



The Carers' Alert Thermometer (CAT): Identifying The Support Needs Of Family Carers Of People Living With MND (plwMND)



O'Brien, M.* Knighting, K.*, Jack, B.*, Fairfield, H. °, Drinkwater, N. °
*EPRC, Faculty of Health & Social Care Edge Hill University; °MND Association



Background

Burden and distress experienced by family carers of plwMND is well known and reported widely within the published literature¹. Evidence-based screening tools to help identify carers at risk of breakdown and plan appropriate support to meet carers' needs are urgently needed.

The Carers' Alert Thermometer (CAT) was developed in a study funded by the NIHR (2011-2014). It is a quick and easy-to-use alert tool designed to be completed collaboratively by carers and non-specialist health staff to identify the needs of carers of family members with cancer and advanced progressive illness in their last year of life.²

The CAT has 10 questions to identify the support needed by the carer to provide care and for the carer's own health and well-being. A traffic light system indicates the level of need for each alert and a visual thermometer signifies the extent of the carer's needs. There is a guidance section for alerts which can be tailored to local services and an action plan to complete with review dates.

(www.edgehill.ac.uk/carers or scan  for more details)

Objectives

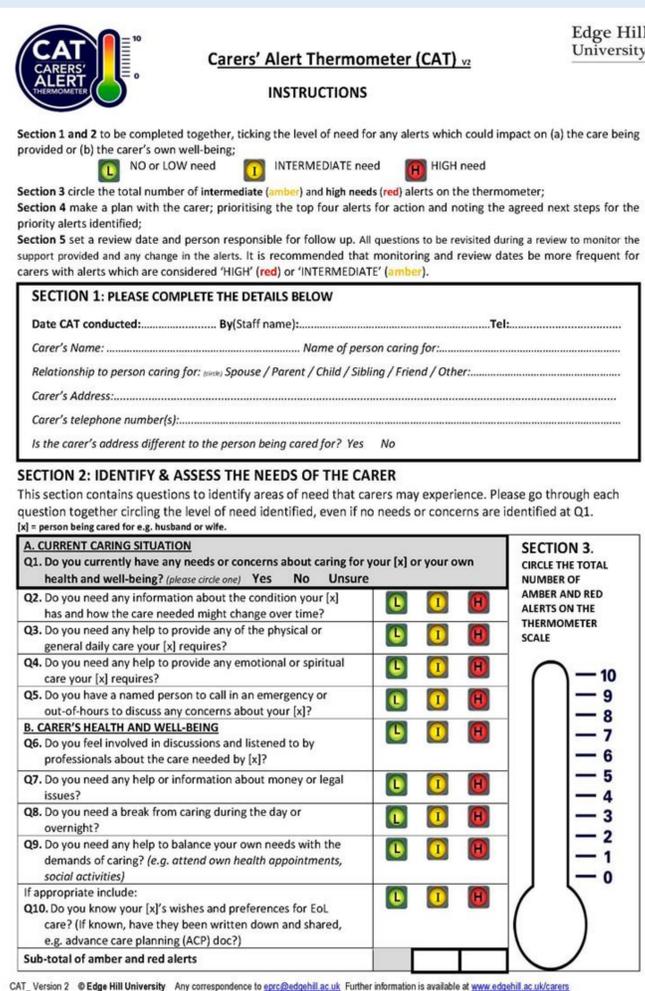
To modify the CAT and pilot it with family carers of plwMND to determine its usefulness in identifying their need for support.

Method

A workshop was held in Oct 2015 with 13 MND Association Visitors (AVs), Regional Care Development Advisers (RCDAs) and a Regional Development Manager (RDM) to review the CAT, provide training on its implementation and demonstrate resources including a DVD.

The CAT was slightly modified to ensure its wording was appropriate for non-healthcare staff to use e.g. removing some patient information and replacing the term 'risk' with 'need'. Participants then trialed the CAT with family carers during routine appointments for a 3-4 month period. Feedback on the utility of the CAT was obtained through a self-completed online survey and telephone interviews.

A second workshop was held in another region in July 2016 to extend the pilot based on the results.



Carers' Alert Thermometer (CAT) v2

INSTRUCTIONS

Section 1 and 2 to be completed together, ticking the level of need for any alerts which could impact on (a) the care being provided or (b) the carer's own well-being:

L NO or LOW need **I** INTERMEDIATE need **H** HIGH need

Section 3 circle the total number of intermediate (amber) and high needs (red) alerts on the thermometer;

Section 4 make a plan with the carer; prioritising the top four alerts for action and noting the agreed next steps for the priority alerts identified;

Section 5 set a review date and person responsible for follow up. All questions to be revisited during a review to monitor the support provided and any change in the alerts. It is recommended that monitoring and review dates be more frequent for carers with alerts which are considered 'HIGH' (red) or 'INTERMEDIATE' (amber).

SECTION 1: PLEASE COMPLETE THE DETAILS BELOW

Date CAT conducted:..... By (Staff name):..... Tel:.....

Carer's Name: Name of person caring for:.....

Relationship to person caring for: (Spouse / Parent / Child / Sibling / Friend / Other):.....

Carer's Address:.....

Carer's telephone number(s):.....

Is the carer's address different to the person being cared for? Yes No

SECTION 2: IDENTIFY & ASSESS THE NEEDS OF THE CARER

This section contains questions to identify areas of need that carers may experience. Please go through each question together circling the level of need identified, even if no needs or concerns are identified at Q1.

[x] = person being cared for e.g. husband or wife.

A. CURRENT CARING SITUATION

Q1. Do you currently have any needs or concerns about caring for your [x] or your own health and well-being? (please circle one) Yes No Unsure

Q2. Do you need any information about the condition your [x] has and how the care needed might change over time? [L] [I] [H]

Q3. Do you need any help to provide any of the physical or general daily care your [x] requires? [L] [I] [H]

Q4. Do you need any help to provide any emotional or spiritual care your [x] requires? [L] [I] [H]

Q5. Do you have a named person to call in an emergency or out-of-hours to discuss any concerns about your [x]? [L] [I] [H]

B. CARER'S HEALTH AND WELL-BEING

Q6. Do you feel involved in discussions and listened to by professionals about the care needed by [x]? [L] [I] [H]

Q7. Do you need any help or information about money or legal issues? [L] [I] [H]

Q8. Do you need a break from caring during the day or overnight? [L] [I] [H]

Q9. Do you need any help to balance your own needs with the demands of caring? (e.g. attend own health appointments, social activities) [L] [I] [H]

If appropriate include:

Q10. Do you know your [x]'s wishes and preferences for EoL care? (If known, have they been written down and shared, e.g. advance care planning (ACP) doc?) [L] [I] [H]

Sub-total of amber and red alerts

SECTION 3. CIRCLE THE TOTAL NUMBER OF AMBER AND RED ALERTS ON THE THERMOMETER SCALE

10
9
8
7
6
5
4
3
2
1
0

SECTION 4: PLAN. Use this table to briefly note the details of up to four priority alerts requiring action now, any actions taken today, and any next steps which have been agreed with the carer.

Brief summary of needs identified by alerts (If there are several needs, ask the carer to "identify which one thing would help you most at this time?")	Any immediate action taken e.g. information clarified, verbal or written information given, referred to see other health care professional	Any next steps required? e.g. Referral to other services, speak to Team Leader/Manager for advice on next steps	Who is responsible for the next step or follow up?	Date of review or follow up

SECTION 5: Date of next review:..... with.....

USE OF CARER DATA

I consent to the following use of my data from this CAT form:

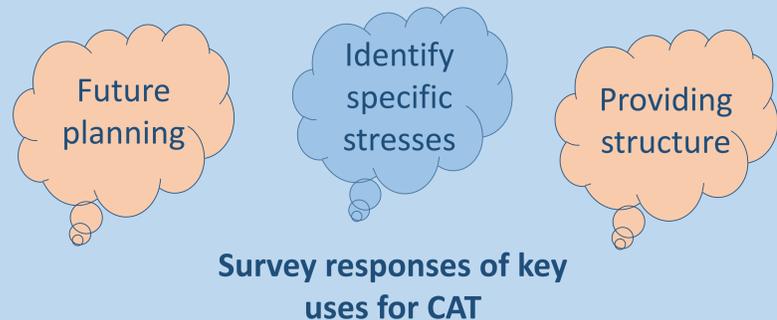
to enable staff to act on my behalf to instigate support from other services/professionals to meet alerts.

Carer's Signature:..... Date:.....

Carers Alert Thermometer - Version 2 © Edge Hill University Any correspondence to epcc@edgehill.ac.uk Further information is available at www.edgehill.ac.uk/carers

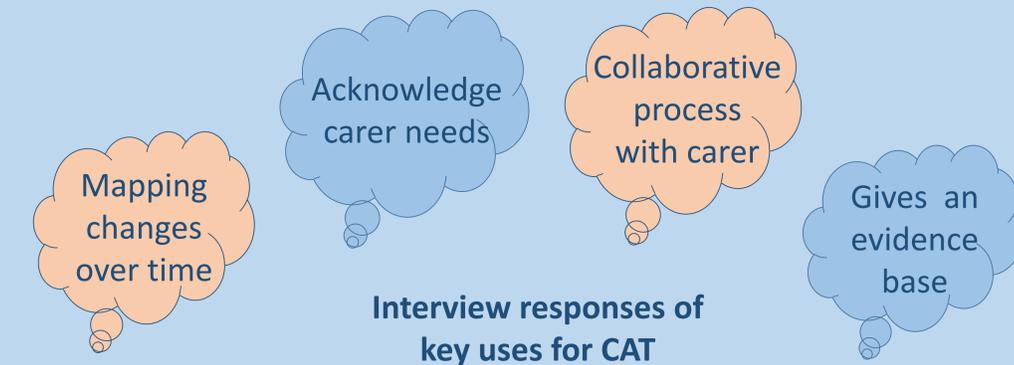
1. Survey results

N= 9 (N= 4 have used CAT. N=5 have not used CAT)
Used with 10 carers at the time of survey
Average **7/10** rating for usefulness



2. Interview results

N=5 (N=3 have used CAT. N=2 have not used CAT)
Used with 12 carers at the time of interviews



Discussion and conclusions

Users found CAT a useful mechanism for raising the topic of carer needs and for mapping the changes to these over time, in a structured and easy to follow format. Specific needs elicited using the CAT have potential to be used as an evidence base for MND and for other H&SC agencies. Further study of specific needs of MND AVs in delivering the CAT would be beneficial.

References

1. Jackson D, Turner-Stokes L, Harris J et al. London: Department of Health, 2011. 2. Knighting K, O'Brien MR, Roe B et al. BMC Palliative Care 2015 May 3;14:22.