



'Just Knowing that I am not on my own'

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'Just Knowing that I Am Not on My Own'

**Evaluation of a Carers' Support Programme
at Northern Ireland Hospice**

Final Report

18th March 2014

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ABSTRACT

Background:

Informal carers of people in receipt of palliative care have unique needs (Harding and Higginson, 2003) for support and information from health care professionals (Hudson et al, 2004). There has been an impressive increase in the number of targeted interventions for informal caregivers in cancer and palliative care (Harding et al, 2012). Recognising the key role played by informal carers of people in receipt of palliative care, and realising their unique needs, Northern Ireland Hospice has developed a range of support that includes a six-week programme for carers to address the caring role and help to meet their health and social care needs.

Aims:

- To provide evidence to inform development of carers support services;
- To assess the programme's influence on care competence, carer's preparedness, information and skills to aid them in the management of their caring role;

Design:

An observational descriptive design was used. Two adapted carer-specific scales were applied to before and after programme delivery. Each group consisted of up to ten healthy adults, who were currently caring for an adult patient in receipt of hospice care. Measures were subject to descriptive analysis and compared using paired statistics.

Results:

Findings concur with the other research studies and policies such as the need for practical and emotional support for carers and the important of developing appropriate and effective interventions to meets these needs (Brereton et al, 2007, Grande, 2009, DH, 2008b, DHSSPS, 2011). However, only half of those invited attended due to a range of practical and emotional reasons. Of those who attended, some noticed increases in post programme anxiety and physical strain and feeling completely overwhelmed, which could be due to possible deterioration in their relative's condition during the six week programme. Fewer participants felt alone after attending the programme and almost two thirds felt that the programme made a difference to them personally.

Conclusion:

Those who attended the programme demonstrated satisfaction, learning and feeling supported in the role of carer. Since the completion of the Carers Programme evaluation, there have been no major changes to format, length, style of programme etc. However, there have been minor adjustments at each group due to this evaluation. Issues such as manual lifting/handling, drug levels and pain relief may be signposted to more appropriate sources. Further work is required to better understand the support provided to the wider group of people, who use carer services in different ways.