



## Synopsis

# Understanding and addressing factors affecting carers' mental health during end-of-life caregiving: synopsis of meta synthesis of literature and stakeholder collaboration

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## Plain language summary

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## Plain language summary

### Background

Family carers give vital support to people nearing end of life, but their own mental health may suffer as a result. We need to understand what improves or worsens carers' mental health and tell stakeholders who can make changes for the better.

### Aim

To summarise what we learnt from a review of research and work with carer advisors and other stakeholders, about what can affect carers' mental health during end-of-life caregiving, and what may help.

### Method

We reviewed research from 2009 to 2019 that looked at factors that may affect carers' mental health when supporting someone nearing the end of life, worked with a carer Review Advisory Panel (6 members; 9 meetings), and did 6 workshops/discussion groups (36 participants) and a survey (43 participants) with carers/patients, practitioners and policy-makers/commissioners.

### Results

One hundred and six reviewed studies showed the following factors can affect carers' mental health: (1) how well the patient was doing, (2) how much caregiving affected carers' lives, (3) how good carer relationships were with the patient and other family, (4) how sufficient their financial resources were, (5) carers' thoughts, feelings and confidence about caregiving, (6) how good the support was from formal services, family and friends and (7) background: mental health may be better in older carers, worse in females. Carer Review Advisory Panel recommendations included awareness raising, carer 'road maps' for guidance, appropriate needs assessment, co-ordinated care through a single contact point, and covering carers' basic practical and financial needs. Review findings and recommendations made sense to other stakeholders. Improvements may require dedicated carer support workers and systems changes.

### Conclusions

Findings and recommendations give some clear pointers towards improvement, including specific carer support roles and improved financial security. Health and social care make huge savings from carers' work, and investment should be made to support carers in return.

For details and resources: <https://arc-gm.nihr.ac.uk/carers-project->

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