

# Volunteer Support to Improve Wellbeing for Patients & Carers in Last Year of Life



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## Background

“There is a pressing need to consider new models of care that can address the reality of a society that needs to support growing numbers of people who will die in advanced old age, whose carers may also be very old and frail (or may have died previously) and whose wider network of support is either geographically dispersed or non-existent.”<sup>1</sup>

Being a carer can be a heavy burden and carers can become lonely and socially isolated. It has been noted that carers experience a level of long term illness and disability which is more than twice the level of the general public. There is also evidence that early intervention to offer emotional and practical support to carers of those approaching end of life improves carer confidence and resilience and supports preferred place of care<sup>2</sup>.

There is currently an underutilised resource within communities of potential volunteers with life skills and experience who, with training and support, could provide a service which would support patients and carers in the last year of life.

## Method

A bid was submitted for funding from the “Building Community Capacity” strand of Reshaping Care for Older People to increase access to a wider range of flexible support options for individuals and their carers facing end of life.

This new service would be led by two experienced Palliative Care Clinical Nurse Specialists based at St Andrews Hospice and Strathcarron Hospice

Volunteers from the local community were recruited, trained and supported by the project leads to enable them to provide support at a time which society still finds difficult to address openly.

Volunteers were recruited by both sites. Initial recruitment was from existing hospice volunteers and via Volunteer Action North Lanarkshire (VANL). All volunteers were interviewed and references taken up. Accepted volunteers were then checked through the Protecting Vulnerable Groups Scheme.

Training sessions were delivered for the volunteers covering: managing difficult conversations, moving and handling, dementia awareness, hand and foot massage. The intention is to provide volunteers with a “toolkit” which they can use to complement their own life skills to enable them to provide appropriate support in many different situations.

## Results

Thirty one volunteers have completed the training so far. Two volunteers have subsequently withdrawn due to personal reasons.

In the first six months of the project a total of 134 referrals were received from various sources.

109 of the patients referred were assessed at home, 25 of the patients were assessed by telephone.

Volunteers complete “activity sheets” which provide details of the input provided along with any comments made by the service users regarding benefits or improvements felt.

Reasons given for referral were often non-specific, identifying a need for emotional and social support.

Befriending / reducing isolation	50 (37%)
Carer Respite / support	61 (45%)
Complementary Therapy	34 (25%)

## Support provided:

Active listening provided by CNS,

Advice and information which helped service users to identify their own needs,

Complementary therapy,

Befriending and carer respite.

In many instances the requirement was for a coordinated approach to provide a combination of services tailored to the individual need.

## Patient and Carer Perspective:

“These couple of hours a week recharge my batteries.”  
- Carer of a 71 year old man with cancer

“I feel part of the human race again.”  
- housebound lady with progressive illness

## Professional Perspective:

“The Befriending service has beautifully complemented existing community supports. Patients and carers enjoy the experience it brings and staff feel real satisfaction in being able to offer referral to a service that can make a real difference.” - District Nurse

## Discussion

The recruitment of volunteers was straightforward. The training programme was well attended and the volunteers were enthusiastic and keen to learn how best to support the patients they would meet.

For some patients the assessments of needs by the clinical nurse specialist identified areas which had not been recognised previously. This provided opportunities for early intervention and support.

Successfully working with other third sector agencies has maximised the use of existing resources, reduced duplication of service provision and is starting to provide support within the community that was previously not available. This collaboration raised awareness and enhanced understanding of palliative care which has been a welcome outcome of the collaboration.

The success of the project is clear from the response of the patients, carers and volunteers. There is a need to increase the provision beyond the current remit of the project. There is a need to reach patients and carers of all ages, living in all geographical areas and with any diagnosis. It is hoped that through collaboration with other agencies locally and the opportunity to share the experience of the project team, this will become a sustainable service which is valued by all those who are involved.

### References:

1. Are We Living and Dying Well Yet (2014) Marie Curie Cancer Care and Scottish Partnership for Palliative Care
2. Carers UK. [www.carersuk.org](http://www.carersuk.org)