The Carers’ Alert Thermometer (CAT): identifying the support needs of family carers of people living with MND (plwMND)

Mary O’Brien; Katherine Knighting; Barbara Jack; Hilary Fairfield; Neil Drinkwater

Edge Hill University, MND Association
What to expect....

- Background
- Development of the CAT
- Pilot project with the MND Association
- Moving forward with implementation
Background to project (2011)

- Carers unmet needs can impact on their psychological and physical health and compromise their ability to provide effective care and support.
- National and international policy priority
- No appropriate tools
Who is a carer?

- Within the UK the term ‘carer’ covers broad definitions:
  - paid carer acting in an employed capacity, supporting a person in their own home
  - an ‘informal carer’, the term family carer is now more often used
- Family carer usually refers to someone identified, by the person being cared for, as important to them and includes spouses, partners, family members and friends who provide care
Project Aims

1. Explore the experience of carers of patients whose expected survival is 12 months or less (EoLC)

2. Identify factors carers find difficult to cope with

3. Have carers & health care professionals rank which of these factors are more likely to result in carer burden

4. Develop and pilot an alert system to be used alongside the GSF to identify carers at risk of increased burden
Project Phases

Phase 1: Interviews/focus groups to identify carer needs when caring for someone dying at home
Participants: carers/former carers

Phase 2: 2 round Delphi survey to rank the key carer needs identified in Phase 1
Participants: professionals from national/regional organisations & carers

Phase 3: Expert panel: further Delphi survey to gain consensus on key carer needs
Participants: professionals with strategic roles in national organisations & carers

Phase 4: Final review of items for inclusion in the CAT
Participants: Project Steering Group & carer representatives

Phase 5: CAT pilot & consult with user groups/stakeholders on any revisions required
Participants: Carers and professionals who had used the CAT in practice
Support for carers

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:

- **NO OR LOW need**
- **INTERMEDIATE need**
- **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.

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**
- **O**
- **G**

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

- **L**
- **O**
- **G**

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

- **L**
- **O**
- **G**

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

- **L**
- **O**
- **G**

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**
- **O**
- **G**

Q7. Do you need any help or information about money or legal issues?

- **L**
- **O**
- **G**

Q8. Do you need a break from caring during the day or overnight?

- **L**
- **O**
- **G**

Q9. Do you need help to balance your own needs with the demands of caring? (e.g. attend own appointments, social activities)

- **L**
- **O**
- **G**

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?)

Sub-total of amber and red alerts

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

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.

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

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: ____________________________

[Additional information includes sections on care plan, next steps, and consent for data use.]
Where are we now?

- Launched September 2014
  - Project website over 3500 visitors
  - Over 250 registrations to access the CAT across 11 countries
  - Range of professionals & volunteers report using the CAT in UK (London/SE, NW, SW), Australia, Italy.
  - Promoted as a resource by organisations in Australia and UK

Pilot sites working with the team:

- Cancer Centre: Implementation pilot (2015), evaluation (2016-17)
- MND Association: Southwest/Northwest.
- Planning stages with other charities and carer organisations
‘Thinking overall about caring for someone with MND, please write down up to THREE WORDS that you think best describe how it feels to be a carer.’
MNDA 2015 Carers’ Survey

Top 4 concerns

- What happens if I become ill?
- What will happen next?
- How will I cope physically?
- How will I cope mentally?
CAT Implementation workshops

- The needs of carers in relation to MND
- Introduction to the CAT & showing of the videos
- Implementation of the CAT to date
- Review of the CAT, guidance notes, additional support doc
- Participants’ stories
- Vignettes- setting the scene for using the CAT
- Q&A on use of the CAT
- Storage of notes
- Links with safeguarding
- Evaluation and next steps
Workshop feedback

- Identifying high risk to alert other professionals.
- Brilliant idea which should work well.
- Useful tool to allow carers to voice their concerns.
- CAT form – not enough space for ‘key professional contacts’.
- Colouring in thermometer so it is all red or white.
- Role play was very useful to put into practice.
Survey Data (to December 2016)

- **Participants:** N=14
  - RCDA (1), AVs (12), service manager (1)

- **Use of the CAT with carers during the pilot:**
  - 7 AVs with 14 carers (Range 1-4 carers per AV)

- **Age of carers:**
  - 36-45 (n=1), 46-55 (n=1), 56-65 (n=3), 66-75 (n=3), 76+ (n=4)

- **How useful did you find the CAT? (Scale 1-10)**
  - Average rating of 7/10 for usefulness
Interview Data (preliminary)

Participants: 7 (4 had used CAT, 3 had not)
Carers involved: 12 carers had completed CATs

Pros
• Provides a structured approach
• Clear and simple to use
• Acknowledges carers needs
• Can be used to join up with other service providers
• Provides evidence base of carers needs

Cons
• Difficult to get time with carer to complete it
• More paperwork can be an issue
• Not all plwMND have family carers
• Some people uncomfortable with the term “carer”
Interview data – benefits of the CAT

It was quite interesting that social services started to sit up and take notice, when we started to actually be talking about risks to carers… it’s a really, really useful tool for us (AV, 6 years)

...one of the most valuable aspects of the tool is that the carer feels they are being assessed as to where they are, they feel “Oh, they're actually asking me”, when all the focus generally is on the person with MND. (AV, 26 years)

what we sometimes think is important isn’t necessarily what they think is important and I’ve got the questions in front of me… then you can pick up on what’s important to them. (AV, 8 years)

It’s given me a structure to be able to say, ‘Well we will come back and re-visit this then.’ (AV, 18 months)
Interview data – Challenges

Barriers to the use of the CAT were primarily circumstantial

I was reminded of the need for speaking to the carer on their own, in a private thing…She thought the home setting would be tricky. So I actually met her in a cafe to do it. (AV, 6 years)

the questions that it (the CAT) was asking weren’t appropriate because she wasn’t caring for him at home. (AV, 2 years)

We’ve been having such a lot of deaths. In fact we are supporting a lot of carers that have been bereaved recently (AV, 8 years)
Interview data – Roles

Issues specific to the identity of the AV and “carers”

And the one where the lady actually completely refused to get involved with it. That was because she said, ‘I am not a carer.’ (AV, 6 years)

I don’t tend to go into houses with bunches of paper, I just tend to take a bunch of flowers, or something. (AV, 5 years)
The future with MND Association

- Continued work with the MND Association, to spread the implementation to further areas
- Exploring potential engagement with MND Scotland

I think that a carer’s job is extremely important so we recognise that within our branch, we do try to support our carers. I think any tool that helps us to do that can only be good, so personally I hope that it works. (AV, 8 years)

I'm confident that with frequent use the tool will become standard for volunteers. (AV - survey)
More information

Published papers & access to the CAT & associated documents/information are available from:
Website  http://www.edgehill.ac.uk/carers/