



UNIVERSITY OF
CAMBRIDGE

Ayrshire
Hospice
Making today matter

SPPC Workshop

**How can we best enable carers to
express their support needs and work
with them to provide the right support?**

Gail Ewing and Lynne Carmichael

What we are going to do today

- Why it is important to support carers
 - What do you do now in your practice?
- Survey and results from Ayrshire Hospice
- Introduction to the Carer Support Needs Assessment Tool (CSNAT) intervention
 - Domains, needs and supportive input
- Lessons learnt from implementing the CSNAT intervention in practice
- Implementing the CSNAT intervention in your practice

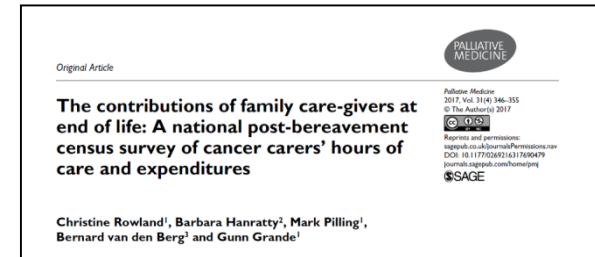
Importance of supporting carers

Majority of patients at end-of-life wish to die at home.
Family carers are essential but often feel
unprepared and unsupported.



69 hours and 30 minutes per week
caring for loved one during last three
months of life

Rowland et al. 2017; Pall Med 31(4), 346-355



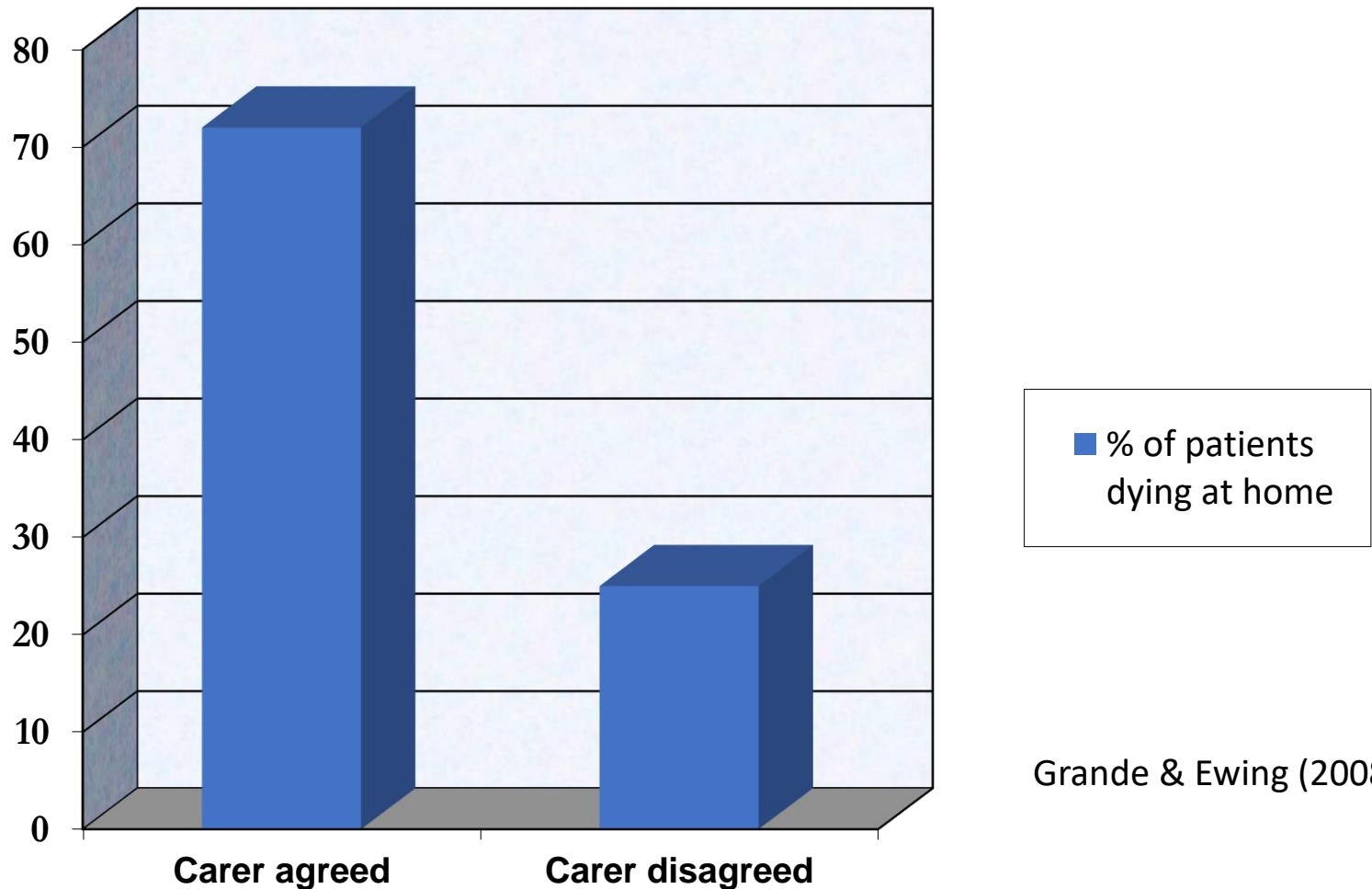
5-7 times more likely to have
psychological health problems than
general population

Grande et al. 2018; Pall Med 32(10), 1605-1614



Likelihood of dying at home

79% (201/255) patients wanted to die at home¹

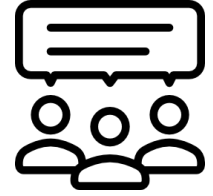


Grande & Ewing (2008)

What do you do now in your practice?

Activity 1

Group activity 1



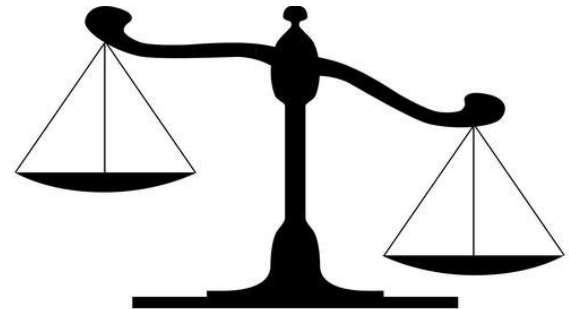
- **We'd like you to consider your existing practice**
- Work in pairs
- 5 minutes to write some notes on the activity sheet
 - The ways in which you currently identify carers' support needs at the moment
 - What works well; what works less well?
 - Who leads the process?
 - Where is the information recorded
 - Are carers aware you are identifying their support needs?

Feedback from groupwork



How do you currently become aware of patients' and carers' support needs in your everyday practice?

What are the positives and limitations of your existing practice?



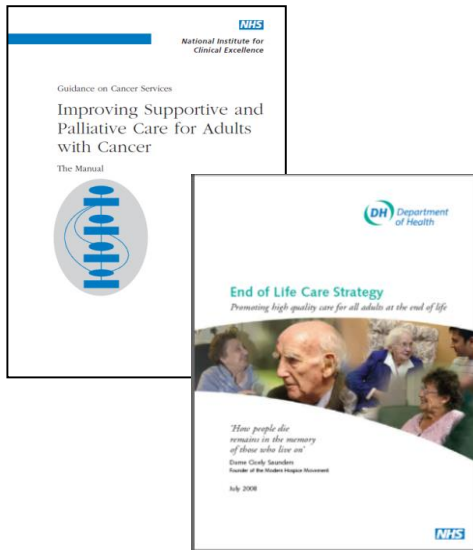
Baseline survey – Ayrshire Hospice

1. What is your profession?
2. Who and how would you define a carer?
3. Do you assess carers needs as part of your role?
How do you do this?
4. Do you document this assessment?
Where?
5. Do you formulate a plan of action for the carer after this assessment?
6. Do you think the carer is aware you are assessing their needs?

Survey results

- Survey sent to - Family Care; Medical team; Nursing; SPCN's, AHP's and Care Assistants.
- Most clinical staff were able to determine who would be classed as a lay carer/ family caregiver.
- All see carer's assessment as part of their role.
- Not a consistent approach,
- No formal assessment or documentation.
- We refer on to other agencies when we identify a carer related issue.
- Agreement that as an organisation we needed to do more to identify and support the needs of carers.

Why did we need a carer intervention?



- 2008: Need to assess and support carers in UK EOLC policy
- No clear guidance on how to do this

No suitable existing tools

Research tools

- longer term care context
- indirect measures
- lengthy 'needs' measures

Practice 'assessment'

- Informal and ad hoc
- Limited or no reference to research literature
- Little consensus on areas assessed

Bridging the research-practice gap

Programme of research and implementation



CSNAT development: qualitative study with 75 bereaved carers

CSNAT validation: survey of 225 current carers in hospice home care

Pilot intervention: CSNAT within hospice home care practice

Feasibility work: on implementation for a trial in hospice home care

Stepped wedge cluster trials: in UK and Australia

Wider implementation: 36 sites delivering palliative care

Hospice case study: focus on organisational and facilitation processes

CSNAT at hospital discharge: qualitative exploratory study HCPs and carers

MND study: suitability of CSNAT intervention for carers of MND people

Feasibility study: CSNAT at hospital discharge with community follow up

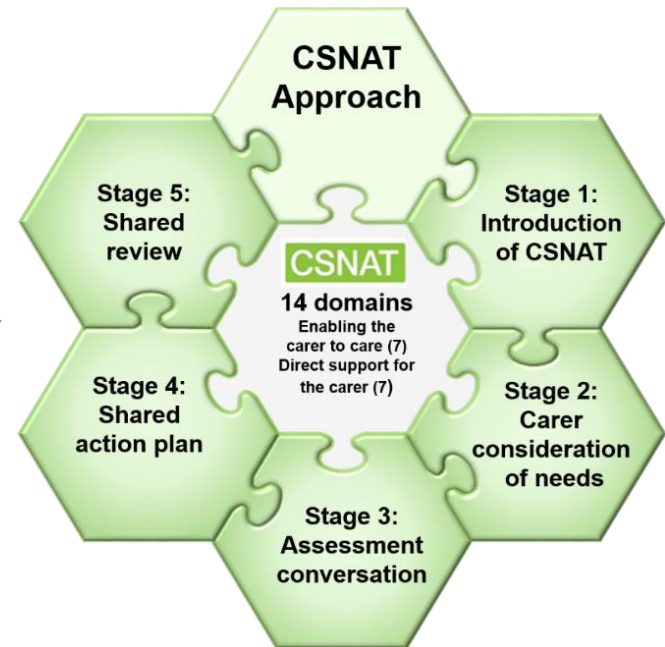
Hospice UK project: national implementation principles and survey

The CSNAT intervention for practice

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				



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.

CSNAT development: listening to 75 bereaved carers



CSNAT: 14 Domains

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

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

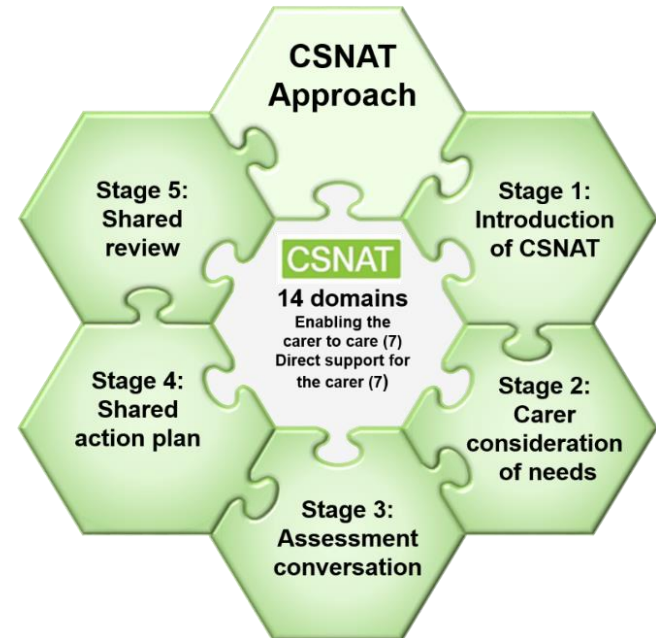
Overnight break from caring

An intervention not just a tool

Your support needs

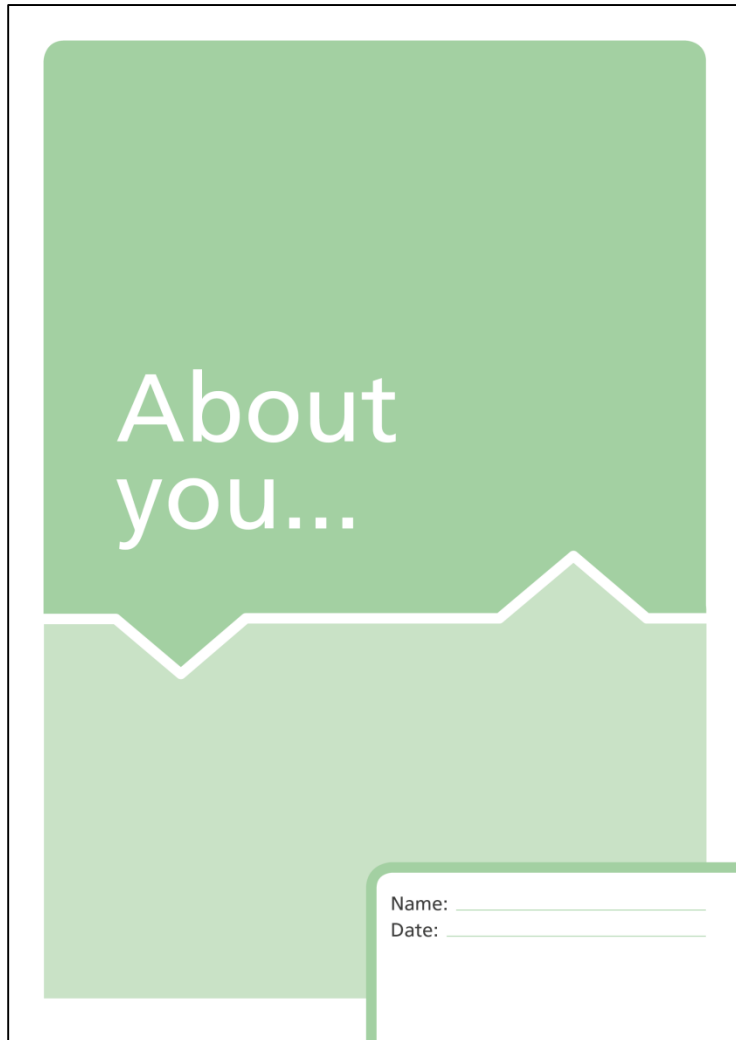
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As a practice intervention, the CSNAT (the tool itself) is integrated into a five stage, person-centred process of assessment and support that is practitioner facilitated but carer led.

About you ...

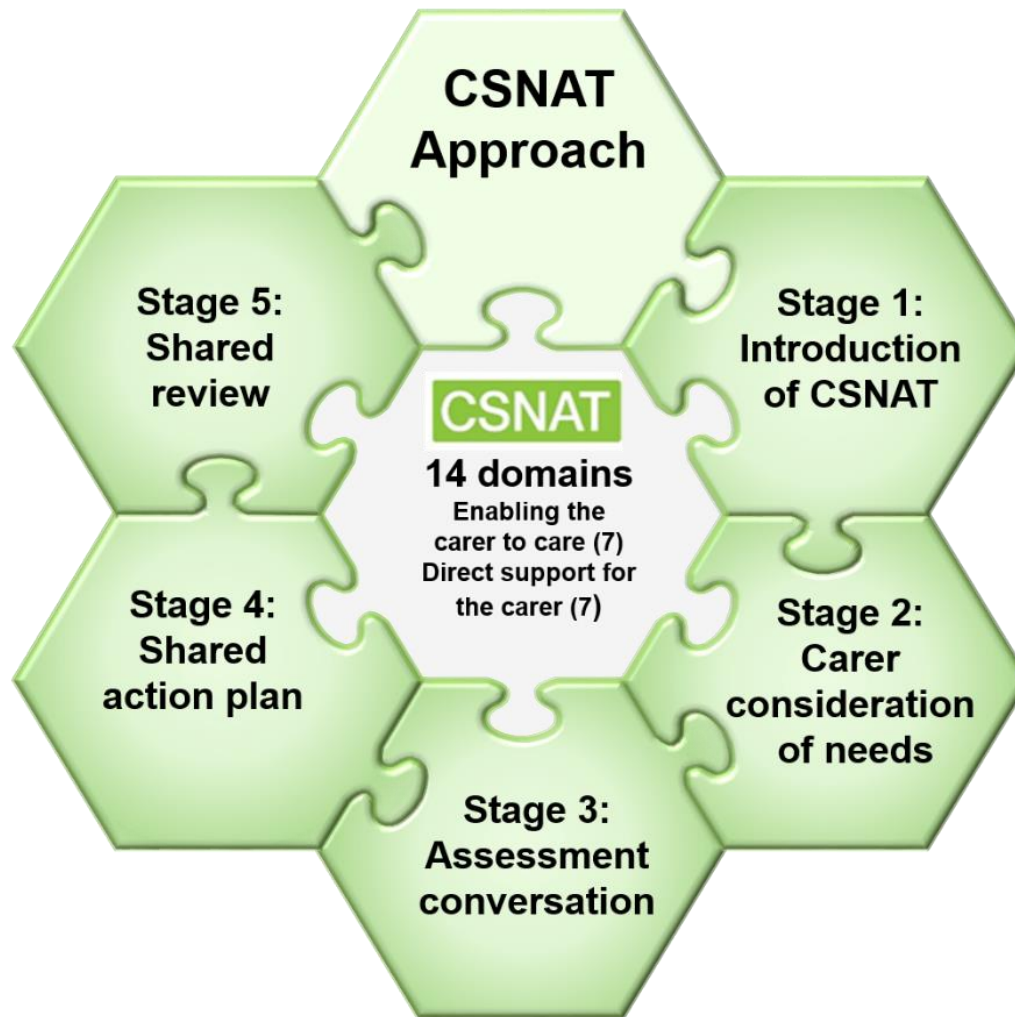


About
you...

Name: _____
Date: _____

How the CSNAT is
introduced is key

**The message to convey
is that the CSNAT is a
conversation starter
not a “questionnaire”
not a “form”**



**This is a change from usual practice which
requires training**

Trials of the CSNAT Approach

RESEARCH ARTICLE

The Impact of the Carer Support Needs Assessment Tool (CSNAT) in Community Palliative Care Using a Stepped Wedge Cluster Trial

Samar M. Aoun^{1*}, Gunn Grande², Denise Howting¹, Kathleen Deas¹, Chris Toye¹, Lakkhina Troeung^{3,4}, Kelli Stajduhar⁵, Gail Ewing⁶

Significant reduction
in caregiver strain in
current carers

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



OPEN ACCESS

Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial

Gunn Eli Grande,¹ Lynn Austin,¹ Gail Ewing,² Neil O'Leary,³
Chris Roberts³

Research

How have carers found 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.” (Carer)

Provides visibility

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.”

(Carer)

Which were the top three domains of unmet needs?

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

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Having time for them themselves in the day

Overnight break from caring



The most common support needs



Shared action plan data from Ayrshire Hospice

- Not a 'fix it' approach: main supportive inputs from staff are explanation/guidance, information and active listening.

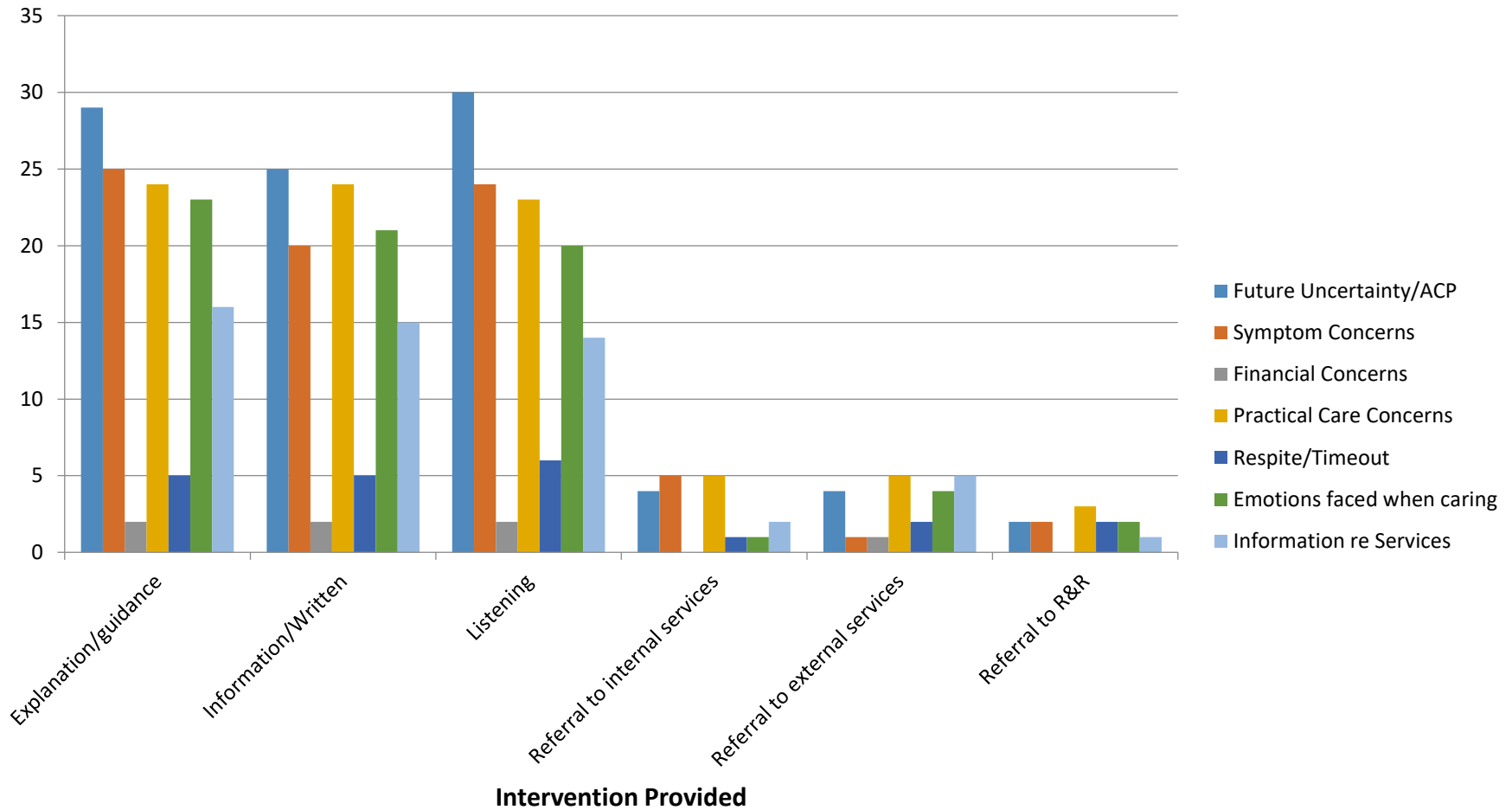
1. Explanation/ guidance – More of guidance on what to do specifically for that patient/carer. E.g. scan results explained. How a person's illness is progressing.

2. Information /written - General information – the same info could be given to anyone, another patient. Could be about services available generally or an overview about treatment. Could be a leaflet or written information.

3. Active Listening- also referred to as supportive listening. The value and appreciation of this often underestimated.

Prior to using the CSNAT Approach, the main action of the hospice team was to refer on to other services

Data from Ayrshire Hospice



Feedback from staff

- A CARER said: *"I'm delighted to be asked these questions; it shows someone cares about me"*
(carer)
- Very positive, very helpful. Relative actively sought me out to have follow up discussion. Could tell it was important to her. Said it was useful to have her husband's opinion on her health & stress when completing CSNAT.

Lessons learnt from implementing the CSNAT intervention in practice

Practitioners need training in using the intervention but services need to plan for implementation - **It doesn't 'just happen'**

Project facilitation group

- Nurse , Community background (project lead)
- Social worker, AHP and Family care
- Nurse, IPU charge nurse



KEY MESSAGE

Representation across all clinical areas

Six stages for project management



Key messages for success



- Time commitment - regular meetings of PF team
- Share the tasks amongst facilitation group
- Project management approach
- Identify champions with the right skill set
- Regular progress meetings with senior management
- Review and adapt in line with feedback from practitioners

Outcomes achieved

- Formal assessment of carers needs is highlighting stresses, concerns and worries much earlier in the patient/carer journey.
- Carers report that they feel listened to.
- A consistent approach
- It can help to structure a challenging conversation
- Evidence of carer support – documented on our electronic system

KEY MESSAGE

Defined pathways to ensure consistent practice

Staff Feedback

"Its like a structured listening tool"

" I would struggle not to use this approach (tool) as part of my every day practice"

"I feel using this tool promotes proactive practice – it highlights uncertainty early on and gives us an option to meet need"

"it definitely adds time to the visit but its time well invested"

The Carers (Scotland) Act 2016

Carer recognition

- Consistent approach
- Preventative basis- early stages of caring role
- Confidentiality issues – conflicts of interest between the carer and cared for person

Local authority responsibilities

- The definition of a carer
- A duty to prepare an adult carers support plan (for carers who are identified through assessment or on their own request)
- Duty to provide support
- Maintain advice and information services
- Involve carers
- Duty to prepare local strategies
- Duty to NHS boards to involve carers pre discharge from hospital

The CSNAT Approach Training and Implementation Toolkit

CSNAT | Carer Support Needs
Assessment Tool



The online training and
implementation toolkit consists
of two learning units

Learning Unit 1

Individual level: training for
practitioners to use the CSNAT
intervention



Learning Unit 2

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



[Further details on csnat.org](https://csnat.org)

Key strategies for implementation

- Get managerial support
- Develop a project facilitation team to lead on implementation
- Identify your 'champions'
- Project facilitation team complete the whole of the CSNAT toolkit
- All practitioners using the CSNAT complete training in its use