



Marie Curie Research Grants Scheme

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Enabling tailored and coordinated support for family carers of people with MND through adaptation of a Carer Support Needs Assessment Tool (CSNAT) Intervention

Duration of project: 18 months

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Budget: £127,560*

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Abstract

Background

Family carers play a vital role in supporting people with life-limiting disease, enabling care at home in accord with patient preferences. However, carers come unprepared for this and learn by stressful trial and error. Carers of patients with MND suffer negative impacts from caregiving, including burden, anxiety, depression and sleep disturbances. Better support can ameliorate these impacts. However, carer interventions to date have had limited effects, and none have been specifically designed for caregiving for MND. To be more effective interventions need to be tailored to individual carers and consider their full range of support needs.

The Carer Support Needs Assessment Tool (CSNAT) Intervention enables practitioners to provide more tailored, timely support within existing care resources. The intervention comprises a comprehensive, validated assessment tool (CSNAT) and a defined 5-stage process, that together allow carers to identify and prioritise their support needs, discuss these with a practitioner, identify solutions (action plan), with follow-up review. Current carer assessment is normally informal, unstructured and reactive with solutions assumed by practitioners. In contrast, the CSNAT Intervention is structured, proactive, enabling carers to define required support. It promotes earlier, smaller scale, tailored carer support to prevent larger scale crisis intervention.

CSNAT encompasses both what carers need (a) to support the patient as 'co-workers' (e.g. understanding the illness, managing symptoms); (b) support for themselves as 'clients' (e.g. physical health, respite). Supportive input may include reassurance, information, education, signposting or referral, e.g. for early Social Care assessment, depending on individual need.

The CSNAT has good validity; the intervention is valued by practitioners and carers and improves carer outcomes. However, it has been limited to hospice cancer care, single service contexts, with practitioners determining its use.

The project will adapt the intervention to MND caregiving (encompassing specific MND carer support needs, a longer caregiving trajectory, involvement of multiple services), and reshape it as a carer-held intervention to empower carers and facilitate continuity and coordination of support across time and service encounters.

Aim

To provide tailored and coordinated support for family carers of people with MND through a CSNAT-MND Intervention that is adapted to (a) their support needs; (b) critical time points; (c) main services encountered, and (d) is reshaped as a carer-held intervention to provide better carer control and continuity.

The study will be conducted in three stages, mapped to three corresponding studies.

Objectives

Stage 1: Capture of carer support needs, key points of change and main services encountered

Design: qualitative study with family carers, supplemented by updated literature review

Sample: N=30-36 carers recruited through three MND care centres.

Data collection: small focus groups and some interviews. Questions will investigate support required by

MND carers at different disease stages, the critical time points and main service practitioners encountered.

This stage will establish main parameters for the intervention process (including timing) and materials (including supporting information and revised CSNAT tool), and provide crucial preparation for Stage 2.

Stage 2: Development of materials and procedures for a 'carer-held' CSNAT-MND Intervention

Design: Iterative qualitative small-group work with carer advisers and practitioners to gain their perspectives on intervention materials and procedures.

Sample: N=10-15 carer advisers recruited from Stage 1 participants and local support groups. N=10-15 practitioners purposively sampled to represent services identified in Stage 1.

Data collection: small, flexible working groups (3-5 members) over time to review and re-shape intervention content

This stage will ensure that intervention procedures and materials are practical, simple and user-friendly both to carers and practitioners.

Stage 3: Piloting of prototype intervention and feasibility study preparation

Design: piloting of the CSNAT-MND Intervention with carers and practitioners

Sampling: new sample of carers using recruitment procedures from Stage 1 and practitioners with whom they use the intervention (N=15-20; N=10 carer-practitioner dyads).

Data collection: cognitive interviews will gain first impressions on the intervention from carers following introduction. Next, carers will try out the intervention during a scheduled practitioner contact and then be interviewed about their experience. The practitioners will be invited to a telephone interview about practitioners' experience.

Stages 2 and 3 will include consultation with participants about appropriate outcome measures for measuring the intervention's potential impact.

The project will deliver a pragmatic CSNAT-MND Intervention suitable for MND carers and MND practice; established parameters for a feasibility study; publications.