

Introduction

Are you an existing palliative care volunteer? Would you like to promote your work within your local community through local media outlets? This Kit has been prepared for you as a summary of important information that you can share through interviews or discussions. Of course, it is your personal stories that people are most likely to remember.

Before speaking to the media remember to:

- Check with your Volunteer Manager and get their ok
- Observe and respect confidentiality for the people you work with
- Check your service's policies and procedures for any specific requirements or restrictions for speaking to the media

Suggested questions and responses

What is a palliative care volunteer?

When we talk about a palliative care volunteer we usually mean a person who volunteers their time to provide practical support to a person in palliative care, their family or loved ones. This might be in the home or in the hospital.

What do palliative care volunteers do?

Offering practical support can mean one or many things. It might include visiting a person in their home and staying with them while their family has a break. Or it might mean going with them on an outing, for a coffee, shopping, or to a medical appointment. Or you might be with them on the hospital ward, just chatting and being there for them, just being present.

How much time does a volunteer have to give?

There is no minimum! The amount of time a volunteer can give will depend on their availability. If you are a volunteer then the service will work with you to determine what you want to do and how much time you spend doing it. Having said that there might be some roles which require a minimum time commitment, like providing respite to a family member might take a couple of hours.

Some volunteers give 3 hours a month, some give 20 hours a month, some more or less depending on availability.

What if I feel uncomfortable talking about death and end of life, but just want to help out?

Lots of people do feel uncomfortable, and that's ok. But it probably means you will be best suited to roles other than personal support.

Some palliative care volunteer services have volunteers who do admin, fundraising, volunteer management, driving, maintenance and other jobs. It's worth asking at your local service and maybe they will have a need that would suit you.

How are palliative care volunteers supported / organised?

Most palliative care volunteer services have a dedicated volunteer manager. The manager is responsible for recruiting and training the volunteers, and then supporting volunteers into their roles. The manager might be full-time, but often they work part time. Some managers are volunteers themselves, and others are senior or community nurses who work in palliative care.

Are palliative care volunteers trained?

Each service will offer induction training to their volunteers. The duration and format of the training will be explained by the service, but for example it might be one day a week for 9 weeks. If you are already volunteering in a health service, or if you are going to perform a role say in fundraising, then the training component might be shorter.

What personal qualities make for a good palliative care volunteer?

- To be compassionate and interested in others
- To be able to be 'with' a person without having to be 'doing'
- To be content to not be 'in control' of the person or their situation
- To be content in themselves, not struggling with their own anxieties or dependencies
- To be able to sit and be with a person when that person's world seems to be spinning into unfamiliar and uncharted territory
- To be willing to listen, observe and learn

One of the big ones is to know your boundaries. Know when you can help and know when it's ok to say 'no, sorry I can't help you with that'.

Palliative Care Services in NSW

Has there ever been a proper study of palliative care volunteers in NSW?

Yes. In 2014 Palliative Care NSW did a state-wide survey of palliative care volunteer services. This gave us a much better understanding of what services existing and the number of volunteers involved.

What did the survey discover about palliative care volunteers and services?

The survey found that in late 2014 there were:

- 38 palliative care volunteer services in NSW
- A total of about 1,242 volunteers on their books
- About 78% of these volunteers are active at any time
- About 22 FTE (full time equivalent) volunteer coordinators

Which are the larger palliative care volunteer services in NSW?

Some of the larger services are:

- Calvary Hospital at Kogarah, south of Sydney, with over 100 volunteers
- Bear Cottage at Manly, offering respite and palliative care to young people, with over 100 volunteers
- Tweed Palliative Support, near Murwillumbah, with about 100 volunteers
- Albury's Mercy Hospital with more than 70 volunteers

(Numbers can change over time depending on volunteer availability and service demand)

Is the number of palliative care volunteers growing or declining?

The number is definitely increasing. People who approaching the end of their life are choosing to die in familiar and friendly surroundings, at home, and the demand for palliative care volunteers to work with them is growing.

The survey found that palliative care volunteers contribute more than 100,000 hours each year in NSW to the support of people, their loved ones and families.

Does having volunteers improve the quality of the service to the patient?

Yes. This has been well known for some time, and that's partly why the use of volunteers in palliative care settings is well respected in Canada, the US, the UK, New Zealand as well as all Australian states and territories.

In 2014 one major report on end of life care in the USA '*Dying in America*' stated a survey finding that "...Hospice programs with the greatest use of volunteers had the highest overall ratings for quality of care" (see page 2-14 of the report).

Starting a palliative care service

How does a palliative care volunteer service get started?

Three things:

Firstly the volunteer service must come out of the heart of the community as an act of love, volunteers will only come from the community if they value their community.

Secondly it has to come out of the heart of the health service to give better patient care, the health service has to be willing to refer people to the volunteer service and to contribute training and support to the volunteers to make sure they can do their job.

Thirdly it has to come out of the heart of a person touched by death. You need a leader to step up and see the need and bring people together. Sometimes this will be a clinician, sometimes a family member who has lost a loved one, sometimes a person in the community who just rises to the challenge.

How do we know if we have a local palliative care volunteer service?

You can search for your nearest palliative care volunteer services at www.palliativecarensw.org.au

(If there is no local palliative care volunteer service...) How can our community start a palliative care volunteer service?

First of all ask yourself *'is there a local palliative care service which will support a volunteer service?'*

A palliative care service is a health care team which has some speciality in palliative care. In smaller centres this is often provided by community nurses, and in larger centres by the local health centre / hospital.

If no - So much depends on a good working relationship with your local palliative care service. Your community might find that a palliative care volunteer service without a local palliative care service won't get the support it needs with training and referrals.

If yes - If there is a local palliative care service then talk with them about their interest in palliative care volunteers. Ask the health service if they are willing to support palliative care volunteers. You will need someone in the health service who can champion the role of volunteers, this might be someone higher up.

What about cultural-specific communities?

Some communities have volunteers who work with their folk in palliative care, for example in the Jewish, Italian or Cantonese communities. But of course they can still access palliative care volunteers if their area has a volunteer service.

If we wanted to start a palliative care volunteer service - what resources are available to us starting out?

There is a lot of experience in NSW to draw-on.

Palliative Care NSW can offer support and direction in setting out, help with introductions, offer access to a database and guide you in policies, procedures and training for volunteers.

Whatever model of operation you chose we will help you connect with other services which can offer their experience and their suggestions.

There is an established network of managers of palliative care volunteer services in NSW that your service can join.

NSW Volunteering may be able to assist and there is also a network of Volunteer Resource Bureaus in NSW – look to see if there is one in your area.

What about costs and operating expenses?

This is an important consideration in starting-up a service. A palliative care volunteer service will cost money to run, and a big part of the expense account will be determined by decisions like whether you pay a volunteer coordinator, whether you reimburse volunteers for travel and how office expenses are met.

Palliative Care NSW can help with estimating how much it will cost to start and run a service. You will probably need upwards of \$20,000 a year even for a small service.

In NSW about 50% of volunteer services are supported and funded through their Local Health Network. About 22% are attached to private hospitals, 18% are funded through NSW Health and about 10% meet their operating expenses through fundraising alone.

How can I learn more?

Look for more information on the Palliative Care NSW website www.palliativecarensw.org.au) and Facebook page.

Call us on 02 9206 2097 at Volunteer Support Services at Palliative Care NSW.

Talk to your local palliative care clinicians, community leaders and volunteer groups.

Come to the palliative care volunteer conference being organised by the Network to be held in Wollongong on the 29th of May 2015 (register at www.palliativecarensw.org.au).