



# Stronger Together in Palliative Care for the Homeless

The use of consultation between professionals from different disciplines to improve palliative care for homeless people

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## INTRODUCTION

Palliative care for seriously ill homeless people is offered late, if given at all. In order to improve this palliative care, a collaboration between the hospice and social care has been set up in Amsterdam. We have investigated whether there is a need for this consultation for other organizations and situations in the Netherlands.

As a result of this reciprocal exchange of knowledge and experience, referred to in this article as 'consultation', both professionals working in social (shelter) services and professionals working in the hospice or in a nursing ward are being better equipped to provide good palliative care to people who are homeless. In addition to this, the patient who is homeless is already familiar with the hospice nurse and the hospice.

## EXISTING COLLABORATION IN AMSTERDAM

Five years ago, a collaboration in Amsterdam between Hospice Kuria (a high care hospice where homeless people are regularly admitted), the social care of HVO Querido (an organization with multiple locations for short-term and long-term shelter care and home support), and the Salvation Army started. Within this collaboration, social workers can request nurse consultations from Hospice Kuria about palliative care for homeless people at an early phase. Subsequently, the Kuria nurse visits the patient and advises the social worker. This allows the patient to remain in their familiar environment for as long as possible. If the care becomes very intensive, the patient can be admitted to Hospice Kuria. Then, the professionals of the social shelter advise the hospice nurse on how to deal with the patient. These shelter professionals have often known the person for a long time. As a result, they can give more insight into the history, behaviour, and needs of the person (see Box 1 with practical example).

### Box 1. Practical example of consultation

54-year old Harry has been with a social shelter in Amsterdam for more than five years. His care provider, a social worker, is familiar with his long history of homelessness, and notices that he is very tired. His situation continues to deteriorate and the Municipal Health (GGD) doctor and the social shelter team are discussing his situation. They indicate that they expect Harry to probably have no more than six months to live. Harry indicates that he would like to stay with the social shelter for as long as possible. The social worker calls a nurse from Hospice Kuria and explains the situation. The hospice nurse then goes to visit Harry. She gives the social worker, the GGD doctor and nurse advice on palliative care, allowing Harry to stay as long as possible at his familiar place of residence. When Harry's disease progresses, he is transferred to Hospice Kuria. His social worker visits him regularly and gives advice to Kuria's nurses and doctor. This advice is for example about dealing with Harry's alcohol addiction, his need for self-control, and his wish to stay in touch with friends.

**Palliative care** is an approach that, according to the World Health Organisation (WHO), improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.

**Homelessness** is defined in various ways in the Netherlands. *Actual homelessness* is used by the Dutch Statistical Office (CBS). This concerns more than 30,000 people who live on the streets, or stay in a social short-term shelter, or are sleeping rough. *Residential homelessness* concerns residents of 24-hour shelter facilities. In this article, we use the definition of homelessness by which we mean both residential and actual homelessness.



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## OUR RESEARCH PROJECT

To get more insight in whether the above approach might be useful elsewhere, in our research, we examined whether there is a need for consultation specifically aimed at palliative care for the homeless in the Netherlands. As a part of the project, in 2016 focus group meetings were organized with 19 professionals (4 focus groups with a.o. nurses, physicians, street pastors, social workers) and 15 people who were homeless or who stayed in a nursing ward (2 focus groups). In the following sections we describe the results of these focus groups. We discuss what makes palliative care complicated for this target group, what homeless people think of the idea of consultation, whether professionals need consultation, what challenges exist for developing consultation, and what is needed besides a consultation for providing good palliative care.

## WHAT MAKES PALLIATIVE CARE FOR PEOPLE WHO ARE HOMELESS COMPLICATED?

The focus groups showed that people who are homeless and in the palliative phase have complex problems and specific care needs. They often have a long history of physical disorders, in combination with problems concerning housing, income and debts, addiction, psychiatric disorders and / or intellectual disabilities. Their disease course is also often unpredictable. For professionals, it is frequently difficult to estimate the life expectancy of a homeless person when seriously ill. Besides this, at the end of life there are often transitions between settings; for instance, from night shelter, to emergency admission to a hospital, to a nursing department. In our focus groups, homeless persons themselves have indicated that they experience that many professionals have insufficient knowledge about specialist (medical) care and the characteristics of the target group. Professionals often know a lot about problems in one discipline, but not in another. In the last phase of life, addiction to alcohol and / or drugs is often still present, and pain management can be difficult. Also, aggressive behaviour and care avoidance behaviour occur regularly. This is behaviour that professionals from outside social shelter or mental health care have less experience with. Furthermore, it often happens that someone who is homeless or has no contact with family and friends.

## WHAT DO HOMELESS PEOPLE THINK OF CONSULTATION?

Homeless participants often suggested practical consultations during the focus groups, such as with a social worker or an expert by experience who helps them to express their needs. In addition, they saw consultation as a good way to train professionals to show understanding and attention, something that, according to them, not all caregivers are good at. Furthermore, homeless people want to be taken seriously and they want tailored care. If professionals start working more together, they believe there are more opportunities to offer appropriate care because professionals can learn a lot from each other.

## DO PROFESSIONALS NEED CONSULTATION?

Professionals indicated the need for consultation on how to deal with problems that occur at the end of life. Professionals saw the consultation of added value in the area of sharing specific expertise and knowledge that they formerly would have had little or no access to; they see it as a means to connect medical and social professionals. This bundling of knowledge is essential due to the complexity of problems among homeless people. Above that, professionals need a better recognition of the palliative phase of a homeless patient. The consultation function can help to accomplish this. Finally, the consultation can also contribute to raising awareness and creating openness to discuss the end of life through providing information, training or coaching in delivering tailored care.

## HOW CAN THIS CONSULTATION BE BEST ORGANIZED?

Professionals often mentioned that the practice of palliative care for homeless people differs per city, professional, and organization. Much depends on the expertise and knowledge already present. It is important to adjust the consultation according to this expertise and knowledge. Therefore, it is necessary to assess at a local level what is needed for consultation and how it can be financed. A point of attention is that this consultation will be tuned in with existing consultation functions for palliative care which are not specifically aimed at the homeless by providing them with basic knowledge about the target group in the palliative phase, and by informing them about the new specific consultation function. Box 2 gives an impression of the aforementioned subjects that are regularly overlooked and where a consultant could help.



## Box 2. Subjects for consultation and knowledge

- Multi-problem and diversity of the target group. E.g. complex somatic problems in combination with addiction or intellectual disabilities.
- Cultural and religious differences. E.g. insight into culture and religion so that needs are better understood.
- Care avoidance. Recognition and dealing with care avoidance and refusal.
- Illnesses and diagnoses. Specific clinical pictures that are characteristic of the target group in the final phase of life.
- Pain treatment. E.g. pain relief in case of addiction problems.
- Discussing the palliative phase with the person who is homeless. Discussion is sometimes difficult, e.g. because of fear of death or no confidence in the professional.
- Addiction and substance use. Knowledge about how to deal with addiction and substance use and the course of the palliative phase.
- Process of dying. The process of dying is often complex due to the above subjects.
- Aggressiveness and behavioural problems. Many professionals have little experience with this type of behaviour.
- Use of volunteers. Advice on how volunteers can be deployed specifically for this target group.
- Aftercare for professionals and fellow patients. For professionals because they have provided intensive care, for target group due to small network and relationship with fellow patient.
- Funeral, commemoration and rituals. Dignity is very important for the target group.

Participants of our focus groups mentioned various characteristics that a good consultant ideally has. A good consultant connects organizations and disciplines, takes initiative, represents multiple organizations and knows the practice from the inside. A low-threshold consultant who is flexibly accessible is of added value, given the problems and the lifestyle of the target group.

### WHAT IS NEEDED IN ADDITION TO CONSULTATION FOR GOOD PALLIATIVE CARE TO THIS TARGET GROUP?

A knowledge platform where knowledge is shared with other professionals was also mentioned by participating professionals in the focus groups as something needed in practice. It can ensure that professionals are generally better and more broadly informed, also

from the angle of other disciplines. For people who are homeless, the deployment of an expert by experience appeared to be important. This person would be able to assist them when they are seriously ill, for example in contacts with care providers.

### CONCLUSION

There is a need for a reciprocal form of consultation regarding palliative care for people who are homeless. Professionals in social care who provide care to incurably ill homeless people want to know more about palliative care options. Professionals who offer palliative care to homeless people in hospices, nursing homes and hospitals, in turn, need advice on how to deal with this target group. Homeless people see consultation as a means to better align palliative care with specific individual needs and often complex problems.