

EVOLVE: HOSPICE VOLUNTEERS SUPPORTING THOSE WITH NEUROLOGICAL CONDITIONS AND COGNITIVE CHANGE

Introduction

The Engaging Volunteers and other Organisations in Leading Versatile Enablement (EVOLVE) Project was an 18-month project by LOROS Hospice to provide targeted home visiting services for people with a neurological condition (MND, PSP, MSA) who also experience cognitive changes. Due to the complex nature of these conditions, people can experience social isolation and occupational deprivation (1) and existing services did not adequately meet the needs of this patient group. As documented in the NICE guidance (2) on MND using a rehabilitative approach, applied consistently over time, can help patients maintain a sense of self. This project was made possible with funding from St James Place Charitable Foundation managed by Hospice UK and took place from February 2017 to July 2018.



Aim of the project:

- To recruit and train volunteers, with a background in healthcare, to provide an occupation focused community service
- To provide consistent support for patients with neurological conditions and cognitive changes
- To provide consistent respite for their carer
- To identify a future service model

Assessment process:

Project Lead completed a risk assessment and goal setting exercise (using GAS) in the home with the patient and carer. Skilled volunteers were then matched with patients based on mutual interests and personality. The volunteer provided weekly home visits of two to four hours enabling patients to engage in occupations following agreed goals. Volunteers received basic training to allow them to confidently look after the patient while their family carer had some respite.

Occupation focused volunteers:

Volunteers have a unique role in supporting complex patients because they have the opportunity to build strong relationships with the family. This was key to allowing carers to leave their loved one with peace of mind and have some much needed 'me-time'. Patients liked the consistency of the same person regularly spending time with them as a change to ever changing health professionals and domiciliary carers.

The Project Lead provided comprehensive training for volunteers and provided ongoing support. Volunteers felt well supported and confident in their roles as they knew help and advice was only a phone call away. Having a health professional to support the volunteers was helpful to provide insight into patients' changing conditions.

- Volunteers are the MDT's eyes and ears and can alert regarding changing circumstances. This led to crisis prevention for some of the patients as concerns were passed on by the Project Lead and acted on by the MDT.

Challenges:

Geography: due to wide catchment area for hospice there was a need for a wide network of volunteers in order to match appropriately. Patients were unable to work towards their goal despite support, however, they greatly benefitted from the consistent social contact with their volunteer.

Outcomes:

Three volunteers supported three patients over a minimum of three months. Two patients continued receiving visits post project.

A total of 68 volunteer visits took place with an additional nine visits by the Project Lead. This adds up to 226 volunteer hours providing face-to-face patient contact and carer respite.

Carers benefitted greatly describing their respite time as "a breath of fresh air" and "a lifeline".

Volunteers enjoyed their support role and found it highly rewarding. Many of them were former carers and felt they were able to use their own experiences to benefit others.

Volunteers are able to support complex patients in their own homes and enjoy the role.

A project evaluation took place and a detailed report was submitted to Hospice UK.

"She is very supportive... very important from a carer's point of view to have somebody that will just listen really. ... there is never an opportunity to say 'I feel like this' or 'I feel like that' and when I am with [volunteer] there's a little bit of that to share."
(carer)

"I just think the project is a brilliant project ... it did what I needed really at the time, definitely."
(carer)

"That my time has been given to someone who appreciates it, whatever their situation, in a small way."
(volunteer)

References

1) MND (2015) 'Cognitive change, frontotemporal dementia and MND'. Northampton: MND

2) NICE (2016) Motor Neurone Disease: assessment and management [online] available from: <https://www.nice.org.uk/guidance/NG42>. [accessed 03/10/2017]

3) St Josephs Hospice (2017) 'Empowered Living Team' [website] available from: <https://www.stjh.org.uk/our-services/community-services/empowered-living-team> [accessed 13/11/2017]

4) Addington-Hall, J. and Hunt, K. (2012) Non-cancer patients as an under-served group. In 'A Public Health Perspective on End of Life Care', ed. By Cohen, J. and Deliens, L. Oxford: Oxford University Press.

5) Naylor, C.; Mundle, C.; Weeks, L.; Buck, D. (2013) Volunteering in health and care; securing a sustainable future. London: The Kings Fund.

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