

Homelessness and end of life care

**Practical information and tools to
support the needs of homeless people
who are approaching the end of life,
and those who are bereaved**

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Homelessness and end of life care

This resource pack has been jointly developed by St Mungo's and Marie Curie Cancer Care as part of a partnership project to improve end of life care for people who are homeless. Funded by the Department of Health from 2008 to 2011, the project continues to help address the obstacles homeless and vulnerable people face in getting appropriate, high quality end of life care.

This project involves close working with St Mungo's residents and staff; primary and secondary healthcare providers; specialist palliative care service providers; and other relevant health and social care agencies.

Since the project began, it has developed an end of life care service at St Mungo's that has succeeded in:

- providing one-to-one support to residents on making informed choices of their preferred place of care until they die, and the type of care they wish to receive
- identifying potential end of life care indicators for advanced liver disease, a primary cause of death among people who are homeless
- delivering training to frontline hostel staff who provide the majority of end of life care support to St Mungo's residents

- rolling out this training to other homelessness agencies across the UK
- co-producing a number of booklets and resources, including this resources pack for hostels in the UK
- starting a pilot bereavement service within St Mungo's to meet the impact the death of residents has on other residents and frontline staff

For more information about the project, contact:

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February 2013

The purpose of this resource pack

Talking about death and dying does not come easily to most of us. It includes talking to family, friends and carers, as well as health and social care professionals about how we would like to be cared for as we approach the end of our lives.

For people experiencing homelessness there may be additional obstacles and barriers when it comes to planning their end of life care needs. Homeless people are more likely to have a combination of chronic physical and mental health issues and substance misuse problems. They are also less likely to access appropriate health and social services, or be willing to engage with healthcare professionals about their care needs.

Who is this resource pack for?

This resource pack is specifically designed to enhance the skills and knowledge base of managers and frontline staff working with homeless people. This includes those working in supported accommodation, assertive outreach, drug and alcohol services, and homeless day centres.

The pack is also intended to assist professionals working in hospitals, GP surgeries, palliative care services and social services who provide health or social care to people experiencing homelessness who are approaching the end of their lives or experiencing bereavement.

What's inside?

This resource pack contains information as well as practical tools and templates useful for supporting the end of life care needs of people who are homeless.

The pack describes effective ways of recognising and meeting their physical, psychological, spiritual and social needs as they approach the end of life. It also offers information about health and social care professionals who can provide support and care. In addition, the pack considers the importance of supporting the needs of significant others in their lives such as their family, friends and peers as well as frontline staff who support them on the ground. This includes any bereavement support they may need.

The pack is particularly relevant for supporting those living in homeless shelters, hostels and specialist projects accommodating homeless people with specific needs such as those with mental health problems.

This resource pack acts as a guide for the various stages of support, from identifying someone who may be approaching the end of their life through to assessment, care planning and into bereavement. It offers guidance on having difficult conversations about people's end of life care preferences and wishes.

Further guidance, support and online resources

Email: endoflifecare@mungos.org

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www.mariecurie.org.uk/stmungos

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What do we mean when we talk about end of life care and palliative care? What does it consist of, who provides it and is it different from the way people normally receive support from health and social care providers?

There are a number of ways to explain what palliative and end of life care mean, so the best place to start is with definitions of both.

What is palliative and end of life care?

What is palliative care?

“Palliative care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. It enables the supportive and palliative care needs of both the patient and their family to be identified and met throughout the last phase of life and into bereavement.”

Source: National Council for Palliative Care (2006)

The first thing to consider from this definition is that it refers to people whose illness is incurable - where the likelihood is that at some point they will die from their illness. For example, when active treatment such as chemotherapy is no longer effective for treating a particular cancer or a person decides not to accept treatment, their illness is likely to be deemed

no longer curative and at this point they can be referred to palliative care services for support. Alternatively, people may continue to receive treatments, but it will only be for palliative care. Many aspects of palliative care can also be applicable very early on in the course of some diseases, and people may receive it as and when required over long periods of time eg for long term incurable illnesses such as motor neurone disease (MND) or multiple sclerosis (MS).

Secondly, it is a holistic approach and the support provided includes the psychological, emotional, spiritual, social and cultural needs of the person living with a life-threatening, incurable illness.

Thirdly, there is an emphasis within palliative care on the importance of open and sensitive communication with the person concerned and their family. People have the right to determine where they wish to receive care and where they wish to die. A personal care plan is an important part of palliative care that helps to preserve a person's autonomy and choice by documenting their personal needs and wishes should their condition deteriorate.

Finally, palliative care is about supporting everyone involved in a person's life, such as family, friends and carers. This will also include you and your team where a resident is residing at a hostel or within a project.

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What is end of life care?

End of life care or terminal care is an important part of palliative care.

It usually refers to the care a person receives during the final phase of their life, when it becomes clear that they are in a progressive state of decline.

While it is often very difficult to know when someone is going to die from a life-threatening disease, many medical professionals may define someone as being terminally ill when it is expected that there is only a short period of time, perhaps a few days or weeks, or at most a few short months, before the person is expected to die.

The care of someone in this final phase of life can be provided in hospital, at home with home-based services, or in a hospice or nursing home.

Many healthcare professionals can be involved in providing such care depending on the person's needs. They may include hospital doctors and nurses, GPs, community nurses, hospice staff, counsellors as well as social service workers, religious ministers, physiotherapists or complementary therapists. Specialist palliative care teams may coordinate some of the services that a person receives at this phase in their life.

In general, end of life and palliative care aims to:

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help people to live as actively as possible until their death
- Offer a support system to help the family cope during the person's final illness and in their own bereavement

Who provides palliative care?

There is a whole range of services to support the holistic needs of people who meet the criteria for palliative care. Support can be provided as and when required over a long period of time, or more intensively as someone approaches the last weeks, days and hours of their lives.

- **General palliative care** can be provided for people with low to moderate palliative care needs by their GPs, community nurses, hospital teams and social care agencies. It will also include the care and support you and your team provide.
- **Specialist palliative care services** are provided for people with moderate to highly complex palliative care needs.

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What are specialist palliative care services?

The main aim of specialist palliative care services is to support people to live as actively and as well as possible until they die. This is normally provided by multidisciplinary palliative care teams. **Their main aim is to offer:**

- specialist advice
- symptom management eg for pain and nausea
- care and support for patients, family members and carers

Many teams also provide bereavement support to families and carers of people who have died in their care alongside community-based bereavement services.

They also work alongside other health and social care professionals, offering specialist advice to GPs and district nurses, as well as working with specialist end of life care nurses, such as Marie Curie and Macmillan Nurses and social services.

It is important to remember that the role of the team is advisory, regardless of whether the person is in hospital or in a community setting. The overall responsibility for medical care remains with the hospital consultant if the person is an in-patient or their GP if they are at home or in a nursing home. However, in specialist palliative care units such as an in-patient unit of a hospice, palliative care consultants have overall medical responsibility for their patients.

Where is palliative care provided?

The end of life care needs of people who are dying can be met in a variety of settings such as a home or hostel, hospital, nursing home or hospice.

Of the half a million people who die in England each year, 70% of people would prefer to die at home. However more than half of all deaths are likely to occur in NHS hospitals, with only 18% of us dying at home; 17% of us are likely to die in a care home, 4% in hospices and 3% elsewhere.

Source: National Council for Palliative Care - Dying Matters Survey (2009)

Being cared for at home requires on-going assessments and planning from those providing the day-to-day care of a resident who is terminally ill (GPs, district nurses, social services), as well as the support you and your team provide. A specialist palliative care team can also provide care, once a resident has been referred to and accepted by them.

If a resident needs to go into hospital, the hospital consultant may involve the in-patient specialist palliative care or community teams on discharge, if appropriate. A person can also be referred to an in-patient unit of a hospice for symptom management, rehabilitation or when approaching the last weeks and days of life. Respite care or attending a hospice day centre or outpatient clinic may also be offered.

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It is really important to remember that while you and others may try to do everything you can to enable a resident to remain in their hostel until they die, if that is their expressed wish, it is not always possible to achieve this outcome as many factors will need to be taken into account. This does not mean that you have let them down – it is a part of the reality of the way things may develop and turn out.

What does a palliative care team look like?

Specialist palliative care teams vary according to location but could include:

- Palliative care consultants and doctors
- General and specialist nurses
- Social workers and welfare officers
- Occupational therapists and physiotherapists
- Other specialist staff ie dieticians and pharmacists
- Counsellors and psychologists
- Psychiatrists
- Chaplains
- Complementary therapists
- Art therapists
- Bereavement support volunteers

Who can refer to a palliative care team?

Healthcare professionals can refer any person with a life-limiting illness to palliative care services, where it is deemed that the complexity of the illness needs the services of a specialist palliative care team. If the person is in the community, this would ordinarily be someone like the person's GP or a district nurse. If in hospital, a person can be referred by a medical consultant or their team. In some areas the criteria for referral to a specialist palliative care team also extend to the person themselves, their families or carers. It is always worth checking this out with your local specialist palliative care team to see whether this is possible.

It is important to remember that the person with a life-limiting illness must give their consent before a referral is made to a specialist palliative care team.

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Palliative Care Consultants (and their medical team) care for people with life-limiting illnesses, with the aim of making their lives more comfortable even though their condition is deteriorating. Symptom control is a large part of their work, but they also deal with social and psychological difficulties, and get involved in the needs of their family and carers.

Specialist Palliative Care Nurses offer pain and symptom control as well as emotional support to people with a terminal illness and their carers. Care from a palliative care nurse may be provided as a result of a referral by a GP, hospital team or District Nurse.

District Nurses organise and coordinate care in the home. They can arrange for services to be provided for people and their carers. Additional services vary from area to area but may include Marie Curie and/or Macmillan Nurses and social services. The District Nurse can also provide information about local services that can be accessed directly such as carers' groups, local hospices, drop-in centres, interpreting services, complementary therapy practitioners and benefits advice.

Community Matrons are experienced skilled nurses who use case management techniques for people who meet the criteria denoting a very high intensity use of healthcare. With this specialist intensive help they aim to enable people to remain at home for longer and have more choice about their healthcare provision.

Macmillan Nurses work closely with GPs, District Nurses and other healthcare professionals to help provide pain or symptom control, guidance and support for their patients, their families and carers at any time in their illness, from the point of diagnosis to death. They predominantly support people with a cancer diagnosis.

Marie Curie Nurses provide high quality nursing care for people in their own homes – this includes hostels and sheltered housing – when they are approaching the end of life. This nursing care is provided to people with any terminal diagnosis. The care provided is frequently out of hours, predominantly overnight, and is focused on supporting a person to die in their place of choice.

Social workers can provide support to help individuals and their families deal with the emotional and psychological consequences of living with a life-limiting illness. They can also support carers to talk about how they are managing and about any additional help and resources available to them.

Welfare officers are trained to help ease financial worries and maximise income. Financial help may be available in the form of welfare benefits, tax credits, grants and loans. Practical and financial problems can often arise when someone is ill. There may be worries about unpaid bills, extra expenses or reduced income.

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Psychologists can conduct psychological assessments, provide counselling for those who face psychological difficulties, run groups for them and their carers, and facilitate communication with healthcare practitioners. They can also provide psychological therapies, training in pain management and help with compliance to treatment.

Physiotherapists and occupational therapists can help people to maintain their strength for as long as possible in order to continue their daily activities. They can also teach techniques to help them deal with breathing or mobility problems and can provide equipment such as wheelchairs.

Dieticians are healthcare professionals who can provide practical information about food. Terminally ill people often experience problems which affect their nutrition, such as loss of appetite, nausea, constipation, mouth sores and swallowing and digestion problems. Dieticians can provide advice on the type of food, the quantity to eat and the timing, or the way that it should be consumed.

Complementary therapists provide a variety of therapies such as acupuncture, aromatherapy, relaxation, chiropractic, homeopathy, massage, osteopathy and hypnotherapy. Complementary therapy is a form of therapy or medicine that “complements” conventional treatments such as chemotherapy or radiotherapy. Complementary therapies may help boost the immune system, relieve pain, improve sleep patterns, increase energy levels, and reduce stress and tension.

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What is palliative and end of life care?

- Palliative care refers to a particular type of care and support available to anyone with an incurable illness eg terminal cancer. The emphasis is on enabling someone to live as well as possible until they die. This support is extended to everyone involved in their lives, including you.
- It is a holistic approach that aims to meet the physical, emotional, psychological, spiritual, cultural and social needs of someone living with a terminal illness, as well as the needs of their family, friends and carers.
- End of life care is part of palliative care and normally refers to the care and support provided in the last few days, weeks or short months of life as a person's health begins to deteriorate. When someone is considered to be in the final phase of their life they may be cared for in hospital, at home with home-based care, in a nursing home, or at a hospice. It is important to remember that it may not always be possible for a resident to die in their preferred place of care.
- Palliative care is a multidisciplinary response to care and is usually provided by a range of health and social care professionals (eg GP, district nurse, hospital medical teams, general and specialist palliative care teams, and social services) and in a variety of settings (home, hospital, nursing home or hospice).
- The main aim of a specialist palliative care team is to offer specialist advice to a person who is terminally ill as well as those caring for them. This can include advice on symptom management (such as pain and nausea) and a range of emotional, psychological and practical support. This support includes you and your team.
- It is mainly healthcare professionals who refer a person to palliative care services, but in some geographical areas the criteria for referral is extended to the person themselves, their families and carers. Check with your local palliative care team if you or your client can refer directly to them, or whether you need to go through your client's GP or their medical team if they are in hospital.

Remember, a person who is terminally ill must be willing to meet with a specialist palliative care team before a referral can be made. If you prefer for someone else to introduce the role and benefits of a palliative care service to a resident, you may wish to ask their GP or hospital team to approach the subject with them.

Knowing when a resident may require end of life care

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“Residents are not always aware that they are dying – some young ones dropped dead recently – they were completely unexpected.” Frontline staff

It is not always easy to determine if, or when, someone is approaching the end of their life. Signs can vary from person to person.

For some, it might be at the time of diagnosis of a condition that carries a poor prognosis (eg motor neurone disease). For others, it may be that they have had a chronic illness for some time, and remain in reasonable good health until they begin to deteriorate in the last weeks or months of life. Some conditions also have a varied prognosis (eg heart failure), in which one person may die within months, while another may survive for many years.

A **diagnosis** normally refers to a particular illness or disorder that has been identified, eg a cancer diagnosis.

A **prognosis** normally refers to the likely outcome of a disease and will include an estimated length of time a person has left to live. Some people do not wish to be told this, and medical teams may underestimate or overestimate it. However it is a useful guide when planning the person’s care.

When considering if a resident might meet the end of life care criteria, ask yourself the question: **‘Would I be surprised if this person were to die within the next six to 12 months?’**

If the answer is ‘no’, you can begin to explore your concerns with the resident and/or, with the resident’s consent, their GP. Saying ‘no’ is enough to warrant some further investigation and does not necessarily mean that the resident is actually dying. An assessment may lead to the resident receiving appropriate palliative care and/or end of life care support, or at the very least is an opportunity to alert others, particularly healthcare professionals, to the possibility that the resident may require this type of care in the near future. If the resident is in hospital, you can also explore, with the resident’s consent, your concerns with their hospital consultant or medical team.

Other factors that may identify a resident as needing end of life care might be:

- **Choice or need** – This is where a person with advanced disease makes a choice for comfort care only and not ‘curative’ treatment, or is in special need of supportive or palliative care. It may include someone with advanced liver disease who may choose to continue drinking knowing that they are most likely to die from their disease.
- **Clinical indicators** – There are general and specific indicators of advanced disease for each of the three main end of life patient groups – cancer, organ failure, and elderly frail or dementia – that help to determine how long someone has to live.

It is not easy to predict how long people will live with any particular illness. But for each of the main types of diseases that people may die from, their illness trajectories could give you an indication.

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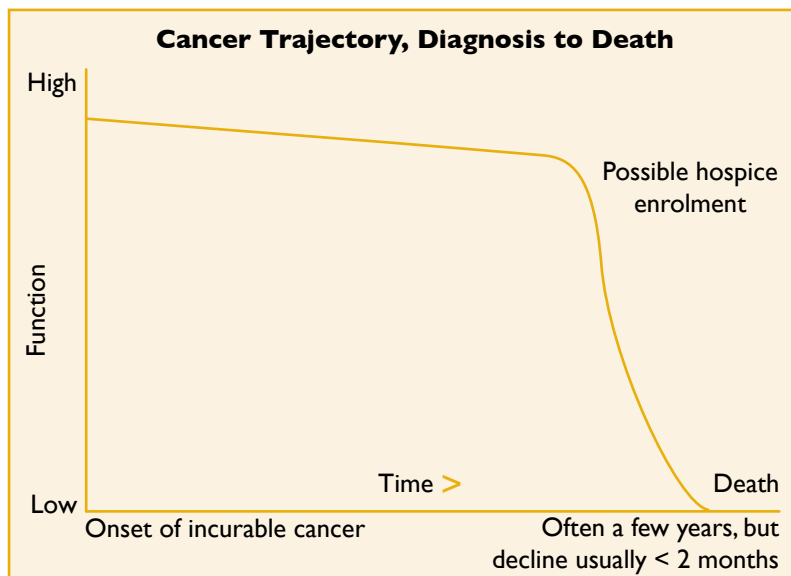
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Disease trajectories

Definition of disease trajectory: The way in which a disease develops over time. It is often referred to as a person's journey from diagnosis to death.

Cancer trajectory

The graph below represents a cancer trajectory. Here a person may have relative stability for a period of time, allowing them to live their lives as actively as possible, as well as giving them and their carers time to prepare for the final stage of life. This stability is followed by a rapid decline, which usually means less than three months to live.

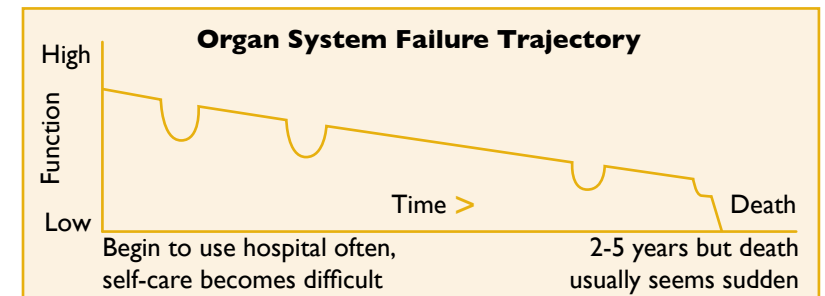


Organ failure trajectory

The graph below represents people who are likely to die from organ failure including liver, heart or kidney disease. This trajectory is characterised by periods of relative stability followed by periods of instability in which a person's health declines, perhaps for a few days or weeks before their health begins to show signs of improving. This may involve periods of time in hospital.

Though a person may recover from these dips in their condition, they are unlikely to go back to their optimum health and there is likely to be a rapid decline towards death at the end. Despite the steady decline over time, their death may be perceived as sudden. This type of trajectory can also make planning for end of life care more difficult, as there is less predictability as to how much time a person may have to live or identifying when they may meet the criteria for specialist palliative care.

This trajectory is particularly evident in residents with advanced liver disease, a primary cause of death for people who are homeless.



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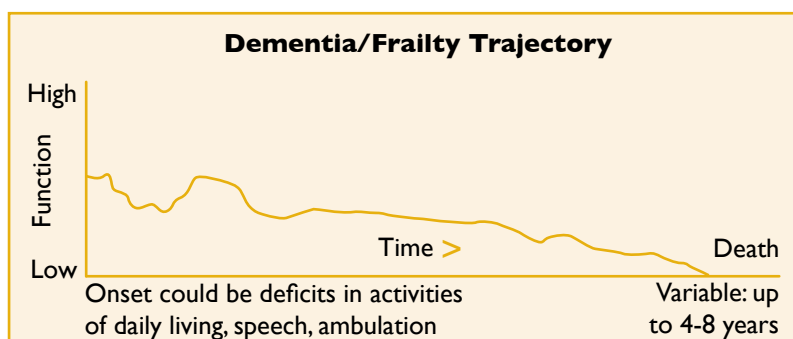
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Elderly frail or dementia trajectory

The graph below represents people who may be elderly frail or have dementia. This patient group needs longer community support as the progression of their illness is gradual and spread over a period of about six to eight years.



Signs of a deteriorating condition

There are also some general and specific predictors that help indicate possible signs of when a person might be approaching the final stage of life. It is important, however, to consider that these should only assist healthcare professionals (consultant, GP or nurse) to make informed decisions about where a person might be in their illness trajectory.

General indicators of end-stage illness might be:

- Weight loss - greater than 10% weight loss over six months
- General physical decline
- Dependence on others in most activities of daily living

However, these general predictors may also refer to other

illnesses, and does not assume that a person is approaching the end of their life.

Cancer indicators

Non-curative patients who are spending over 50 per cent of their time in bed or lying down is indicative of a prognosis of three months or less.

Heart disease indicators

At least two of the indicators below:

- Stage III or IV heart disease – shortness of breath at rest or after minimal exertion
- Patient thought to be in the last year of life by the care team – the ‘surprise’ question
- Repeated hospital admissions with symptoms of heart failure
- Difficult physical or psychological symptoms despite optimal tolerated therapy

Chronic obstructive pulmonary disease (COPD) indicators

- Disease assessed to be severe by medical staff
- Recurrent hospital admissions
- Fulfils ‘long-term oxygen therapy’ criteria
- Person suffers shortness of breath after 100 meters on the level, or is confined to the house through breathlessness
- Signs and symptoms of right heart failure
- Six weeks of systemic steroids for COPD in the preceding 12 months

Advanced liver disease indicators

There are no formally recognised prognostic indicators in the UK at present.

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Advanced liver disease

“The problem relates to the fact that residents can go down and down and then bounce back up again and their symptoms get better, it’s peaks and troughs.”

Frontline staff

Alcohol-related liver disease can be a primary cause of death for many people who are homeless. It can be further exacerbated if someone has a long-term liver infection, such as hepatitis B or hepatitis C.

Unlike other disease trajectories, people are likely to move through stages of feeling unwell, more often than not involving crisis admissions to hospital followed by periods of wellness, though never recovering fully. This can be their experience from anywhere between two years to weeks and days before they die, with the level of support and likely admissions to hospital increasing towards the end of their lives.

When feeling well, people may choose not to want to talk about the seriousness of their illness or to engage with any services, particularly end of life care services. Some may even think that, as they are feeling better after a period of illness, everything is all right. Most will struggle to stop drinking even when they are feeling unwell.

There are many things to consider when addressing the concerns of a person with advanced liver disease who you feel may be approaching the end stage of their life. Some of these

concerns may be easily addressed, but given the unpredictable nature of advanced liver disease, some may be harder to pin down and resolve.

Main concerns will include:

1) Predicting when a person is likely to die from advanced liver disease

As there are no prognostic indicators for advanced liver disease, this can make it difficult to link the signs and behaviours of advanced liver disease with possibilities for palliative care support, including exploring with residents their future needs and wishes.

However, in the absence of prognostic indicators, there are some physical and behavioural symptoms that may indicate that someone is approaching the end of their life, and may be helpful as a guide to you when initiating conversations with a resident, their GP or hospital medical team.

Physical symptoms

- Swelling of the abdomen (ascites)
- Yellowing of the whites of the eyes and the skin (jaundice)
- Bleeding from the rectum, mouth and nose
- Not eating
- Fluid in the legs (oedema), difficulties with walking and balance
- Prominent veins
- Tiredness or malaise
- Periods of memory loss and confusion (encephalopathy)

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Behavioural symptoms

- Withdrawn
- Isolated
- Poor self-care
- Continued or binge drinking
- Requests for detoxification
- More frequent admissions and longer stays in hospital

A person with liver disease can experience the symptoms and behaviours mentioned above sporadically over a short number of years or several months. An increase in the frequency of these symptoms occurring, and shorter gaps between admissions to hospital, are indicators that the person's disease may be progressing and that it is an appropriate time to begin asking more questions about end of life care support.

2) Having enough information about a person's condition

The more you know about the extent of a person's liver impairment, the better you will be able to anticipate the support they will need at home.

As a person with liver disease becomes more unwell, you may, with their consent, have ongoing discussions with their hospital medical team or GP about whether they may be approaching the end of their life. Often a liver consultant or GP may tell their patient that if they do not stop drinking, they are likely to die within a certain period of time – eg a year or possibly months.

While this may not be a definitive prognosis, it would indicate how serious the person's liver is impaired and, especially if they were to continue drinking alcohol or use other substances, that they may be approaching the end of their life sooner than is realised.

Remember that you and your colleagues are more likely to observe any changes in a resident's health or behaviours, particularly as you know and see them on a regular basis. The more healthcare professionals know about your concerns, the more likely a resident's well-being can be managed appropriately.

3) What additional support are people likely to receive?

From external agencies:

As a person goes through several periods of feeling unwell, the bulk of their medical and nursing care needs will either be managed at home in their project by their GP or by a hospital medical team.

If a person meets the criteria for end of life care, a palliative care team may then be able to offer additional support, either in the community or in hospital. However, these support may vary from location to location or offered on a 'as and when basis', meaning that their service could dip in and out over time according to a person's needs at any given moment. It may include support in managing pain and other symptoms, or hospice respite.

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The palliative care team may also be able to have important conversations with the person about advanced care planning; offer them psychological and emotional support; and provide support to you and your team.

Whether a person has or has not met the end of life care criteria (as determined by their GP, hospital medical team or other healthcare professionals), it is always worth making contact with the people involved in their care if you have any concerns, are looking for advice or would like to know more about the kind of support your local palliative care provider can offer.

Within a resident's hostel:

A resident may wish to remain at home in their project throughout their last months and weeks of life, or there may be limited availability of more appropriate places of care to move to.

When supporting a resident with advanced liver disease at home, it is important that you are realistic about the support you can expect to receive from health and social care professionals in the community, and what can be managed within the hostel or project.

What may surprise you is that you can manage much better than you might initially realise. Apart from the nursing and medical care a resident receives, support at home could include emotional, psychological and practical support. This may appear challenging or difficult at times, particularly when residents make informed decisions that are felt to be unbeneficial to their overall health, such as continued drinking knowing they are likely to die as a consequence.

“It is very hard to stand aside and watch someone drink themselves to death. We encourage them to try things but cannot force them.”

Frontline staff

Hard as it may be, it is important to find a way of continuing to support and advise a resident while at the same time respecting the choices they make. Empowering residents in this way may shift the dynamic of the relationship you and your team will have with them, especially if the emphasis has previously been on them stopping drinking. This may lead to a more open and trusting relationship in which to explore the seriousness of their illness with them, of finding out more about their preferences and wishes, and of letting them know that whatever decisions they are likely to make, you and your team will support them as best you can.

A resident may request or accept the offer of a detox and rehabilitation programme in the last months or weeks of life. If medically assessed as appropriate, it may increase life expectancy by some months or even years, or it may not. Seeking clarification from medical professionals is very important. It may also be the case that they are unable to undertake a rehabilitation programme, but a detox may give them an opportunity to be reflective about what their preferences and wishes might be, or provide some reprieve from the symptoms they are experiencing.

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It is important to allow residents to be as realistic as possible about the choice they make around detox and rehabilitation. There should also be good communication between the community or hospital-based services about the importance of detox at such a late stage in a resident's illness trajectory.

More information on prognostic indicators is available on the [Gold Standards Framework website at www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)

For more information, you can refer to the joint study by St Mungo's and Marie Curie Cancer Care published in 2011 – *Supporting homeless people with advanced liver disease approaching the end of life*. This study highlighted the need for hostel staff to be able to identify the symptoms that a resident is showing at the end of their life. A significant proportion of hostel residents who die each year have advanced liver disease that can lead to psychological and physical symptoms that hostel staff might not recognise as a sign that a resident is dying. To read the study, visit: www.mariecurie.org.uk/stmungos

Making a referral for palliative and end of life care

It is important to gather as much information as you can before making your concerns known to the resident, their GP, hospital medical team or palliative care professional. The following checklist aims to help you do that.

Where an actual prognosis is known:

- Who is the source of the prognosis? (eg consultant, GP, nurse specialist)
- Is the resident aware of their prognosis?
- Is their prognosis months, weeks, days or imminent?
- What are the main reasons for a potential referral (eg physical, psychological, social)
- Has a referral been made to a palliative care service?

Where a prognosis is *not* known but there are concerns that someone may be approaching the end of their life:

- What is the primary or secondary diagnosis?
- Who is the source of the diagnoses? (eg consultant, GP)
- What are the main concerns for the resident?
- Is the resident aware of your concerns?
- Who else is aware of these concerns?
- Have these concerns been discussed with any of the following: consultant, GP, nurse specialist or district nurse?

Identifying early on if someone is approaching the end of their life is beneficial for both the resident and those supporting the resident. It can allow more time to effectively plan appropriate care and support for the resident. It may be that on initial referral to specialist palliative care services no particular action is taken, but the resident's future support needs and wishes may be identified and their illness trajectory (journey) can be monitored.

Denial and crisis management is the alternative, but this can be avoided if there is some acknowledgement of the situation and planned care is implemented.

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Case study – Jose, aged 34, diagnosed with advanced liver disease

Jose lived in a 'continued use' hostel where residents were allowed to continue their use of alcohol and other substances. He had a history of poly substance misuse from an early age, and also had hepatitis C.

Following a number of admissions to hospital, mainly for ascites and jaundice, Jose was informed that he would die within 12 months if he did not stop drinking. And if he abstained from drinking for nine months, he could be considered for a liver transplant, particularly given his age.

But Jose struggled to stop drinking. On a couple of occasions, he managed to abstain for several weeks before relapsing again. Abstaining was most apparent at times when he felt unwell, often following a crisis hospital admission. He also struggled to remain in hospital when admitted and often self-discharged back to the hostel.

In the last 12 months of his life, Jose attempted both a community and hospital detoxification programme but was unable to complete either. When feeling well he would underestimate the seriousness of his condition, citing his age as a reason why he was not going to die, or state that the symptoms were related to other factors. This made it all the harder for staff and others to engage fully with him about the seriousness of his illness, and in gaining more knowledge about his preferences and wishes.

Staff also became worried about their ability to care for him, and anxious about how they would cope as his health deteriorated. Moving to a more appropriate project was not an option, as he had no entitlement to housing benefit.

Jose accepted support from the community palliative care team in the months leading up to his death. The initial referral was for symptom management, particularly pain management, and the team visited him four times, as well as met with his hostel team on three occasions.

Nearer the end of his life, Jose made a request to return to his native country to re-connect with family whom he had not seen in 18 years. The palliative care team began making arrangements to enable him to fly home with the support of a palliative care nurse and a staff member. However, his health deteriorated rapidly, and following an admission to hospital he died several days later. A major part of his care at the end was from the in-patient palliative care team.

Learning points:

- Jose was supported by the palliative care team in the last months of his life. With his continued substance misuse, they supported his GP in managing his symptoms, particularly pain. The bulk of his nursing care was from a nurse-led intermediary care team and as a hospital in-patient. It is nearly always anticipated that someone with advanced liver disease will have several admissions to

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hospital in the last months of their lives. Their deaths are often perceived as sudden, though not unexpected, and some may die suddenly at home.

- The community palliative care team also supported hostel staff in the last months of his life. They attended three team meetings to address staff concerns as Jose's health deteriorated, especially their concerns about the possibility of him dying unexpectedly at the hostel.
- The palliative care team was also a link between the hostel and hospital, helping as a first port of call with admissions, and in planning Jose's discharges with the medical team. On occasions when Jose self-discharged, they helped intervene to have him re-admitted.
- Finally, and most importantly, Jose was able to stay at the hostel to the last days of his life. The hostel was his preferred place of care, and he held a very paternal view towards many of the staff. Despite becoming too unwell to get home to his family, he did get to reconnect with them in other ways. With the emphasis on 'everything's been done that could be done' to get him home, the possibility of getting home kept him going for some time, and he knew that the people caring for him had his best interests at heart.

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- **It is not always easy to know when a person may begin to need end of life care support.** This varies according to the different types of illness people can die from eg cancer, organ failure, elderly frail or dementia, and even varies for people with the same type of illness.
- **There are certain indicators that can help healthcare professionals identify if someone is going to die from their illness.** For instance, when a person's illness is no longer responsive to treatment (such as chemotherapy or radiotherapy for a cancer diagnosis), or when someone refuses treatments, opting instead for comfort care only.
- **Healthcare professionals may estimate the length of time a person has left to live (referred to as a prognosis).** It is important to remember that people do not always wish to be told their prognosis and medical teams may under or over estimate it.
- **It is hard to predict when someone is likely to die from advanced liver disease,** making it more difficult to plan care. Please refer to the section in this chapter on advanced liver disease for further information.
- **The surprise question** is a useful guide to begin to question if a resident may be approaching the end of their life. Ask yourself this question: *'Would I be surprised if this person was to die within the next six to twelve months?'*

If the answer is 'no', you may wish to explore your concerns with the resident, and/or, with the resident's consent, their GP or medical consultant. It is also enough to justify initiating some further discussion and considerations; however it does not always mean that the resident is imminently dying.

- **When raising your concerns with other health and social professionals have as much medical information as possible about a resident's illness or prognosis.** Remember that a resident does not need to have a known prognosis before you raise your concerns. An initial enquiry may reveal that a resident either meets the criteria for end of life care support, or may require it further down the line but in the interim period still require some level of support at home. This is particularly important when your concerns are for someone with advanced liver disease, who can have many months or short years remaining to live.
- **It is important to remember that you and your team are the ones who are most likely to know a resident the best** as you interact with them on an everyday basis. What you have to offer other health and social care professionals is invaluable, and you should never hesitate raising any concerns you have with them. Identifying early on if someone is approaching the end of their life is beneficial for both the resident and those supporting the resident, as this can allow more time to effectively plan appropriate support needs with, and for, the resident.

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Ongoing assessments are an important part of the support a resident receives as their health begins to deteriorate. Like other types of assessments, there are those which are undertaken by external services and those you and your team will need to undertake. These assessments ensure a resident's wishes are known, and that their hostel or project is appropriate to enable end of life support and care to be provided to them. These assessments can be formal or informal.

Assessments carried out by healthcare professionals

Once a person meets the criteria for specialist palliative care, an initial assessment is undertaken by the community or hospital palliative care team, depending on where the person is residing at the time. This assessment will help identify a person's current support needs, (eg symptom management, nursing or personal care). The assessment will include the care and support the person is already receiving from you and your project, as well as their GP, district nurse, social services and hospital consultant.

Through ongoing assessments, the palliative care team will then consider any likely changes to the person's health. Further deterioration in a person's health may require more input from the team. As a person approaches the end stage of life, decisions will need to be made as to whether their current home is the best place to reside, or whether a more appropriate place of care is needed, such as a hospice or nursing home. A person's care needs may also change

unexpectedly and quite immediate decisions could sometimes be necessary.

The palliative care team will offer you and your team ongoing advice and support in managing a resident's care at home, including out of hours support if you have any serious concerns.

The following will require assessment by a health professional:

Advance care planning (ACP)

An important part of an external assessment is called 'advance care planning'. This is a discussion about future care between an individual and their care providers (eg GP, nurse or social worker). The difference between ACP and general care planning is that the process of ACP is to enable a person to make some specific choices about their future healthcare should a time come when they lose capacity to make decisions for themselves. A person will lack capacity if they are unable to make a particular decision because of an impairment or disturbance of the mind or brain, whether temporary or permanent.

These discussions may include a discussion about the decision by someone not to want particular medical treatments in the future.

Advance decision to refuse treatment (ADRT)

Previously known as a living will or advance directive, this is a decision a person can make to refuse a specific medical treatment, in whatever circumstances they specify, even if it may

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put their life at risk. The ADRT will not be used if the person is able to make informed choices at the time the treatment is being offered, and only applies in the event where a lack of capacity is clearly demonstrated. However, what an ADRT cannot be used for is to refuse basic nursing care to keep a person comfortable.

An example of an ADRT document is listed in this resource pack in Section 7: Tools and templates.

Mental Capacity Act 2005

“What if I can't speak for myself?” Resident

The Mental Capacity Act 2005 supports those who have capacity to plan for their future. It also protects those who lack capacity, providing the guidelines that ensure any decision taken on their behalf will be made in their best interests. It is underpinned by five key principles:

1. An assumption of capacity
2. All practical steps are taken to support people to make their own decisions
3. People have the right to make unwise or eccentric decisions
4. Any decision made on behalf of a person who lacks capacity must be in their best interests
5. Rights and freedoms must be restricted as little as possible

It is important for people to know that this kind of directive exists, and that there are healthcare professionals such as their GP or the specialist palliative care team who can sit down and talk with them about their future choices for care. There are various leaflets available about advance care planning (ACP) and advanced decision to refuse treatment (ADRT) – please refer to the information below – which may be helpful to review when opening up discussions with a person with whom it may be appropriate to talk about ACP with a healthcare professional. Equally, the person may not wish to talk about it, and that is OK too.

Continuing care

When a person is approaching the last few months of life, they may be eligible for continuing care. Continuing healthcare funding from the NHS is available for anyone entering the last phase of life. It is designed to provide appropriate end of life care support at the person's place of residence. Applications for funding can be fast-tracked for end of life care, if necessary. There is no strict time limits imposed, but funding is normally applied for within the last few months of life, and is usually needs-led.

The assessment for continuing care is normally carried out by a senior clinician, such as a GP, consultant, specialist palliative care nurse, or district nurse. Care and support can include 24-hour care, where appropriate, in the last weeks or days of a person's life. This is very helpful to know if you are concerned about how you could manage the end of life care needs of a resident at home during the last weeks and days of their life.

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For information about the differences between general and advance care planning: www.mungos.org/endoflifecare and look under the Resources section.

For information about the Mental Capacity Act 2005: www.mungos.org/endoflifecare and look under the Resources section.

For guidance on Advance Decision to Refuse Treatment: www.mungos.org/endoflifecare and look under the Resources section.

Assessments carried out by hostel and project staff

“All the residents died in hospital but we try to keep them at the hostel as long as we can.”

Frontline staff

Alongside any assessments carried out by health and social care providers will be the ongoing assessments by you and your team. As homeless people generally have many barriers to accessing healthcare, your assessments are important for ensuring that a resident's needs can be met at their hostel or project for as long as possible, particularly if this is their expressed wish, or in the absence of alternative places of care.

Key factors to consider when undertaking an assessment:

- Written consent
- Diagnosis and prognosis
- Medical information available
- Key professionals and current service provision
- Client's preferred place and alternative places of care
- Mental health and substance misuse issues
- Mobility and handling assessment, and personal care issues
- Living arrangements – appropriateness of building for providing care
- Family, friends and relationships
- Cultural considerations

Your initial assessment most likely determines if, or when, a resident is likely to meet the end of life care criteria. This involves gathering as much medical information as possible, and getting to know who is currently involved in their care before deciding on any conversations with the resident and/or healthcare professionals. If a resident's GP, hospital consultant or medical team assess that the resident does not meet the palliative care criteria at the time you raise your concerns, you may still need to monitor the resident's needs, as a referral to palliative care may come a bit further down the road.

Please refer to Section 7: Tools and templates for a palliative care assessment tool and an assessment checklist that may be useful to you when undertaking assessments for a resident who may be terminally ill.

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“Generally I think that residents do know deep down when they are deteriorating and in effect dying.”

Frontline staff

Your assessments will need to consider any observed changes in the resident's health (physical, social, psychological, spiritual) and then, with the resident's consent, you will need to liaise accordingly with their GP, hospital consultant or palliative care team about any serious concerns you or the resident may have.

It is important to remember that you and your colleagues are most likely the ones who will observe changes in a resident's physical, emotional or spiritual well-being.

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The list below may help you to identify various signs, symptoms and behaviours that a person may experience during their illness trajectory. It is not expected that people with an advanced illness will experience all of these symptoms, and they are likely to move in and out of some of them depending on how they are feeling.

PHYSICAL SYMPTOMS	PSYCHOLOGICAL RESPONSES	SOCIAL CONCERNS	SPIRITUAL NEEDS
<ul style="list-style-type: none"> • Different types of pain • Nausea and vomiting • Diarrhoea • Constipation • Breathlessness • Pneumonia • Weakness/ fatigue • Dizziness • Bed sores • Poor sleep • Jaundice • Bleeds/haemorrhages • Palpitations • Poor appetite • Itching • Memory problems • Confusion • Fluid in the abdomen or legs • Difficulty with: <ul style="list-style-type: none"> - walking - dressing - getting out of bed - eating/swallowing 	<ul style="list-style-type: none"> • Denial/ambivalence • Anxiety and shock • Depression • Withdrawal • Disbelief • Despair • Blame and guilt • Hope • Acceptance • Sadness and regret • Optimism • Feeling vulnerable • Psychiatric problems • Loss of self confidence, self esteem, self worth • Fear • Anger 	<ul style="list-style-type: none"> • Disruption of daily routines • Frequent GP/hospital visits • Changes to status/roles • Social isolation • Loss of humour/enjoyment/ friends • Financial losses • Communication difficulties • Poor engagement with services 	<ul style="list-style-type: none"> • Seek to identify personal identity • Trying to find meaning to suffering and pain • Life after death questions • Quest after a higher being/ power

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Even where a resident does not meet the criteria for end of life care at a particular point in time, it is still important to assess the appropriateness of your project or hostel for providing the right environment as early on as possible.

Place of care issues may arise at some further point, such as access in and around the building (stairs, shared facilities, communal areas, outside areas), degree of privacy and the impact a resident's illness may have on other residents or staff. There may also be health and safety issues to consider such as the storage of medicines, or access to the hostel or project for staff providing end of life care.

Your assessments will also need to consider a resident's profile. This includes their level of insight and understanding of their illness trajectory, and their willingness to engage with you, your colleagues and others (such as health and social care providers). As you may already know, many homeless people see themselves on the periphery of mainstream health and social care, and many health and social care professionals will struggle to understand the complexities that underlie a resident's symptoms and behaviours when trying to support them.

The more healthcare professionals know about the difficulties a resident may have in accessing services, the more they will be able to assess their support needs appropriately. There may also be many practical things to consider, like legal matters, if a resident wants to make a will or consider their funeral arrangements.

An assessment might also highlight potential risks when a resident becomes ill outside the hostel, for example collapsing on the street or suffering memory loss. You might want to consider offering the resident some form of identification that they can carry with them, such as a rubber wrist band with the hostel contact details on it. You can explain to residents that, should they become unwell away from the hostel, the hostel can be contacted to provide information to those concerned, such as the ambulance service, A&E or hospital services. The hostel could then share information about the resident's wishes and preferences, if these are known and with the consent of the resident. There are many companies that could produce these wrist bands at a low cost.

Finding out about people significant to the resident is also important. They may include fellow residents or family and friends the resident has not seen for some time but may wish to reconnect with prior to their death. It is also important to identify these people and their connections with the resident when considering who might be able to provide the most appropriate support to the resident when needed. If the resident identifies these significant people, it is useful to have this recorded in their file.

Using the eco-map

The eco-map (see page 29) is a helpful tool in understanding the important roles that people play in a person's life. It can be useful to complete with a resident if they are comfortable with

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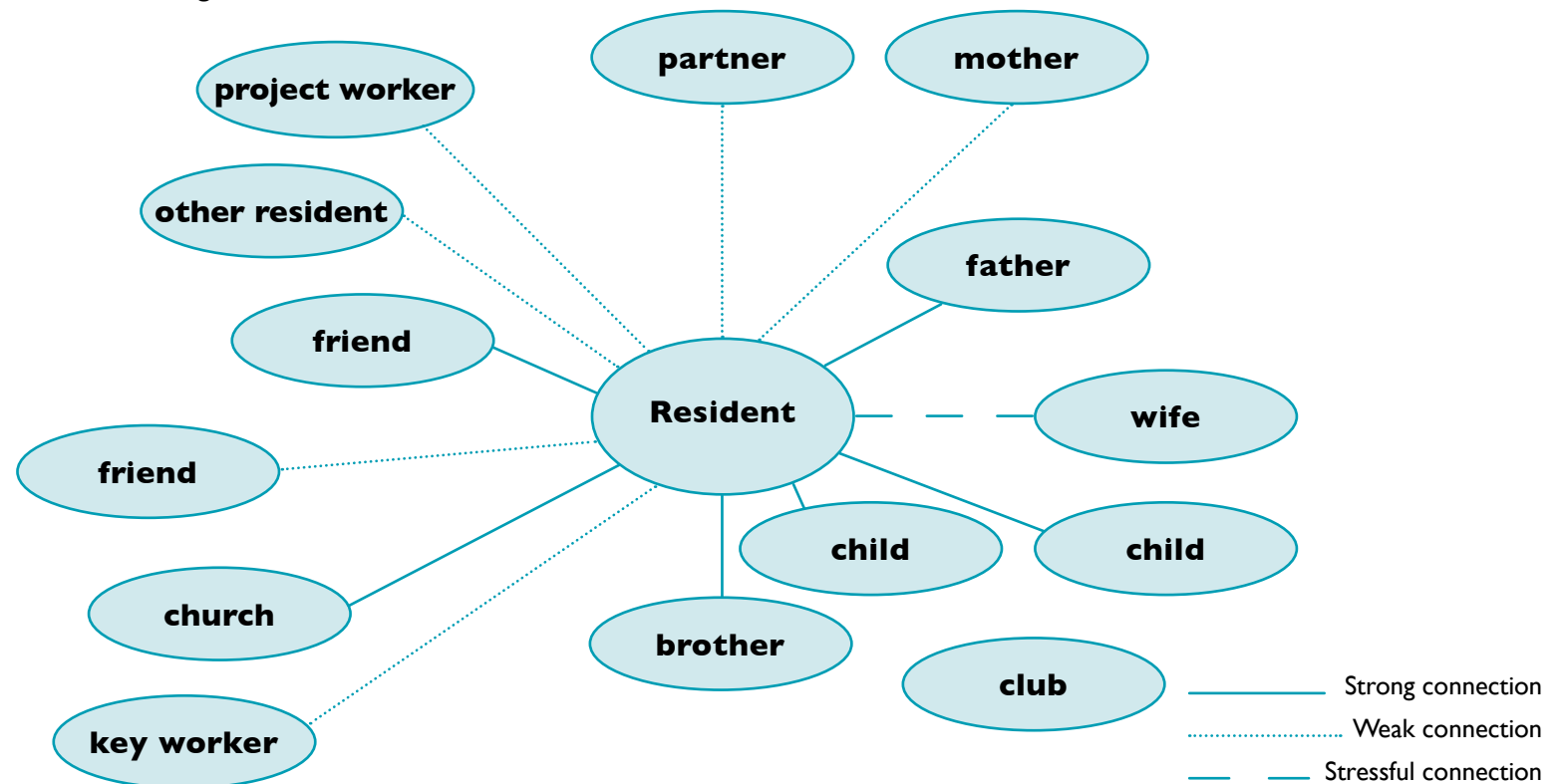
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it, as it can help them to understand the different ways in which people in their life is important to them.

A person might not be a strong connection when it comes to providing care and support but may still remain a very significant person in a resident's life. This may include a partner, family member, friend or peer, and even community groups or organisations that a resident is involved with. It also means that the needs of those people who are important to the resident are considered, including after the resident dies.

To use the eco-map, place the resident under review in the centre of it. Then locate the people or organisations important to them. Using the different types of lines below as a guide, draw a line between each person or organisation and the resident under review according to how strong, weak or stressful the connection is. The connection may relate to emotional or practical support that a person or organisation can offer to the individual.



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A resident's expressed preferences and wishes

"I want to die here, with all my friends around me." Resident

It is important for everyone involved in the care of a resident to establish as much as possible what their preferences and wishes are. This may be about their future care. It may also be about what they would like to do (or not do) for the time they have remaining. This could include reconnecting with family or friends, or travelling to a place they had always wanted to see.

It may also include expressed wishes that may not be in their best interest. For instance, residents with advanced liver disease who make informed decisions to continue drinking in the knowledge that they are likely to die as a consequence.

Although health and social care professionals may have conversations about a resident's preferences and wishes, you and your colleagues can also initiate these conversations as you are more likely to know the resident best.

Having these conversations will help you in your intentions to provide the best care you can, and perhaps even forging a stronger relationship with them in the final months and weeks of their lives.

Such conversations may occur spontaneously and informally. There may also be times when a planned conversation is needed, for example, if you or your team are concerned that a resident's care needs may be too challenging to manage. Ideally, any conversations about a resident's expressed wishes and preferences should be recorded (with the resident's consent). Though not a legally binding document, it will be helpful for healthcare professionals to know a resident's preferences and wishes when trying to meet their support needs.

Once it has been established with a resident that they are approaching the end of their life, you may wish for them to consider the question – 'What are the five things I would like to do before I die?' – as a way of finding out what their expressed wishes are.

For more information on how you can initiate these conversations, you can refer to the leaflet by the National Council for Palliative Care's Dying Matters Coalition: www.mungos.org/endoflifecare and look under the Resources section.

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Exploring a resident's preferences and wishes

This may include:

- Where they would like to be cared for until they die
- What treatments they would want or not want as their health deteriorates
- Things they would like to do before they die (eg reconnect with family)
- Who they might like (or not like) to have around if they are ill or after they have died
- Who they might want to give away their possessions or pets to after their death
- Legal arrangements (eg writing a will)
- Any cultural, religious or spiritual preferences
- The kind of funeral or celebration they would like
- How they would like to be remembered

Preferred priorities of care

There is a document known as preferred priorities of care, which could be of help to you and the resident for recording their preferences and wishes. This document gives people the opportunity to reflect on their preferences and priorities and write them down so that they can be communicated to any care staff in different settings and be carried out if the resident loses capacity. For more information, please refer to: www.mungos.org/endoflifecare and look under the Resources section.

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Case study – Ellen, aged 52, diagnosed with advanced cancer

Ellen lived for seven years in a one-bedroom flat in a semi-independent project for people with enduring mental health needs. She had a history of schizophrenia, and was under the care of a community mental health team. She lived in her flat in relative independence for five years before being diagnosed with cervical cancer.

On Ellen's initial admission to hospital, the medical team felt that due to her psychiatric history, she showed poor insight into her condition and was unlikely to accept active treatment for her cancer. They also felt that moving back to her flat was not a viable option, particularly as no members of staff were in the project after 6pm each evening.

Following five weeks as an in-patient, Ellen insisted on being discharged home and refused to consider going to a nursing home. Following a case review at the project, attended by the community psychiatrist, community psychiatric nurse, district nurse and GP, it was agreed that everything would be done to allow Ellen to return home for as long as possible, particularly as her prognosis was likely to be short months.

Following the case review, a referral was made to the community palliative care team and Ellen was discharged home. It was also felt that she had capacity and that her decision to refuse treatment should be respected once she was given appropriate information and advice about the seriousness of her condition. Ellen remained at home for the next 12 months and despite her insistence that she never wanted to go into hospital again, half way through

her illness, she agreed to an outpatient medical assessment. She continued to show poor insight into her prognosis, although staff always believed she was aware of the seriousness of her condition, choosing instead not to talk about it.

Ellen was a very private person and seldom allowed people into her flat. Introducing a package of care was slow to begin with, and it was offered on a needs-led basis. She also made contact with her brother who lived abroad, and the project installed a computer in her flat so that she could have regular contact with him on Skype.

In the final months of Ellen's life, as her health began to deteriorate, she accepted more and more support. In the final weeks, she had a full package of care including a pendant alarm which could alert a night station when staff were not in the project.

District nurses, care assistants and the community palliative care team visited regularly or when needed. Case reviews were held every four to six weeks, and project staff were involved in every aspect of planning, playing an active role given their closeness to Ellen.

Following a fall, Ellen's health deteriorated rapidly, and on admission to hospital it was realised that she had only hours or short days to live. With the support of the community palliative care team and hospital medical team, Ellen was assessed for continuing care and her funding was fast-tracked. In Ellen's home, a hospital bed was installed and she received 24-hour care throughout the final two weeks of her life.

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Learning points:

- **For the management of care at home to be effective, a multi-disciplinary approach is key.** Although Ellen appeared to show poor insight from initial diagnoses and prognosis, and the project staff were worried that they may not manage her care at home, a case review meeting before her discharge allayed those initial concerns. It also allowed the project staff to make an informed decision for Ellen to return home. Regular ongoing reviews can help to ensure that a resident's preferences and wishes are being met appropriately.
- **Finding out more about services that are available** to residents with advanced cancer will allow you to make informed decisions as to how long a resident can remain at home or be able to die at home if this is their expressed wish, as was the case with Ellen.
- Having the **additional support** available from health and social care professionals, including psychological and practical support, can free up your time so that you can spend more quality time with a resident. Knowing that Ellen was receiving 24-hour care at home helped staff to spend more time just being with her, rather than worrying about having to manage her care or having to decide on an alternative place of care for her.

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Assessing a resident's palliative and end of life care needs

- Ongoing assessments are an important part of managing care, particularly as a resident's health begins to deteriorate. Assessments need to be undertaken by health and social care professionals (eg GP, specialist palliative care teams, District Nurses, social services), and by you and your project staff. Some assessments can be undertaken jointly.
- Key areas of an assessment include:
 - Ongoing medical, nursing and personal care needs (eg pain management)
 - Psychological, social and spiritual needs
 - Place of care issues (eg stairs, mobility access, shared areas, complex nursing needs, alternative places of care such as nursing homes).
 - Impact on staff and other residents
 - Residents' preferences and wishes, including preferred place of care

A palliative care assessment tool and checklist is available in Section 7 of this resource pack.

- **Prepare yourself** before you have conversations with the resident about their preferences and wishes. Read any clinical records (eg discharge summaries), get up-to-date information from the resident's healthcare professionals on their current diagnosis and prognosis, and try to understand the level of

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insight the resident has about their prognosis. You may wish to find out if the conversation about a poor prognosis has already taken place between the resident and their healthcare professional.

- **Knowing as much as you can about the resident's preferences and wishes** will help you to plan their care. This also includes the kind of things they would like to do (or not do) for the time they have remaining. It may also include expressed wishes that may not be in their best interest. For instance, they may choose to continue drinking in the knowledge that they are likely to die as a consequence.

- A resident can also make **informed decisions** about their future healthcare should the time come when they lose capacity to make decisions for themselves. This includes decisions to refuse specific medical treatments. Known as an **advance decision to refuse treatment (ADRT)**, it will not be used if the person is able to make informed choices at the time the treatment is being offered, and only applies in the event where a lack of capacity is clearly demonstrated. It is important that a healthcare professional takes the lead in such conversations with the resident (such as the specialist palliative care team, a hospital consultant or GP). It is also possible that the resident would like you to be present when these conversations are taking place.

An example of an ADRT is available in Section 7 of this resource pack.

- **Continuing healthcare funding** can be fast-tracked for end of life care, if necessary. It is designed to provide appropriate end of life care support at the patient's place of residence. There is no strict time limits imposed, but funding is normally applied for within the last few months of life and is usually needs-led. Care and support can include 24-hour care, where appropriate, in the last weeks or days of a person's life.
- **Remember you and your colleagues** are the ones most likely to observe changes in a resident's physical, emotional or spiritual wellbeing.

Making your concerns known to the relevant health and social care professionals as early on as you can will enable them to make the best decisions about how to care for a resident. Let them know as much as possible about the home environment of the resident, particularly if you are worried about how you are going to provide continued care in the resident's home. Case review is one way to bring together all those involved in a resident's care and it is something which you can initiate.

If a resident is in hospital, you can also insist on being part of any discharge and aftercare planning meeting before decisions are made to discharge a resident home. Hospital medical teams may not always know where a resident is living, so your input will be invaluable. Sometimes, it may lead to an alternative place of care being sought before discharge, but more often than not, it is about putting the right mechanisms in place to ensure a resident has the best package of care set up on discharge from hospital.

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“I’ve lost on the way to this journey the special thing that most of us need – dignity ...I suppose I just need to talk about it.”

Resident

Why it can be difficult

Letting others know about where and how we would like to be cared for as we approach the end of our lives can be a struggle, especially as many of us do not feel comfortable talking about death and dying in the first place.

In fact, according to a survey published in 2010, it was found that only one in five of us were likely to discuss where we would like to die, or the kind of care we would like to receive at the end of our lives.

However, the more that others know about where and how we would like to be cared for, the more they are able to plan our care. While it is not always possible to die in our expressed place of care, such as home, the more health and social care professionals know about our preferences, the greater their chance of meeting these wishes.

For people who are homeless, additional obstacles and barriers might make it even more difficult for them to talk to others about their end of life care needs. These include:

- their multiple needs, usually a combination of different physical and mental health problems, in conjunction with substance misuse problems

- a history of poor engagement with health and social care services
- ambivalence about their diagnosis or prognosis
- place of care options – limited availability of alternative places of care suitable to meet their needs and wishes
- maladaptive coping strategies, such as using alcohol and substances to block out distressing emotions

There are also our own fears and concerns to consider, such as:

- saying the wrong thing
- making the person angry or sad
- being rejected by the person
- concerns that the person will give up or lose hope
- risk of damaging our relationship with the person, which may lead them to disengage
- not being able to fulfil their wishes
- not knowing enough about the practicalities of end of life care, funerals and wills
- fear of intrusion – the person may wish to live day to day and not think ahead
- not feeling skilled enough to have conversations about death and dying with others, including the resident, significant others, and health and social care professionals
- dealing with strong emotions
- dealing with difficult questions
- the circumstances are not within our usual role and tasks
- not knowing enough about the person’s diagnosis or prognosis to have the confidence to initiate these conversations with them

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What is there to communicate about?

There are always going to be things that need to be considered when talking and planning with a resident about their end of life care. As a resident's health begins to deteriorate, their level of need for support is likely to increase, and may well require more monitoring and assessment by you and your team, along with the health and social care agencies involved in their care.

This requires the need for ongoing conversations with the resident, those significant to them, and other health and social care professionals. While some conversations will occur spontaneously, particularly with the resident, others will need to be planned. At every opportunity it is important that you first consider what has been communicated; who the most appropriate person is to lead the conversation; and the right time to have the conversation before it takes place.

Some key areas of communication include a resident's:

- Physical, psychological or spiritual needs
- Insight into their illness trajectory
- Willingness to engage with others, including healthcare professionals
- Concerns for the future
- Preferences and wishes or advance care planning

Other areas of communication include:

- Personal or nursing and medical care issues
- Living arrangements – appropriateness of their accommodation for providing care
- Health and safety risks (eg for other agencies; storage of medicines)
- Relationships and significant others (refer to the eco-map in the previous section)
- Legal arrangements
- Concerns of, and the impact on, staff and other residents
- Consequence of the resident's presenting behaviours eg their drinking or substance misuse

What makes for good communication?

- Respecting residents and the choices they make
- Demonstrating empathy
- Setting the scene – appropriate place and time
- Active or reflective listening
- Acknowledging feelings
- Appropriate use of language
- Acknowledging your own feelings when talking about death and dying
- Being specific – knowing what you want to talk about, and knowing what you want to say
- Prioritising information
- Being aware of non-verbal communication – both yours and the resident's

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When to have the conversation

Timing

There is no right or wrong time to have these conversations. Timing will depend on many different factors, including the resident's health at the time and the choices they wish to make. You do not have to have these conversations all in one go either. It's all right to open the subject but then come back to it later.

The surprise question

It might be helpful to ask yourself 'Would I be surprised if this person died in the next six to twelve months?' If the answer is 'no', it would be a good idea to start thinking about having a conversation about their needs and wishes.

Spontaneous conversations

Sometimes conversations arise naturally while someone is well, with no urgent need to plan ahead. The ideal would be to seize these opportunities so that you can learn about the person's wishes when there is no pressure to do so. Obviously this may change over time, but if you have spoken about it in the past it will be easier to do so in future. For example:

- **Throwaway comments:** People can make comments such as 'Will you come to my funeral?' or 'I might not be here by then'. It's good to tune in to these comments. They may provide a way of opening up conversations about people's wishes, fears or concerns.

- **When someone dies:** Conversations often arise naturally when someone dies. Speaking with the person individually, or in a group, about how to respond to another person's death can lead to questions about their own wishes.

Planned conversations, initiated by you

There may be times when you feel you need to raise the subject of a resident's end of life wishes with them, eg if they have been given a poor prognosis or if you are worried that their care needs may be too challenging for you and your team to manage.

Setting the scene

In opening up conversations with a resident, make sure that wherever possible, you are not likely to be called away and that you are in an appropriate environment, such as in a quiet space with minimal risk of disruptions or interruption.

Once you ask a question, you may not know how a resident will respond or how long you may need to spend with a resident in that time. If you have other things planned, you will become distracted and a resident may close down. If you have to leave for any reason, just simply explain that you have to leave and arrange another time as soon as you can to carry on the conversation.

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Factors to consider:

- Do not assume that residents do not want to get involved in end of life discussions simply because they do not raise the issue themselves.
- Prepare yourself before seeing the resident. Read any clinical records (eg discharge summaries); and gain up-to-date information on their current diagnosis or prognosis, as well as their insight into their own prognosis.
- Discussions should be voluntary and not initiated as part of routine record-keeping or care.
- Respect a resident's right to choose not to talk. If a person is in denial, confronting this may only lead to further psychological distress, and they may withdraw. Denial can also be a coping mechanism that a resident may need at that time.
- Make notes of things that have been said, ensuring other members of your team know where they are recorded. Record-keeping will save you from unnecessary repetition or discussions, which can be highly emotive and may cause distress to the resident. Similarly, any visiting health and social care professionals should summarise each visit in the same notes.
- Keep eye contact and be aware of non-verbal communication – both your own and the resident's.
- Tailor the information you give to the resident's level of understanding and information needs. Do not feel you have to be a medical expert; and in fact, while you may come to know many medical terms, a resident will know their own body and a language in which to best describe the symptoms they are experiencing.
- Be realistic. Do not make promises that cannot be delivered and don't feel guilty if things don't turn out as planned.
- Silence is OK. During discussions, there may be moments of silence. There is not always a need to fill these gaps. Residents may simply be taking their time to think about, and filter, their emotions. Give them the space to reflect on what is being discussed and when you feel it is appropriate, restart the dialogue by asking 'Is it all right to continue?'

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For the reasons mentioned above and others, it is important to stop and think of what it is you, or other professionals, want to communicate about with a resident. Always give yourself enough time to prepare well for the conversations you are likely to have.

Ask yourself the following:

1. Why do I feel I need to speak about this?

For example:

- You notice a resident is struggling to live independently as their health deteriorates.
- Their nursing and medical needs may require a more appropriate place of care.
- You notice that they have become more isolated and withdrawn since they are told of their life-limiting prognosis.
- You know very little about what a resident's preferences and wishes are as they are approaching the end of their life.

2. Why might I find it difficult?

It is important that our own fears of talking about death and dying do not stop others from thinking and talking about their end of life needs. Is the difficulty yours or theirs (or both)? Remember that it is a taboo subject, and as it may not be within your normal role and responsibilities, it may feel very new and outside the comfort zone of what you know and normally have to deal with.

3. Who else can help?

It is important to remember that you and your team are not on your own when it comes to having conversations with a resident, particularly a difficult conversation. There are others you can turn to for support and information. These include the specialist palliative care team; the resident's GP; hospital medical teams; social care professionals; and your work colleagues, all of whom should have an interest and commitment to the welfare of the resident.

It is also important to know that you do not have to assume responsibility for difficult conversations. For instance, the responsibility for breaking bad news to a resident about their prognosis, or about other matters such as an advanced decision to refuse treatment, should rest with their hospital consultant, GP or their community palliative care team (if they are involved).

However, a resident may be happy for you to attend such a meeting so that you can hear the information that is given. Remember, a resident may choose to listen only to what they want to hear, and you need to be able to respect this. The benefit for you in attending such meetings with a resident is that you will then know what they know, and this may be helpful in any further conversations you may have with them.

In the event that you get to know of a resident's prognosis before they do, try to ensure that their consultant or medical team arranges a meeting to inform the resident as soon as possible. Knowing their prognosis before they do can place you in a compromised situation, and if the resident were to find out, they may resent it.

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4. What do I know about the resident?

Knowing as much as you can about a resident, such as their likes and characteristics, and having a rapport with them, can help pitch the right tone and language to use, and anticipate any concerns or issues that may arise. As other team members will also have a rapport, it is important to check with them as to how they think the resident will respond to conversations around their physical and emotional needs. You can also check with others who are significant to the resident, such as a partner, family members and friends, as long as the resident is happy for you to do so.

More often than not, communication between healthcare professionals and hostel staff can be poor. For this reason your role in the planning of their care is a pivotal one, particularly in the absence of alternative places of care. It is important to feel confident in knowing that what you have to offer matters to the overall planning of a resident's care.

With a resident's consent, letting healthcare professionals know as much as you can about a resident's background will help them anticipate any concerns and issues that may arise, thus helping them make more informed decision about their care.

On the other hand, the more you know about a resident's diagnosis and prognosis, the more likely a resident's healthcare needs can be managed at their residence for longer. Never feel afraid to ask the resident's healthcare professionals any specific questions on their behalf (with the resident's consent).

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Open-ended questions	<ul style="list-style-type: none"> • How are you feeling? • Do you have thoughts about where things are going with your illness? • Can you tell me more about that?
Reflective listening	<ul style="list-style-type: none"> • If I have got you right, you seem to be saying...
Clarifying	<ul style="list-style-type: none"> • Can you give me an example of what you are talking about? • Can you please give me more information about your religious beliefs and practices so that we can take the best care of you?
Summarising	<ul style="list-style-type: none"> • What I hear you saying is that... Have I understood that correctly? • So, we have talked about... Is that your recollection as well?
Use of minimal prompts	<ul style="list-style-type: none"> • Yes, go on

Finally, it's important to remember that:

- A resident (or a significant other) may need his or her own coping strategies and defences to deal with the situation they face. It is important not to undermine these coping strategies as any attempt to solve or 'fix' things may be feared and resented.
- A resident will often change their mind or not remember what has previously been agreed.
- Some residents may not wish to engage in a conversation with significant others or healthcare professionals. If this is their choice, it should be respected.
- We will not always get it right. You might miss opportunities and wish you had been able to speak earlier. This is part of life and you do not need to feel guilty.
- As professionals, we are not personally responsible for solving residents' or significant others' problems.

Further reading

Download Dying Matters' guide: End of life choices – Talking about end of life choices with people who are homeless at www.mungos.org/endoflifecare and look under the Resources section.

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- **Talking about death and dying is no easy matter**, and many of us will struggle to let others know what our wishes are as we approach the end of our lives. This can make it hard for those involved in the planning of our care. The more others know about where and how a person would like to be cared for, the better their care can be planned according to their wishes.
- **For people who are homeless, additional obstacles and barriers may exist** that makes it even harder for them to talk about their end of life care needs. These include presenting physical, mental health and substance misuse issues; poor coping strategies; and limited availability of alternative places of care (such as nursing homes). Letting health and social care professionals know (with a resident's consent) as much as you can about a resident, will help inform the decisions they need to make in planning their care.
- **It is helpful to acknowledge your own fears around talking about death and dying** and that these fears do not prevent residents from talking to you or others about their end of life needs. Our own fears may include saying the wrong thing; being rejected by the resident; not feeling skilled enough to have conversations about death and dying; or making them angry or sad.
- **Before initiating the conversation, it is important to stop and think** of what you, or other professionals, would like to communicate about with a resident. Always give yourself enough time to prepare well for the conversations you are likely to have. In planning your conversations, you may wish to consider the following questions:

What do I or others need to speak about?	eg physical, psychological, social or spiritual needs; alternative place of care; preferences and wishes; and advanced care planning
Who do I need to speak to and about what?	eg the resident, health or social care professionals, significant others
Who can help me?	eg the resident's GP, hospital medical team, social services, specialist palliative care team
When should we/I talk to a resident?	There is no right or wrong time to have conversations about end of life care. Timing will depend on many different factors, including the resident's health and the choices they wish to make.

Factors to consider:

- Do not assume that residents do not want to get involved in end of life discussions simply because they do not raise the issue themselves.
- Respect for a resident's right to choose not to talk.
- Do not feel you have to be a medical expert.
- Be realistic. Do not make promises that cannot be delivered and don't feel guilty if things don't turn out as planned.

Bereavement

Section 5: Bereavement

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At some stage in our lives almost all of us will have encountered the loss of someone, whether it is someone very close to us, or someone we were acquainted with, such as a neighbour or work colleague. The way in which we manage our grief reactions depends on many factors, and is an important indicator for determining the level of support we may need as we move through the bereaving process.

So what do we mean when we talk about bereavement, and the experience of grief? There are a number of ways to explain what they are about, so the best place to start is with a definition of both.

The term *bereavement* describes the situation we find ourselves in when we have lost someone to whom there has been a strong attachment. The sense of loss can be a personal and highly individual experience.

The term 'grief' itself means pain. It is the physical, emotional, social, spiritual and cognitive reactions to bereavement that often involves strong, painful feelings and emotions. When someone we have loved or cared for dies, we are likely to experience many different types of emotional and physical reactions – some more intensely felt than others at different times in the grieving process. We are also likely to experience changes in our behaviour and social situations as we begin to adapt to our loss.

It is important to remember that grief is a natural process that takes time, and must not be rushed or hurried along.

How we grieve depends on many factors, such as:

- **Our personality** – this includes our belief systems, adaptive coping strategies and our self esteem
- **Our environment** – this includes our home life, working life, supportive networks, cultural backgrounds and religious affiliations
- **Prior experiences of loss and change** – including childhood experiences, particularly separation
- **Nature of the loss** – whether the death was sudden or anticipated, or whether there was a prolonged or short illness
- **Significance of the loss** – our relationship with the person who has died, whether the relationship held a strong attachment or dependence, or if we are dealing with multiple losses
- **Degree of bereavement support** offered or available

Three component model of bereavement care

For most of us, grief reactions are part of a normal process of grieving that will eventually fade. No matter how difficult or painful our experience might be at times, we will manage without the need for professional intervention.

For some, however, additional support such as bereavement counselling, may be seen as appropriate and helpful at some point in the grieving process. A small minority of us may require specialist interventions such as from psychiatric services, where grief has been made more complicated by enduring mental health issues.

For further information, refer to the Three Component Model of Bereavement Care proposed by NICE: www.mungos.org/endoflifecare and look under the Resources section.

Bereavement

Section 5: Bereavement **Bereavement, grief and homelessness**

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While not every person who is homeless requires professional interventions, additional barriers may exist that could make them more susceptible to being vulnerable in bereavement.

Such barriers include:

- **Living with multiple needs** – usually a combination of different physical and mental health problems, in conjunction with substance misuse problems
- **A history of poor engagement with health and social care services** – making it all the more difficult to engage with local bereavement services
- **Difficulty expressing their feelings about their loss** – using unhelpful long-term coping strategies such as alcohol and drugs to mask their grief
- **Poor supportive networks, with minimal or no contact with their family** – making it all the more difficult to give meaning to their grief

Most long-term homeless people are also more likely to have experienced multiple losses in their lives as a result of being homeless, including childhood losses such as the loss of a stable nurturing environment; loss of education and income potential; loss of secure housing; and loss of self-esteem.

Many will have had the experience of losing friends and peers at their hostel or project, or amongst those they got to know on the streets or other projects along the way. These losses will have a direct bearing on the beliefs they carry about their own mortality.

Planning as early as possible for the impact the loss of a resident may have on others, including you and your team, is an important consideration. It can help you to identify potential risk factors for other residents, but it can also, where possible, be an opportunity to plan with a resident how they would like to be remembered when they die.

Planning in advance contributes greatly to managing the intensity of the grief reactions likely to occur following the death of a resident.

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Physical

- Hyperactive or underactive
- Change in appetite
- Weight change
- Shortness of breath
- Sleep problems or fatigue
- Physical distress
- Chest pains
- Abdominal pains
- Headaches
- Nausea
- Aches and pains

Behaviours

- Forgetfulness
- Searching for the deceased
- Needing to retell the story of how deceased died
- Not expressing feelings to protect others
- Distraction
- Slowed thinking
- Difficulty concentrating

Emotional

- Sadness or despair
- Anger
- Guilt
- Fear
- Relief
- Irritability
- Loneliness or isolation
- Meaninglessness
- Longing
- Helplessness
- Shock
- Disbelief or denial
- Bewilderment
- Numbness
- Regrets

Social

- Overly sensitive
- Dependent
- Withdrawn
- Avoiding others
- Lack of initiative
- Lack of interest

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“When they finally die, they deteriorate very quickly.”

Frontline staff

When a death occurs suddenly, the grief response can be different from an expected or anticipated death. To begin with, people who suffer a sudden bereavement are usually in deep shock as well as suffering from grief. Since there is little to no opportunity to prepare for the loss, say good-bye, finish unfinished business or prepare for bereavement, grief reactions are likely to be more intense.

Families, friends or carers are suddenly forced to face the loss of the person instantaneously and without warning. As well as the usual feelings found in bereavement, this type of loss can generate more intense grief responses.

Some people may also experience depression or post-traumatic stress disorder, which may require an assessment by a medical professional (such as their GP), or a therapist.

Probable immediate reactions following a sudden death are:

- **Shock and numbness** – unable to believe what has happened
- **Over-stimulation, excitement or euphoria** – rushing around, busying selves with practical tasks

- **Feeling shaky, nauseous and tearful** – some people feel this immediately, others not for some time
- **Anger** – at what happened, at whoever allowed it to happen
- **Guilt** – about what didn't happen, of feeling responsible somehow. Questions may include 'could we have prevented this?', 'if only we...'; 'what if ...'
- **Blame** – includes self-blame and blaming others. It is often perceived as a way of dealing with grief, but gives only temporary relief, and is viewed as non-supportive
- **Searching** – trying to understand, to give meaning to what has just happened
- **Anxiety and panic** – at the thought of breaking down or 'losing control'
- **Denial of emotions** – ie 'I'm not angry', 'I'm not upset'

Physiological reactions include:

- loss of appetite
- headaches
- physical pain
- sleep problems
- muscular tension
- nausea and diarrhoea
- tightness in the chest

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Given that many people who are homeless die suddenly, whether from an accidental overdose, intentional suicide, cardiac arrest, or perhaps from a fall or road accident, it is important to consider the impact this sudden loss will have on everyone, particularly during the period of shock about the sudden death.

Recognising the traumatic impact of a sudden death may help towards finding the most appropriate emotional and practical support, whether for an individual resident or team member, or for everyone as a whole. There are many services that have a lot of experience of helping people during the early days of a sudden bereavement. For more information see:

www.suddendeath.org

www.uk-sobs.org.uk (for survivors of bereavement by suicide)

www.cruisebereavementcare.org.uk

www.bereavementuk.co.uk

When a death occurs suddenly or unexpectedly, and is violent or unnatural, it is reported to a coroner. A coroner will then seek to establish the medical cause of death, and where the cause of death remains in doubt after a post-mortem, an inquest will be held.

Understanding grief in a scientific context

Although grief and mourning are as old as human history, the scientific study of dying and grieving is a relatively new field and continues to evolve with every new research initiative and support programme that is developed throughout the world.

Understanding more about the ways in which people approach and adapt to loss and change is helpful to your understanding of how to support yourself, other colleagues and residents.

Please refer to the end of this section for a summary of the main theories of grief and bereavement.

Understanding grief in a cultural context

Different cultural and religious groups deal with grief in different ways. Even within the same groups, there will be considerable variations depending on individual beliefs, practices and personalities. Our beliefs about the meaning of death help us to make sense of it, and cope with the mystery and fear surrounding dying.

It is important to be able to honour and express our grief in a way that is appropriate to us, regardless of whether this conflicts in some way with other beliefs and existing customs. It is equally important to be sensitive to the way others express their grief, and as best we can, maintain a respect for the customs and beliefs they bring to the grieving process.

If you work with people from different cultural and religious background, you need to be aware of the different beliefs and rituals associated with death.

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Assumptions about cultural and religious beliefs based on little understanding or racial stereotypes can only be unhelpful, and it is impossible to respond sensitively to a person's wishes and needs from such a base point.

However, it is also important not to make assumptions about people based on their particular ethnic, cultural or religious background. The support and information you provide should be sensitive to the individual needs of every resident.

Please refer to Section 7 for a brief outline of the different rituals that may apply.

Understanding rituals

In every culture, death is surrounded by rituals and customs that help people grieve and mourn. The term mourning is often used to describe the culturally-patterned expression of grief or the rituals surrounding a death or significant loss (ref: De Spelder).

While rituals of bereavement may differ from culture to culture, what they offer us are ways of expressing our grief – both privately and in public – and an opportunity for communities to support those who are bereaved. For instance, in some cultures, wailing and rending of garments is normal, while in others, quiet introspection and prayer might be more typical.

In some instances, a person's experience of grief may be at odds with cultural expectations. Someone who is usually quiet and reserved may not feel that he or she can publicly cry as might be expected. Another person may experience a level of despair that feels out of step with their own culture's belief in life after death. Despite cultural norms and expectations, people need to grieve in ways that feel right to them.

Given the differences in mourning rituals and customs, it may be difficult to know how to be sensitive to a grieving person from a different cultural background. When supporting an individual, whether a family member of the resident who has died, another resident or a team member, it is always helpful to know something about their cultural background, especially if unfamiliar or different to your own. In those instances, it might be helpful to consider the following questions when supporting them in their grief in a sensitive way.

- What emotions and behaviours are considered normal grief responses?
- What are the bereaved person's or persons' beliefs surrounding death?
- Who is expected to attend mourning ceremonies, and how are attendees expected to dress and act?
- Are gifts, flowers or other offerings expected?
- What special days or dates will be significant for the bereaved person/s?
- What types of verbal or written condolences are considered appropriate?

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Knowing the expressed wishes of a resident about how they would like to be remembered, including the kind of funeral they would like, can help all those who are bereaved to feel that they are part of something special that the resident has put together.

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A resident may choose someone very close to them to have such discussions – a significant other, family member, friend, another resident, keyworker or other team member – who may then endeavour to ensure their wishes are carried out as much as possible. You may wish to refer to online resources such as www.lastingpost.com, a website providing useful guidance and checklists, as well as the facility for people to record their future wishes online in the event of their death.

It is also possible that many of us will struggle to convey to others our wishes before we die. Or when a death is sudden or unexpected, we may not have had the chance to express our wishes to anyone. While it is really helpful to know what type of funeral a resident wants, or how they wish to be remembered, this opportunity may not always present itself. Yet, in the absence of family or significant others, this does not mean we are not able to come close to planning the kind of service they would have liked, or how they would have wanted to be remembered, from the way we knew them when they were alive.

When someone dies, it is usually a family member or someone significant to the person that will sign the death certificate, and

assume responsibility for arranging the funeral of the deceased person, including the cost of the funeral. The cost may either come from the estate of the person who has died or, if no money is available to pay for the funeral, from the named person on the deceased's death certificate.

However, in the absence of a significant other or family members, or where no one is in a position to be able to pay for a funeral, the local authority in which the resident resides will assume responsibility. Where a resident has made a specific wish to be buried or cremated, this will be honoured, and where unknown, it is normally a cremation that takes place.

As a public service, your hostel or project can become actively involved in the funeral service, perhaps being able to take a leading role in the type of music, poetry or eulogies to have in the service. This is a great opportunity for everyone to come together to celebrate the life of a resident, and to bring a particular kind of closure to the initial period of the grieving process.

It also sends a positive message to other residents that being remembered in this way really matters, even if just by a few. It is important to discuss the resident's expressed wishes with the Local Authority as early on as possible; particularly as this will give you time to plan with other residents what kind of service to arrange.

There are also many different rituals and celebrations that can be considered to reflect the nature and personality of the resident who has died, and it can be a good opportunity for

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everyone to come together to show their mark of respect for the resident's life. This is particularly important in situations where it has not been possible to know the expressed wishes of a resident, or where there is no opportunity to attend or plan their funeral.

The funeral may be a non-religious or ecumenical service in the project or in the community, and can include music, poetry or anything else that celebrates their life. Rituals involving social interactions are also found to be beneficial, and can include talking with others about the deceased, being with others, going out and eating together.

Other ways to commemorate the life of the resident who has died can include:

- A remembrance plaque
- A memorial bench
- A book of condolence
- A shared meal
- The planting of a bush or tree in the garden
- Holding a service for the deceased resident

It is also important to respect the wishes of those who do not want to attend a service or memorial. We may have no way of knowing what the reasons are, but to another resident a death may bring back painful memories of loss, or a struggle to manage feelings and emotions.

Bereavement – is what happens to you
Grief – is what you feel
Mourning – is what you do

Supporting residents

“When there is a death people are pretty shocked. They do not like others to die in the hostel. For a lot of clients, it is supporting their own mortality.”

Frontline staff

Supporting residents in bereavement can take many forms, and can be provided formally and informally, as well as for brief or sustained periods of time. This support can be made available to individuals or to residents as a whole.

To ensure a person feels fully supported in bereavement, it is important to consider not only their emotional needs but also their practical, social and spiritual needs as well.

Make sure they have appropriate information and advice about loss and bereavement; about the things they need to do; and the types of support available to them.

It is also important to give them moral support, honouring and acknowledging their experience of loss while at the same time giving them lots of reassurance about their ability to cope and about how their grief reactions are part of a normal process of grief.

The key to supporting residents in bereavement is being able to anticipate and plan for the impact the death of a resident will have on individual residents, and residents as a whole, as early on as possible.

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As already emphasised, where it is known that a resident is approaching the end of their life, identifying potential risk factors for other individual residents early on will help you to initiate a package of support that may help reduce the impact the loss will have on them. Support should be offered immediately following a death, and also for a period of some months afterwards, since emotions may surface some time after the actual death.

Remember that a resident does not necessarily need to have known, or have been close to, the resident who died for grief reactions to occur. Their death may simply act as a trigger for other major events and difficulties in their own lives, including prior multiple losses, significant recent losses or multiple needs.

When a resident dies there can be so many different things to be considered. There is the initial emotional and psychological impact of the death, and all the practical arrangements.

Informing residents as early on as possible following the death, as well as including them in any practical arrangements where appropriate, will help minimise the intensity of the grief reactions that are likely to occur, particularly those immediately after the resident's death.

Where it is not possible to notify residents individually, do ensure that those closest to the resident who has died are identified and informed before notifying other residents. This includes significant others, friends and close peers. As best you can gather everyone together to inform them of the death,

keeping an announcement on a noticeboard as a last resort. Continue to keep residents informed of any practical arrangements, including when you or your team are likely to remove the resident's belongings from their room, and on what is happening, such as funeral arrangements, or when someone else is about to move into their room or flat. Where an inquest is being carried out, it is important to keep residents informed, confidentiality permitting, of what is happening, particularly if it is likely to take some time for the coroner to reach their findings.

Most important of all, include them in any practical arrangements. Make it possible for people to attend a funeral or service and for them to contribute ideas for a celebration or service within the project. Services can also be an opportunity to remember previous residents who have died, particularly if known to any current residents, and others known to them.

Offer support to residents on a one-to-one basis and as a group. This could be part of a resident's usual key worker sessions but also outside these meetings in more informal ways. Encourage and facilitate discussion about a resident's death at residents' meetings.

Familiarise yourself with bereavement services that are available to residents, and display information about these services as well as more general information about loss and bereavement around the project. This allows people to access information any time they feel the need for it.

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One of the main barriers to residents being supported in bereavement may well be their ability to engage with local bereavement services or fit in with bereavement services structures. Services may require that people are open to talking about their bereavement, are willing to attend a number of agreed sessions, and are not intoxicated when attending a session.

It is useful to contact your local bereavement support service to discuss potential barriers or obstacles to residents engaging with them, and the support they may have to offer residents.

This could include attending a residents' meeting to talk specifically about loss and grief. Talking to your local bereavement service is also an opportunity for you to ask how best to support when a resident dies, particularly as you and your colleagues may be the main source of support a resident will accept.

If a resident was supported by your local palliative care team, then you can approach them for support and advice. Alternatively, you may contact the local GP who can advise you of counselling services available in the locality.

Some do's and don'ts

- **Do acknowledge a resident's grief** by reassuring them that they are not alone or unsupported. Continue to affirm and acknowledge their loss months after a death, and around significant dates such as birthdays and anniversaries.

- **Do not be afraid to express your own sense of loss** at the death of a resident with other residents if appropriate, while at the same time maintaining professional boundaries.
- **Do be available to listen or to help in any way you can.** Ensure you give enough time when it comes to asking residents how they are feeling so that you can be attentive in that moment.
- **Do familiarise yourself about the nature of loss and grief reactions in bereavement.** This will help you to feel more confident or at ease when talking to residents about their own experience of loss.
- **Do consider residents as much as possible in the practical arrangements following a death,** especially when it comes to funeral arrangements, rituals and celebrations.
- **Don't assume that a resident automatically needs formal bereavement support,** as they may just need time to come to terms with their loss. Ensure they have sufficient information about the kind of support available to them, as just this may be enough.
- **Don't feel you are there to resolve their grief.** Residents may need their own coping strategies and defences to deal with their loss, and any attempt to solve or fix things may be feared or resented.
- **Don't let your own sense of helplessness keep you from reaching out.**

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- Don't tell them what they should feel or do.
- Don't change the subject when they mention their loss.
- Don't avoid mentioning their loss out of fear of reminding them of their pain – they haven't forgotten it.
- Don't assume that just because months have gone by that everything is OK.

Interventions to consider

- Support your local bereavement service to engage with residents
- Consider clients as much as possible in the practical arrangements following a death
- Set realistic goals – know what may not happen
- Be informed about the nature of loss and grief reactions in bereavement
- Continue to affirm and acknowledge the loss months after a death

Supporting staff

“I do get emotionally involved ... I talk to my wife about it to try to make sense of what is happening at work.”

Frontline staff

When a resident dies, you and your colleagues may be so involved in supporting residents or attending to practical arrangements, that your own feelings go unrecognised. It may also feel like 'business as usual', as you go about managing the daily tasks and responsibilities you have to do.

Being busy can be helpful in coping with the initial impact of the death – but finding time to work through your grief reactions, both as individuals, and as a team, should not go unrecognised. As a team you need permission to grieve, to be able to show and express emotions, and to be able to take care of your own needs in a way that is appropriate to you. Perhaps you might think that expressing your emotions is considered 'unprofessional' or a sign of weakness, or inappropriate. If this is the case, it is important to try to challenge this, as it may lead to feelings being suppressed and possible problems not being addressed.

Coming to terms with the loss of a resident will impact differently on staff, and indeed within different hostel and project settings. For instance, some projects may experience the loss of residents more frequently than others, depending on the nature and type of project it is.

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Furthermore, as individual staff, your relationship to a resident may differ – some of you may have developed a particular kind of rapport with a resident over time, or perhaps had been their main support as they approached the last weeks and days of their life. This does not lessen the impact the loss will have for other staff but due to this closer connection to the resident, the intensity may be greater. It is also possible that some of you will have experienced loss and bereavement in your personal life; these feelings can often re-emerge in response to a death at work.

The way we seek to manage our grief reactions will also differ. Our own personal belief systems, adaptive coping strategies, cultural and religious affiliations, and our supportive networks of family, friends and outside interests, can determine how best we manage.

What helps?

- Learn as much as you can about loss and bereavement, familiarising yourself with the grieving process. In doing so, you may become more reassured that your reactions, and that of your team, are part of a natural process of grieving.
- Acknowledge that you may feel overwhelmed at times by the intensity of your feelings, but that all these feelings are normal.
- Honour and express grief in a way that feels appropriate to you.
- Use your supportive networks. Talk openly and honestly to others you feel safe with.

- Use your support systems at work to help you manage your grief. As emotions are unpredictable in bereavement, you might feel OK to be at work and then suddenly find yourself struggling to cope.
- Do not remain silent about what has happened, and about how you feel. Find a good listener, and be open and honest about your feelings.
- Consider seeking bereavement support if needed, particularly if you become stuck with difficult emotions or reactions.
- Acknowledge that there may be more than one loss present.
- Do more of the things that benefit your well-being. Be sure to include pleasurable things such as treating yourself to your favourite food without feeling guilty, or having a nice hot bath. Engage in enjoyable activities such as going for a walk, spending time with someone you enjoy being with, or engaging in a favourite hobby.

Assessing your own needs and that of the whole team following a death

You and your team might like to consider the following exercises as a way of reflecting on what is going to be most helpful for dealing with the loss of a resident.

The team exercise may be something you can all do together, while the exercise about your own needs is something you can share with those you feel closest to, such as a partner, family member or friend.

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Assessing your own needs following a death

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Your need for support from the community (ie partner, family and friends)

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Actions that will assist in reducing stress or distress (including pleasurable activities)

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Actions that will assist your team in reducing stress/distress (include here activities such as a shared meal or going to a movie).

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Go to Section 7 for templates of bereavement support exercises for staff.

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Things that can help

- Knowing that grief is a process that takes time
- Knowing that there is no right way to grieve
- Being with others
- Getting back to normal routines
- Knowing that grief is a journey that takes a different length of time for each person
- It's very easy to feel guilty when we shouldn't – check whether it is rational
- Accepting that reactions to grief are normal

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Dr Colin Murray Parkes' phases of grief

In Dr Parkes' book *Bereavement, studies in adult grief*, he identifies that many people who are bereaved will experience the following stages very differently – sometimes quickly or slowly, in a different order, or not experience a stage at all.

Dr Colin Murray Parkes' phases of grief	Interpretation
Numbness and shock	The bereaved person feels numb or is disbelieving. This is a defence mechanism that allows them to survive emotionally; and there is a sense of unreality.
Separation and pain	This stage shows itself in waves of distress, intense yearning for the person who has died, and for the deceased to return. The feelings of yearning become less intense while periods of despair increase. During this stage, the bereaved may feel guilty that they did not do enough or blame others for the person's death.
Despair	This stage may show itself in low mood, difficulties with concentration, anger, guilt, restlessness and hopelessness. The bereaved person may withdraw and disengage from other people and activities they usually enjoy.
Reorganisation and recovery	This stage involves detaching from the deceased person and investing in other relationships and the future. Energy levels increase, and an interest in activities of enjoyment returns. Grief never ends but thoughts of sadness lessen and happier memories of the deceased person increase.

Reference: *Bereavement, studies in adult grief* by Dr Colin Murray-Parkes (1998) and *Separation and loss within the family* by John Bowlby and Colin M Parkes (1970).

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Section 5: Bereavement Kübler-Ross' model for death and bereavement counselling, personal change and trauma

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Elisabeth Kübler-Ross' book, *On death and dying*, explains the five stages of grief – also known as the grief cycle. It is important to bear in mind that Kübler-Ross did not intend this to be a rigid series of sequential steps – it is a model or framework.

As a person's grief and other reactions to emotional trauma are unique to them, they do not always experience all of the five grief cycle stages that are described below. Some stages

might be revisited, and some stages may not be experienced at all. Transition between stages can also ebb and flow, rather than occur in progression of each other.

Kübler-Ross' model acknowledges that there is an individual pattern of reactive emotional responses which people feel when dealing with death, bereavement, and great loss or trauma. Her model recognises that people have to pass through their own individual journey of coming to terms with death and bereavement, after which there is generally an acceptance of reality which enables the bereaved person to cope.

Kübler-Ross' grief cycle	Interpretation
Denial	Denial is a conscious or unconscious refusal to accept facts, information and the reality relating to loss. It is a defence mechanism that allows people to survive. Some people can become locked in this stage when dealing with a traumatic change.
Anger	Anger can manifest in different ways. People dealing with emotional upset can be angry with themselves, and/or with others, especially those close to them. Awareness of this stage can help people who are experiencing the anger of someone who is facing loss or is bereaved to remain detached and non-judgmental.
Bargaining	In the bargaining stage, people facing death can attempt to bargain with God or another higher being that they believe in.
Depression	This stage means different things depending on who it involves. It is natural to feel sadness, regret, fear, uncertainty, etc. It shows that the person has started to accept the reality of the situation.
Acceptance	This stage varies according to the individual's situation. It is an indication that there is emotional detachment and objectivity. People who are dying can enter this stage a long time before the people they leave behind.

Reference: The grief cycle model was first published in *On death and dying* by Elisabeth Kübler-Ross, (1969); interpretation by Alan Chapman (2006-2009).

Bereavement

Section 5: Bereavement

J William Worden's tasks of mourning

J William Worden's book *Grief counselling and grief therapy: A handbook for the mental health practitioner* introduces the concept of grief having to be 'worked through' so that a bereaved individual can move on to a new life. His theory is based on the need of the bereaved to detach from the deceased person in order to move on.

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J William Worden's tasks	Interpretation
To accept the reality of the loss	This means acknowledging that the deceased person is no longer alive and will never again be part of the bereaved person's life.
To work through the pain of grief	It is necessary for the bereaved person to go through the pain of grief in order to get the grief work done. Anything that allows the bereaved person to avoid or suppress pain will prolong the course of grieving.
To adjust to an environment in which the person who has died is missing	In this task, the bereaved has to adjust to all of the changes that happen following the death of the loved one. This will also include changes in the role of the bereaved person eg wife to widow. The bereaved person may suddenly feel that 'life is not fair' or become irritated with friends and family who do not understand.
To emotionally relocate the person who has died and move on with life	In this task, the bereaved person acknowledges the value of the relationship they had with the person who died but continues to live their life. The deceased person is not forgotten but enjoyment in life for the bereaved is resumed.

Reference: *Grief counselling and grief therapy: A handbook for the mental health practitioner* by J W Worden (1991).

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Margaret Stroebe and Henk Schut's dual process model

Margaret Stroebe and Henk Schut's publication, *The dual process model of coping with bereavement: rationale and description in death studies*, identifies two oscillating coping processes – loss and restoration.

Stroebe and Stut state that most bereaved people can expect to experience oscillation between a loss orientation (coping with loss through grief work) and a restoration orientation (adjusting to the many changes caused by loss). There will gradually be less attention to loss-orientated tasks and more to restoration-orientated tasks.

Therefore, early in bereavement, there is generally comparatively little attention to forming a new identity but much greater attention to events relating to the death; conversely, in time, there will be a gradual reversal of attention to these different tasks.

Dual process model summary

This model describes feelings and activities following bereavement as being divided into loss orientation and restoration orientation.

- Loss-orientated activities include grief work, denial or avoidance of restoration orientated activities.
- Restoration-orientated activities would include attending to the changes arising from the death and doing new things, as well as accepting a new role and identity.
- Both kinds of activities are very important for recovering from a bereavement.
- The bereaved person may move back and forth between the two from the death of the loved one.

Based on *The dual process model of coping with bereavement* by Margaret Stroebe and Henk Schut (1999).

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- **Bereavement** is the situation we find ourselves in when we have lost someone to whom there has been a strong attachment.
- **Grief** is the physical, emotional, social, spiritual and cognitive reaction to bereavement that often involves strong, painful feelings and emotions. The term itself means pain.
- **How we grieve depends on many factors**, such as:
 - Personality – belief systems, coping strategies and level of self-esteem.
 - Environment – home and work life, and supportive networks.
 - Prior experiences of loss and change, including childhood experiences.
 - Nature of the loss – whether the death was sudden or expected.
 - Significance of the loss – relationship with the person who has died.
 - Degree to which bereavement support is offered or available.
- It is **important to remember** that not every person who is homeless will require professional interventions. However, additional barriers may exist for some that could make them more susceptible to being vulnerable in bereavement.
- **Grief is a personal and highly individual experience**, with a broad range of reactions – some more intensely felt than others throughout the grieving process. For most of us, these ‘grief reactions’ are part of a normal process of grieving that will eventually fade. For some, additional support may be required.
- **When a death occurs suddenly, the grief response can be different** from the response following an expected death, and is likely to generate more intense grief responses.
- **Different cultural and religious groups deal with grief in different ways.** If you work with people from different cultural and religious backgrounds, you need to be aware of the different beliefs and different rituals associated with death.
- To ensure a resident feels fully supported, **acknowledge their grief.** Continue to affirm and acknowledge their loss, particularly on significant dates such as birthdays and anniversaries.
- Ensure that **appropriate information and advice** about loss and bereavement is made available to those who might need it.
- **Inform residents as early as possible following a death** and include them in any practical arrangements where appropriate. There are many different rituals and celebrations that can be considered to reflect the nature and personality of the resident who has died.

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- **Keeping busy can be helpful** in coping with the initial impact of a resident's death – but the need to find time to work through your grief reactions, both as individuals and as a team, should not go unrecognised.

It is important to remember:

- Grief is a natural process that takes time, and must not be rushed or hurried.
- There is no right or wrong way to grieve – everyone is different.
- Familiarise yourself with the nature of loss and grief reactions in bereavement. This will help you to feel more confident or at ease when talking to residents about their own experience of loss.

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Education and training resources

College of Medicine

Working together with the London Pathway, the College of Medicine is developing a series of short courses, training and peer education programmes for health and social care professionals working with homeless people.

www.collegeofmedicine.eu

End of Life Care for All e-learning resources

The National End of Life Care Programme has developed e-learning resources – End of Life Care for All – to facilitate the education and training of staff involved in delivering end of life care across health and social care. The resources include modules on advance care planning, assessment, communications, skills, symptom management, bereavement and spirituality.

www.e-elca.org.uk

National Council for Palliative Care

The National Council for Palliative Care runs a wide range of events on all aspects of palliative care. Where possible, these events are given Continuing Professional Development (CPD) accreditation. The charity provides an introductory end of life care training programme, Care to Learn. It is relevant to all staff caring for people at the end of life, in particular those working in care homes, housing organisations, other community settings and hospitals.

www.ncpc.org.uk

Macmillan's Learn Zone

Macmillan Cancer Support provides a number of free web-based education resources on their Learn Zone website.

www.learnzone.org.uk

The National End of Life Care Programme

The National End of Life Care Programme was set up to improve care at the end of life for all, wherever they live. This website aims to support the programme by sharing good practice, resources and information.

www.endoflifecare.nhs.uk

Help the Hospices

The leading charity supporting hospice care throughout the UK, Help the Hospices represents and supports local hospices. Their work includes a wide range of training and education programmes; informative and practical resources for hospice staff; and support for quality care and good practice.

www.helpthehospices.org.uk

E-journals and e-books

- *Oxford Handbook of Palliative Care*
- *Palliative Medicine*
- *International Journal of Palliative Nursing*
- *End of Life Journal* with St Christopher's

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Alcohol and drug services

NHS Choices has a database of alcohol addiction support services.

www.nhs.uk

Rehab Online

Provides a directory of residential rehabilitation services for adults who misuse drug and/or alcohol in England and Wales.

www.rehab-online.org.uk

The London Drug and Alcohol Network

Provides a directory of drug and alcohol services across London.

www.ldan.org.uk

Drinkline

Tel: 0800 917 8282

A national helpline which offers help to callers worried about their own drinking and support to the family and friends of people who are drinking. Provides advice to callers on where to go for help.

Drinkaware

Promotes responsible drinking and finds innovative ways to challenge the national drinking culture to help reduce alcohol misuse and minimise alcohol-related harm. Provides facts about the effects of alcohol, and tips and tools to cut down on alcohol consumption.

www.drinkaware.co.uk

British Liver Trust

A national charity working to reduce the impact of liver disease in the UK through support, information and research.

www.britishlivertrust.org.uk

Liver Transplant Support

Features people's stories on their experiences of liver transplantation. Visitors to the site are also able to share their thoughts and stories through the site's online forum.

www.livertransplantsupport.com

Animal care

Dog Trust Hope Project

The project provides assistance to dogs whose owners are homeless or in housing crisis. It also offers advice to homeless dog owners and free veterinary care to their dogs.

www.dogtrust.org.uk

Cinnamon Trust

Provides practical help when any aspect of day-to-day care poses a problem – for example, walking the dog for a house-bound owner. It also provides long-term care for pets whose owners have died or moved to residential accommodation which will not accept pets.

www.cinnamon.org.uk/cinnamon-trust

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Bereavement UK

Offers information about death, dying, bereavement, funerals and self-help counselling.

www.bereavementuk.co.uk

Bereavement Advice Centre

Provides a helpline and web-based information on a variety of issues on bereavement.

www.bereavementadvice.org

CRUSE Bereavement Care

Provides advice, counselling and information on practical matters for bereaved people.

www.crusebereavementcare.org.uk

Winston's Wish

A support service for bereaved children and teenagers.

www.winstonswish.org.uk

Carer support

Carers Direct (NHS)

Offers information, advice and support for carers.

www.nhs.uk/carersdirect

Carers UK

Provides information and advice on all aspects of caring including benefits and tax credits; and support for carers and the people they care for. They also provide an online support forum and a UK-wide services directory.

www.carersuk.org

Dealing with death

Natural Death Centre

A charity which provides information on environmentally-friendly funerals and how to organise a funeral yourself. It also publishes The Natural Death Handbook, a guide covering the practical, emotional and spiritual aspects of death and dying.

www.naturaldeath.org.uk

If I should die

Advice on funeral arrangements and costs, wills, inheritance law and terminal illness. Includes information on counselling and a collection of comforting poems.

www.ifishoulddie.co.uk

Arrangements for memorial services

Templates and checklists that people may wish to consider to record their wishes regarding their funeral or memorial service.

www.lastingpost.com

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Body and Soul

Body and Soul supports people with a HIV diagnosis. They offer services such as counselling, legal advice, complementary therapies, support groups and advice on relationships and health issues.

www.bodyandsoulcharity.org

Turning Point

Social care organisation for people with a dual diagnosis of mental health and drug or alcohol problems.

www.turning-point.co.uk

Legal, financial and immigration issues

Advice now

Information on the law and rights including housing, homelessness, benefits and immigration.

www.advicenow.org.uk

Citizens Advice

Helps people to resolve their legal, money or other problems by providing free, independent and confidential advice.

www.citizensadvice.org.uk

Gov.uk

Provides information on money, tax and benefits.

www.gov.uk

Refugee Action

Provides a reception service for newly arrived asylum seekers, as well as advice and advocacy.

www.refugee-action.org.uk

Refugee Council

A multilingual website providing free advice and information to refugees and asylum seekers.

www.refugeecouncil.org.uk

Repatriation Help

Advice and information on repatriation for families and funeral directors.

www.repatriationhelp.com

Organ donation

www.uktransplant.org.uk

www.nhs.uk/Conditions/Organ-donation

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Charities providing palliative and end of life care

Marie Curie Cancer Care

Provides free hands-on care to people with all terminal illnesses in their own homes, and vital emotional support to their families.

www.mariecurie.org.uk

Macmillan Cancer Support

Provides specialist healthcare information as well as emotional and financial support for people with cancer, their families, friends and carers. They can also provide details of local support services and cancer information centres.

www.macmillan.org.uk

The National Council for Palliative Care

An umbrella charity for all organisations involved in palliative care, end of life care and hospice care in England, Wales and Northern Ireland. It promotes the improvement of palliative care services for all people with life-limiting conditions.

It also promotes palliative care in health and social care settings, across all sectors, to government, national and local policy makers.

www.ncpc.org.uk

Sue Ryder

Provides specialist palliative care through its seven hospices in the UK, including in-patient care, day services and care at home.

www.sueryder.org

Other sources of support and information

Samaritans

Offers emotional support 24-hours a day for people experiencing feelings of distress or despair, including those that could lead to suicide.

www.samaritans.org

Saneline

Provides care and emotional support to people with mental health problems, their families and carers as well as information for other organisations and the public.

www.sane.org.uk

Healthtalkonline

A website where you can watch, listen or read interviews of people who share their experiences of health and illness. You can also find information about conditions, treatment choices and support.

www.healthtalkonline.org

Support groups

Self Help UK

A directory of patient support, self-help groups and charities.

www.self-help.org.uk/directory

British Liver Trust support groups

www.britishlivertrust.org.uk

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Online support groups

www.horsemouth.co.uk

Education and training resources

www.dailystrength.org/support-groups

Alcohol and drug services

www.cancerbuddiesnetwork.org

Animal care

The Alzheimer's Society *Talking point* – offers an online discussion forum for people with dementia and their carers.

Bereavement

<http://forum.alzheimers.org.uk/forum.php>

Carer support

Macmillan Cancer Support offers an online community for people affected by cancer.

Dealing with death

www.macmillan.org.uk

Health and well-being

The Multiple Sclerosis Society offers discussion boards for patients and carers.

Legal, financial and immigration issues

www.mssociety.org.uk

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Guidelines on getting consent to share information across organisations

The guidelines below are a brief summary of the main aspects of how to ask for consent to share information across organisations, including the legal requirements that govern these situations.

When to share information?

You may need to share information in order to ensure the delivery of coordinated and integrated social services and healthcare to older people and adults.

Some examples of when this information needs to be shared include:

- Provision of appropriate care services
- Improving the health of older people in the local community
- Protecting older people and communities
- Supporting older people in need
- Investigating complaints
- Developing inter-agency strategies
- Performance management and audit
- Research
- Staff or volunteer management and protection

Why do we need to share information?

Initiatives requiring a multi-agency approach cannot be achieved without the exchange of information about individual patients and clients; levels of activity; the nature and level of resources; and about their approach to addressing the issues. Therefore,

they include a commitment from all involved to enable such information to be shared.

The first principle of the Data Protection Act 1998 requires that personal information must be used fairly and lawfully. Consequently, you should obtain consent from the patient or client to share their information. For the sharing of sensitive personal information, explicit consent is required – that is, informed written consent.

If consent is not given because the patient or client is either unable or unwilling to give explicit consent, then the information will only be released in exceptional circumstances.

The list of what constitutes sensitive personal information is contained in Section 2 of the Data Protection Act 1998 and this list includes racial or ethnic origin, physical and mental health condition, etc.

How should a practitioner go about asking for consent?

The general principles of the Mental Capacity Act give us some clear guidelines:

- A person must be assumed to have capacity unless it is established that the person lacks capacity.
- A person is not to be treated as unable to make a decision unless all practicable steps to help the person to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because the person makes an unwise decision.

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- An act done or decision made under this Act for, or on behalf of, a person who lacks capacity must be done, or made, in the person's best interests.
- Before the act is done, or the decision is made, regard must be had as to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

What specific steps do practitioners need to take?

1. Check that the person has capacity to consent.
2. If the person can consent, explain the following:
 - Who their information will be shared with, and that they can limit who this will be shared with
 - How this will help with their care
 - That they can refuse their consent and explain the consequences – sharing their information, prevents them from having to undergo repeat assessments and delays or difficulties in receiving services
 - That they can withdraw their consent at any time
 - That there may be occasions where it may be necessary to override their wishes in relation to sharing information, for example, to protect them or others
3. Ask the person the questions on the consent form and to sign the consent form.

How does a practitioner know if the person can consent to share information on their own behalf?

Can the person:

- (a) Understand the information relevant to the discussion?
- (b) Retain the information?
- (c) Use or weigh that information as part of the process of making the decision?
- (d) Communicate his/her decision (whether by talking, using sign language or any other means)?

What should the practitioner do if the person is not able to consent on their own behalf?

Is there any person previously identified by the individual?

This includes, if practical and appropriate, to consult them about:

- Anyone caring for the person or interested in their welfare
- Someone with lasting power of attorney granted by the person
- Anyone appointed for the person by the court

What if there isn't anyone previously identified by the individual?

Consider (if known) the person's past and present wishes and feelings; their beliefs and values; and other factors they are likely to consider if they were able to do so. Can you form an opinion on information-sharing, respecting the known wishes of the person concerned and (although not previously identified) consult with a representative about consent?

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You need to consult with the person's carer or representative about consent. If this is not possible, then the information would only be released in exceptional circumstances.

How do I know what is in the person's best interests?

Don't make any decisions based on:

- The person's age or appearance
- Their condition, or an aspect of their behaviour, which might lead others to make unjustified assumptions about what might be in their best interests

Are you trying to prevent harm to the person?

Are your actions proportionate to the likelihood of harm to the person taking place? For example, is it likely that the person will suffer harm if you do not take any action, or are there some wider concerns about general safety?

Template 1

Homelessness and end of life care Consent form
To share and protect personal information

Client's name Date of birth

Your statement of consent
Please read this form carefully, complete the restriction section if appropriate and sign as indicated.

I agree that the information provided may be shared with other health and social care agencies who can contribute to my care.

I understand that:

- This information will be used for the purpose of providing a service or care to me.
- Agencies may use anonymous information for statistical purposes and that the law may allow in some circumstances for other agencies to be provided with information about me.
- I may withdraw my consent to share information at any time and this may result in a reduction of services that are available to me.
- I have the right to restrict what information may be shared and with whom, but this may affect the provision of care to me.
- My information will be held securely on paper and on computer in accordance with the Data Protection Act 1998.

I have made the following restrictions (if applicable):

Signature: Date:

Print name:
Please note that you can alter your consent at any time.

Statement of representative (if applicable)

I represent the person on this form and (please mark as appropriate):

I agree with the decisions that have been made regarding the sharing of information.

I disagree with the decisions that have been made regarding the sharing of information because:

Signature: Date:

Print name: Relationship to person:

Source of legal authorisation e.g. LPA (if applicable):

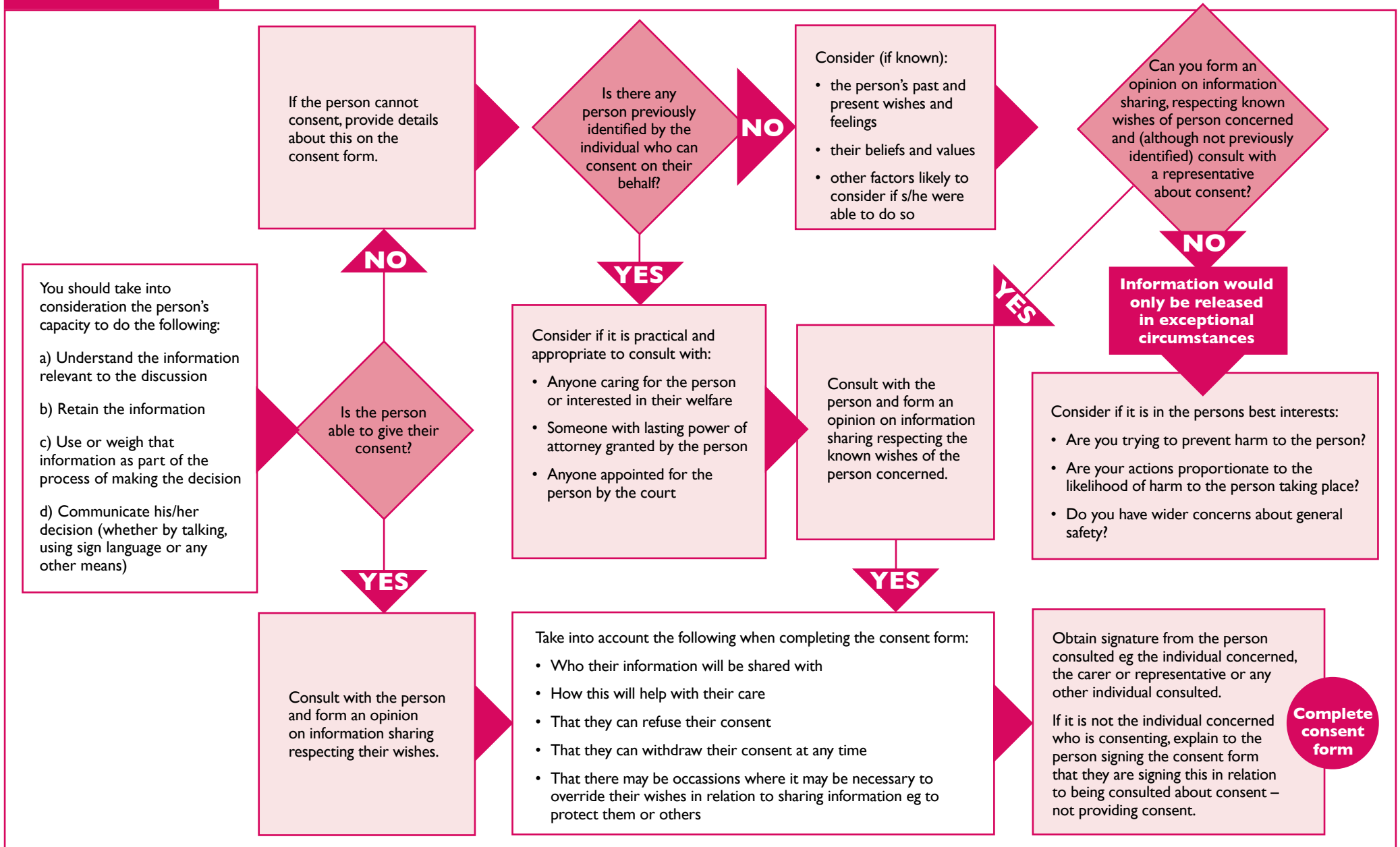
Client's name Date of birth

Download the Consent form here:

www.mungos.org/endoflifecare

The consent form is a practical tool to help safeguard a resident's rights, including their right to refuse or restrict information. This template offers guidelines on the importance of gaining consent to share a resident's information across organisations. You can refer to the consent process chart on the next page.

Consent process chart



Information sheet for service users and carers: Confidentiality and information sharing

Why do we need to keep information about you?

We ask for your information so that you can receive the right support. We keep this information, together with details of your care, because it is needed to check that we are providing the right service.

This information is kept in paper files in secure locations and on a secure computer system.

The way that information about you is collected is governed by the Data Protection Act 1998, which says how personal information must be stored and handled. If you want more information about the act, it can be found on www.legislation.gov.uk

Why do we need to share information?

You have a right to have information about you kept confidential, but we may need to share some information to make sure that you get the services that you need. Wherever possible, information will only be shared with your agreement.

Sharing information reduces the need for you to repeat the same information. It is sometimes shared to protect you or other people who may be at risk.

When your information is used for teaching, statistical or research purposes, the information that identifies you personally is removed unless you have previously agreed that it can be revealed.

Who is your information shared with?

Information will only be shared with staff or volunteers directly involved with the provision, planning and management of the support provided to you.

Sharing information without your agreement

There are some situations in which we may have to pass information on without your consent, including:

- When we are required by a law or court order
- When it is necessary to protect you or someone else
- To prevent, detect or prosecute a serious crime
- Where professionals need to share information as part of their duty of care to you

If possible, this will be discussed with you before it is done.

Looking at your own information

If you want to look at the information we keep about you, you can ask to see it. You have the right to change anything that is incorrect. If you wish to see your information, please contact the manager of your service.

We try to keep our information as accurate and up to date as possible – please let us know if your details change eg address, telephone number, GP.

Sharing information with carers and relatives

Carers are often a vital part of the support that people receive. Many people are pleased for their carers to be involved in discussions about this. However carers do not have an automatic right to be involved, even if they are your next of kin or nearest relative. You can decide what you wish to keep private and what you are willing to be shared.

It may be necessary to ask for information and views from carers (without disclosing confidential information), and their right to confidentiality will be respected in the same way, subject to the same exceptions.

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Template 6

Homelessness and end of life care

Record of an advance decision

To my family, my GP, my Health and Welfare Attorney (where applicable) and all other persons concerned, this advance decision has been made by me, entirely without influence from any other person whether they might stand to gain from my death or otherwise.

Full name (in block capitals)

Address

.....

.....

Date of birth

.....

I declare that, if at any time:

- I am unable to participate effectively in decisions about my medical care

and

- Two independent doctors (including one consultant) are of the opinion that I am unlikely to recover from my illness or impairment

and

- The gravity of my condition or suffering is such that treatment seems to be causing distress beyond any possible benefit, then in those circumstances my directions are as follows:

1. I am not subject to any medical intervention or treatment aimed at prolonging or sustaining my life such as those in 'Detailed instruction' below, even if this means my life is at risk. This does not necessarily mean withdrawal of life-enhancing medication as I would not want the withdrawal of any treatment which may reduce distress or provide pain relief or if the withdrawal would adversely affect my quality of life.

2. Any distressing symptoms, including any caused by inability to eat, drink or simply receive nutrition, are to be fully controlled by appropriate analgesic or other treatment, even though that treatment may shorten my life.

Detailed instruction

Please insert your personal requests here in relation to the types of medical intervention you would find unacceptable (for example, artificial resuscitation and/or an artificial feeding tube inserted through the stomach wall). Continue on a separate sheet if necessary.

.....

.....

.....

.....

Template 7

Homelessness and end of life care

Bereavement support exercises for staff
Assessing your own needs following a death

Name Date

Consider	How will you meet your own identified needs?
Your need to feel and express emotions as appropriate	
Your need for one-to-one support	
Your need for group support	
Actions that will assist in reducing stress or distress (including pleasurable activities)	

Proposed review date

Template 8

Homelessness and end of life care

Bereavement support exercises for staff
Assessing your needs as a team following a death

Group name or location Date

Consider	How will you and your team meet the identified needs?
Opportunities to express emotions and concerns	
Opportunities for peer support	
Actions that will assist your team in reducing stress or distress (including activities such as a shared meal or going to a movie)	

Proposed review date

Download the *Record of an advance decision* here: www.mungos.org/endoflifecare

A tool you can use for recording the decisions a resident may wish to make about their future care, in the event they lose their capacity to do so. Note: It is important that an appropriate healthcare professional (such as a GP or specialist palliative care nurse) initiates conversations about advance decision-making with the resident, and supports them to fill in the form.

Download the *Bereavement support exercises for staff* here: www.mungos.org/endoflifecare

This exercise may be used to help you reflect on your needs, and what would be most helpful to you, following the death of a resident. It is something you can consider alone, or with someone you are close to.

Download the *Assessing your needs as a TEAM following a death* here: www.mungos.org/endoflifecare

This exercise may be used by you and your team to reflect on your needs, and what would be most helpful, following the death of a resident. It is an exercise you can consider doing at a team meeting, debriefing session, or at other times when you come together as a team.

Death and dying: religious practices chart

Faith	As death approaches	When death is imminent	Immediately after death	Method of disposal	Funeral customs	Mourning practices
Buddhism	The dying person needs peace and quiet to allow for meditation. A monk or religious teacher should be invited to talk to the dying person and chant passages of scripture.	The ideal is to die in a fully conscious and calm state of mind. If a monk is not available, a fellow Buddhist may chant to encourage a peaceful state of mind.	No special requirements relating to the care of the body. Buddhists from different countries will have their own traditions regarding care of the body. If a monk or religious teacher is not present, inform the monks of the appropriate school.	Buddhists bury or cremate according to local traditions.	Usually within three to seven days, a service may take place in the house prior to going to the cemetery or crematorium. Monks may be invited to remind the mourners of the impermanence or life.	There are great variations according to the country of origin – eg in Sri Lanka, Buddhist mourners may return to work in three or four days and place no religious restrictions on widows. Some Vietnamese Buddhists have a series of rituals; mourning may last 100 days and mourning for a husband or father may last for three years.
Christianity <i>(Practices vary depending on denomination)</i>	As death approaches, some Christians may wish for prayers and anointing with oil by a minister or priest.	Where appropriate, a priest or minister might be notified. Many Christians will wish to receive communion (which will include some form of repentance and forgiveness). Prayers of commendation may also be said.	No special requirements.	The body is either buried or cremated. Increasingly, only close family are present at the burial of the body or the ashes.	It is customary in some areas to hold a prayer service in the house for the dead person before the funeral. For Orthodox Christians, Roman Catholics and some Anglicans, the funeral involves a church service with a mass or communion. Sometimes the body is placed in the church the night before and in Orthodox funerals, the casket remains open throughout the service. Protestant services are simpler and the body is not usually visible.	There is usually no official mourning period or mourning dress. There may be a service of thanksgiving sometime after the funeral.

Death and dying: religious practices chart

Faith	As death approaches	When death is imminent	Immediately after death	Method of disposal	Funeral customs	Mourning practices
Hinduism	Hindus may receive comfort from hymns and reading from the Hindu holy books. Some people may wish to lie on the floor. The family should be present.	The family may wish to call a Hindu priest to perform holy rites. A dying Hindu should be given Ganges water and the sacred Tulsi leaf in the mouth by their relatives. A person should die with the name of God being recited. Hindus often wish to die at home.	The family will usually want to wash the body themselves. If no family is available, health workers should wear disposable gloves, close the eyes and straighten the limbs. Jewellery and religious objects should not be removed.	The body is cremated as soon as possible, with the exception of children under three years old who are buried.	Part of the service takes place at the home. The pandit (priest) chants from the scriptures and the chief mourner (usually the eldest son) performs the rituals. Mourners walk around the coffin which is then closed and taken to the crematorium for further prayers.	Mourners and friends return to the deceased's house. In India, the period of mourning and austerity (10 to 16 days) culminates in rituals enabling the dead person's soul to join the ancestors. In Britain, these very important rituals occur soon after the funeral and involve gifts to priests or to charity. There may be further rituals at one, three and 12 months.
Islam	Other Muslims, usually family members, join the dying person in prayer and recite verses from the Qur'an. The dying person may wish to have their face towards Mecca (south east).	The Declaration of Faith (Shahada) is said and, if possible, the dying person responds 'I bear witness that there is no God but God and Muhammad is His Messenger'.	Health workers who are not Muslim should ask permission to touch the body and then use disposable gloves. The body must be kept covered. Soon after death, there is a ritual washing of the body by same-sex Muslims. Post-mortems are disliked.	The body is always buried.	Ideally burial is within 24 hours of death. Male family members carry the coffin either to the mosque or directly to the cemetery where the funeral prayer is said; women are not included. The body is buried in a deep grave facing Mecca. In bigger cities, there are special areas for Muslim burials; and in some, they are allowed to bury the shrouded body without the coffin. In some instances, the body is embalmed and taken back to the country of origin for burial.	Islamic law requires friends and relatives to feed mourners for three days. After this, the family should officially return to normal life though unofficial mourning may continue until the 40th day. It is ended by Quranic readings and a meal.

Death and dying: religious practices chart

Faith	As death approaches	When death is imminent	Immediately after death	Method of disposal	Funeral customs	Mourning practices
Judaism	A rabbi may be called to join the dying Jew in prayer and facilitate the recitation of the 'Confession on a Death Bed'.	The dying person should not be left alone. Jews present should recite psalms and when death occurs, the 'Declaration of Faith' (Shema).	Health workers should handle the body as little as possible and cover with a white sheet. The Jewish Burial Society will collect the body and perform a ritual wash before burial. Post-mortems are disliked.	Burial of the body is as soon as possible in simple coffins. Some non-orthodox Jewish communities permit cremation. Funerals do not take place on the Sabbath (Friday evening to Saturday evening) or holy days.	The service takes place in designated Jewish burial grounds. Prayers are said in a chapel and at the graveside. Although women now attend funerals, the male mourners recite the prayers and place the coffin in the grave.	After burial, there are three periods of mourning throughout which designated mourners recite prayers thrice daily and refrain from certain activities. In the first week (shiva), mourners remain at home; the 30 days (shloshim) concludes the mourning period for all (though children of the deceased would mourn for a year). When mourning is concluded, the tombstone is consecrated with a ceremony at the cemetery.
Sikhism	A dying Sikh may receive comfort from reciting hymns from the Sikh holy book. A relative or any practising Sikh may do so instead.	A Sikh person should die with the name of God, Woheguru (wonderful lord), being recited. Some Sikhs may want to have Amrit (holy water) in their mouth.	Health workers should not trim hair or beard. The body should be covered by plain white cloth. The five articles of faith (5ks - uncut hair, wooden comb, metal bracelet, cotton undergarments, steel sword) should remain on the body. Family members may wish to bathe the body themselves.	Cremation of the body as soon as possible.	Similar to Hindus but dressing the person in the 5Ks. After a short ceremony in the home, the body is taken to the gurdwara (temple) for a service and then to the crematorium for further prayer.	Up to 10 days of reading from the scriptures attended by relatives and friends. At the conclusion, the eldest son is given a turban as a sign that he is now the head of the family.

Source: www.cumbria.gov.uk/elibrary/Content/Internet/536/656/3838485955.pdf

Authors' biographies

Main contents page

Peter Kennedy is the Palliative Care Coordinator at St Mungo's, a charity responsible for supporting 1,700 homeless people in various homeless projects across London and the neighbouring counties.

Peter's role includes the development and delivery of palliative care services to individual residents who may be approaching the end of their lives. He also provides training to frontline staff on end of life care, and is currently developing an in-house bereavement service for St Mungo's.

Since qualifying as a social worker in 1995, Peter has worked predominantly in the areas of homelessness and addictions. He began working in the field of end of life care in 2002, first as a social work manager in a hospice in the west of Ireland, and then as a principle social worker at St Christopher's Hospice in London.

Peter is co-author of a study about clinical indicators for liver disease. He is also a Mindfulness-based Practitioner, and has recently completed an MSc in Mindfulness-based Approaches at the University of Wales.

Christina Sarafi completed her undergraduate degree in Psychology at Aristotle University in Greece, followed by an MSc in Health Psychology at University of Nottingham.

Christina's involvement in this project occurred while she was carrying out an internship at Marie Curie Cancer Care. She is now training to become a mental health worker at Central and North West London NHS Foundation Trust.

Christina is currently working in a community outreach rehabilitation team offering individualised outreach and support services to people with severe mental health problems, and their families. Her past experience includes working with people with mental health problems in both in-patient and community settings.

Wendy Greenish was a manager in the health services, working in both the acute and community sectors.

In 2006, Wendy joined Marie Curie Cancer Care where she was responsible for designing and delivering various training courses for staff and volunteers supporting people at the end of their lives. She was also instrumental in enabling the introduction of a palliative care service based at St Mungo's.

Wendy is co-author of studies about end of life care for people with dementia and clinical indicators for liver disease.

This resource pack has been jointly developed by St Mungo's and Marie Curie Cancer Care as part of a partnership project to improve end of life care for people who are homeless.

Funded by the Department of Health from 2008 to 2011, the project continues to help address the obstacles homeless and vulnerable people face in getting appropriate, high quality end of life care.

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Marie Curie Cancer Care

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St Mungo's

Homelessness charity St Mungo's manages more than 100 emergency and recovery projects and works to prevent homelessness. Mainly based in London and the South, we house and support more than 1,700 people on any one night and each year help thousands of men and women with housing, health and work.

Marie Curie Cancer Care

Given the choice, most of us would want to die at home, surrounded by the people and things we cherish. Marie Curie Cancer Care makes this possible. Our nurses give free hands-on care to people with all terminal illnesses in their own homes, and vital emotional support for their loved ones. We allow families to make the most of the precious time they have left together.