

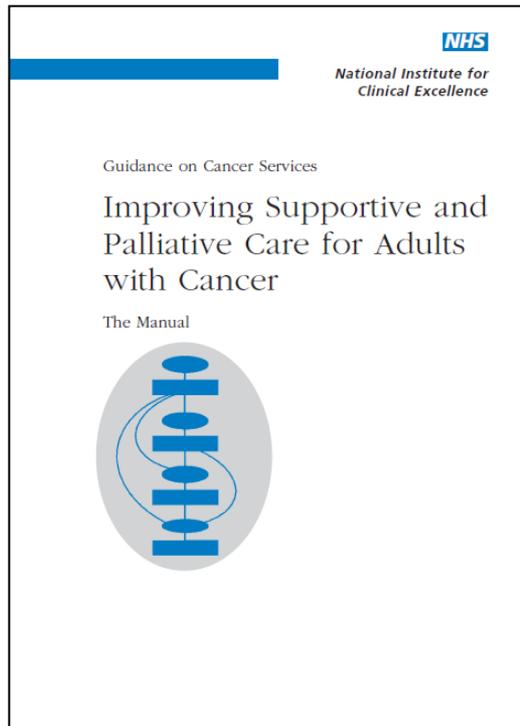
# The Role of Carers to Support People in Community Settings

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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)

Community care: care in private homes

# Importance of carers

- Carers of people with cancer provide an average of nearly 70 hours of care per week in patients' last three months (National survey)<sup>1</sup>
- Carers are crucial in enabling end of life care and death to happen at home<sup>2-4</sup>
- Family factors play an important role in 'inappropriate' or 'avoidable' terminal hospital admissions<sup>5-7</sup>

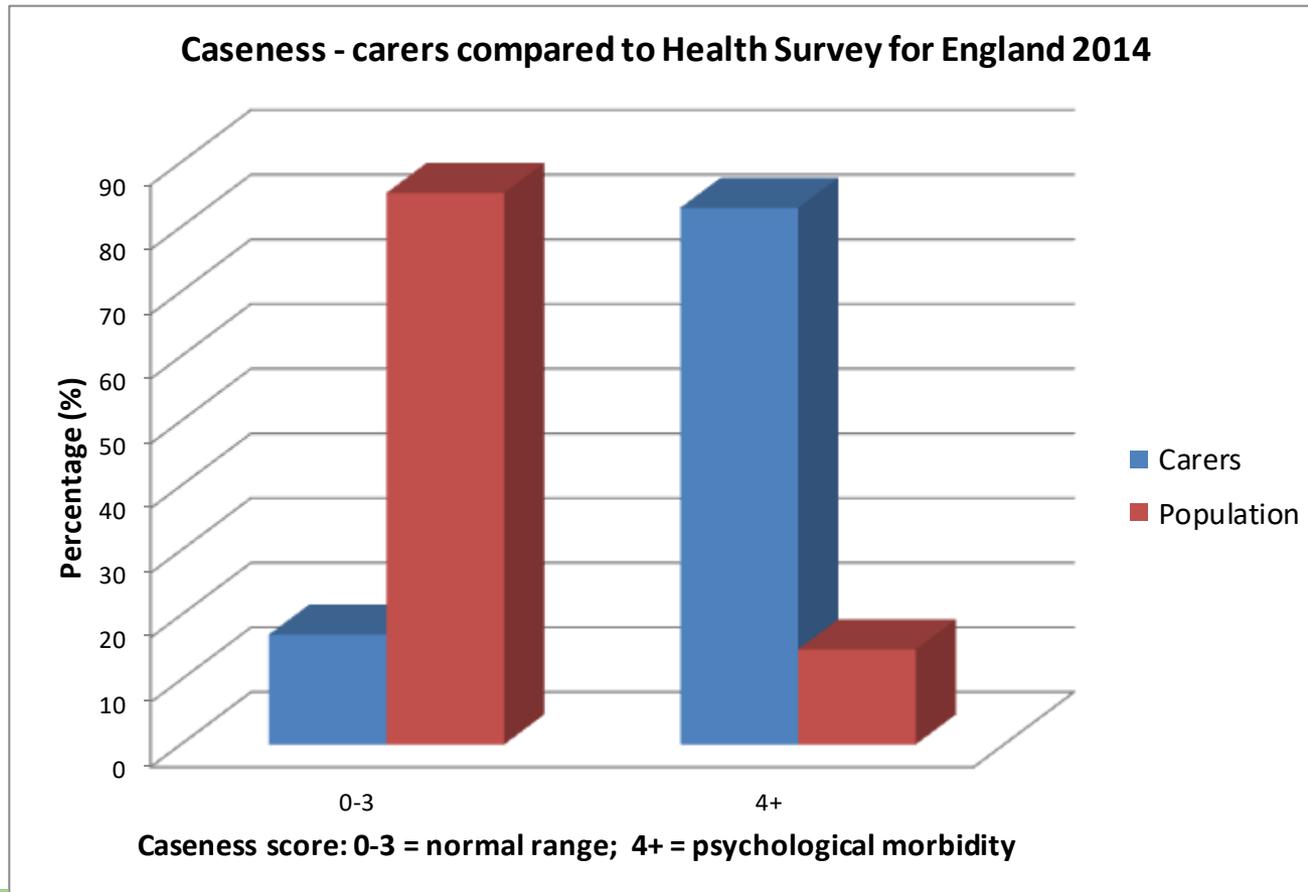
# The impact on carers

- Psychological
- Physical
- Social
- Finance & work
- Activities
- Quality of Life
- Bereavement<sup>1,2</sup>



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# Carers with clinically significant psychological morbidity ('caseness') compared to population (%)

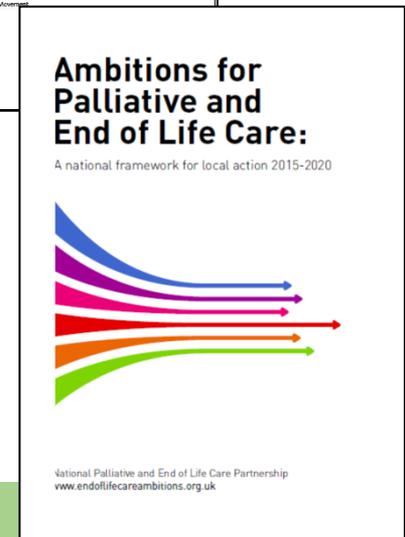
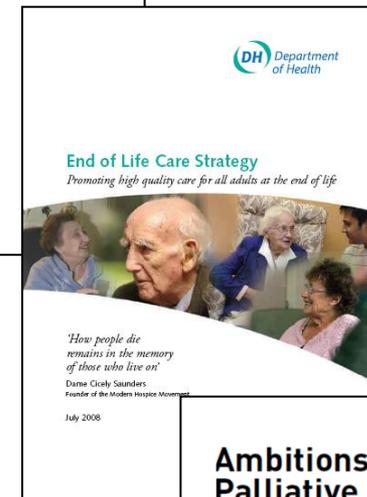
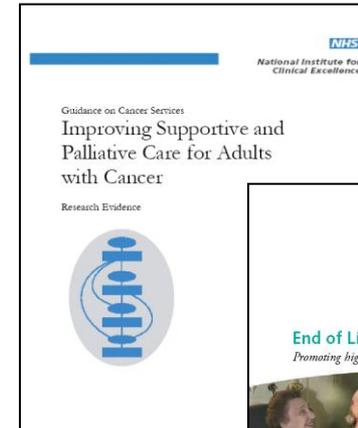


# Covid-19 impact

- Shift of deaths from hospital to private homes (excess non-Covid deaths England & Wales)
  - *BMJ* 2020;369:m2115 doi: 10.1136/bmj.m2115
  - <https://wintoncentre.maths.cam.ac.uk/coronavirus/covid-excess/>
- More remote working, less face to face contact
- Carers are expected take on more skilled tasks
  - <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0198-community-health-services-sop.pdf>

# Policy and practice background

- Carers' needs should be assessed and addressed<sup>1-4</sup>
- Lack of guidance on how this should be achieved
- No consistent approach in practice, mainly informal
- Need to assess to know who needs support with what



<sup>1</sup>NICE (2004); <sup>2-3</sup> DH (2008,2014); <sup>4</sup>National & EOLC partnership

# Achieving carer support in practice

## Carer Support Needs Assessment Tool (CSNAT) Intervention and implementation principles

Gunn Grande & Gail Ewing

# Carers need support within two roles

Enabling support for patient (co-worker role)	Direct support for carers (client role)
Knowing who to contact when concerned	Own physical health concerns
Understanding the patient's illness	Dealing with their own feelings and worries
Knowing what to expect in the future	Beliefs or spiritual concerns
Managing symptoms including medicines	Practical help in the home
Talking to the patient about their illness	Financial, legal or work issues
Equipment to help care for the patients	Having time for them themselves in the day
Providing personal care for the patient	Overnight break from caring
<b>Long Term Conditions:</b>	Managing relationships

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Carers' support needs span health and social care

# Domain: providing personal care

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## Met/unmet needs with

- Helping the patient with ADLs
- understanding changes in mobility as MND progresses
- how to move/turn patient in bed, to manage patient falls
- being able to give a carer perspective on help with ADLs
- strain of being the only person patient permits to help
- Incontinence / soiling
- paying for private carers

## Supportive input

- Early training 'from day 1' on lifting, bedbaths, catheter care
- Pro-active advice on how to access care services
- Provision of different types of equipment to help provide care
- Practical advice on washing / cleansing rather than told to leave till next care visit
- Referral to continuing health and help completing forms
- Help from neighbours when patient falls

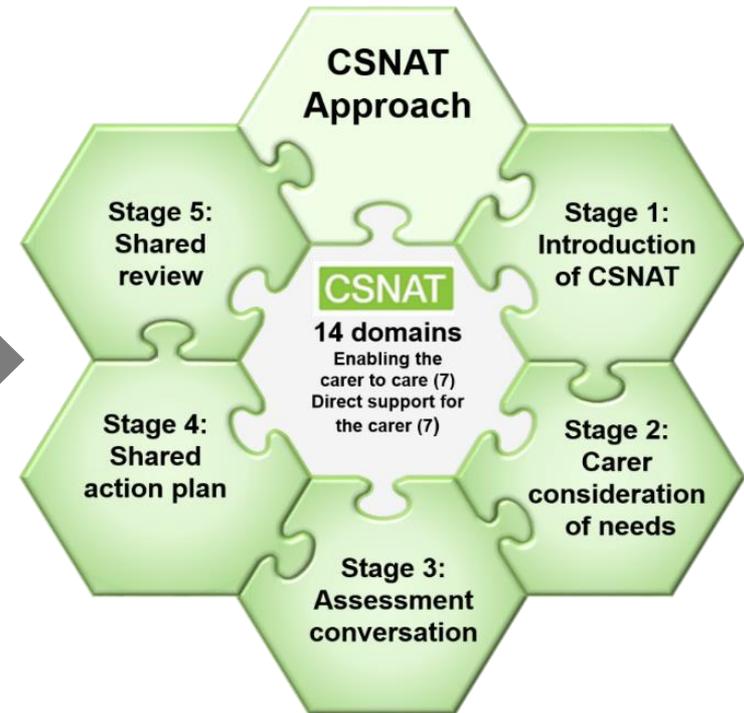
# The CSNAT intervention for carers

**CSNAT** Carer Support Needs Assessment Tool

## Your support needs

We would like to know what help you need to enable you to care for your relative. For each statement, please tick the box that best represents your needs.

Do you need more support with...	No	A little more	Quite a bit more	Very much more
1 ...understanding your relative's illness				
2 ...having time for yourself in the day				
3 ...managing your relative's symptoms, including giving medicines				
4 ...your financial, legal or work issues				



## Two components

- An evidence based, comprehensive tool, self-completed by carers to express and prioritise their support needs
- Used within a 5 stage person-centred process of assessment and support that is practitioner facilitated but carer led.

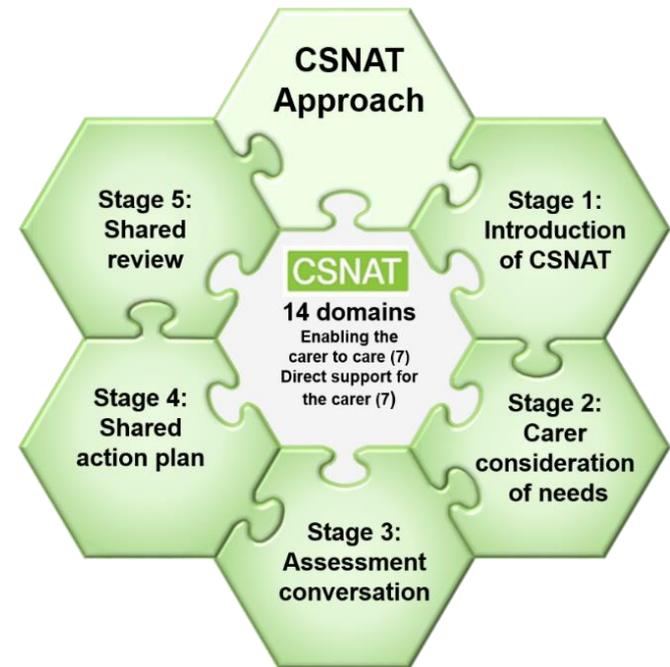
# Key principles embedded

- Structured and comprehensive rather than selective and informal
  - otherwise important problems are often missed
- Person centred and tailored to carer priorities
  - we do not know what individual carers need help with
- Helping carers review and express their needs
  - carers have difficulty voicing their support needs

# CSNAT Intervention implementation

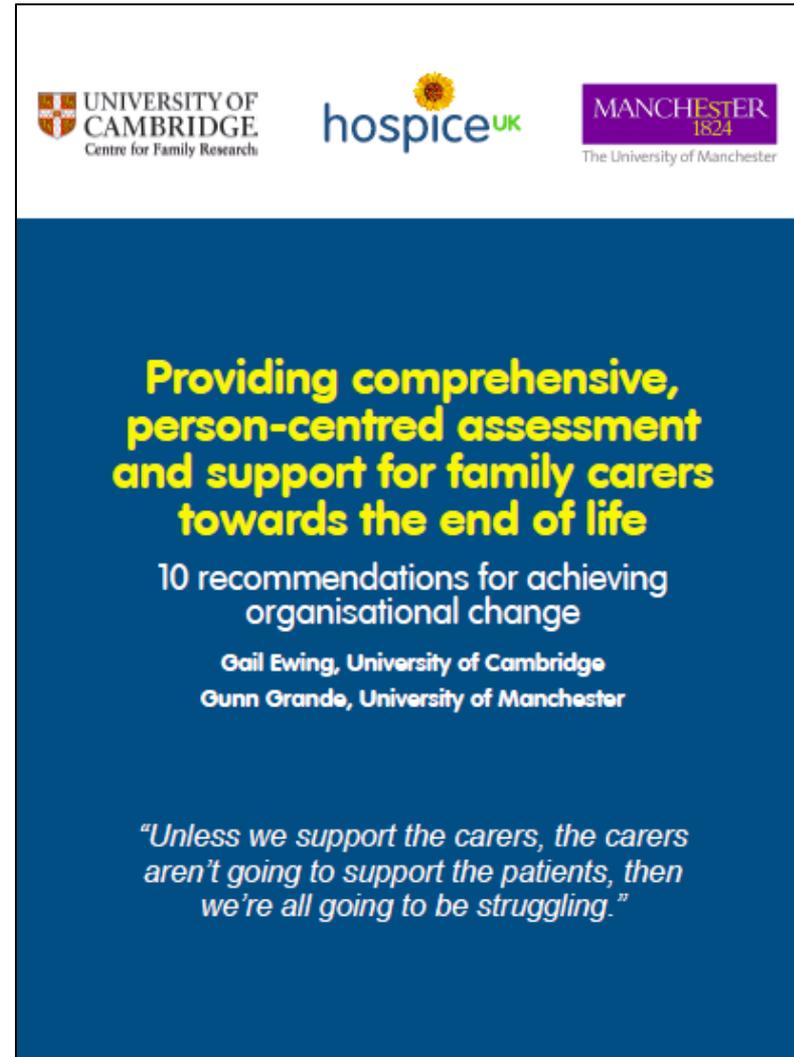
Change in practice

- Staff training
- Broad stages and principles to be adapted to each organisation
- Implementation protocol: when, where, who by, what
- Lessons learnt for remote link up



# Implementation

- Must embed carer support within care pathways for consistent support
- Core components
  - consistent identification of carers
  - information on their situation
  - separate assessment of support needs
  - a system for recording assessment and actions



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**Providing comprehensive, person-centred assessment and support for family carers towards the end of life**

10 recommendations for achieving organisational change

Gail Ewing, University of Cambridge  
Gunn Grande, University of Manchester

*"Unless we support the carers, the carers aren't going to support the patients, then we're all going to be struggling."*

# Implementation

- A process for training staff
  - Available time/workload capacity
  - Senior management support
  - Role models/champions
  - Pathways for communication
  - Monitoring/auditing processes and outcomes
- Deciding where carers 'fit'

# Increased reliance on carers in years to come

Increased dependency on carers during Covid-19

Over the next decades there will be increases in:

- people over 85<sup>1</sup>
- those with life limiting illness<sup>1</sup>
- dependency in the final years of life<sup>2</sup>
- number deaths<sup>3</sup>

Formal services are unlikely to be able to meet demand



Supporting carers in their role a key part of meeting future demands

# Thank you

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