

Meeting our needs?

- the level and quality of dementia support services in Scotland



Alzheimer Scotland
Action on Dementia

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Fay Godfrey, Alzheimer Scotland

Rachel Guy, Alzheimer Scotland

Kirsty Jardine, Alzheimer Scotland

Jan Killeen, Alzheimer Scotland

Jim Jackson, Alzheimer Scotland

Maureen Thom, Alzheimer Scotland

Dr Gillian Wilson, formerly Alzheimer Scotland

The research was carried out by Lindsay Kinnaird; the report was written by Lindsay Kinnaird and edited by Kate Fearnley Alzheimer Scotland.

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Executive summary

1 Introduction

- 1.1 Community care services are an essential support for people with dementia and carers alike. This study examined three of the most important services: day care, home care and overnight respite.
- 1.2 The views and experiences of people with dementia, informal carers and professionals combine to reveal a picture of community care services under considerable pressure.
- 1.3 Effective community support services are fundamental to the successful delivery of current health and social care policy, but previous studies have shown that the necessary support for carers and people with dementia to cope with the illness is not always available.
- 1.4 Dementia is a key health issue facing the nation. There will be a 75% increase in the number of people with dementia in Scotland by 2031.
- 1.5 The Scottish Government has identified dementia as a national priority.

2 About the study

- 2.1 Interviews were carried out with social work care managers in 17 Scottish councils to obtain their views and experiences of the level and quality of community care services for people with dementia relative to the demand they encounter.
- 2.2 A population needs assessment was carried out. The proportion of people with dementia who should be receiving community care services in each council area was compared with the number recorded as receiving services.
- 2.3 A freedom of information questionnaire was sent to all 32 Scottish councils asking about the provision of day care, home care and overnight respite services for people with dementia. Councils were also asked for a copy of their current operational eligibility criteria.
- 2.4 Approximately 160 carers and 70 people with dementia provided their experiences and views on community care services.
- 2.5 The study was designed to give a general picture of community care services for people with dementia across Scotland; it is not a comparison between councils.

3 Who needs a community care service?

- 3.1 Health Department Letter (2004) 44 estimates that 28% of people with dementia should be receiving community care services, but does not provide a specific target for day care, home care and overnight respite.

- 3.2 National statistics show considerable unmet need and wide variation between councils in the proportion of people with dementia receiving day care and home care services. However, deficiencies with these statistics mean we cannot be certain how many people with dementia are receiving these services. In addition there are no dementia-specific national statistics on the number of people receiving overnight respite.

4 Study findings

- 4.1 Many community care services provide appropriate support to people with dementia and their carers but both those arranging services and recipients reported difficulties with availability and quality.
- 4.2 Most councils had a waiting list for day care. Some councils also had a delay for home care services.
- 4.3 Specialist dementia day care was valued by people with dementia, carers and social work care managers alike. However, there is a shortfall in day care provision appropriate to the needs of people with dementia in the majority of councils.
- 4.4 There is a lack of alternatives to day care for people with dementia and an over-reliance on traditional models of day care.
- 4.5 The majority of home care services are task orientated rather than support orientated; people with dementia are not being assisted to carry out tasks in order to maintain skills and a level of independence.
- 4.6 There is a shortfall in the level of home care provision in many councils. The amount of time care workers are allocated for each person means they are often under pressure to carry out tasks quickly and move onto the next person.
- 4.7 The vast majority of overnight respite for people with dementia is provided in care homes, with a lack of alternatives to meet the varying needs of people throughout the different stages of the illness.
- 4.8 Some care managers reported a lack of understanding of dementia amongst home care workers and a fear within mainstream day care of working with people with dementia.
- 4.9 Councils' eligibility criteria for community care services differ, with a tightening of eligibility thresholds in many councils.

5 Conclusion and recommendations

- 5.1 This study has demonstrated serious deficiencies in the provision of core community care services for people with dementia. It is essential that steps are taken now to relieve the pressure on services and plan for the future increase in the numbers of people with dementia.

5.2 Alzheimer Scotland makes the following recommendations for action by the Scottish Government and councils:

- Increased provision of specialist dementia day care and development of the level and quality of day opportunities available for people with dementia.
- More time allocated to home care workers to:
 - enable a support-orientated service to be provided where appropriate
 - provide high-quality personalised care, recognising that rushing in and out is confusing and disorientating for people with dementia
 - acknowledge that more time may be required to provide services for people with dementia than for other care groups.
- Greater variety and choice in respite options that recognise different needs and the availability of overnight respite within the home as part of a package of care where appropriate.
- Improved training in dementia care for staff delivering community care services to people with dementia.
- Clear consistent council eligibility criteria for community care services that provide understanding of how decisions are reached and ensure people with dementia receive the same level of service, in accordance with their assessed needs, wherever they live in Scotland.
- A consistent standard of dementia-specific data collected at council level in a uniform format that enables accurate national statistics to be produced. This is essential for achieving effective strategic planning by providing an accurate picture of provision in each area and enabling analysis of the level of unmet need.
- Increased funding now for community care services to meet the current needs of people with dementia and future funding increased in line with demographic changes and the increase in the number of people with dementia.

1 Introduction

Summary

- Dementia is a key health issue facing the nation over the coming decades as our population ages; there will be a 75% increase in the number of people with dementia by 2031.
- The Scottish Government has identified dementia as a national priority.
- This study reveals a picture of community care services under considerable pressure.
- 27 councils spent less than their Grant Aided Expenditure on older peoples' services in 2005/06.
- Effective community support services are fundamental to the successful delivery of current health and social care policy.

Community care services are an essential support for people with dementia and their carers. This report combines the views and experiences of people with dementia, informal carers and social work care managers on the level and quality of community care services in Scotland.

The study examined three of the most important community services for people with dementia: day care, home care and overnight respite. It found that pressure on services and variable levels and types of provision mean that the right services are not necessarily available when and where they are needed by people with dementia and their carers.

1.1 Dementia

Dementia is the gradual and progressive loss of the powers of the brain. The most common cause is Alzheimer's disease; other causes include vascular dementia and Lewy body dementia. These diseases damage and kill brain cells which causes the symptoms associated with dementia.

There are currently 59,000¹ to 66,000² people with dementia in Scotland in 2008³, approximately 1,500 of whom are under the age of 65. Dementia is a major cause of disability in people aged over 60. It contributes 11.2% of all years lived with a disability, more than stroke (9%), musculoskeletal disorders (8.9%), cardiovascular disease (5%) and all forms of cancer (2.4%)⁴.

Dementia is a key health issue facing the nation over the coming decades as our population ages; there will be a 75% increase in the number of people with dementia in Scotland by 2031⁵. The Scottish Government has identified dementia as a national priority from 2008⁶.

1.2 Why people with dementia need community care services

An estimated 44% of people with dementia live at home and require care at least once a day; 13% live alone and a further 30% live with family⁷. People living alone need support and stimulation to remain independent for as long as possible, whilst those living with family require community care services to maintain and support the caring relationship.

Most care for people with dementia is provided by informal carers, typically a family member. Caring for a person with dementia is more complex and demanding than caring for someone with physical disabilities. The unpredictable and progressive nature of the illness affects the person's memory, understanding, judgement and personality. As a consequence carers of people with dementia endure high levels of stress and associated symptoms.

Yet it is clear from previous studies that the help which people with dementia and their carers need to support them in coping with the impact of the illness and maximising independence and quality of life has not necessarily been available. A 2006 survey of 334 carers of people with dementia revealed major gaps in the provision of services for people with dementia and their carers in Scotland⁸. Only 37% of those surveyed felt that the services available were sufficient for their needs; 30% said day care was unavailable for the person with dementia and 50% could not access home support. Almost all (99%) said they had to cope with stressful symptoms of dementia, such as no longer being able to leave the person with dementia alone, difficulties in showering and bathing and incontinence.

1.2.1 Day care

Day care services, usually provided in a day care centre, offer an opportunity for the person with dementia to socialise, and day care activities can also help the person to maintain skills. They also provide carers with a period of respite. Specialist services cater specifically for the needs of people with dementia, whereas there can be many different needs to accommodate within mainstream day care for older people.

Not everyone will be suited to day care; day opportunities such as support to participate in leisure activities are also important for people with dementia.

1.2.2 Home care

Home care provides support for the person with dementia to live at home and includes the provision of personal care, practical help and social support. These services are vital for people with dementia who live alone and also have an important role in supporting family carers.

Services should assist the person with dementia to carry out tasks when appropriate in order to help maintain skills and maximise independence. It is also important that home care services are responsive to the changing needs of people with dementia, which will fluctuate as well as increase over time.

1.2.3 Overnight respite

Overnight respite provides a short period of care: usually from one night up to a couple of weeks for the person with dementia, normally outwith the home. Respite should fulfil the needs of both the person with dementia and their carer.

As dementia is a long term progressive illness, overnight respite options should be flexible and adapt to changing needs so they can be an ongoing part of helping people with dementia to stay in the community.

1.3 Policy background

The aim of community care is to enable people to live for as long and as independently as possible in their own homes or in the community. Services should be needs-led. The Scottish Government is responsible for the policy direction and funding mechanisms of community care whilst councils have a duty to undertake community care assessments and put in place services to meet assessed needs.

The Social Work (Scotland) Act 1968 (as amended) forms the basis of community care regulations in Scotland and places the organisation and provision of welfare services with council social work

departments. The National Health Service and Community Care Act 1990 aimed to shift the balance of care from hospitals and institutions to community based settings; it placed a duty on councils to assess for community care services.

1.3.1 Funding of community care services

The majority of council funding is generic, which means councils allocate spending according to their locally determined priorities. Twenty-seven councils spent less than their Grant Aided Expenditure (GAE)^A on older peoples' services in 2005/06⁹.

New funding arrangements for councils are being put in place that will mark a shift away from GAE and ring-fenced grants. Councils will be given greater autonomy in deciding how resources are spent in return for contributing to the delivery of Scottish Government priorities. Improving support for frail older people and family carers including significantly extending respite and other carer support are included in these priorities¹⁰.

1.3.2 Current policy

In addition to declaring dementia a national priority, the Scottish Government has set targets for increasing the level of older people with complex care needs receiving care at home and improvements in the early diagnosis and management of people with dementia. The Government has also said that care should be anticipatory, assisting people to self-manage long-term conditions¹¹. Effective community support services are fundamental to the successful delivery of these policy priorities for people with dementia.

The *21st Century Social Work Review* recognised the need for social work to adapt to meet the challenges of an ageing population and greater complexity of needs. It highlighted the need to design services around the needs of people who use them and become better at preventing crises by responding early to emerging problems.¹²

1.4 Outline of report

This report describes the study undertaken by Alzheimer Scotland into the views and experience of social work care managers, carers and people with dementia on the level and quality of community care services in Scotland.

Chapter two outlines the purpose of the study and the research methods adopted.

Chapter three considers the number of people with dementia likely to need a community care service and compares it to the number of people recorded as receiving services.

Chapter four provides the study findings, bringing together the views and experiences of people with dementia, carers and social work care managers.

The final chapter outlines recommendations for action to address the problems identified by the study.

^A Grant Aided Expenditure is the method of calculating each council's indicative spend on each of its services based on its population needs. It is also the basis for calculating the amount of Revenue Support Grant the Scottish Government gives councils.

2 About the study

2.1 Introduction

The purpose of the study was to provide an understanding of current community care provision for people with dementia in Scotland, focusing on three of the most important services: day care, home care and overnight respite.

Different methods were adopted to examine the level and quality of these services from the perspectives of the person with dementia, informal carer and professional.

The study was designed to give a general picture of community care services for people with dementia across Scotland; it is not a comparison between councils.

2.2 Population needs assessment

The proportion of people with dementia who should be receiving community care services in each council area was calculated. This was then applied to the number of people with dementia recorded as receiving services.

Given the short-comings in the statistics on the number of people with dementia receiving services, this chapter is provided as a context for the study rather than as conclusive evidence of the level of unmet need people with dementia have for community care services.

The population needs assessment is outlined in the following chapter.

2.3 Freedom of information request to all Scottish councils

A freedom of information questionnaire was sent to all Scottish councils. It asked about provision of day care, home care and overnight respite services for people with dementia. Councils were also asked for a copy of their current operational eligibility criteria for community care services.

Responses were received from 30 of Scotland's 32 councils. The value of responses was limited by inconsistency in answering questions between councils and some of the requested information not being available to councils.

Analysis of responses is presented in chapter four.

2.4 Interviews with social work care managers

Face-to-face semi-structured interviews were carried out with social work care managers directly involved in the care management of people with dementia in 17 councils; over half of Scottish councils, including urban and rural areas. Interviews were carried out over a four month period between September and December 2007 on an anonymous confidential basis. The participating councils are listed in appendix 1.

The interviews sought the care managers' views and experiences of the level and quality of day care, home care and overnight respite services for people with dementia relative to the demand they encounter. The interviews also explored eligibility for services.

Findings from the care manager interviews are presented in chapter four.

2.5 Questionnaire to carers of people with dementia

A questionnaire was sent to carers of people with dementia. The questionnaire asked for responses only from those who are currently caring for someone with dementia at home. The questionnaire was distributed through carer support groups and Alzheimer Scotland's membership list and services. Approximately 1,000 questionnaires were distributed.

Responses were received from just over 160 family relatives of people with dementia who were currently receiving, or would benefit from receiving, community care services. The majority of respondents were the person's primary carer.

The questionnaire sought their experiences and views of community care services and asked if the person with dementia received an appropriate level and quality of support. It also asked what additional services they required to support them in their caring role.

Analysis of the responses is presented in chapter four.

2.6 Questionnaire to people with dementia

A questionnaire was sent to people with dementia via an advocacy organisation, a day care service for people with dementia and Alzheimer Scotland's membership list and services.

Because of the nature of dementia it was known that many people would be assisted to complete the questionnaire. However, the questionnaire asked for the person with dementia's views as opposed to those of the person helping them to complete the form. It sought their experience of community care services and asked if they received an appropriate level and quality of support. Approximately 200 questionnaires were distributed.

Responses were received from 70 people with dementia who were receiving or required community care services.

Analysis of the responses is presented in chapter four.

3 Who needs a community care service?

Summary

- There is a lack of dementia-specific data on the number of people receiving community care services.
- Available statistics show a considerable level of unmet need for day care and home care services.
- There is a need for a consistent standard of dementia-specific data to be collected by all Scottish councils in order to provide accurate national statistics that reflect the level of provision and unmet need.

3.1 Introduction

This chapter considers the number of people with dementia who are likely to need a community care service and compares it to the number of people who are recorded as receiving a service, in order to provide the context for the study.

There is a lack of dementia-specific data on the numbers of people receiving community care services. In addition the national statistics that do exist on day care and home care are likely to under-represent the actual number receiving services, as some people with dementia will be included in the data on people aged 65 and over.

3.2 Estimating the number of people with dementia who need a service

Not everyone with dementia will have a need for day care, home care or overnight respite. People in the early stages of the illness may manage independently or with some help from family and friends. In the later stages of the illness there will be a need for full time care, with around 40% of people with dementia in long term care institutions such as care homes¹³.

The frequency with which care or supervision may be required by older people was measured by Isaacs and Neville¹⁴ and adapted by Melzer et al¹⁵ for people with dementia (table 1). However, this does not distinguish between people living in the community and people in long term care and thus does not provide an ideal basis for calculating the number of people with dementia who will require community care services.

Interval of need for care	% of people with dementia
Independent (not needing care)	6%
Long interval (care needed at some time during the week)	11%
Short interval (care needed at some time daily)	48%
Critical interval (constant care or supervision needed)	34%

Table 1: Interval of need for care for people with dementia

Health Department Letter (2004) 44¹⁶ adapts the Melzer intervals of need and provides approximate percentages of people with dementia who will need services at the different stages of the illness. It estimates that 28% of people with dementia should be receiving community care services^B. This would mean approximately 17,500¹⁷ people with dementia should be receiving community care services in 2008.

Based on this formula the number of people with dementia requiring community care services by council area is shown in appendix 2. Different levels of need will exist within this group; some people will manage relatively independently with a small amount of support whereas others will require an intensive package of community care services.

3.3 Day care

According to the most recent national statistics 4,232¹⁸ people with dementia received a day care service in 2006 (appendix 3). This is 7% of all people with dementia and 25% of those estimated in HDL (2004) 44 to need some form of community care service. There is wide variation between councils in the proportion of people with dementia who need a community care service reported to be receiving day care, with the highest level 69% in Glasgow, but 15 councils provided day care to less than 20%.

HDL (2004) 44 sets no specific target for day care, so it is difficult to know what level of under-provision this indicates. However, if the highest level of existing provision in Glasgow is used as a target for all councils, this would mean 64% of those needing day care (7,476 people or 12% of all people with dementia) were not receiving it in 2006. This is illustrated in Figure 1.

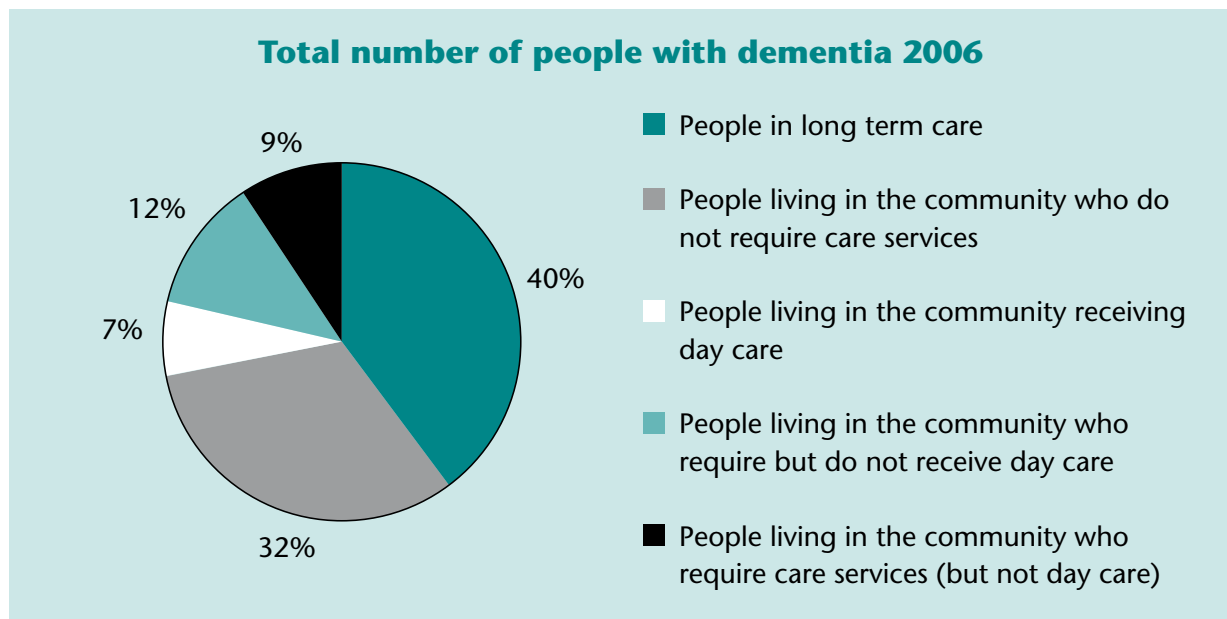


Figure 1: Proportion of people with dementia living in the community and in long term care

^B The estimated number of people with dementia needing care at least once daily is 44%. HDL (2004) 44 reached this 28% estimate by assuming, from those requiring care at least once a day, all people living alone in the community and half of those living with families require services.

Alzheimer Scotland’s report on short breaks in 2004 highlighted that 2,655 people with dementia received a day care service in 2001/02¹⁹. Therefore the level of unmet need has decreased over this period.

3.4 Home care

According to the most recent national statistics 3,679²⁰ people with dementia received a home care service in 2006 (appendix 3). This is 6% of all people with dementia and 22% of those estimated in HDL (2004) 44 to need community care services. As with day care, there is wide variation between councils in the proportion of people with dementia who need a community care service reported to be receiving home care. The highest level was in Dundee (54%), but 19 councils provided home care to less than 20%.

HDL (2004) 44 sets no specific target for home care, so it is difficult to know what level of under-provision this indicates. However, if the highest level of existing provision in Dundee is used as a target for all councils, this would mean 60% of those needing home care (5,484 people or 9% of all people with dementia) were not receiving it in 2006. This is illustrated in Figure 2.

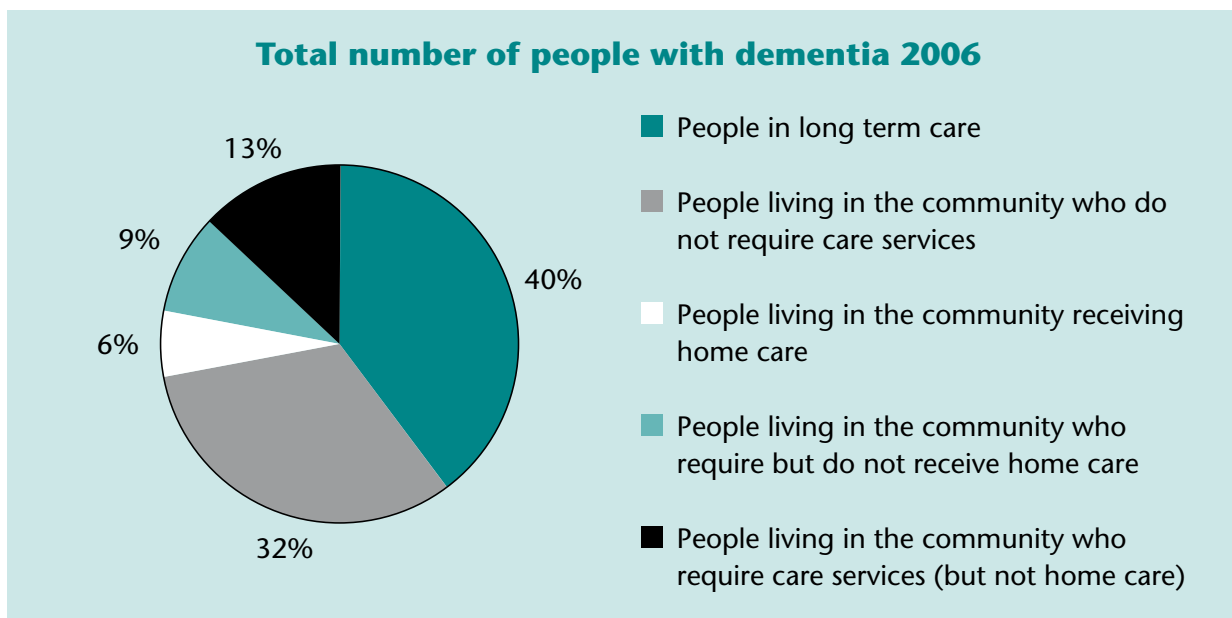


Figure 2: Proportion of people with dementia living in the community and in long term care

Alzheimer Scotland’s report on short breaks in 2004 highlighted that 3,662 people with dementia received home care in 2002/03²¹. There has therefore been no notable increase in the number of people with dementia receiving a home care service and the proportion of people with dementia receiving home care has fallen from 6.3% to 6.1%.

3.5 Overnight respite outwith the home

National statistics on the number of people with dementia receiving overnight respite do not exist. Audit Scotland collects information on total overnight respite nights provided to people aged 65 and over^c (appendix 4). These statistics show a wide variation in the number of nights provided by councils, ranging from 1,891 to 143 nights per 1,000 of the population aged 65 and over. They also highlight that most respite is provided in care homes and that in 12 councils this is the only type of provision.

^c This will include other care groups aged 65 and over and exclude people under the age of 65 with dementia.

A survey by Murphy and Archibald²² in 2004 found a total of 31,875 nights (4,554 weeks) were delivered to people with dementia living in the 15 Scottish councils that responded. The average percentage of people with dementia living in the community who received breaks was almost 12%. However, there was significant variation between councils in the number of people with dementia who received a short break, ranging from 27% to 1%.

3.6 Conclusion

Deficiencies with national statistics mean we cannot be certain how many people with dementia are receiving day care and home care services. In addition there is no national information on the number of people with dementia receiving overnight respite. The national statistics that are available show a considerable level of unmet need for home care and day care services.

The wide variation that exists between councils in the proportion of people with dementia receiving day care and home care reflects different recording practices by councils in addition to different levels of provision. The *Independent Review of Free Personal and Nursing Care in Scotland* highlighted the need for the Scottish Government and councils to improve local information and central monitoring of community care services²³.

There is a need for a consistent standard of dementia-specific data to be collected at council level in a uniform format that enables accurate national statistics to be produced. This would provide a true picture of the level of community care provision for people with dementia in each area and also provide an accurate measure of the level of unmet need.

4 Study findings

Summary

- Many community care services provide appropriate support to people with dementia and their carers but both those arranging services and recipients reported difficulties with availability and quality.
- Specialist dementia day care was valued by social work care managers. However, there is a shortfall in provision and a lack of alternatives to traditional models.
- Carers and people with dementia value home care and day care services. However, experiences are mixed and many are not getting the support they need.
- There is a delay in community care services being provided in the majority of councils; the stage at which the delays occur varies.
- There is a shortfall in day care provision appropriate to the needs of people with dementia in the majority of councils.
- There is a lack of alternatives to day care for people with dementia and an over-reliance on traditional models of day care.
- Most home care is task orientated; people with dementia are not being assisted to carry out tasks in order to maintain skills and a level of independence.
- There is a shortfall in home care provision in many councils; waiting lists were operating in three councils and all the necessary care is not provided in others.
- The vast majority of overnight respite for people with dementia is provided in care homes with a lack of alternatives to meet the varying needs of people at different stages of the illness.
- There is a lack of knowledge and understanding of dementia amongst people delivering community care services to people with dementia.
- Councils adopt different criteria in relation to determining who is eligible for community care service, with thresholds increasing in many cases.

4.1 Introduction

This chapter sets out the findings of the study. Interviews with social work care managers and surveys of carers and of people with dementia combine to reveal a picture of dementia services under pressure, where people with dementia cannot rely on their needs being met. It is a picture which varies between different councils according to the availability of appropriate services.

Many dementia services are successfully arranged and are valued by service users and carers. Several care managers praised specialist services that were meeting the needs of the person with dementia. However, both those arranging services and the recipients reported difficulties with the availability and quality of services. There is often a delay in receiving services and the service provided may not meet the needs of the person with dementia and the carer. There is particular concern over task-oriented home care, lack of flexible day care services and an almost universal and inflexible model of overnight respite which relies on provision in care homes.

This chapter includes the findings from interviews with 17 social work care managers, surveys of people with dementia and of carers and a questionnaire to all Scottish councils. The study was designed to give a general picture of community care services for people with dementia across Scotland; it is not a comparison between councils.

4.2 The general picture

The responses from the three groups in our study - care managers, carers and people with dementia - were consistent with each other. This section gives a brief overview of the findings from each group.

4.2.1 Social work care managers

In interviews with 17 social work care managers, nine praised specialist day care as providing an essential support to people with dementia. However, there was a shortfall of appropriate provision in many of the councils and a lack of alternatives for those for whom traditional models of day care were unsuitable. Some care managers said their home care service enabled people with dementia to maintain skills by assisting them to carry out tasks where appropriate. However, in the majority of councils home care was predominantly task orientated. Additional issues with home care included care workers not having enough time in the home to provide the required care and a shortfall in the level of home care provision in many councils. The vast majority of overnight respite was being provided in care homes, with a lack of alternatives and only one council routinely providing overnight respite at home. Most care managers said there was some level of delay in receiving community care services; the eligibility threshold for services was also increasing in a number of councils.

4.2.2 Carers of people with dementia

In our survey of 163 carers, where the person with dementia was attending day care, the majority considered the level of service provided sufficient for the person's needs. There were many positive comments about the service provided. However, in approximately 30% of cases the carer felt that the person with dementia needed more day care. Experiences of home care services were more mixed. A number of carers made positive comments about the standard of service provided. However, approximately 40% felt the care worker did not have enough time in the home to provide the required care and 28% believed that the care workers did not have a sufficient knowledge of dementia. In 70% of responses the person with dementia had not received overnight respite; when carers were asked what additional community care service would benefit them most respite breaks were the most needed service. Many carers commented on a lack of and unsuitability of respite provision.

4.2.3 People with dementia

In our survey of 70 people with dementia approximately 63% of people attended day care, with the majority considering the level of service provided sufficient for their needs. In 15% of cases the person would like more day care or would like to attend day care but had not been told about the service. Approximately 70% received home care; 16% of respondents felt the care worker did not spend enough time in the home to provide the necessary care. The majority of people with dementia had not received overnight respite, in many cases the person either did not want this service or the service was not required. Of the 26% of people who had received overnight respite one third had a negative experience that would reduce the likelihood of using respite in the future.

4.3 Assessment and waiting for services

Most care managers said that their councils have an open referral system whereby referrals come from a variety of sources including carers, family members and general practitioners. In some

councils referrals were predominantly from medical professionals as a result of social work care managers being aligned to community health care. Councils typically carry out an initial partial assessment of applicants, which is then used to prioritise the person on a waiting list according to level of need and risk involved.

The majority of councils had a waiting list for day care. There was also a delay for home care services in some councils, with three of the 17 councils operating a waiting list for home care services. In some other councils home care services built up gradually and there was a delay in the full package of home care being provided.

“There is a wait for home care services until money becomes available or circumstances deteriorate. We rely on informal carers to do things, usually the family who are under the most stress.” Care manager

Whilst there was some level of delay for services in most councils the stage at which the delay occurred varied. For example, in one council there was an average three month delay to be seen by a social work care manager, but after this delay services were generally put in place relatively quickly. In another council the assessment would be carried out within a month. However, there was a lengthy delay for day care and a waiting list for home care services.

Just over half of the care managers said there had been an increase in the number of people with dementia coming into contact with their social work service, placing pressure on existing resources and increasing waiting time.

“People with dementia are an increasing client group, but our staffing levels have not increased to reflect this. When I first came to this team 6 years ago we did not have a waiting list and now at times we have a waiting list of around 40 people with dementia.” Care manager

Responses from carers and people with dementia showed mixed experiences; some had managed to access services without difficulty whereas others had difficulty getting into the system or receiving appropriate services.

“When I contacted the social work department three years ago the response was quick and the service was excellent.” Daughter of person with dementia

“I contacted my GP about getting a care manager but was informed this was only provided if immediate care was required.” Wife of person with dementia

In our carer survey 85% of people with dementia had received an assessment of their needs. In 33% of cases when the person with dementia had received an assessment the carer had not received an assessment of their own needs as a carer and a further 19% of carers did not know if they had received an assessment. In our survey of people with dementia 25% had not received an assessment of their needs and a further 27% did not know if they had received an assessment.

4.4 Day care

Councils directly provide and commission day care services for people with dementia. In many councils people with dementia attend mainstream day care in the earlier stages of the illness and specialist provision as the illness develops. In our carer survey, in approximately 65% of carer responses the person with dementia attended day care: of these 55% attended specialist provision and 39% attended day care for older people^D.

^D The remainder attended generalist day care for younger people.

4.4.1 Level of provision

Whilst some care managers said the level of day care provision in their area was adequate for the need they encountered from people with dementia, most raised issues with the level of provision. In six cases there was an overall shortage of day care places appropriate for people with dementia, resulting in lengthy delays and restrictions on the number of days a person can attend day care. In other cases there was a need for more specialist services, longer days or weekend provision.

The questionnaire to all Scottish councils showed that the level of specialist provision for people with dementia varies between councils. In some councils specialist provision is very limited and in one council specialist day care is not provided.

Approximately 30% of carers who received day care services felt the level of provision was not sufficient. Similar to the issues raised by the care managers the need was for specialist day care, longer days and weekend provision.

"Weekend provision would be good as I have a teenage son and husband to consider."

Daughter of person with dementia

"Day care should be available every day for carers, people with dementia require constant care and four hours a day is only a small proportion of the time." Carer

4.4.2 Appropriateness

It was evident from people with dementia, carers and care managers that day care works well for many. It is fulfilling an important role for both the person with dementia and the carer.

"Day care is excellent, it not only helps the person with dementia it helps the carer. It gives you a part of your life back; I could never manage without their wonderful support." Carer

"I would have gone downhill without day care." Person with dementia

Many care managers said that specialist provision in their area provided appropriate activities and catered well for the different stages of the illness. However, some felt there was an over-reliance on traditional models of day care, with a lack of suitable alternatives. People with dementia had to fit the available service rather than services being suited to their needs. The Care Commission has highlighted the need for improvements in person-centred planning in day care setting²⁴.

"In this area many men have been involved in manual outdoor work and we then expect them to spend their time indoors. There is a gap for activities in recognition of the type of work men did."

Care manager

Lack of individualised care in two councils meant people with dementia would be stopped from attending day care as the service was not able to adapt to their changing needs. There was no screening in one council resulting in people at different stages of the illness attending day care at the same time. This restricted the ability to provide activities appropriate to the needs of attendees and could also be a distressing experience for people in the earlier stages of the illness.

4.5 Day opportunities

Not everyone will be suited to a group environment; some people with dementia will not enjoy day care and it is important that there are alternatives. Day opportunities are activities that provide stimulation for the person with dementia. They can be individual or group activities, for example support to participate in leisure activities or walking groups. In our survey of people with dementia 17% of people did not want to attend day care. The importance of stimulation for people with dementia who did not want to attend day care was apparent from carers' responses.

"My husband would benefit from support to enable him to go out and do activities such as bowling; he does not require actual day care but would love access to social activities and men's company."

Wife of person with dementia

The questionnaire to all Scottish councils showed that the level of day opportunities for people with dementia provided by councils varies widely, with ten councils not providing any. This is consistent with the findings from the care manager interviews, with a few councils facilitating a relatively wide range of activities, some providing a limited range and others not providing any.

"We have a team of support workers who provide social support with the emphasis on getting people out. We have also just introduced an arts support worker who visits people at home and can introduce them to art if they have never done it before." Care manager

"There is no alternative to day care, we have a sitter service but that is not stimulating." Care manager

4.6 Home care

The majority of home care services are provided by councils' own in-house or direct service organisations. Most councils use voluntary and private sector organisations to top up or complement their own service.

From responses to the carer questionnaire 63% of people with dementia received home care, with 70% receiving home care from the council's own service and the remainder receiving services from voluntary or private organisations or some combination of the three providers. The majority of home care provision for people with dementia is generic and specialist home care is relatively unusual.

4.6.1 Task orientated or support orientated

People with dementia should be supported to maintain skills in order to prolong maximum independence²⁵. People should be assisted to carry out tasks for themselves where appropriate instead of having things done for them.

A few care managers said there was scope within the council home care service to enable the person with dementia to carry out tasks with support. Two care managers said their home care service was very good at helping people with dementia to maintain skills.

"We look at what people are still able to do for themselves and encourage them to do it rather than taking over." Care manager

However, most care managers said their own council home care service was predominately task orientated. This was as a result of time pressure on the home care service and restrictions on the care worker's time within the home. Some care managers said they would go to an outside agency if they wanted the person with dementia to be assisted to carry out tasks.

A number of carers expressed concern at the time restrictions placed on care workers in the home and the impact this has on the service they can provide. One care manager said that in the majority of care reviews the families are concerned at the confusion caused to the person with dementia by the speed at which care workers come into the home and carry out tasks.

"Our own home care has a directive, so through no fault of the care worker, they are very task orientated." Care manager

"It is definitely task orientated, they basically do not have the time for assisting and it is far quicker to do something for someone, which is unfortunate really." Care manager

"Home care workers don't have enough time allocated to encourage independence so they do things which the person may be able to do with support." Carer

4.6.2 Time in the home

The amount of time care workers have within the home is key to the quality of service they can provide. A recent study of intensive home support for people with dementia found regional variations in the inclusion and non-inclusion of care workers' travel time within allocated care hours²⁶.

Most care managers raised difficulties with the amount of time care workers are allocated for each person or the appropriateness of the timing of visits.

The amount of time the care worker has for each person means they are often under pressure to carry out tasks quickly and move on to the next person. These brief visits can be confusing and unsettling for people with dementia. One care manager said this means the care worker cannot encourage the person with dementia to eat and the meal may still be sitting there when the next care worker goes into the home.

Some carers said the time pressures on care workers means they are not completing tasks and cut visits short. Approximately 40% of carers said the care worker did not have a sufficient amount of time in the home to complete the necessary tasks.

"Care workers are coming into a complex situation and have a number of tasks to do in a very limited period and then have someone else to see straight after." Care manager

"Sometimes I go into a house and the person can tell me what their care worker is doing for the next two hours, which should not be the case. They are telling the person so they do not have to stay for the full time." Care manager

"They come for less than the 30 minutes and often leave after 10." "The morning care workers don't have enough time to do all the tasks." Carers

The time of day that care workers go into people's homes are not always appropriate and a number of care managers felt these were inflexible. For example, 'tuck in' times may be too early

to suit the time the person would like to go to bed. One care manager felt that if the home care service could be more flexible in times they could go into the home they would meet needs better and enable the person with dementia to live longer in the community. Some carers also raised issues with the timing of visits.

“The prompt for medication is often at a worrying time for example a prompt for a sleeping pill at 18.30.” Relative of person with dementia

4.6.3 Restrictions on tasks

Ten care managers said restrictions on the tasks care workers were allowed to perform caused difficulty with maintaining people with dementia at home. In five cases this related to being able only to prompt for medication. In their experience this caused significant problems as people with dementia may forget to take medication or take too much.

“Medication is our biggest problem, carers are not allowed to administer, only prompt, and this sometimes leaves people only with the option of long term care.” Care manager

One council was operating a medicines management scheme in one locality to tackle this problem; care workers are trained to administer medication, supported by primary health care.

Housework was also an issue which caused difficulties in some areas. In three of the 17 councils care managers said that there were restrictions on both the tasks that could be done and the time allotted to carrying out housework. In two councils housework was not provided as part of their home care service. Care managers in these councils felt that this made people with dementia vulnerable if they purchased this service privately. One said it undermined a good care package if the person was then living in an unclean environment. There has been a reduction in the amount of domestic home support^E provided by councils in recent years²⁷.

4.6.4 Level of provision

Four of the 17 care managers said that the amount of home care provision available for them to access was sufficient to meet the level of need they encountered. However, most said the level of provision was not sufficient to meet demand. Waiting lists were operating in three councils and some care managers said they would not necessarily get the full package of home care they requested for a service user and needs would not always be met.

“I have a new referral who is caring for his wife whose dementia is quite advanced, he struggles to get her ready in the morning for the transport to the psychiatric hospital and I am not able to put in home care to help him because it is not available.” Care manager

Stricter decision-making processes had also been put in place in some councils for approving the home care services that care managers had assessed as being required by the individual. Restrictions had been put on the amount of outside agency care that could be purchased by care managers due to budget restrictions.

“Sometimes we are told we can only do half a package. Before we would just go to a private agency and get the service if our own home care could not provide it, now we can only do it if we get it cleared due to the budget restrictions.” Care manager

^E Domestic home support refers to non personal care services such as household cleaning.

4.7 Overnight respite and short breaks

Overnight respite should fulfil the needs of both the person with dementia and their carer. Respite should include activities, maintain independence and skills and be an enjoyable experience for the person with dementia. Dementia is a long term progressive illness, with care needs changing over time. Respite options should be flexible and adapt to changing needs so they can be an ongoing part of helping people with dementia stay in the community²⁸.

From carers' comments it is apparent that whilst respite has worked well for some, others have had bad experiences or were apprehensive about using respite. Only 30% of respondents had used respite, significantly less than those who received day care and home care; 7% did not know about overnight respite. In our survey of people with dementia 26% had received overnight respite.

"I did not know we could ask for breaks." "No one has mentioned respite." Carers

When asked what additional community care services carers would benefit from, respite breaks were the most needed service.

"My husband and I continue to support each other, my physical problems increase as his cognitive facilities decrease; I know a week of respite would help me to continue." Wife of person with dementia

4.7.1 Where breaks are provided

Overnight respite in a person's home is not provided by most councils as a part of a package of care. Many councils would only provide this care in exceptional circumstances to deal with emergency situations and for a short period only. Many care managers attributed this to the cost of providing this service. Only three respondents to the carer questionnaire had received overnight respite at home for the person with dementia.

"The lack of overnight care is one of the biggest failures of social work provision in Scotland."
Care manager

One council provided overnight respite in the home and this was charged at the same rate as overnight respite outwith the home. In the care manager's experience care at home worked well for some people but did not work for everyone, as some people become agitated with a person in the home.

It was apparent from the carer responses that overnight respite in the home is a service some carers would appreciate. Familiarity is important to people with dementia and a number of carers were reluctant for the person with dementia to have overnight respite outwith the home as they were concerned that the person's condition would deteriorate.

"I would be happy if someone could come and stay overnight and I could go to my parent's house for a sleep." Wife of person with dementia

The majority of overnight respite for people with dementia is provided in care homes. Six care managers said respite was also provided in other settings. These were very sheltered housing, a specialist dementia unit and in the home of a volunteer. National statistics on respite for those aged 65 and over show that the vast majority of respite is provided in care homes and in twelve

councils this is the only provision²⁹. In responses to our carer survey overnight respite had been provided in care homes in the vast majority of cases.

4.7.2 Appropriateness

Current guidance on respite highlights the need for respite to be needs-led and responsive to the service users' and carers' choices³⁰. New draft guidance on respite states that whilst traditional models of respite will be appropriate for some, service users and carers should be able to select from a wider variety of alternative options reflecting different needs and circumstances³¹. However, our study shows there is clearly a lack of variety and choice for people with dementia and their carers.

People with dementia need some freedom and independence during respite. A care home setting is often too restrictive for people in the early to moderate stages of the illness. A number of carers commented on the lack of suitable respite provision for younger people with dementia. Often younger people with dementia are offered respite in settings designed for the needs of older people. Some of those who had received an overnight respite commented on the lack of appropriate respite for their needs; a third of those who had received respite had a negative experience. These experiences included a lack of appropriate activities, the person wanting to be in their own home and personal items going missing.

"My husband would like respite care but the only current respite care available is in care homes which is not suitable as he is too young." Wife of person with dementia

"My last short break did not help as there was a limited range of activities; my memory is not good but my brain is fine" Person with dementia

4.7.3 Level of provision

The level of respite provision is a fluid concept. Typically councils will have some designated respite beds and additional provision will be purchased as required, meaning the actual level of provision is always changing.

"We could fill many more respite beds, the difficulty is we cannot fill them consecutively and as soon as a respite bed is available someone would say, 'look it was empty'. I appreciate a respite bed is never going to be a money spinner but it is a desperately needed service." Care manager

Four care managers felt the level of provision in their area was adequate and they did not encounter difficulties in gaining access to respite. However, most care managers felt that the level of provision available was not sufficient to meet the level of demand.

Many relied on the private sector to varying degrees. This proved difficult because of conflicting priorities, with private providers needing to fill beds on a long term basis. It was difficult to plan in advance in these areas, which resulted in carers not being able to plan their breaks in advance.

In contrast the difficulty experienced in other areas, where there was more use of designated beds, was the need to plan well in advance as designated beds booked up quickly. This meant carers were unable to have respite when it was needed most.

"Severe shortage of beds means booking up to a year in advance so I am unable to get a break when I really need it like now!" Carer

4.7.4 Entitlement

Benefit rules in relation to respite breaks are complex and hinder regular short periods of respite. If there is a minimum of 28 days in between periods of respite care, the person can receive as many overnight breaks as they wish without implications to benefit entitlement. If there are fewer days between periods of respite, the number of overnight breaks is cumulative, and benefits will be affected once the person has received 28 days of respite.

Most councils worked to a set maximum amount of respite weeks any one client can receive in a year. This was most often six weeks, but up to eight weeks in some councils. In most councils additional respite would be provided if necessary, but would be charged at the full cost rather than the subsidised respite rate.

Many care managers felt the set amount of respite was sufficient for most people and few would be accessing this amount. There had been a tightening in three councils and they were no longer able to promote a rolling programme of respite to people with dementia and their carers. People who had previously received respite breaks would be reassessed to see if it was necessary.

“Before I was able to promote a rolling programme of respite; people knew they had a break coming up. But we are not able to do this now and there are times when people don’t get the respite they really should.” Care manager

“I have just been told my care manager needs to reapply for funding for my 2008-09 respite and I will almost certainly lose part of my allowance.” Wife of person with dementia

In other councils there was not a standard amount of weeks set that allowed people to plan over the year. In one council respite breaks had recently been restricted to those at a higher level of risk and families were only receiving a planned package of respite in high stress situations.

4.8 Understanding of dementia

It is important that the people delivering community care services to people with dementia have an understanding of the illness and its effects.

“A lot of people think they have an understanding of dementia but they have not and it is just assumptions they are making.” Care manager

Three care managers said that within mainstream day care there was a lack of understanding and a fear of working with people with dementia. In two of these cases care workers were reluctant to accept people with dementia in the early stages of the illness and had to be reassured the service was appropriate to the needs of the person.

Some care managers questioned the level of understanding home care workers had of dementia. It largely depended on the individual care workers, and levels of understanding varied. This was an experience shared by a number of carers.

“Home care workers are very good or very poor, there is no quality standard.” “I don’t think the staff are supported or trained enough.” “Most carers are good but have very little training and understanding of dementia, some are scared.” Carers

One care manager said council home care workers were not properly trained to work with people who have dementia whereas another said that private home care workers are not aware of the significant issues when going into people's homes. A recent study of intensive home support for people with dementia found that care workers were not informed when they were contributing to the provision of intensive home support or provided with additional supervision in recognition of the complexity of the persons needs³².

One care manager said they felt their council was now doing a lot more to prepare and train home care workers for the job. Another said the home care workers had identified a need for training in dementia awareness and they hoped this would be delivered in the near future.

People with dementia may be reluctant to accept services initially and how the service is set up to deal with this is very important. One care manager felt they were lacking the persistence to work with people with dementia to build a relationship and encourage them to accept services. If people were very resistant then services may be withdrawn a lot earlier than would have been the case in the past. In contrast another council had a support worker who worked with people who were resistant to services; they could spend time with the person with dementia to build a relationship and encourage them to accept assistance.

4.9 Eligibility criteria for community care services

Eligibility criteria are a means of determining who is entitled to receive a service. People's needs are assessed against set criteria designed to ensure those with the greatest need and who are most at risk receive a service first. The criteria should also ensure that people are dealt with fairly and consistently and understand the basis on which decisions have been made.

Scottish councils determine their eligibility criteria for community care services. Audit Scotland's review of free personal and nursing care highlighted a considerable variation in how priority levels are defined, which it considered to be non transparent to the public³³.

In England the Department of Health set national eligibility criteria in 2003, which councils were required to adopt when responding to all new referrals and requests for assistance³⁴. English councils can still determine the threshold at which services become available; a Government-initiated review of councils' eligibility criteria is to be carried out in response to inconsistency in determining who is eligible for services both within and between councils³⁵.

4.9.1 Threshold for services

Audit Scotland's analysis of the thresholds at which services become available identified variation between councils, with some restricting services to the top one or two levels of priority, typically defined as critical and substantial needs³⁶.

Alzheimer Scotland requested a copy of the current operational eligibility criteria from each council (appendix 5)^f. There were significant differences between the eligibility criteria of the councils in terms of language used and clarity of content. Priority levels were similar in relation to representing a sliding scale of risk with the first category describing immediate crisis and subsequent categories reflecting diminishing urgency or level of difficulty for people in meeting their needs of daily living.

^f Four councils are currently reviewing their eligibility criteria and they were therefore not available for analysis. In a further three cases the councils did not have formal criteria.

Priority thresholds at which services became available differed between councils (appendix 5). Two councils restricted services to their highest priority group, with a further six providing services to their top two priority levels. Eight councils provided services to their top two levels of priority and would make services available to the third level when resources permitted. The majority of councils did not provide community care services to the lowest priority group.

4.9.2 Changes to eligibility threshold

Councils can make both temporary and longer-term changes to eligibility for services. A council may temporarily restrict the level at which services are provided in response to an impending budget overspend or they may make a longer-term policy decision to change the threshold at which services are provided. Audit Scotland identified a tightening of eligibility for services in some councils as part of their review of free personal and nursing care³⁷. The *Independent Review of Free Personal and Nursing Care in Scotland* also noted that a number of councils had tightened their eligibility criteria for access to free personal care since 2002³⁸.

In our study five of the 17 care managers said there had not been a recent change to the eligibility criteria and the threshold at which services are made available remained the same as before. However, the majority of care managers said there was a tightening of the threshold for services or a formal change to their eligibility criteria.

Two councils were in the process of reviewing their eligibility criteria. In one case it was expected it would result in a tighter restriction on the level at which a service can be provided. In the other case services would be limited to those in high priority need and would be withdrawn from those currently receiving services who did not meet this threshold. One council had reviewed their eligibility criteria and services had been reprioritised from three levels of need to two. Two councils had temporarily restricted services to new applicants assessed at the highest priority level in response to budget overspends. In one council the decision on who received services was now being taken at a higher management level and funding was provided in only high risk cases.

“If you cannot provide a service for everyone you provide a service for those who need it most - it makes sense but it represents another chipping away at the service we provide.” Care manager

“You really have to sell it in a way you never had to before, they keep changing the criteria, so we have to adapt accordingly to try and get the support - it is jumping through hoops.” Care manager

In other cases the tightening resulted in care managers having to be more persuasive and provide greater justification in putting their case across for people to be given community care services. In some cases people who might previously have received a service are now not eligible. Three care managers said that this tightening had not impacted on people with dementia as much as other care groups.

Other implications were lower risk applicants not being allocated a care manager, a reduction in the preventative work, and care managers case loads involving a greater proportion of complex cases than before.

“We are not in a position to be developing services; we are struggling to keep our heads above water.”
Care manager

“The kind of money spent on older peoples’ services does not correlate with the actual statistics so the increase in older people will mean a lot more demand than there will be resources.” Care manager

4.10 Conclusion

The findings of the study reveal serious inconsistencies and insufficiencies in the amount and quality of care services available to people with dementia living at home. Whilst many receive good services and are successfully supported, carers of people with dementia and care managers alike report problems, including:

- Delay for assessment and delivery of services.
- Insufficient provision of specialist dementia day care and of home care services and low use of respite.
- Inflexibility of service models, including a lack of alternatives to day care.
- Lack of support-orientated home care and lack of options for overnight respite.
- Lack of understanding of dementia among care staff affecting the quality of care.
- Differences in eligibility criteria and in service provision meaning that there is variation in what is available to people with dementia and carers in different areas of Scotland.

The picture is one of services under pressure, struggling with limited resources to meet existing needs. The availability of appropriate services for people with dementia and carers is shown to be reducing with tightening eligibility criteria and pressure on provision, at a time when the number of people with dementia is growing, and will continue to grow.

5 Conclusion

This study has demonstrated serious deficiencies in the provision of core community care services for people with dementia and their carers in Scotland. Service provision is inconsistent and often not of a sufficient level or quality to effectively support people with dementia and carers.

Although many people with dementia and carers receive good services and are successfully supported, there is great variation. Our study has revealed key deficits in the amount and quality of care services available. There is a shortage of specialist day care appropriate for the needs of people with dementia and a lack of alternatives for those not suited to day care. There is a lack of support-orientated home care that enables people with dementia to maintain skills.

Overnight respite is predominately provided in care homes, with a lack of flexible alternatives; our surveys of people with dementia and carers revealed a low take-up of this essential service. It is also worrying that many councils are raising the service eligibility threshold at a time when the number of people with dementia is increasing; delaying services until circumstances deteriorate may not be cost-effective in the long term and goes against the principle of anticipatory care.

It is essential that steps are taken now to relieve the pressure on services and address these deficiencies, given that the number of people with dementia is growing, and will continue to grow substantially over the coming years. The *Independent Review of Free Personal and Nursing Care* recommends that the Scottish Government begin planning now for demographic change and the increase in the number of older people³⁹.

Alzheimer Scotland makes the following recommendations for action by the Scottish Government and councils.

5.1 Recommendations

- Increased provision of specialist dementia day care and development of the level and quality of day opportunities available for people with dementia.
- More time allocated to home care workers to:
 - enable a support-orientated service to be provided where appropriate
 - provide high-quality personalised care, recognising that rushing in and out is confusing and disorientating for people with dementia
 - acknowledge that more time may be required to provide services for people with dementia than for other care groups.
- Greater variety and choice in respite options that recognise different needs and the availability of overnight respite within the home as part of a package of care where appropriate.
- Improved training in dementia care for staff delivering community care services to people with dementia.
- Clear consistent council eligibility criteria for community care services that provide understanding of how decisions are reached and ensure people with dementia receive the same level of service, in accordance with their assessed needs, wherever they live in Scotland.
- A consistent standard of dementia-specific data collected at council level in a uniform format that enables accurate national statistics to be produced. This is essential for achieving effective strategic planning by providing an accurate picture of provision in each area and enabling analysis of the level of unmet need.

- Increased funding now for community care services to meet the current needs of people with dementia and future funding increased in line with demographic changes and the increase in the number of people with dementia.

This study has revealed that all is not well with dementia services in Scotland in 2008. It is vital that action is taken now to redress the deficiencies highlighted in this report, and to plan and invest for the future.

6 Appendices

Appendix 1 - Social work care managers were interviewed in the following councils:

Aberdeen City

Aberdeenshire

Argyll & Bute

Dumfries & Galloway

Dundee City

East Ayrshire

Edinburgh City

Falkirk

Fife

Glasgow City

Inverclyde

Midlothian

North Ayrshire

Renfrewshire

Scottish Borders

South Lanarkshire

West Lothian

Appendix 2 - Number of people with dementia who need community care services by council area

2008	Number of people with dementia - Eurodem prevalence rates	Number of people with dementia -Dementia UK prevalence rates	Number of people with dementia who need community care services HDL (2004) 44*
Aberdeen City	2,588	2,314	686
Aberdeenshire	2,986	2,659	790
Angus	1,657	1,479	439
Argyll & Bute	1,422	1,269	377
Clackmannanshire	551	489	146
Dumfries & Galloway	2,372	2,115	628
Dundee City	2,055	1,842	546
East Ayrshire	1,494	1,326	395
East Dunbartonshire	1,420	1,266	376
East Lothian	1,331	1,188	353
East Renfrewshire	1,228	1,099	326
Edinburgh City	5,807	5,208	1,542
Western Isles	436	392	116
Falkirk	1,780	1,579	470
Fife	4,851	4,333	1,286
Glasgow City	6,475	5,776	1,715
Highland	3,048	2,722	808
Inverclyde	1,098	983	291
Midlothian	953	846	252
Moray	1,183	1,051	313
North Ayrshire	1,795	1,597	475
North Lanarkshire	3,443	3,043	908
Orkney Islands	289	257	76
Perth & Kinross	2,236	2,001	593
Renfrewshire	2,030	1,801	536
Scottish Borders	1,658	1,477	439
Shetland Islands	289	258	77
South Ayrshire	1,836	1,644	487
South Lanarkshire	3,766	3,349	996
Stirling	1,137	1,015	301
West Dunbartonshire	1,129	1,011	300
West Lothian	1,489	1,305	391
SCOTLAND	65,831	58,694	17,434

* Based on both Dementia UK consensus prevalence rates and Harvey/Hofman et al

Appendix 3 - Number of people with dementia receiving day care and home care by council area

	Number of people with dementia needing community care services HDL (04) 44	Number of day care attendees with dementia*	% of people who need a community care service who received day care	Number of people with dementia who received home care*	% of people who need a community care service who received home care
2006					
Aberdeen City	672	175	26	238	35
Aberdeenshire	748	135	18	132	18
Angus	427	85	20	37	9
Argyll & Bute	370	66	18	70	19
Clackmannanshire	141	69	49	34	24
Dumfries & Galloway	603	103	18	91	15
Dundee City	536	85	16	288	54
East Ayrshire	389	87	22	40	10
East Dunbartonshire	358	72	21	126	35
East Lothian	342	2	1	0	0
East Renfrewshire	311	153	49	44	14
Edinburgh City	1,513	158	11	544	36
Western Isles	114	22	19	21	18
Falkirk	459	112	24	137	30
Fife	1,243	177	14	339	27
Glasgow City	1,744	1,210	69	320	18
Highland	765	196	26	160	21
Inverclyde	287	75	26	76	26
Midlothian	247	14	6	38	15
Moray	299	39	13	88	29
North Ayrshire	464	117	25	86	19
North Lanarkshire	877	141	16	141	16
Orkney Islands	73	8	11	10	14
Perth & Kinross	569	91	16	35	6
Renfrewshire	528	187	35	96	18
Scottish Borders	429	52	12	26	6
Shetland Islands	73	26	36	17	23
South Ayrshire	472	98	21	60	13
South Lanarkshire	955	238	25	125	13
Stirling	289	51	18	29	10
West Dunbartonshire	298	71	24	74	25
West Lothian	375	117	31	157	42
SCOTLAND	16,968	4,232	Average = 25%	3,679	Average = 22%

Source: Scottish Government community care statistics

*Some of those receiving home care and day care services will be the same people.

Appendix 4 - Overnight respite population aged 65 and over

	Total overnight respite nights provided	Number of nights per 1,000 of population 65 plus	% of respite nights not in a care home
2006/07			
Aberdeen City	11,040	342	1.1
Aberdeenshire	13,839	385	4.5
Angus	6,898	336	0
Argyll & Bute	4,623	258	0.3
Edinburgh City	9,833	143	3.2
Clackmannanshire	4,488	608	0.8
Dumfries & Galloway	5,074	168	0
Dundee City	8,243	321	0
East Ayrshire	6,447	326	25.4
East Dunbartonshire	3,982	218	3.9
East Lothian	3,696	228	1.8
East Renfrewshire	6,953	464	15.9
Western Isles	3,632	679	0
Falkirk	7,789	339	5.6
Fife	16,977	287	2.2
Glasgow City	26,213	306	0.9
Highland	11,072	295	2.2
Inverclyde	2,526	180	20.9
Midlothian	4,103	327	not recorded
Moray	3,573	236	7.5
North Ayrshire	9,772	418	0
North Lanarkshire	10,023	214	0
Orkney Islands	2,317	655	0
Perth & Kinross	11,868	443	3.9
Renfrewshire	8,980	331	0
Scottish Borders	5,016	237	3.0
Shetland Islands	6,289	1,891	0
South Ayrshire	9,570	428	1.0
South Lanarkshire	18,932	389	0
Stirling	6,805	481	0
West Dunbartonshire	4,876	333	12.3
West Lothian	3,945	195	0

Source: Audit Scotland council performance indicators www.audit-scotland.gov.uk/performance

Appendix 5 - Eligibility criteria and provision of services

Council	Eligibility criteria
Aberdeen City	Under review
Aberdeenshire	Emergency/high/medium/low. Services made available to top two priority levels and made available to medium priority if resources available.
Angus	No formal criteria. Priority for services based individual needs.
Argyll & Bute	Very high/high/medium/low/ not appropriate. Very high and high assessed need will receive a service.*
Clackmannanshire	Priority 1 to 4. Priority for services based on individual needs.
Dumfries & Galloway	Information not provided.
Dundee City	High/medium and low. Those assessed as needing a service will receive it but may have to wait for elements of the package.*
East Ayrshire	Critical/substantial/moderate/low. Services available to all categories with the exception of low priority.*
East Dunbartonshire	Very high/high/medium/low. Services available to all categories with the exception of low priority.
East Lothian	Critical/substantial/moderate/low. Threshold for services currently set at critical and substantial needs.
East Renfrewshire	Critical/substantial/moderate and low. All with the exception of low will receive a service.*
Edinburgh City	Critical/substantial/moderate/low. Policy is to meet critical and substantial needs, current budget constraints mean only new and reviewed cases with critical needs receive a service.*
Western Isles	Priority 1 to 4, only priority1 will receive a service.*
Falkirk	Under review
Fife	Urgent/high/medium and low. Urgent and high priority receive a wider range of services than medium priority, low priority would receive information.
Glasgow City	Priority 1 to 4. All with the exception of priority 4 would receive a service.*
Highland	Critical/substantial/medium/low. Critical and substantial have priority for services, medium should receive services within 6 months, low priority provided with information and may be eligible for meals at home.
Inverclyde	Priority 1 to 5. Priority 1 and 2 would receive a service.*
Midlothian	Critical/substantial/moderate/low. Threshold currently set at critical and substantial, other priority groups would be kept on a waiting list in the meantime.
Moray	Emergency/high/medium/low. All levels will receive a service, there may be a delay or waiting list to provide service to moderate and low criteria.*
North Ayrshire	Critical/substantial/moderate/low. Services provided to critical and substantial only.

North Lanarkshire	Critical/significant/moderate/low. Critical and significant eligible for services, moderate needs will be met where resources allow and low needs will not be met.
Orkney Islands	Under review
Perth & Kinross	Priority 1 to 4. Priority 1 and 2 would receive a service, not normally provide a service to priority 3 and 4.
Renfrewshire	Priority 1 to 3. Priority 1 and 2 service priorities, priority 3 would receive a service when resources become available.
Scottish Borders	Critical/substantial/moderate/low. Critical, substantial and moderate considered for services. Higher needs prioritised for available resources.
Shetland Islands	Essential/needed/no risk - older people prioritised for services based on individual needs.
South Ayrshire	No formal criteria - older people are prioritised for services based on their individual needs.
South Lanarkshire	No formal criteria - older people are prioritised for services based on their individual needs.
Stirling	Priority 1 to 3. Priority 1 and 2 fully resourced, priority 3 within available resources.*
West Dunbartonshire	Under review
West Lothian	High/medium/low. High and medium assessed needs receive a service but those with a medium need may have to wait for the service to be provided.*

* **Supplemented with information from Audit Scotland's review of free personal and nursing care, as incomplete or no information was provided by the council to Alzheimer Scotland.**

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Meeting our needs

- the level and quality of dementia support services in Scotland

Community care services are an essential support for people with dementia and carers alike. This report is the outcome of a study investigating the views and experiences of people with dementia, carers and social work care managers across Scotland. It reveals a picture of dementia services under pressure, in which people with dementia cannot rely on their needs being met.

Whilst many people with dementia and carers receive good services and are successfully supported, there are serious deficiencies in the amount and quality of care services available. This report looks at the problems from the perspective of the professionals whose role it is to arrange services and the service users and carers who depend on them.

The report sets out key recommendations to challenge policy makers and community care planners to improve the level and quality of community support for people with dementia at a time when the number of people with dementia is growing, and will continue to grow.

Alzheimer Scotland
22 Drumsheugh Gardens
Edinburgh EH3 7RN

www.alzscot.org

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