ConnectED Briefing #20

Supporting people with Dementia living at home



The Issue

People living with dementia at home may draw on adult social care for support. Commissioners in Bristol wanted to find what helps people living with dementia to remain in their own homes.

What commissioners wanted us to find out

Commissioners wanted to know what services or interventions help people with dementia to improve their quality of life or wellbeing, and what can help to prevent unwanted moves to a care home or admission to hospital.

What we did

We searched for relevant systematic reviews published since 2019. We also looked for relevant guidance published by the National Institute for Health and Care Excellence (NICE). We excluded reviews which looked at Technology Enabled Care (TEC) for people with dementia because this is covered in a recent ConnectED Briefing¹

What we found

We found eight systematic reviews. Three looked at a range of interventions for people with dementia and their carers,²⁻⁴ and three focused specifically at support for carers.⁵⁻⁷ One review focussed on what happens during a crisis,⁸ and another looked at support designed to prevent hospital or nursing home admission.^{8,9} We found one relevant NICE Guideline.¹⁰

What the evidence suggests

Care co-ordination (also described as 'case management')

Care co-ordination begins with a thorough assessment of the needs of the person with dementia and their carer. A tailored support plan is then created with the person, which may include a range of interventions such as care at home, respite care, or helping people get to places in the community. The co-ordinator supports the person with dementia and their carer by connecting health and social care services and making changes in response to changes in the person's needs.

Care co-ordination can improve the quality of life of people living at home with dementia and reduce the stress experienced by their carers.^{3,4} Combining care coordination with regular monitoring enables practitioners to notice and respond promptly to new or changing needs, and may prevent issues becoming a crisis This reduces the likelihood of people moving to a care home, meaning it can often be a cost-effective option.^{3,7,9}

Occupational therapy

Occupational therapy interventions focus on promoting people's independence through the use of meaningful activities and making changes to the environment. These interventions support people with dementia to carry out everyday activities, improving their quality of life.^{2,3} Occupational Therapists work with carers to develop strategies to support people with dementia with daily tasks and create a supportive home environment. As well as reducing their own feelings of stress, carers reported seeing fewer behavioural and psychological symptoms of dementia following occupational therapy support.^{2,3}

Supporting carers

Carers of people with dementia often experience high levels of stress, and are continually balancing their caring role alongside looking after their own needs.⁵ Carers value emotional

support and practical help, including support to access community resources and care services.⁶⁻⁸ Over time, the behavioural and psychiatric symptoms of dementia increase and carers need support that responds to their changing role. Providing accessible information about what to expect as a person's dementia progresses, and exploring the emotional impact of these changes (referred to as 'psychoeducation') can reduce the risk of carers experiencing depression.⁵⁻⁷ Training carers how to care for someone with dementia can increase their feelings of "mastery" (sense of being skilled in their role).⁶ While support for carers has a positive effect on carer well-being and sense of burden, it only has a small effect on reducing the risk of the person with dementia moving to a care home.⁷

Preventing Moves in a 'Crisis'

A 'crisis' means an event where there is perceived to be a high risk of harm, necessitating an immediate intervention or change. Medical issues, significant changes in behaviour, and high levels of carer stress can trigger a crisis for people with dementia.⁸ Care co-ordination (including robust support to carers), timely access to medical treatment, and psychosocial support are key to preventing unplanned moves to a care home or hospital admission.^{3,8,9} This relies on comprehensive community support services being available.

Other interventions

There is evidence that other interventions, not directly delivered or commissioned by adult social care, can have positive outcomes for people with dementia. These include multicomponent cognitive stimulation therapy,³ reminiscence therapy,⁴ and biobehavioural interventions.⁴ These interventions may improve the behavioural symptoms for people with dementia, their functional abilities and their mood, but they do not appear to have a significant effect on reducing the rate of people moving out of their homes.

What the NICE guidance suggests

People with dementia should have a named health or social care professional who is responsible for co-ordinating their care. In order to promote independence and wellbeing, the guidance recommends people with dementia should be offered a range of tailored activities, group cognitive stimulation therapy, group reminiscence therapy, and occupational therapy.¹⁰

Carers of people with dementia should be offered psychoeducation that includes education about the progression of dementia, skills training and support with strategies for how to provide care, including responding to changes in behaviour. The guidance highlights that interventions for carers are most likely to be effective when provided as group sessions.

What this means for practice

Current evidence does not suggest a single intervention to promote people's wellbeing and prevent or delay hospital or nursing home admission. People living with dementia and their carers need tailored co-ordinated support, planned and delivered by people who understand dementia and its progression.

Social care commissioners should work with mental health colleagues to ensure that therapeutic support, including psychoeducation, is available to carers of people with dementia.

Quality of information

We are moderately confident that we have included the best available evidence for what supports people at home living with dementia. The studies involved in these reviews looked at many different kinds of support, which were not always well described, making comparisons difficult. Some studies had small numbers of people involved, and did not contain enough information about their characteristics (particularly the stage of their dementia) to be confident that their findings could be applied more widely. Some studies needed more follow up for evidence of longer term outcomes. The NICE Guideline makes recommendations in the areas where the most robust evidence is available.

For more information about this briefing, contact

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Resources for further support

- The vision of Dementia and Hope | Research in Practice
- NICE Quick Guide for Discussing and Planning Support after Dementia Diagnosis: <u>Dementia-quick-guide.pdf (nice.org.uk)</u>
- Overview | Dementia: assessment, management and support for people living with dementia and their carers | Guidance | NICE

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