



**FEANTSA**

# End-of-life Care for Homeless People



FEANTSA

## End-of-life Care for Homeless People

### Context

Thousands of homeless people in Europe are at risk of dying prematurely. According to estimates, at least 453 homeless people died in France in 2013.<sup>1</sup> The true number is likely to be much higher as experience of homelessness is not necessarily recorded on death certificates, so that the huge impact homelessness has on people's health and wellbeing, morbidity and mortality often goes unnoticed. While governments across Europe are drawing up ambitious strategies to end homelessness, there is a lack of statistics available about death among homeless people and very little is formally recorded about the thousands of lives lost across Europe due to homelessness.

The first section of this paper therefore aims at raising awareness of multiple morbidity and mortality among homeless people. The second part discusses the barriers that people who are homeless face to accessing end-of-life care and assesses the particular end-of-life needs homeless people can have. In its conclusion, the paper sets out key recommendations for both policy makers and service providers in the homelessness and healthcare sectors on how to improve end-of-life care for homeless people.

### Part One: Fragility of Life and Mortality among Homeless People

#### Homelessness and Ill-health

Housing is a social determinant of health that impacts on a person's opportunity to live a healthy life. Poor quality of, or lack of, accommodation is the cause of many of the health issues homeless people face, and often complicates treatment and recovery. There are clear causal and consequential links between homelessness and poor health outcomes. Ill-health can cause, contribute to and exacerbate homelessness and homelessness can cause, contribute to and exacerbate ill-health. There is no easy answer to the cause and consequence debate but what we do know is that once a person becomes homeless, the impact on both their physical and mental health is significant.

People who are homeless experience higher levels of physical and mental ill-health than their housed counterparts.<sup>2</sup> They are at increased risk of suffering from a wide range of health problems, including seizures, chronic obstructive pulmonary disease, musculoskeletal disorders, tuberculosis and skin and foot problems. Some people who are homeless, particularly rough sleepers and long-term users of homeless shelters and hostels, are disproportionately affected by multiple morbidity including problematic alcohol or drug use, mental health issues and physical health problems.<sup>3</sup> In addition, homeless drug and alcohol users tend to use these substances more frequently, in increased quantities and in less safe ways. Risk behavior is directly correlated with housing instability, with the highest levels of risk being experienced amongst rough sleepers and those in emergency accommodation.

<sup>1</sup> Peer support among adults with serious mental illness: a report from the field by Davidson, Chinman, Sells and Rowe, 2006

<sup>2</sup> Identified chronic health issues for people experiencing homelessness include: blood borne viruses, particularly Hepatitis B and C, skin infections; tuberculosis; cardiovascular disease; depression; post-traumatic stress disorder; malnutrition; dental decay and tooth loss.

<sup>3</sup> Uribe, J. (2011), "Homeless population in Barcelona: profiles, health situation and access to health care services", pp. 4-6, European Network of Homeless Health Workers (ENHW), issue n° 13 – Spring 2011



**FEANTSA**

Despite this excess burden of illness, people who are homeless often experience difficulties in accessing and using health services. Providers of these services often lack the resources and flexibility to promote timely responses to the complex healthcare needs of homeless people.<sup>4</sup> This relationship between the need for healthcare and its actual utilisation has been named the 'inverse care law' - in other words, those who most need care are the least likely to receive it.<sup>5</sup>

## **Homelessness and Mortality**

Homeless people often die from preventable and treatable health conditions. This is often as a result of accumulated and untreated complex health needs and multiple morbidity. This means rates of premature mortality are extremely high among the homeless population.

While life expectancy among the general population throughout Europe has been increasing over the past two decades, persisting premature mortality among the homeless population is evidence of the extreme health inequalities experienced by people who are homeless. In England, the average age of death for homeless men is 47 years and for homeless women it is even lower at just 43 years, compared to 77 years for the general population. In Denmark, people who live on the street die an average of 20 years earlier than the general population.

In addition, homeless people are seven times more likely to be killed in an accident and almost four times more likely to commit suicide than the average citizen. They are also more often victims of violence. This shows that homelessness puts people at great risk of injury and, in some instances, death.

Despite this, there is a lack of data and information about the causes of death among homeless people. Collecting data and information on the deaths of homeless people would enable us to track trends in relation to the deaths of people who are homeless. In addition, a deeper analysis of who is dying, and why, would improve the understanding of how homelessness causes premature death and would allow for work on how such premature deaths could be prevented.

## **Part Two: End-of-Life Care for Homeless People**

### **Increasing Demand for End-of-Life Care**

The fact that people experiencing homelessness suffer from multiple morbidity and from life-limiting illnesses indicates a clear need for end-of-life care for this population. While estimates are not available, researchers suggest an upward trend in the ageing of the homeless population. The combination of the high level of morbidity amongst homeless people and the ageing of the homeless po-

<sup>4</sup> Complex health service needs for people who are homeless, Australian Health Review, 2011, 35, 480–485

<sup>5</sup> Hart, Inverse care law, The Lancet, 1971

<sup>6</sup> Health at a Glance: Europe 2014 presents the most recent data on health status, risk factors to health, and access to high-quality care in all 28 EU member states

<sup>7</sup> Crisis Report : Homelessness : a silent killer, December 2011

<sup>8</sup> Psychiatric disorders and mortality among people in homeless shelters in Denmark: a nationwide register-based cohort study. (The Lancet, 2011)

<sup>9</sup> Crisis Report : Homelessness : a silent killer, December 2011



**FEANTSA**

population suggests that there will be increased demand for end-of-life care services in the immediate future.

### **Provision of End-of-Life Care is a Human Right for All**

End-of-life (EoL) care is highly effective in relieving pain and other physical symptoms of ill-health, and in maximizing dignity for someone who is dying. EoL care is delivered with treatment that begins at the time of diagnosis and continues throughout the disease trajectory, using a holistic approach that improves the quality of life for patients and their families by addressing not only pain and symptoms, but also psychosocial, legal, and spiritual problems associated with life-threatening illnesses and dying.

Consequently, the provision of palliative care, where possible, should be part of a continuum of health care for all persons faced with life-limiting illnesses. A right to palliative care can be implied from the overall international human right to health, as well as from the right to freedom from torture and cruel, inhuman, and degrading treatment; although EoL care is not specifically included in the European Convention, it is part of standard medical best practice and so subject to equalities and discrimination rulings. While end-of-life care can be seen as a human right for all, homeless people are often very far away from and are even denied access to end-of-life care, and die without adequate support, if they receive any support at all. We now highlight some of the barriers homeless people face when accessing end-of-life care.

### **Barriers to Accessing End-of-Life Care**

#### *Absence of home/stable home*

Most people prefer to die at home and there is a Europe-wide trend towards, and objective of, allowing people to die at home rather than hospitals. End-of-life care is organized in such a way that care is provided at home with the family playing a central role. This kind of end-of-life care assumes that people are stably housed and are supported by a network of friends and family. Where end-of-life care is structured in order to provide home care, it does not consider homeless people, who have neither a home nor very often a family to support them.

#### *Abstinence Rules*

Even when hospices and palliative care are provided in the community, they are often inaccessible for homeless people. One barrier to accessing hospice- or hospital-based end-of-life care is due to the abstinence-only rules and policies that exclude a large part of the population, notably problematic drug and alcohol users and those experiencing co-occurring mental ill-health and problematic drug and/or alcohol use. Often, staff are unsure or unaware of how to deal with these issues when they present. Drug-using homeless people are often seen as having challenging behaviours, and so are often denied access to the care they need. In addition, people who are homeless fear they will not be able to have access to drugs or alcohol in such services.

#### *Lack of Trust*

Another barrier is lack of trust, previous bad experiences with healthcare professionals, and fear of being discriminated against and having their dignity denied, or of being treated with a lack of respect because of their homelessness.

<sup>10</sup> Homelessness, Aging and Dying, Simon Communities of Ireland, Ireland, 2013



**FEANTSA**

## **Specific End-of-Life Care Needs of Homeless People**

### *Preference to Die in a Familiar Setting*

Homeless people often refuse end-of-life services because they prefer to die in a place that is more familiar to them (such as a shelter or hostel), and the EoL services often will not provide the service to the shelters or hostels.

### *Fears about End-of-Life*

Homeless people express many fears and uncertainties that are similar to the housed population. One common source of anxiety, for instance, is the fear of not receiving adequate support to fight pain. Other fears expressed by homeless people are quite specific showing how homelessness influences concerns about death: for instance, the fear of dying anonymously and not being remembered by anyone. A similar fear is that of not being found and/or dying in a public place. A common fear expressed by homeless people includes the fear of being buried in a mass grave or being cremated anonymously. Some even fear that their bodies might be used in medical experiments.<sup>11</sup>

### *Companionship*

Like the general population, homeless people often wish to reconnect and reconcile with their families when they are coming to the end of their life. Some homeless people however prefer not to get in touch with family because of a fear of being a burden or fear of revealing their homelessness. They simply want to have any compassionate person around them at that time of their death, whether they be homeless friends or even care providers. Homeless or not, people do not want to die alone.

## **Part Three: Recommendations**

Clearly, interventions are needed so that quality end-of-life care can be provided to homeless people. Evidence shows that, given the opportunity, homeless people at the end of their life are willing to work on their advanced care directives and end-of-life preferences. It is widely acknowledged that treating people who are homeless with respect and within a supportive environment is essential for successful engagement. Research shows that homeless people are very concerned with the way they are treated, especially at a very vulnerable stage in their lives.

### *Acknowledgement that people who are homeless are an ageing population, and that their needs/changing needs must be met*

There needs to be recognition of the particular health needs of people who are homeless, especially those aged of 50 and older who have health needs more associated with the over-65 housed population. Also, it has to be acknowledged that the life expectancy of people who are homeless is considerably reduced,<sup>12</sup> and that the majority of older homeless people will have become homeless at a later stage in life.<sup>13</sup>

<sup>11</sup> Dying on the street, Homeless Persons' Concerns and Desires about End-of-life Care, Society of General Internal Medicine, 2007

<sup>12</sup> Homelessness, Aging and Dying, Simon Communities of Ireland, Ireland, 2013

<sup>13</sup> The Causes of Homelessness in Later Life: Findings From a 3-Nation Study at: <http://psychogerontology.oxfordjournals.org/content/60/3/S152.full>



FEANTSA

### *Low Threshold Strategies*

The end-of-life care system should adopt low-threshold approaches, which have minimal conditions for admission and reception of care. It is widely recognized that harm reduction strategies generally make access to services less restrictive and make support and care for homeless people more accessible. For example, integrating harm reduction strategies for alcohol (for instance by permitting on-site alcohol use) and drug use (for instance by providing sterile syringes) gives the potential to remove a crucial barrier to homeless people accessing end-of-life care services and therefore allows improved end-of-life care to be provided to homeless people. In places where the homeless population is quite large, a section of hospice/palliative care provision could be made 'low threshold'.

### *End-of-Life Care Services Should Partner Up with the Homeless Sector*

One way of improving care for dying homeless people is to forge partnerships between end-of-life care providers and the homelessness sector. Hospice care provided in a shelter can facilitate access to end-of-life care for homeless people. Another example is an end-of-life coordinator who can act as a bridge between health and social services and end-of-life care services. End-of-life coordinators have an important role to play in helping reduce access barriers in healthcare and, when interacting with health care professionals, in advocating for the right of homeless people to quality end-of-life care.<sup>14</sup> The support provided by the charity St John of God (Sant Joan de Déu) in Spain is a very good example of acknowledging, respecting and managing the 'psychosocial' care needs of homeless people. The Psychosocial Care Team (EAPS) covers this need, meeting from both ends: palliative care services and homeless organizations.

Improvements in communication between hostel staff and health professionals are necessary to provide residents with the relevant information to facilitate discussions about the choices available to them around care. Extra funding should be allocated to provide quality end-of-life care for homeless people. Discharge policies and protocols are key when dealing with people who are homeless who are sick and/or dying, to ensure care pathways are planned, especially for provision of care for people not sick enough for hospital as well as those who are terminally ill.<sup>15</sup>

### *Training for End-of-Life Care Professionals*

It is crucial to educate end-of-life care professionals about the complex and diverse needs of homeless people at the end of their lives; for example, many homeless people die from multiple organ failure, whereas community EoL care services may be more familiar with people who are dying from cancer. There is often a lack of knowledge and experience among healthcare professionals of managing end-of-life care for homeless people, and they can find it difficult to deal with multiple morbidity and addiction. For instance, pain and symptom management is a critical component of end-of-life care, but professionals might be reluctant to provide it for fear of not finding the balance between fighting pain and providing for drug use.

### *Appropriate Accommodation and Support*

Ensure the provision of accommodation facilities for older people who are homeless to meet their changing needs, especially as their health deteriorates and they come closer to death. There is a need to ensure accommodation for people who are homeless is accessible for people with mobility issues, and that bed spaces are of sufficient size and design for nursing care and support to be provided in the shelter/hostel. In addition, there is a need to support the early intervention and negotiation with service users where there is

<sup>14</sup> <http://www.mungosbroadway.org.uk/endoflifecare>

<sup>15</sup> Homelessness, Aging and Dying, Simon Communities of Ireland, Ireland, 2013



**FEANTSA**

the prospect of increasing care needs and possible residential care.<sup>16</sup>

### *Training and Support for Homelessness Staff*

Homelessness staff are regularly exposed to the deaths of residents during the course of their work. It is often difficult for homelessness staff to talk to clients about death and dying, and resources can guide them on how to initiate conversations about end-of-life care. Training should be offered to homelessness staff so that they understand how important their role can be for homeless people who are dying and so that they are better equipped to meet the end-of-life care needs of their clients/users. Such training should also enable homelessness staff to recognise and therefore act on signs and symptoms and offer support as the conditions of homeless persons deteriorate. It is important to improve the skills of staff of homelessness services to better understand and manage behaviours and coping strategies of homeless people who are dying. Staff in homeless services and service users should also be given support to help them cope with the loss of service users, often to violent death.<sup>17</sup> Staff should also receive guidelines on how to manage what to do after someone dies with dignity.

### *Resources for Homeless People*

Resources should be available for people who are homeless to help them understand their rights related to end-of-life care, and also to help them voice how they wish to be cared for, and by whom, and what their wishes for before and after they die are. Many homeless people have experienced multiple loss and grief that change their perspective on death and dying, and make it even more difficult for them to communicate about death and dying. Bereavement services should be accessible for homeless people to help support them when needed. In several cities across Europe, public memorial services are organized for homeless people who have died, to mark their passing and to honour those who have died. This is important in itself and also raises public awareness about homeless deaths.<sup>18</sup>

### *Information and Research*

There is a need to develop a better understanding of the causes of death amongst people who are homeless and a better understanding of older peoples' pathways into and out of homelessness. Additional research on the health and wellbeing of people who are homeless is also required.

<sup>16</sup> <http://www.simon.ie/findingthewayhome/index.html#/1/>

<sup>17</sup> [www.mungos.org/endoflifecare/resources\\_section](http://www.mungos.org/endoflifecare/resources_section)

<sup>18</sup> Morts de la Rue, France, Belgium



FEANTSA



Funded by the European Union

This publication has received financial support from the European Union Programme for Employment and Social Innovation "EaSI" (2014-2020).

For further information please consult: <http://ec.europa.eu/social/easi>

The information contained in this publication does not necessarily reflect the official position of the European Commission.