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Key messages

- Family members provide most at home care for people with dementia and involvement continues in hospitals and care homes.
- Dementia affects family relationships and the wellbeing of relatives.
- Many family members gain fulfilment from supporting a relative with dementia.
- How dementia impacts on family supporters'/carers' wellbeing relates to psychological and relationship influences.
- Psychological interventions for carers can produce positive outcomes.

Evidence briefing:

The psychological needs of families and carers of people with dementia

Family carers, as well as people living with dementia, need information, education and support throughout the dementia trajectory. The aim of this document is to provide an evidence-based summary of the psychological needs of family members and carers of people living with dementia, and to recommend evidence-based ways of addressing such needs. It is not intended to be read as a set of recommendations for practitioners but aims to aid commissioners and other stakeholders to shape the service landscape.

Key messages

■ Family members provide most of the care and support for the two-thirds of people with dementia who live at home⁽¹⁾.

For people with dementia to continue to live well, it is vital for services to meet the needs of family members/supporters. 87 per cent of people with dementia interviewed for the recent report *Turning up the volume: Unheard voices of dementia*⁽²⁾ reported that they were assisted by family members while only 14 per cent had help from a paid carer. The cost of care from relatives, neighbours and friends is estimated at £26.3 billion per annum⁽³⁾. Without such care, many people with dementia would have a poorer quality of life and more would have to move into formal care settings.

■ Dementia affects family relationships and the wellbeing of relatives.

Dementia impacts upon the relationships between the people directly affected and their families and friends⁽⁵⁾. There are fewer opportunities for shared activities and communication becomes harder but love and happiness often remain⁽⁶⁾. In families where a person has young onset dementia, 75 per cent of

parents reported their children experienced conflict with the parent with dementia, had problems at school, and suffered psychological/emotional problems⁽⁷⁾. For further information see *Evidence briefing: Psychological needs of people with young-onset dementia*.

■ Family involvement and care frequently continues when a person with dementia is in hospital or living in a care home.

Acute hospital environments are bewildering for people with cognitive impairment. Many relatives would welcome the opportunity to stay at the hospital to reassure the person with dementia and be involved in advising staff on care⁽⁴⁾. Many family members wish to remain involved with the person with dementia following that person's move into care. This can give an opportunity for 'quality time' as aspects of personal care are taken over by care staff. Carers are less likely to feel guilty and anxious about a relative's care if they are given opportunities to remain involved rather than excluded.

- **In particular, dementia has a major impact on the psychological wellbeing of family members who take on the role of ‘primary carer’.** 61 per cent of carers reported their health had suffered⁽²⁾. About half of primary carers experience high levels of burden⁽⁸⁾ and 20–33 per cent report significant levels of depression^(9,10). Almost three quarters of carers report grieving for losses, including loss of intimacy and loss of past roles of the person with dementia⁽¹¹⁾. Carers’ feelings may also affect the care they provide, with one study finding that over a third of carers reported behaving in ways that were potentially abusive to the person cared for⁽¹²⁾. Higher levels of depression in carers are associated with higher health service use by carers and therefore also higher costs⁽¹³⁾ and higher levels of burden are associated with earlier admission to residential care⁽¹⁴⁾.
- **Despite the demands, many family members gain satisfaction, pride or fulfilment from supporting a relative with dementia, feel they develop skills, and grow as a person from the experience.** Positive aspects are not just the opposite of the negatives but seem to be a different dimension⁽¹⁵⁾. Commitment to the relationship, being able to accept the changes in a relative and deliberately making an effort to adopt a positive perspective are all associated with positive reactions⁽¹⁶⁾. Some adults providing care to a parent find they develop a new and positive relationship. Also, even though it can be hard to explain dementia to an affected person’s grandchildren, relationships between grandparents with dementia and grandchildren can often be positive. There is some evidence that people with dementia whose relatives gain positive benefits are less likely to move into residential care.
- **How dementia impacts on family supporters’/ carers’ wellbeing is not directly related to the level of dementia or the amount of help needed by the person with dementia but to psychological and relationship influences.** Carer coping and wellbeing are influenced by the prior relationship between both parties, the carer’s physical and mental health, and personality (e.g. whether the person is a worrier), and the behaviour of the person with dementia^(6,8,10,16). Self-efficacy beliefs (i.e. whether the carer believes they have the capacity to cope) seem to be a major influence⁽¹⁷⁾. Carers who hold the belief that the person with dementia and their relationship with them are essentially the same as they used to be (i.e. they believe the person is ‘still there’) have fewer negative and more positive emotions⁽¹⁸⁾.
- **Research shows that a number of psychological interventions for carers can be effective in producing positive outcomes.** Psycho-educational programmes, skills training, individual and family counselling, cognitive behavioural therapies, and multi-component programmes can all reduce carer stress⁽¹⁹⁾. Short interventions, (e.g. six sessions of skills training), can have a long-term benefit⁽²⁰⁾ and intensive programmes (e.g. a 12-day residential programme for people living with dementia and primary carers) have been shown to significantly delay and reduce moves to care homes⁽²¹⁾. Carers appreciate it when professionals treat them as equal partners and true ‘experts-by-experience’. Common factors in effective interventions appear to be that they involve the person with dementia as well as the carer, that they are flexible enough to be individually tailored⁽¹⁸⁾ and that they are intensive or involve active participation.⁽²¹⁾ For further information see *Evidence briefing: Psychological therapies for people with dementia*.

Calls to action

- **Ensure interventions are developed or adapted and evaluated to meet the needs of those whose voices are seldom heard,** including people from minority ethnic groups, of different sexualities, and carers of those with rare dementias, or learning disabilities and dementia⁽¹⁹⁾.
- **Co-produce commissioning, service evaluation, research and development with carers.** Carers can bring their expertise by experience to complement the academic and clinical expertise of researchers and

Calls to action

- Ensure interventions are developed or adapted and evaluated to meet the needs of those whose voices are seldom heard.
- Co-produce commissioning, service evaluation, research and development with carers.
- Include access to psycho-education, counselling, and skills training for carers.
- Ensure carer interventions are evidence-based.
- Strengthen support for children and young people in caring roles.

professionals and this contributes to good outcomes. Carers' contributions need to be planned and costed at the outset of initiatives to enable full participation.

- **Include access to psycho-education, individual or family counselling, and skills training in options for carers.** These evidence-based options may be offered as part of a multi-component programme. Cognitive behaviour therapy should also be available for any carer who is clinically depressed.
- **Ensure the elements of carer interventions are evidence-based.** Interventions should be flexible

Example of good practice

SHARE (Support, Health, Activities, Resources & Education) an intervention to help couples plan for the future. SHARE is a seven-session intervention developed in the US. It is focused on enabling the person with dementia and a key carer to work together to plan for their future with dementia. The sessions involve a range of structured discussions that enable couples to develop their understanding of dementia, think about their care values and their preferences for future care, and plan how to draw on resources as the dementia gets worse. Research has found that the intervention is acceptable to couples and feasible to use in practice. It is an acceptable way of reinforcing relationships and enabling advance care planning^(23,24).

Example of good practice

START (STrAtegies for RelaTives) a carers' psycho-educational and skills-training intervention. START is a manual-based, eight-session intervention focused on enabling carers to cope with caring. It is based on an extensively researched programme developed in the USA and has recently been positively evaluated in a UK randomised controlled trial (RCT). The sessions of the programme cover material which carers then put into practice at home, with support from a manual. Topics include psycho-education about dementia; carer stress and sources of emotional support; understanding and managing behaviour of the person with dementia; changing unhelpful thoughts; promoting acceptance; assertive communication; relaxation; planning for the future; increasing pleasant activities; and maintaining the skills learnt. The UK RCT found that, compared with treatment as usual, START improved quality of life and reduced depressive symptoms of carers at no extra cost. The delivery of the programme by psychology graduates, with supervision by qualified applied psychologists, rather than qualified

enough to be tailored to individual needs and should be either intensive or involve active participation. It is helpful if some aspects of the intervention include the person with dementia, along with the carer.

- **Strengthen support for children and young people in caring roles with parents or grandparents,** ensuring that their particular needs as children are protected. This should be a routine consideration whenever a person is diagnosed with young onset dementia, and a family approach should be used to find out whether it is an issue.

health care professionals helped to keep the cost down^(25,26). Milne et al.⁽²⁷⁾ describe evaluation in routine practice of a very similar intervention, finding a range of benefits for attenders.

Example of good practice

Individual and family counselling

Individual or family counselling is frequently provided for carers of people with dementia and there is evidence that it is helpful in alleviating depression. A study across the US, Australia and the UK evaluated the provision of five sessions of counselling for carers. The first and last of the sessions were provided to the primary carer alone, while the remaining three were provided to whichever members of the family the carer felt should be invited. The sessions took place over a three-month period during which family members could also telephone for support. The topics were flexible to the needs of the families but all aimed to provide emotional support for carers. The intervention produced significant improvements in the degree of depression experienced by carers, with the impact lasting for the two years of follow up⁽²⁸⁾. In the original US studies, gains were retained for at least five years. In the UK, a similar flexible counselling approach is often adopted by Admiral Nurses, experienced, registered nurses, employed to provide expert practical, clinical and emotional support to families living with dementia to help them cope⁽²⁹⁾.

Acknowledgements

This document was prepared by the British Psychological Society's Dementia Advisory Group (lead author Jan Oyeboode).

The authors would like to thank Jean Tottie of Together in Dementia Everyday (TIDE) and Dr Barbara Woodward Carlton, ex carer and Alzheimer's Society Research Network volunteer, for their comments, advice and suggestions.

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