

Immediate versus delayed short-term integrated palliative care for advanced long-term neurological conditions: the OPTCARE Neuro RCT

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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Plain English summary

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Plain English summary

This study aimed to find out if short-term integrated palliative care altered symptoms or well-being for people living with long-term neurological conditions. It also studied the effects on their caregivers and on health and social care costs.

People living with multiple sclerosis, idiopathic Parkinson's disease, motor neurone disease, multiple system atrophy or progressive supranuclear palsy, and with unresolved symptoms or complex needs, were recruited into the study across seven UK centres. Participants were randomly assigned by chance to receive either short-term integrated palliative care or standard care for 12 weeks. After 12 weeks, the standard care group also received short-term integrated palliative care. The circumstances of patients and caregivers in the two groups were compared at 12 weeks using questionnaires. A small number of people were also invited to talk more about their experiences in an audio-recorded interview. Health-care staff views were also sought through an online survey and focus groups.

A total of 350 patients and 229 caregivers were recruited. At 12 weeks there were no significant differences between the two groups. However, patients receiving short-term integrated palliative care showed an improvement from baseline to 12 weeks for several physical symptoms. The costs of care were also lower and there were no harmful effects, compared with standard care. Conversely, in the standard care group, care satisfaction lowered from baseline to 12 weeks. The in-depth interviews showed that the impact of short-term integrated palliative care encompassed three themes: (1) adapting to losses and building resilience, (2) attending to function, deficits and maintaining stability and (3) enabling caregivers to care.

Our results suggest that short-term palliative care confers more benefits than harm and costs less than standard care. Future research should focus on refining palliative care approaches for long-term neurological conditions, including better integration between neurology and palliative care, and improving the management of symptoms.

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