

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

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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



"To allow people the deaths they want, end of life care must be radically transformed..."

DYING FOR CHANGE

Charles Leadbeater
Jake Garber

CARERS UK
the voice of carers

circle
Palliative Care
2000-2010

UNIVERSITY OF LEEDS

Valuing Carers 2011
Calculating the value of carers' support



Home Care
across Europe

Current assessment of health challenges



HM Government

NHS
SCOTLAND

Recognised, valued
and supported:
Next steps for the Carers Strategy

LIVING AND DYING WELL

a national action plan for palliative
and end of life care in Scotland

Help the
Hospices



Identifying carers'
needs in the
palliative setting

HM Government

Carers at the heart of
21st-century families
and communities

"A caring system on your side.
A life of your own."



Published by

WE ARE
PACIFICAN,
Carers Strategy



Improving support
looking after someone

CSNAT

Carer Support Needs
Assessment Tool

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

Commissioning Guidance for Specialist
Palliative Care:
Helping to deliver commissioning
objectives

Developed in collaboration with:
Association for Palliative Medicine of Great Britain and Ireland
Consultant Group in Palliative Care Performance Group
NHS Carers' Strategy Unit
National Institute for Health Research
Palliative Care Unit, Royal Free London School of Medicine
November 2012

The State of Caring
2013

CARERS UK
the voice of carers

Carers'
services
guide

Setting up support services for carers of people
with life-limiting and terminal illnesses
Second edition
November 2008

Amendments for
Palliative and
End of Life Care:

A national framework for local action 2015-2020

Royal College of
General Practitioners

Supporting Carers:
An action guide for general
practitioners and their teams



Royal College of
General Practitioners

Carer Support Needs Assessment Tool (CSNAT)

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 patients

Providing personal care for the patient

Direct support for carers (client role)

Own physical health concerns

Dealing 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

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				

"It's opened up conversations in a different way, it's not just ticking boxes...it's what comes out of that..."

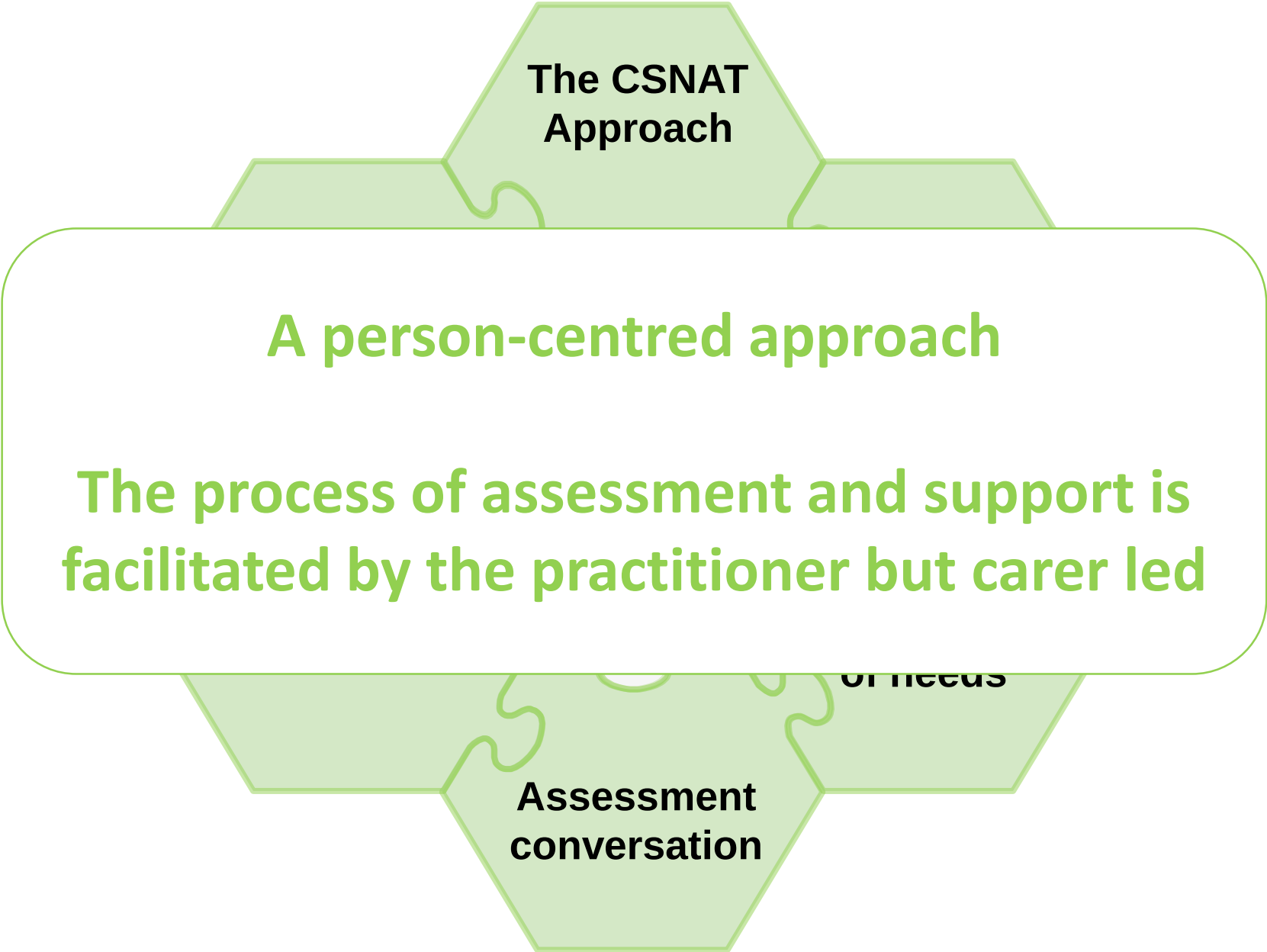


Carers' views on the CSNAT

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



The CSNAT Approach

The diagram illustrates the CSNAT Approach using a puzzle metaphor. At the top is a green puzzle piece labeled 'The CSNAT Approach'. Below it is a large white rounded rectangle with a green border containing the text 'A person-centred approach' and 'The process of assessment and support is facilitated by the practitioner but carer led'. At the bottom is another green puzzle piece labeled 'Assessment conversation'. To the right of this piece, the text 'of needs' is partially visible. The puzzle pieces are interlocking, suggesting a cohesive process.

A person-centred approach

The process of assessment and support is facilitated by the practitioner but carer led

Assessment
conversation

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

 31 teams plus 9

Total = 88

Licence requests

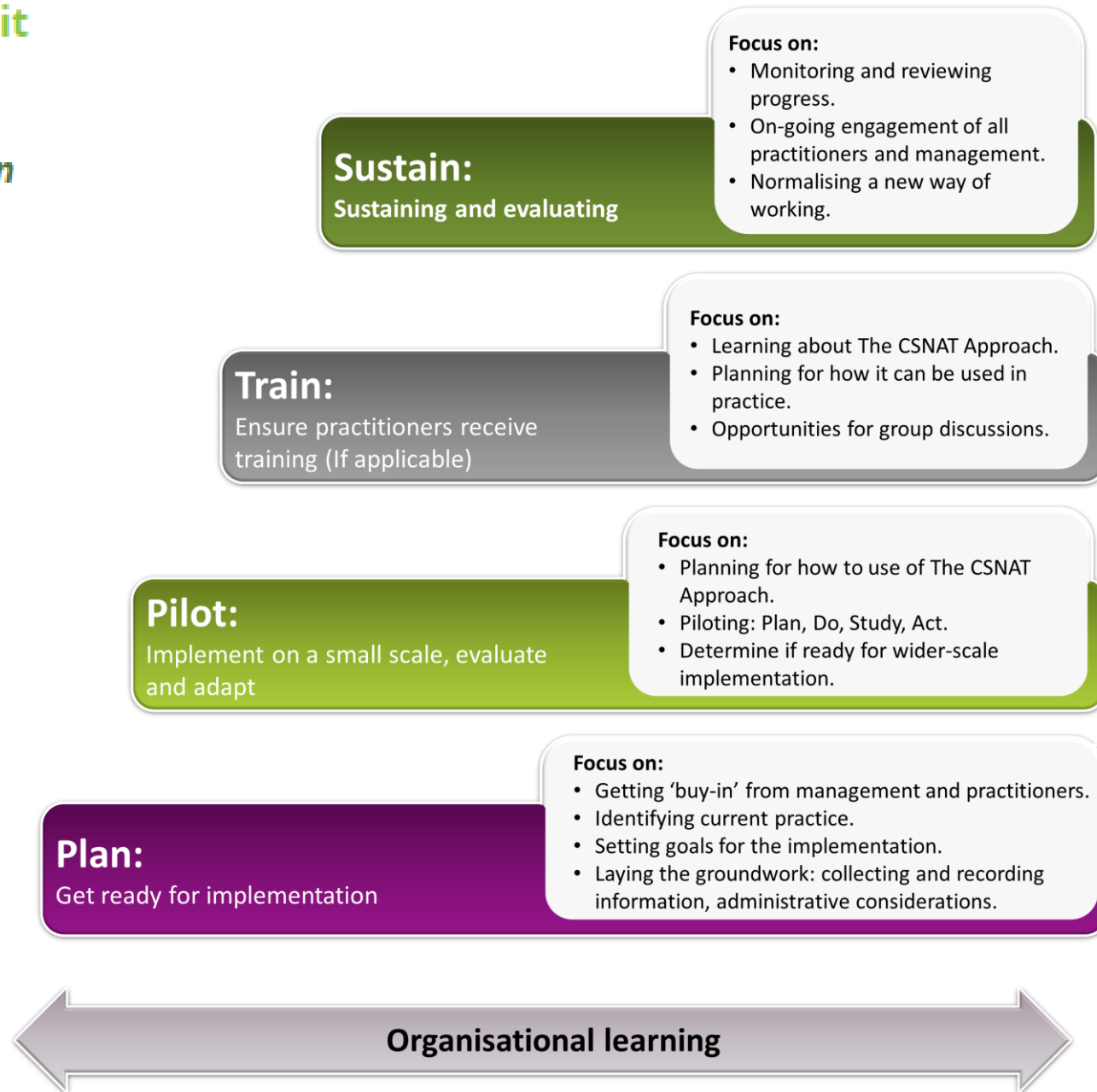
Australia, Brazil, Canada, China, Denmark, England, France, Germany, Gibraltar, Greenland, Iceland, India, Ireland, Italy, Netherlands, New Zealand, Norway, Philippines, Rwanda, Scotland, Singapore, Slovenia, Spain, Sweden, Thailand, USA, Wales

The CSNAT Approach Implementation Toolkit

CSNAT | Carer Support Needs
Assessment Tool

Plan, Pilot, Train, Sustain

- 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



Management support

- Ensure management support is in place from the outset.

Project facilitation team

- Management, team leader/manager/practitioner 'on the ground' to lead on the overall implementation project.

Selecting sub-champions

- Sub-champions within each team who will support their colleagues in the use of The CSNAT Approach.

Plan

Plan:

Get ready for implementation

- 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

Pilot:

Implement on a small scale, evaluate and adapt

- Planning for how to use The CSNAT Approach.
- Piloting: Plan, Do, Study, Act.
- Determine if ready for wider-scale implementation.

Train

Train:

Ensure practitioners receive training (If applicable)

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

Sustain

Sustain:

Sustaining and evaluating

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

The CSNAT Approach Implementation Toolkit

CSNAT

Carer Support Needs Assessment Tool

Plan, Pilot, Train, Sustain

Learning Unit 1

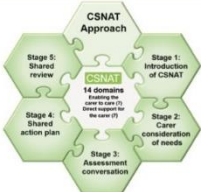
CSNAT Carer Support Needs Assessment Tool

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 some of the carers' 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 corridor.
- The CSNAT Approach legitimises the carers' 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 if they... When we'd been judged, come down and sit down and have a consultation with me. And although they always asked, it was more like, as they went out the door. Sometimes it was a long conversation on the doorstep. **"**

" I think really they could have spoken to you more, asked you more, if you understand what I'm saying there. It's just, how are you? Are you alright? And I'm one of these people who'll say, 'Yeah, I'm fine'. **"**

" When people ask you how you are it's being polite, if you know what I mean, it's something in our culture, you ask how people are even though you're not really that interested, do you know what I mean? It's just like something that you expect people to say, and most of the time you just give stock answers, you don't actually dredge up and think about, well, how do I really feel, are they really asking a proper question or are they just being polite, so in that respect I would say something much more formal is more preferable because people then know that it's a real concern rather than it's just someone being polite and getting you to talk and that, if you understand sort of what I mean. **"**

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

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
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- Burdett Trust for Nursing
- NHS National Institute for Health Research (NIHR)
- Bupa Foundation: The Medical Research Charity
- National Association for Hospice at Home

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


*National Institute for
Health Research*

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



Carer Support Needs
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