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

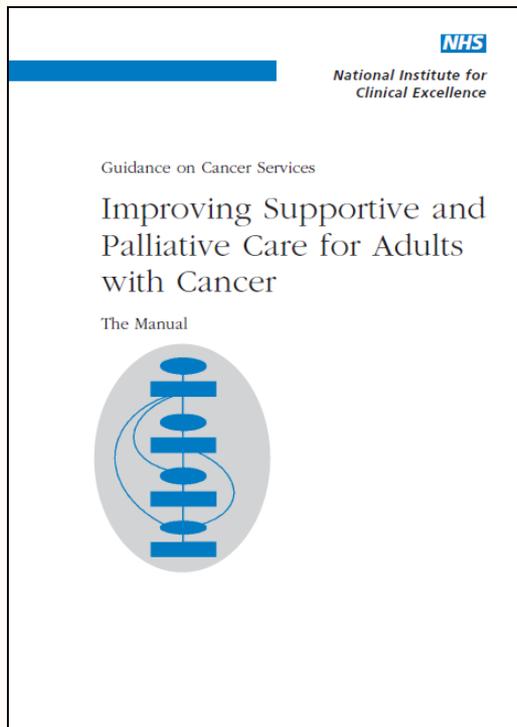
Gail Ewing, Gunn Grande, Janet Diffin

Lynn Austin, Debra Jones

CSNAT

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 finances⁴⁻⁷
- 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

CSNAT

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.

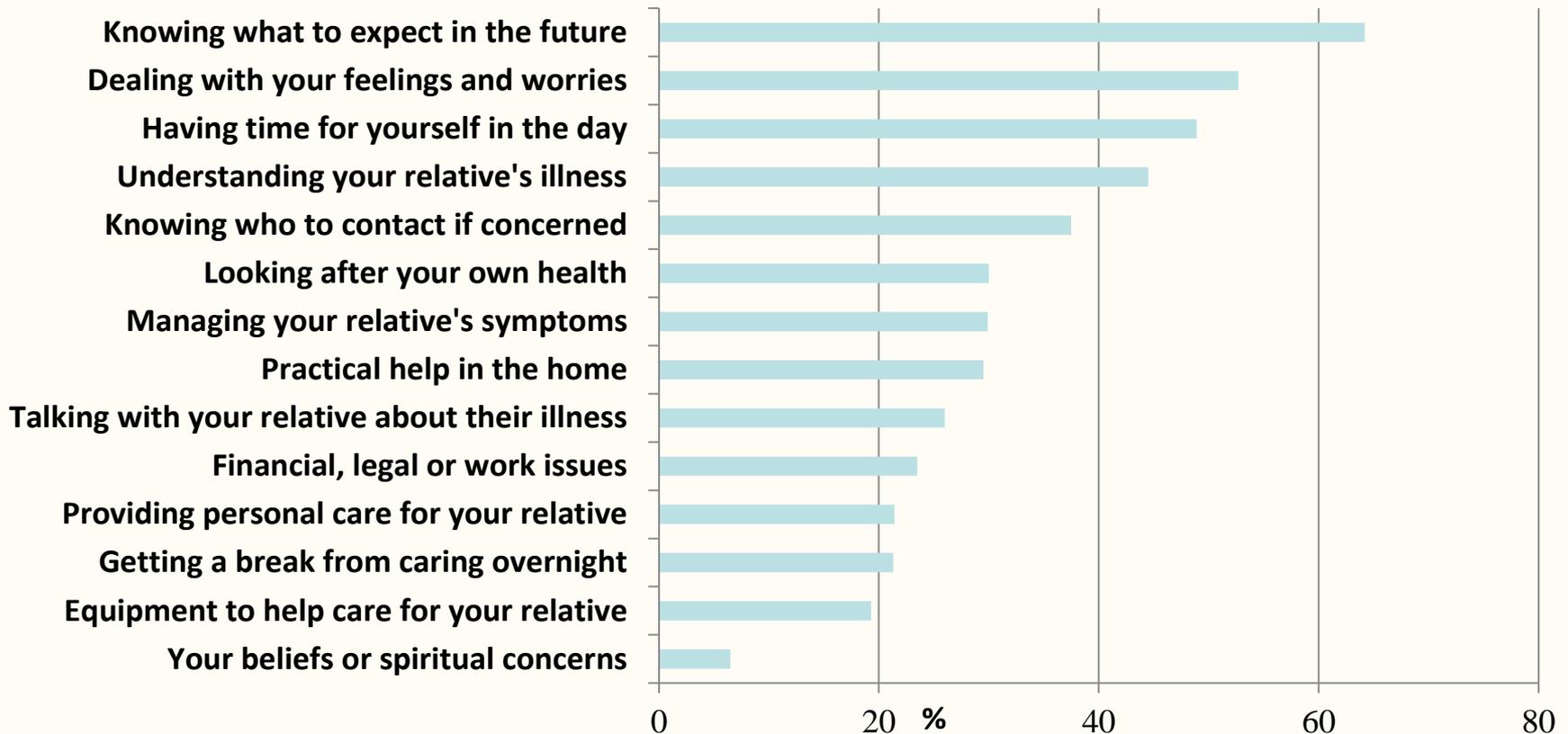
Do you need more support with...	No	A little more	Quite a bit more	Very much more
...understanding your relative's illness?				
...having time for yourself in the day				

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

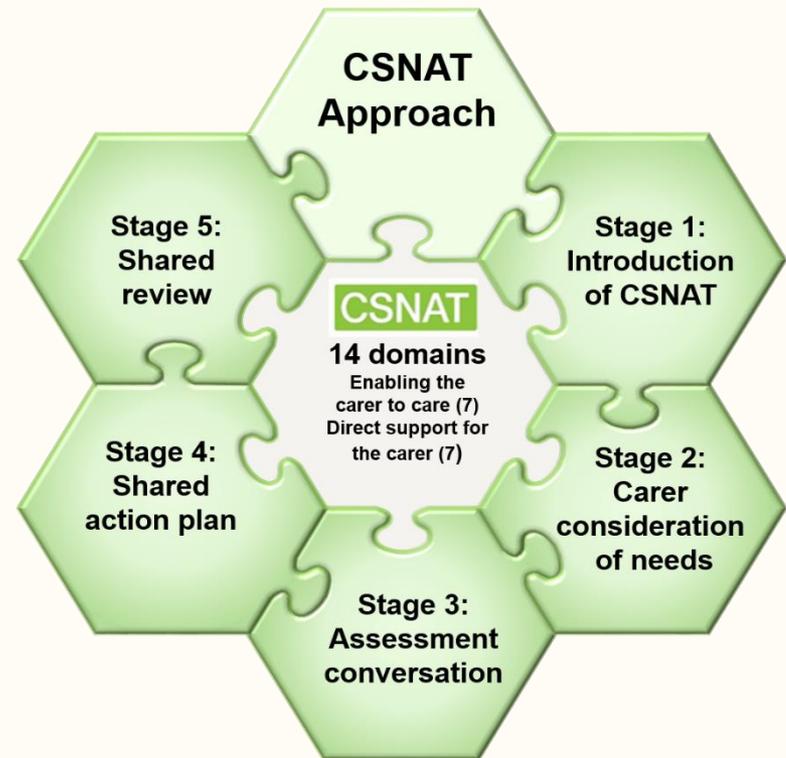
“What I found particularly useful is the things that I thought she [the carer] might not be able to cope with were the things she was coping with, and the things she wasn’t able to cope with. I was quite surprised.” (HCP)

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

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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

Research

OPEN ACCESS

Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial

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ABSTRACT
Objectives To test the impact on family carers of a Carer Support Needs Assessment Tool (CSNAT) intervention to facilitate carer-led assessment and support during end of life care.

Method Mixed method, part-randomised, stepped wedge cluster trial with 6 palliative home care services comparing carers receiving the intervention with those receiving standard

assessment and support in line with government recommendations.

INTRODUCTION
Family carers are central to enabling patients to remain at home at end of life.¹⁻³ However, carers may suffer worse physical and psychological well-being prebereavement and postbereavement

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

368 *Journal of Pain and Symptom Management* Vol. 55 No. 2 February 2018

Original Article

The Impact of Supporting Family Caregivers Before Bereavement on Outcomes After Bereavement: Adequacy of End-of-Life Support and Achievement of Preferred Place of Death



Samar M. Aoun, BSc(Hons), MPH, PhD, Gail Ewing, BSc, PhD, Gunn Grande, BA(Hon), MPhil, PhD, Chris Towe, RN, BN(Hons), PhD, and Natasha Bear, BSc, Masters Biostatistics

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Abstract

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

Ayrshire Hospice
Making today matter

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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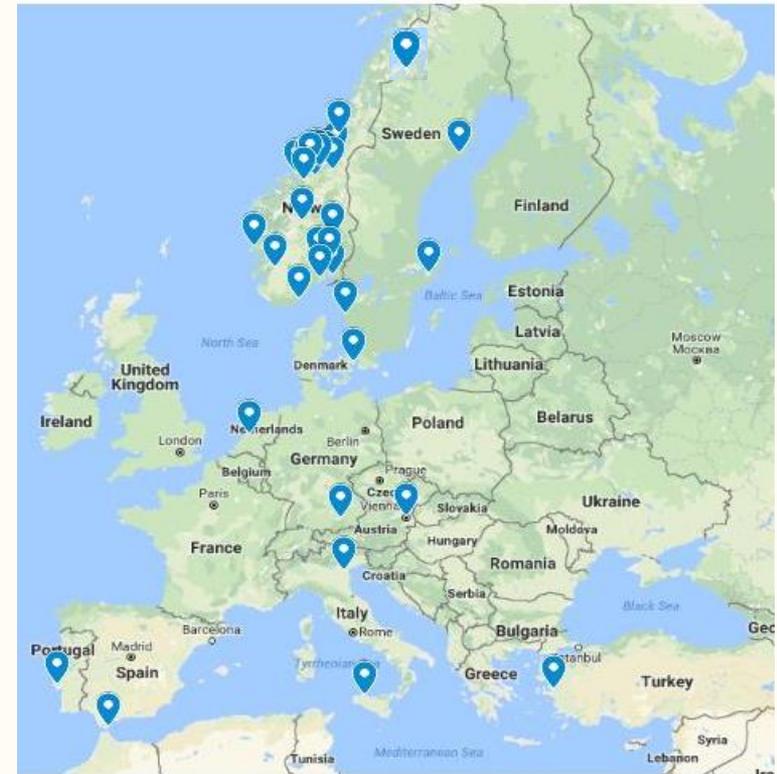
Implementation

Two key elements:

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

Training and support: 90 UK healthcare organisations involving 380 practitioners

Implementation

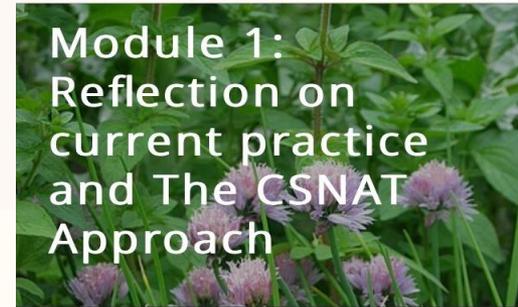


Implementation: online toolkit

The CSNAT Approach Implementation Toolkit

CSNAT | Carer Support Needs Assessment Tool

Plan, Pilot, Train, Sustain



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

Learning Unit 1

CSNAT | Carer Support Needs Assessment Tool

Your activity workbook

Learning Unit 1 (Module 1)
Background to The CSNAT Approach and evidencing current practice

Name: _____
Role: _____

This activity workbook has been designed to be used in conjunction with Learning Unit 1 of the online training package.

Common questions

"A change in my practice isn't necessary"

- The CSNAT Approach does involve a new way of working and you may be wondering why this is necessary. Although you may already discuss many of the CSNAT domains with carers as part of your existing practice, how and when these domains are discussed is often different when using The CSNAT Approach.
- Your existing approach may help to identify carers who have support needs, however, you may have identified some limitations. For example, it may not be obvious to the carer that an assessment of their support needs is taking place, or the conversation about their support needs may often take place on the doorstep or in the car.
- The CSNAT Approach highlights the carer's individual concerns and makes the process of assessment and support more **comprehensive and visible**.

Carers' view on the 'door-step' conversation / 'How are you?'

"I think I would have liked it if they often would have asked to come down and sit down and have a conversation with me, they although they always asked if we were ok, as they were not the other carers in our care conversation on the doorstep."

"I think really they could have gotten to you more about you know, if you understand what the thing that is said, how are you? or how are you? And the rest of these people when it says 'Yeah, fine, fine'."

"When people ask you how you are it's being polite, if you know what I mean, it's something or you know what I mean? It's just the something that you would people to say, and most of the time you just give short answers, you don't actually always go and think about, well, how are I really, are they really asking a proper question or are they just being polite, so in that respect I would say something more formal is more preferable because people that know that it's a real concern rather than it's just someone being polite and getting you to talk and meet if you understand sort of what I mean."

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

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Aoun SM, Ewing G, Grande G, Toye C, Bear N. [The impact of supporting family caregivers pre-bereavement on outcomes post-bereavement: Adequacy of end of life support and achievement of preferred place of death](#). J Pain Symptom Manage. 2018 Feb;55(2):368-378. doi: 10.1016/j.jpainsymman.2017.09.023. Epub 2017 Oct 10