The Carer Support Needs Assessment Tool Intervention (CSNAT-I)

Gunn Grande University of Manchester

Gail Ewing University of Cambridge

Morag Farquhar University of East Anglia

https://CSNAT.org.uk

Why did we develop CSNAT-I?

- Carers (family and friends) provide crucial support for people with cancer and life limiting diseases and are central to making end of life care at home possible[1-5]

- Caregiving can have considerable impact on carers' own health[6]

- If carers can no longer cope
  - Quality of care for patients suffers[7]
  - Contributes to 'avoidable' or 'inappropriate' hospital admissions[8,9]

[1]Gomes & Higginson (2006); [2]Costa (2014); [3]Wahid et al (2018); [4]Turner & Flemming (2019); [5]Rowland et al (2017)
[6]Grande et al (2018); [7]Park et al (2009); [8]Gott et al (2013); [9]Reyniers et al (2016)

Why did we develop CSNAT-I?

- Supporting carers is essential

- Carer assessment and support often informal and inconsistent in everyday practice

Carers told us about **doorstep conversations**:

'How are you?'

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

Why did we develop CSNAT-I?

- What are carers' support needs during end-of-life caregiving?
- How do we help practitioners assess and address those support needs in a simple, but effective way?

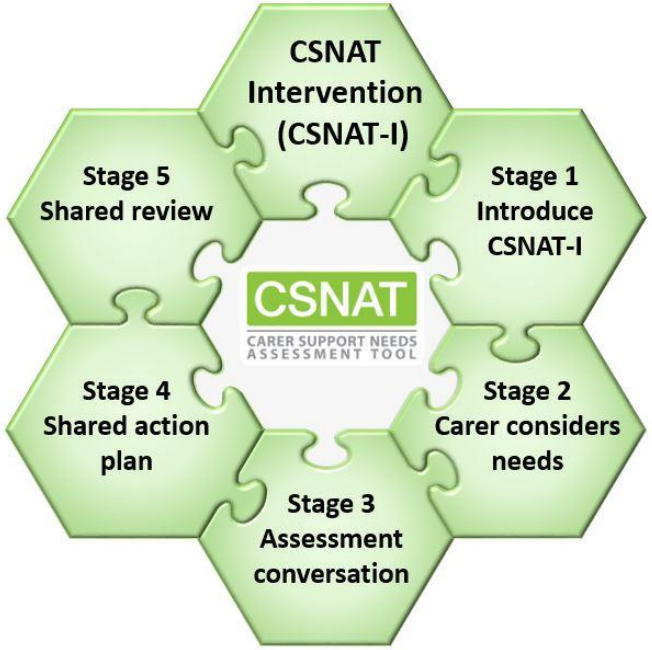
Shutterstock 644027602

Overview

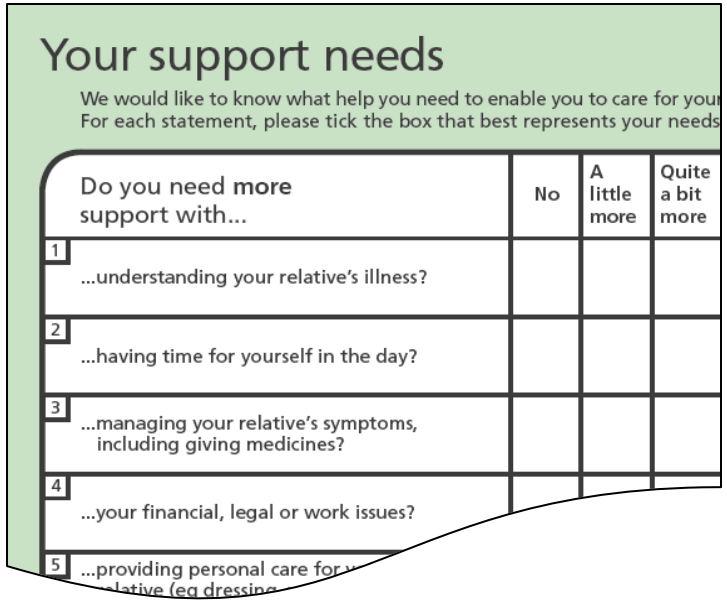
1. What is the CSNAT Intervention (CSNAT-I)?
2. How was it developed

   CSNAT and Intervention stages
3. Benefits and outcomes
4. Implementation in practice
5. Further information on CSNAT-I

1. What is the CSNAT Intervention (CSNAT-I)?



A person-centred process for delivering support for carers



Your support needs

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

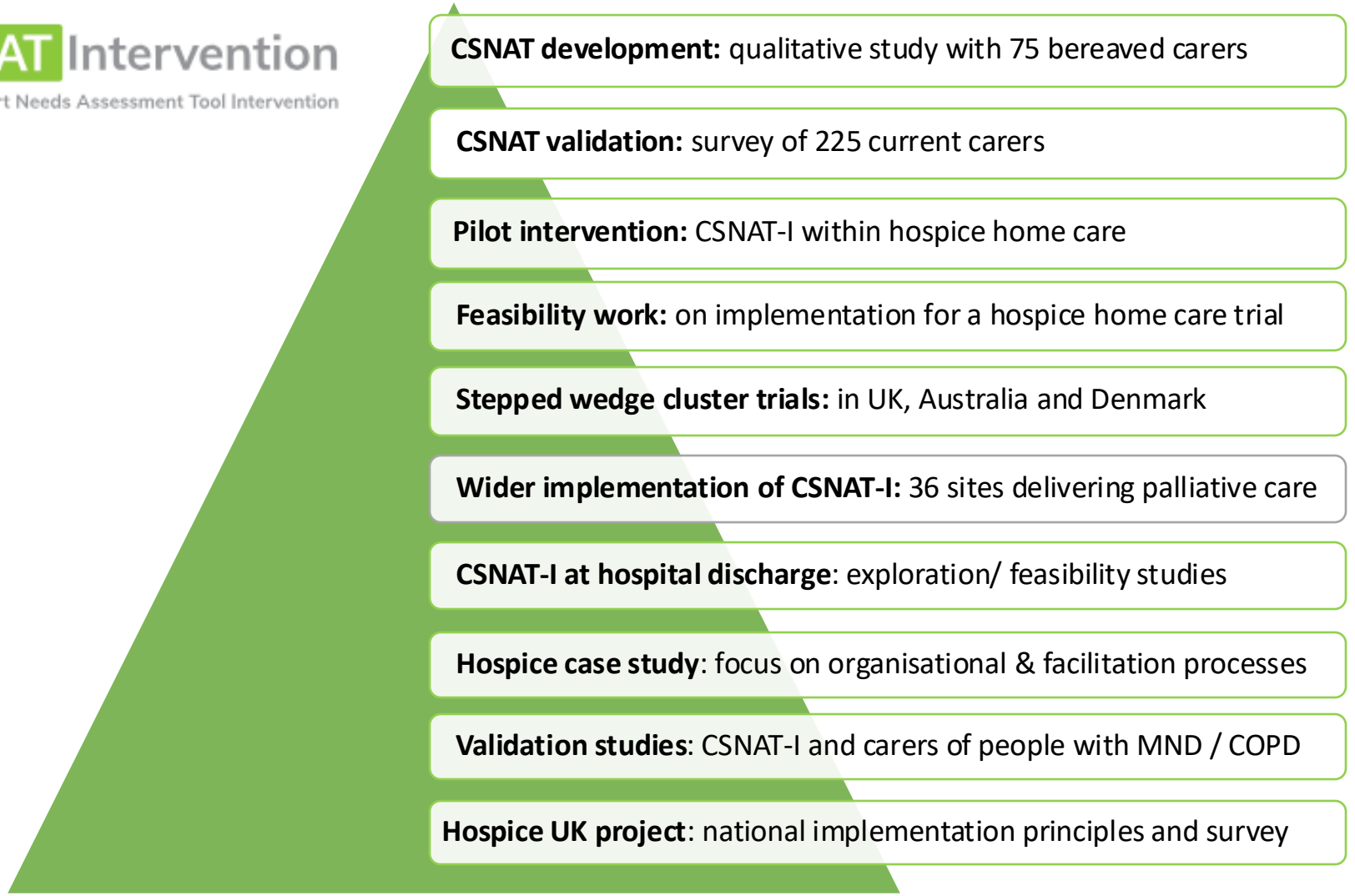
Do you need more support with...	No	A little more	Quite a bit more
1 ...understanding your relative's illness?			
2 ...having time for yourself in the day?			
3 ...managing your relative's symptoms, including giving medicines?			
4 ...your financial, legal or work issues?			
5 ...providing personal care for [illegible] relative (eg dressing			

The intervention uses an evidence based, comprehensive tool (CSNAT) to help carers **start a conversation about their support needs** with practitioners. The intervention is facilitated by practitioners but it is **carer-led**.

2. Developing CSNAT-I to support carers

CSNAT Intervention

Carer Support Needs Assessment Tool Intervention



MANCHESTER 1824 The University of Manchester

UNIVERSITY OF CAMBRIDGE

UEA University of East Anglia

Developing the CSNAT questions – we asked carers

Your support needs

We would like to know what help you need to enable you to care for your
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
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?			

Hospice care

- 75 carers: to identify support needs and shape tool
- Tested with 225 carers

Long term conditions

- Validated with 33 MND carers;
- 11 COPD carers
- Literature review in COPD

Broad areas of support need (domains) on the CSNAT

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

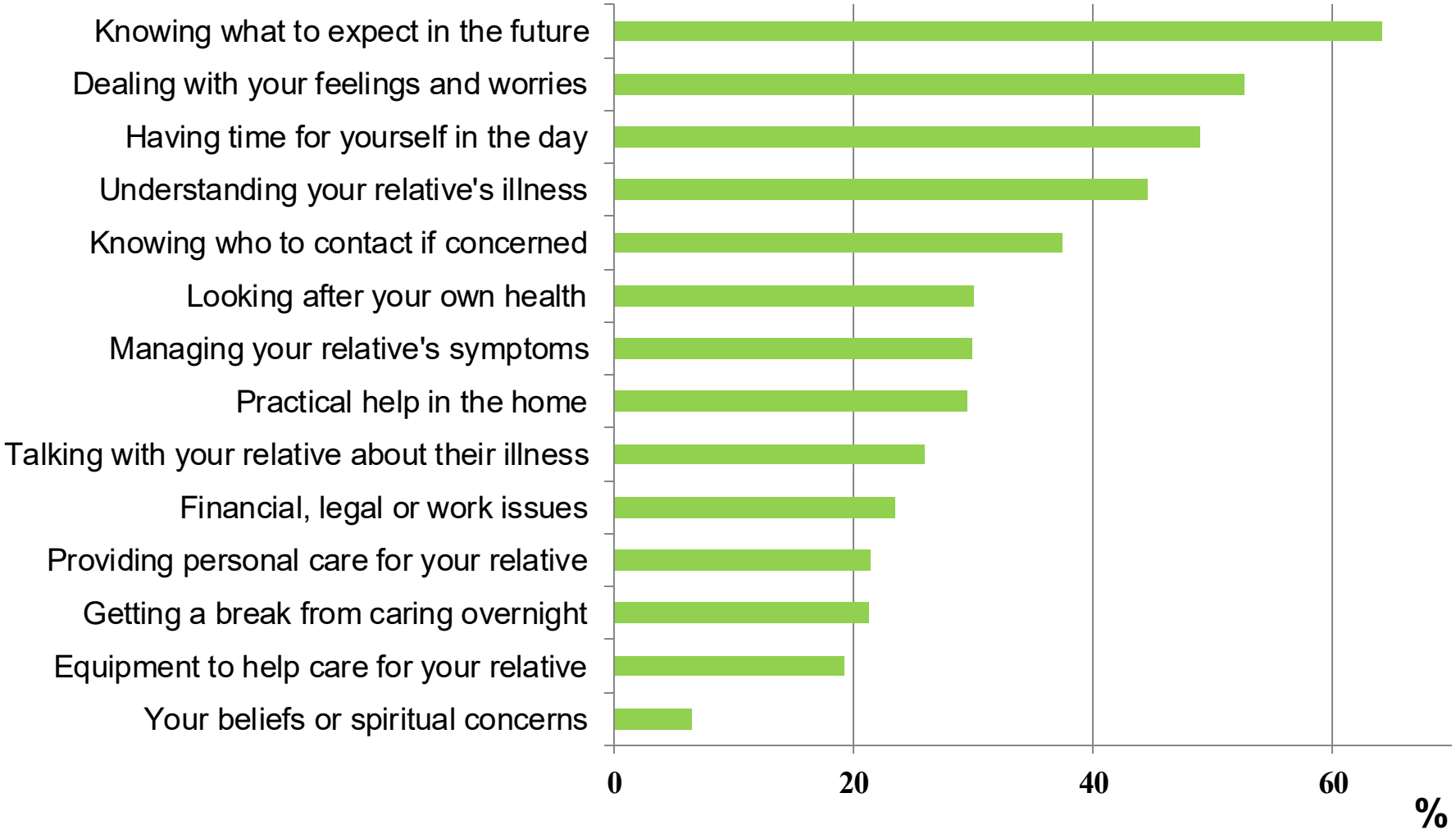
Long Term Conditions:

Managing relationships

Ewing & Grande, 2013; Ewing et al, 2013; Micklewright & Farquhar, 2020; Ewing et al 2020; Micklewright & Farquhar, 2022

Which domains come up most often?

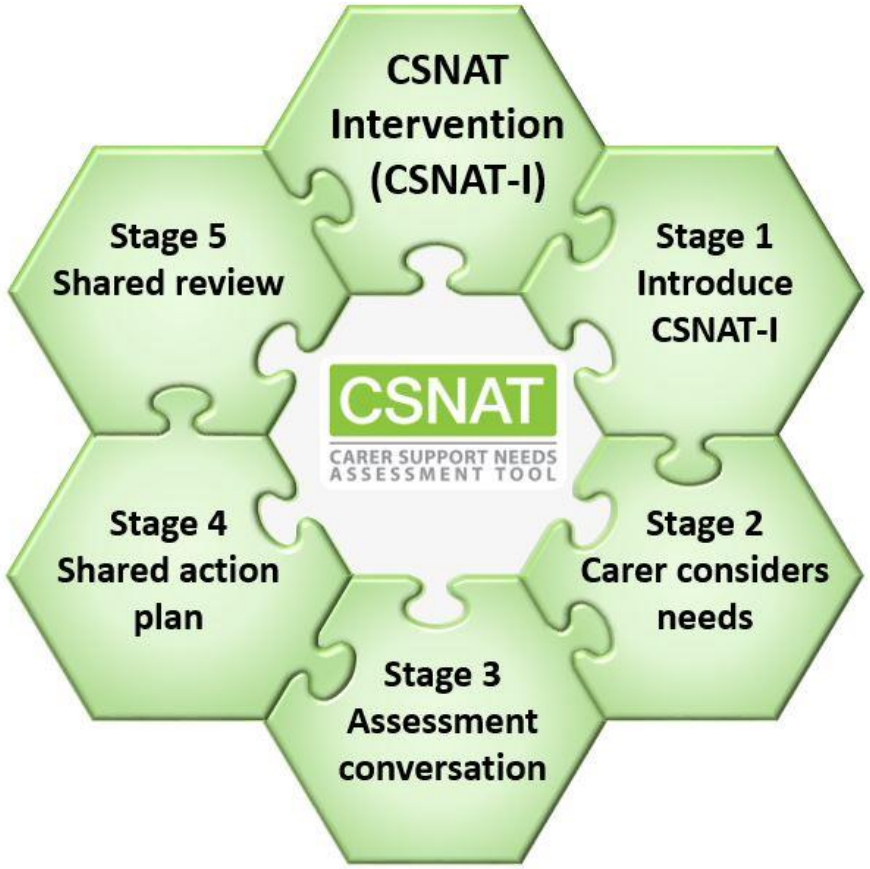
Testing of CSNAT domains with N=225 carers



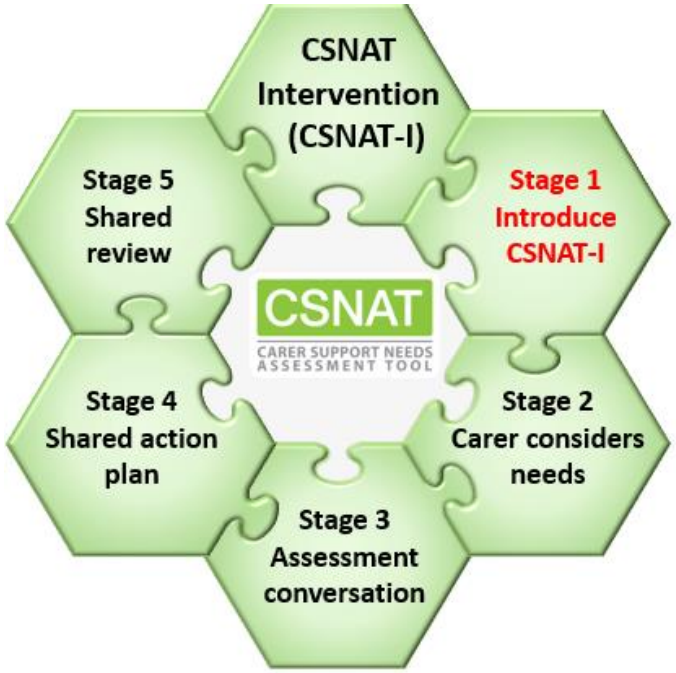
Content validity: all items used, no items missing

How do we develop an effective process for assessing and addressing carers' support needs?

- A tool on its own is of little use



Stage 1: Introduce CSNAT-I



*'..now, can we have a few minutes to talk about […] what help that **you** need'*
(UK H@H practitioner 1)

..this is about you

Stage 1: Introduce CSNAT-I

User friendly A5 folded booklet

The 'About you' booklet

- No need to use the term 'tool' or 'CSNAT'
- Doesn't refer to the person as a 'carer' or 'caregiver', a term they may reject.

  "I wasn't really his carer, I was his wife"

It is important that carers realise that this is the start of a process of support that will include a discussion with a practitioner.

Enables carers to see their needs as legitimate

"I was constantly looking after my wife, and that was it, my needs were second and I never approached them and say: 'look I'm struggling here'. I would just dismiss it and carry on" (Carer, HUK)

"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)

Carer support normalised as ‘routine’ care

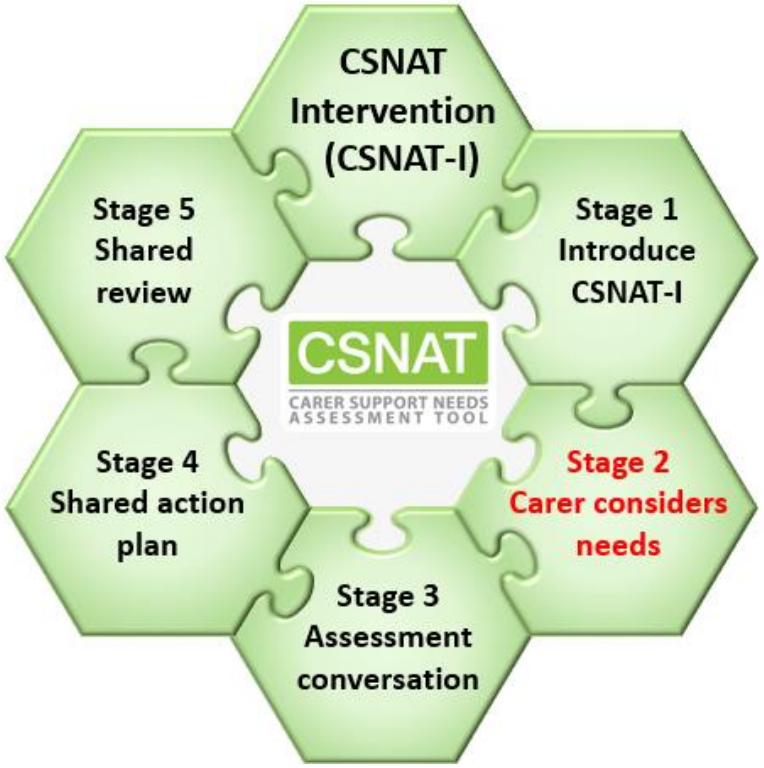
Project with carers of people with MND/ ALS:

Would you like to have CSNAT as a carer-held document?

Carers’ response: No!

“Important that it is introduced by practitioners as a routine, ‘legitimate’ part of care”

Stage 2: Carer considers needs



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 needs at the moment.

Do you need more support with...	No	A little more	Quite a bit more	Do you need more support with...	No	A little more	Quite a bit more
1 ...understanding your relative's illness?				9 ...looking after your own health (physical problems)?			
2 ...having time for yourself in the day?				10 ...equipment to help care for your relative?			
3 ...managing your relative's symptoms, including giving medicines?				11 ...your beliefs or spiritual concerns?			
4 ...your financial, legal or work issues?				12 ...talking with your relative about his or her illness?			
5 ...providing personal care for your relative (eg dressing, washing, toileting)?				13 ...practical help around the home or elsewhere?			
6 ...dealing with your feelings and worries?				14 ...knowing what to expect in the future when caring for your relative?			
7 ...managing relationships?				15 ...getting a break from caring overnight?			
8 ...knowing who to contact if you are concerned about your relative (for a range of needs including at night)?				16 ...anything else? (please write in)			

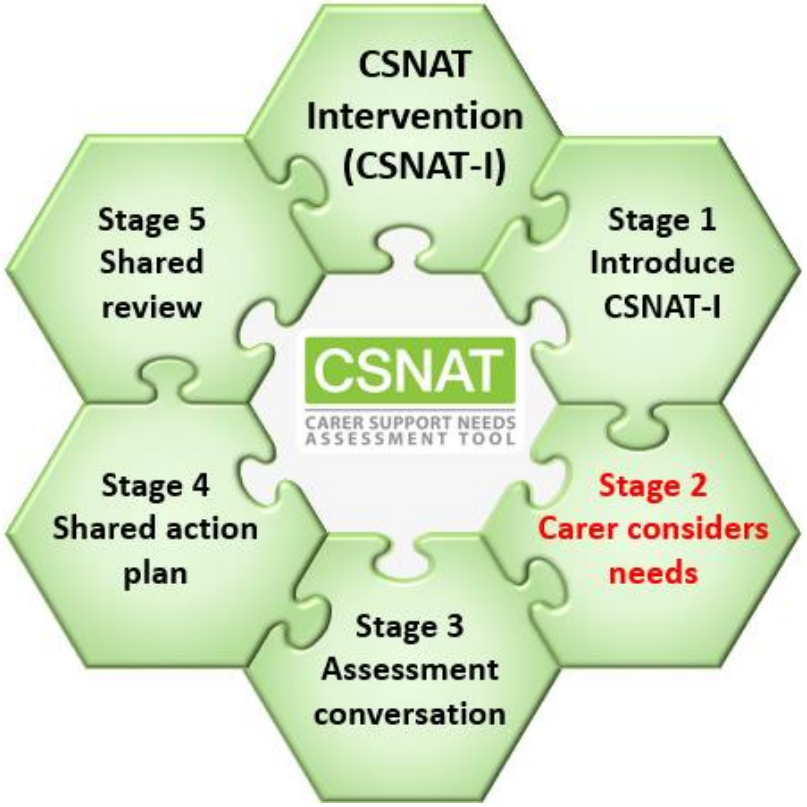
*Please consider which of the above you **most** need support with at the moment. A practitioner will then be able to discuss these support needs with you.*

The tool (CSNAT) is on the inside of the 'About you' booklet

- 15 evidence-based questions
- An 'anything else' section
- provides visibility of broad areas of support need that carers have
- helps carers structure their thoughts

"You think, right, I'm going to sit and have a look at this, just for five minutes, tick it off or make little notes, and then speak to them the next time they come." (UK carer)

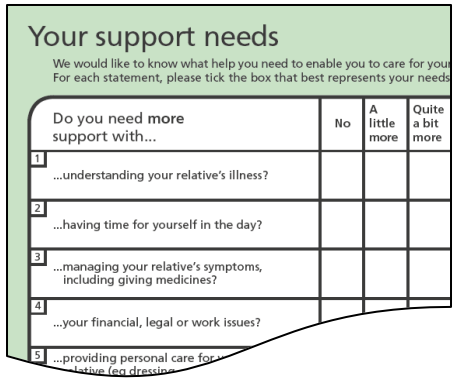
Stage 2: Carer considers needs



'Often the carers are presenting in a stressed and rather chaotic state and ask for help but don't know what help they want. I always give the CSNAT to the person prior to the meeting so they can self-reflect on their situation and feedback has been that this is very helpful.'
(UK Hospice Practitioner)

Helps carers gather thoughts and express needs

Having a ‘Visual aid’


Your support needs

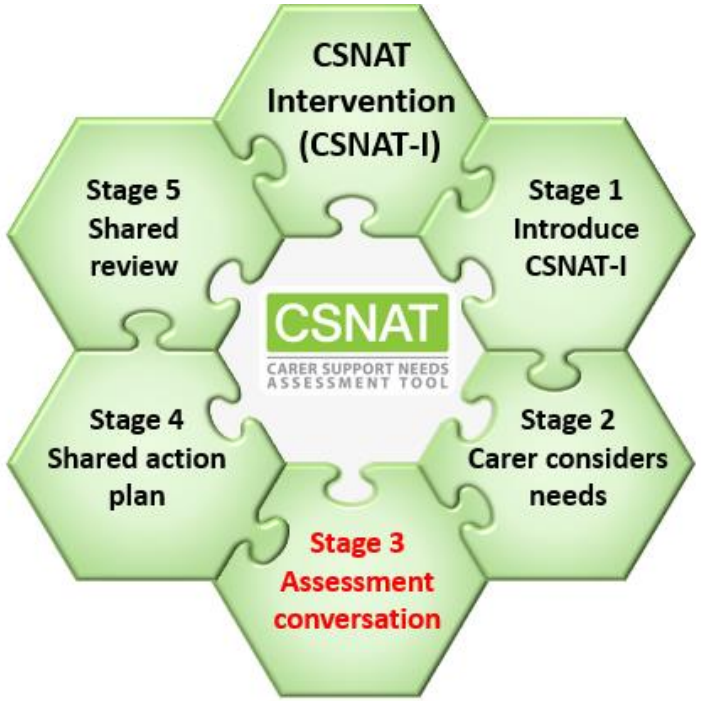
We would like to know what help you need to enable you to care for your
For each statement, please tick the box that best represents your needs

Do you need more support with...	No	A little more	Quite a bit more
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?			
5 ...providing personal care for			

“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...” (Carer)

“And quite often in that kind of situation it is ‘oh I don’t know what I want’, you know, they can’t focus, but the CSNAT allows them to focus on that... (HCP)

Stage 3: Assessment Conversation



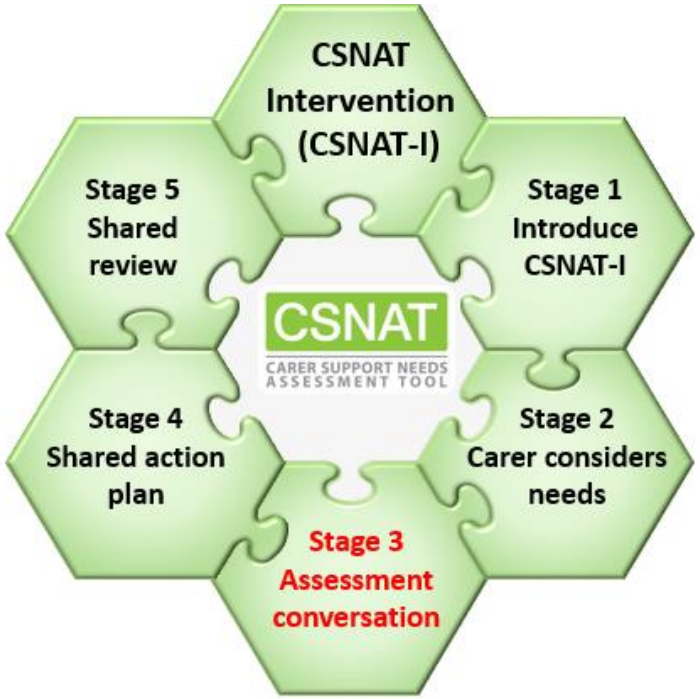
Prioritised domains are the focus of the conversation

Intention is **NOT to discuss all tool domains**

The carer's ***individual support needs*** in each of the prioritised domains are explored

The carer is given the opportunity to say ***what they would find helpful*** *in meeting these needs*

Stage 3: Assessment Conversation – carer centred

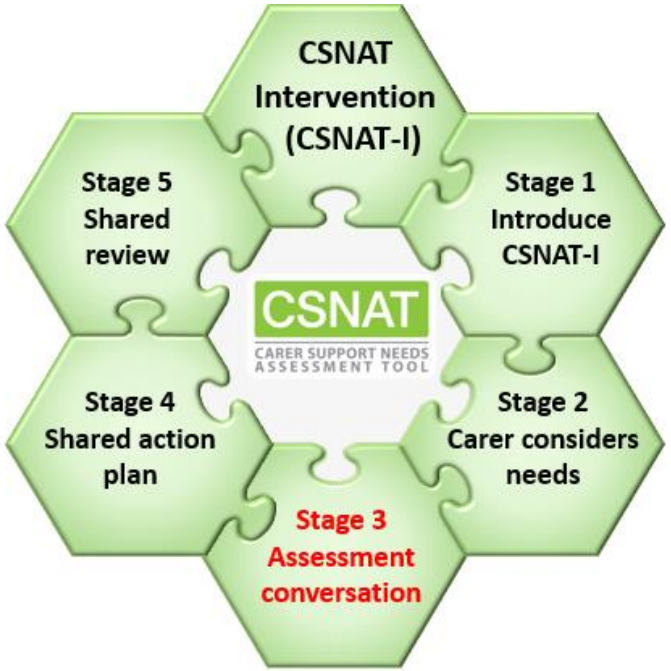


Focuses on carer's own priorities

'For me as a practitioner it allows me to gather all of the carers concerns and then ask them to prioritise what they want to explore/discuss further'
(UK Hospice practitioner)

'One important experience is that the domains indicated by the carers as most important, are quite often different from the ones that we as health care providers expected beforehand.'
(Norwegian Hospital practitioner)

Stage 3: Assessment Conversation – carer centred



Identifies carer's *individual* needs

A carer may have ticked on the tool that they need more support e.g. with the domain 'managing your relative's symptoms including giving medicines'

It is during the conversation that the carer's specific, individual support need is discussed - eg for one carer - to understand more about the meaning of changes in the patient's breathing, for another carer – to have more information on the patient's prescribed medication.

Stage 3: Assessment Conversation – carer centred

‘One size does not fit all’

How to move/ turn patient in bed

Strain of being the only person patient allows to help

Incontinence and soiling

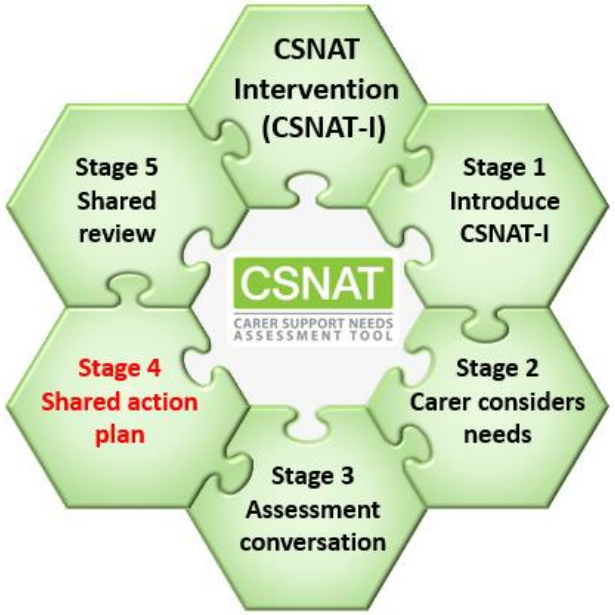
Domain: Support with personal care

Understand changes in mobility as disease progresses

Be able to give a carer perspective on help with ADL

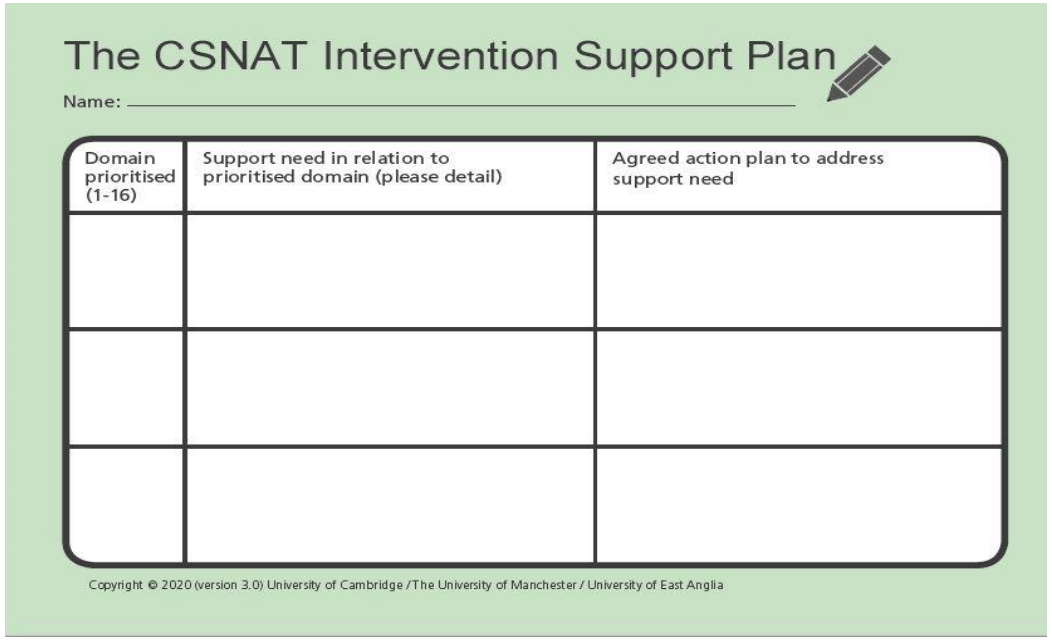
Ewing et al (2020)

Stage 4: Shared Action Plan - what carers find helpful



'.. it's quite complementary to the way we work as social workers as well, in identifying carer's support needs really and helping them to look at issues themselves and to come up with some solutions of their own too and I just find that's a very helpful way of working (UK CAS study 1)

The assessment conversation and action planning is recorded on a Support Plan on the back of the 'About you' booklet.



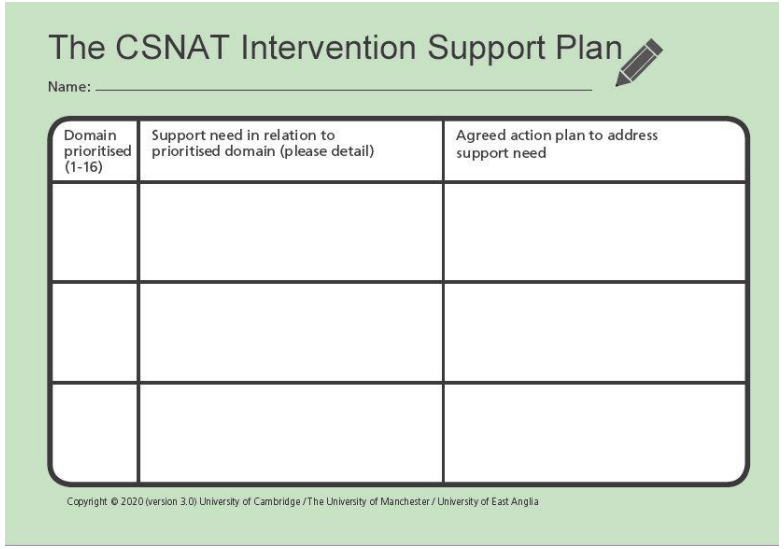
The CSNAT Intervention Support Plan

Name: _____

Domain prioritised (1-16)	Support need in relation to prioritised domain (please detail)	Agreed action plan to address support need

Copyright © 2020 (version 3.0) University of Cambridge / The University of Manchester / University of East Anglia

What types of supportive input might be provided?



The CSNAT Intervention Support Plan

Name: _____

Domain prioritised (1-16)	Support need in relation to prioritised domain (please detail)	Agreed action plan to address support need

Copyright © 2020 (version 3.0) University of Cambridge / The University of Manchester / University of East Anglia

Agreed actions to meet those needs

Friends/family help. Include how friends/ family could provide some support, e.g. getting a short break in the day, help with practical tasks.

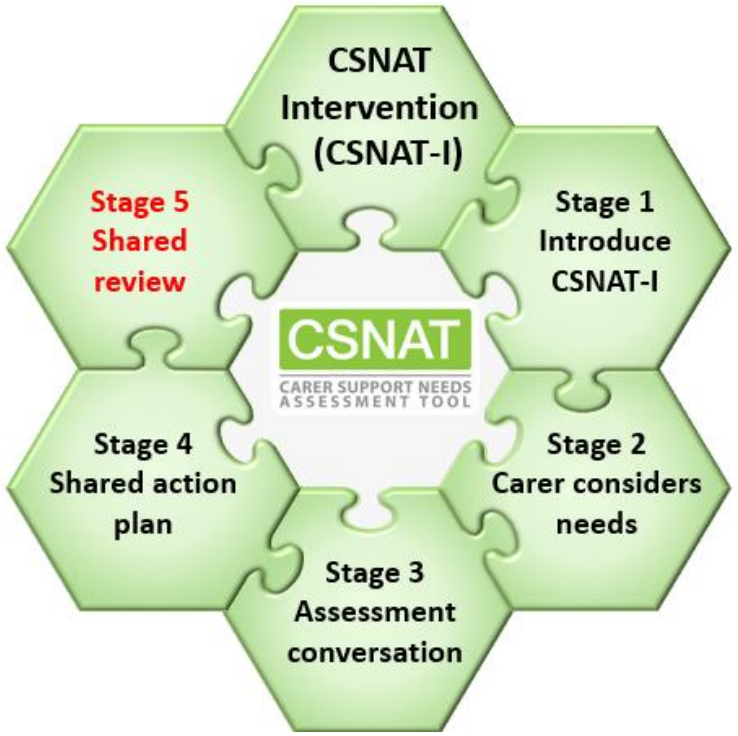
Support directly delivered by you at the time of the assessment conversation: 'active listening', providing reassurance, giving some general information, offering specific advice or providing some educational input.

Most often used: remember to add to the plan

Signposting. Not all support can, or has to be, provided by you or your organisation. Signposting leaves the carer to make contact themselves.

Referral on. In some instances, you will need to facilitate further support for the carer by referring them (with their consent) to another service internally or external to your organisation.

Stage 5: Shared review – because needs change

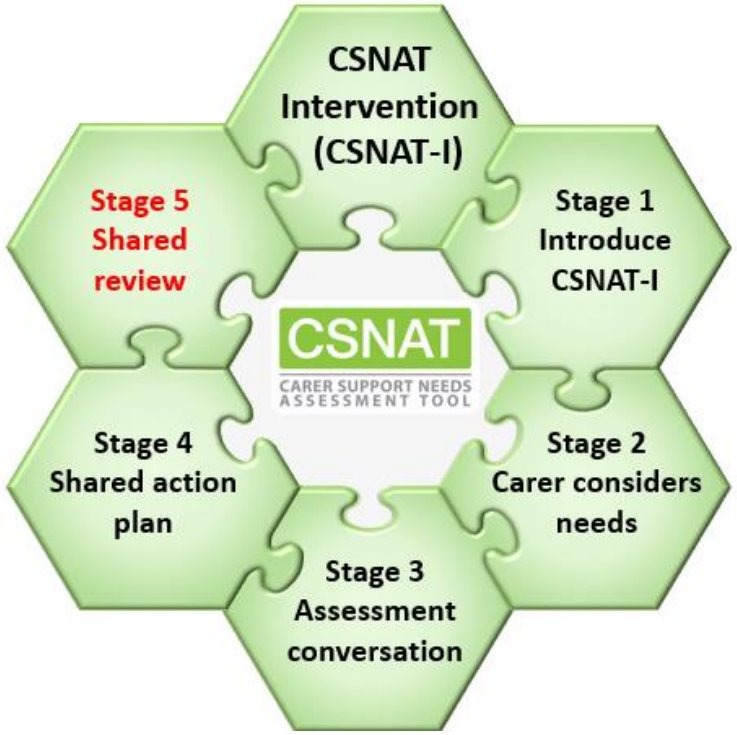


Carers' support needs are constantly changing and need to be reviewed

Two ways:

- **review of effectiveness** of the action plan (and updating support provided as necessary)
- **full reassessment process**
  - key trigger points (responding to changing situation for patient or carer)
  - after a defined period of time

Stage 5: Shared review



..requested by carers

'… that is something that's come up in the carers' support group, the carers that attend that have said […] "we would welcome being able to redo a carer's support assessment form or have a review of our needs", so that's something that's come up, so the review part of it, I think it gives it more structure, that actually you are offering the review and creating the support plan.

(UK CAS study 4)

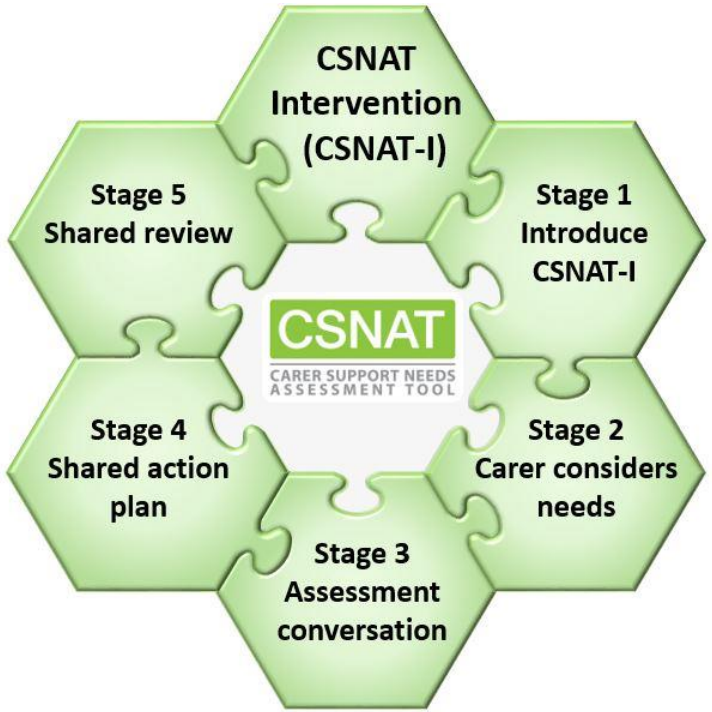
The CSNAT intervention for carers

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
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				



The CSNAT Approach Support Plan

Name: _____

Domain prioritised (1-15)	Support need in relation to prioritised domain (please detail)	Agreed action plan to address support need

Copyright © 2016-19 v2, The University of Manchester and University of Cambridge

Key principles of the CSNAT-I process

- CSNAT: consistent and comprehensive domains
  - So problems are not missed
- Introduction: ‘About you’, part of routine care
  - So carers feel it is legitimate to talk about needs
- Consideration: visible domains and time to reflect
  - So carers can organise thoughts
- Assessment conversation: focus on carer priorities and perspectives
  - So carers can tell us what their prioritised, individual support needs are and what supportive input may help
- Action plan: shared solutions
  - So response is tailored to carers’ prioritised support needs
- Shared review: ensuring meaningful follow up
  - As carers’ situation can change

3: CSNAT-I Benefits and outcomes

Australia (RCT) [1]

Significant **reduction in caregiver strain** while caregiving

Denmark (RCT) [2]

Significant **improvements in carer satisfaction** and **reduced carer distress** while caregiving

UK (RCT) [3]

Significantly **lower levels of early grief** and **better psychological and physical health** in bereavement

Sweden (Pre-post design) [4]

Significantly increased **preparedness for caregiving**

(1) Aoun et al, 2015; (2) Lund et al, 2020; (3) Grande et al, 2017; (4) Norinder et al 2023

Reflected in what carers have said about CSNAT-I

- Helps identify and express support needs
- Enables necessary reflection
- Provides validation, reassurance, empowerment

RECOGNISES THE IMPORTANCE OF THE CARER

'[CSNAT-I] is fantastic as the carer is recognised. Often the carer is forgotten and if the carer "goes down", the patient suffers.'

Aoun et al (2015b). Palliative Medicine; 29(6): 508-517. doi: 10.1177/0269216314566061

Practitioners told us that CSNAT-I ...

.. provides a holistic and consistent approach

.. enables more inclusive and open communication

*.. gives carers **permission** to reflect on their situation*

.. facilitates conversations between patient and carer

.. helps with equity of support provision by the organisation

.. facilitates ACP conversations

PERMISSION TO ASK FOR HELP

'The reassurance that you're not the only one, it's not selfish to ask for help for yourself. If you see other people doing it then it's okay to do it yourself sort of thing.' (2)

A STARTING POINT FOR A CONVERSATION

'I have to figure out for myself what's important to me. So, I think it kind of felt good to have that structure like that.' (3)

A JOINT EFFORT

'It's discussion, you know, and we'll find the answer together, it's not me finding the answer, it's not you finding the answer, we'll work together & we'll find the answer.' (1)

(1) Australia study; (2) UK study; (3) Swedish study

4: Implementation in practice – key elements

Training of practitioners

Organisational preparation

Implementation planning

Supportive Networks

Training: Individual and organisational

- CSNAT-I is a change in practice

CSNAT-I Training and Implementation Toolkit

Everyone using CSNAT-I

Learning Unit 1

Individual level: training for practitioners to use the CSNAT Intervention

Learning Unit 2

Organisational level: assistance for a team to plan, pilot and sustain implementation

Implementation team

https://arc-gm.nihr.ac.uk/training/register

Organisational preparation

People needed for planning and implementation

Support from Senior Management – to enable TIME and RESOURCES for carer support

A CSNAT-I ‘Implementation Team’ – to lead and oversee implementation in practice

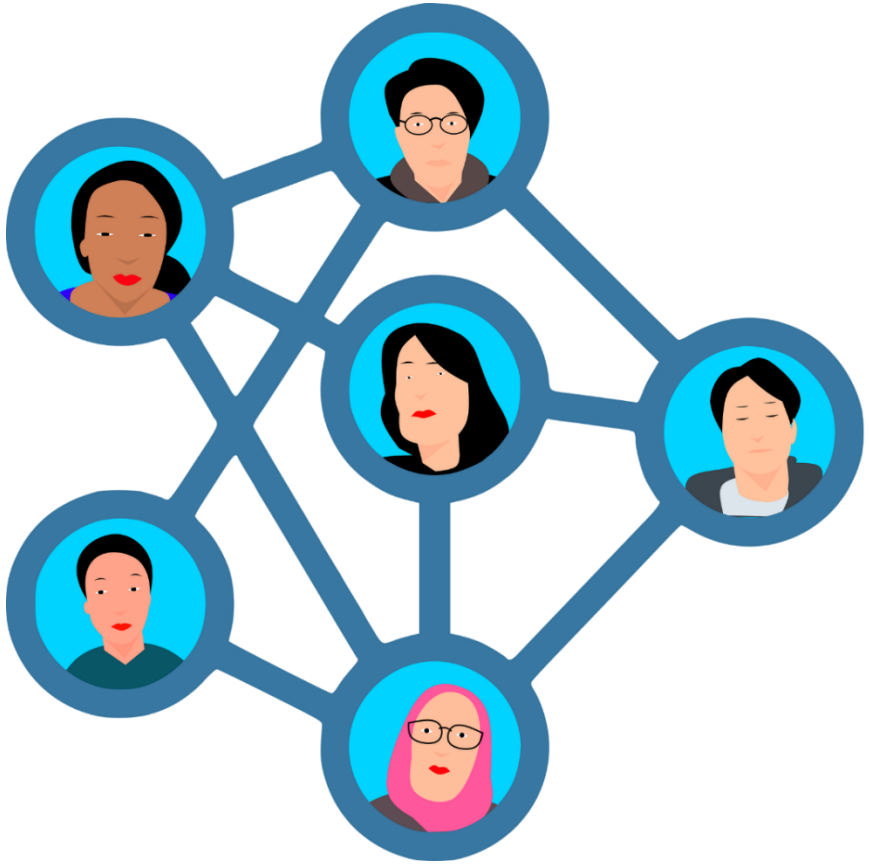
CSNAT-I ‘Champions’ to act as role models, problem solvers to support practitioners using CSNAT-I

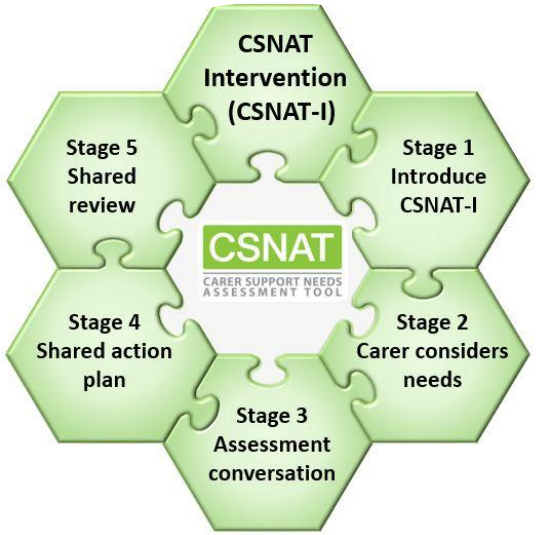
Implementation Planning

- Implementation does not ‘just happen’ – need to be proactive
- A clear plan for how each CSNAT-I step will work in practice that ***fits with organisational routines***

Stages of The CSNAT Intervention	
Introduction to carer	**When; Where** **Who by**
Carer consideration of needs	**When** will carers be able to do this?
Assessment conversation	**When** will it happen, **How**, **Who** will complete
Action planning	**Who by** **How** will input be recorded?
Shared review	**What** are key trigger points for pro-active review

Supportive networks

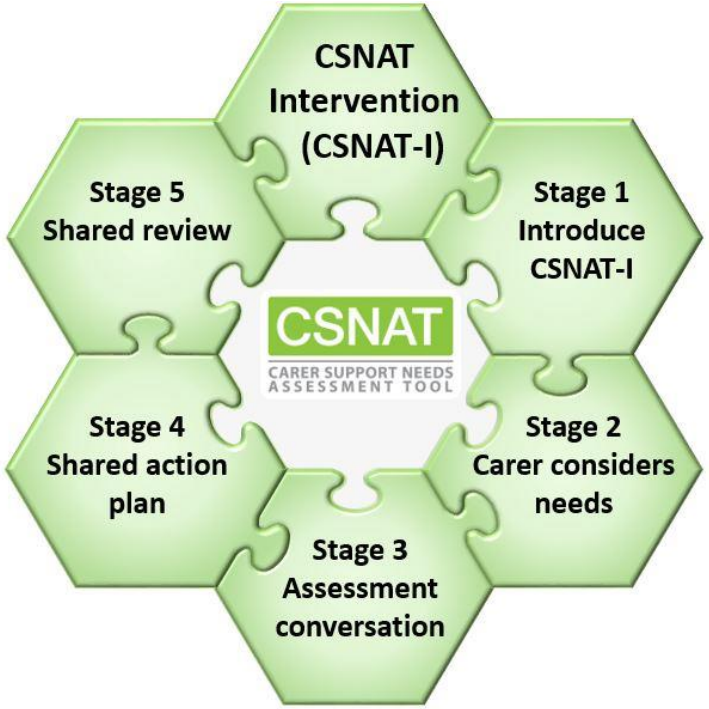




- Post-training sessions to support implementation in practice
- Building a wider network of support for CSNAT-I

Image by mohamed Hassan from Pixabay

Summary: key points to remember



- CSNAT-I is more than an evidence-based tool, it is a **practice intervention**
- CSNAT-I is a new way of working that is **practitioner facilitated but carer-led**.
- Its impact derives from the **person-centred process** used for assessment and support
- **Planning** is key to successful implementation in practice

Information on our website https://CSNAT.org

The Carer Support Needs Assessment Tool Intervention (CSNAT-I)

Enabling tailored support for carers in everyday practice

What is the Carer Support Needs Assessment Tool Intervention (CSNAT-I)?

CSNAT-I is an intervention for supporting carers (family members/friends in an unpaid supportive role), delivered using a five-stage person-centred process of assessment and support. The intervention uses an evidence-based, comprehensive tool (the CSNAT) comprising 15 domains (broad areas of support need). The tool enables carers to identify, express and prioritise domains where they need more

CSNAT Licensing

The CSNAT (the tool itself) is protected by copyright, held by the Universities of Cambridge, Manchester and East Anglia. Therefore, a licence is required for all uses of the tool.

Register for the Training and Implementation Toolkit

The Toolkit is available free of charge and has CPD endorsement so practitioners can gain professional accreditation. The Toolkit is hosted by NIHR ARC Greater Manchester

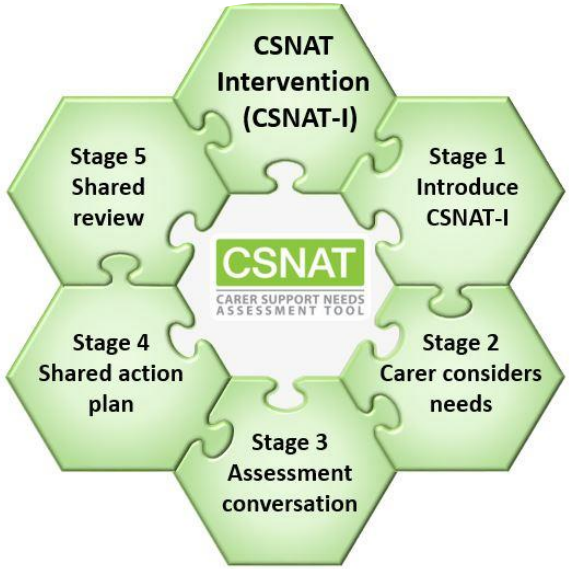
Site funded by NIHR ARC Greater Manchester and NHS England

References

- Ewing G, Grande GE. Development of a Carer Support Needs Assessment Tool (CSNAT) for end of life care practice at home: a qualitative study. Palliat Med 2013; 27: 244-256.
- Ewing G, Brundle C, Payne S, Grande G. The Carer Support Needs Assessment Tool (CSNAT) for Use in Palliative and End-of-life Care at Home: A Validation Study. J Pain Symptom Manage 2013: 46: 395-405.
- Aoun SM, Grande G, Howting D, Deas K, Toye C, Troeung L Stajduhar K Ewing G. The Impact of the Carer Support Needs Assessment Tool (CSNAT) in Community Palliative Care Using a Stepped Wedge Cluster Trial. *PLoS One* 2015; 10(4):e0123012
- Aoun S, Deas K, Toye C, Ewing G, Grande G, Stajduhar K. Supporting family caregivers to identify their own needs in end-of-life care: Qualitative findings from a stepped wedge cluster trial. Palliat Med 2015, Vol. 29(6) 508–517
- Ewing G, Austin L, Diffin J, Grande G (2015). Developing a person-centred approach to carer assessment and support. British Journal of Community Nursing; 20(12): 580-584.
- Ewing G, Austin L and Grande G. The role of the Carer Support Needs Assessment Tool (CSNAT) in palliative home care: qualitative study of practitioners' perspectives of its impact and mechanisms of action. Palliat Med. 2016 Apr;30(4):392-400.
- Grande GE, Austin L, Ewing G, O'Leary N, Roberts C. Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial. BMJ Supportive & Palliative Care 2017: 7 (3): 326-334. doi: 10.1136/bmjspcare-2014-000829. Epub 2015 Dec 30.
- Austin L, Ewing G, Grande G (2017) Factors influencing practitioner adoption of carer-led assessment in palliative homecare: A qualitative study of the use of the Carer Support Needs Assessment Tool (CSNAT). PLoS ONE 12(6): e0179287. https://doi.org/10.1371/journal.pone.0179287
- Ewing G, Croke S, Rowland C, Grande G. Suitability and acceptability of the Carer Support Needs Assessment Tool (CSNAT) for the assessment of carers of people with MND: a qualitative study. BMJ Open 2020;10:e039031. doi:10.1136/bmjopen-2020-03903
- Micklewright K & Farquhar M. Does the Carer Support Needs Assessment Tool cover the established support needs of carers of patients with chronic obstructive pulmonary disease? A systematic literature search and narrative review. Palliative Medicine 2020; 34(10):1305-15 DOI: 10.1177/026921632093924
- Micklewright K, Farquhar M. Face and content validity of the Carer Support Needs Assessment Tool (CSNAT), and feasibility of the CSNAT intervention, for carers of patients with chronic obstructive pulmonary disease. Chronic Illness. March 2021. doi:10.1177/1742395321999433.

Thank you

Any questions?



https://CSNAT.org