



NHS Education for Scotland

Transcript of 'Being Homeless at the End of Life' (NES Bereavement Webinar, 2021) video.

Chair: Dr Graham Whyte, Associate Postgraduate Dean for Grief & Bereavement, NHS Education for Scotland.

Speakers:

- Ellie Wagstaff, Policy and Public Affairs Manager (Scotland), Marie Curie.
- Dr Joy Rafferty, Specialty Doctor in Palliative Medicine, Strathcarron Hospice.
- Support: Philip Smith, Senior Officer, NHS Education for Scotland.

Graham Whyte (GW): Okay, so welcome everybody to this evening's webinar. This is the 12th webinar in this Bereavement series entitled Being Homeless at the End of Life. So, delighted to welcome our two speakers Ellie Wagstaff, who's policy and public affairs manager with Marie Curie Scotland and Joy Rafferty, Specialty Doctor in palliative medicine at Strathcarron Hospice. I tell you a bit more about our speakers in a second, but just a little bit of housekeeping.

First of all, so for those of you that haven't attended one of these webinars before, the structure of this is that we'll have a roughly 45-minute presentation, and then there'll be time for questions at the end. So just to introduce our speakers in a bit more detail, as I said, Ellie is policy and public affairs manager at Marie Curie, and joined the charity back in 2019, and she's responsible for leading and supporting the delivery of Marie Curie's work around Scotland.

Particularly around health inequalities, including homelessness, digital health and social care. And she recently co-authored a report along with Joy entitled "Dying in the Cold," which is looking at homelessness and end of life care. And that's calling for urgent reform of the palliative care support for people experiencing homelessness and also greater expansion of the training for frontline organisations and tailored bereavement support for those experiencing homelessness, but also those homeless organisations and staff looking to support those people. Dr Joy Rafferty is a Specialty Doctor, as I said, based at Strathcarron Hospice. In the past, she's worked as a GP in the Edinburgh access practice, which is the GP practice looking after people experiencing homelessness within Edinburgh, and her particular interest is in how palliative care can be improved for people who are homeless and other hard to reach groups. And her master's dissertation was in homelessness and palliative care in Scotland. And I say, she co-authored the report with Ellie. So, Joy's going to kick us off. So, without further ado, I'll hand you over to Joy.

Joy Rafferty (JR): Thank you very much. So, hi everybody, and thanks ever so much for the invitation to speak today about homelessness and palliative care. So first up, we thought we'd have a little poll just to see what services people work in. So, I think Phil's going to do that just to see really where people are from.

Phil Smith (PS): Hi everyone, this is Phil supporting the bereavement session today. You should see the poll we have on screen right now. We'd like to hear from you on what kind of background you're coming from today, thanks.

JR: Great, so that's great. Thanks very much, so that's really interesting. So, it looks like we've got people from a mixture of different services today. So hopefully there'll be something in this that'll be useful for everybody. So really the plan today is to talk a wee bit about homelessness, just give a bit of background about homelessness in Scotland, a little bit about what palliative care is for those of you who don't work in palliative care. Talk about some of the barriers people experience in homelessness face when trying to access services. A bit about loss and bereavement in homelessness, deaths within homeless projects and hostels, and then go on to talk about what could actually make things better. I'll then hand over to Ellie who will then go on to talk a bit about the report we did and some of the policy recommendations and government work that we've been involved in. So that's the plan for this evening. So, who is homeless in Scotland? So, thinking about definitions, being homeless means that you have no suitable accommodation in which to live. So that includes people who are rough sleeping, so have no appropriate shelter of any kind, but also people who are in temporary accommodations. So temporary flats, refuges, hostels and also those who are sofa surfing. So, people who are moving around friends and family but without any stable base.

So, I think we're going to try and have another poll again, just to see really what you think about how many people were homeless in Scotland in 2019 to 2020. This is the last year we've got full figures for. So, if people want to have a guess or if you know. Okay, thanks, so again, a real mix of answers there.

So, if we can go back to the slides, Phil, that would be...So, if you said 31,300 people, you were right in that that was the number of households that applied to the local authorities for homelessness and support and were then assessed as being homeless. If you said 35,600, you were also right. That was the number of adults within those households. 15,700 was the number of children in those households. We're given a total of 51,300 people within households that applied to local authorities for homelessness support within that year.

However, we do know that many people who are homeless don't apply to local authorities for homelessness support. We know this from extrapolating some data from the Scottish Household Survey, but also surveys of people using third sector homelessness services as well. When people are asked: to have they accessed homelessness support via their local authority, we know that quite a few people don't.

So, I think probably there's maybe around 60 to 70,000 would be kind of an estimated number of the amount of homeless people there are in Scotland. So, you are all right. I think it's worth saying at this point that homelessness is often not just about housing. So, most of us, if for some reason we were to lose our home tomorrow, wouldn't necessarily end up homeless or wouldn't necessarily end up in homelessness for long periods of time. So particularly complex homelessness, repeat homelessness, is very much a symptom of other difficulties and other issues that are going on in people's lives and complexities.

So why think about homelessness and palliative care? Well, we know that people who are experiencing homelessness do have worse health than the general population. 80% of homeless people have at least one physical health problem, and there's increased prevalence of many diseases, as shown in the table here, compared to the general population. We know that death rates are higher in people who are homeless, about four times that of the general population. And recently we've started to get figures over the past couple of years about homeless deaths in Scotland.

And from that, there's around 200 people who die in Scotland every year while they're homeless. And sadly, Scotland has the distinction of having the highest rate of homeless deaths in the UK. And it's nearly three times that of England and more than three times that of Wales, so not a good statistic.

The average age of death for people who are homeless in Scotland is shockingly low. It's just 39 for women and 43 for men. So, thinking about palliative care, I noticed not everybody, you know, works in palliative care. So just a wee bit of background on what palliative care is. So, it's care provided for people with a life-limiting condition that aims to improve their quality of life. It's a holistic approach, looks at meeting people's physical needs. So, symptom control, practical support, people's psychological needs, so emotional support, talking about worries and concerns, social and cultural needs.

So, things like affairs in order, having connections with other people and spiritual needs. So being cared for in a way that fits with people's beliefs, issues around meaning and purpose, loving and being loved. It also aims to support people around the person with the life-limiting conditions. So, their family, their friends, those who are caring for them. The emphasis in palliative care is really on quality of life and planning for the future. So, supporting people to die well, but also to live well until they die. So, when we think about this for people who are homeless, we know that people experiencing homelessness have complex palliative care needs. We know that compared to other groups at end of life, they have significantly worse symptoms at end of life. And yet the people experiencing homelessness tend to have poor access to quality palliative care, worse outcomes, and often die without accessing end of life care. A couple of concepts that I think it's worth mentioning here, there's not really time to go a lot into this today, but some recommendations that came out of work that was done by St. Mungo's in London by Caroline Shulman and Briony Hudson was this instead of, when thinking about people who are homeless, instead of thinking about people with palliative care needs, thinking about people whose health is of concern.

So often people who are experiencing homelessness have quite uncertain trajectories, and it can be really difficult sometimes to tell when people are approaching the end of their lives. Often people have multiple crisis hospital admissions with some recovery of health in between times before dying in a way that sometimes seems unpredictable. Although sometimes often when you look back over the past year or so of somebody's life, there is a degree of predictability there, certainly in work we've done with homelessness, with staff working in homelessness. When you ask people, oh, have you got anybody, you know, in your hostel and your project with palliative care needs, people will tend to say no. If you ask people, have you got people whose health you're concerned about? People with advanced deteriorating ill health or people who you wouldn't be surprised if they died in the next six months. Then often there's many more people that are identified.

Another helpful concept is of parallel planning. So, homelessness services tend to be very focused on recovery and rehabilitation and rightly so, but I think this can often create a bit of an issue in terms of identifying people with palliative care needs because people often have potentially reversible illnesses. So, for example, perhaps people with alcoholic liver disease, and we know that if they were to stop drinking alcohol, then their health would recover to some degree. But we do know that for some people, that's unlikely to happen.

So, this parallel planning approach allows you to run both things at the same time. So, you can still be having those conversations about recovery, about rehabilitation, offer people opportunities to engage with that, but at the same time addressing, well, what happens if you do keep drinking? What do we need to think about?

What if you're admitted to hospital again and doing both things at the same time? So, moving on to think about some barriers that are for people experiencing homelessness to access and support, I

mean, this is particularly thinking about bereavement and palliative care support, but I think some of these concepts are universal in terms of accessing services and accessing healthcare.

So, this concept of tri-morbidity. So, when people have a physical health problem, mental health problems and problem substance misuse, I'm including alcohol in that, they often overlap and add additional complexity to things. We know that over 60% of people experiencing homelessness have a history of substance misuse. And we know that problem substance misuse is both a cause and a result of homelessness. 14% of homeless applications in Scotland, people gave their reason for becoming homeless as substance misuse. And we also know that as a result of homelessness, people can turn to taking more alcohol, taking more drugs to try and help with life on the streets, mental health or other issues associated with their homelessness.

In terms of mental health issues, half of all people experiencing homelessness have a mental health diagnosis. But self-reported mental health problems in people experiencing homelessness are much higher at 80%. Again, looking at applications for people who are applying to local authorities for homelessness support, 20% of people say that they became homeless because of problems with their mental health. And again, mental health is affected by homelessness. So, all these issues are very intertwined and add complexity to accessing support. Often, services will tend to work in one area, perhaps not so much in other areas or people may be excluded from, for example, a mental health service, if they also have substance misuse issues going alongside that.

Another barrier is complex trauma. So, I think in Scotland, we're starting to become much more aware of the links that there are between adverse childhood experiences, complex trauma and homelessness, the criminal justice system. We know that 85% of UK-born people with multiple exclusion homelessness have experienced childhood trauma or exclusion. We know that Post Traumatic Stress Disorder is really common in people who are homeless with a lifetime prevalence of 79%. And we know that trauma affects symptoms. So, we know that people who have experienced trauma tend to have worse symptoms at end of life. But trauma also significantly impacts people's ability to access services and to benefit from services. So, if you have had experienced significant trauma in your past and have been let down repeatedly by people, it could be really difficult to trust services, to trust that people will do what they say they will, people can be avoidant of services, they can struggle to build relationships with professionals and can often end up being seen as the difficult patient or the clients who won't engage. And often this is because of past trauma. Also, service issues, I think a lack of awareness of the difficulties that people experiencing homelessness might face can be an issue.

And it's great that so many people have joined us today to think about some of these issues. There's a real need for additional flexibility and assertive follow up. So, for example, many people experiencing homelessness might not attend appointments and end up being discharged from services. But actually, if you've not got an address to get appointment letters to, or not got money for bus fare or often people who are going through difficulties just won't open any official-looking mail because any official-looking mail tends to be bad news.

So perhaps won't get appointments and won't engage with things also, if you're not quite sure what day it is, because so much else going on in your life, again, attending for appointments at fixed times can be really challenging. People experiencing homelessness, often discharge against medical advice early from hospital admissions. This can be because of actual stigma, perceived stigma, competing priorities, worries about substance withdrawal, not being appropriately treated and other complexities going on in their lives. So, there's a real need for professionals to take the initiative. We know that when homeless people are surveyed, they repeatedly say that they're unlikely to spontaneously approach professionals if they're seriously ill. And it's really helpful if professionals take the initiative and visit places where they regularly are or where they're staying. Continuity of care can be really

difficult. So, if people are generally presenting within crisis in crisis situations, perhaps to A and E, but then not attending follow up, it can be really difficult to have continuity of care.

Also, services often work within very fixed geographical boundaries, and if you're moving around, then you might not be able to have that continuity of care. And again, trauma really plays into how well people can engage with services. And also, what we were talking about before, how services can sometimes work in silos. So, your mental health service, which is very separate from your substance misuse service, very separate from your physical health service, and all these things can make care very challenging for people. Also, people can be involved with multiple agencies. So, if people experiencing homelessness may be involved with housing, social work, perhaps criminal justice systems, substance misuse services, mental health services, voluntary sector services, and often if these services don't talk to each other or they're not interlinked, again, that can make care are very fragmented. And also, people experiencing homelessness are often socially isolated. Perhaps don't have friends or family who can take them to appointments or encourage them to attend. Thinking specifically about end-of-life care, there's a real lack of options for people who are homeless, who are approaching the end of their life in terms of where they can go.

So, as we see most, the average age is very young, which often excludes people from places like care homes. Often, people don't want to be in hospital at end of life, but sometimes that ends up being the default option because there's not good options in the community of where people can be. If your home is the homeless hostel, it may be that you wish to remain in the hostel at end of life, but how that's going to be, how staff will feel about that can vary considerably.

And I think it's worth just moving on to talk about a wee bit about loss and bereavement. Just homelessness is loss. There's just such profound loss involved with homelessness. Some of the things will come up on the screen, they are just some of the things that people can lose when they become homeless. And often these things have a domino effect. So perhaps it will be that somebody has had a bereavement and then that leads on to perhaps deterioration in their mental health.

They perhaps stop going to work. They maybe don't engage with their employers. They may lose their job, then impact on their finances. They then get into rents arrears, all these things can snowball, and there's just often profound loss associated with homelessness. And moving on to think a wee bit about bereavement, I think it's worth saying that neither Ellie nor myself are particular experts in bereavement. I know some people on this call are. So, some of this information is from research and experience from other projects. But we do know that bereavement is a significant contributory factor in people becoming homeless. So, it can be a domino effect because of grief, but also practical issues. So perhaps somebody's partner dies, and the house is in their partner's name, they're not married, people may end up losing their accommodation that way.

Another example, a lady who has had a child with a disability, the child died and at the same time as grieving for the child, suddenly her income in terms of child benefit, disability living allowance, carers allowance, suddenly stops and can no longer afford the house. So, bereavement can really contribute to people becoming homeless. We know from the research that people who are homeless often experience the death of the people around them. And often these are repeated bereavements as well.

Again, from the research, we know that many people who are homeless often think about death, and it's worth saying that these deaths are often shocking deaths, often distressing deaths. So, they tend not to be so much the deaths of granny in her bed at home with the whole family around, slipping away peacefully at the end of a long life, but they're deaths by suicide, deaths by violence, deaths related to substance misuse, or perhaps deaths in distressing circumstances in terms of the person perhaps just being found dead. And often very sudden deaths as well without much warning.

And you will find people who are in their 40s and they will talk about how all of their friends and contemporaries have died, and they'll only be 40. Also linking back to what we were saying about childhood trauma, there's often death experience when the person is very young. So, CARIS who are a charity in London working with people who are homeless did a piece of qualitative research talking with people about their experiences of loss, people experiencing homelessness, about their experiences of loss, one of the stories that stayed with me was of a young man, who, when he was 10, he lived with his grandmother, and she brought him up. And then when he was 10, he was taken then to live with other family members that he didn't have such a good relationship with, and his gran then died.

That loss of his gran had a really profound effect on him. And then when he became homeless a number of years later, he would sleep on his gran's grave for the first year of his homelessness. And often these early deaths, early loss of attachment figures can have profound effects on people. And we know that people may deal with these losses in less healthy ways. So, if you're already struggling with your mental health, you're already struggling with substance issues, with the alcohol issues, and then you lose somebody, then these things can be compounded by that. And we know that people experiencing homelessness after bereavement have increased risk of depression, loneliness, isolation and suicidal thoughts.

So, moving on to thinking about deaths within homeless projects or settings. So, when somebody does die, say within a homeless hostel, it can often be very traumatising for other clients, so it can bring back and echo previous losses that they've experienced in their lives. Often when a death happens in that kind of setting, then there tends to be police involvement, it goes to procurator fiscal, those investigations go on and staff can often say that they end up feeling quite criminalised or traumatised just by the investigations going on around that.

And sometimes that even happens even when it's a known death, for example, somebody's been dying or something that, you know, it's an expected death. There can still be all that investigation that goes on.

And we know that people who work within the homeless sector are often exposed to the deaths of people that they care for. And often in very difficult and traumatic circumstances. And because of that, they have a high risk of secondary trauma and burnout.

So, a study then in Canada with 250 people who worked in the homeless sector found that a quarter had burnout and around a third had symptoms of PTSD. And this matters, it matters because it reduces staff's quality of life, it reduces their job performance, but also people end up not staying in the job long. People move on to other jobs. Often there can be guilt and distress from staff or people around the person who's died, about could they have done more? Should they have done more? And sometimes these things can lead to reluctance to have planned palliative care, perhaps say in a hostel because people know how difficult sometimes it is when they've had deaths on site. So that's all a bit depressing. So, moving on to think about what might actually help. So, I think the first thing that helps is just recognising that it is an issue and that we need to do something about it. So again, delighted that so many people have joined us today. Bereavement support, so we know that not everybody who is bereaved & needs formal support, and often informal support can be really helpful. But I think people do need people around them who have the skills and willingness to support them.

And we do know that often people experiencing homelessness might be quite isolated. We know that formal bereavement support is of most benefit to people who don't have family support and they're at high risk, such as people experiencing homelessness. We know that when staff are provided with

support after a death, it can improve their resilience and enable them to keep going on and doing the very difficult job that they do. But I think it's also worth saying that anybody who is providing bereavement support to people who are experiencing homelessness or working in homelessness, tends to be providing that support within the context of ongoing loss and often challenging lives, and they need to be adequately supported and supervised to do that. And again, going back to, I think there is this real need for a proactive approach.

We can't just sit and wait, expect people to come and find us or find our services, but the real need for outreach and not expecting people to come to us, but reaching out. So, one of the things that I looked at in my dissertation is what's being done elsewhere in the world. And there's a number of great projects, particularly in England at the moment, that are doing a lot around bereavement support.

So, in Suffolk, there's a hospice, St. Nicholas Hospice, who have trained some hostel support workers in providing bereavement support. And I'm a big fan of people who work in homelessness, often they really are very experienced and very skilled in working with people who have experienced complex trauma, perhaps have substance issues, perhaps have challenging behaviour and often really have the skills to support people. And it's just sometimes providing people with a wee bit of extra training or a few extra skills, and then they can go on doing what they do with their clients.

The same project also looked at and trained some service users as well. And again, I think that's a really welcome development that people with lived experience of homelessness can then go on to help other people in that situation. There are also projects going on both in Suffolk and in Cheshire with hospice bereavement counsellors going into hostels and homelessness projects to provide support.

Often, that takes quite a long time to develop and needs quite regular attendance and building up trust, building up visibility before people engage. And in London, St Mungo's, a homelessness charity have partnered with **Cruse** and so they have some volunteers' who Cruse have done bereavement support training with, and St Mungo's have done homelessness training with, and then those volunteers go and provide people with a listening ear and in the role of compassionate listeners to people experiencing homelessness, and also can support staff within homeless projects.

Another thing that I think is really welcome in a number of settings in England is this concept of memorials. So, when somebody dies within a service, there's perhaps a memorial service or a wall or a book or a tree's planted, there's some sort of memorial, some sort of event that commemorates that person's life. And I think it helps other residents or clients to then reflect on the life of the person who's died. Also, can help staff to talk about their loss. But also, I think it can help people see that their death does matter. And because when homeless people are asked what they worry about death, one of the things is dying anonymously and being forgotten after they die. And memorials can help people also talk about their loss, but also can help other residents start to think about their wishes and what they would like. So, I suppose the question that we we're left with is how we make things better in Scotland. I think we're very; Ellie and I are both very keen to have any chats about partnership working, any ideas anybody has and how we can move things forward in Scotland to make things better.

Just a few resources, I think the slides will be available later. So, this toolkit is produced by St. Mungo's in London, there's, lots of great resources in there, has resources for people who work in the homeless sector to kind of think through about if there is a death in service, what's the kind of practical aspects? What's the emotional aspect? What you might be able to do about memorial. And just kind of think these things through.

There's a good section in this end-of-life care pack on bereavement within homeless settings. And the last link is linked to our report, which Ellie's, I'm going to now hand over to Ellie and she's going to talk about, thank you.

Ellie Wagstaff (EW): Thank you so much, Joy. It's great to be here, everybody, and thanks for having us.

So, a little bit, what I will be talking about today, just thought it would be good to just give sort of a brief context of policy of homelessness in Scotland, and then I'll be moving on to talk about some of the reports, recommendations and things that we've had around bereavement.

And I'd just like to finish with a short case study, which I've been permission given to use from Cyrenians, which is just a specific example of somebody who they supported in their last year of life.

So, to start looking at the homelessness in Scottish policy context, you can see a couple of the commitments from the recent programme for government that was announced by the Scottish Government just a couple of weeks ago, specifically relating to homelessness. So, investing in an additional 50 million over the course of parliament over the next few years to tackle homelessness with an expected 12 million this year. So that's a welcome development in terms of tackling such a longstanding issue and I think reemphasizes and highlights the importance of continuing to include health as a component of that support.

It also includes a commitment around homelessness prevention, which prevention Joy had touched on very briefly earlier. And I think that while working towards that aim is really important, it also has to be an equal consideration alongside the conditions that people will likely be continuing to have and will be continuing to progress even after any resolution to accommodation might be arrived at.

So, the impact of physical health and mental health and problem substance and alcohol use, as Joy has mentioned, can be very, very long-lasting. So, it's why it's so important that support around prevention continues to include the integration of health and social care services, including bereavement for that as well. Bereavement is recognised as a cause of homelessness and it's important to state that, but also the continuing need for it to be integrated into the health and social care services that people experiencing homelessness provide.

As Joy mentioned, the profound impact of loss has many different capacities and many different strands which can impact a person. So, we strongly believe that this would be a really necessary commitment and part of the components to that. It's also good to see the inclusion of alcohol and substance misuse support being pledged to be part of the national care service as well, which has been pledged to come into parliament over the next, towards the end of the Parliament in the next few years.

Having that resource and support available is really important, but also having the access to other health and social care services we believe is equally as important as well.

So, when we're looking at the pandemic response, which has been happening since the start of last year in the context of homelessness, we saw a very rapid shift to get the homelessness communities and population into accommodation during COVID, which was incredibly important and a real achievement, and also showed the collaboration which is possible that really just seemed to materialise overnight.

And it's really important that that approach to homelessness continues. But we know that the impact

of dying, death and bereavements has been significantly intensified by COVID-19 for everybody. And the impact of grief and bereavement on people who are experiencing homelessness is very relatively unknown as is whether they have been able to access and engage with the palliative care support that they will have needed as well during this time, which Joy has already covered some of the challenges with access and engagement for that. So, moving on to the "Dying in the Cold" report that we had also co-authored towards the middle of the year around May, I think it was, time is running away from me. Marie Curie hosted a homelessness and end of life summit in October last year, and Joy was one of our key speakers to present her research and her dissertation.

So, the event also included presentations from Deep End clinicians, but also those frontline homelessness service experiences which are so key as they are often the very first point of contact that somebody in these circumstances will come into contact with. The event was really well attended by national, local governments, representatives, palliative care specialists, general health specialists and students, a very, very wide-ranging array of clinicians and expertise that were in the room, and the feedback and the question and answers that we were able to gather has really helped to shape and to inform some of the recommendations from that input.

So, there were a series of eight or nine recommendations in the report specifically, and we kind of grouped these into three core sections. So, the first one looking at improving access and provision of palliative care and end of life care for people who are experiencing homelessness. Really, we're looking to facilitate the provision of specialist palliative care teams, and that would include clinical nurse specialists and link workers with medical support who can work collaboratively with existing services for people experiencing homelessness and other forms of severe multiple disadvantages as well.

Using that expertise as well to inform the development of new models of palliative care, the experiences that people experiencing homelessness may have had in relation to trauma that Joy has already covered and the impact that they can have on the end-of-life experience, but also, for any family members who are left once that person has died.

So, we'd also look for those models to be flexible and to be able to be delivered in all care settings and to be able to use the specialist support mentioned from clinical nurse specialists as well as input from the third sector as well and people who have lived the experience of homelessness. We'd also made a recommendation around closing the digital poverty gap by increasing up to date digital devices, to help facilitate more remote consultations for people experiencing homelessness.

Joy has already explained in great detail about the issues that clinicians can face when they're trying to engage and to create consistent relationships with people experiencing homelessness who continue to move around as a transient population and who may struggle with trust issues from complex trauma that Joy's already discussed.

So, the remote consultation aspect of that could help mitigate some of the barriers that people who are people are experiencing homelessness could face. And we also really support a recommendation that was made by GPs at the Deep End to increase the provision of link workers from 50% to 100%. Link workers have such an important role and a vital role in engaging with and kind of building those relationships with people who are experiencing homelessness as well.

And being able to have an increased capacity for them is something which we truly believe would help support end of life experiences for this group. So, the second kind of group of recommendations that we've made was around palliative care training, being made available for people who are delivering homelessness services.

And that would really help to identify people who could benefit from a palliative care approach much earlier. So, when we're, as Joy mentioned, the frontline organisations can be the first point of contact for somebody experiencing homelessness, but also, when frontline organisations are faced with these situations, they usually have very little or minimal contact with palliative care services.

So, improving links to hospices and to other palliative care services and great to improve palliative care training, just to even provide a general background to palliative care and how it could be supportive to a person, it's something that we very much believe in and is something that Marie Curie, in partnership with many other organisations, including Pathway and the Oak Foundation and UCL has been working on a palliative care training programme specifically for palliative, for homelessness frontline service staff. So, we, once we have more details of that, we're very happy to share that with those that it would be relevant to, but again, the programme would be an overview to part of palliative care and include multiple different strands of the support that people can provide.

And that would also include bereavement and grief as well. So, moving on to the final recommendation, which is kind of most relevant to tonight's webinar is around more tailored bereavement support for both those who are experiencing homelessness and homelessness service staff, who are often exposed to the deaths of those that they care for, sometimes in very difficult circumstances.

So as Joy has mentioned, the circumstances in which people die can be very sudden, very shocking, and being able to access the right support that frontline organisations need as well is really critical for their own mental wellbeing but also to build resilience and to help carry out their role as best as they possibly can. One of the other recommendations kinds of more generally for palliative care that Marie Curie had been making and along with a lot of other organisations during the elections was the call for a new national palliative care strategy.

And we were pleased to see that as a commitment in the programme for government as well. And within the palliative care strategy as part of our manifesto calls, we had really called for that to be a really inclusive whole system approach that engages with multiple health and social care organisations but also aims to tackle health inequality and inequities, which includes homelessness as well.

So, I'd just like to kind of wrap up with a case study, which I'd been given permission to use from Cyrenians who had supported this man from the point of his diagnosis. So, he'd had a lifetime of substance and alcohol misuse, which had really taken over after some complex trauma that he had received when he was younger, he'd been married with two daughters, had a career that he really, really enjoyed as a taxi driver, but as a result of his addiction issues and lifetime of problem substance alcohol use, he was diagnosed with lung cancer. And he was moved into temporary accommodation and Cyrenians really stepped in to be that support and that liaison, and also to communicate with his family because he completely lost touch with his family and he'd been struggling to make those connections and because of the past and previous experiences, that had been a real difficulty.

And I think it's really just to highlight how important frontline organisations are in supporting both the person and the families with bereavement and that end-of-life care support. Because when the gentleman was admitted to hospital, he deteriorated very quickly and Cyrenians were able to facilitate his family to come into the hospital and to make amends for everything that had happened in the past and all of the hurt and the pain and the regret from both sides was able to be talked about and left behind. And the end-of-life experience for this gentleman was in the end very positive because he had his family around him and they were able to hear positive stories about him and Cyrenians tell me, at that point, they weren't looking at him as a man who had very complex

and severe health needs, it was the dad, the brother, the uncle, and to have those positive experiences at the end of life, I think has really helped support them in their bereavement now that the gentleman has died.

And I think it just shows how important and how crucial frontline organisations are, the amazing work that they do in facilitating those relationships to ensure, to try and ensure that end of life experiences can be as positive as possible and to still maintain that contact, even after the person has died.

The person who was looking after this family from Cyrenians was also very involved in helping the family and supporting the family in arranging the funeral and still keeps in touch with them today, just to check in to see how they're doing and to keep up to date with how they're managing. And so, it's that level of support that really, really starts to make a difference for both the person who's in that position for the patient to know that their family and any past experiences have the opportunity to be kind of overcome and for the person to be able to die well and to be dying in a positive environment with the people that mean the most to them.

But as we know, but from the background that Joy has given, that's not always possible, and in a lot of cases, it isn't for people who maybe have no next of kin and have no family to support them. So having those earlier conversations about palliative care and how it could potentially help is equally as important.

So I will thank you all for listening and just to reiterate, I know that Phil will share the presentation afterwards, but for any of you who are interested in hearing more about the reports on the work that Joy does, please do get in touch with us and if there's any partnership opportunities that you think could work, I think Joy and I, she said-we're very open to that and can catch up to see what might be possible.

So, thank you very much.

GW: Oh, well, thank you very much, Joy and Ellie, that was an excellent overview of difficult situations that we maybe face with some of these people. When you look at the numbers, it's quite sobering when you think that's almost 1% if I've done my sums correctly of the population that are maybe homeless in Scotland at any one time.

Just to reiterate to people, they certainly encourage questions. So, if you wanted to input your questions in the question box, that'd be really helpful. And just while we're waiting for some of them to come through, I'll maybe kick off, it's the chairman's prerogative. But just looking at that in terms of the numbers and obviously there's a need to do better. If people are looking to maybe kind of set up palliative care services or try and reach these people, what would your suggestions be about where would they start? It's obviously a kind of hard-to-reach group. So, what might be the tips, I suppose, in terms of how to start to identify the need and look for these people in their local areas? I don't know if there are any comments about that, but...

JR: Yeah, so I think what, sorry, can you hear me okay? Am I unmuted?

GW: Yes.

JR: So, I think really what Ellie was saying about really the importance of frontline organisations that are already working with people experiencing homelessness and often have really good links with people and, you know, good experiences in this area.

And sometimes I think it is very much about upskilling them, and certainly some of the work we've been doing with St. Columba's Hospice in Edinburgh and through this Echo programme is about providing some education for staff working in homeless hostels, working in projects, step down units around what palliative care is. And, you know, just some of the issues around this and how you might start having conversations about end of life with people really, and upskilling those who are already working with people.

So, I think that's probably where to go first. I don't know what you think Ellie.

EW: Yeah, I completely agree. I think that's why we're lobbying so hard for, as Joy says, for the upskilling of frontline organisations to be able to empower them with the palliative care knowledge and to be able to support that early identification of people who might be presenting symptoms or might benefit from a palliative care approach. So, I'd absolutely agree with that.

GW: Yeah, okay. Okay, so there's a couple of questions coming in. The first one, asking, is there any data for those who maybe have no recourse to public funds being homeless at the end of life? I don't know if that's something you know anything about. So, in relation to maybe immigration status and other things like that?

JR: Yeah, that's a really interesting question. I'm not aware of any data around people who have no recourse to public funds, but I think they are, you know, an even more vulnerable group, I suppose. In terms of, yeah, if you don't have recourse to public funds, it makes you, even within homelessness who are already a very vulnerable group, I think they're an extra vulnerable group. I'm not aware of any data or research around that. I think, I suppose the one thing to say about that is that a number of hospices are part charitable funded.

So sometimes that can help in terms of accessing support. Because it's not just relying on NHS funding as well.

GW: Okay, okay, thank you. Another question here, maybe linked to more for a policy point of view, possibly, but talks about how lots of services for older adults seem to do really well at caring for, a kind of biopsychosocial needs and joined-up approaches. and given the information we shared about life expectancy, for those who are homeless, just asking the questions, wondering if we have the right approach to separating healthcare services by chronological age. I suppose we can often come across that sometimes in terms of accessing longer term care for people under 65 and that type of thing. But I don't know if either you get any comments about that.

EW: Yeah... Oh, sorry, you go first, as a question in...

JR: I was just going to say, yeah, I think that is really tricky. And I think when you meet people experiencing homelessness who are in their 30s and 40s, they often have the sort of end stage COPD or the diseases of people in their 70s and 80s. I know when the access practice did a little bit of work about the kind of multi-morbidities that people using in their service had, you know, again, it's comparable to people decades and decades older, but yeah, services often have cut-off ages, certainly often care homes, you know, which it can be an option for people at end of life who won't take people under 65. So, I think there is a real need to kind of look at the whole picture. Sorry, Ellie, you may go.

EW: No, that's all right, I was just going to say kind of to dip into that one of the sub recommendations that we made in the report as well was I think, from Joy's dissertation thesis and wider general knowledge that there's a lack of community palliative care beds for kind of homelessness settings.

And that could potentially help to support people who are at the end of life who would prefer to not be admitted into hospital and as a place of, to offer as a place of choice for somebody in that position to be around people who are familiar to them from the relationships that they built through frontline organisations.

So that was just an additional point.

GW: Okay, thank you. I've got a question here more relating to the training side of it. I know you touched on Echo and other things, but someone's asking what's the best way to access support and training to start looking at introducing these across services?

EW: So, I think so Joy, you'll notice know from, sort of contributing again to the training for the Echo model, which has been running in Edinburgh. I think as I said the kind of collective training that Marie Curie and other partners have been working on will sit alongside that, and to give just a little bit more detail about it, we're hoping that the resources will be online, and be able to be accessed by everybody in Scotland, and the idea hopefully is that each group will have sort of a local facilitator and a local lead to get in touch with people who they think might benefit from the training and to be able to lead the online sessions, the webinars, and then to have a facilitated discussion afterwards.

So, the resources aren't online yet. And so, we'll keep you posted as to when that could be, but we're hoping to have that up and running probably next year.

JR: Yeah, and just to add, I think anybody that's interested in training or would think it would work for their organisation, please, please get in touch and we'll certainly see what we can do and what's available.

GW: You may be inundated. Next question's asking, can either of you point to any good practice in providing specialist spiritual care support in this area or any thoughts about how this could be provided?

EW: I would say it's perhaps not specifically related to homelessness, but the Scottish Partnership for Palliative Care have some resources which they host on their website and potentially faith in older people might be a good point of call to see if they have any resources available relating to this, Joy, I don't what you think?

JR: Yeah, I mean, I think for the people who work in palliative care, they'll probably know that like, you know, chaplain spiritual support tends to be an integral part of palliative care, perhaps much more than most other areas of medicine. So, I think that's why we're really keen. If we can get specialist teams of people who are experienced within homelessness, that there would be spiritual support within that. And I think also recognising that spiritual support can also be, you know, provided by generalists or by people like your homeless sector workers as well. So, for example, in the toolkits, there's various things that you can work with, that people can work with through their clients about what's important to them, what they want, you know, what they want extra support with, what gives them meaning, what gives them purpose. So, I think that that also can add an aspect of spiritual support.

GW: Okay, thank you. Next point was maybe a bit of a point rather than a question, but just talking from somebody who's had an interest in working for patients with palliative care needs, but with substance abuse or misuse issues in the past, and obviously they've hinted about the overlap there. They're trying to set up kind of Scottish national guidelines for addictions and palliative care group and how we might link in with the homelessness side of things from that point of view.

So, I don't know if any additional comments or thoughts from that point?

JR: Yeah, absolutely, I think there is such a degree of overlap here. And again, just thinking about what palliative and end of life care looks like for people who are perhaps coming towards the end of their life, and often that can be because of substance misuse as well. So, absolutely, please, please do link in with us, that would be really interesting.

GW: And a further question here. Again, thank you for the webinar, but quite shocked by the statistics that are provided about the young average age of death. And wondering if there's any additional research or work looking into homelessness as in older adults and if you know anything about that?

JR: So, I know that there is quite a number of papers that have been published on homelessness and older adults, I think mainly in the North American setting, but yeah, yeah, I think there has been quite a bit of work and sometimes of how perhaps disenfranchised grief and bereavement can be an impetus in people becoming homeless later in life as well.

GW: Thank you, and next question talks about, I suppose I'm talking about hard-to-reach groups, but just asking, are you aware of any issues for people with palliative care needs who are being released from prison and are homeless on released from prison and how that maybe impacts?

JR: Yeah, so I think there's such an overlap, I think between homelessness, substance misuse, the criminal justice system, and often, all links to kind of trauma and past trauma as well. Often sometimes that is people's route into homelessness can be being released from prison and certainly working in the homeless practice, that was quite a regular thing that you saw, was people who'd just come out of prison and into homelessness. So yeah, I think there are, I know there's quite a bit of work going on to try and improve palliative care in prisons as well, and I think that's again something that would link in really nicely to the work around homelessness.

GW: Yeah, I suppose it does have a, perhaps a more identifiable population if you can get that experience in maybe palliative care, like you say, in prison, isn't it? So hopefully you can get that additional support at an early stage, if possible. Just checking if there's any additional questions, I think that's possibly us coming to the end of the questions and we're not far off the end of time.

So, it doesn't look like there's any more questions. So, it just remains for me to thank you both very, very much for your talks, I think it's obviously generated a lot of interest and questions and I'm sure people will be interested in seeing the presentation if they haven't been able to join for tonight's webinar.

So, thanks, thanks again for your time and efforts in putting that together. And as I say you've opened the invitation for people to get in touch with you if they want more information or to try and work with you or collaborate with you. So, thanks, thanks again for that. We will be sending out a link for feedback for those of you who have joined the webinar again for any comments regarding it, or also suggestions for future webinars. So please fill that out when you get it. And we'll also put the slides and also recording of the webinar in due course up on the Support Around Death website.

And just for those who maybe aren't aware, we are offering a full one-day virtual conference, which is free for health and social care professionals in Scotland, on the 24th of November. If you haven't seen any information regarding that, there is more details on the Support Around Death website. So please sign up for that as well.

Grand, so thank you very much, Joy and Ellie, and I wish everyone else a good night and thank you for coming tonight.

EW: Thanks for having us.

The film was produced in September 2021 and can be found at www.sad.scot.nhs.uk or <https://vimeo.com/639899707>

For more information visit www.sad.scot.nhs.uk or contact supportarounddeath@nes.scot.nhs.uk

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