);
They receive appropriate information that allows them to seek help (31).

2. For healthcare staff

Enables a consistent approach across settings to providing bereavement care;
Enables staff to respond flexibly to the diverse range of needs of bereaved individuals (5);
Allows staff to be confident in their interactions with bereaved older people;
Allows staff to consider how they currently interact with bereaved older people, and how they may develop their practice;
Acts as a staff training tool (6).

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3. Bereavement follow up

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4. Bereavement support resources

- 1. Bereavement support organisations
- 2. Bereavement support information
- 3. Social support services
- 4. Organisations for older people
- 5. Information for healthcare staff

1. Pre bereavement preparation

Many older people die after a period of illness and palliative or terminal care that is provided in hospital, in a care home or in their own home. For the spouse, partner or other relative this can be a time of great distress, worry and confusion. The time leading up to the death is when healthcare staff have an opportunity to build a relationship with families that enables them to prepare relatives for the death and for what it may be like afterwards. When the older person knows that their spouse or partner, or other relative is dying there may be opportunities for them to adapt to the situation and to plan for the time of the death. The amount and nature of information provided, however, will be based on judgement of what it is assumed that the older relative needs and will be able to understand. The relationship between staff and family may also enable support at the time of death and in the days, weeks and months afterwards.

This section of the guidelines looks at what can be done before the death to help an older person prepare for the loss of someone close to them. It also provides guidance on the identification of those who may need further support after the death.

Recommendation 1.1

Create a supportive environment

Recommendation statement

Allow the older person to prepare for their relative's death in a supportive and caring environment

Rationale

From an early stage in the patient's illness or when a care home resident enters the home healthcare staff will develop a relationship with them and members of their family. Staff have the opportunity to build a supportive relationship that helps family members prepare for their inevitable loss.

Criteria

Facilitate dialogue between patient/resident, relatives and staff about the end of life

An appropriately trained and experienced doctor or nurse who knows the patient should communicate openly with family members, giving reliable and consistent information (33)

Give relatives the opportunity to be with the dying person

Advise relatives about sitting with the dying person

Staff can support the relative by inviting them to speak about their relationship with the dying person: 'tell me how the two of you met...'

A member of staff should sit with the patient or resident when relatives are not there

Identify and draw on other sources of support – family, faith group/chaplain, friends

Provide hospitality to relative – drinks, meals if available, place to sleep

Ask the relative about specific cultural or religious requirements around death, dying and bereavement when there is a need

- ✦ *Nobody ever said until a week before he died and they put him in a side ward (spouse, female, 80s)*
- ✦ *I was sorry I wasn't there because we were so close (spouse, female, 80s)*
- ✦ *Some relatives want to stay overnight, which is fine with us too (staff nurse, hospital)*
- ✦ *I think the challenge occurs when the person is at end stages for a long long time. I can see that, you know I can see that telling on the relatives. You have to call the relatives when you think the person is going to die but then its up to them to choose how they stay or whatever. It's very hard to know how to do the right thing in that situation (ward administrator, hospital)*

Recommendation 1.2

Support the older person to prepare for the loss

Recommendation statement

Facilitate an older person's preparation for the death of someone close

Rationale

The death of someone close is usually difficult for family members. Being prepared for the event can help people to accept the death and have a stable adjustment to bereavement. Older people may need help to understand that their relative is dying.

Criteria

Check out with the relative what they already know or assume

Give the relative information that they can cope with:

- diagnosis
- prognosis
- care decisions
- what the death could be like

Frequently reiterate the information

Include the family in decisions about end of life care

Involve the family in the care of the dying person (34)

Maintain a high standard of care for the dying person

Give the family the opportunity to plan ahead for the time of the death and make their wishes known:

- financial arrangements
- funeral arrangements
- burial or cremation

Discuss with the relative what bereavement may mean for them (35):

- a shock
- being alone
- difficult times (after the funeral, birthdays, anniversary of the death)
- what they may plan for the future

- ✦ *We have a role to make sure people are preparing because it often makes bereavement easier (GP)*
- ✦ *It was a shock, but we'd cried together beforehand and I was prepared a bit better (bereaved spouse, female, 60s)*
- ✦ *I asked the GP what her death might be like, and it was as he said (bereaved spouse, male, 60s)*
- ✦ *If the family are involved with the patient's care, it helps them through their bereavement process (ward sister, hospital)*

Recommendation 1.3

Assessment of possible bereavement care needs

Recommendation statement

Assess whether there may be bereavement support needs

Rationale

Bereavement care provision delivered by healthcare staff depends on the family member having support needs. Through the relationship that has developed in the time leading up to the death staff have an opportunity to assess risk factors for complicated grief. Any risk factors may be communicated by hospital or care home staff to the GP or community nursing team, or to other services where necessary.

Criteria

Risk factor assessment can be carried out informally through routine conversation with the bereaved older person

Risk factor assessment may be carried out in the time before the death, at the time of the death, or in the weeks afterwards

Use knowledge of the family and judgement of their coping strategies as well as risk factors before making a decision about communicating concerns to other services (having risk factors does not automatically mean there will be follow up needs) (36)

Communicate concerns to other services as appropriate: GP/community nursing team/social work department. Ensure the bereaved older person's consent before contacting others.

Initiate follow up of the bereaved older person where necessary

Assessment criteria	Risk factors
Relationship to deceased	Spouse/partner, parent, adult child, grand parent, sibling, carer, cared for
Circumstances of the death	Sudden, untimely, trauma, suicide, prolonged death
Family/friends/community support	None identified, or unreliable
Health	Poor physical health, previous mental health problems
Other bereavement(s), last 2 years	One or more, relationship as above
Perceived support needs	Relative's stated needs

- ✧ *There must be 3 or 4 brief questions to elicit crucial information, like the CAGE questionnaire (37) to identify alcohol problems (GP)*

2. Bereavement care at the time of the death

When a death occurs healthcare staff may have been involved with the care of the ill person and have had the opportunity to develop a relationship with their family. However, in many cases staff may only have had a very short relationship with the patient and family, or no relationship at all. Sudden death is recognised as being harder for relatives to accept and come to terms with. Support at this time can make the situation a bit easier to bear. Things that can be done for a relative who has been suddenly bereaved may be similar to what you can do for someone who expected their relative to die. However, for sudden deaths the relatives' reactions may be much more acute and your support will have added importance. Recommendations provided are equally applicable for the care of a suddenly bereaved older person or someone who is well known to staff.

This section of the guidelines covers the time of the death and what can be done to facilitate the bereaved older person's acceptance and understanding of the death.

Recommendation 2.1.

Breaking the news of the death

Recommendation statement

Sensitively break news of the death to the next of kin or other relative

Rationale

Close family members usually are with a dying person at the end of their life. However, there are times when this is not possible, for example, when the relative lives overseas or the death has been sudden. The news then needs to be given to the relative by phone or preferably in person, if they have come to the hospital or care home, or are visited at home.

Criteria

Introduce yourself and the hospital/home

Be honest, compassionate and empathetic

Find out if there is someone there to support the bereaved older person (38)

It may be appropriate to first inform another family member (son/daughter) rather than an older spouse or partner

Invite the relative to the hospital/home if appropriate

At the hospital or home, provide a comfortable private room with a telephone (35,39)

Set aside up to ½ hour to talk to the relative

You may start by saying 'I am sorry to give you very sad news' (40)

Go on to inform the bereaved older person at a speed that they can follow and use plain language, for example, the words 'dead', or 'died' (38,39)

Allow time for the initial reaction (38,39)

Provide a short explanation of events

Answer questions truthfully if the information is known (38)

If you can't answer a question, say you don't know

Give verbal and non verbal reassurance of the normality of their reaction (38)

Explain the processes that need to be gone through following a death i.e. registration

Contact another family member if the bereaved older person is alone

Contact the GP if not already aware of the death

Find out if there are any specific cultural or religious requirements

If requested, contact the faith group leader or other person who can support

Provide your details and encourage the relative to contact you if they need more information or clarification

- ✧ *I prefer it if the relatives are here prior to the person passing away (staff nurse, hospital)*
- ✧ *We'll phone the relatives and let them know, and ask if they want to come and see the dead relative here (staff nurse, hospital)*

- ✧ *Sometimes it's not the next of kin if they are elderly, it's a son or daughter (staff nurse, hospital)*

Recommendation 2.2.

Respond to immediate support needs

Recommendation statement

Provide comfort to the bereaved older person at the time of the death

Rationale

Older people will have diverse reactions to grief. Sadness, distress, denial, anger, shock, or aggression are common when someone has died suddenly. However, people may also have feelings of acceptance or inevitability after an expected death which can create a feeling of guilt at not being sad. The relative should feel able to express their feelings to someone who is there to support them and who responds with compassion and empathy.

Criteria

Set aside up to 1 hour to spend with the bereaved relative

Allow the bereaved to express their feelings and acknowledge them, saying that 'it is normal to feel that way' (41)

Express words of sympathy

- 'I am very sorry'
- 'this must be very difficult for you'
- 'he/she will not be in pain any more'

Sit in silence with the bereaved older person if they do not wish to talk

Provide time for the bereaved person to talk with a nurse or doctor who knew the person who died about their feelings, about the person who died, and what the loss means to them (40)

Be empathetic by asking open questions about the person who died and their relationship with those left

Give explanations: illness, events at death, care provided

Answer questions and listen to concerns

Provide refreshments, tissues, and telephone

Explore religious and/or cultural needs before commencing last offices

Ask the relative if they would like to help you with washing the dead person's body (42)

Carry out last offices sensitively and respectfully

Allow the relative to be with the dead person for as long as they need, in private or accompanied (warn the relative that the dead person may feel cold) (39)

When a relative is on their own, if possible contact another family member or friend to accompany them from the hospital/care home

Stay with them until they are ready to leave the hospital/care home (38)

Provide a contact telephone number

Accompany the relative to the door of the hospital/care home when they leave (40)

- ✧ *There needs to be something written down saying, its not so much how you care for people when they are dying or whatever, its to say this is what you could say or can say (nursing auxiliary, hospital)*
- ✧ *I have no problem with the relatives staying in the ward for as long as they like. I don't rush them out, elderly people shouldn't be rushed (staff nurse, hospital)*
- ✧ *Immediately after a death you know, I would be saying 'do you want me to leave the room, do you want some time with mum?' I think its just you know giving them time and space but making sure that they know that the support's there (social care officer)*

Recommendation 2.3

Facilitate ongoing support

Recommendation statement

Organise ongoing support for the relative where there is a need

Rationale

A judgement of whether or not a relative may require further bereavement support may be made. Staff can use the risk factor assessment of the relative to direct them in deciding whether or not there are support needs. Where there has been no assessment previously carried out, this can be done through conversation with the relative at the time of the death (see recommendation 1.3).

Criteria

With the bereaved older person's consent, communicate concerns based on risk factor assessment and judgement of the person's coping abilities to other healthcare professionals on the day of the death:

- GP
- district nursing team
- social work department (if the older person has immediate care/accommodation needs) (39,40)

Inform the GP/district nursing team/social work department of the situation and concerns at the earliest opportunity

If you have concerns about a relative and they are registered with a different practice from the deceased:

- find out if they want to have their GP informed
- communicate the information to the GP

Draw on family members to provide support and if not already present contact them by phone

Invite the bereaved older person to contact or visit the ward, home or general practice if they have questions about the death, about practical arrangements, to discuss other concerns (38), or for further support

Provide a follow up appointment at the ward, care home, or general practice (see Recommendation 3.3)

Inform the dead person's GP practice by phone about their death within 1 day, or as soon as possible.

- ✧ *Definitely from a ward aspect, we don't offer anything substantial for support apart from, 'feel free to pop in any time' (senior staff nurse, hospital)*
- ✧ *We do invite them back to visit us and to come and say hello if they are passing, come in for a fly cup or if they've made friends with other residents, to come and see them (senior nurse, care home)*
- ✧ *We give them a card that, we put down our contact details so that they can, if they've got any questions or queries or if we've gone over something and*

they've forgotten or, because really you're not listening at that time (staff nurse, hospital)

- ✧ *If we know about them and we know them then we will make a point of going to visit them, but if they're not people who are known to us, even if they are elderly because I think we've got about 700 over 75 patients at the surgery, so there's no way that they're all going to be known to us, and these are the ones that I think quite honestly would fall through the net (district nurse)*

Recommendation 2.4

Information

Recommendation statement

Provide oral and written information to the bereaved older person

Rationale

Healthcare staff should provide oral and written information that people find useful and easy to follow. Some information will be immediately helpful for directing the relative to the practical arrangements that need to be made in the days following a death. Other information may be of use in the weeks and months following the loss to support the bereaved older person to make sense of their feelings. Additionally, bereaved older people will need to be directed to where they can get help locally for a range of difficulties they may experience in the weeks and months following their loss.

Criteria

Provide oral and written information:

- practical arrangements that must be made after a death
- emotional, psychological, physical and social effects of bereavement
- sources of support

Spend time with the bereaved older person helping them understand what they have been told

Reiterate the information as necessary because the bereaved older person will not remember all that is said

Encourage the bereaved older person to contact you later if they need more information, or to go over something again

Highlight other services that the bereaved older person may contact if they have a need:

- GP
- social work department
- voluntary sector services
- faith groups

Resources are provided at the end of the guidelines

- ✧ *I always take time and speak to them, I never hand them booklets or anything like that. I like to tell them verbally what's happening. Its what to do as regards funeral arrangements, practical things because a lot of them have never had to do it before (staff nurse, hospital)*
- ✧ *I think I got leaflets like where I could ask for help and things like that, but it's such a confusing time, you just try and cope and do the best you can yourself really (spouse, female, 80s)*
- ✧ *We have a little leaflet that we had made up with how to register a death and what they need to take up to the registrars, the local undertakers, local*

ministers and things like that, the family are maybe nae so familiar. We also include the named nurse or the ward managers name and the telephone number that they can contact at any time if they want to come back and discuss, or just talk through their experiences and the care of their loved one (ward sister, hospital)

3. Bereavement follow up

The support of older people becomes a role for general practice and community staff in the days, weeks and months after bereavement. Hospital staff are able to provide limited bereavement follow up but may do small things like sending a sympathy card and inviting the bereaved older person to make contact if they have further questions or concerns. Bereaved older people, however, rarely reach back into services and may look for bereavement support elsewhere. Care home staff may also feel that they have little input as regards follow up for bereaved relatives. However, there are things that may be done, particularly by home managers from their base within a local community and established relationship with residents' families.

Recommendation 3.1

Plan follow up for the bereaved older person

Recommendation statement

Identify bereaved older people in the community and plan follow up

Rationale

Identification of all recently bereaved older people allows general practice staff to provide an equitable service that offers appropriate follow up and support. Bereavement for older people may go unrecognised when they are not the nearest relative of the deceased, for example, they may be grand parents or siblings. It is therefore important when caring for bereaved relatives in general to consider that there may be others affected.

Criteria

Death notification received from the hospital

- An identified member of staff* at the practice notifies all GPs and community nursing staff of the death
- GP who knows the family should make contact with the closest family member
 - visit in first 3 days (before funeral), or phone, or send sympathy card or letter (43)
- If a member of community nursing staff knows the family
 - contact by phone or visit in first 3 days
 - home visit in first 2-6 weeks (44)
- GP/nurse notifies the identified member of staff* if planning to visit
- If no member of staff responds to initial communication, the identified member of staff* should notify the GP whom the deceased/family member was registered with, who may then follow up
- Note the bereavement in the medical records of the bereaved person (43)
- Where necessary, discuss needs of bereaved older people at multi-disciplinary team meetings

Alternatively hospital or care home staff may have contacted the GP if they have concerns about a bereaved older person. In such cases, contact should be made with the bereaved older person and a bereavement follow up visit may be arranged if the person has a need and is in agreement.

If the relative is registered with a different GP from the deceased and there are needs, inform the practice with the relative's permission

When in contact with bereaved relatives be aware of other family members who may be affected by the death. Try to find out what their needs may be and if necessary make contact:

- brothers and sisters
- grand parents
- parents

* The person who co-ordinates notification of practice staff should be identified by the GPs depending on roles within the practice

- ✧ *Sometimes it might be on the phone (contact after the death), it depends on the circumstances, but usually we're going out and visiting. We probably all in this practice have different ways of doing that, we all do it differently and I think a lot depends on the individual patients and relatives who we're dealing with, how you might do that (GP).*
- ✧ *If its an elderly person and they're registered with us you can usually always find reasons to go back and fore and visit them (district nurse)*
- ✧ *If somebody goes into hospital who you don't know very well then quite often you know, you don't know what happens and it can sometimes be quite a few weeks before the information filters through (district nurse)*

Recommendation 3.2

Bereavement visiting for the older person

Recommendation statement

A community based practitioner (GP/district nurse/community nurse/care home manager) will carry out a bereavement visit to recently bereaved older people at least once

Rationale

Follow up of bereaved older people allows the nurse/doctor/care home manager to express sympathy, acknowledge the loss, assess how the person is coping and to appropriately decide whether to continue to follow up, to withdraw, or to refer on to other services.

One or more follow up meeting allows the bereaved older person to clarify issues about the death that were unclear, to speak about the dead relative, and to feel that their grief is acknowledged by healthcare staff.

Criteria

Below is an example of a visit plan that can be used for an older person:

- Visit before funeral – GP/district or community nurse/care home manager
- Visit 2-6 weeks after funeral – DN or community nurse (if relative known)/care home manager
- Further follow up is dependent on need
- Arrange phone contact after 3 months, if the person is in agreement – GP/district nurse/community nurse/care home manager

Visits should preferably be from someone known to the bereaved relative, who knew the dead person and is aware of the history of illness and care (44)

Set up to 1 hour aside for the visit

Take a compassionate approach (43)

Provide a safe environment that enables open discussion

Acknowledge the loss and their grief (44)

Allow the relative to talk about the dead person, being bereaved, and listen to what they say (34,41,43,44)

Validate how people feel, saying 'it is alright to feel like that' (38)

Support the bereaved older person to accept the reality of the loss

Reflect on events, clarify understanding

Clarify with the relative any specific cultural or religious requirements there may be around bereavement

Identify difficult times (after the funeral, birthdays, anniversary of the death)

Acknowledge practical difficulties

Support and acknowledge efforts to cope

Support with decision making (44), but discourage impulsive actions (i.e. moving house)

Give permission to take a break from grieving (38)

Explore possible coping strategies

During later visits (6 weeks or more since the death) and where need has been identified, provide contact details for organisations (Cruse Bereavement Care, counselling services, other voluntary sector organisations)

Provide health information and advice as necessary

Find out whether other family members should be contacted i.e. an older person who is a grand parent or sibling of the deceased

Communicate concerns to the GP, refer to other services i.e. mental health services, with the person's consent

Arrange further follow up based on clinical or social need, or conclude follow up where there are none

Conclude follow up with agreement from the bereaved older person

Invite the bereaved older person to make contact if they have further need, or to make an appointment with the GP

Other opportunities can be used to see how a bereaved older person is coping:

- removal of clinical equipment from the house
- collecting belongings from the care home
- visits to the GP practice for other reasons
- chance meetings

Be willing to talk about the deceased years after the death

- ✧ *And the nurses were all good, I couldn't fault any of the nurses that come and attended to him. There was two of them come back to see me after the first week, but as for a doctor, no they never come near hand or nothing (bereaved spouse, female, 60s)*
- ✧ *I tend to let them speak about how they're feeling. Quite often they want to speak about what happened, because although they can speak about generally how the person was and what was wrong with them to other people, they quite often don't go into all the details of everything that happened. I let them speak and then start asking them how they're feeling and how they're coping through the day, how they're sleeping, if they're eating, if they're getting out, if they've got people visiting. I don't sit and say it quite like that but these are all the things that I sort of mentally go through (district nurse)*

Recommendation 3.3

Follow up from non community based staff

Recommendation statement

Follow up of bereaved older people by staff who have an ongoing relationship with them.

Rationale

Hospital or care home staff who looked after the person who died, and knew the bereaved relative can be involved in follow up as well as community based staff. There are small things that may be done from the ward or care home to support the relative. The things identified below may be supportive and comforting for the bereaved older person.

Criteria

Follow up phone call to relatives 1-3 days after the death

- allow time for the call
- ask how the relative is feeling
- ask whether they have any questions about the death
- find out how the family are coping
- find out how the funeral arrangements are progressing
- ask whether they have any other concerns
- don't be afraid to mention the dead person by name (45)
- notify GP of any concerns raised that hospital/home staff can't address (with the bereaved older person's permission)

Send a sympathy card (35,36,46)

Invite relatives to contact the ward or home by phone or to visit in person if they have further support needs. Provide contact details for a named person who knew the family well and can answer questions about the death.

Arrange a follow up meeting for the bereaved older person with a member of staff who knew the patient and family:

- give a date and time about 3 weeks after the death
- at the appointment the bereaved relative will see someone who knew the family and was present at the death
- at the appointment answer questions, clarify events that led to the death, support emotionally
- communicate concerns with the relative's agreement

If appropriate, attend the funeral to represent the practice, ward or home and to show ongoing care for the person and their family

- ✧ *One thing that we did as well was that we phoned them the day after just to see how they were and just you know 'did you manage to sleep last night?' or 'when you left did you have a wee cry?' Just pleasantries 'has your sister from (overseas) arrived?' Because you'd spent so much time with them you knew*

everything that was going on so you had conversation with them (ward sister, hospital)

- ✧ *When this person's mum died, then the funeral and that, staff went to the funeral. I felt, you know the family came in about and spoke, you felt as if you were a family member (social care officer)*

4. Bereavement support resources

Listed below are some resources and contact details for services that provide bereavement support or address other social support needs that bereaved older people may have. Many resources are internet based and have been assessed as containing information that may be useful to bereaved older people or to healthcare staff. However, it is best to be familiar with the contents of resources before handing the information to bereaved older people. Other resources are written materials that can be accessed via the internet. The resource list should be supplemented with sources of support available locally. The list is divided into five sections:

1. Bereavement support organisations
2. Bereavement support information
3. Social support services
4. Organisations for older people
5. Information for healthcare staff

A brief description of each service, contact details and preferred route of referral is provided. Some organisations require the bereaved person to make contact themselves, for example, Cruse. Other services can be contacted via referral from the general practice, hospital or care home.

1. Bereavement support organisations

Cruse Bereavement Care

Cruse supports people through bereavement. It is a voluntary organisation that provides one-to-one counselling, group therapies, and offers support to help the bereaved to understand their grief and cope with their loss.

Cruse England and Wales, daytime helpline: 0844 477 9400

Email: helpline@cruse.org.uk

Website: <http://www.crusebereavementcare.org.uk/index.html>

Cruse Scotland, national phoneline: 0845 600 2227

Website: <http://www.crusescotland.org.uk/>

Cruse Bereavement Care in Northern Ireland, telephone: 028 9079 2419

Email: northern.ireland@cruse.org.uk

Website: <http://www.cruseni.org/?tabindex=1&tabid=2338>

National Association of Widows

The National Association of Widows offers support and friendship to people who have been bereaved of their partners. Other widows and widowers run the service.

<http://www.nawidows.org.uk/>

Self referral

Facing Bereavement

This website contains articles written by experts on many aspects of bereavement.

<http://www.facingbereavement.co.uk/>

Counselling and psychotherapy

British Association of Counselling and Psychotherapy (BACP)

A service that enables potential clients to find a suitable counsellor.

<http://www.bacp.co.uk/>

Counselling and Psychotherapy in Scotland (COSCA)

A useful resource for people who are interested in finding/using a counsellor or psychotherapist.

<http://www.cosca.org.uk/>

Self referral

2. Bereavement support information

Dept. of Work and Pensions

What to do after a death in England and Wales

When a close relative dies, there are many decisions and arrangements that will have to be made, often at a time of personal distress. This leaflet gives help and guidance about what to do when someone dies.

<http://www.dwp.gov.uk/docs/dwp1027.pdf>

Scottish Government

What to do after a death in Scotland

Practical help and guidance through the arrangements that have to be made after a death. Includes legal and financial information.

Printed copies are provided to bereaved relatives by some NHS organisations in Scotland. It is also available from registrars, some undertakers and on the internet.

<http://www.scotland.gov.uk/Resource/Doc/213661/0056769.pdf>

What to do after a death in Scotland: Social Security supplement

A booklet that provides information on paying for a funeral, administering the estate, and additional help available. It is available from Registrar's offices and can also be found on the internet.

http://www.stirling.gov.uk/d49s_apr.pdf

Citizens Advice Bureau

Benefits and bereavement

Information on benefits available to bereaved people, eligibility and how to apply.

In England, Wales and Northern Ireland:

[http://www.adviceguide.org.uk/index/your_family/family/what to do after a death.htm](http://www.adviceguide.org.uk/index/your_family/family/what_to_do_after_a_death.htm)

In Scotland:

[http://www.adviceguide.org.uk/scotland/life/benefits/benefits and bereavement.htm](http://www.adviceguide.org.uk/scotland/life/benefits/benefits_and_bereavement.htm)

Marie Curie Cancer Care

Bereavement: Helping you to deal with the death of someone close to you

A booklet that gives information about the practical and emotional issues that may arise for the bereaved. It contains information that is relevant to all bereaved people, not just those whose relative died of cancer. Sections include: what will happen immediately after the death; registering the death; the funeral; coping with grief; administering the estate.

<http://www.mariecurie.org.uk/Documents/PATIENTS-CARERS-FAMILIES/Updated-pdf/bereavement.pdf>

Department of Health

Help is at Hand

This guide is aimed at the wide range of people who are affected by suicide or other sudden, traumatic death. It also provides information for healthcare and other professionals who come into contact with bereaved people, to assist them in providing help and to suggest how they themselves may find support if they need it.

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_092247.pdf

NHS Scotland

Talking about Bereavement

This booklet provides information that helps people to understand bereavement, and what the bereavement journey may be like. It also provides coping advice and resources that may help.

<http://www.healthscotland.com/uploads/documents/9227-TalkingAboutBereavement.pdf>

The Royal College of Psychiatrists

Mental health information: bereavement

<http://www.rcpsych.ac.uk/mentalhealthinfoforall/problems/bereavement/bereavement.aspx>

This leaflet contains information about:

- How people normally grieve after a loss;
- Unresolved grief;
- Places to get help;
- Other sources of information;
- How friends and relatives can help.

3. Social support services

Directgov: public services all in one place

This website directs readers to all aspects of local government provision in the UK.

<http://www.direct.gov.uk/en/index.htm>

4. Organisations for older people

Age UK

The UK's largest charity working with and for older people.

<http://www.ageuk.org.uk/>

Age Scotland

Age Concern Scotland and Help the Aged Scotland have combined to form a new charity, Age Scotland, dedicated to improving the lives of older people.

<http://www.ageconcernandhelptheagedscotland.org.uk/>

Telephone: 0845 833 0200

5. Information for healthcare staff

Department of Health

Bereavement general information

Though applicable to health services in England and Wales, contains links to documents of interest to practitioners elsewhere e.g. the policy document for NHS staff, 'When a patient dies.'

<http://www.dh.gov.uk/en/Healthcare/Secondarycare/Bereavement/Bereavementgeneralinformation/index.htm>

The Scottish Government

Bereavement Care in Scotland

Website of the policy development group for ***Shaping Bereavement Care***, a framework for action to develop bereavement care within the NHS in Scotland.

The work covers four main themes:

- Issues around the time of death
- Issues around ongoing bereavement support
- Issues around staff support and training
- Issues around the co-ordination of bereavement work

<http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/bereavement>

Shaping Bereavement Care can be seen at the following web address:

http://www.sehd.scot.nhs.uk/mels/CEL2011_09.pdf

The Scottish Grief and Bereavement Hub

This is an online resource for those professionally involved in bereavement services. It is a meeting place and acts as an interface between bereavement care, bereavement research and bereavement service planning across the health and social care services and the voluntary sector in Scotland. Anyone with an interest in bereavement care is invited to join the Hub and share information and make contact with others.

www.knowledge.scot.nhs.uk/bereavement

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