Investing in family carers: a model for practice implementation of a person-centred approach to carer assessment and support within palliative care (Plan, Pilot, Train, Sustain)

Janet Diffin, Gail Ewing, Gunn Grande

j.diffin@qub.ac.uk

Tweet using #CSNAT
Website: csnat.org / Twitter @CSNAT_
Family carers and palliative care

• Demand for palliative care is increasing across Ireland and the UK.

• Family carers provide vital practical and emotional support throughout the palliative trajectory: appropriate and timely support is vital.
Development of the Carer Support Needs Assessment Tool (CSNAT)

Professor Gunn Grande
The University of Manchester

Dr Gail Ewing
University of Cambridge
Why was the CSNAT developed?

There was a need for an ‘evidence based’ and direct measure of carer support needs that was easy to use in practice.
## Carer Support Needs Assessment Tool (CSNAT)

<table>
<thead>
<tr>
<th>Enabling carers to care (co-worker role)</th>
<th>Direct support for carers (client role)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowing who to contact when concerned</td>
<td>Own physical health concerns</td>
</tr>
<tr>
<td>Understanding the patient’s illness</td>
<td>Dealing with their own feelings and worries</td>
</tr>
<tr>
<td>Knowing what to expect in the future</td>
<td>Beliefs or spiritual concerns</td>
</tr>
<tr>
<td>Managing symptoms and giving medicine</td>
<td>Practical help in the home</td>
</tr>
<tr>
<td>Talking to the patient about their illness</td>
<td>Financial, legal or work issues</td>
</tr>
<tr>
<td>Equipment to help care for the patients</td>
<td>Having time for them themselves in the day</td>
</tr>
<tr>
<td>Providing personal care for the patient</td>
<td>Overnight break from caring</td>
</tr>
</tbody>
</table>
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></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>...having time for yourself in the day</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

“It’s opened up conversations in a different way, it’s not just ticking boxes...it’s what comes out of that...”
Carers’ views on the CSNAT

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.

When they come to see you, a lot of the time you forget things that you want to speak about, so if it’s all down in [CSNAT] she can bring up various pointers.
The CSNAT Approach

14 domains
- Enabling the carer to care (7)
- Direct supports for the carer (7)

Introduction
Shared review
Shared action plan
Assessment conversation
Carer consideration of needs
CSNAT programme of development and testing

**CSNAT development:** Focus groups 75 bereaved carers

**CSNAT validation:** Questionnaire study with 225 current carers

**Piloting** CSNAT within hospice home care practice

**Feasibility** work for a trial in hospice home care

Stepped wedge cluster trials in **UK** and **Australia**

**National implementation** across **36 UK sites** delivering palliative care

**Hospice case study:** project model of implementation
Training for practice

As part of our research studies
48 palliative care services

Funded training workshops
hospice UK  31 teams plus 9

Total = 88

Licence requests

Australia, Brazil, Canada, China, Denmark, England, France, Germany, Gibraltar, Greenland, Iceland, India, Ireland, Italy, Netherlands, New Zealand, Norway, Philippines, Rwanda, Scotland, Singapore, Slovenia, Spain, Sweden, Thailand, USA, Wales
The model is informed by the CSNAT research programme and feedback from 88 organisations across the UK and Ireland using the CSNAT in practice.
Initial steps to practice implementation

- Ensure management support is in place from the outset.
- Management, team leader/manager/practitioner ‘on the ground’ to lead on the overall implementation project.
- Sub-champions within each team who will support their colleagues in the use of The CSNAT Approach.
Plan

• Getting ‘buy-in from management and practitioners.
• Identifying current practice.
• Setting goals for the implementation.
• Laying the groundwork: collecting and recording information, administrative considerations.
Pilot

- Planning for how to use The CSNAT Approach.
- Determine if ready for wider-scale implementation.
Train

- Learning about The CSNAT Approach.
- Planning for how it can be used in practice.
- Opportunities for group discussions.

Train:
Ensure practitioners receive training (If applicable)
Sustain

- Monitoring and reviewing progress.
- On-going engagement with all practitioners and management.
- Normalising a new way of working.
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
Acknowledgements

The findings of the research projects helped to inform the Plan, Pilot, Train, Sustain model and the content of The CSNAT Approach Implementation Toolkit.

- Dimbleby Cancer Care
- Marie Curie
- Hospice UK
- Burdett Trust for Nursing
- NHS National Institute for Health Research (NIHR)
- Bupa Foundation: The Medical Research Charity
- National Association for Hospice at Home

Special thanks to all the practitioners and carers who took part in our research projects.
For further information

See our website: csnat.org

Follow us on twitter: @CSNAT_

Contact:
  j.diffin@qub.ac.uk

Prof Gunn Grande: gunn.grande@manchester.ac.uk
Dr Gail Ewing: ge200@cam.ac.uk