

# **Bereavement Care for Older People**

## **Draft Guideline for Practice**

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## **Draft guideline for bereavement care for older people**

This document contains draft guidance for healthcare staff on providing bereavement care for older people. It has been developed by Audrey Stephen, a Research Fellow at The Robert Gordon University in Aberdeen. The guideline is the output of a PhD project that was designed to explore bereavement care for older people as it is provided in non specialised healthcare services. The project aimed to identify enhancements to current bereavement care provision for older people through development of the guideline for staff to use to inform their practice.

The guideline has been designed for the use of healthcare staff in general practices, hospital wards, nursing and residential homes. All staff who, from time to time, care for bereaved relatives in the course of their work can use the guideline. 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 guideline;

PART B. Draft guideline 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, cognitive, affective and social changes.<sup>1</sup> For most people those closest are the greatest source of pleasure, and consequently their loss is the greatest source of pain.<sup>2</sup> 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.<sup>3</sup>

Loss of a spouse or partner is a usual experience for older adults. In 2008 in Scotland 44,307 people aged 65 years of age or more died.<sup>4</sup> 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.<sup>5</sup>

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 in Scotland.<sup>6</sup> 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.<sup>7</sup> 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.<sup>6</sup> The guideline presented in this document has 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 care homes. Through contact with relatives of patients in the time leading up to a death, healthcare staff in these settings are ideally placed to ensure that older people set out on their bereavement journey with appropriate information and support to help them cope.

## **PART A**

### **DEVELOPMENT OF THE GUIDELINE**

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 the research 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 draft guideline.

## **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 describing older people's experiences of bereavement were identified in the available literature:

1. health effects;
2. loneliness;
3. continuing bonds with the deceased;
4. changed relationships with the self and others.

### **1.1 Health effects**

Bereavement and loss of a spouse or partner in particular, often takes place at a time when the older person has the increased likelihood of suffering from health problems. Coping with a loss can result in an older person having increased mental and physical health symptoms, including depression. In older people in general, depression has been found to be worst in those with poorer physical health,<sup>8,9</sup> and who have had a recent bereavement.<sup>8</sup> Intensively caring for the deceased person in the period leading up to the death may also lead to increased incidence of depression.<sup>9,10</sup> In addition, symptoms of post traumatic stress disorder have been identified in bereaved older people, in which feelings of helplessness, being unable to express needs, and fears of illness or death for themselves are reported.<sup>11</sup>

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. However, older people may be more resilient than other age groups and more likely to resolve their regrets leading to better mental health outcomes.<sup>12,13</sup> This may not, however, be the case for physical symptoms which are often chronic in nature.<sup>14</sup>

The frequency and intensity of physical and mental health symptoms in bereaved older people means that there can be a need for healthcare providers to maintain a link through follow up or regular surveillance of recently bereaved older people.

## **1.2 Loneliness**

Loneliness is a particularly dominant experience for 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.<sup>15-18</sup> Loneliness has also been identified as affecting bereaved older widows and widowers socially and/or emotionally.<sup>19</sup> More intense social loneliness was found where there was:

- slower disease progression in the person who died;
- poor health;
- more importance attached to receiving support;
- social anxiety;
- less support during the marriage;
- talking about the death more often;
- attaching less importance to contact with others.

Predictive factors for emotional loneliness were:

- having been unable to predict the death;
- poor physical health.

The study underlines the need to understand coping in widows and widowers and how this influences their support needs. It also highlights the vulnerability of bereaved older people to social and emotional isolation.

Loneliness is worsened 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. Costello<sup>20</sup> explored older people's perceptions of loneliness following loss of their spouse or partner and found that feelings of loneliness begin with the realisation that the lost person will not return. In addition, loneliness and social isolation were part and parcel of the social experience of ageing, and loss often meant being socially disenfranchised. Loneliness is not fully recognised or treated as a separate entity from grief leading to difficulty in coming to terms with the situation. Providing meaningful support and advice consequently challenges the wider social network and health and social care service providers.

## **1.3 Continuation of the bond with the deceased**

In recent years bereavement care has moved from being aimed at helping the bereaved to break bonds with the deceased to reflect more up to date knowledge that maintaining a bond with the deceased can facilitate adjustment.<sup>21</sup> 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.<sup>16,17</sup> In her study of the challenges of sustaining a meaningful life as a widowed spouse or partner, Hockey<sup>22</sup> 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<sup>15,23</sup> 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.

#### **1.4 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. As discussed above, 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.<sup>24</sup> 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.<sup>25</sup>

## **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)

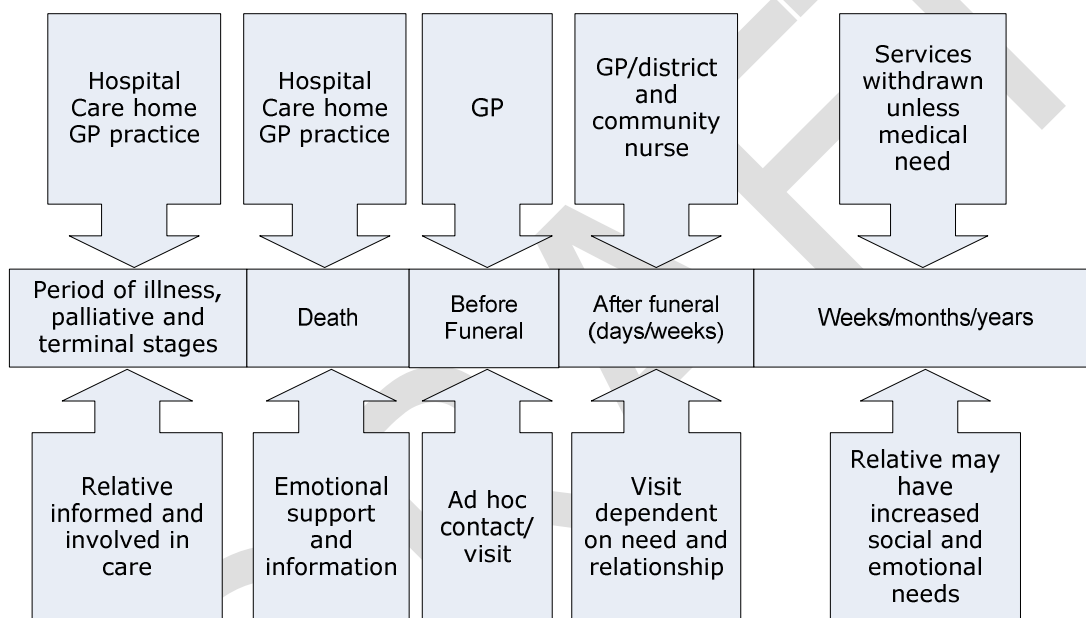
Interviews took place in a number of locations across Aberdeen and Aberdeenshire.

## Findings

### 2.1 Timeline for bereavement care

Interviewees described their contributions to bereavement care for older people in their area of practice. In general, bereavement care appears to be provided on a timeline, and where on the line healthcare staff have contact with a bereaved older person depends on where the staff member is employed (Figure 1. below).

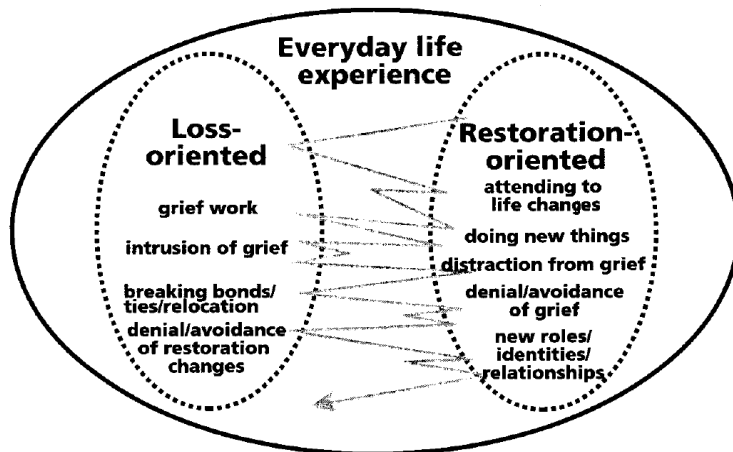
Figure 1. Timeline for bereavement care



The figure indicates when different staff groups have contact with relatives, and what is done to support them at that time. Where a death has been sudden there is no time to prepare relatives, and support may begin at the time of the death. Bereaved older people interviewed, however, did not describe their experiences of bereavement as linear. Bereavement for them is a continual cycle of facing emotional challenges, facing lifestyle changes associated with the loss of a husband or wife, and forming strategies that help them to cope. This has been described previously in the Dual Process Model of coping with loss (see figure 2).<sup>26</sup>

The model shows that a bereaved person experiences two types of coping with grief; loss oriented or restoration oriented. Loss oriented grieving includes initial numbness and disbelief, going over the illness and care of the husband or wife, and missing the husband or wife. Restoration oriented coping includes the bereaved

Figure 2. The Dual Process Model (26)



relative taking steps to deal with, for example, financial difficulties or learning to do tasks usually carried out by the other partner. The bereaved oscillate between both coping styles and in addition, take time off grieving by concentrating on other things.

This 'spider's web' of responses to grief often occur in the months and years after the loss. This may be when the relative is finding out what the loss means to them emotionally and socially, and is also a time when healthcare staff are less available to support.

## 2.2 Relationship with the family member

The follow up of a bereaved older person by healthcare staff depends on having had a relationship with them before the death of the patient or resident. The relationship before the death enables staff to prepare the relative and support them at the time of the death and, depending on where the service is located, into the bereavement. However, levels of preparation vary due to many factors and affect the reactions people have to bereavement. Interviewees often felt that even with preparation the death may still come as a shock.

Interactions with bereaved relatives usually come to a point where the relationship can be brought to an acceptable conclusion. This could mean that the staff member passes on concerns to others, but could also mean that the bereaved relative is being allowed to work their own way through their loss. Relatives are invited to contact services again if they have a need, though staff reported very few experiences of people making contact again. It appears that relatives do not see healthcare staff as an obvious place to look for support. However, for some staff

opportunities arise to check how the bereaved older person is coping through chance meetings, or when the relative comes to the GP practice for other reasons. This means that there is never a complete ending of the relationship and that staff are willing to speak about the bereavement when the need arises.

### **2.3 Communication**

Interviewees in the study describe little communication between healthcare sectors (wards to GPs, or care homes to GPs) as regards bereaved relatives. Hospital and care home staff routinely inform the patient's GP practice about the patient or resident's death, however, they did not know what was done with the information and whether it led to follow up of bereaved older people. Within general practices staff also report having a system for notifying GPs and district nurses of the death of a patient. However, this may or may not result in a bereavement visit to the next of kin. Those who slip through the net are the relatives of people who have died suddenly, and those who are not known to practice staff. Community nursing staff and GPs may at times communicate about the needs of bereaved relatives, and in some cases direct them to counselling or voluntary sector organisations, or refer them on to mental health services where necessary. However, after the first weeks and when people have to cope with the reality of the bereavement, less support is available. At this time bereaved older people's needs may be social, and there may be an opportunity for additional communication with social work departments and voluntary sector services.

## **PART B**

### **DRAFT GUIDELINE FOR BEREAVEMENT CARE FOR OLDER PEOPLE**

The findings outlined above directed the development of the draft guideline. In addition, examples of experiences of receiving and of providing bereavement care described by interviewees, and suggestions for things that could be included also fed into the process. To ensure a complete approach to bereavement care for older people was given in the guideline, items from current bereavement research, bereavement theories, and other guidelines, for example, in palliative care were identified and included.

#### **The layout of the guideline**

The guideline has 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 guideline 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 guideline can also be found in previous research studies and are referenced in the guideline. In addition, quotations from interviews are provided following each recommendation to validate the inclusion of some criteria in the guideline.

## **Intended outcomes of using the guideline**

### **1. For bereaved older people**

They are cared for consistently whatever the circumstances or care setting;

Their support needs are identified and addressed;

Care received is experienced as compassionate and supportive;

Where there are follow up needs, they are communicated to services that can provide support;

They are supported to be independent;

They receive appropriate information that allows them to seek help.

### **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;

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;

As a staff training tool.

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- Recommendation 2.4 Information

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- Recommendation 3.1 Plan follow up for the bereaved older person
- Recommendation 3.2 Bereavement visiting for the older person
- Recommendation 3.3 Follow up from non community based staff

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- 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: expected death**

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 come to terms with 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 thought 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 guideline 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.

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## 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 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, and come to terms with their inevitable loss.

#### Criteria

Communicate openly with family members, giving reliable and consistent information<sup>27</sup>

Encourage family members to come together and support each other

Give relatives the opportunity to be with the dying person

Advise relatives about sitting with the dying person

A member of staff sitting in when relatives are not there

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

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

- ✦ *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

### Prepare the older person for the loss

#### Recommendation statement

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

#### Rationale

The death of someone close is always hard to bear. Being prepared for the event can help people to come to terms with the situation and to more readily accept the death and adapt to bereavement.

#### Criteria

Help the older person to understand that their spouse/partner or relative is dying

Give the relative(s) information that they can cope with:

- prognosis
- time scale
- care decisions
- what the death could be like
- what to expect in bereavement<sup>28</sup>

Frequently reiterate the information

Include the family in decisions about end of life care

Involve the family in the care of the dying person<sup>29</sup>

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:

- undertaker
- funeral arrangements

Identify with the relative what bereavement may be like:

- a shock
- being alone
- difficult times (after the funeral, birthdays, anniversary of the death)

- ✘ *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)*
- ✘ *It was quite distressing, I knew the prognosis (bereaved spouse, male, 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

Document risk factor assessment (Appendix 1)

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)<sup>30</sup>

Communicate concerns to other services as appropriate: GP/community nursing team/social work department. However, 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, young person, trauma, suicide
Family/friends/community support	None identified, or unreliable
Health	Poor physical health, previous mental health problems
Other bereavement(s), last 2 years	1 or more, relationship as above
Perceived support needs	Relative's stated needs

An assessment form is provided in Appendix 1 (Form 1).

- ✦ *There must be 3 or 4 brief questions to illicit crucial information, like the CAGE questionnaire<sup>31</sup> 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 guideline covers the time of the death and what can be done to facilitate the bereaved older person's acceptance and understanding of the death.

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## Recommendation 2.1.

### Sensitively break the bad news

#### Recommendation statement

Sensitively break bad news of the death to the next of kin (or proxy)

#### 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 bad 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

Be honest, compassionate and empathetic

Introduce yourself and the hospital/home

Find out if there is someone there to support the bereaved older person<sup>32</sup>

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<sup>28,33</sup>

You may start by saying 'I am sorry to give you very sad news'<sup>34</sup>, then go on to inform the bereaved older person at a speed that they can follow and using plain English (is dead, or died)<sup>32,33</sup>

Allow time for the initial reaction<sup>32,33</sup>

Provide a short explanation of events

Answer questions<sup>32</sup>

Give verbal and non verbal reassurance of the normality of their reaction<sup>32</sup>

Explain the process following a death (if relative not coming to the hospital/ home)

Contact another family member if the bereaved older person is alone

Contact the GP if not already aware of the death

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

- ✧ *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 and denial, anger, shock, and aggression are common when someone has died suddenly. 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

Express words of sympathy

- 'I am very sorry'
- 'this must be very painful for you'
- 'you will miss him/her terribly'
- 'you will have some lovely memories of him/her'
- 'it was a privilege to look after him/her'
- 'he/she will not be in pain any more'

Allow the bereaved to express their feelings and acknowledge them, saying that 'it is alright to feel that way'<sup>35</sup>

Provide time for the bereaved person to talk with a nurse or doctor who knew the person who died about their feelings; the person who died; and what the loss means to them<sup>34</sup>

Give explanations: illness, events at death, care provided

Reassure the relative that they did all they could

Answer questions and listen to concerns

Touch the bereaved person<sup>32,34</sup>

Don't be afraid to show your own emotions<sup>32,34</sup>

Provide refreshments

Carry out last offices sensitively and respectfully

Allow the relative to be with the dead person before and after last offices, for as long as they need, in private or accompanied (warn the relative that the dead person may feel cold)<sup>33</sup>

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<sup>32</sup>

Accompany the relative to the door of the hospital/care home when they leave<sup>34</sup>

- ✧ *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)*

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## Recommendation 2.3

### Facilitate ongoing support

#### Recommendation statement

Organise ongoing support for the relative where there is a need

#### Rationale

The circumstances of the death and the bereaved older person's reaction will indicate whether or not there may be ongoing support needs beyond the first few days of bereavement. 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 and Appendix 1).

#### Criteria

With the bereaved older person's consent, communicate concerns based on risk factor assessment (Appendix 1) 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)<sup>33,34</sup>

Inform the GP/district nursing team/social work department of the situation and concerns, and ask them to visit the bereaved older person

If the relative is 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 the ward, home or general practice if they have questions about the death, about practical arrangements, or to discuss other concerns<sup>32</sup>

Provide contact details for the ward, care home, or general practice. Give the name of someone who knows the family and was present at the death.

Inform the relative that if they want to meet with staff at a later date to discuss the death, that this can be arranged

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, as I said already '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)*

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## 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 as 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
- counselling services
- faith groups

Resources are provided at the end of this guideline

- ✎ *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)*

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### **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 that they would like addressed. Bereaved older people, however, rarely reach back into services and may look for bereavement support elsewhere. Nursing and residential 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.

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## 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

- Receptionist notifies all GPs and DNs of the death
- GP who knows family to make contact with the closest family member – visit in first 3 days (before funeral)/phone if not in/send sympathy card or letter<sup>36</sup> if unable to contact
- If DN or community nurses know the family – phone in first 3 days, home visit in first 2-6 weeks (after funeral)<sup>37</sup>
- GP/nurse notifies receptionist if planning to visit
- If no member of staff responds to initial communication, receptionist notifies GP whom deceased/family registered with, who may then visit
- Note the bereavement in the medical records of the bereaved older person<sup>36</sup>

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

If the relative is registered with a different GP from the deceased, 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 and try to find out what their needs may be:

- brothers and sisters
- grand parents
- parents

✧ *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)*

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## Recommendation 3.2

### Bereavement visiting for the older person

#### Recommendation statement

A community based practitioner (GP/district nurse/community nurse/care home manager) carries 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/care home manager
- 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, when there are more likely to be support needs – GP/DN/community nurse/care home manager

Visit from someone known to the bereaved relative, who knew the dead person and is aware of the history of illness and care<sup>37</sup>

Set time aside for the visit

Take a compassionate approach<sup>36</sup>

Provide a safe environment that enables open discussion

Acknowledge the loss and their grief<sup>37</sup>

Allow the relative to talk about the dead person, being bereaved, and listen to what they say<sup>29,35-38</sup>

Validate how people feel, saying 'it is alright to feel like that'<sup>32</sup>

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

Reflect on events, clarify understanding

Reassure them that they did all they could

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

Acknowledge practical difficulties

Support and acknowledge efforts to cope

Support with decision making (i.e. moving house)<sup>37</sup>

Give permission to take a break from grieving<sup>32</sup>

Encourage social activities (previous and new)

Explore possible coping strategies

Acknowledge that other family members may look for support from the bereaved older person. Offer further support, or to contact other agencies that may be able to help (social work dept.)

Provide contact details for organisations (Cruse Bereavement Care Scotland, 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 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 you know, 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'm not, 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 had contact with them in the hospital, nursing or residential home where the patient/resident died.

##### 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 can be done from the ward of care home that can be supportive for the relative. The things identified below can be very supportive and comforting for the bereaved older person.

##### Criteria

Follow up phone call to relatives 1-2 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<sup>39</sup>
- notify GP of any concerns raised that hospital/home staff can't address (with the bereaved older person's permission)

Send a sympathy card<sup>28,29,30</sup>

Provide contact details for the ward or home, and a named person who knew the family well and can answer questions about the death

Invite relatives to contact the ward or home by phone or to visit in person if they have further support needs

If required, arrange a follow up meeting for the bereaved older person with a member of staff who knew the patient and family

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

Support relatives' efforts to thank staff – gifts, donations

- ✦ *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)*
- ✧ *At the funeral they collected, was it £600 I think it was and well I donated it to the Macmillan nurse and they bought chairs for the day room with the £600. I said, 'well at least it's done something' and the dayroom I used quite a lot when (husband) was in' (bereaved spouse, female, 60s)*

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## **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. Some of the services are located locally while others are nationally provided. Other resources are written materials that can be accessed via the internet. The list of resources 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 Scotland**

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

Two branches in North East Scotland:

Aberdeen: 01224 626199

Deveron: 01888 562145

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

Self referral

#### **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/>

## **The National Bereavement Partnership**

The National Bereavement Partnership is a registered charity offering a service that provides information, advice and support for people who have experienced bereavement, and for professionals working with the bereaved, particularly in the context of post-mortem examinations.

<http://www.natbp.org.uk/home.shtml>

Helpline 0845 226 7227

Address: Office No 3D, 3 Bear Street, Barnstaple, North Devon, EX32 7DB

Email: [info@natbp.org.uk](mailto:info@natbp.org.uk)

Self referral

## **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**

### **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 all NHS organisations in Scotland, it is also available 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.housingcare.org/downloads/kbase/2585.pdf>

## **Citizens Advice Bureau**

### ***Benefits and bereavement***

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

[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/NR/rdonlyres/CB08CE6E-C711-4227-910A-A694704BBD54/0/bereavement\\_booklet.pdf](http://www.mariecurie.org.uk/NR/rdonlyres/CB08CE6E-C711-4227-910A-A694704BBD54/0/bereavement_booklet.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](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/4476-Talking%20about%20Bereavement.pdf>

## **The Royal College of Psychiatrists**

### ***Mental health information: bereavement***

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

In this leaflet you will find 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**

#### **Aberdeenshire Council: Services for Older People**

[http://www.aberdeenshire.gov.uk/care/help/older\\_people.asp](http://www.aberdeenshire.gov.uk/care/help/older_people.asp)

For contact details of local social work offices see website.

Self referral or via a general practice.

#### **Aberdeen City Council: Community Care in Aberdeen**

[http://www.aberdeencity.gov.uk/Carers/ns\\_car/car\\_care\\_management\\_home.asp](http://www.aberdeencity.gov.uk/Carers/ns_car/car_care_management_home.asp)

Self referral or via a general practice.

### **4. Organisations for older people**

#### **Age Concern and Help the Aged in Scotland**

The two charities have combined and offer a range of support and help for older people.

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

Telephone: 0845 833 0200

Registered office:

Causewayside House,

160 Causewayside,

Edinburgh

EH9 1PR

## **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>

#### **Grampian Bereavement Resource and Interest Group (GBRIG)**

GBRIG is a group which formed in Grampian to share experience and promote the delivery of high quality bereavement care, linking people together as they seek to help people make their journey through bereavement. Many bereavement support resources and information are contained on the website.

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

#### **The National Bereavement Partnership**

The National Bereavement Partnership is a registered charity offering a service that provides information, advice and support to people who have experienced bereavement and professionals working with the bereaved, particularly in the context of post-mortem examinations.

<http://www.natbp.org.uk/home.shtml>

Helpline 0845 226 7227

Address: Office No 3D, 3 Bear Street, Barnstaple, North Devon, EX32 7DB

Email: [info@natbp.org.uk](mailto:info@natbp.org.uk)

## Appendix 1.

### Form 1. Bereavement assessment form

Name (bereaved older person).....Age.....

Address.....

Name (person who died)..... Relationship..... Date of death.....

Date	Assessment criteria	Circle appropriate response	Notes
	1. Relationship to deceased	Spouse/partner Parent Adult child Sibling (if also next of kin) Grandchild Carer Cared for person	
	2. Circumstances of the death	Sudden Young person Trauma Suicide Untimely	
	3. Family/friends/ community support	None Unreliable	
	4. Health status	Known health condition(s) (specify) New symptom(s) (specify) Previous mental health problem(s) (specify)	
	5. Other bereavement(s) in last 2 years	1 or more (relationship)	
	6. Perceived support needs	Relative's stated needs	

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