Dignity in death

Could the Six Steps of the national End of Life Care Pathway be applied to support people who are homeless and use substances? By **Chrissie Dawson**

In Southampton, the rise in frequency of hospital attendance at A&E among people who were homeless and using substances, particularly alcohol, prompted commissioners of local alcohol services to explore ways of managing the already overstretched A&E department and providing better care for the individuals. Working with the hospital's alcohol nurse and homeless healthcare teams, conversations about the inequities of the End of Life (EOL) Care Pathway for Southampton's chronic substance users and homeless population began.

To understand the barriers and challenges, a workshop was convened with professionals from health and social care settings, hostels and homeless healthcare. It soon became apparent that the EOL pathway afforded to someone with cancer or heart disease was not being replicated for our homeless and substance using population. Why was this?

A lack of understanding around supporting someone at the end of life, coupled with a limited awareness of the community services available, meant that the default position was to dial 999, meaning clients would end up in A&E. This often resulted in clients dying on a ward in unfamiliar surroundings, or discharging themselves back from where they came.

With the help of the care home education team, we explored how the six steps of the national EOL Care Pathway could be applied to support the staff in regular contact with this group.

Step 1: discussions as the end of life approaches

Conversations around death and dying always were something of a taboo, but why more so for this cohort? The use of the 'surprise question', 'Would you be surprised if the person in front of you were dead in a year?', was arguably difficult to apply to someone who regularly relies on substances. Is this the reason discussions about abstinence and managing drinking were more likely to occur than a dialogue facing the real dilemma around their inevitable EOL journey and death?

The 'we can do this' attitude and passion of hostel workers and health professionals providing EOL care led to a forum being formed to work through the barriers to overcome the many challenges. The group looked at issues around the confidence of hostel workers to begin or pick up on cues for EOL conversations, attitudes towards and the accessibility of palliative care and how the national drive for this group of people to 'achieve their preferred place of care' at the end of their lives could be achieved.

Death and dying along with birth and taxes are the certainties of this world – so why is it so difficult to either begin the dialogue or pick up and run with the cues; 'I've not got long for this world' can so often be met with 'Don't be daft, you'll be around forever!'

Highly skilled EOL education facilitators provided the much needed confidence and common sense approach to having 'the conversation', helping to alleviate concerns around saying the wrong thing or upsetting and spoiling the relationship with the client.

Step 2: assessment, care planning and review

How can you have an EOL plan and how could palliative care work in this arena?

One of the difficulties with this client group is that for years people have said 'you will die if you don't stop drinking'. Getting people to take discussions about dying seriously is a challenge, coupled with the fact that their mental capacity is often altered by alcohol and

grasping when their wishes are truly being expressed, or when they may be changing their mind on an issue as important as resuscitation, is difficult.

These latter aspects continue to be a work in progress, but the fact that discussions are occurring more frequently and earlier in an individual's life is very positive for health professionals and voluntary sector staff.

Advance care planning discussions have been introduced within the hostel services and an Advance Care Plan (ACP) document was developed to capture the details relevant to this group, such as, 'Who will look after my dog?', or 'I'm not religious and don't want a religious funeral', while at the same time ensuring the information required by health professionals around preferred place of care is captured.

This process has provided opportunities for clients to build bridges with people from whom they have become estranged, or to say who their key 'other' is that they would like to be around in their last days or informed of their death.

Services also adopted areas of practice from the wider EOL agenda, such as individuals having a 'Message in a Bottle': a simple recognisable device which holds client-specific information, such as their resuscitation status. Elements specific to this client group, like planning who would take care of a much-loved dog, specific health needs and the often volatile and uncertain prediction around EOL have also been considered.

CLIENTS AND HOSTEL WORKERS ARE SUPPORTED BY PRIMARY CARE, THE ACUTE HOSPITAL AND COMMUNITY TEAMS TO CONTINUALLY REVIEW THE NEEDS OF THEIR PATIENTS AND THEIR PREFERENCES FOR CARE AS THE DYING PHASE APPROACHES

In all, the professionals working with alcohol users said they could now concentrate on the real care needed as they felt they had a voice to discuss the topic of death with their clients and clinicians. Work undertaken by St Mungo's also helped to encourage local networks that the scope was there to make the necessary changes.

Step 3: co-ordination of care

So, now it's been talked about, who needs to know and how is this information captured? It's no good keeping all the information in the vaults of your organisation, seen by no-one other than hostel staff.

If 999 is dialled, the ambulance crew need to know the patient they are attending actually doesn't want to be carted off to A&E, to die in an acute hospital with no-one around them they know.

Building on existing relationships with health professionals was key, for example a client telling you they do not want to be resuscitated has to be covered legally by a GP or authorised health professional and therefore requires the necessary paperwork to be completed and signed by the appropriate clinician. Staff have been engaged in the process and have gained confidence in requesting and advocating the expressed views of the individual.

Relationships between health professionals is crucial, differing expertise between community nurses and those in an acute hospital have always been recognised and respected. Now was the time to have the confidence to 'hand-over' to community colleagues who are highly experienced in palliative care, but not necessarily substance misuse. Good communication, commitment by staff and shared care planning have all supported this.

Step 4: delivery of high quality services

There will always be times when someone is really unwell at the end of their life and hostel workers will feel anxious about some symptoms which can occur as death approaches. Close working with the acute hospital alcohol nurse and visits to the wards has helped to manage these fears around some of the more graphic symptoms associated with liver disease deaths.

This, coupled with support from the community nursing teams, has led to people's wishes in this group being respected and their preferred place of care achieved, while receiving the care and support they require in a dignified manner. As well as support between the different teams and services, there were challenges in finding suitable accommodation for people. Many care homes were not able to cater for drinkers. One local provider was supported to work flexibly and introduced EOL care as an option within their service remit. This service now provides a residential setting where individuals can choose to spend the last weeks of their life.

Step 5: care in the last days of life

Over eighteen months later and more individuals are having the opportunity to achieve their preferred place of care at the end of their lives. More hostel workers are reporting that clients approaching the end of life are beginning to talk about their feelings and on occasions, contact with family and friends has been resumed.

At the same time, staff are feeling confident, if not liberated, in supporting individuals during difficult times. Clients and hostel workers are supported by primary care and community teams to continually review the needs of their patients and their preferences for care as the dying phase approaches.

Step 6: care after death

Clinicians from the homeless healthcare team and GPs in primary care have formed positive relationships with the hostels supporting the homes to ensure that timely verification and certification of death occurs.

Staff are aware of the impact a death can have on other clients, especially for those where relationships have formed. They are now able to provide support to manage difficult feelings and emotions.

The regular forum meetings have provided the opportunity to discuss those 'doubting Thomas' moments, reflect and share good practice. They have also proved invaluable as an additional resource for practical and emotional support for the staff who have supported deceased clients.

Whole system discussions about EOL have resulted in a more enlightened view from clients and voluntary sector staff. There has been a palpable shift, from viewing death as something negative, to drawing on the positives of meeting the wishes of an individual in terms of where and with whom they would like to die.

Inevitably there have been a range of views and a range of experience from staff groups about death and dying, from outright fear to a degree of acceptance and a facility to talk about such issues. Taking the topic forward with voluntary sector colleagues has allowed everyone to deepen their understanding and take the opportunity to learn more.

Templates have helped people frame difficult questions, which have led to a more process-driven approach in trying to establish people's end of life wishes with whoever that individual feels comfortable talking to.

From a service user's point of view, it's still early days when it comes to seeing services shift to a more open view of homeless/alcohol dependent individuals and offering them a range of services, but we're getting there.

The success of this work has led commissioners and health professionals to explore other areas. Providing staff working with various client groups with the skills to approach EOL care and ensuring more people's wishes at the end of life are achieved, can only be positive for all involved.

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Case study

John Andrews (not his real name) was residing in a Southampton hostel – he had been identified as someone who could benefit from EOL support by the Homeless Health Care Team (HHCT).

John was admitted to hospital and a member of staff from the hostel went to visit him, along with the HHCT nurse, to talk about EOL support. The EOL support plan was completed with John and the nurse explained his medical condition.

John initially thought EOL support was to try and reverse the damage to his liver. The member of staff explained his medical treatment was only a small part of EOL support. He was encouraged by this and engaged well with support after returning to the hostel.

One of the main things John wanted was help with a funeral plan. A list was drawn up of the persons he wanted notified in the event of his death. He had not been in touch with his family for some time. Although distressing, John said he was comforted that the right people would be informed. John continued to drink heavily and use heroin. He overdosed twice in a short space of time and had to be resuscitated using Naloxone. On one occasion staff administered 5 doses of Naloxone before the ambulance crew arrived. The paramedic administered more Naloxone and informed staff they had probably saved his life as he had gone over so far.

Completing the EOL support plan with John helped him to realise the reality of his situation.

A personalisation application has been made to fund his support needs and to enable his individual wishes to be acted upon, which includes help to see his family. John has also just started a three week detox programme and will be returning to the hostel once completed.

John will then be supported to move on to the most appropriate accommodation. The Resettlement Worker from the hostel will continue to provide EOL support, as will the HHCT. With John's permission, EOL information will be passed onto any other individuals or agencies supporting him.