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## CLINICAL REVIEW

## Assessing and helping carers of older people

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This is the last in a series of four articles about assessing older people

Carers are an essential source of support to older people and take responsibility for most of their care needs. Although many carers find aspects of the caring role satisfying,<sup>1</sup> caring responsibilities can lead to a decline in their own physical and mental health<sup>1-3</sup>—especially when caring for those with dementia<sup>4</sup>—and adversely affect their employment and education prospects, financial position, and ability to participate in social and community life.<sup>2</sup> It is therefore important to identify people who have an important informal caring role. An assessment of the carer and his or her individual needs, and of the caregiving situation, can improve the health and wellbeing of the carer and ensure the provision of timely and appropriate support services.<sup>1</sup>

### How do we identify carers?

Many carers do not formally recognise themselves as carers because they consider their input to be integral to their family duties. Therefore, whenever doctors have patients with serious long term illnesses or disabilities, they should identify the caring input of key family members. The rights of carers are widely recognised in policy and legislation, with carer policies focusing on benefits, services, employment, and the provision of carers with the right to request an assessment of their support needs.<sup>5</sup> In some countries, social (support) workers have a responsibility for providing support to carers. However, medical practitioners, especially general practitioners (family physicians), are the first point of access for patients in many countries and are well placed to identify and screen for people in an important caring role, detect those at risk of physical and mental health problems, and provide follow-up or referral as appropriate.<sup>6</sup> Carers may also present directly to their family doctor with physical or mental health problems as a result of their caring responsibilities, or to seek information, advice, and support.

### How should a carer assessment be undertaken?

Although several high quality studies have recommended the need for carer assessments, less evidence is available on how

the assessment should be structured and what domains it should cover. In addition, we do not believe that most medical practitioners have the time or expertise to complete a comprehensive carer assessment. We suggest that recognition of carers, a brief assessment of their needs, and, where indicated, referral should be the primary medical role. The referral could be to a staff member in the general practice with interest and training in carer issues.<sup>7</sup>

However, large observational studies of carers in Europe<sup>8</sup> and Australia show that key areas for assessment are:

- Any positive or satisfying components of providing care
- The suitability of the home environment
- The physical and psychological health of the carer and the care recipient
- The functional needs of the care recipient
- The levels of carer burden and carer stress
- The carer's cultural background, employment, and financial status
- The carer's information needs
- The presence of carer abuse.

Factors that have been shown to correlate with low wellbeing in carers include:

- Disturbed behaviour in the care recipient
- Being a female carer
- Rating the current relationship as poor
- Having no social support
- Having a narrow range of coping strategies.<sup>9</sup>

During an assessment, provide an opportunity for the carer to express his or her needs and allow collaborative decision making. We recommend using an assessment tool to guide the conversation and obtain vital information.<sup>10 11</sup> Many multidimensional and self reported carer assessment tools are available,<sup>12</sup> but there is little evidence to recommend one above the other, and few are designed to use within the time constraints

### Summary points

Identifying carers is important because many do not recognise themselves as such, and care responsibilities can affect their health and financial and social aspects of their lives

Comprehensive carer assessment may not be feasible but doctors can identify carers, briefly assess their needs, develop a care plan in collaboration with the carer, and refer where needed

Key areas to ask about include physical and mental health needs of the carer and care recipient, information needs, financial status, levels of carer burden and stress, and the positive aspects of caring

Asking the question "Overall how burdened do you feel?" is a useful, quick way to assess carer distress

Provide specific interventions to carers where indicated, including education, information, counselling, and support

To help the carer, provide the care recipient with specific interventions, including regular service provision, aids and equipment, and respite care

Monitor carer on an ongoing basis and provide support after residential placement or bereavement

### Sources and selection criteria

As well as using our personal reference collections, we searched the Cochrane database and reviewed guidelines from the National Institute for Health and Clinical Excellence. Where appropriate we selected systematic reviews and meta-analyses. Observational studies and consensus guidelines were used to define elements of carer assessment.

### Case scenario I

Mr Brown is an 82 year old man with moderate dementia; he also has hypertension and lower limb osteoarthritis and has had a recent mild stroke, which caused a right hemiparesis and has slowed his walking. He lives at home with his 78 year old wife who is his carer. They have no children. Mrs Brown is a cognitively intact but increasingly frail woman with ischaemic heart disease and worsening cardiac failure. She now does the driving because her husband lost his driver's licence, and she has recently taken over management of the couple's financial affairs.

of primary care. The figure<sup>11</sup> provides a structured and detailed screening, assessment, and intervention template for use in practice, adapted from resources available to help medical practitioners identify and support carers.<sup>10-16</sup> Many assessment tools are available to measure aspects of the carer experience, particularly distress. The best known is the Zarit burden interview (ZBI) a 22 item questionnaire.<sup>17</sup> These tools are not in common use in primary medical practice but are regularly used in research settings. However, a recent review of six short form versions of the ZBI suggests that although the ZBI-12 is suitable for all caregiving populations,<sup>18</sup> asking the single question (item 22 on the ZBI)—"Overall how burdened do you feel?"—is useful for quick assessment.<sup>19</sup>

## What are useful carer interventions?

Because caregiving situations, carer characteristics, and coping strategies are diverse and complex, interventions must have multiple components and be individually tailored, flexible, of sufficient frequency and duration (or ongoing), and developed in consultation with the carer.<sup>20-23</sup> The figure shows interventions linked to assessment items. Referral pathways vary with health and social care systems. Many studies have looked at interventions specifically designed to help carers of patients with dementia and stroke.<sup>23</sup> Eagar and colleagues suggest that the support needs of carers looking after patients with various illnesses do not differ, other than the extra support needed to cope with the emotional pressures on carers dealing with the behavioural changes associated with dementia.<sup>24</sup>

Small but consistent benefits have been shown for multicomponent educational programmes and multicomponent psychological interventions for carers, and programmes with greater intensity are associated with a larger effect size.<sup>10-26</sup> In particular, cognitive behavioural therapy interventions have

shown moderate effects on carer burden, anxiety, and depressive symptoms.<sup>27</sup> Although the benefits have been shown mainly for carers, there are also benefits for the care recipient in mood and behaviour, and the involvement of both care recipient and carer improves the effectiveness of these programmes.<sup>25</sup> Family support interventions and support groups have been shown to be effective mainly in the context of mental illness and dementia.<sup>24</sup>

Respite care can be provided regularly or sporadically and may occur in the home, in centre based care, or in institutional care.<sup>24</sup> A Cochrane review found no evidence of effectiveness for provision of respite care but cautioned that this might be because of a lack of high quality research.<sup>28</sup> A systematic review concluded that respite care had small effects, was beneficial only in subgroups in better controlled studies, did not delay entry to residential care, and did not negatively affect frail older people.<sup>29</sup> Despite the limited evidence of effectiveness, respite care should be considered if provided flexibly in response to the specific needs of carers.<sup>30</sup>

A recent systematic review of randomised controlled trials of case management for community living patients with dementia and their carers found weak evidence that it delayed admission to an institution, and inconclusive evidence of its effectiveness in organising formal care and services and reducing informal caring hours.<sup>31</sup> The effect of case management on carer burden and depression is mixed.<sup>32-33</sup>

Evidence based clinical practice guidelines suggest an approach based on early and ongoing carer assessment and flexible provision of interventions according to carer preference and assessed need.<sup>10-27</sup> Increased needs should be anticipated if there are major changes in health status of the care recipient or carer, or environmental changes for the carer. Support may still be needed for the carer after the care recipient moves to a residential care setting or after his or her death.

**Case scenario II**

Mrs Brown comes in one day for her usual prescriptions. You note her cardiac failure is not optimally controlled and she seems rather subdued. You advise changes to her drugs and ask how things are at home. She says her husband needs lots of attention and things can be difficult. You say you wonder if this is affecting her health and ask if she can come back later that week to check how the drugs are working and discuss the situation at home. She agrees but quickly adds "I do want to keep looking after him at home." You reassure her that you just want to help her stay well and support her care of her husband.

She is happy with this and returns a few days later, when you ascertain that her cardiac failure is better controlled, you ask who else helps her at home (see figure). It turns out that they have no immediate family or paid carers. When asked about her biggest difficulty in caring for him, she mentions that he sometimes gets angry and hits out at her, especially in the car as a passenger or when she has to shower him. When asked how else she helps him, Mrs Brown says he gets up several times to go to the toilet at night and needs help in getting back into bed. This interrupts her sleep. Informal discussion about managing household tasks revealed that she had difficulty keeping up with shopping and paying bills, and she said that she felt overwhelmed by her husband's care needs. She was unaware of the services that were available to her and had limited understanding of the progressive nature of her husband's dementia or how to manage his challenging behaviours.

**Case scenario III**

Mrs Brown was given help with bathing and personal care for her husband three days a week, and this reduced his aggressive behaviour towards her. Mr Brown refused to attend a day respite centre, but Mrs Brown did receive in-home respite for several hours twice each week, which allowed her to get to her medical appointments, do her shopping, and pay her bills. She was also able to attend a regular carer support group, which provided education about caring and dementia, and she found this helpful because of the information provided and the support available from staff and other carers. At review three months later Mrs Brown is still stressed but says she is coping with her husband much better. Her cardiac failure is well controlled and she sees you regularly for follow-up.

## What are the challenges for carer assessment and intervention?

A major challenge facing clinicians is the limited time available for assessment. However, the broader benefits flowing from effective support of carers need to be recognised. Clinicians may find that family members do not identify with the term "carer" and are therefore less likely to seek assessment. Carers, spouses in particular, may decline to use support services or accept interventions for themselves because of a perceived lack of need or loss of control,<sup>34</sup> or the reluctance of the care recipient to accept services.<sup>35</sup> Other barriers to service use include the inflexibility of service providers in what they will provide and the amount of time available, the complex application procedures needed to enable access, a limited understanding or knowledge of what is available, and the financial cost of the services.<sup>36</sup>

From the family doctor perspective, ongoing contact and support, the development of a therapeutic relationship with the carer, and a flexible approach are likely to be needed to encourage carers to accept help. One practical approach is to suggest a trial of a service for a limited period, with the option to stop after that time. Another approach is to involve other family members in discussing what services might be helpful. It is useful to emphasise to carers that they are the most important people providing care, so that their health and wellbeing must be maintained to allow them to continue in that role. Monitor carer on an ongoing basis and provide support after residential placement or bereavement.

## Conclusion

Carer assessment and the provision of individually tailored interventions are essential elements in the healthcare of older people. The figure suggests ways to achieve this. Steven Zarit, one of the originators of carer research, has stated "the implications of research as well as principles of good practice unequivocally support the premise that assessing caregivers is

a necessary and essential part of working with older clients in virtually every setting."<sup>37</sup>

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Patient consent not required (patient anonymised, dead, or hypothetical).

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**Improving practice***Educational resources for carers*

CarersUK ([www.carersuk.org/](http://www.carersuk.org/))—Carer organisation website that provides information and practical advice for carers; UK focus

Family Caregiver Alliance ([www.caregiver.org/caregiver/jsp/home.jsp](http://www.caregiver.org/caregiver/jsp/home.jsp))—Carer organisation website that provides information and advice for carers; USA focus

*Educational resources for healthcare professional*

Royal Princess Trust for Carers (<http://professionals.carers.org/>)—Resource for professionals working with carers; UK focus

Supporting Carers in General Practice e-learning programme ([www.e-lfh.org.uk/projects/supportingcarersingeneralpractice](http://www.e-lfh.org.uk/projects/supportingcarersingeneralpractice))—Well designed continuing educational programme; requires registration and is available readily only to UK based health professionals

Family Caregiver Alliance ([www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1695](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1695))—Carer organisation website for professionals working with carers; USA focus

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# Figure

<b>Carer Details</b>	
Name: ..... Age: ..... Sex: M/F Relationship.....	
<b>Carer Assessment</b>	<b>Intervention</b>
<b>Practicalities</b> Co-residence? Yes <input type="checkbox"/> No <input type="checkbox"/> Do you drive? Yes <input type="checkbox"/> No <input type="checkbox"/> Mode of transport.....	Transport assistance Home visits
<b>Carer health and wellbeing</b> How would you rate your health? Excellent <input type="checkbox"/> Good <input type="checkbox"/> Fair <input type="checkbox"/> Poor <input type="checkbox"/> Do you have any health concerns? Do you have regular health checks? How stressed do you feel in caring for the care recipient? Not stressed <input type="checkbox"/> Somewhat stressed <input type="checkbox"/> Very stressed Do you feel angry or depressed with your caregiving situation? Rarely <input type="checkbox"/> Occasionally <input type="checkbox"/> Most of the time	General health check  Mental Health Assessment Referral for <i>Psycho-educational or Cognitive behavioural therapy</i>
<b>Caregiving Details</b> How long have you been providing care? What assistance do you provide? How many hours a week/per day do you provide care? Do you have support from family members or friends? What caregiving activities cause you most concern?	Support services <i>Transport/Home help/ Meals/Aged care service/ Community nursing service</i> Home modifications <i>Equipment/Aids</i> Practical Advice/Problem Solving <i>Nutrition supplements/ Sleep Disturbance/ Behavioural Problems</i> Respite <i>Short/long term Residential/in home</i> Referral for Counselling <i>Individual, family or group</i> Information/Education <i>Care recipient illness/prognosis Carer associations/ support centres/networks</i> Planning for emergencies <i>Emergency response Systems/ Personal ID equipment</i>
<b>Support Services</b> What support services are being utilised? What support services do you feel you need to manage?	
<b>Care Recipient Details</b> What aspects of the care recipient's health are of concern? Functional <input type="checkbox"/> Memory <input type="checkbox"/> Behavioural	
<b>Caregiving Concerns</b> Social isolation <input type="checkbox"/> Financial strain <input type="checkbox"/> Stress on relationships <input type="checkbox"/> Time for self <input type="checkbox"/>	
<b>Financial barriers and concerns</b> Employment Status  Financial and Legal Issues	Financial assistance/advice <i>Government benefits, charitable organisations</i> Legal support <i>Health care directives, guardianship, power of attorney</i>

Carer assessment and recommended interventions template; adapted from various sources<sup>10-16</sup>