

# “Exploration of support workers and volunteers initiation of advance care planning and quality of life conversations in palliative care”

Sharan Watson, Post Graduate Lecturer ,University of Derby and Alison Hembrow, Support & Information Nurse Specialist,  
Treetops Hospice Care



## Introduction:

Treetops Hospice Care, in partnership with University of Derby are commencing a research project exploring the outcomes of developing support workers and volunteers, in initiating conversations around quality of life.

Treetops Hospice are a pilot site for NHS England for Personal Health Budgets (PHB's), their work has began to explore not only if PHB's have been awarded, but in addition to this, discovering that the “conversations” around what's important right now to the patient / carer and what can make a difference right now toward end of life, can be just as important. Volunteers and support workers may be advantageous in having these conversations with the right support and development.

This is a current ongoing research project being developed with the support of SEED Funding from University of Derby.



## Objectives:

- Explore with participants how they engaged with individuals around preferences and wishes prior to this support and training
- Capture their motivation for taking part
- Explore the participants experience of using a different approach once they have been exposed to the training
- Explore perceptions of whether this approach has made a difference
- Consider self-perceived changes in confidence / competence in having these conversations

## Rationale for study:

- Vital piece of work which directly could impact on improving individuals and their carer's wellbeing, by focusing on their quality of life and what is important to them right now.
- Policy drivers have acknowledged that there is a much greater need and demand for person centred care than professionals in health and social care can meet (HEE, SFC & SFH, 2017).
- Community based initiatives have on engaging conversations around preferences and wishes (Abba et al, 2013; Abel and Kellehear, 2016). This follows the principles of a “public health” approach to end of life care, and that a “de-professionalisation” of psychological and social care, resulting in volunteers and support staff engaging in these conversations, could result in being able to include all individuals irrespective of diagnosis (Abel and Kellehear, 2016).
- Treetops Hospice is ideally placed with its support from specialist palliative care and its ability to engage and support volunteers, as a pilot site for NHS England for Personal Health Budgets (PHBs).
- The research will build on an existing work of perceived confidence / competence after the delivery / exposure to end of life care training / education (Whittaker et al, 2017).

## Study design and methods:

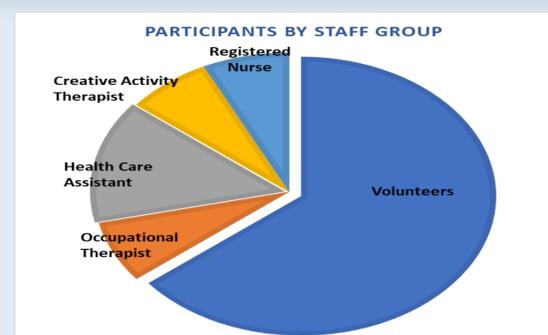
\* First Stage: Face to face interviews prior to exposure of new training / model of developing these conversations and pre-training Likert questionnaire adapted from EMET (2017) see appendix.

Pre and post Likert and qualitative questionnaire for changes in self-perceived confidence / competence

\* Second Stage: Post training Likert questionnaire adapted EMET (2017), Face to face in depth interviewing of participants during the follow up.

\* Interviews will be recorded and transcribed verbatim.

The data from both stages of the study will be analysed using NVIVO and synthesised to address the study objectives.



**L**ife  
Tell me about your life

42 year old lady with recently diagnosed breast cancer with bone metastases in her pelvis. Unable to weight bear and using a wheelchair. 15 year old daughter.

**I**mportant  
What's important to you?

To be as independent as possible, to get out of the house for more than just hospital appointments  
To make memories with her daughter  
Being outside in the fresh air

**S**upport  
What support do you have?

Mum, dad, daughter (15)  
Lives at mum and dad's currently

**T**ime ahead  
What's important for your time ahead?

To be able to access parent's garden in my wheelchair to enjoy the birds in the garden and the countryside beyond.  
To teach my daughter the names of the birds that visit the garden.

**E**nding  
What would make a good ending for you?

Knowing that I have made so memories with my daughter that she can treasure when I am no longer here.

**N**ow  
What's important to do now?

To find suitable funding to put in a ramp for me to access the garden easily.



## Expected outcomes:

1) Identify how participants engaged with individuals around preferences and wishes prior to this support and training, capturing their motivation for working at a hospice and for taking part

2) Identify from the participants whether their experience of using a different approach once they have been exposed to the training has made a difference with enabling these conversations and value their feedback to inform further training developments and dissemination.

3) Consider any changes in self-perceived changes in confidence / competence in having these conversations. Due consideration that trainees' responses is very subjective, numerous empirical studies that show self-report does not straightforwardly reflect actual skill, generally, self-reports yield larger change scores than evaluation of actual performance (Davis DA, Mazmanian PE, Fordis M, et al, 2006). Where resources allow, multiple assessments including actual workplace performance and patient outcomes should be used to assess actual application of that knowledge to workplace performance (Wass V, Van der Vleuten C, Shatzer J, et al, 2001), where resources are limited, a validated tool such as the EMET, offers a feasible /economical means of measuring a limited aspect of training's impacts.

## The four principles of person-centred care



The Health Foundation (2016)

## References

Abel J, Kellehear A. (2016) Palliative care reimagined: a needed shift *BMJ Supportive & Palliative Care* 2016;6:21–26.

Davis DA, Mazmanian PE, Fordis M, et al. (2006) Accuracy of physician self-assessment compared with observed measures of competence: a systematic review. *JAMA* 2006;296:1094–102. doi:10.1001/jama.296.9.1094.

Health Education England, Skills for Health and Skills for Care (2017) *Person-Centred Approaches: Empowering people in their lives and communities to enable an upgrade in prevention, wellbeing, health, care and support*. HEE, SFH & SFC : London.

Health Foundation (2016) Person-centred care made simple: What everyone should know about person-centred care. Available at: <https://www.health.org.uk/publication/person-centred-care-made-simple>

NHS England (2017) Personal Health Budgets. Available at: <https://www.england.nhs.uk/personal-health-budgets/areas-introducing-personal-health-budgets-in-end-of-life-care/southern-derbyshire/>

Wass V, Van der Vleuten C, Shatzer J, et al. (2001) Assessment of clinical competence. *Lancet* 2001;357:945–9. doi:10.1016/S0140-6736(00)04221-5

Whittaker, B., Parry, R., Bird, L., Watson, S. and Faulk, C. (2017) Development, validity and reliability testing of the East Midlands Evaluation Tool (EMET) for measuring impacts on trainees' confidence and competence following end of life care training. *BMJ Supportive & Palliative Care*; Published Online First: 02 February 2017. Available at: <http://dx.doi.org/10.1136/bmjspcare-2016-001100>