IMPLEMENTING AN ADAPTATION OF THE CARER SUPPORT NEEDS ASSESSMENT TOOL (CSNAT) INTERVENTION TO PROVIDE TAILORED SUPPORT FOR FAMILY CARERS OF PEOPLE WITH MOTOR NEURONE DISEASE

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Family carers face substantial demands when supporting people with Motor Neurone Disease (MND) (Aoun et al., 2013). Timely support from healthcare professionals is crucial to enable carers to fulﬁl their caregiving role and to look after their own wellbeing. The CSNAT intervention is an evidence-based approach for person-centred assessment and support. This project aimed to adapt the CSNAT intervention to the context of MND care, and test its implementation within specialist MND services.

Stage 1 involved interviews and focus groups with carers (n=33) to explore carers’ support needs at key stages of the patient’s illness; stage 2 involved workshops with carers (n=19) and practitioners (n=22) to adapt the content of CSNAT intervention and its delivery within MND care. Stage 3 involved implementation of the adapted CSNAT-MND in three specialist MND services, and interviews with practitioners (n=6) and carers (n=6) exploring their experiences of the intervention.

Content of CSNAT-MND included an additional domain on support with relationships. Intervention implementation adapted to (1) legitimise assessment of carer support needs as part of routine care in MND by practitioners, (2) deliver of a stand-alone introduction stage of the CSNAT-MND intervention and (3) provide a dedicated assessment and planning conversation at a subsequent contact. This basic model was then suited to ﬁt the working practices of three different MND services. This project provides insights into how carers of people with MND want to be assessed and supported, how this process can be delivered, and the feasibility of implementing the CSNAT-MND in routine practice.

WHAT DO INFORMAL CARERS OF PEOPLE LIVING WITH BREATHELESSNESS IN ADVANCED DISEASE WANT TO LEARN ABOUT ’WHAT TO EXPECT IN THE FUTURE’?

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Aim Breathlessness is distressing, disabling, and common in advanced disease. Informal carers (family/friends) can lack knowledge and conﬁdence in caring, experiencing anxiety and uncertainty. The Learning about Breathlessness programme (LaB) addresses this.

LaB1 identiﬁed six topics carers want to learn about breathlessness. LaB2 is co-developing (with carers, patients and clinicians) a prototype web-based educational intervention for carers on breathlessness. Content for ﬁve of the six topics was developed, but additional work was needed for the sixth topic, ’What to expect in the future’, to ensure utility and sensitivity.

Method Two disease-speciﬁc focus groups and six interviews with bereaved carers of people with breathlessness due to