
CONFERENCE ABSTRACT

A compassionate communities' programme to support volunteers to be carers at the end of life

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Introduction

Volunteers are engaged in co-designing Compassionate Isle of Man along with the Programme Lead in Hospice Isle of Man. Volunteers sit on the Steering Committee which includes Third sector and statutory organisations and the Community Development Group to plan the project and also use their own lived experience to use and manage the Facebook site which informs the public about the programme.

End of life care requires a sensitive approach and emotional preparation in order to support people in difficult times. Compassionate Isle of Man uses a bottom up approach which drives discussion and participation rather than more autocratic styles of organisation. The aim of this study was to use this approach to develop a training package for volunteers and to support them to act as carers for those with life limiting illnesses in the community. A longer term aim is to evaluate the impact of this package on the volunteers' wellbeing.

Methods

The training package was co-designed with 25 volunteers based on discussions about end of life care and their previous life experiences. It includes learning how to use social media, safety issues such as lone-working and reporting problems, loss and bereavement, adult and child protection, GDPR/confidentiality, and personal wellbeing. The volunteers are also trained in using personal protective equipment, patient mouth care and dementia awareness. A 'WhatsApp' group was set up to communicate with the volunteers and they are provided with a handbook of the contents of the course. The training package was delivered over several months. Debrief sessions follow every episode of support in the community using a strengths-based approach in which, for example, they draw out common themes from their supportive experience and written reflections are discussed. The lessons learned are incorporated into further training.

The evaluation uses a mixed methods approach with qualitative data from diaries and interviews and also a set of questionnaires: a brief intake questionnaire to capture basic

demographic characteristics (age and sex) and open-ended responses to four key questions on their reasons for and expectations of volunteering, the Warwick- Edinburgh Mental Wellbeing Scale, the Short Form – 6 Dimensions (SF-6D) health-related quality of life measure and a visual analogue scale designed to measure empowerment. The group has an embedded researcher to document real time observations.

Preliminary results/conclusions

Training began in October 2018. The first person supported in the community was in June 2019 and, to date, about 20 volunteers have provided 140 hours of support. The group has initiated their own coffee mornings and now uses the 'WhatsApp' group for peer support. Baseline wellbeing and empowerment data has been collected; results of the evaluation will be presented in April 2020.