End of life choices

Talking about end of life choices with people who are homeless

Dying Matters

Let's talk about it
When homeless people die it is often perceived as untimely and undignified by those supporting them. We can’t always say that we’re surprised that they died but might wish we’d been able to talk more openly about their wishes for the end of life.

This guide aims to take away some of the concerns about this subject. We’re not pretending that it will make death easy to cope with, or bring about the ‘perfect death’, but there may be ways of making it slightly easier to know how a client wants to be cared for, by whom and their wishes for before and after they die.

### Why it can be difficult

As a society we do not easily talk about dying and death, making it harder for us to talk about our end of life care needs with others. For homeless people, additional obstacles or barriers might include:

- combined chronic physical and mental health issues and poly substance misuse
- being unlikely to seek health advice early
- being less likely to access appropriate health and social services
- being less likely to engage with healthcare professionals

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

- saying the wrong thing
- making the person angry or sad
- being rejected
- that the client will give up or lose hope
- damaging our relationship with the client, which may lead to them disengaging
- not being able to fulfil their wishes
- not knowing enough about the practicalities, such as end of life care, funerals and wills
- feeling that we’re intruding; clients may wish to live day to day, not think ahead
- not feeling skilled enough to have conversations about dying and death
What are we trying to talk about, and why?

It’s important that we get to know as much as we can about the informed choices clients wish to make about their life and death. These may include:

- where they would like to be cared for until they die
- what, if any, treatments they would want or not want as their health deteriorates
- things they would like to do before they die
- who they might like (or definitely not like) around if they’re ill or after they’ve died
- who they might want to have their possessions or pets after they die
- any cultural, religious or spiritual preferences
- the kind of funeral or celebration they’d like
- how they would like to be remembered
When should we talk?

Timing
There is no right or wrong time to have these conversations. Timing will depend on many different factors, including the client’s health at the time, and the choices they wish to make. You don’t have to have these conversations all in one go either. It’s ok to open the subject and 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.

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 clients’ wishes when there is no pressure. Obviously these may change over time, but if you’ve spoken about it in the past it will be easier to do so in future. For example:

- **Throw away 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 clients individually or in a group about how to respond to that person’s death can lead to questions about their own wishes.

**Physical Symptoms**
Some of the following symptoms may indicate that someone is nearing the end of their life, so may prompt you to initiate conversations. (Taken from Supporting homeless people with advanced liver disease who face death, Marie Curie Cancer Care, 2011)

- Distended abdomen
- Jaundice
- Bleeding from the rectum, mouth and nose
- Not eating
- Memory loss
- Fluid in the legs, difficulties with walking and balance
- Prominent veins
- Tiredness, malaise
- Confusion
- Withdrawal symptoms
Preparation

Stop and think
It’s really important to give yourself time to prepare well for the conversations you’re likely to have.

Ask yourself:

- Why do I feel I need to speak about this? For example:
  - You notice a client is struggling to live independently as their health deteriorates
  - You feel that a client’s nursing and medical needs may require a more appropriate place of care
  - You notice that someone has become more isolated and withdrawn since told of their prognosis
  - You know very little about a client’s preferences and wishes as they are approaching the end of their life

- Why am I finding it difficult?
  It’s important that our own fears of talking about dying and death don’t stop others from thinking and talking about their end of life. Is the difficulty yours or theirs (or both)?

- Who else can help by providing information and support?
  This could include the specialist palliative care team, GP, hospital medical team, health and social care professionals and key worker

- What do I know about the person?
  Knowing the client, such as their likes and characteristics, and having rapport can help you pitch the right tone and language, and anticipate any concerns or issues that may arise

Planned conversations, initiated by you
There may be times when you feel you need to raise the subject of a client’s end of life wishes with them, for example if they have been given a poor prognosis or if you are worried that their care needs may be too high for you and your team to manage.
Training and support

Although dying and death are a natural part of life, they can still be hard to talk about. Having training or accessing information about the following may help.

- Communication skills for conversations about end of life care
- Understanding what palliative care is and its approach to supporting someone nearing the end of life
- Planning end of life care
- Bereavement
- How to arrange a funeral and different options that are available locally

Setting the scene

In opening up conversations make sure you have enough time for discussions, and that you’re in the right environment, for example in a quiet space with minimal disruptions.
Support

It is important to have the support of other staff and colleagues and to know who is there to support you.

Policies and procedures

As an organisation, it can help to have policies and procedures in place around end of life care. Procedures can include the co-ordination of care with other agencies that support not just the client, but also you and your colleagues. You might also wish to consider setting up a focus group with residents to hear their views to inform your policies and procedures.

Tools

The Blue Wallet Scheme, designed by the National End of Life Care Programme, is designed to enable people to record their wishes around dying, death and bereavement and keep it with them in case of emergency. It contains contact details, information about medical conditions, but also wishes and preferences about what they want to happen if they die. It could be offered to all clients.

Dying Matters leaflets and resources

Dying Matters have produced a number of leaflets and posters that aim to prompt and support conversations. They can be given to clients. (See further information at the end of this leaflet)
Being realistic

- It’s important to have realistic expectations about what may happen in end of life care and not feel guilty if things don’t turn out as planned. What matters is that you tried.

- Make it clear that you’re asking clients what they’d like to see happen in an ideal world, and that it’s not always possible to make it happen exactly as we’d like. For example, although many people may choose to die at home, it is not always possible for this to happen.

- Make it clear that comments are not set in stone and can be revisited.

- You won’t always get it right. You might miss opportunities and wish you’d been able to speak earlier. This is part of life and you don’t need to feel guilty.
Making a record

Make a note of things that have been said, and ensure other members of your team know where this is.

Remembrance

It can be hard to find time to stop and remember the person when they’ve died. There are some really nice ways of doing this. Both staff and residents can share ideas and use these times and spaces to remember that person.

- Having a wall or place where you can write the name of every person who has ever lived in your hostel
- Photos
- Annual memorial services
- Planting a tree
Finally, it’s important to remember that:

- A client (or 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 as any attempt to solve or ‘fix’ things may be feared and resented.

- A client will often change their mind.

- Some clients may not wish to engage in conversation with significant others and/or healthcare professionals. If this is their choice, it should be respected.

- As professionals, we are not personally responsible for solving clients’ or significant others’ problems.
Further information

Dying Matters is an inclusive, national coalition with thousands of members from across all sectors. Dying Matters is generating, leading and supporting collective action to promote public awareness and debate on issues of dying, death and bereavement in England. To find out more, join, or access more copies of this document visit: www.dyingmatters.org or call freephone 08000 21 44 66. My Life, My Choices is a guide for homeless people about the end of life choices available to them.

The National Council for Palliative Care is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all. www.ncpc.org.uk

Care to Learn: This is a self study module, designed to help staff provide end of life care in residential settings.

Homeless charity St Mungo’s provides accommodation for more than 1,600 people every night in emergency shelters, hostels and supported housing, mainly in London and the south of England. It also has outreach services working with rough sleepers in Westminster, Southwark and Reading. www.mungos.org

Marie Curie Cancer Care provides end of life care to terminally ill patients in their own homes, or in one of its nine hospices. www.mariecurie.org.uk

Supporting homeless people with advanced liver disease who face death (2011) presents the findings of research carried out by the Marie Curie Palliative Care Research Unit at University College London. The work was commissioned by St Mungo’s and Marie Curie Cancer Care as a result of a joint project funded by the Department of Health to enhance end of life care for people who are homeless.

Homeless Link is the only national charity supporting people and organisations working directly with homeless people in England. www.homeless.org.uk
The National End of Life Care Programme works with health and social care services across all sectors in England to improve end of life care for adults by implementing the Department of Health's End of Life Care Strategy.
www.endoflifecareforadults.nhs.uk

Routes to success: End of Life Care – Achieving quality in hostels and for homeless people
This publication aims to provide a practical guide to support hostel staff in ensuring that people nearing the end of their life receive high quality end of life care.
www.endoflifecareforadults.nhs.uk/publications/rts-hostels

Planning for your future care is a guide for patients which explains advance care planning and outlines the different options available to them.
www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare

Coming soon: The blue wallet scheme is designed for people to record their wishes around dying, death and bereavement and keep it with them in case of emergency. It contains contact details, information about medical conditions, but also wishes and preferences about what they want to happen when they die. It allows professionals to identify when the individual has begun discussions. This is being trialled by St Mungo’s in association NEOLCP and Marie Curie Cancer Care. For further information on this exciting project, please access the NEOLCP website.

The National End of Life Care Strategy (2008): Promoting high quality care for all adults at the end of life

This document is based on conversations with service users and staff at Framework Housing, Nottingham and Luther Street Clinic, Oxford. It was co-written by Peter Kennedy, Palliative Care Co-ordinator, St Mungo’s and Jo Black, Involvement Manager, NCPC.

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