



**European Association for Palliative Care**  
*Non Governmental Organisation (NGO) recognised by the Council of Europe*

# **Colourful Lives of Volunteers in Hospice and Palliative Care in Europe**



## **Final Report on the work of the first EAPC Task Force on Volunteering in Hospice and Palliative Care**

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**February 2018**

## **Acknowledgements**

### **The Task Force would like to thank:**

- EAPC Presidents Professor Sheila Payne and Professor Philip Larkin and their respective Boards for their interest, encouragement and support.
- Professor Catherine Walshe, EAPC Board link to the Task Force for her guidance, support and encouragement.
- The Task Force Steering Group members for their hard work, commitment, willingness to share their skills and experience throughout the life of the Task Force and for their optimism and encouragement when sometimes things seemed impossible!
- Jos Somsen for her leadership of the Charter project.
- The wider Task Force membership for their engagement, help and support.
- Delegates and attendees at Symposia and open meetings and all those who responded to research projects and consultations

## Executive Summary

### 1. Introduction

This report gives an overview of the work and achievements of the EAPC Task Force on Volunteering (TF) in Hospice and Palliative Care (HPC). The EAPC Task Force on volunteering began in December 2013 and brought together practitioners, volunteers and researchers. Our approach involved both research and the sharing of practice and experience. The Steering Group comprised seven professionals and volunteers from Austria, Germany, Italy, Netherlands, Germany, UK and Poland and the TF had a wider membership of 32 people from 13 countries.

Findings from the work of the TF demonstrated that volunteers play a diverse and vital role within HPC services. With a demand for HPC steadily increasing in many countries, volunteers will continue to play a vital role in the future care of patients and their families.

### 2. Context for the work of the Task Force

Volunteers play an important role in a civil society and have had a long involvement in hospice and palliative care services in many countries in Europe. In some circumstances it has been volunteers who have identified a need for and set up services. Many HPC services depend on volunteers to enable them to deliver the range and quality of services that they provide<sup>1</sup>. This includes both emotional and practical support to patients and families in hospices, hospitals, patient and family homes and in care homes. In some countries, volunteers also provide valuable support to the wider organisation through administration, fundraising and awareness raising. They have an important role to play and bring a unique quality to the care of patients and their families. However, it is clear, that despite a history of involvement in HPC, volunteers, are not always acknowledged as a part of the team around the patient and family, or their skills and expertise recognized.<sup>23456</sup>

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<sup>1</sup> Scott R (2015) "We cannot do it without you"- the impact of volunteers in UK hospices. *European Journal of Palliative Care*. 22(2): 80-83

<sup>2</sup> Davis-Smith, J. (2004). *Volunteering in UK hospices: looking to the future*, London: Help the Hospices.

<sup>3</sup> Andersson, B. & Ohlen, J. (2005). Being a hospice volunteer. *Palliative Medicine* 19, 602-609.

<sup>4</sup> Addington-Hall, & J.M., Karlsen, S. (2005b). A national survey of health professionals and volunteers working in voluntary hospices in the UK 2: Staff and volunteers' experiences of working in hospices. *Palliative Medicine* 19 (1), 49-57.

<sup>5</sup> Barron, A. (2008). Sharing Good Practice; The Management of Hospice Volunteering. Retrieved on August 21, 2011 from <http://www.leighbarron.com>

<sup>6</sup> Goossenssen A, Somsen J, Scott R, Peltari L (2016) Defining volunteering in hospice and palliative care in Europe: an EAPC White Paper. *European Journal of Palliative Care*. 23 (4): 184-191

### **3. Aims and Activities**

The overarching aim of the work of the TF was to develop a greater understanding of volunteering in the field and influence the development and improvement of practice. Specific aims were to explore:

- The roles undertaken by volunteers in HPC in Europe
- How volunteering is managed
- What training is offered to volunteers
- What the challenges are for volunteers, managers and organisations
- The numbers of volunteers involved in each participating country

#### **Activities**

There were five main areas of work:

1. A baseline survey of volunteering in HPC in Europe to explore numbers, roles, management, training and challenges.
2. The development of an EAPC White Paper on the contribution, position, identity and value of volunteering in HPC in Europe.
3. The development of a Charter for hospice and palliative care volunteering in Europe
4. A stories project gathering the experiences of volunteers and volunteer managers in their own words
5. International symposium in Vienna in April of 2015 and a Series of Open Task force meetings where volunteers, paid staff and researchers engaged in sharing knowledge, practice and ideas through focused presentations and workshops.

These are discussed in more detail below.

### **4. Outcomes from activities**

#### **4.1 Baseline Study of Volunteering in Europe**

This study explored the numbers, roles, management, training and challenges faced by volunteers and volunteer managers. Led by Professor Lukas Radbruch and Dr Katharina Pabst, from the University of Bonn. A total of 366 participants from 36 different countries took part, including 144 volunteers and 44 volunteer co-ordinators. The study suggests that volunteering is well established in many HPC services in Europe. Findings indicate that there is a desire to see volunteers accepted as having a separate and unique role alongside paid staff and family caregivers. It appears that volunteer numbers are growing. They have less time to give and have higher expectations of how their time will be used.

A key finding to emerge from this study was that very few countries collected data on volunteer numbers and activity.

## 4.2 White Paper on Volunteering

One key focus of the TF was to explore and define the role of volunteers, clarifying the position, identity and value of volunteering in HPC in Europe with the intention of producing a White Paper.

The approach included:

- Analysis of existing literature
- Gathering information during two international symposia on volunteering
- Focus group and consensus discussions at task force meetings at the EAPC World Congresses in Prague, 2013, Lleida, 2014 and Vienna, 2015.
- The development and circulation of discussion texts on the definition, typology, roles and position of volunteers to experts in Austria, Germany, Ireland, Italy, Netherlands, Poland, Portugal, Romania, and the UK which enabled a consensus to be reached.

The White Paper “Defining volunteering in Hospice and palliative care in Europe” was published in the European Journal of Palliative Care in 2016.<sup>6</sup>

## 4.3 The development of an EAPC Charter on Volunteering

The development of the Charter was closely linked to the work leading to the White Paper. The aim of the Charter is to

- “Promote the successful development of volunteering for the benefit of patients, families and the wider HPC community.
- Recognise volunteering as a third resource alongside professional care and family care, with its own identity, position and value.
- Promote research and best practice models in the recruitment, management, support, integration, training and resourcing of volunteers”<sup>7</sup>.

Feedback and ideas from people from 13 countries (Australia, Austria, Belgium, Croatia, Germany, Hungary, Ireland, Italy, Netherlands, Poland, Portugal, Romania and UK) was incorporated into the Charter. The Charter was subsequently accepted as an EAPC Charter and was launched at the EAPC 15<sup>th</sup> World Congress in Madrid in May 2017.

For more information on the Charter please see:

<http://www.eapcnet.eu/Themes/Resources/VolunteeringCharter.aspx>

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<sup>7</sup> Voice of Volunteering EAPC Madrid Charter on Volunteering in Hospice and Palliative Care. (2017)  
<http://www.eapcnet.eu/Themes/Resources/VolunteeringCharter.aspx>

For more information on the Background information to Voice for Volunteering: The EAPC Madrid Charter on Volunteering in Hospice and Palliative Care please see:

<http://www.eapcnet.eu/Portals/0/Policy/Images/Charter%20background%20final%20-%20webversion.pdf>

#### 4.4 The Story Project

Recognising that too often we speak about volunteers and their work rather than learning directly from them about their experiences in their own words, the TF developed the Stories Project. The aim of the project was:

- To understand more about why volunteers do what they do
- How they experience volunteering
- What it means to them to be a volunteer in HPC
- To understand more about the role of volunteer managers and what working with volunteers means to them.

A total of 37 volunteer and 13 volunteer manager stories were received from eight countries. The stories were translated into English and a small team undertook the analysis using a qualitative framework approach.

It is clear that volunteers find significant meaning in what they do. For many it is an important part of their life and their values. They told of how much they learned from encounters around death and dying and the importance of 'being there' for patients during this period in their life.

The analysis of the Volunteer Managers stories has still to be undertaken.

#### 4.5 International Symposia and Open Task Force Meetings

##### International Symposia

**Prague 2013.** The idea for the TF was launched at an international Symposium on volunteering, "Colourful Life of Hospice Volunteers" held at the EAPC Congress in Prague. Around 100 delegates from 32 different countries attended the event and included volunteers, volunteer managers, palliative care professionals and researchers. The day produced a rich source of information and feedback was very positive. It was agreed that we should continue to run similar events if funding was available.

**Austria 2015.** Costs and lack of funding prevented a repeat of this in Copenhagen in 2015, however, the TF was pleased to be invited to hold a second Symposium: "Colourful Life of Hospice Volunteers" at the Austrian Palliative Care Congress in Vienna on 9<sup>th</sup> April 2015. This was held in partnership with Hospice Austria, who also funded this event. Over 160 delegates from 12 countries attended and delegates again comprised volunteers, volunteer managers, palliative care professionals and researchers. The aim was to

continue to gather information on volunteering in HPC from different countries to inform the work of the TF and to discuss the development of the Charter. Networking between European countries, learning from each other and recognition of volunteers were also important goals.

Once again lack of funding prevented a similar Symposium being held in Madrid.

## **Open Task Force Meetings and Presentations**

### **Task Force meeting in Lleida**

The first open meeting of the TF was held at the EAPC Congress in Lleida in 2014. Members from Ireland, Netherlands, UK, The Azores, Austria, Italy and Germany attended. This provided an opportunity to discuss the proposal for the stories project and White Paper on volunteering.

### **EAPC Congress in Copenhagen**

The TF delivered a Meet the Expert Session attended by over 30 delegates in Copenhagen. Presentations gave a brief overview of:

- Early outcomes from the Task Force work
- Similarities and differences in volunteering in different countries including factors that influence volunteering and their impact, roles, training and legislation, the changing nature of volunteering and the challenges and opportunities.
- Values, principles and definitions of volunteering, the unique role that volunteers play, and considerations for organisations as they develop volunteering.
- Further discussion and feedback the content of the Charter.

### **EAPC Congress in Dublin**

The TF held a second open meeting at the EAPC Congress in Dublin in June 2016. This meeting included an update on Task Force progress from Leena Pelttari and series of short presentations on approaches to volunteering research including:

- Professor Anne Goossensen “ A Care Ethical Perspective on HPC Volunteering – the consequences for designing research”.
- Professor Catherine Walshe gave an overview of the “Training of Volunteer Managers and Volunteers as part of the research team” and
- Dr. Ros Scott spoke on a “Theoretical Model of Volunteering and Hospice Sustainability”.

Subsequent discussions took place considering the different approaches to volunteering research and there was an agreement there should be a volunteering research interest group within the Task Force. This group is now established and held a first meeting at the EAPC Congress in Madrid. This will interest group will be a focus of the Second Task Force on Volunteering.

## **5. Reflections**

The work of the first TF was successful in achieving most of the aims. It has helped to

develop a clearer understanding of HPC volunteers in Europe; their activities, management and training and the challenges facing volunteers, volunteer managers and organisations. The profile of volunteering has been raised through the Charter, symposia, publications and blogs.

It is clear that there are many similarities across Europe in volunteering and there is strong agreement on the importance of volunteers in contributing to the holistic care of patients and families.

It proved impossible, however, to gather accurate data on the numbers of volunteers involved as only a small number of countries collect such data on an annual basis. It is clear that this is an area that needs to be addressed.

Throughout the life of the Task Force, new contacts, alliances, networks and friendships have been made which empower and strengthen joint working across countries in the further development of volunteering.

## **6. Next Steps**

Much has been achieved and there is still much to do. The work of the First TF has formally come to an end. However, second TF had recently been approved by the EAPC Board which will ensure the completion of the European Survey and Stories project in addition to focusing on the implementation and evaluation of the impact of the Charter.