NHS Highland area: Specialist dementia support for families, carers & communities – Research Project

Executive Summary

Supported by Argyll & Bute Council, the Highland Council and NHS Highland
1. Introduction

This report is the result of a 2 year research project undertaken by Alzheimer Scotland, funded by the Big Lottery and supported by NHS Highland, Argyll & Bute Council and the Highland Council. The project aim was to study the experiences of family carers living with dementia in NHS Highland area, with an emphasis on those living in rural locations, and to identify what could be done to improve support for families living with dementia.

The outcomes of the project were to:

- produce a resource guide for families living with dementia which was shaped by the views and experiences of the carers involved in the project
- produce a report that highlights models of best practice in supporting carers and provides recommendations to overcome barriers to accessing support for families living with dementia.

2. Context

The research took place at a time of great change within health and social care policy, with Scotland delivering its first National Dementia Strategy. In addition the ‘Promoting Excellence’ framework and the ‘Standards of care for dementia in Scotland’ were launched to enhance staff knowledge about supporting people with dementia as well as to enshrine the rights of people with dementia to support, involvement and to be treated with dignity and respect.

These changes come at a time of a rapidly growing aging population that will result in an estimated doubling of the number of people with dementia in the next 25 years from 82,000 to 164,000 nationally.

3. Methodology

a) Engaging with families

- Overall the project engaged with 137 family carers via semi-structured interviews, questionnaires and focus groups
- 52 interviews were conducted
- 48 questionnaires were returned.

b) Engaging with staff

Staff questionnaires were distributed. A total of 107 staff responded:
- 59 from Health
- 30 from Social Work
- 13 from the third sector
- 5 from the independent sector

Five focus groups and four interviews were conducted to further explore initial findings.
c) Engaging with General Practitioners
Questionnaires were distributed via Survey Monkey to GP practices across NHS Highland. 21 were completed, 15 were from Highland and six from Argyll & Bute. In addition 2 focus groups were conducted with GPs to further explore initial findings.

4. Findings

a) Diagnosis
More than half (54%) of those interviewed identified negative aspects of the diagnosis process when supporting someone through this stage, particularly those living in remote rural areas. The main issues related to:

- the time it took to get a diagnosis
- lack of explanation and information
- lack of involvement of family carers
- lack of staff consistency during the process of obtaining a definitive diagnosis
  - using the ‘D’ word: 39% of those dissatisfied highlighted staff being reluctant to use the word dementia with the person and the family
- lack of follow up support.

b) Information
Overall it was identified that carers were around twice as likely to have a negative experience as a positive one in relation to obtaining information. Again this was most common when families lived in remote rural areas.

The most common information that families received related mainly to:

- legal and financial issues (e.g. Power of attorney, guardianship etc)
- welfare benefits
- dementia, types of and symptoms.

This was most often provided by:

- Mental health staff (Consultant, physician or Community Psychiatric Nurse)
- Alzheimer Scotland (Dementia Link Worker or similar single point of contact such as Dementia Advisor, or via local services and resource centres, the Dementia Helpline, support groups or welfare service)
- Social work
- Carer Centres

Staff often have limited access to common dementia information resources used nationally:

- 60% of local authority staff identified they had no access
- 54% of health staff identified they did not have access.
- 39% of 3rd sector staff responded they did not have access.

Staff saw GPs as most responsible overall for providing information to families. However, in contrast, only 5% of family carers interviewed reported receiving information on any aspect of dementia from their GP. This highlights a disparity in relation to who it is perceived should and who does provide such information.
c) Impact of supporting someone with dementia
The impact can be far reaching and affect many aspects of family carers’ lives, particularly their emotional health and wellbeing. Common experiences were:
- increased social isolation
- strain upon family relationships
- physical health problems associated with stress, anxiety etc.

Social isolation, finances and family relations tended to have a greater impact on families where the person with dementia was younger (particularly in their early-mid 60s).

d) Support for the person with dementia
The most commonly accessed supports for the person with dementia were home care (52%) and day care (50%). The most beneficial supports were identified as:
- **Community based supports** (community and voluntary group activities): 62% of those who accessed this identified it as most beneficial.
- **Day care**: 58% of those who accessed this identified it as most beneficial.
- **Home care**: 29% of those who accessed this support identified it as most beneficial.
- **Mental health services** (Psychiatrist, CPN): 20% of those who accessed this identified it as most beneficial.

Families living in ‘remote rural’ areas (living over 10 miles from a small town of 3000 people or more) were less likely to access support:
- 42% of those living in remote rural areas and supporting someone at ‘mid – advanced’ stage of dementia were receiving **home care**, in comparison with 68% of those living in small towns or within 10 miles of a small town
- 33% of those supporting someone at ‘mid – advanced’ stage of dementia in remote rural areas accessed **day care**, in comparison with 64% of those living in small towns or within 10 miles of a small town

Other barriers identified by families included: unsuitability and inflexibility of support offered, cost and lack of awareness of support available.

e) Support for the carer
The most common supports accessed were:
- short term residential respite (37% of carers interviewed)
- home based respite (31% of carers interviewed)
- carer centres (23% of carers interviewed)
- peer support (21% of carers interviewed)

Supports identified as being of particular benefit by those who accessed them included:
- drop-in supports
- peer support
- respite, with emphasis on ‘home based respite’
Of those living in remote rural areas, 47% did not access any of the main types of support listed above, in comparison to 14% from rural areas and 21% from small towns or larger communities.

Other barriers to support included: unsuitability of what was offered, staff approaches and the inability to leave the person with dementia whilst accessing carer support.

5. Recommendations

Practice Recommendations:

a) The process of diagnosis should be conducted swiftly with immediate referral on to specialist staff for confirmation of the diagnosis, examination for subtype of dementia and provision of post diagnostic support.

b) Clear pathways of communication need to be established between:
   - the GP
   - specialist staff involved in diagnosis
   - agencies providing support post diagnostic support
   - the person with dementia and the family

c) Staff involved at diagnosis and post diagnosis stage should actively seek to involve not only the main family carer but also broader family and other natural support networks.

d) All staff involved in providing health and social care who have contact with families living with dementia, have a responsibility to ensure they have access to the relevant information and supports in their own area. Local resources can be downloaded from www.alzscot.org/familiesguide.

e) Families must be involved, informed and kept up to date. Attention needs to be paid to ensuring that those holding powers of attorney are involved in all Care Assessments and re-assessments. A copy of the completed assessment and the outcome of the assessment should be provided to the person and the family except in exceptional circumstances.

f) GPs and other staff involved with the family need to be proactive in ensuring the good health of carers due to the significant stress that accompanies caring for someone with dementia. GPs should maintain a carers’ register and promote frequent check ups.

g) Agencies need to work collaboratively and communicate better in order for families to have faith in the overall health and care packages and how they are delivered.

Service Delivery Recommendations:

a) The person with dementia should be at the heart of developing care supports that meet their needs and wishes. Local authorities need to ensure the option of Self Directed Support (SDS) is adequately promoted and people are supported to access it.

b) Agencies should look to expand upon forms of respite that allow the carer the choice of being at home or to be involved in meaningful activity within the community.

c) Local authorities should review the processes relating to Carers’ Assessments, to make it a more positive and worthwhile process for carers.
**Strategic Recommendations:**

a) A clear integrated pathway for diagnosis and post diagnostic support should be introduced across both local authority areas.

b) A single point of contact should be established for the family to access information, advice and support in line with the Alzheimer Scotland 5 pillars model of post-diagnostic support. This is also important at the later stages of the illness to ensure that health and social care is integrated, as is set out in Alzheimer Scotland’s 8 pillars model of community support for people with dementia.

c) Statutory service providers need to ensure there is no inequality of access to supports available for those living in remote rural areas.

d) There should be recognition from the local authorities of the value of providing forms of ‘low-level’ support out with the criteria traditionally used in assessing need, which often focus upon crisis intervention and priority of need. Such preventative measures of support can make significant economic savings in avoiding crisis situations.

e) Service planning and commissioning should be informed by a full knowledge and appreciation of existing services, community based assets and resources in order to maximise these, avoid duplication, utilise skills at a local level and optimise partnership working. The project highlighted good examples of partnership working to increase capacity for improving access to dementia specific support. Integral to this is the involvement and representation of people with dementia and carers in service design and planning.

**Capacity Building Recommendations:**

a) Statutory bodies and other relevant agencies should seek to ensure voluntary organisations and community groups are fully supported to ensure they have a clear understanding about dementia and ways of supporting people with dementia and their families, in order for communities to become dementia friendly.

b) Methods of delivering the main beneficial supports to carers should be examined to see how best they can be delivered in remote rural areas. This should include examination of use of telephone and internet based support.

c) Staff who are in direct contact with families living with dementia should be provided with training to ensure that they are skilled in carer engagement and at the appropriate level on the Promoting Excellence framework for dementia knowledge and skills.

Link to full report: [www.alzscot.org/carers-research-project](http://www.alzscot.org/carers-research-project)
