



UNIVERSITY OF
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Supporting carers during end of life care using the Carer Support Needs Assessment Tool (CSNAT)

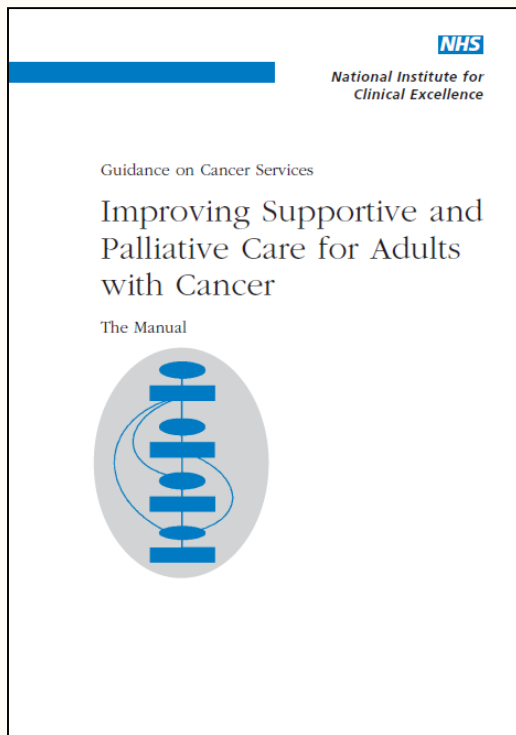
Gail Ewing, Gunn Grande, Janet Diffin

Lynn Austin, Debra Jones



Carer Support Needs
Assessment Tool

Definitions



“Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management”

(NICE 2004)

Outline

- Importance of carers in palliative and end of life care (EOLC)
- Overview of CSNAT programme of research and implementation
- What we have learnt

Carers' contribution to EOLC

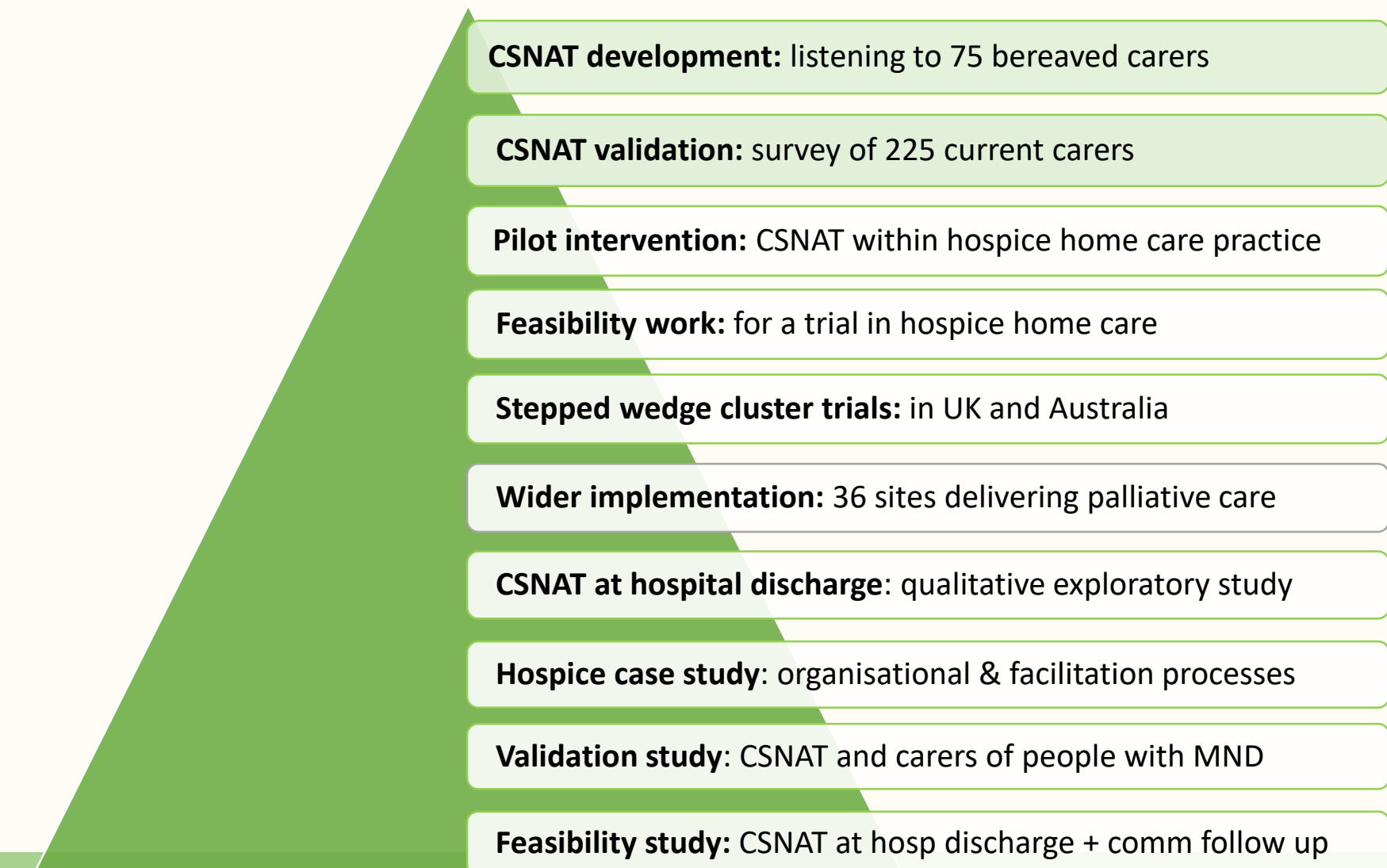
- 500,000 carers provide care in the last year of life in UK p.a.¹
- National census survey of carers of people with cancer²: median 69 h 30 min of care-giving each week
- Significant impacts on carers' health, social isolation and pressures on work and finances ⁴⁻⁷
- EOLC policy recommends: carers' needs should be "assessed, acknowledged and addressed" ⁸

How do we do this?

¹Payne & Hudson, 2008; ²Rowland et al, 2017 (Gunn Grande); ⁴ Aoun et al. 2005;

⁵ Grande et al. 2009; ⁶ Staiduhar et al. 2010; ⁷ Aoun et al. 2016; ⁸ NICE 2004

Programme of research and implementation



CSNAT development: listening to 75 bereaved carers

CSNAT validation: survey of 225 current carers

Pilot intervention: CSNAT within hospice home care practice

Feasibility work: for a trial in hospice home care

Stepped wedge cluster trials: in UK and Australia

Wider implementation: 36 sites delivering palliative care

CSNAT at hospital discharge: qualitative exploratory study

Hospice case study: organisational & facilitation processes

Validation study: CSNAT and carers of people with MND

Feasibility study: CSNAT at hosp discharge + comm follow up



Carer Support Needs Assessment Tool

Enabling carers to care (co-worker role)

Knowing who to contact when concerned

Understanding the patient's illness

Knowing what to expect in the future

Managing symptoms and giving medicine

Talking to the patient about their illness

Equipment to help care for the patient

Providing personal care for the patient

Direct support for carers (client role)

Own physical health concerns

Dealings with their own feelings and worries

Beliefs or spiritual concerns

Practical help in the home

Financial, legal or work issues

Having time for them themselves in the day



Overnight break from caring

14 support need domains

The Carer Support Needs Assessment Tool (CSNAT)

Your support needs

We would like to know what help you need to enable you to care for your relative or friend, and what support you need for yourself. For each statement, please tick the box that best represents your support needs at the moment.

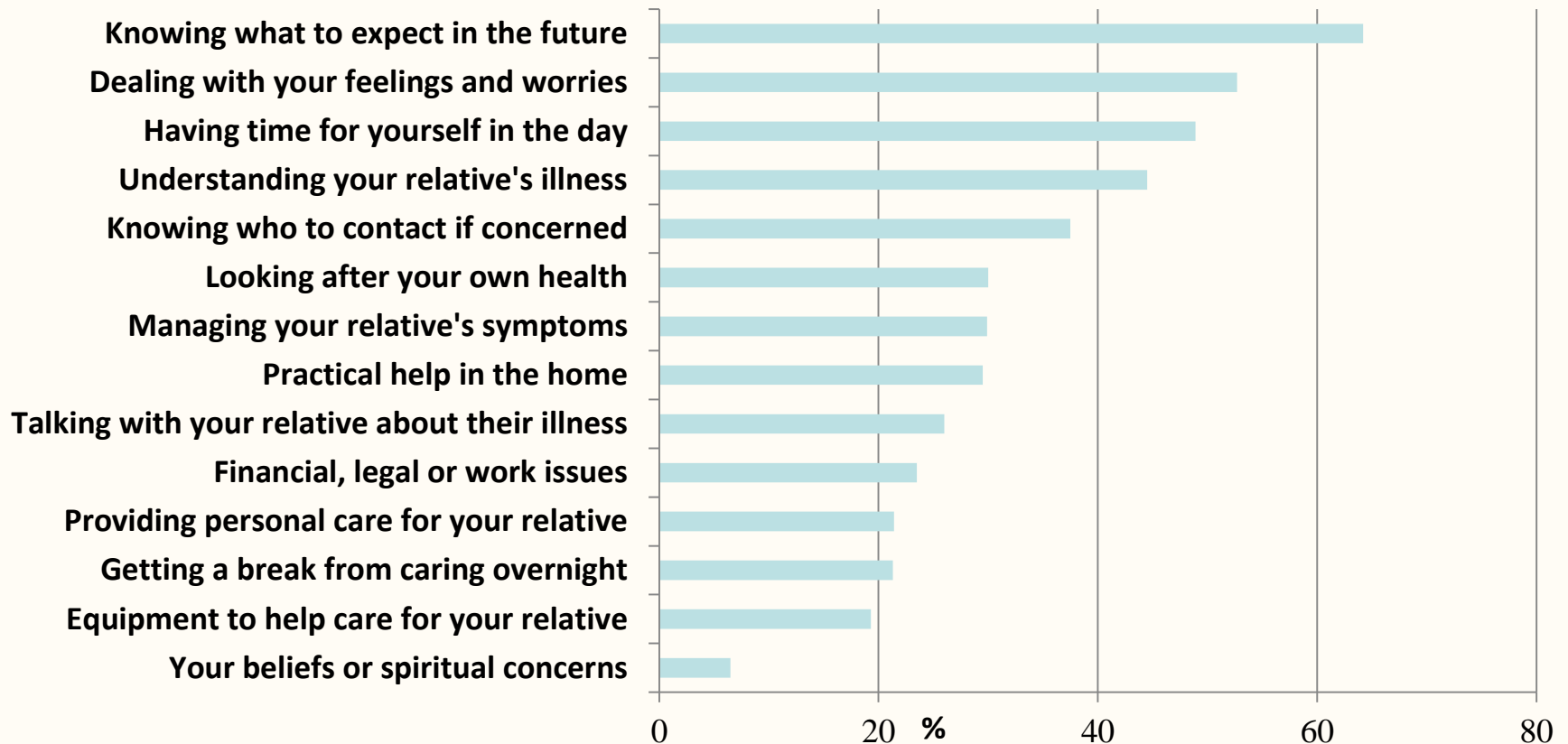
Do you need more support with...	No	A little more	Quite a bit more	Very much more
...understanding your relative's illness?				
...having time for yourself in the day				

CSNAT validation

Carers wanted more support with...

All items used

No missing items identified



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Positives: identifying carer priorities

Not always as practitioners expect

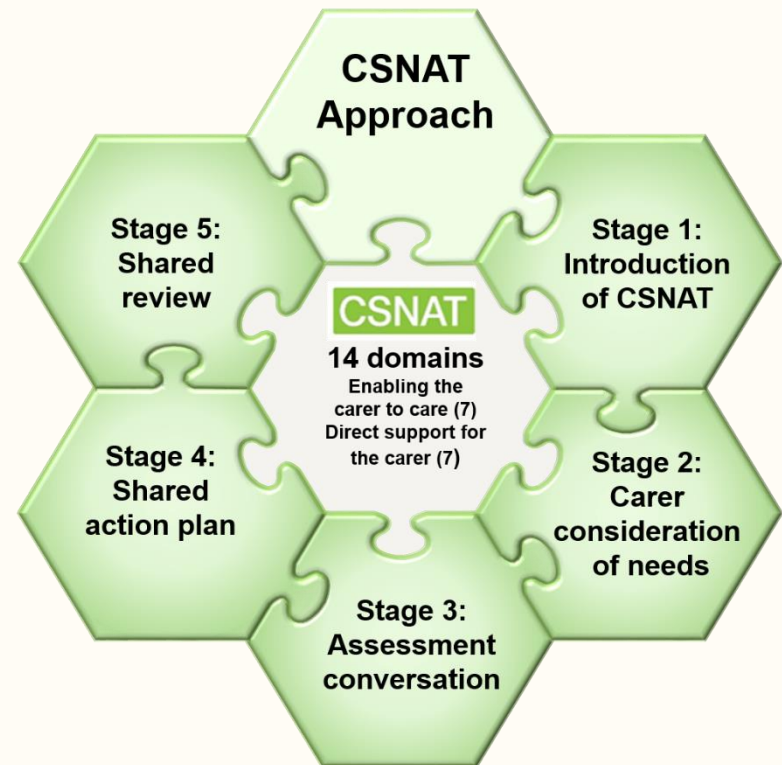
“What I found particularly useful is the things that I thought she [the carer] might not be able to cope with were the things she was coping with, and the things she wasn’t able to cope with. I was quite surprised.” (HCP)

CSNAT as a tool for practice

Your support needs now

We would like to know what help you need to enable you to care for your relative or friend and what support you need for yourself. Please tick the box that best represents your needs now, for each statement below.

Do you need more support with...	No	A little more	Quite a bit more	Very much more
.. understanding your relative's illness				
.. having time for yourself in the day				
.. managing your relative's symptoms, including giving medicines				



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Outcomes when caring



RESEARCH ARTICLE

The Impact of the Carer Support Needs Assessment Tool (CSNAT) in Community Palliative Care Using a Stepped Wedge Cluster Trial

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OPEN ACCESS

Citation: Aoun SM, Grande G, Howling D, Deas K, Toye C, Troeung L, et al. (2015) The Impact of the Carer Support Needs Assessment Tool (CSNAT) in Community Palliative Care Using a Stepped Wedge Cluster Trial. PLoS ONE 10(4): e0123012. doi:10.1371/journal.pone.0123012

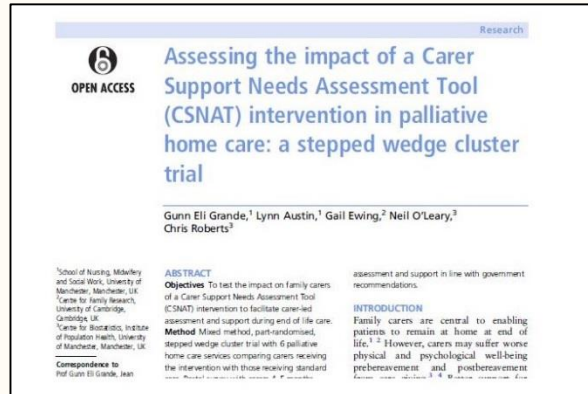
Abstract

Family caregiving towards the end-of-life entails considerable emotional, social, financial and physical costs for caregivers. Evidence suggests that good support can improve caregiver psychological outcomes. The primary aim of this study was to investigate the impact of using the carer support needs assessment tool (CSNAT), as an intervention to identify and address support needs in end of life home care, on family caregiver outcomes. A stepped wedge de-

Australian trial
(N=322 carers)

Significant reduction in
caregiver strain in
current carers in the
intervention group

Outcomes in bereavement



UK trial (N=681 carers)
Significantly lower levels of early grief and better psychological and physical health in bereavement



Australia
Significantly greater perception of pre-bereavement support needs being met in the intervention group

Positives: visibility and legitimacy of support needs

“These are the questions that are in your head but you don't even know that they're in your head.

Whereas if something's written down, you can ask people, if they don't know, you can be signposted on to somebody else to get the answers.” (Carer)

“But I think what this does, it puts it in the minds of the carers that they are allowed to have needs and that it's okay to ask for help because we've made that introduction.” (HCP)

Positives: evidencing carer support



Informal identification of needs can go unrecorded and unrecognised

The Carer Support Needs Assessment Tool (CSNAT)

Your support needs

We would like to know what help you need to enable you to care for your relative or friend, and what support you need for yourself. For each statement, please tick the box that best represents your support needs at the moment.

Do you need more support with...	No	A little more	Quite a bit more	Very much more	Do you need more support with...	No	A little more	Quite a bit more	Very much more
1. Understanding your relative's illness?					8. Looking after your own health (physical problems)?				
2. Having time for yourself in the day?					9. Equipment to help care for your relative?				
3. Managing your relative's symptoms, including giving medicines?					10. Your beliefs or spiritual concerns?				
4. Your financial, legal or work issues?					11. Talking with your relative about his or her illness?				
5. Providing personal care for your relative (eg dressing, washing, toileting)?					12. Practical help in the home?				
6. Dealing with your feelings and worries?					13. Knowing what to expect in the future when caring for your relative?				
7. Knowing who to contact if you are concerned about your relative (for a range of needs including at night)?					14. Getting a break from caring overnight?				
					15. Anything else (please write in)?				

Please consider which of the above you **most** need support with at the moment.

A practitioner will then be able to discuss these support needs with you.

Has being asked about **your** needs today made a positive difference to how you feel? ☐ Yes ☐ No

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Version 2 May 2016

Organisations are able to evidence the needs of carers and support they provide

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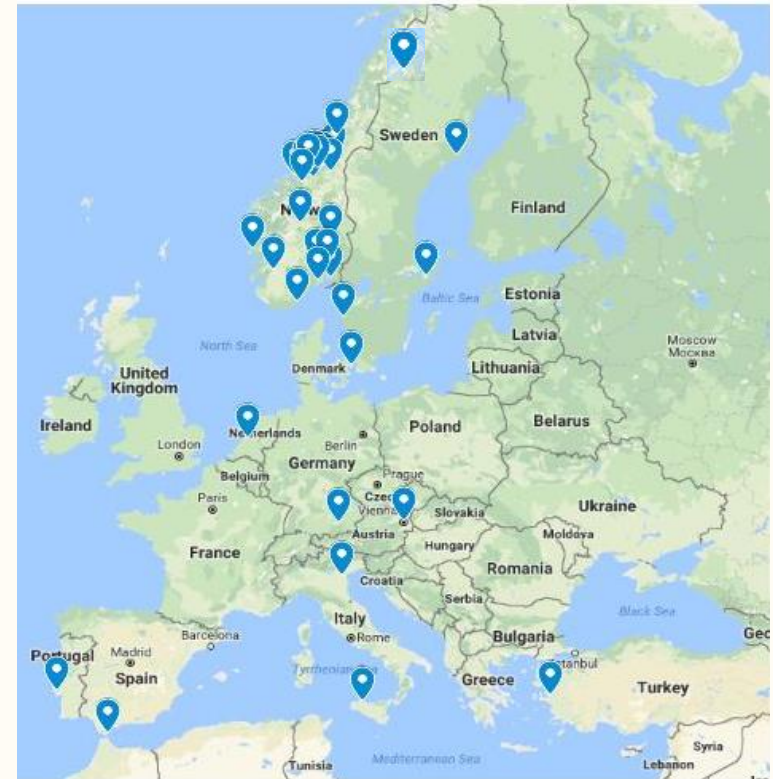
Implementation

Two key elements:

- Training for practitioners
- Organisational structures and processes to support implementation

Training and support: 90 UK healthcare organisations involving 380 practitioners

Implementation



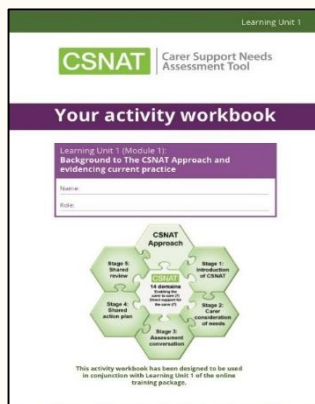
Implementation: online toolkit

The CSNAT Approach Implementation Toolkit

CSNAT

Carer Support Needs Assessment Tool

Plan, Pilot, Train, Sustain



Module 1: Reflection on current practice and The CSNAT Approach

Introduction

Module 1: Reflection on current practice and The CSNAT Approach

Module 2: Planning – getting ready for implementation

Module 3: Piloting – getting started with implementation

Module 4: Cascading training

Module 5: Sustaining the implementation of The CSNAT Approach

**Collaboration for Leadership
in Applied Health Research
and Care Greater Manchester**

NHS
National Institute for
Health Research

CSNAT: what next?

Carers of people with conditions other than cancer

- MND
- Stroke
- COPD
- Dementia

Supporting carers in other settings than home care

- Hospital discharge planning
- Hospital outpatient clinics
- Hospice inpatient units, day services
- Primary care

Supporting patients

- Support Needs Approach for Patients (SNAP): UEA

Thank you

For further information please email:

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Gunn Grande gunn.grande@manchester.ac.uk

[Website: csnat.org](http://csnat.org)

Thank you to

National Association for Hospice at Home (Kay Greene, Gill Booth); those supporting CSNAT training (KG, Lynne Carmichael, HUK); all the carers taking part

Our funders

Burdett Trust for Nursing, Dimbleby Cancer Care, BUPA Foundation, NIHR Research for Patient Benefit, Marie Curie Research Fund, Hospice UK, Marie Curie and MND Association, NIHR CLAHRC-Greater Manchester

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