

# European Association for Palliative Care (EAPC) Task Force on mapping palliative care provision for prisoners in Europe

**Dr Mary Turner**

**Reader in Health Services Research, School of Human & Health Sciences,  
University of Huddersfield, UK and Co-chair of the Task Force**

## **Background**

The number of prisoners across the world has increased by 20% in the last 15 years from almost 9 million to 11 million [1], despite the fact that in the majority of societies the overall level of crime is declining [2]. The main reason for this increase is that prison sentences are getting harsher (particularly for serious crimes, but also for non-violent offences) [2], and increasing numbers of people are imprisoned for longer sentences than they would have received a few years ago. As a result of longer sentences, more prisoners are ageing in custody. Ageing brings an increased risk of ill health, and older people tend to have greater and more complex healthcare needs than younger people. In addition, it is generally accepted that long-term imprisonment accelerates ageing by about 10 years, which means that a prisoner aged 50 will have an equivalent health status to someone aged 60 in the general population. A major consequence of this is that increasing numbers of prisoners are facing the end of life in custody, and many of them will require palliative care.

Palliative care is defined by the World Health Organisation as:

***An approach that 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.*** [3]

Prisoners should receive the same standards of healthcare that are available in the community [3], and this includes palliative care. Therefore, as a result of demographic changes in prison populations, the need for palliative care to be provided in prison is increasing. However, different countries have different approaches to dying prisoners; in some places such prisoners would always be released at the end of life, whilst in other countries compassionate release is rare. To date there has been very little international research in this area, so as yet there is no European overview of palliative care provision for prisoners.

## **Development and aims of the Task Force**

In 2017, the European Association for Palliative Care (EAPC) established a Task Force to investigate palliative care provision for prisoners in Europe. The aims of the Task Force were twofold: first, to establish a network of people interested in palliative care for prisoners for the purpose of sharing ideas and good practice; and second, to undertake some mapping work to explore various aspects of palliative care provision in prisons in Europe. The Task Force is led by a Steering Committee, with two co-chairs, Mary Turner (UK) and Aline Chassagne (France); members of the Steering Committee are from Belgium, Scotland, Czech Republic, Slovakia, Portugal, France, Spain and Australia.

The Task Force was launched at the EAPC Congress in Madrid in May 2017. An open meeting was held to which all congress delegates were invited, and the purpose and aims of the Task Force were discussed. Open meetings have been held at each subsequent annual EAPC

Congress, to share the work of the Task Force and develop the network. The network, which started with around 20 members, has grown steadily through conference presentations and word of mouth, and now consists of 75 members from 18 different countries in Europe and beyond. A newsletter is produced three times a year and emailed to all members of the network; it provides an update on the work of the Task Force, and includes examples of good practice and recently published papers and articles relevant to palliative care for prisoners.

### ***The Part A Survey***

The Steering Committee decided to undertake the mapping work in two parts. The first step (Part A) was to develop background understanding of prison systems and processes in relation to palliative and end of life care in the participating countries. A second phase (Part B) will look in more detail at palliative care provision in specific prisons in selected countries; this will be undertaken in late 2019 and early 2020. For Part A, a survey questionnaire was created by the Steering Committee; a draft survey was circulated to members for comments, and then further work took place at the EAPC Congress in Bern, Switzerland in May 2018 to incorporate feedback and suggestions and develop the survey.

The final tool was agreed in July 2018 and consisted of 40 questions in six sections. The first section sought information about types and categories of prisons, and the second focused on prison populations. Section C was concerned with the provision of healthcare in prison, including palliative care, and also sought information about deaths in custody. The fourth section explored policies and practices relating to palliative care, including early release on compassionate grounds. Section E asked for examples of good practice in relation to palliative care, and the final section detailed what approvals would be required in each country for further research in Part B of the mapping project.

### ***Data collection***

The survey was designed to be completed through online searches, as it was presumed that the information required would be in the public domain. For this reason, and because no personal or identifiable data were sought, ethical approvals for this phase of the project were not required.

Members of the Steering Committee who were designated country leads in each participating country took responsibility for completing the survey. Data were collected through online searches of publicly accessible sources, including government departments of health and justice, prison administrations and prison advocacy organisations. The sources used for each question (e.g. website addresses) were recorded, together with the date on which the information was accessed. The survey was completed between September 2018 and April 2019, and the countries that participated were (in alphabetical order) Australia, Belgium, Czech Republic, England & Wales, France, Portugal, Scotland and Slovakia (although Scotland and England & Wales are all part of the United Kingdom, they have different prison systems and governance so completed separate surveys).

### ***Data analysis***

The responses from each country were collated for each question in order to facilitate analysis, and each question was analysed in turn. Numerical data were subjected to simple statistical analysis, whilst for free text data, thematic comparisons were made as far as possible between different countries. The amount of data available in the public domain varied

widely between countries, and it has to be acknowledged that in some areas the quality of the data was quite poor. Nevertheless, the survey revealed some interesting findings.

### ***Key findings***

The survey showed wide variations in the numbers and types of prisons, although there were some similarities. In all countries, prisons are funded by the state, and most countries (apart from France) have completely separate prisons for men and women. All countries also have separate institutions for young offenders, although the age at which people are classed as young offenders is variable. All countries also operate some form of security classification for prisons, ranging from high security to minimum security.

Across all eight countries, men constitute the vast majority of the prison population (around 95%). The prison population rate (i.e. the number of prisoners per 100,000 of the population) ranges from 88 in Belgium to 205 in Czech Republic. Data on the age of prisoners were only available in some countries, and the age bands used were different, making comparisons difficult; however, there was clear evidence of rising older prisoner populations in Australia, Czech Republic, England & Wales and France.

Findings about healthcare in prisons revealed that although most prisons provide some sort of healthcare, relatively few have in-patient facilities, and dedicated palliative care units are only found in a small number of prisons in one country (England & Wales). In most countries, deaths from natural causes outnumber those from non-natural causes (suicides and homicides), and it is reasonable to assume that at least some of these can be anticipated and would benefit from palliative care interventions.

The survey revealed a range of different approaches to release on compassionate grounds at the end of life and, where data were available, relatively small numbers of prisoners were granted compassionate release (apart from in France where it is much more commonplace). There were also examples of good practice in relation to palliative care in prisons found in three countries (England & Wales, France and Scotland). The full report of the Part A Survey will shortly be made available on the EAPC website.

### ***Next steps for the Task Force***

The Steering Committee is now focusing on Part B of the mapping project, which will be undertaken over the next year. We are planning a qualitative study to explore in more depth the specific issues related to providing palliative care in prisons. The Task Force project is due to complete in May 2021.

Further information about the Task Force is available on the EAPC website:

<https://www.eapcnet.eu/eapc-groups/task-forces/prisoners-palliative-care>.

If you have an interest in palliative care for prisoners and would like to join the Task Force Network, please email Mary Turner at [m.turner@hud.ac.uk](mailto:m.turner@hud.ac.uk).

## **References**

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