

Timely support for carers of people at the end of life through the Adult Carer Support Plan



Care and support through terminal illness

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Introduction

- The Carers (Scotland) Act (2016) places a duty on local authorities to prepare an Adult Carer Support Plan for all carers.
- There are an estimated 500,000 people caring for someone with a terminal illness in the UK.^[1]
- Timely identification, assessment and support can reduce the overwhelming pressure of caregiving, increase competence, confidence, satisfaction and the quality of care given.^[2,3]

Aim

To provide evidence on the supportive needs of carers of people with a terminal illness to inform recommendations regarding the optimal timescales for the creation of Adult Carer Support Plans under the Carers (Scotland) Act (2016).

Methods

- 1 Literature review**
Synthesise qualitative and quantitative research from last 5 years.
- 2 Secondary qualitative analysis (SA)**
22 transcripts from bereaved carers who cared for people with a range of malignant and non-malignant diagnoses.
- 3 Focus groups (PFG)**
2 focus groups in 2 Scottish cities with bereaved carers. Thematic analysis and consensus workshop to extract themes across datasets.
- 4 Stakeholder event**
Health and social care professionals and third sector representatives to discuss and disseminate findings and inform implications.

Box 1: Methodological process.

Results

- Themes included; triggers and barriers to identification, the support needed and received (practical, psychological, respite, information and communication and co-ordination), issues relating to end of life care and the impact of speed of terminal decline.
- Identified needs were diverse and can be divided into those which support the carer to care for the cared-for, and the needs of the carer themselves.^[4]

Identification of carers

'Because for every carer, there's somebody that isn't well. So the onus has to go on GPs, receptionist, hospital people.'
[PFG 1].

Support with physical care

'And OK the medical profession can cope with the, you know, dispensing drugs and all the rest of it, and blah, blah, blah, but I needed to understand what the hell was going on.....' [SA, Glioma 23].

Psychological support

'...and I was greeting like a big wean, I must admit, when these guys came round me, and they told you, you know, 'cause they knew what you were going through.... But I was still emotionally, I don't know how to put it. I was still fragile...' [PFG 1].

Respite and replacement care

'I couldn't even go to the toilet, when I went to go to the toilet she was screaming. So her and I sat up all night, me in one chair and her in the other.' [SA, Frailty 2].

Co-ordination of care

'I think at first you think you can do it all, and then you very quickly realise you can't.' [PFG 2].

Speed of terminal decline

'...she [GP] came in a couple of days after to see how I was coping and she says "we didn't expect it so quick" so whatever happened in the end I don't know.' [SA, Cancer 2].

Box 2: Themes and illustrative quotes.

Conclusions

- Ensuring that those caring for someone in the last six months of life get the support they need as quickly as possible is crucial to reduce the risk of a breakdown in the care provided.
- Health and social care professionals need to take a radical, reactive move to presume that every patient has a carer, and ensure they understand their entitlements.
- It should be the ambition of the Carers (Scotland) Act (2016) that identification happens early in the illness trajectory, before the terminal phase of illness.

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