

Volunteering in palliative care: Can you trust a volunteer with confidential patient information?

Posted on [March 25, 2019](#)

ONLY 59 DAYS TO #EAPC2019 ... AHEAD OF THE 16TH WORLD CONGRESS OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE TO BE HELD IN BERLIN, GERMANY, 23 TO 25 MAY 2019, WE BRING YOU SOME SPECIAL POSTS TO WELCOME YOU TO BERLIN.

*Today, **Steven Vanderstichelen, Ros Scott and Leena Pelttari**, EAPC Task Force on Volunteering in Hospice and Palliative Care, raise an important question that will be discussed further in a plenary session in Berlin.*

Volunteers play a very important role in palliative care worldwide. While we know much about what tasks they perform, what training they have, what support they need, who they work with, and why they do it, there is still a lot that we don't *understand* about volunteers.

Clockwise: Leena Pelttari, Ros Scott and Steven Vanderstichelen.

A remarkable example of this is that paid staff still don't know whether they can *trust* volunteers. It seems that health services and coordinators find themselves in an ongoing struggle regarding how much information about patients they should let slip from their lips. The introduction of GDPR (General Data Protection Regulation) has further pushed health services to err on the side of caution. While these regulations apply no differently to volunteers than they do to paid staff, health services may, due to their uncertainty, tend to restrict volunteers further in their access to patient information. Even in health services that require their volunteers to sign a confidentiality agreement, as is the case in Belgium, practices of information sharing with volunteers vary greatly across health services. Many physicians and nurses seem unsure as to how much patient information a volunteer can be trusted with.

Why the hesitation?

As we see it, there are two, not entirely unreasonable but misguided reasons for this. First, we don't trust volunteers because we don't know how to regard them. It's a mental shortcut we all too often take. Those who are qualified to do something, so our instincts tell us, are paid well to do it. As a society, we find it hard to believe someone will do anything for free, let alone do it well – and volunteers are often highly qualified for the work they do. Secondly, we care about our patients and our responsibility to them. There's merit to being cautious when it comes to protecting our patients and loved ones at their most fragile time, near the end of life. However, these patients are the volunteers' patients too! Being overly cautious can impede volunteers' work and – inadvertently – the care for patients. The volunteer role of 'being there' and being an intermediate between patients and paid staff is reliant on trust and patients feeling comfortable in their presence. Good volunteer care hinges on knowing the patient, including their care needs and wishes. When volunteers are sufficiently informed, they are able to adjust their approach to the patient as an individual. This requires trust from patients

How can we reconcile trust with caution?

When does caution become a barrier to good patient care and how can healthcare paid staff and volunteers find a middle way? Perhaps lessons can be learned from models in which health services don't 'own' the volunteers, but rather work together with them as partners. If both parties have a voice in collaboration, only then can trust be established and an understanding be reached. Similarly, health services should ensure that volunteers have a visible place in their approach to compliance with GDPR.

So, can volunteers be trusted with confidential patient information? Yes, but only if paid staff and health services are willing to recognise and trust their unique role and treat them as partners.

If you're coming to #EAPC2019 in Berlin and would like to hear more about this, please join us in the plenary presentation, **'The Liminal Space Palliative Care Volunteers Occupy and the Roles they Perform within it: A Qualitative Study'** on Friday 24 May. We're also delighted to be part of the **International Symposium: Volunteers at the Heart of Hospice and Palliative Care** on 25 May. (See links below).

About the authors ...

Steven Vanderstichelen is a doctoral researcher at the [End-of-Life Care Research Group](#) (Vrije Universiteit Brussel – Ghent University) and a steering group member of the EAPC Task Force on Volunteering in Hospice and Palliative Care.

Ros Scott and **Leena Pelttari** are the Co-chairs of the [EAPC Task Force on Volunteering in Hospice and Palliative Care](#). Click on the link to find out more about the task force or join us at the Open Meeting on Friday 24 May at 12:55-14:15 (Room 5) at the 16th EAPC World Congress in Berlin.

[Click here](#) to sign the Voice of Volunteering Charter.



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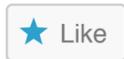
If you are coming to the [16th EAPC World Congress in Berlin](#) please join us on **Friday 24 May** when **Steven Vanderstichelen** will be giving a plenary presentation on **'The Liminal Space Palliative Care Volunteers Occupy and the Roles they Perform within it: A Qualitative Study'** (Convention Hall II, 15:30-15:50). (Steven also has a poster: 'The Perspectives on Volunteer-professional Collaboration in Palliative Care: A Qualitative Study').

And look out for the **International Symposium: Volunteers at the Heart of Hospice and Palliative Care – Saturday 25 May 2019 at 10:00 to 17:00**. [See more here](#). View the [full EAPC World Congress programme here](#).

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3 Responses to *Volunteering in palliative care: Can you trust a volunteer with confidential patient information?*



Jane Scripps says:

March 25, 2019 at 10:38 pm

What needs to be added to this conversation is the following perspective, i.e. that of the volunteer holding confidential information that may not come into the realm of the paid hospice worker. I do not see a sense of knowing this and where the volunteer has partnered with the person being cared for (also known as the patient by paid hospice workers, and more often as a 'whole' person by a volunteer). Volunteers are not delivering healthcare, more than that they are delivering social, spiritual, emotional care and this is often confidential. Once carefully recruited, trained and always provided with good supervision and support such 'life' experts have a unique role they already play an understanding of which isn't seen in this blog or amongst many comments I see.

[Reply](#)



Steven Vanderstichelen says:

March 26, 2019 at 2:05 pm

Hi Jane,

Thank you for your insightful comment! It is precisely because of this close relationship with patients that they are such an important intermediate between people with care needs and paid caregivers. I would argue that this social, spiritual and emotional care that volunteers uniquely provide is in fact healthcare, and is a particularly important part of palliative care. However, they provide it from a very warm, personal and human place and it becomes less of a professional service delivery.

Perhaps this blog does take a predominantly health service centred perspective (perhaps precisely because it is the health services that need to be convinced!) and does lack the acknowledgement of this unique role from the volunteers perspective. Thank you for adding to the discussion!

[Reply](#)



Varghese K Abraham says:

March 29, 2019 at 1:58 am

Volunteering in Palliative Care – A special call and commitment. It's a service and not a job. They can be the voice of the

voiceless. Throughout the world, many people are extending their hands only because of their compassion and love towards the fellow beings. Here in Palliative Care, I strongly believe all volunteers are taking an “extra mile” to improve the quality of life of the patients and their families. In Palliative Care, Trained volunteers are special agents to connect the disconnected.

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