

Dementia Gateway: Support following diagnosis

Key messages

- Early diagnosis provides a chance for both practitioners and people with dementia and their carers to work together and set goals for care and support, and make important decisions about post-diagnostic support needs and care.¹
- People living with dementia (and their families) currently find it difficult to get information, advice and support about their diagnosis, and access to available services throughout their life with dementia.³
- Few studies have investigated the availability and take-up of post-diagnostic care and support services by people with dementia and their carers living in isolated and rural areas.⁴
- Education and psychosocial interventions, including information, advice and support for newly diagnosed people is a priority and helps people with dementia and their carers cope with the psychological distress caused by the impact of a diagnosis and the implications including potential losses.^{4,5,7}
- There is no substantial evidence to show that memory clinics are better able than GPs to support people with dementia and their carers in terms of post-diagnostic treatment and coordination of care.⁸
- Community mental health nurses have an important role in offering emotional and practical support to people with dementia and their families who have been recently diagnosed.¹⁰
- Changing family structures and lifestyles and geographically dispersed families have led to a wider range of relationships where people may give or receive care and support.⁵

Introduction

This summary highlights key messages from the research on post-diagnostic support for people with dementia and their carers. It is not intended to be a comprehensive review of the literature on this topic. The material on which this summary is based was identified through focused searching of the literature published from 2008 to 2012. Some material outside of this date range is also referred to where relevant.

What is the issue?

The importance of continued intervention following a diagnosis is emphasised in the National Dementia Strategy.² as many people experience an ongoing need for information, support and advice as a direct result of the challenges and insecurity faced at the time of diagnosis.³

Many people diagnosed with dementia think that very little can or will be done for them, especially when they are newly diagnosed.

Early diagnosis provides a chance for both practitioners and people with dementia and their carers to work together and set goals for care and support, and make important decisions about post-diagnostic support needs and care.¹ After a diagnosis of dementia, people with dementia and their carers should be provided with the right support to help them manage, adjust and plan for the future.⁴

The diversity of care provision following diagnosis is clear and it is impossible to pigeonhole interventions into neat categories. However, they might loosely be divided into

formal support; and informal support which includes family caregiving.⁴ Formal support includes:

- early intervention
- community support services
- intermediate and long-term care (i.e. rehabilitation, day care and respite services' and long-term residential care).⁴

Both formal and informal services complement each other in helping people with dementia and their carers to get better outcomes and delay admission to long-term care.⁶

Aims of post-diagnostic support

The main aim of post-diagnostic support services for dementia is to help people to continue living well in the community, provide information and support; help people to manage issues as a result of getting a diagnosis; and delay admission to long-term residential care.^{6,9}

Support following diagnosis is also important for carers of people living with dementia.³ Problems faced by spouses and partners are amplified by a lack of understanding about the diagnosis and symptoms of dementia, highlighting the significance of supporting family members by increasing their knowledge and awareness of dementia.¹¹

Information and advice

Following a diagnosis of dementia, health and social care professionals should provide people with dementia and their family with written information about things that include: the signs, symptoms, course and prognosis of

dementia; treatments; local care and support services; and where to get financial and legal advice.¹²

But research indicates that people living with dementia (and their families) currently find it difficult to get information, advice and support about their diagnosis, and access to available services throughout their life with dementia.³

The status of research

Although research documenting the journey from receiving a diagnosis to accessing post-diagnostic services and support is limited, existing research does explore key conditions needed for dementia care delivery, including early interventions, person-centred approaches, rehabilitation, and more innovative approaches to day and respite services.⁴

Not much is known from the perspective of the person with dementia about their expectations and experiences of being referred to a memory clinic for the first time and about the attitudes and worries of their family carers.¹³

Though there is some evidence to support the provision of information services for people with dementia and their carers, a systematic review concluded that generally there is relatively little information about this issue, and further research is needed to understand which particular elements (e.g. direct help to navigate services) are effective.¹⁴

There is limited evidence to establish the effectiveness of the dementia advisor role.² Further information is needed on the extent to which they make contact with hard-to-reach groups such as those living alone and those who are from minority ethnic groups.³

The evidence base on how informal caregivers can be enabled to provide support is limited.⁴ And few studies have investigated the availability and take-up of post-diagnostic care and support services by people with dementia and their carers living in isolated and rural areas.⁴

Formal support

Formal support can be accessed through GP and other health and social care professional referrals.⁴ Formal support may be very broadly categorised as follows:

- i. Early intervention and immediate support
- ii. Community support services
- iii. Intermediate and long-term care
 - rehabilitation
 - day care and respite services
 - and long-term residential care.⁴

Where language or acquired language impairment exists, professionals need to provide accessible information, interpreters, and psychological interventions in the preferred language.¹²

i. Early interventions

There are a wide range of early interventions to meet the needs of people with dementia and their carers at the early stages of the illness, including medication such as antidepressants, and psychosocial interventions such as peer support groups, education, and counselling.¹⁵ Research suggests that medical interventions should not be used alone but combined with psychosocial approaches.¹⁶

Psychosocial interventions

Education and psychosocial interventions which include, information, advice and support, for newly diagnosed people is a priority and helps people with dementia and their carers cope with the psychological distress caused by the impact of a diagnosis and the implications, including potential losses.^{4,5,7}

In a study of an intensive structured psychosocial intervention programme involving tailored counselling, education and support groups for people with mild Alzheimer's disease and their spouse carers, support groups were valued.¹⁷ People with dementia felt motivated by their peers; had better self-esteem; felt supported in finding strategies to manage everyday life; and experienced better social relations. Caregivers were better able to cope with the challenges of managing their partner's condition, and they were also more confident with social relations. The study indicates that early tailored counselling and support may improve outcomes for individuals and maintain wellbeing.¹⁷

Dementia advisor role

The dementia advisor should be a single point of contact for people living with dementia, providing information and signposting to local services. They can help to identify any problems the person with dementia or their carers may be experiencing, and help refer individuals, without delay, to the most appropriate specialist services available.²

Memory clinics

Memory clinics have a key role in improving diagnosis and care.^{18,19} They have extended their remit from diagnosis to also providing post diagnostic treatment and care coordination, particularly after the introduction of anti-

dementia drugs (cholinesterase inhibitors) in the 1990s.⁸ But there is no substantial evidence to show that memory clinics are better able than GPs to support people with dementia and their carers in terms of post-diagnostic treatment and coordination of care.⁸

ii. Community support

Early referral to appropriate services in the community is an important factor in improving the quality and effectiveness of dementia care.²⁰ However, not everybody with dementia will have the need for community support shortly after a diagnosis, for example, those who live independently or rely on their family for help.

Community mental health teams CMHT are a key part of dementia care provision in the community.⁴ In particular, community mental health nurses have an important role in offering emotional and practical support to people with dementia and their families who have been recently diagnosed and one study reported that training that incorporated counselling skills made a significant impact in addressing a person's psychosocial needs arising from the difficulty of getting a diagnosis.¹⁰

iii. Intermediate and long-term care

Intermediate and long-term care includes: rehabilitation; day care and respite services; and long-term residential care.⁴

Rehabilitation

Where approaches to rehabilitation are holistic and encompass wider aspects of care including, physical, mental and spiritual interventions with a focus on improving overall wellbeing, more positive outcomes are said to be reported for people with dementia.¹⁶

Day care

Traditional day centres that do not specialise in dementia may not be appropriate for individuals unless specialist services in small group settings or a drop-in basis are also included.^{4,21} Family carers can benefit from community respite services, providing anything from a few hours to several weeks respite.⁴ In one study, the most common reasons cited by people with dementia for unwillingness to attend day services were the belief that they did not need day services, that they preferred their own company, a belief that they would not enjoy it; and concerns about losing their independence and being institutionalised.²²

Care homes

In 2007, about half of people with dementia were living in care homes, and despite the aim of post-diagnostic dementia care services to enable people to live well in their own homes, sometimes residential care is the only option when the condition is too advanced.⁴

Informal support

Changing family structures and lifestyles and geographically dispersed families have led to a wider range of relationships where people may give or receive care and support.⁵ Informal support is also essential in locations where access to formal specialist post-diagnostic services is limited.²³ England's National Dementia Strategy places importance on the role of formal and informal peer support.²

Support groups range from time-limited educational programmes to less formal peer support groups.⁴ Support groups should provide opportunity for people with dementia and their carers to come together and meet

others in a similar situation (the social aspect) as well as provide psychological (strategies for coping) benefits.²⁴

Memory cafes

An example of informal peer support is the memory cafe, which provides an environment where people with dementia and their carers can come together in an informal environment and seek advice, support and signposting.⁴ Memory cafes are organised by local branches of Alzheimer's Society and Admiral Nurses.⁵ An evaluation of Ashton, Wigan and Leigh Memory Service, (an eight-week support group for people newly diagnosed with dementia), concluded that people with dementia experienced positive outcomes such as decreased anxiety and depression and general increase in emotional wellbeing. The service addressed topics such as: practical issues concerning medication, legal aspects; grief and loss; memory aid techniques; and how to maintain daily activity.²⁵

Family caregiving

With the majority of people with dementia being cared for by a spouse or relative, the significance of the family carer role is now even more recognised.⁴ Carers face enormous responsibility in terms of having to make key decisions that affect them and their relative and will need information about dementia and the treatments and services available, as well as legal, financial and benefits advice.¹² As well as access to emotional support, recognition of their own health needs is essential.¹²

A review of the effectiveness of support groups for carers of people with dementia, found that support groups have a significant positive effect on carers' psychological wellbeing, depression, burden, and also provide a social outlet.²⁶

Implications from the research

The research suggests that people living with dementia and their families strongly value continued intervention following diagnosis – especially information, support and advice to help them adapt to the changes to their lives following diagnosis.³

The carer's role needs to be acknowledged and if they are supported properly and well informed, people with dementia also benefit and this can delay the need for residential care.¹²

Community mental health nurses have a potential role to implement counselling interventions that allow people with dementia and family members to develop effective strategies for living with early stage dementia.¹⁰ It is necessary to carry out research into the views of people with dementia and their families on the provision of nurse counselling after diagnosis, and how this affects factors as wellbeing, use of active self-care strategies, and use of social support.¹⁰

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