

EffectivenessMatters

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Dementia carers

Effective information,
support and services
to meet their needs



- Carers are the mainstay of dementia care in the UK and the Alzheimer's Society estimate that at least 670,000 people are acting as a primary carer.
- As dementia is on the increase, carers will be essential in helping health and social services meet the demand for care.
- Carers are known to experience high rates of depression and anxiety. Their need for practical and emotional support to relieve the stress of caring is equally high.
- Psychosocial therapy can improve carers' health and well-being; combining two or more psychosocial interventions is likely to be more effective than a single intervention.
- Developing carers' coping skills can improve their psychological health and well-being.
- Carers indicate they need staged access to clear and understandable information about dementia generally and on the availability of advice and support services.

This issue of *Effectiveness Matters* has been produced by CRD in collaboration with the Yorkshire and Humber AHSN Improvement Academy. The views expressed in this bulletin are those of the authors and not necessarily those of the AHSN or the University of York.

Background

Dementia is a major public health issue. Around 800,000 people in the UK have the condition, and as people live longer this figure is likely to double in coming decades.¹

As most sufferers live at home, carers are the mainstay of dementia care in the UK. The Alzheimer's Society estimate that at least 670,000 people are acting as a primary carer.¹

Many carers do not see their caring role as separate from the relationship they have with the person they care for.³ Carers can experience high rates of depression and anxiety. Their need for practical and emotional support to relieve the stress of caring can be high.² Supporting carers improves their quality of life and that of the people they care for.⁴

Support also helps people to continue caring, saving the UK public purse an estimated £8 billion every year.¹ As the burden of dementia increases, carers will be essential in helping health and social services meet the demand for care.³

This issue of *Effectiveness Matters* summarises the evidence about ways of providing information, support and services to meet the needs of carers for people with dementia. The bulletin is based mainly on existing sources of synthesised and quality-assessed evidence, and aims to complement recent scoping work undertaken by the Yorkshire and Humber AHSN Improvement Academy.⁵

What carers want

There is a substantial qualitative evidence base capturing the experiences of both carers and people with dementia. From a review of 46 studies⁶ five themes around which patient and carer experience might be improved have been identified. These are: seeking a diagnosis, accessing support and services, addressing information needs, disease management, and communication and attitudes. The review found that carers often felt it took too long to access support and that they had to push to obtain information. Carers perceived a lack of knowledge about available services by primary care providers, which led to difficulty obtaining help. Areas where improvements could be made include the improvement of communication and attitudes around dementia generally and primary care providers' awareness and delivery of person-centred care approaches.

These themes are reinforced by recent mixed-methods research in the UK.² This research identified three critical points where carer support is valued and needed, namely at diagnosis, when

taking on an "active" caring role and at the point when the person with dementia's capacity begins to decline. The research suggests that these critical points present important opportunities for health and social care professionals to provide carers with information, advice and to signpost available support.²

Who should provide support?

Most of the contact carers have with health and social care professionals is short-term and episodic. The NICE quality standard acknowledges the vital importance of carers and recommends that health and social care professionals in direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings should ensure carers are involved in the implementation of each quality statement.⁷ Supporting evidence on how best to ensure carer involvement in each setting is currently lacking. NICE also recommends that carers are supported in a variety of ways (see box).⁸

Information for carers

Carers have indicated that they need clear and accessible information about dementia generally and on the availability of advice and support services.^{2,6} Carers have different information needs at different time points so there is a stated preference for staged information giving. This would enable carers to find out more when they need to and avoid the quantity of information provided from being overwhelming. Signposting to reliable local and national information sources is essential.

Providing "core" information, which is repeated or topped up over time has been recommended.² Ensuring that information is given consistently over time could be achieved by the use of an information checklist by professionals.

Information interventions can be delivered via a number of formats. Information delivered as part of group psychoeducational interventions has been shown to impact on depressive symptoms.⁹ Evidence assessing the effectiveness, feasibility, and quality of internet-based interventions for carers of people with dementia has also been subject to review.¹⁰ Although supporting evidence is limited, delivering information online appears beneficial and combining tailored information with interaction between caregivers shows promise.

NHS England has commissioned two free online services. A weekly email service will provide

information on care, support, and understanding the condition from reliable sources such as the Alzheimer's Society. A webchat facility, again in conjunction with the Alzheimer's Society, has also been developed and can be accessed via NHS Choices.¹¹

What should be offered?

The NICE Quality Standard states that carers should be offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs (see Box).

Psychological therapy can improve carers' health and well-being. The relatively small effect sizes and the large variability between studies make it difficult to make definitive statements about what will be most helpful for whom.⁸

Multicomponent interventions

Psychosocial interventions include psychoeducation, counselling, supportive therapy, and behavioural management interventions.¹² Evidence suggests that combining two or more psychosocial interventions is likely to be more effective at improving the psychological health of carers than a single intervention.¹²⁻¹⁴ Multicomponent interventions typically include a mixture of counselling sessions, group work, provision of information and telephone support, delivered by a range of professionals including specialist nurses, social workers, counsellors, psychologists and gerontologists. There is no clear evidence to show which interventions in combination are most beneficial.

Developing coping skills

Although limited, there is consistent evidence that developing carers' coping skills improves their psychological health,¹³⁻¹⁷ and when combined with continuous support can help reduce the level of carer burden.¹⁴ Group sessions involving CBT and delivered over eight or more weeks, have been shown to reduce depressive symptoms. Sessions typically involve teaching coping skills, problem solving and stress management. Carers receive information about dementia and support, and some interventions encourage carers to participate in activities to improve their mood.¹⁶ Similar sessions delivered individually to carers have been found to be effective.¹⁵

A recent UK study has found a manual based coping strategy to promote the mental health of carers is cost-effective compared to usual care.^{17,18} The intervention entailed eight sessions of manual based coping strategy therapy as an adjunct to

NICE Recommends

Carers should be offered an assessment of emotional, psychological and social needs and where appropriate offered psychological therapy.

Care plans for carers should include:

- Individual or group psychoeducation
- Peer-support groups
- Support and information by telephone and internet
- Training about dementia, services and benefits
- Communication and problem solving training

Practical support to enable carers to participate in interventions (transport or short-break services) should be provided.

usual care. Sessions were delivered to carers over 8 to 14 weeks, by supervised psychology graduates without clinical qualifications. Carers also received a manual and a CD to guide relaxation exercises. The study found that at eight months, the START coping intervention was cost-effective compared to usual care.¹⁸ The intervention was associated with reductions in depressive symptoms and improvements in health related quality of life.¹⁷ This study was well conducted and the conclusions can be deemed reliable.

Informal support systems

There is some evidence of limited quality to suggest that support groups are beneficial for carers' psychological wellbeing.¹⁹ Support groups can involve psychoeducation, training or mutual support. Groups that are based on theoretical models and provide prolonged contact time, appear to be most successful in improving carer wellbeing. A Swedish evaluation suggests group education and discussion (five 2-hour sessions) may improve health-related quality of life at a similar cost to usual care.²⁰

There is little evidence for developing informal support systems through befriending schemes. A UK evaluation found that access to a befriender facilitator, utilised by half of the carers who were eligible for the scheme, did not improve carers' wellbeing and was not cost effective.²¹ There was very limited evidence that those carers who engaged with befrienders for longer than six months may be more likely to show improvements in depressive symptoms.

Respite care

The temporary relief from the stresses of caring that respite care provides is highly valued by carers.^{12,22} The NICE Quality Standard recommends that carers have access to a comprehensive range of respite/short-break services that meets both their needs and those of the person with dementia.⁷

Respite care covers a range of diverse services which may be planned or unplanned, involve overnight or day care, provided for a few hours a week to several weeks by trained and untrained staff or volunteers. However, it is important to recognise that many carers may be using informal respite, with help from family and friends. And there is considerable evidence that carers feel they benefit from respite care.^{12,22} A Cochrane review²³ has highlighted the limitations of the evidence for respite care, finding that studies are generally small, short-term, use outcome measures that do not measure changes in carers' quality of life, and do not take into account the importance of tailoring respite care to the varied needs of carers.

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About Effectiveness Matters

Effectiveness Matters is a summary of reliable research evidence about the effects of important interventions for practitioners and decision makers in the NHS and public health. This issue is produced by CRD in collaboration with the Yorkshire and Humber AHSN Improvement Academy. *Effectiveness Matters* is extensively peer reviewed.

