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

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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?

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
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.

<table>
<thead>
<tr>
<th>Do you need more support with...</th>
<th>No</th>
<th>A little more</th>
<th>Quite a bit more</th>
<th>Very much more</th>
</tr>
</thead>
<tbody>
<tr>
<td>...understanding your relative’s illness?</td>
<td><img src="#" alt="Circle" /></td>
<td><img src="#" alt="Circle" /></td>
<td></td>
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<tr>
<td>...having time for yourself in the day</td>
<td><img src="#" alt="Circle" /></td>
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</tbody>
</table>

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**Note:**
- A checkmark (✓) indicates the level of support needed for each statement.
- The options range from 'No' to 'Very much more'.
Carers wanted more support with...

- Knowing what to expect in the future
- Dealing with your feelings and worries
- Having time for yourself in the day
- Understanding your relative's illness
- Knowing who to contact if concerned
- Looking after your own health
- Managing your relative's symptoms
- Practical help in the home
- Talking with your relative about their illness
- Financial, legal or work issues
- Providing personal care for your relative
- Getting a break from caring overnight
- Equipment to help care for your relative
- Your beliefs or spiritual concerns

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.

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<tr>
<td>having time for yourself in the day</td>
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<tr>
<td>managing your relative's symptoms, including giving medicines</td>
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Outcomes when caring

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)
Informal identification of needs can go unrecorded and unrecognised

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*

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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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Website: csnat.org

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