



Background information to

“Voice of Volunteering”

- The EAPC Madrid Charter on
Volunteering in Hospice and Palliative Care

Introduction

This document provides background information on the context within which the goals of the Charter “Voice of Volunteering” have been developed. The Charter will be launched at the EAPC-congress in Madrid, May 2017, and can be read and signed [here](#).

Volunteering in hospice and palliative care: a definition

Radbruch & Payne et al (2010) suggest that “volunteers provide an indispensable contribution to palliative care. The hospice movement, as a civil rights movement, is based on volunteer work” (Radbruch & Payne et al, 2010, p 26). Volunteers in some countries in Europe have historically had a long involvement in this movement, often starting hospice and palliative care services. Many services now depend on the contribution of volunteers to enable them to deliver the range and quality of services that they provide.

A definition of hospice and palliative care volunteering was developed through consultation with experts in a number of countries and considers volunteering to be:

“The time freely given by individuals, with no expectation of financial gain, within some form of organized structure other than the already existing social relations or familial ties, with the intention of improving the quality of life, of adults and children with life-limiting conditions and those close to them (family and others).”
(Goossensen, Somsen, Scott & Pelttari, 2016, p 186).

Hospice and palliative care volunteering can take different forms: 1) Community volunteering (both in direct patient contact and in indirect, more facilitative roles), 2) Voluntary board membership, and 3) Professionals working within their discipline without receiving payment (Goossensen, Somsen, Scott & Pelttari, 2016).

Volunteering as a third resource in Hospice and Palliative Care

Volunteering should be understood as a third resource in hospice and palliative care, alongside professional care and family care, with its own identity, position and value. Hospice and palliative care volunteers are an integral part of both the international Hospice and Palliative Care community and the international volunteering community.

In care-focussed roles volunteers provide day to day emotional and social support and companionship to patients and their families¹, can provide (or assist in providing) physical care or complementary care to patients, and bring additional skills and expertise to the care of patients and their families. Most importantly, they bring a sense of 'normality' and connection to everyday life into the care of people with a life limiting condition. Volunteering can help prevent exhaustion in family carers and can be crucial in enabling people to die at home. The unique contribution of volunteering in direct patient contact lies in 'being there' for the patient and their families. Volunteers in direct patient contact are carers in their own right, citizens who care for their fellow citizens. They are human beings compassionate to the needs of dying people and their families. With their undivided time and attention they may develop a deep connection, sometimes enabling the patient and family to share intimate thoughts and feelings.

Volunteers often provide practical and administrative support to the organisation, can be crucial in raising necessary funds, and can play a key role in involving 'hard to reach' populations. Volunteering should never be intended to replace care provided by paid staff. Professional care will always be needed in addition to the care provided by family and volunteers.

Volunteers have a different perspective on the organisation's strengths and weaknesses. They can offer valuable feedback to the professionals and to the organisation on the way patients and their families experience the care given and can therefore help to improve the quality of care. For Hospice and Palliative Care volunteers themselves, this work means spending their time and using their talents in a meaningful way, gaining personal growth and new experiences. Volunteering gives people of all ages and backgrounds (with the right skills and abilities) the opportunity to use their life experience and skills in a flexible way to meet the needs of patients and their families.

Management and training of volunteers

Only with proper management and coordination can volunteering reach its full potential and quality. Careful management, recruitment, selection, basic and ongoing training, supervision and support are needed to ensure the quality of the volunteers' work. In this unique field of care, people with the right skills, values and attitudes are needed. Volunteer work is freely given, but volunteers do commit to certain responsibilities and duties.

For volunteers with direct patient contact the selection, training and supervision should include topics such as:

- Fundamental qualities that make a good volunteer like open-mindedness, being able to listen carefully without judgement, being receptive, a commitment to ongoing learning and widening their vision of the world
- Sensitivity to the diversity of the needs of patients and their families
- Reflection on their own motivation and bereavement experiences
- Philosophy and principles of hospice and palliative care
- Role, identity and confidence as a hospice and palliative care volunteer, including

¹ When we speak of patients and families, we also refer to other people (non-family members) that are close to the patient.

- boundary issues and volunteers' rights and responsibilities
- Careful collaboration with family carers and professional carers
- Communication skills
- Self care, including acknowledgement of emotional impact
- Skills in providing personal care (for instance safe moving and handling) if providing direct patient care.

The aim of training should be to enhance the 'natural' competencies of being 'human' to another human being and to prepare volunteers for the environment they work in.

Managing the effective collaboration between volunteers and paid staff is important. This may include training paid staff in working with volunteers, including volunteers in the team and the sharing of information between volunteers and paid staff (with patient consent). It also means providing clarity to everyone involved about volunteers' rights and responsibilities in relation to their work.

Supporting Hospice and Palliative Volunteering

Hospice and palliative care volunteering rarely receives the funding it needs. Volunteering is an important and valuable resource, but it does require investment of resources. Adequate funding is needed to ensure good management and quality, and for reimbursement of all the costs that volunteers incur, such as travel costs, insurance, supervision and training.

Just like any area within hospice and palliative care, volunteering needs research to evaluate and inform practice. Universities, teaching hospitals and other institutions are needed to create evidence to understand its impact and value and further develop the quality of hospice and palliative care volunteering. When possible volunteers or their representatives should be involved as co-researchers or in research design. The results gained from research should be easily accessible to anyone, including volunteers, volunteer managers, their organisations, policy makers and other stakeholders. It is also helpful if regional and national hospice and palliative care organisations promote the quality of volunteering by facilitating the development of best practice guidance, training and quality programmes, embracing 'being there' as the core concept of hospice and palliative care volunteering in direct patient contact.

European, national and regional governments need to develop and implement legislation that supports non-governmental organisations, volunteering in general and hospice and palliative care volunteering in particular. Any legislative barriers to the development and empowerment of (hospice and palliative care) volunteering should be taken away.

Developing the Charter

The Charter and this background document were developed by the Steering Group of the EAPC Task Force on Volunteering in Hospice and Palliative Care. The views and information in the Charter and in this background document have initially been gathered in a symposium on hospice and palliative care volunteering in Prague (May 2013). Further information was gathered through feedback on draft versions of the Charter, elicited in workshops at congresses in Vienna (April 2015), Copenhagen (May 2015) and Dublin (June 2016), and

through email-consultation with researchers, volunteer and staff representatives and EAPC Board members. The ideas of people from at least 13 countries (Australia, Austria, Belgium, Croatia, Germany, Hungary, Ireland, Italy, The Netherlands, Poland, Portugal, Romania and UK) were incorporated in the Charter and in this background document. The Steering Group would like to thank the EAPC Board, the Task Force members and all who participated in the consultations.

Further reading

For more information on the work of the Task Force on Volunteering in Hospice and Palliative Care, click [here](#). For more in-depth information on the definition, identity and value of volunteering in hospice and palliative care, see the [EAPC White Paper on Volunteering](#). The Charter will be launched at the EAPC-congress in Madrid, May 2017, and can be read and signed [here](#).

References

Goossensen, Somsen, Scott and Peltari (2016). Defining volunteering in hospice and palliative care in Europe: an EAPC White Paper, *European Journal for Palliative Care* 23 (4) pp 184-191.

Radbruch, L. & Payne, S.E. et al (2010). White Paper on standards and norms for hospice and palliative care in Europe: part 2, *European Journal of Palliative Care*, 17 (1) pp 22-33. 2010.