

# Department of Health Consultation: How can we improve support for carers?

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on 29<sup>th</sup> July 2016

This submission is based on a **robust programme of research** which has involved responses from over **1000 carers** across a range of studies and work with over **500 practitioners** on implementation of carer assessment and support throughout the UK. Our programme of work has been funded by Burdett Trust for Nursing, Dimbleby Cancer Care, the BUPA Foundation, Marie Curie Cancer Care, Hospice UK and NIHR. In the submission below we provide (1) an executive summary of key aspects of improving support for carers in relation to four of the consultation areas; (2) an outline of our research programme which informs our submission; (3) detailed feedback on each of the identified key aspects of improving support for carers; and (4) our recommendation for a separate focus on support for carers in palliative and end of life care.

## (1) Executive summary of key aspects of improving support for carers

### Area 1: Identifying people as carers

Family members and friends who support the patient are already known to healthcare professionals, but are not identified as 'carers' and recorded as such. There is a need to focus on this already known group:

- *Healthcare professionals may be best placed to identify carers through their work with patients*
- *Identification must be accompanied by maintenance of carer details and a separate carer record to enable systematic assessment and support*

### Areas 2 & 3: Providing information and advice; Services and other formal support for carers

Each of these consultation areas refers to different types of supportive input for carers. In order to deliver meaningful support, the following issues are key:

- *Carers have **two distinct roles** requiring different supportive input:*
  - To enable them to support the patient as effectively as possible (as 'co-workers')
  - To support themselves (as 'clients')
- *An individual rather than a generic approach to supporting carers is crucial*
  - One size does not fit all, carers differ substantially in supportive input required.

## Area 4: Valuing and involving carers when helping the person they care for

To enable this aspect of support, the involvement of healthcare professionals is crucial:

- *Carers prioritise their ‘co-worker’ role and need to be supported in this role:*
  - Social Care assessment only addresses carers’ support needs as ‘clients’ helping them maintain their social health and well-being, but healthcare input is required to meet their support needs as ‘co-workers’

### (2) Our research programme on carer assessment and support

Much of our research has focused on how to translate into practice health policy recommendations that carers’ needs should be ‘assessed and addressed’ within palliative and end of life care. The key aspects for improving support for carers identified above derive from our research programme. Building this robust evidence base has been accomplished through a longstanding collaborative relationship with the National Association for Hospice at Home and the active involvement of practitioners and carers at all stages of the research programme.

#### A systematic tool (the Carer Support Needs Assessment Tool (CSNAT))

Many tools provide indicators of carer difficulty such as burden or distress without identifying what supportive input is actually required. In contrast, CSNAT provides a **direct measure** of what supportive input carers need to manage their caring role.<sup>1</sup> Our research gathered views of more than **300 carers** showing that carers need two different types of input: support to enable them to support the patient and support to look after their own health and wellbeing. The CSNAT enables carers themselves to identify the areas in which they need more support: the questions asked are very acceptable to carers and the tool itself is feasible to use by practitioners because of its length (14 items) and simple screening format.<sup>2</sup>

#### A person-centred approach to assessment and support

Our research has clearly shown that carers’ support needs are very **individual** (‘one size does not fit all’), often not what practitioners expect, and that a carer-led approach is crucial. Based on practitioners’ feedback, we have defined a 5 stage approach that incorporates the CSNAT into a process of assessment and support that is practitioner facilitated, but carer-led giving clear guidance for using the tool in practice (the CSNAT Approach).<sup>3,4</sup>

#### Evidence of impact of the CSNAT Approach

The CSNAT Approach has been shown to have significant impact in two cluster trials, in Australia and in the UK, which involved over **900 carers**. Both trials showed beneficial effects: reduced carer strain while currently caring<sup>5</sup> and lower grief and better physical and psychological health post bereavement.<sup>6</sup> Our qualitative studies have obtained views of over 150 practitioners and managers. Identified benefits of using the CSNAT Approach include making it easier to express needs,<sup>4,7</sup> legitimising support for carers who are often reluctant to

accept help for themselves,<sup>4,7</sup> and providing practitioners with guidance and a structure to facilitate discussions with carers about their support needs.<sup>7</sup>

### A CSNAT training and implementation toolkit

Within current palliative care practice, no framework is used routinely to ensure a comprehensive, systematic assessment is offered to all carers. An important stumbling block for systematic support is the **lack of a separate carer record**. Thus we have developed and rolled out a one day CSNAT training workshop to introduce the evidence based CSNAT Approach to services and identify implementation considerations: planning processes, facilitation and organisational considerations, particularly around record keeping. Interest in provision of evidence based carer support is considerable, demonstrated by our work with more than 80 palliative care services including a series of training workshops for hospice services supported by Hospice UK.

## **(3) Detailed feedback on each of the identified key aspects of improving support for carers**

Our recommendations in the four consultation areas are based on our work over the last decade on support for carers in palliative and end of life care. The recommendations are likely to have relevance for any healthcare services supporting patients and carers in the last year(s) of life.

### **Area 1: Identifying people as carers**

- *Healthcare professionals may be best placed to identify carers through their work with patients*

Healthcare professionals are at the 'front line' of care and are therefore in a unique position to identify carers. There are considerable challenges in identifying carers in general, in part because most people do not identify themselves as being 'carers', but rather see themselves as husband/ wife, son/ daughter, friend etc. The most effective way of identifying 'carers' is therefore probably to ask patients to identify who their next of kin are who provide them with the most support. This identification of NOK/ carers happens regularly within palliative/ end of life care, as the remit of palliative care includes supporting family (in the widest sense) as well as the patient. However, it is likely to serve as a sensible route for identifying carers in other healthcare interfaces wherever there is a care dependent patient with cognitive capacity, and without family members having to label themselves as 'carers'.

- **Identification must be accompanied by maintenance of carer details and a separate carer record to enable systematic assessment and support**

#### **Maintenance of carer details**

Within palliative care services, the issue is not so much about identifying people as carers but about recording information about people who are already known to practitioners as carers, as in practice recording of this information can be very limited. The name may be recorded *within the patient record*, but it may only be a first name without any other details such as address, relationship or age. Neither do databases have full details about main carers, although patient details are recorded. Much could be gained in terms of identification of carers through completion of this information on existing systems.

#### **No separate carer record**

As carers are part of the 'unit of care' in palliative care services, they are often seen together with the patient. In current practice, identification of carers' needs is ad hoc and informal and if recorded, it is *within the patient record*. Lack of a carer record within palliative care represents a considerable hindrance if the Department of Health wishes to establish comprehensive, systematic assessment and support for carers in palliative and end of life care – a provision that is likely to have an impact on prevention of admission of patients to hospital at the end of life and on patients' choice home death.

#### **Data protection issues: recording carer details**

The large group of services we have worked with have identified the need for guidance on how to ensure proper recording of carer details and maintenance of a separate carer record, whilst negotiating data protection issues. This represents a significant barrier to ensuring that systematic carer assessment and support is documented. Rather than leaving individual services to resolve this difficulty on their own, national guidance is warranted, potentially from a national working group, focusing on this key issue.

### **Areas 2 & 3: Providing information and advice; Services and other formal support for carers**

These two areas are very much addressed by our research programme: carers with whom we have worked have highlighted the following as key to their support:

- ***Carers have two distinct roles requiring different supportive input:***

#### **Support to enable them to support the patient as effectively as possible (as 'co-workers')**

Carers of palliative patients are actively engaged in this aspect of their role, taking responsibility for a range of aspects of patient care. Different types of supportive input including 'upskilling' carers to fulfil this role more confidently and effectively are required,

not just signposting them to support available or involving them in planning, although the latter aspects are also very important. Much of this can be directly delivered by healthcare professionals, such as targeted information, reassurance and validation their care provision, explanations and advice or training to enable carers to care.

#### Direct support for themselves (as 'clients')

Carers also need support to preserve their own health and wellbeing. This may involve support from health care professionals directly, such as 'active listening' allowing carers to talk over feelings and worries. It can also include e.g. relief from caregiver responsibilities for a while, help with sorting out practical matters, which may be more likely to involve the introduction of services and other formal support services.

- *An individual rather than a generic approach to supporting carers is crucial*

A clear message that has come from carers throughout our programme of research is that **support should be tailored to their individual situation and needs**. There is a time and place for 'generic' information, but many booklets and leaflets given to carers go unread because they are not needed at that time, the information is already known or they don't address their particular concerns. Carers have also told us that input that is individualised is perceived as most supportive: e.g. someone to listen to their concerns at the visit, not referral to a counselling service; finding a way of getting a short break for a coffee in the garden, not necessarily a weekly respite visits for 2 hours.

#### Area 4: Valuing and involving carers when helping the person they care for

- *Carers prioritise their 'co-worker' role and need to be supported in this role:*

Standard social care assessment leaves a **clear gap** in carer assessment and support in palliative/end of life care. Carers' main support needs relate to support enabling them to support the patient, for instance understanding the patient's disease, its course and management, what to expect in the future and who to contact in a crisis. This requires brief, flexible healthcare-related information, advice and education to upskill carers as 'co-workers'. Carers also need support for themselves as 'clients', for instance help with respite, their own physical health, work and finances, for which social care assessment would be appropriate. However, carers' well documented reluctance to express need for support to look after themselves may delay such social care assessment. The CSNAT addresses both aspects: enabling healthcare practitioners to support carers as 'co-workers', whilst proactively identifying needs as 'clients' that may e.g. facilitate early social care assessment.

#### (4) A separate focus on support for carers in palliative and end of life care

Our submission has addressed support for carers in the **context of palliative and end of life care**. Most care in the last year of life takes place at home and in this context carers play a crucial role in enabling patients to remain at home for as long as possible and to die at home if that is their wish. This is the preference for the majority of patients and enabling this choice is a priority of the Department of Health. There is clear evidence from our own work<sup>8</sup> and that of Gomes and Higginson<sup>9</sup> that home death is more likely where there is a supportive carer.

If we wish to promote patient choice of a home death, we need to provide **effective support** for their carers. On the basis of our research, for this to be achieved, we believe the **focus needs to be on the key issues we have identified**: assessment and support for carers that takes account of their two distinct roles, use of an individual (person-centred) approach to tailor support, the essential part to be played by healthcare practitioners in supporting carers as ‘co-workers’, and much warranted attention to recording systems about carers and their support.

The CSNAT research programme of research has developed a comprehensive assessment tool which is integrated into a person centred process of assessment and support that has been used in specialist practice and which shows clear evidence of impact. **Further details of the research is available at <http://csnat.org>.**

In the next month we begin a new study in collaboration with **Hospice UK**, to investigate processes and structures required to support carers across the hospice sector. Our robust evidence base from specialist palliative care now has the potential for transfer to generalist care to support the wider population of carers of palliative patients within primary care. We would welcome the opportunity to discuss this with you.

## References

1. Ewing G, Grande G. Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: A qualitative study. *Palliat Med.* 2013; 27(3) 244-256.
2. 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. *Journal of Pain and Symptom Management.* 2013; 46 (3) 395-405.
3. Ewing G, Austin L, Diffin J, Grande G. Developing a person-centred approach to carer assessment and support. *British Journal of Community Nursing.* 2015; 20 (12) 580-584.
4. 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; 30(4): 392-400
5. 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.
6. Grande G, Austin L, Ewing G, O'Leary N, Roberts C. (2015) Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial. *BMJ Supportive and Palliative Care.* First Published 20th December 2015: doi:10.1136/bmjspcare-2014-000829
7. Aoun S, Toye C, Deas K, Howting D, Ewing G, Grande G et al. Enabling a family caregiver-led assessment of support needs in home-based palliative care: Potential translation into practice. *Palliat Med.* 2015; 29(10): 929 – 938.
8. Grande GE, Ewing G. Death at home unlikely if informal carers prefer otherwise: implications for policy. *Palliat Med.* 2008; 22:971–2.
9. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006; 332:515–21.