



“I’m not a complainer”:
Interviews with older people and
carers on their experiences of health
and social care in NHS Highland

FINAL REPORT OF RESEARCH FINDINGS
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Interviews

The interview number is placed in brackets following a name, quotation or reference from that interview. All interviewees have been given false names to protect their identities.

Abbreviations

AMD – Age-related Macular Degeneration
COPD – Chronic Obstructive Pulmonary Disorder
DNACPR – Do Not Attempt Cardiopulmonary Resuscitation
HSCN – Highland Senior Citizens Network
JIT – Joint Improvement Team
NHS – National Health Service Highland
OPAH – Older People in Acute Hospital
OT – Occupational Therapist
RCOP – Reshaping Care for Older People

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Foreword

“I’m pleased that somebody is listening. It might be some help.”

The report that follows is the culmination of an eighteen month Qualitative Research programme carried out by an experienced researcher on behalf of the Highland Senior Citizens Network. The project was funded from the Reshaping Care for Older People Change Fund.

The research was designed to capture the voices of Service Users and Carers who had received recent or current care in a Highland Hospital, Care Home or Care at Home. Those interviewed have been able to express their feelings with complete confidence and in the sure knowledge that their anonymity is safeguarded.

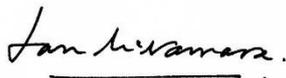
The voices that speak from the pages express their needs. They also express their appreciation and gratitude for good quality care when it is delivered. What cries out from the pages are that needs are not always being met, even though providers will know that this is often the case.

It is our purpose and resolve, as encapsulated in our motto, ‘Nothing about us without us’, to ensure that as older people we are included in designing and shaping services to achieve the desired outcomes that service users, their carers and service providers all desire.

This hope was articulated by one interviewee

“I think what you are doing here is great because maybe it will feed back through the system but it could also just end up in a great big thick document stuck down the back of a chair somewhere.”

To do justice to those interviewed it is vital that their needs are heard and acted on. The voices heard in the Highlands of Scotland will also be echoed across the whole of the country.



Ian McNamara (Chairman)
Highland Senior Citizens Network
April 2014

EXECUTIVE SUMMARY

"I'm pleased that somebody is listening. It might be some help." (17)

Patient consultation is essential to achieve policy imperatives concerning personalisation, self-management and co-production in health and social care services. HSCN has commissioned evaluative research to highlight the formative factors determining the effective delivery of older people's services in NHS and to offer insight into older people's perspectives and experiences of service quality. This independent user-led research aims to open up a dialogue with service providers and to facilitate patient-driven improvements in health and social care. The project has been conducted against the policy background of the integration of health and social care for adults, the Re-shaping Care for Older People initiative to shift the balance of care to the community and the drive towards 'person-centred' care outlined in the Healthcare Quality Strategy. NHS also has to address the demographic challenge of service delivery to the increasing older population in the Highlands. The Highland Council estimates by 2035 the number of people over 65 will increase by 79% and the percentage of older people aged 75+ will more than double.¹

Key research questions and methods

The project focussed mainly on older patients recently discharged from hospital and/or in receipt of care packages. Service users and their relatives were asked which elements of their services had worked well and what improvements, if any, could be made. Topics included home care, hospital care, discharge planning, care homes, transport and community-based services. Qualitative interviewing and data analysis were used to reveal the complexity of people's experiences, feelings and expectations of their services and the decisions they make about their care. Semi-structured interviews were conducted with a purposive sample of older people aged over 60 years and their relatives in Inverness-shire, Ross-shire, Sutherland and Lochaber. In total 34 service users, aged 62 to 94 years old, were interviewed along with 38 carers and relatives and six professional health and social care workers.

Summary of findings

On the whole there is satisfaction with medical treatment and nursing care, with interviewees praising hard-working staff in both primary and secondary care. Similarly people are generally happy with the quality of home carers coming into their homes. Good quality care homes with motivated staff, good leadership and a welcoming environment are also valued highly. Although the interviews show that older people appreciate their services and are very happy with many aspects of health and social care, there are several common emergent issues. Areas for improvement include:

- home care capacity and organisation
- hospital discharge planning and medication
- communication with relatives in hospital
- the eye clinic for AMD patients
- anticipatory care and 'rehabilitation'
- support for carers, day care and respite
- the quality of local care homes
- services for people with dementia
- public and patient transport in remote rural areas
- the NHS complaints system.

Key areas of user need

Older service users and carers appreciate caring, hard-working professionals who deliver high quality services and support them in living their lives as fully as possible. They are also clear about the difficulties they encounter and the issues they would like to see improved. Key areas of need arising from the interviews with older people and carers are outlined briefly below:

Home care

An integrated and reliable home care service with increased capacity and extended service range along a re-ablement model with longer visits and night care.

Hospital admission and care

- *Discharge planning* - involvement of relatives and medication ready at discharge
- *Communication with relatives* - contact person to answer questions and give information
- *Advocacy* for families and patients making decisions about care
- *Eye clinic* - information, advice and support for Age-Related Macular Degeneration patients
- *Dementia care* – appropriate high quality specialist care for people with dementia and extension of Butterfly Scheme
- *Anticipatory care* planning to reduce admission
- *Falls* reduction on wards amongst frail older patients
- *Dignity* in personal care arrangements

Carers

Recognition, support and information for carers with opportunities for respite and day care.

Care homes

High quality local care homes with support from volunteer 'lay' inspectors.

Remote rural areas

Local innovative solutions to service delivery issues like public transport, patient transport, respite and dementia care services.

Complaints system

Patients are supported to give their feedback and reassured there will be no impact on care.

Older patient voice heard

Independent user-led collection of feedback for quality assurance and service innovation.

The research shows that older people are happy with many aspects of their services but several areas for improvement emerge. Some issues are relatively straightforward while others are very challenging and would require significant resources to implement. The key challenge is keeping people at home and in their communities where they want to be. An integrated and holistic home care service is necessary to achieve this key RCOP objective. In addition it also requires the development of other vital support services such as transport, as well as strategies to tackle social isolation. Older people's views should be heard and valued. They should have more control over their lives and be allowed to participate in the planning, design and delivery of services on which they rely for their health and well-being.

1. INTRODUCTION

“It is about putting people at the heart of our NHS. It will mean that our NHS will listen to people’s views, gather information about their perceptions and personal experience of care and use that information to further improve care”.²

Patient consultation and participation are essential to achieve policy imperatives concerning personalisation, self-management and co-production in health services. HSCN has commissioned evaluative research to highlight the formative factors determining the effective delivery of older people’s services in NHS and to offer insight into older people’s perspectives and experiences of service quality. This independent user-led research aims to open up a dialogue with service providers and to facilitate patient-driven improvements in health and social care. It identifies service priorities and care needs for older people, their carers and families to inform service planning and to ensure older people become partners in the design and delivery of the services on which they rely for their health and well-being.

The research employed qualitative research methods to collect and analyse the views of older service users and carers on health and community services in Highland. Qualitative interviewing and data analysis were used to reveal the complexity of people’s experiences, feelings and expectations of their services and provide insights into the decisions they make about their care. The project focussed mainly on older patients recently discharged from hospital and/or in receipt of care packages. Semi-structured interviews were conducted with a purposive sample of older people aged 60 years and over and their relatives in Inverness-shire, Ross-shire, Sutherland and Lochaber. In total 34 service users, aged 62 to 94 years old, were interviewed along with 38 carers and relatives and six professional health and social care workers. The research questions focussed on what has worked well, what should be improved, whether needs have been met and what are the service priorities for older people and carers. Topics included hospital care, discharge planning, home care, care homes, transport and community-based services. The aim has been to capture and understand as far as possible the patient’s journey through health and social services from their individual point of view. The focus is on the personal accounts given by the participants and the impact of navigating multiple services on older patients and their families.

The research has been funded from the Change Fund. HSCN commissioned this work with the intention of making it accessible to a wide public audience. In view of this, a brief outline of key policy issues relevant to the research themes is provided. It is not within the remit of this report to put forward a comprehensive review of policy but simply to highlight the current trends for those outwith the health and social care sector. Research methodology is discussed in Section 2, a thematic analysis of the interview data is presented in Section 3 and the report concludes with a summary of findings and an outline of key areas of need in Section 4.

Demographic and health context

By 2035 the population of Highland is estimated to be 255,257, an increase of 15.2 per cent from 2010. Over this time it is the 75+ age group that is projected to increase the most, more than doubling by 2035, which is greater than the rate for Scotland as a whole (Figure 1).

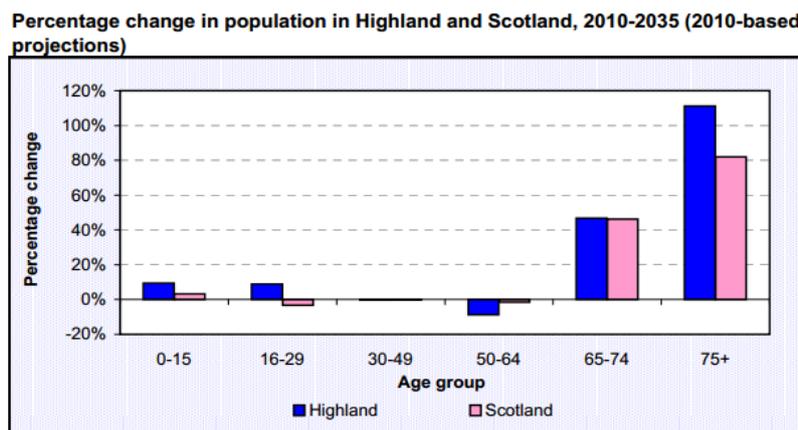


Figure 1
Highland Council Area Demographic Factsheet³
National Records of Scotland (27/2/2014)

The Scottish Public Health Network (ScotPHN) assessment of the health and social care needs of older people in Scotland reveals key characteristics which are significant in service planning and delivery for this increasing older population. It highlights the level of health need and the take-up of services amongst different age groups across primary and secondary care. For example in 2011/12 it finds 15.5% of GPs and practice nurse face-to-face contacts with patients were for those aged 75+⁴. The risk of emergency hospital admission and consequent lengths of stay not only increase with age but the average length of stay for 75+ age group is greater in rural and remote NHS Boards⁵. It finds more rural areas tend to have older populations⁶. Nearly one in four single pensioners (23%) and older smaller households (22%) are believed to have care needs, compared to 13% of all households with at least one person needing regular care. One in 8 (12%) of those aged 65+ provide unpaid care to someone inside or outside the home. As carers get older, the report suggests that they may take on more caring responsibility. The prevalence of limiting long-term conditions also increases with age. Two-thirds of adults aged 65 years and over reported a long-term health condition, compared with around one third of the 16-64 age group. Among those aged 65+, many have multiple, long-term conditions, requiring continuity and co-ordination of care⁷. The report suggests that the management of multiple, long-term conditions could be “*one of the biggest challenges facing the health care system*” (p. 68). The report concludes that:

“The data presented indicate that current health and social care needs of older people are substantial, but despite the presence of significant health problems, self-

reported health tends to be relatively good. The evidence suggests that, taking into account the projected demographic trend, needs will increase, but the way in which needs are met will have to change.” (p. 20)

Policy context

In order to meet this demographic challenge of a growing older population with increasing and complex health and social needs, older people have become a priority in policy-making and service planning. Implicit in this policy drive is the view that older people should be valued as an asset and not seen as a burden. The emphasis is on encouraging participation, choice, self-management and a sense of control in health and social care provision. Listening to service users and giving them responsibility is a fundamental principle of this direction in policy. Some key initiatives are summarised below.

Service integration

From April 2012 the integration of adult health and social care in Highland has meant NHS taking over essential services for older people such as care at home. Highland is in the forefront of the Scottish Government’s programme of reform of health and social care services. Integration aims to make health and social care provision *“joined-up and seamless”*⁸ in Scotland and will have an important impact on the care and welfare of older people.

Re-shaping Care for Older People (RCOP)

The Scottish Government ten year programme, Reshaping Care for Older People, aims to *“shift the balance of care”* by increasing anticipatory care, prevention and community services enabling older people to stay at home for longer⁹. In recognition that the increasing older population necessitates the re-design of health and social care services, the Scottish Government allocated an Older People's Change Fund to 32 Health and Social Care Partnerships. It aimed to enable the development of innovative services with an emphasis on health promotion and well-being and a move away from traditional models of institutional and hospital care. The Scottish Government outlines its vision in *“Re-shaping Care for Older People: A Programme for Change 2012-2020”* as follows:

“Older people in Scotland are valued as an asset, their voices are heard and older people are supported to enjoy full and positive lives in their own home or in a homely setting.” (p. 5)

The strategy emphasises that older people should be better informed about their options to allow them to be more involved in planning their own care¹⁰ and also highlights the importance of co-production and partnership with older people and carers:

“working with older people, their carers and the third sector to build an approach to providing care, based on co-production principles, to develop new community driven models of care provision, and to help older people maintain their independence wherever possible.” (p. 18)

Another RCOP theme concerns the creation of *“coherent and integrated care pathways that improve our ability to support people, particularly those with complex care needs, to remain at home or to move smoothly between services and settings.”* The update RCOP “Getting On” refers to the development of the Reshaping Care Pathway with four “pillars of interventions” namely, *“preventative/anticipatory care, proactive care and support at home, effective care at times of transition, hospital and care homes”*.¹¹

‘Person-centred care’

Patient centred care is a key priority for the Highland Quality Approach in NHH, which uses a triangle to illustrate the key aspects of their vision which places the individual at the top.



Source: NHS Highland
http://www.nhshighland.scot.nhs.uk/AboutUs/HQA/PublishingImages/hqa_figure1.jpg

The principle of ‘person-centred care’ underpins the current direction of health and social care policies which recognise service users are individuals who should be

agents in their own care. Person-centred care is one of the three Quality Ambitions in the Healthcare Quality Strategy and defined as:

*“Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrates compassion, continuity, clear communication and shared decision-making”.*¹²

In the Joseph Rowntree Foundation’s *“A better life: valuing our later years”* (2013) by Imogen Blood, one of the *“seven challenges”* stresses the importance of looking for the ‘individual’ rather than the stereotype:

*“We all need to make the effort to see and hear the individual behind the label or diagnosis, taking into account the increasing diversity of older people as a demographic group.”*¹³

Asset-based approaches, personal outcomes and empowerment

In *“Assets for Health”*, Sir Harry Burns points out that a sense of control is associated with better health outcomes. He explains how co-production uses an ‘assets based approach’ to help people have control of their lives by developing the capacities of individuals and communities¹⁴. The Health and Social Care Alliance Scotland explains how an assets based approach can empower people:

*“Asset approaches recognise that individuals and communities are part of the solution, work with people rather than viewing them as passive recipients of services, and empower people to control their future.”*¹⁵

In *“Talking Points: Personal Outcomes Approach - Practical guide”* Cook and Miller emphasise that service users and carers should be at the heart of the care they receive. A personal outcomes approach is about engaging with service users, identifying what is important to them and working together to achieve their goals rather than being service led¹⁶. This emphasis on participation also extends to carers. The Carers Strategy states carers should be *“equal partners in the planning and delivery of care and support”*¹⁷. The introduction of Self-Directed Support¹⁸ is intended to allow people greater choice and control over the way they are supported by giving them more control over their individual support budget to meet their particular needs. With a similar emphasis, ‘self-management’ also aims to empower individuals with long term conditions and enable them to have a sense of ownership while receiving all the appropriate support.¹⁹

Priority 1 of Scotland’s new national Action Plan for Human Rights 2013-17 is also empowerment²⁰. It calls for increasing people’s understanding of human rights and their *“meaningful participation”* in decisions affecting their lives. Priority 4 is concerned with achieving high quality health and social care. Initial aims under Priority 4 include:

“Putting human rights at the heart of health and care integration; pursuing a human rights based approach to independent living, self-directed support, and learning disability practice and to reducing health inequalities; increasing awareness of the rights of carers; and increasing understanding of human rights in mental health care and treatment.”²¹

Listening to service users

In his report of the “Mid Staffordshire NHS Foundation Trust Public Inquiry 2013”²², Robert Francis QC stresses the importance of listening to patients:

“In introducing the first report, I said that it should be patients – not numbers – which counted. That remains my view. The demands for financial control, corporate governance, commissioning and regulatory systems are understandable and in many cases necessary. But it is not the system itself which will ensure that the patient is put first day in and day out. Any system should be capable of caring and delivering an acceptable level of care to each patient treated, but this report shows that this cannot be assumed to be happening.” (p. 5)

Francis warns of the consequences of not listening to the patients, finding that in spite of staff and patient surveys indicating dissatisfaction, no action was taken:

“Trust management had no culture of listening to patients ... The failure to respond to these warning signs indicating poor care could be due to inattention, but is more likely due to the lack of importance accorded to these sources of information.” (p. 44)

He finds the Trust failed to prioritise patients and that *“patients and relatives felt excluded from effective participation in the patients’ care.”* (p. 46)

In summary the current drive towards personalisation, self-management and co-production aims to give the individual more control over the health and social care services on which they depend. Listening to and empowering the service user have not only become key priorities to deliver these policy imperatives, but are increasingly viewed as fundamental in promoting better health outcomes and safeguarding the patient.

2. METHODOLOGY

Qualitative research methods aim to provide an in-depth understanding of the perspectives of the research participants by examining their experiences and the way they make sense of them. In conjunction with a flexible design, a qualitative approach allows ideas and views to be expressed in order to capture the individual's experience and its context. People do not experience services in isolation but against the background of their life at home and in relationship with other services.

Sample frame

The research objective necessitated a purposive sample of older people aged 60 years and over who were using health, social and community services within the NHS Highland area. Relatives were also interviewed as appropriate for the following reasons:

- to reach the experiences of older people who were difficult to access e.g. people with dementia who did not have capacity to give consent or very frail people who were not well enough to be interviewed.
- to gain the relatives' point of view in recognition that relatives and full-time carers play an active role in supporting older people in the community and therefore have an important perspective to share.

This research aimed to interview a sufficient sample to reflect a range of ages, health needs and geographical location. Interviewees were recruited by two main routes as detailed below:

Gatekeepers

Gatekeepers from NHSH and the third sector introduced the project and obtained consent for passing on contact details to the researcher. The researcher then discussed the study with the potential participant prior to arranging an interview. This was considered an essential and appropriate way of accessing people, given the potential sensitivity of the issues involved. Participants were made aware that the study was independent of NHSH and assured that confidentiality would be maintained and participation was voluntary. A letter of access was obtained from NHSH Research and Development following a formal application process. The use of NHSH gatekeepers was an important element in recruiting participants. The older person or relative was approached by someone already known to them who could gauge their health condition and cognitive capacity, ensuring as far as possible the interview was not too onerous for the participant and consent could be obtained. This was essential in order to access a range of older people in differing states of health and levels of frailty, who might otherwise not come forward. Families were also involved where appropriate.

HSCN advertising and networking

Interviewees were sourced via HSCN advertising and networking with other local organisations.

In total 53% of interviews were sourced via NHS gatekeepers, 23% via HSCN networks, 13% by third sector gatekeepers with 8% making contact with HSCN directly and 3% referred from other interviewees. The interviewees came from Inverness (33%), Inverness-shire (17.5%), Ross-shire (17.5%), Sutherland (21%) and Lochaber (11%). Interviews were conducted with 34 older service users, 38 carers and six health and social care professionals. Of the 38 carers, 13 were aged over 60 themselves and therefore were also older service users in their own right. The age of the service users interviewed about their personal experiences ranged from 62 to 94 and carers talked about relatives aged 62 to 97. The age groups of both service users and 'cared for' relatives were reflected as follows: 60-69 (16%), 70-79, (23%), 80-89% (42%) and 90+ (19%). In total 62 interviews have been undertaken with 78 individuals. In addition seven follow-up interviews were carried out.

Interviews

Semi-structured interviews were the most appropriate method for gathering data for the following reasons:

- Sensitivity of the issues involved. People were able to talk about the health conditions, treatment and prognosis for themselves or their relatives. In several cases interviewees had been bereaved and were talking about the relative they had lost recently.
- Complexity of the issues – the interviewees were able to discuss different services and how they interacted.
- Feelings and values underpinning decisions could be discussed.
- Convenience of interviewees. Interviews were usually conducted in the participant's home which enabled people to take part in spite of difficulties due to health, mobility or access to transport.
- People could express their views freely in confidence.
- Context could be given.
- Flexibility to allow for participants' range of experiences.

Interviews were undertaken from December 2012 to February 2014 with follow-up interviews from September 2013 to February 2014. People were usually interviewed in their homes where further information was provided and written consent obtained. Some participants wanted to be interviewed with spouses or other relatives present. Where these people contributed, written consent was also obtained. The interviews were recorded and the average duration was 43 minutes.

The main question areas looked at the following:

- Health background
- Hospital stays and clinics – acute and community settings
- Home care packages
- Primary care
- Services in the community
- Care homes

Participants were asked what areas had worked well for them and what improvements, if any, could be made. They discussed what they valued and if there were there gaps in their provision. A thematic analysis of the data was conducted and this is detailed in the following section.

3. THEMES

The themes emerging from the interviews are examined in detail in this section. Each theme is followed by a few examples of longer patient stories. The themes are:

- Home care
- Hospital discharge
- Hospital care
- Delayed discharge
- Carers
- Care homes
- Remote rural areas
- Dementia
- Complaints
- Primary care
- Community services

Home Care

"To live happily in our own home we need carers who enjoy caring for old people. It can't be an easy job. We are not all made alike unfortunately. Most important for all of us is to see the same familiar faces as much as is humanly possible." (39)

The home care service is highly valued and provides essential support enabling older people to stay at home and allowing carers to cope for longer. Providers included both independent and NHS services. People receive up to a maximum of four daily visits to assist with getting up, dressing, showering, heating meals, taking medication, going to bed. The following aspects of home care services are commonly raised by interviewees.

Quality of carers

Home care workers are praised for the quality of care given and valued for providing both practical support and social contact. On the whole service users and carers found them to be caring, kind, attentive and hard working. Only three interviewees had felt concerned about a particular carer coming into the home and had complained informally to the respective provider, who had addressed their issues.

Older people appreciate the kindness and loyalty of their carers, who often go the 'extra mile' to help them out. After night time home dialysis, Sandy's (9) carer comes in the morning and puts the bags in the bin. She bursts the new bags and hangs them up so Sandy only has to connect them when he goes to bed. He cannot do it himself because his hands are too weak due to arthritis. This service was going to stop, but his carer refused to stop and says it only takes about five minutes. He is

very happy with his carers and he does not mind if they are late. They usually come between 7am and 8am, but he tells them to come whenever they want.

Hugh's wife (30) has dementia and is now waiting for a place in a care home. He was very happy with the home carers. They had a very good rapport with her. He felt they had been well trained and knew what they were doing. They always came on time. Hugh says "*I can't say enough for them*" and found they were "*absolutely first class*".

Lack of capacity

It is difficult to get home care in some areas and to obtain enhanced care packages when further support is required due to increased needs. This has implications for patient safety. Carers report struggling to get enhanced care packages. Tom (17) was 75 years old with dementia and assessed as needing four visits daily but his wife was told that the service could not be provided because there were no home carers available. Jessie said "*apparently once you leave Clachnaharry, we don't exist out here*". She was determined to get her husband home, saying:

"I've got to take him home. I can't leave him in there and I certainly will not put him to a home." (17)

Eventually Tom was able to come home with some extra home care following the installation of a stair-lift and improvements to the bathroom.

Longer visits

Longer visits would help to meet people's needs adequately particularly if they are very frail and/or have dementia. Carers are having to rush around so they can leave early enough to get to the next client. People think they are under too much pressure. Time for social contact is important as the carer may be the only person coming into the house that day. Longer visits would allow care packages to be more focused on the individual and their particular needs.

Alison's sister sometimes took their mother, who had dementia, for a little walk during the day and Alison says "*that's the kind of care that she needed and it couldn't be done in 45 minutes*" (2). Alison thinks in an ideal world a carer should be allocated for a morning for someone with dementia. A longer visit would mean the carer could take their time with the person who needs company and attention. Alison thinks the carers should spend more time with them so they can have a little chat and not just get them dressed and make their breakfast.

Organisation

Agreed rotas can break down. Lack of cover for annual leave or sickness has an impact on reliability and results in carers not turning up or arriving very late. Carers are asked to cover someone else's clients because of sickness or annual leave. Travelling plans that mean carers go from one area to another and back again. People think managers do not always understand local geography if they are not based locally.

A couple of times Hugh (30) said the provider could not send anyone and he did the care himself. For one day he was quite happy to help out. If one of the carers was ill, the replacements came in at exactly the same time which he thought was good for a person with dementia. In one case a couple (28) had no carer come to the house for four days as seen in the patient account below.

Interviewees have suggested improvements:

- bank of relief carers to provide cover for regular carers who are unavailable due to annual leave and sickness
- improved communication if carers cannot come – warning given and triggering of contingency measures
- 'zoning' of areas to reduce travelling times and enhance efficiency
- managers should be more 'hands on' and see how the carers work on the ground.

Consistency of carers

Having the same carers is essential for many people such as those with dementia. It is important for home carers to get to know the users so they can meet their needs, notice problems and provide a vital social contact.

Convenience

Sometimes visits are too early or too late in the morning. Times vary from 7.30am to 10.30 am. A few find they are going to bed very early in the evening and face a long time lying in bed before a carer returns in the morning to get them up. Concerns arise over skin care due to immobility as well as boredom and isolation.

Night care

Relief care at night would enable carers to get an unbroken night's sleep which would safeguard their own health and preserve their ability to care for their relatives at home.

Training and support for home carers

There is concern about an apparent lack of support or back up for home carers who encounter difficult and unexpected circumstances when they reach a person's home. The carer has no flexibility if the person is found in circumstances which necessitate more time due to, for example, states of confusion, ill-health or incontinence. Sometimes they are not trained adequately to deal with equipment such as an oxygen supply or to recognise emergent health concerns like deterioration in skin condition.

Re-ablement

Longer visits would enable home carers to help with re-ablement and promote independence.

Different providers

More than one provider serving one individual can be confusing.

Range of tasks

A need for other 'domestic' care has been expressed. For example, Nancy (39- see account below) who has osteoporosis and osteoarthritis, had help with carrying out and hanging up laundry in her care plan. At a six week review this was removed because it was classed as 'domestic'.

Remote rural areas

The '4 day on 4 day off' rotas do not necessarily fit in with other part-time jobs and may make it difficult to recruit staff. More flexible arrangements are needed in remote rural areas where many workers have several part-time jobs on which they depend.

Patient story (6)

Martin's mother had COPD and was becoming increasingly frail and she needed more care. Up to that point they had received help in morning and evening. Martin feels it was a battle getting it in the first place. They asked for additional care at lunch and teatime. When she came home from hospital, the GP came to assess her. There was a delay until the extra care was put in place. The family stepped in when his Mum was bedridden and they kept the care going. They didn't want her to go back into hospital. They had to wait six weeks between the request and getting the

extra care. By the time the enhanced package came, they were over the worst. He couldn't do everything because he was working. He didn't want to do all the personal care and felt it wasn't appropriate for him to do this for his mother.

They got the same carers most of the time but it wasn't always consistent. He believes older people need consistency particularly if they become confused. They would hand over a rota but there was always some kind of change. The family wouldn't mind if they got a phone call. Some of the carers were not trained to deal with the oxygen and they felt nervous about it. Luckily Martin was often there to show them but he didn't feel it was really his role. If his Mum had been by herself, what would they have done? Most of the carers were very good, caring and pleasant. His Mum enjoyed their company. Very occasionally they didn't turn up at all. Martin blames most of it on poor management:

"Their objective is to care, well that's not caring when the system is breaking down and the staff are under pressure and there's no backup".

Sometimes his Mum had to go to bed very early - sometimes 6.30pm or 7pm - but she didn't complain much. This would arise when the manager asks if another carer could fit them in if the regular one was ill. Martin thinks the OT assessment in hospital can be superficial and people should be seen in their home environment. They were waiting a few weeks for a stair-lift to be put in but his mother died soon after it was finally installed. Martin says:

"We didn't want to jump up and down too much ... everybody is very aware of the pressure that all the services are under but I think it is so important for people to get a thing when they need it."

Patient story (3 & 39)

Bob's Dad has dementia and was coming out of respite following his Mum's discharge from hospital after a stroke. They asked immediately for extra home care because of the impact of the stroke on her ability to care for her husband, Jim. Nancy's speech came back but her strength and mobility were affected. She also has osteoporosis and osteoarthritis. Bob says his Mum found it difficult doing domestic tasks. She could spend most of the morning trying to peel potatoes so they didn't have to eat frozen chips. Bob was desperate to get more help for his mother who he thought was exhausted and struggling to cope. He had to fight for it:

"The only way I got it to happen was by keeping asking for names further and further up the ladder."

At the six week review Bob found the staff member very condescending. She was going on about his Mum's independence but talking to her like a child. They wanted to reduce the home care hours again. His Mum got annoyed and insisted on having

the hours kept because she needed the help. Bob thinks they wanted to save man hours. They were also talking about cutting the half an hour to 15 minutes which he said was absolutely "*insane*". He describes the carer going in to the house next door and then heading off to a different area only to return to his Mum an hour later. He finds the quality of most care workers is very good. He doesn't think the service was particularly consistent or reliable with frequent changes in who is coming and when. However, he does think it has improved recently and they are better at turning up now. Nancy cannot straighten up her back and she finds it difficult to manage certain tasks. She uses a walking frame and finds it difficult to carry the laundry basket. Helping with hanging out wet laundry or putting it into the tumble drier had been in the care plan but the carers were now being told they were not allowed to do it. The carers tell his Mum they have time while she is eating to do something. Bob wants a "*common sense approach*". His Mum's carers help anyway without reporting it. At the review they told her that hanging up washing, etc. was domestic care and she had to pay for that. Nancy says it had all been itemised in the care plan – washing to be put in machine or hung up as requested – but it was to stop:

"Bless my dear carers ... They say 'What a piece of nonsense. You know, if we had ten minutes to do something, why shouldn't we?'" (39)

Patient story (28)

Doris is 85 years old and describes herself as "*reasonably fit*", although she suffers a lot of pain due to osteoarthritis in her shoulder. Her husband, Iain, is 88. In 2009 he had a stroke and later suffered a shingles related complication. He has been left with some loss of vision and hearing, reduced dexterity and impaired grip and difficulties with swallowing and talking. At the moment he also has a slight incontinence problem. Iain is no longer able to use his computer and finds it very difficult getting in a car. They have both given up driving. Iain misses driving his car. They live in sheltered housing in a village in a remote rural area. They use the local subsidised taxi and the community facility bus for local trips to the dentist and health centre. Iain gets around the bungalow in his wheelchair, but he finds the doorways are too narrow to make it easy manoeuvring. He gets support to attend the local lunch club, where they purée his food to make it easier for him. Doris says it does look horrible but thinks it's necessary so Iain can eat his meal. The couple said the community nurses were very good and had told them to phone up if there was anything that they needed. At the moment Iain receives two home care visits a day to assist with getting up, washing/showering and going to bed. Sometimes the timing of the evening visit means Iain has to go to bed very early but he is happy with this. Doris finds it very difficult to transfer Iain herself between the bed and chair.

The home care staff work on a 4 day on/4 day off rota. Generally Doris and Iain are very happy with the quality of care provided. One morning recently the carer did not turn up. The home care provider did not phone the couple to warn them, explain

what was happening or to check if they could manage without a visit. No one came for four days. When the next carer arrived four days later, the couple told them what had happened. The couple were never contacted by the provider with an explanation or apology. They were uncertain who the provider was and they did not complain. Doris said:

“Well, I’m not a complainer usually ... unless something really serious happens”.

Hospital Discharge

"I think it was just a Friday afternoon and they wanted to get as many people out of the beds as possible." (12)

Although there was satisfaction expressed with the discharge process, there were widespread problems experienced by interviewees as outlined below.

Lack of discharge planning

Patients and relatives are told they will be staying in hospital but then are subsequently discharged at short notice. This causes problems for both relatives and patients trying to organise suitable transport and make pickup arrangements. It can be particularly difficult for patients organising transport home to remote rural areas.

Following an operation on her femur, Esther (12) stayed in hospital for a couple of weeks. On Friday morning the physiotherapists checked she could get up stairs with crutches and they said she would be discharged on Monday. Esther intended to contact friends from the west coast to pick her up and take her back home to a remote rural area in the north. She was resting after lunch and remembers waking up:

"Suddenly somebody was shaking me and I looked up ... she said get up and get packed up. She said you're going to be discharged this afternoon ... but ... I've got to get friends to come and get me from Ullapool and I don't know whether they'll be able to come and meet me this afternoon. Well, she said you better start making those telephone calls" (12).

To Esther it felt like *"we've had enough of you, off you go"*. While Esther was waiting for her friends, a doctor came and said they needed to take a final x-ray. Esther was in the x-ray department when her friends arrived.

Raigmore pharmacy

Patients report having to wait for medication before they can be discharged. In some cases medication has followed patients home by 'taxi'. Medication is not always explained adequately to relatives and patients on discharge. Maureen's Mum was sent home with a big prescription of pills and the family didn't know what everything was for. Maureen does not think there is enough information given to relatives or enough communication between the hospital, the family and the GP:

"That happened lots of times where she'd be sent home with a big bag of medication ... but no information and no time to talk to us, you know. We just had to pick it up" (31a).

Patient transport

Long waiting times for patient transport are reported. For example, 76 year old Dolina (1) was told at 8.00 am that she had to leave the ward by 8.15 am. When she left, there was a woman sitting in the dayroom waiting for the bed. Dolina then waited for about five hours in the discharge lounge for patient transport. Her medication was not ready but she had to leave anyway because the transport had arrived and they couldn't guarantee when it would return.

Early discharge

In some cases relatives think older patients are being discharged too soon leading to re-admission to hospital. Isobel (4) was 80 years old and had COPD and osteoporosis. She was admitted as an emergency into hospital with breathing difficulties. Isobel was discharged to her own home one Friday but her daughter, Catherine, found her to be very poorly the next day when she went over to see her. Catherine called NHS 24 and a GP was sent out to see Isobel. At first the GP was very negative saying the hospital would not have sent Isobel home unless she was well enough. Catherine said she knew when her mother wasn't right. The doctor examined Isobel and then sent her straight back to hospital. Isobel had a chest infection and was put on steroids and antibiotics. Catherine found the GP's attitude awful and felt glad she had been there. What if her mother had had no family? Catherine says Isobel wouldn't have complained herself.

"It's just the old way ... doctors are up here and I'm down there and whatever they say is correct" (4).

Isobel was extremely ill and stayed in hospital for over a week.

Delayed discharge

Some patients and relatives describe waiting weeks for home care packages and care home places after being declared medically fit to be discharged. This is looked at in further detail in a following section.

Patient story (3)

Bob's mother was admitted to hospital after having a stroke. On Tuesday he was told she would be in hospital for a few days, but the following day they phoned to tell him she was getting out that day and asked if he could come and pick her up. Bob was told he could leave his car at the entrance and take his mother out in a wheelchair. When he got to the ward, a nurse said the discharge letter had not been completed and the drugs had not arrived from pharmacy. Bob was asked if he could come back in 2 hours. He admits he *"totally lost it"* and was *"fizzing"*. His mother

was sitting there waiting to be discharged. Bob took his mother home anyway and asked another family member to pick up the letter and drugs later in the day. The Social Worker had asked to be informed of the discharge date but hadn't been notified and consequently home care was not re-instated in time. After Bob phoned the out of hours Social Work Service, the carer eventually arrived later that evening.

Patient story 14

Frances's mother, May, was admitted to hospital from her care home with breathing difficulties. She had a chest infection and they were worried she might not make it through the night. May was very weak and sore and not herself for days. Frances found there was not a particular person that you could speak to in order to gauge how things were going. There is no ownership of the patient – they go into a receiving ward and then they are moved to different wards with different staff:

"For patients and relatives it's difficult cos you're speaking to a nurse one day and then it's a different shift ... you might arrive and the person's been moved and you don't know that".

Frances found it very difficult. The consultant changed and she wondered who to speak to about what was going on. She was frustrated:

"When you do ask a nurse, it's almost like goodness don't ask me, almost like a rabbit in the headlights, it's almost like oh no, no, it's not my problem ... head down"

In the old days Frances says you could phone a secretary and make an appointment to speak to a doctor, but you can only do that now if the doctor wanted to speak to you and she doesn't think that happens very often.

"You have to be quite tenacious really to speak to a medical person because you wouldn't know who to speak to ... and before you know it, the patient's home".

Frances thinks highly of Raigmore but finds communication with patients and relatives is very poor. The staff are very busy and you don't want to ask. Frances feels there should be a time set aside or a particular person allocated to tell you what's going on.

"As a relative ... you just don't want to ask. They are busy ... You just feel no, I'll just wait, I'll just leave it. Oh no, they're in their meeting."

May spent a week recovering, then she was discharged.

"As soon as there was a glimmer of improvement, she was home, back to the residential home again".

Frances had visited her mother the evening before but there had been no word about discharge. In the morning Frances got a phone call telling her not to come in because her mother was going home. Frances was very surprised, but she was told her mother had taken a turn for the better.

"Part of you is delighted and you think well that's marvellous ... but ... from [her condition] the night before I knew she couldn't have been [well enough], but home she went."

The care home thought May should go back into hospital. They phoned Frances and the GP. May was in a very poor state when Frances got to the care home. Frances was very upset and asked the hospital why they hadn't said anything to her the evening before. Why couldn't she have been kept another night? She was told *"well she was sitting up and looking out of the window this morning"*. Frances realises that they need the beds but she was very upset that she wasn't kept more informed. She was distressed to see her mother so ill:

"I was very upset at the state she was in and thought this is just awful that they would quickly turn her around."

Staff were nice but Frances blames the system. It was eventually decided to leave May in the care home although she seemed worse than when she went into hospital. Her mother was disoriented. She couldn't walk and hadn't been out of bed for a week. Frances says the discharge was not planned. The care home did not know about it either. Frances thinks if her mother was going back to her own home, the hospital would have kept her in. Frances wonders if it happens with care home patients because they have somewhere to go. However, Frances says they were sending her to a residential not a nursing home. They could all have coped better with it if they had been better prepared.

May was sent back to the care home without any drugs - it was all so quick. Patient transport took her to the care home but the drugs arrived by taxi afterwards. There was no discharge letter or morphine. Apparently they had decided to try her without morphine but Frances didn't understand how they could send her home without that. The doctor could try this in hospital but she felt you shouldn't do it and just send her home.

Patient Story (46)

Denis visited his wife, who has Multiple Sclerosis, on Sunday night and he asked a nurse if there was any word on her getting out. He was told no, she would be in a few days and she might be moved to another ward. Denis is over 65 himself and works full-time. On Monday he was driving away from the town when he got a call at about 10.30am from the hospital saying *"Oh Trish is getting home today"*. Denis

says "*this is happening all the time ...it's soul destroying*". Their daughter, Rona, happened to have a day off work so she organised transport for her mother. Due to her condition, Trish cannot travel in a conventional car any more. She needs to be wheeled directly into an accessible vehicle. She cannot be lifted. It was 4pm before her daughter could organise suitable transport to get her mother home. Denis says there is no follow up after leaving hospital. His wife was discharged on the Monday, but she'd only been home for 45 minutes and they had to phone the GP as she'd deteriorated. The GP didn't seem to know she was being discharged. Since then the GPs have been in nearly every day since. Denis says it's "*just madness*". They should have kept her in for longer. They don't blame the nurses but wonder why the District Nurse doesn't get told that Trish has been in hospital. They think maybe the whole discharge procedure could be improved. The daughter says waiting for patient transport is "*a complete nightmare, depending on how busy they are you can be there for hours*". It takes time to organise an appropriate taxi. Once she had to push her mother home in the wheelchair because all the taxis were occupied on the school run. They have to pay for a private taxi. In the past they have had to wait for the pharmacy to send the medication, but this time it was ready. Her daughter says as she didn't pick her mother up until late afternoon this time, they had known about the discharge since 10.00 am so they had time to organise the medication. The daughter says waiting for medication is "*par for the course*" and she would pick it up from the pharmacy herself if she could. She thinks it's a waste of bed resource. It could be a bit more streamlined and a lot of it comes down to communication. She doesn't feel the family is involved in discharge planning:

"They generally just tend to say she's being discharged and then we'll start running about trying to sort [it] out, cos I think they forget at hospital level that we have to make sure that her carers are back in place. Transport's a big thing for her because ... you can't get her in a normal car anymore ... I often think it's just a case of they reach a bed crisis and they look at it and go 'who can we send home?'"

Hospital Care

"The clinical care in Raigmore is second to none. It's other aspects of this that are the problem." (15)

The majority of these interviewees were very satisfied with the quality of the medical treatment and care received in acute and community hospital settings. Only a few were unhappy about the clinical treatment received and these are looked at in the Complaints section. On the whole people were also happy with the quality of their nursing care and the hospital environment. Issues raised included communication, care for people with dementia and overstretched staff.

Kindness and compassion

People valued being treated kindly with respect and compassion, being able to ask for attention even if they had to wait for a nurse to become available and feeling able to ask questions. Patients value and remember kindness, compassion and reassurance. Eileen was grateful for reassurance:

"[The nurse] got annoyed with me because I couldn't sleep. She said you must try to sleep but I remember one of the male nurses, he sat with me half the night, he made me a cup of Bovril, just talked you know, real just sort of reassuring" (48).

Another woman, a retired nurse herself, believes basic kindness and comfort are extremely important:

" put themselves in the situation of the individual they're dealing with ... think if you were in that situation ... a little tender loving care goes a long long way, a good night's sleep and decent food and some TLC goes a lot towards helping people and that's very simple, it doesn't cost that much." (52)

Rona went to hospital to pick up her mother, Trish, who has Multiple Sclerosis and is very immobile. She needs to be hoisted out of the bed. Rona went in to the ward with a wheelchair and the nurses said they could not help because they were busy. She could not move her mother because she was catheterised:

"To me that's their job, you know, and I appreciate there's a lot going on but it's just the ... body language is almost ... like 'what do you want now?'"

Rona said they were too busy talking about the Christmas party and who was going to have time off. She was not impressed. She says nursing is not just a job, it is vocational. It was not really appropriate and she says *"I just think it's just little things that make a difference"*. In another ward they are very attentive and they come and help to feed her mother because they know she can't feed herself. She thinks as *"individuals"*, the staff have been really good but it's *"systems"* which are at fault –

the NHS budgets and the communication. The nurses in the second ward were absolutely brilliant.

Maureen describes one ward as "*first class*" (31a) and praises the doctor, nurses and the auxiliaries. Although their mother was in a single room, they took such an interest, popping in and out. If the family asked for a meeting, the doctor gave them time and they all felt reassured. The staff spent time getting to know their mother and they all encouraged her. Maureen felt better with that kind of treatment and not so worried about her mother. The family took turns to stay with her and the ward never complained. The staff said they felt if some of the family were there, their mother would be more comfortable and "*they were more than delighted*". The doctor was "*so nice*" and every time he came in, he said thank you to them for staying because it made such a difference to their mother. She was settled with her family there. Maureen says "*at that point no nurse could give her the kind of attention she needed. She needed ... someone all the time*" (31a). Sometimes she would get up five times to go to the toilet. The nurses were extremely busy and it left them to get on. Maureen never saw anyone just standing about in that ward. She felt she could ask them questions. Her mother has been transferred to a community hospital but she is not very happy there. In a single room, Maureen feels her mother is just left. Maureen found five auxiliaries in the corridor chatting even though she could hear a buzzer going. It did not give a good impression.

Jen (16) was frustrated that the community hospital would not deal with her mother's mental health issues. She was screaming out in pain although the nurses insisted she had been given sufficient pain relief. Her mother had been on anti-depressants for many years and had now been taken off them:

"The nurse is saying it's all in her head but whether it's in her head or whether it's physical, it's still pain" (16).

Jen just wanted them "*to listen for a start*". They thought her mother was being "*wicked*". Her mother kept falling on the ward but the staff said it was controlled falling which she did herself, calling it an "*Oscar performance*". Jen didn't think they were making allowances for her mother's history of mental health problems. She was left alone a lot of the time. Jen's step-father often put her to bed and was there to help at meal times.

Communication and information

Communication with patients and families in hospital settings is a recurrent theme and a desire for improvement in terms of both quality and quantity is expressed. There are three clear strands – access to useful and accurate information, poor communication skills and lack of communication between services. Poor communication was one of the main problems identified by patients with Macular Degeneration, which is examined in detail below. In particular, relatives would like an allocated time slot or a named person so they have a ready and clear mechanism

to get information and updates about the patient. Relatives find it difficult to find out what is happening. They would like more access to senior staff who can answer their questions, which can otherwise remain unanswered for some time. They may be referred to the wider team but often find they do not get any information from them or that it may conflict with what they have already been told. Frances finds there is no single point of contact and on a busy ward with staff on changing shifts, it is not always easy to identify the appropriate person to speak to:

"You have to be quite tenacious really to speak to a medical person because you wouldn't know who to speak to ... and before you know it, the patient's home." (14)

Frances says communication can be very bad and there is no ownership of the patient as he/she is moved from ward to ward:

"For patients and relatives it's difficult cos you're speaking to a nurse one day and then it's a different shift ... but then you might arrive and the person's been moved and you don't know that".

In some cases assumptions are made about the patient and relatives' experience of the situation and extent of knowledge which can lead to insensitivity about diagnosis and prognosis. Jessie (17) went to see her husband, Tom, who had dementia, after he was admitted following a fall at home. She wondered why he was so sleepy and didn't seem to know her. Both she and her daughter were worried and asked the staff but didn't get an answer:

"They didn't tell me. I asked them. I asked why is he sleeping like that all the time and then he doesn't know where I am or who I am. You know, he was out" (17).

Tom was moved to another ward where Jessie found the experience completely different. On the new ward she was told that Tom had been heavily sedated but nobody had explained it to them. She had been given the impression that it was just a matter of time. On the new ward they stopped sedating him out and let him come back on his own which he did. Jessie says of the consultant: *"he explains everything so that you understand it you know ... and that's what I like about him"* She goes on:

"They're marvellous in Ward __. Marvellous. I can't fault them for anything, the nurses or the doctors, they're really marvellous" (17).

For some there is a power imbalance between doctors and patients affecting the relationship and the communication. Tina (40) describes her experience being treated for mental health problems. She found a power imbalance:

"When you are unwell ... it's hard to express your own views because you can be a bit muddled up, but even when you've recovered to the extent that you think you can express your own views ... they have so much more influence ... You just feel unequal somehow to them." (40)

Tina contrasts this experience to her present consultant who treats her as an equal. He did not make her take medication that she had requested not to take. He respected her views. She finds she can get on well with him - he is polite, punctual and has sense of humour.

Sometimes DNACPR forms can be handled insensitively. For example, Frances thinks it should not be the first thing mentioned to a relative because it is extremely alarming. The person's condition should come first as a way of preparing someone who may not realise how critical their relative's health is. Frances thinks if a doctor realises how bad things are, they should paint that picture first and say that it could go either way. They should make it seem like they are covering every area just in case rather than start with the worse scenario first. Then they could introduce the subject of the DNACPR form by asking what the person would want if things deteriorate. Frances says this would be more natural and suggests that the staff will try to do all they can. She says it seems to be the first thing people ask now and they do not lead up to it in any way.

Lack of staff

Patients find the wards are very busy and can appear understaffed. Sometimes patients and relatives do not like to 'bother' busy staff with questions or requests.

Dignity

Male staff members assisting older female patients with personal care can be distressing for some. It is not a problem for everyone and is also separate from medical care which is viewed differently.

Dementia care

Lack of dementia awareness and specialist training for staff in some wards is reported. Having patients with dementia on shared wards can cause distress to relatives and other patients, who can be disturbed by behaviour like walking around and shouting. Staff do not necessarily have the training or time to deal with the added care issues for people with dementia. The Butterfly Scheme has been praised and carers want their relatives treated as individuals and with respect.

Heather's (38) father has dementia. She says, crying, "*I feel like they've just given up on him*". She worries about her future because she does not have children to do these "*this awkward stuff*" for her. The family have been on "*a bit of a roller coaster*". In hospital the nurses asked him if he took the gout tablets and he said no, so they stopped giving them to him. However, even though he has dementia, they did not check with the family. In fact Heather's Mum gives him this tablet every morning.

Eye clinic for AMD

Patients are not given adequate information about sources of help for people with Macular Degeneration. There is no post-diagnosis counselling sign-posted or peer support given in the clinic. People do not necessarily know about the low vision clinic and information about aids and equipment can be inadequate. One interviewee says the doctors do not see beyond the present situation and "*the finer points of communication aren't there*" (52). Another described it as a "*big blight over the whole of that eye clinic ... everybody knows but you've got to know the questions to ask before they tell you*" (8). The onus should not be on patient to find help and support. Another person describes the effect of such a diagnosis:

"At the time you've been diagnosed, you're shell-shocked and what you need is, you need to talk to someone and have somebody there to listen to you." (55)

When Agnes (7) had first seen the consultant, he said he would see her in two weeks' time. No appointment came so a third sector support worker told her to go to casualty with a flask of tea and sandwiches because she was not happy Agnes had not been seen by anyone. Agnes sat in casualty for about three hours. When Agnes saw the consultant, he said it had been a mistake and they ought to have booked her in for two weeks' time but it had been booked for two months' time. She did not make a formal complaint.

Moira (8) wanted proper after-care. She says you are told you are losing your sight and you are turned out into a waiting room full of people. Your vision is blurred because you have been given drops. You need to be put in a room with a volunteer so you can talk to someone. Moira says there are things that can be done for patients. She says people have a need to talk and to find something they can do. It is the communication which worries her most of all. You cannot get information or ideas about what you should be doing. If she had lost her sight completely then she would need more care services. She wants to be as independent as possible in her own home.

Patient transport

Long waiting times are reported at the point of discharge. In remote rural areas it can be unreliable with transport being cancelled at short notice resulting in patients missing hospital appointments and having to wait weeks for new ones.

Risk of falls

Frail patients had fallen on the ward, sometimes sustaining further injuries, although relatives do not usually attach any blame to the staff.

Suggestions for hospital environment

One interviewee suggested that patients and visitors should use separate lifts in Raigmore to stop the spread of infection (30). Another suggested that there should be visitors' toilets on upper wards (41).

Patient story 2

Alison's mother has dementia and was admitted to hospital with a chest infection. When Alison's mother gets agitated, she likes to get up and walk around. This was difficult on the ward and the nurses tried to keep her in a room or ward. She started to get hostile. Alison had never seen her mother like that before. She was lashing out. It was very distressing. Alison didn't want to be disrespectful to staff, but she tried to go up there as often as possible. She didn't feel her mother was getting cared for adequately. Sometimes she wasn't dressed properly and had no underwear on. Other times she had food spilt down her. Alison went to shower her once or twice a week and to do her hair. It seemed to make her mother feel better. The staff didn't have time to deal with other extra needs:

"I never ever felt ... at ease when she was in hospital. We felt every spare moment we had we should be up there spending time caring for her and doing what the staff didn't have time to do".

One night her mother wanted to lie on her other side. Alison asked the staff for help, but the looks she got, they weren't nice. She felt like she'd interrupted their tea break. They weren't friendly. Alison believes all these things add to the upset when you are looking after someone. It makes you feel even more upset. The ward was forced to lock the door to stop her mother getting out. Alison felt mortified as she stood with other visitors waiting to get in and knew the door had been locked because of her mother. Alison got the impression:

"They just wanted her out because she was just giving them so much aggro and causing them so much extra work and they were already busy ... They were obviously not trained in dementia and, maybe quite rightly so, they weren't interested ... they just wanted to get her out so they could get on with the job they were doing. Once her medical care was taken care of they'd done their bit."

One nurse, whose father also had dementia, knew exactly what to do with her Mum and she was fantastic. Her mother used to call one of the nurses her "favourite":

"If she saw my Mum she would come over and just give her a hug or touch her cheek and give her a cuddle and my Mum thought the world of her."

Others she would call "not nice names" and Alison wondered what had happened.

About a year later her mother was admitted again with a broken hip, but this time the experience was entirely different. It was a different ward where they seemed to understand her and knew how to talk to her. They had the Butterfly Scheme which Alison thought was a nice symbol, a "*nice way to signify what they have*". They wrote down a bit about her mother such as the food she liked. This time she was confined to her bed so Alison thought it was easier for staff. It was a quieter ward and not so busy. Alison didn't feel they had to be up there all the time.

Patient story (32)

Terry is 91 and believes that:

"the general public and some of the people who are in charge have absolutely no idea the work that these girls and men [do] at the sharp edge, in other words nurses, doctors, physiotherapists, cooks, the lot. They're the finest workers that could be found and I have absolutely no complaints about any of them and they all do it with a smile, amazing, but the work they get through in a day." (32)

Terry was very happy with all aspects of his care including the food. He describes his transfer from the acute to the community hospital by ambulance as "*like being in a Rolls-Royce*". He says:

"I was treated like a personal person to them and nobody else. I was treated just with dignity." (32)

He does observe that hospital staff are very busy and thinks there ought to be more staff on duty. He was transferred from an acute setting to a community setting and there was only one little item to mention. He would get up about 7 am and sit in his chair. They don't like patients to go to bed until the night shift come on after 8pm. He was sitting for all that time:

"It's not a criticism, not a criticism, but you're absolutely exhausted to the core sitting doing nothing".

At the changeover, the staff have got so much to do. They might manage to put you to bed at 8pm but "*you mustn't be selfish*". He would have liked the option to go to bed earlier but he is adamant he doesn't want to criticise anyone. He knows it's the system. He wants to call it an observation not a criticism. On the whole they "*dealt with every problem they were confronted with*". For example, it became a bit cold and his neighbour asked for a heater which was put in straight away. He found the community hospital quieter, better for recuperation with time to think. The acute hospital was so very busy with noise all the time and people running around. Again he says this is "*no criticism at all*".

His sister took him home from the community hospital and the nurse took him to the car and showed him how to get in it. He was very happy with the OT assessment:

"It turned out that we were two very elderly people trying to do what youngsters do and we do [it] to the best of our ability."

He was also very happy with the OT service which delivered a raised toilet seat to his home on the day of his discharge. He says *"what a boon it has been"*.

Terry says *"Criticism is all round them every day of the week and I don't want to be part of it if I can"*.

Patient Story (4)

Isobel was 80 years old and had COPD and osteoporosis. She was admitted as an emergency into hospital with breathing difficulties. Isobel was discharged to her own home one Friday but her daughter, Catherine, found her to be very poorly the next day when she went over to see her. Catherine called NHS 24 and a GP was sent out to see Isobel. At first the GP was very negative saying the hospital wouldn't have sent Isobel home unless she was well enough. Catherine said she knew when her mother wasn't right. The doctor examined Isobel and sent her straight back to hospital. Isobel had a chest infection and was put on steroids and antibiotics. Catherine found the GP's attitude awful and felt glad she had been there. What if her mother had had no family? Catherine says Isobel wouldn't have complained herself.

"It's just the old way ... doctors are up here and I'm down there and whatever they say is correct".

Isobel was extremely ill and stayed in hospital for over a week. On one ward a doctor had filled in a DNACPR form without consulting the family. Isobel did not seem to be aware of it. Catherine looked at the form and found there was no printed name, only the signature of a doctor with no date. The staff nurse took her into a room and explained what it was all about. Catherine felt real shock and concern.

Isobel was taken into hospital again with a nose bleed the following month and was there for four days. She had another nose bleed a couple of days after discharge and was re-admitted. Isobel then caught the flu and was isolated in her own room but she wasn't told why. She was deaf and things weren't always fully explained to her. The oxygen cylinder tubing knocked out her hearing aids so often she just took them out. Isobel was then transferred to another ward and put into a single room. The staff were in gowns and masks, but Isobel couldn't hear properly and didn't understand what they were doing. She felt like a leper and it got her down. Isobel didn't get a shower for two weeks. She was reluctant to ask because everyone

seemed so busy. She couldn't hear the nurses properly and she was concerned about being a nuisance. Catherine said her mother shouldn't feel she was being a nuisance and taking everyone's time. Her mother and other older patients needed someone who would listen:

"Someone that's willing to sit down and not make them feel that I am having to rush away ... just have the time to sit and listen to them and what their needs are and make them comfortable ... it's a long day in hospital ... sitting there in a chair. Try and make it a little easier for them."

Trying to get information was a nightmare. Catherine tried to speak to a staff nurse but they were all on their lunch. The doctors were on lunch too. No one seemed willing to come and speak to her.

Isobel was transferred to the community hospital. She found her chair was very uncomfortable because she got sore with her osteoporosis. Catherine asked if her mother could have another pillow. She was told patients could only have two pillows each. Catherine took in her own cushions instead but the next day Isobel told her that she had to take them away because of the germs and health and safety concerns. Catherine thought they would want to make the patients comfortable. On one occasion Isobel wanted to go through to the main room to eat her meal with other patients. She wanted to have some company, but she needed help to get out of the room. Isobel asked a nurse for assistance but was told she would be as well to stay put and have the food brought to her. Isobel didn't hear everything that was said and they didn't explain why she couldn't join the other patients. She thought she was being a nuisance because of the oxygen cylinder. At home Isobel has long tubing to enable her to move around. In hospital she has to take off the oxygen to get to the toilet. A nurse said they would order the longer tubing. Catherine offered to bring in the tubing from home. She knew her mother would rather not use a commode and would prefer to walk to the toilet herself. Isobel didn't want to be seen as a nuisance or a complainer.

Catherine always thought her mother would be able to stay at home. Before going into hospital two months ago Isobel was very independent and able to live alone. Only during the week of the interview did Catherine think her mother will probably have to go into a care home. Isobel died a few weeks after the interview.

Patient story (38)

David's daughter, Heather, says she attended her father's reviews in hospital. She could ask questions but they would not always answer. She prepared her questions and e-mailed them in advance:

"They were very good at skimming past and you might get an answer to one, three and five if you were lucky. So no, they weren't great at giving us information."

There was one nurse who she would highly recommend:

"She couldn't have been more helpful. When I phoned at lunchtime she says the doctor's doing a round later on, is there any questions you want me to ask and when I went in at night time ... answered all my questions. 'Is that everything answered for you?'"

Generally she felt communication was pretty poor. She didn't get answers to all her questions:

"Sometimes when, you know, you phone up to the hospital, it's like they're too busy you know. Oh can you phone back later? And right ok. And you phone back and you're getting a one word answer and you feel like you're just being a bloody pest you know and yeah I know they're busy. I appreciate that you know. I do appreciate what they're doing but it doesn't help when you're wanting answers and you can't get them".

Delayed Discharge

*"I got that used to it ... I think that's what put me off home ... there was no problem."
(36)*

Some patients are declared medically fit but are unable to leave hospital due to lack of a care home place or home care package. The following issues are raised in the interviews:

Deciding about a care home

The interviews give insight into the complexity of the decision-making process for patients and relatives in view of the stressful circumstances and the shock of hospital admission. Relatives are also individuals with differing attitudes, experiences, expectations and knowledge which means they react differently to the situation. They do not necessarily understand how the hospital and care systems work and do not always anticipate having to decide on care homes. They may have imagined taking their older relative to see round a care home but this may become impossible, which makes choosing even harder. Patients and relatives can find it difficult because of the stressful situation and perceived power imbalance affecting communication with staff. To the family the older person is primarily a father or mother or spouse, not a patient. The interviews highlight the significance to families of placing a relative in a care home and the emotions involved. Coming to terms with what has happened takes time and relatives are shocked by the rapid deterioration of the older person. Relatives find it very difficult to make a decision about a care home under pressure. It is not generally anticipated. The older patient has been viewed by both themselves and the family as managing well before the emergency admission. There is also concern about the quality of local care homes. It is a difficult decision to choose the best place for the person and the ability to choose is very important. Sometimes they have to go on a waiting list for the care home of their choice. The family and the patient are often influenced by the professionals' views on appropriate care.

Waiting for home care

Other patients are waiting weeks for home care packages to be put in place. Families are concerned about the relative being discharged before the package is in place because of the potential risk. They can be concerned about their own ability to cope with the new situation and support their relative at home. They are in need of information, support and time to adjust to the effect on the whole family.

Impact of delay

Relatives may be worried about the risks of sending a patient home, but they are also concerned about the deterioration of the patient during delay. Relatives and patients are aware of physical and mental deterioration due to lack of mobility, lack

of stimulation and loss of confidence. Patients become anxious about managing at home. There is nothing in place to deal with this. Rapid deterioration can also fuel family anxieties about their relative returning home. The family is shocked by the impact of the health crisis, often a fall, and find they are coping with apparent new behaviours e.g. delusions, aggression. In people with dementia, their condition appears to accelerate.

Elsie says she was in hospital waiting for a care home for “*five months and longing to go home*” (37). She originally wanted to go home but was persuaded that she could no longer manage and chose to move to a care home. Elsie was in hospital for several weeks waiting for an appropriate care home place. Maggie believes her mother deteriorated being in hospital for such a long time. She was lying in bed for over 6 weeks and did not even get up to go to the toilet. Maggie thinks it was not good for her osteoporosis and believes her mother should have been up and dressed more quickly. Maggie says it is not good to spend all day in a dressing gown and believes “*She has become frail with being in hospital*” because her muscle tone diminished and she became institutionalised. Elsie did not want to do anything and would not even read a newspaper or anything. Maggie describes the boredom level as “*beyond a joke*”. The last two weeks they got her dressed and took her to the day room to eat her meals and watch TV. Maggie found that helped because “*It’s all about confidence*”.

Patients and relatives alike are divided on whether an interim placement would be beneficial. Although relatives can be concerned about deterioration, they are equally concerned about the effect of multiple moves on a vulnerable patient.

Delayed discharge audit

The HSCN project contributed to an NHS delayed discharge audit by collecting and comparing two patient stories in detail. Elsie (37) was delayed because of waiting for a care home place and Joan (36) was waiting for a home care package. Due to their length, the whole accounts appear in Appendix A. The stories highlighted the lack of anticipatory care and lack of communication. The families did not feel involved in the assessment or decisions, but did feel their relatives received high quality care and praised staff. Both patients were eventually happy with the outcome – one returning home with a care package and the other moving into a care home where she had settled in well. The main issues are detailed below:

Anticipatory care

- No anticipatory care planning evident for either case. Both patients admitted following falls at home.

Communication

- Families felt in both cases communication with senior staff could be improved and increased.

- In particular Joan's family were unhappy that assumptions were made about their knowledge of their mother's condition and its implications. The family did not know their mother had dementia and were very shocked by her state of health and sudden deterioration. They were told the team would keep them informed but they felt junior doctors were unable to answer their questions. Although the situation improved following a meeting with the consultant, they still wanted more communication.

Information

- Joan's family felt they didn't get enough information. They had to find out about home care themselves. It was not mentioned by staff. They would have liked to know what was available.
- Elsie said she had been given enough information but she also relied on a close friend to find out information on her behalf.

Discharge planning

- Joan's daughters differed in their views – one felt she had had to ring up to find out about progress whereas the other said she had been contacted sometimes by the Social Worker. They were happy with the Social Worker and thought she was a good single point of contact.
- Elsie's daughter also felt she could talk to the Social Worker.

Assessment of needs

- Joan's family did not appear to have been involved in the assessment or asked what support they could provide.
- Elsie's daughter wanted to discuss the consultant's view that her mother should go into a care home because she was concerned it was not what her mother wanted. She did not get the opportunity but she did discuss it with the Social Worker.

Decision making

- The families were not expecting to make decisions about receiving home care or choosing care home. Both patients had been managing well at home prior to admission.
- The hospital and Joan's family appeared to have different views on the patient's wishes. The daughters thought Joan was worried about going home and wanted to stay in hospital. Staff told the family that Joan was saying she wanted to go home. The family did not think the staff should accept everything said by Joan given her condition. Both Joan and her family were agreed she was not ready to go into a care home, which was suggested by the hospital.
- Elsie wanted to go home and did not want to go into a care home. The doctor told her that she could no longer look after herself and she finally

agreed. The daughter was told by the Social Worker that her mother had decided to go into a home.

Attitude to delay

- Joan's family thought their mother deteriorated in hospital and lost confidence about going home due to the delay. Joan said she got used to hospital and she thought it had put her off going home. Joan did not think she had sufficient OT input with practising the stairs and they did not keep her "going".
- Elsie's daughter believed her mother had also deteriorated physically in hospital and she thought her mother was kept in bed too long. She was pleased that they started to get her dressed and take her to the day room to have meals and watch TV because this helped her regain confidence.
- Both families thought their mothers were bored and had nothing to do. Joan's daughter wondered if someone could come in to arrange activities for them. Joan herself said she had nothing to do and tried to chat to other patients but that had caused problems on the ward.

Interim strategy & placements

- Joan's family would not accept fewer than three home care visits but did agree to take their mother home without the fourth visit which they could cover themselves. They did not want to take her home without home care support. They would consider telehealthcare options to keep their mother at home.
- Elsie would have considered an interim care home place.

Discharge

- Both patients were discharged without any problems. Little notice was given but this was not an issue for either family or patient.

Were support services ready?

- On her return home Joan's home care was in place. All equipment and adaptations were also in place. She has been followed up by regular GP visits.

Home care

- Both patients and their families were very satisfied with the quality of the home care service and its reliability.

Telecare

- Joan's family refused telecare. They thought their mother would misuse the alarm and believed a bed sensor would be inappropriate because their mother liked to get up for long periods during the night.
- When she was at home Elsie had a community alarm which she had had to use when she fell and broke her hip. She thinks it saved her life.

Quality of hospital care

- Both families and patients were satisfied with the quality of nursing and medical care received in hospital. They praised the staff.

Treated with respect

- Joan's family did not feel she was left with much dignity because of her condition and they found this difficult to answer.
- Elsie believes she was treated with respect. Her daughter did not think arrangements on the ward e.g. toileting & washing allowed for much dignity for patients but her mother accepted it.

Have needs been met?

- Both patients and their families believed their care needs have been met. No one thought any other services or support were required at this point in time.

Complaint

- Neither patient nor family felt they had any issues to complain about concerning recent admission or subsequent community services.

Improvements

- Both families thought communication and information could be improved.
- They also thought their mothers were too long in hospital with nothing to do resulting in deterioration and loss of confidence. Joan's family blamed the 'system' rather than the hospital.

Outcome

- Both patients and their families expressed satisfaction that the right outcome had been achieved. The patients were both happy with their respective situations. The families thought their mothers had improved dramatically since leaving hospital. Elsie and her daughter in particular thought the care home was excellent.

Carers

"If every single carer tomorrow just didn't go to the person or look after the person they were caring for, I bet you within five hours society would be crumbling. Where would you get people? And instead of appreciating those millions of unpaid hours ... it's quite bizarre really that you often get the feeling that the more you do, the less help you will get because the person is being looked after ... so it's a very lonely thing I would say being a carer." (50)

The struggle faced by carers to find appropriate timely help and support is a dominant theme. In this project carers included both sons and daughters who were trying to work and/or bring up families as well as older people caring for their partners and spouses while routinely suffering health problems themselves.

Caring experience

Carers are devoted to their loved one and the caring role, but find it is a lonely and exhausting experience:

"You just carry on because you think well this is my duty to my husband, I've got to be strong enough to do it. But I think again you become invisible to the person you're caring for because they live in their little world and everything ... is theirs for them, you know, and it can get very depressing and lonely" (51).

In these interviews many of the carers were also older and looking after spouses with dementia. They find it particularly difficult to cope with the increasing demands if the person deteriorates and to deal with challenging behaviour such as anger, aggression and leaving the house suddenly.

Lack of support

The experience is characterised as a long relentless struggle in which they must constantly push for help. Bob feels he has to fight for his parents:

"If Mum and Dad didn't have sons to kick up a stink to do things where would they be in this wonderful system?" (3)

People express a need for more support services to alleviate the relentless exhaustion and stresses of caring. Carers feel they are left without support until they reach breaking point:

"It seems to me from my experience and from the experience of other people that carers have to be at breaking point before they actually get some help." (2)

Carers have no option but to struggle on with or without support:

"It doesn't just suddenly happen. It just creeps up and you just keep coping as much as you can. It's not like you would've thought 'right well this is where I need to get ... need to speak to someone'. You just try to keep going." (2)

Lack of information

Carers do not feel they get adequate information and advice about services and their rights.

Lack of respite care

Carers value having high quality trusted respite care which can give them a break. However, in remote rural areas the older person often has to leave the area and be out of reach of family, friends and community. The fear of being sent away means that some are reluctant to take up respite even when it is offered. Interviewees strongly believe that older people should be allowed to stay in their communities and there should be flexible local facilities to enable this to happen. In one community there is a facility with one bed that alternates as a respite and Bluebell bed. Although this is highly valued, sometimes respite can be cancelled if it is required as a Bluebell bed. People would like a dedicated respite bed within the area.

Lack of day care

Concern has been expressed about the closure of day care resources in recent years. Day care is extremely important because it provides regular respite for the carer (enabling them to meet regular domestic/work commitments) but also offers the service user an important opportunity for social interaction and stimulation. Day care is highly valued but perceived as oversubscribed with long waiting lists and sometimes there are difficulties getting transport to facilities. One interviewee describes trying to get day care for her husband who has dementia. Jessie (17) could not leave him even to do essential jobs:

"It was getting quite difficult to get him in and out of the car so if I went into the shop I just left him, ran in for what I needed and back out again." (17)

She also thought it would be good for Tom to have company and stimulation. The Social Worker gave her incorrect information about a potential facility. In the end she phoned the centre up herself and managed to get her husband a place.

Quality of care homes

Carers make every effort to keep their relatives at home rather than send them to a care home. They are also concerned over the quality of local care homes and find it very hard making a decision to place an older person in a care home.

Value of carers

Carers want to be valued and recognised for their role. One person describes the apparent 'invisibility' of carers:

"I know some of us are looking after our family and they say well that's a thing that you're supposed to do, look after your loved ones but I just feel that sometimes we're just invisible ... I'm not complaining because I don't mind looking after my husband as long as I'm fit enough to do it, but I think you're invisible to everybody else. Everybody asks how the person is that's in the wheelchair but they never look at the carer and say how are you? The person in the wheelchair is being looked after by the person that's wheeling the wheelchair ... but nobody says they need help ... the poor person behind it is invisible." (51)

Patient story (2)

Alison and her sister wanted help to care at home for their mother who had dementia. They wanted someone to come and sit with her for an hour. Alison thinks they were being left to cope because she lived with her mother and her sister lived nearby:

"I got the impression that because we were close by, we were just kind of left to get on with it".

The family had spent two years pushing for help. The GP referred them to the CPN but she was on holiday for three weeks so there was a delay in seeing her. Alison describes it as a *"long time when you are daily trying just to get through every day"*. Everyone said the CPN would get them help, but the CPN told them they wouldn't get a Social Worker and left the sisters feeling quite depressed. The CPN was very negative and said Social Work Services were overstretched. Alison says they were left *"totally empty with no light at end of tunnel"*. Alison tried contacting Carr Gomm for help but they told her that she couldn't get help without a Social Worker. She just wanted someone to come for an hour but she needed a Social Worker referral. Alison says *"We just seemed to be going up the ladder but still just seemed not getting anything"*. When they left her mother on her own she was constantly phoning Alison and her sister. They couldn't get on with their jobs. Alison went to the GP and broke down. The GP was helpful and said perhaps they could get the District Nurse in so that maybe she could get things going. The District Nurse was good and got her mother referred to a local facility and put her name on the waiting list for day care but it was a huge list. Her mother went into the unit twice a week for 8 weeks. Alison felt some relief, knowing she could get things done at work but most importantly knowing her mother was safe. Alison phoned Social Work Services and asked to speak to the manager directly and that's how they finally got a Social Worker. She was desperate. Her mother wanted Alison there all the time. Alison felt she couldn't spend time with her husband or her children aged 11 and 15.

Sometimes her mother left the house and Alison had to go with her. She couldn't let her go on her own. Alison cycled home from work at lunchtime to make sure that her mother had something to eat. Her mother was also starting to get hostile at home. Alison also got helpful information from Alzheimer's Scotland. They were starting to get help but it was so slow:

"It seems to me from my experience and from the experience of other people that carers have to be at breaking point before they actually get some help. It seems like they deal with people that are in urgent need of help ... I feel vexed because I feel it could have been a lot easier for us if we had got carers in to help us in the morning and evening months before my Mum had to go into a Care Home. It would have been less distressing and stressful for my Mum and my sister and I, if we had been able to get help way back". (2)

Alison was at breaking point. She wasn't sleeping and was trying to work out a way to cope with private home carers. Alison thought she and her sister were getting to the point where they weren't going to be fit to look after their mother – they were "wrecks". It was exhausting:

"It's a hard job to do for anybody but when you're emotionally involved with the person, that's what makes it even harder. You've got to try to detach yourself from the situation when ... the situation gets a bit ugly and they're not the person you remember ... that's really hard to take and it's hard not to get upset even when you know it's not them, it's the illness talking ... that's not her, it's the illness, she doesn't mean what she's saying."

They reached breaking point and managed to get respite care because Alison's sister was going away and she couldn't manage on her own. During the week her mother fell twice and the care home thought she'd damaged a rib. She also developed a chest infection. Alison took her out a day early and got their doctor to check her. She took her to hospital and she was quite ill. They told Alison her mother needed residential care but neither she nor her sister had wanted to do this. Alison thinks it was quite good someone else made the decision. The Social Worker tried to come up with options - what if she got one hour of care a day, what if her mother got into day care? For Alison this was too late:

"All those things came too late. That's the sort of help we could have done with months ago. That would have helped us to look after her".

Alison describes the relentless struggle:

"It doesn't just suddenly happen. It just creeps up and you just keep coping as much as you can. It's not like you would've thought 'right well this is where I need to get ... need to speak to someone'. You just try to keep going."

Alison thinks there's not enough help for carers. It might be out there but people don't know what's there. Her mother only got Attendance Allowance two years ago.

Alison found out about it because she had a friend who was a home carer. Alison doesn't think people should have to wait so long to get help. Everything they got came too late, but at least she had her sister to support her.

Patient story (24)

Bridget cares for her friend, Doreen, who has had a stroke and is diabetic. They live in a remote rural area. She has asked for respite but Doreen would have to go wherever there's a vacancy. Bridget thinks it would be absolutely amazing to get a small place built in the village and then people wouldn't have to go away from their homes. She says:

"I think it's terrible that people have to go away from their homes and probably never come back."

She says that a 94 year old man was taken away this week. Last time Bridget had a 'break' was when Doreen was taken into hospital with pneumonia. She went into an acute hospital and then into a community hospital for about a fortnight. It was last winter and Bridget wasn't well either. The community nurses came in to check on her and staff at the local centre did her shopping. Bridget went to a meeting with Social Work Services and it was arranged that Bridget should get a regular break. Although Doreen agreed at the meeting, she doesn't really want to go to the nearest town where there is a care home – it's about an hour's drive. However, it was arranged but then they called yesterday and cancelled it. Doreen says she would use something in the village. Bridget just says it doesn't matter. The local centre is a lifeline and Bridget says *"I couldn't manage without the centre"*.

Patient story (42)

Margaret, 76, was caring for her husband with dementia. The GP organised a CPN to come out but she said she didn't think Margaret needed help because she was coping well. The CPN told her everything was going well, the house was clean and her husband was clean and tidy. He was being washed and fed and cared for. She gave her a card for a private care provider at £16 an hour. Margaret says *"You just carry on you just have to"*. One day she happened to see a notice in the library about the new dementia resource centre and she went over there. They were very helpful and a worker came to take her husband out once a week - for a run in the car or for coffee or to the barbers. The worker got her a Social Worker who arranged some respite in a care home. Margaret thinks her husband got good quality care and it prepared her for him to go into a care home permanently. She told him it was *"a little holiday"* to give her a break:

"Things were quite confused for me. I was getting so tired. The thing was I couldn't get Roy to go to bed at night and I couldn't get him into his pyjamas, get all his clothes washed and everything. So I got so tired and he was up and down all night. He had toilet problems so some nights I was maybe up six, seven times during the night."

She hadn't been getting enough sleep. Roy put the incontinence pads down the toilet and blocked the drains probably about three times. They were always things she needed to clean up and all the washing to do. Some days she had four loads - not just sheets, but bed covers and everything:

"I had no sleep and I couldn't have carried on much longer with no sleep because otherwise I would've, you know, probably had a nervous breakdown or been ill or something and it was a case of either him or me."

Both of them got chest infections and she had to nurse him although she was really run down herself. Eventually it was decided that her husband should go into a care home. When a place became available at a nearby home, the support worker told her she had to say yes now or that would be it. Margaret was very happy with the quality of the care home but she says *"I still feel guilty ... I know it's good for him and he's got company and that now"*. He likes to sit in the foyer so he can talk to people coming in and out. Margaret says:

"I think they're wonderful. I really think it's a lovely home ... I miss him terribly".

Care Homes

"It's such a very very important decision. I mean you're entrusting somebody that you care for so much and you're putting them in the hands of somebody else to look after them and you want to make sure it's right. You want to do right by the parent ... you want to make sure they get the best care they deserve." (2)

Choosing a care home for a relative is an extremely stressful and difficult process, often exacerbated by having to make the decision under pressure. In the interviews people discuss their feelings and experiences.

Decision-making

People feel it is a very important responsibility to choose the best place for their parent or spouse and feel responsible for securing their future wellbeing and safety. Even if relatives have come to terms with the decision and believe it is ultimately in the best interests of the older person, they feel guilty for a range of reasons. They find it difficult to give up a caring role and to continue to stay in the family home without their loved one. Some feel they have betrayed the older person or gone against their wishes. To remove someone from their home is a significant event in their lives which provokes a complex emotional response. It is a common experience that relatives find themselves having to make this crucial decision when the patient is suffering a health crisis in an acute hospital setting. Relatives are shocked at what is often a rapid and severe deterioration in the patient's condition and are concerned by the implications for their ability to live independently. The family has not necessarily anticipated having to make long term care decisions and they are not prepared for this additional pressure. In these interviews patients and relatives commonly express a wish to return home and the idea of a care home is often introduced by a professional, usually a hospital doctor or GP. Some of these patients become classified as 'delayed discharge' because they are medically fit but they are waiting for a care home place of their choice to become available.

Jen (16) talks about the shocking decline of her mother, who eventually returned home with a care package:

"It seems dreadful that a woman 6 weeks ago ... could go out for lunch four times a week ... all of a sudden she's just this wee old lady sitting in a chair shaking ... but certainly the woman that had a fall six months ago is not the woman that's sitting in that house now." (16)

Agnes (39) explains how difficult it was to come to terms with her diminishing ability to care for her 88 year old husband with dementia. At 84 she had osteoporosis and osteoarthritis. She had just come out of hospital following a stroke. Her husband was in respite care while she tried to recover:

"I was too weak to do anything but I just longed for him being home." (39)

She says "after 63 years married, it's hard, it's hard". Eventually Agnes realises she could not go on:

"I am a sensible person and I realise I know I couldn't care for Jim now without help." (39).

Her husband is now in a care home permanently but in a different town about two hours' drive away. The family want to move him back when an appropriate place becomes available locally. It was one thing to accept she could no longer look after him herself but quite another that she could only go twice a week to visit him. Agnes says she accepts he has gone into a care home but says:

"If only he was here so as I can go maybe every other day ... Maybe death's easier than this you know ... I couldn't keep on going to _____ like this. He was just taken away just like that, you know".

Professional input

In these interviews care decisions are also influenced by professionals who play a key role in discussions about entering a care home. Helen describes her mother telling her what a doctor had said to her in hospital:

"She didn't know who he was but she said 'the chief doctor here has said to me that I need to go into a nursing home because I'm not taking care of myself.'" (15)

Helen was very angry that this was suggested because both Helen and her mother had expressed their wishes that she be cared for at home. The GP without telling Helen, also asked her mother if she was happy. Her mother said she wanted to go home. The GP then asked her if she would go into nursing home. Helen felt that her mother was being treated as a burden, commenting:

"It would have been very handy to have her off his list because he was having to come so often." (15)

She thinks it is "almost unethical" to suggest older people go into care homes if they have had poor Care Inspectorate reports and she was concerned that her mother would not receive the appropriate level of care.

At 94 Elsie was recovering from a hip replacement in hospital when a doctor said he thought she should go into a home:

"He gave me this lecture. You're a grown woman and you must know that you can't look after yourself ... because you just can't do things like you used to ... You just have to accept it." (37)

According to her daughter, Maggie, the doctor was worried that her mother might go home and be fine but equally she might deteriorate. He said she did not need nursing care but did require someone to be there at night. He did not want to see Elsie re-admitted to hospital. Maggie says she wouldn't have been happy to think her mother was at risk, remarking *"It's amazing how quickly old people go down with just that one thing"*. Maggie wanted to discuss the care home suggestion with the consultant but she did not get the opportunity. She had waited during visiting hours in the hope of talking to him but he never came to the ward at that point. She was concerned her mother didn't want to go into a care home. When the Social Worker phoned Maggie telling her that her mother had decided to go into a care home, she was astounded her mother had agreed. Elsie is now very happy in the care home and thinks both the staff and the food are very good. Elsie says the doctor was right:

"Of course I know myself that I am too old now to look after myself ... so I just accept it." (37)

Interim placements

There were divergent views over whether an interim care home place would be acceptable to enable a patient to leave hospital and wait for the care home of their choice to become available. Irene (50) describes what it's like trying to look for a suitable place and her frustration that there was no care package so her mother could return home in the interim:

"Good care homes, they don't grow on trees. You have to wait until somebody dies in one of them for a place to become available. That's not going to happen overnight ... A family has to have time to look round places ... but then you just play a waiting game ... you may show an interest and put mother's name on a waiting list, you're still going to be waiting. So she can wait in hospital. She can go into a care home but there's nothing in between even if a family would request it. Because what they have to realise is a person who needs something, like an elderly mother, is not just a little Lego figure that can be placed here and there ... she is the matriarch in a family and that family has also to be sure that the decisions they're taking for your mother, who has done so much for you your whole life, are the correct ones when it comes towards the end of hers." (50)

Irene believes some kind of relief night cover would have made all the difference and allowed her to carry on caring for her mother at home for as long as possible, which is what she wanted to do.

Quality of care homes

The quality of care homes in the Highlands is a very widely held concern and people value having the freedom and time to choose the one they believe is right for their relative. The most common qualities valued in a care home are outlined as follows:

- Motivated, caring, kind staff who enjoy being with the residents
- Consistency of staff – regular staff get to know residents well
- Cleanliness
- Good quality fresh food with menu choices and tailored to dietary requirements
- Good trusted communication between staff and relatives e.g. if something goes wrong or anything is needed
- Good management and leadership
- Private room with their own furniture and personal possessions
- Trained staff e.g. dementia care
- Dementia specific unit
- Friendly and welcoming atmosphere
- Medical support – regular visits from GP
- Flexible open visiting – relatives always welcome
- Residents treated with dignity and respect over issues like nursing, bathing, toileting
- Activities and outings as appropriate
- Garden space and an opportunity for fresh air and exercise

The traditional image of a care home with residents sitting in silence around a TV is criticised and poor quality is routinely associated with unpleasant smells and a sterile atmosphere. High staff turnover is generally treated by relatives as an indicator of a poor quality care home. Motivated caring staff is the aspect most often cited as of greatest importance.

Patient story (2)

Alison and her sister were desperate. Alison didn't expect she would have to think about care homes. They had built the annex so her mother wouldn't have to go into a care home. Mum kept her Dad at home when he was ill and Alison wanted to do the same for her Mum. It was a really hard thing to accept. The ideal would have been to get carers in so they could keep her at home which she knew was important to her mother. Alison would rather look after her than put her in a care home she was not happy with. Unfortunately it seems it's easier to go into a care home than to get carers in to keep people at home. Her family were everything to her and she would have wanted to stay at home. Alison feels she let her mother down:

"I always thought she deserved to be cared for at home by her family because my Mum was a homely person. Loved her family around her."

There were places in a care home conveniently close by and Alison wanted it to be good because it would feel less of a wrench to have her Mum in there. However, she had a look at the Care Inspectorate reports and they weren't very good. The staff member showing them around had an old grubby looking uniform. Alison says *"I didn't like the feel of the place"*. She saw three rooms. Across the corridor from one

there were three brown wooden doors but she didn't know which one was the toilet. The bathroom had a torn floor covering and there was a hoist over the bath. The staff said they waited outside if the person didn't need help but Alison didn't feel confident they would wait. The majority of residents had dementia but it didn't have a specialist unit. She was shocked that the care home had nothing special for people with dementia. The room was not en suite and the shared toilet had three steps down to it. The care home felt cold and Alison felt she just had to get out of it. She wondered where her mother would go for a wander there. Her gut reaction was there was no way that her Mum would go there.

The family refused the first place offered and then they were offered something about an hour's drive away. The Social Worker told them there was nowhere else, but also said there was no rush because their mother hadn't been classified as delayed discharge. That was a weight off Alison's shoulders because now they had the weekend to make a decision. She phoned one care home which she liked and where her mother was already on the waiting list. The manager arranged for her Mum to be assessed at the hospital with the family there which was lovely. The following week they were able to offer the place to her mother. It was just a weight off her mind. If it had to be care home, then she believed this one was the best. Alison is satisfied that they found the best place for her Mum. She has a lovely room with a good view, with all her own furniture and belongings. Mum is able to keep own personal stuff including her furniture and TV. The family tell them what toiletries to get for her. Alison thinks these details are important even for those who can't communicate anymore:

"I'm sure it means something to them so I think it's important to still do things like that for them. They're still people ... they're still individuals. It's not like you should treat them like they don't matter anymore, it doesn't matter what you give them."

The home is very welcoming to the family and the staff are very approachable. You can ask about anything. The staff are very good and the family have got to know them so well as they are up there every day. The core staff get to know the residents very well. It's a modern building with a layout like a community centre with plenty of daylight with plants and nonslip floors:

"It doesn't look like a traditional care home ... It doesn't smell like a care home. It's very very clean".

The cook is very good and takes notice of what they like. They get fresh vegetables. Nothing is too much trouble. If she needs a drink or cup of tea at an odd time, it's never a problem. Alison feels there could always be more staff on duty and she's sure it's the same in all care homes. Alison advises other people to visit the care homes at an early stage and get their relative's name on the waiting lists. It is better to do it when not under stress and you can make a clear decision. If you are not thinking clearly and it is urgent, you might make a mistake.

Patient story (30)

Hugh says there was a case conference held about his wife Iris who has dementia. The Social Worker, the staff nurse and his daughter were there to discuss what was required. Iris can't get up on her own and can hardly eat. She has lost movement and she's frightened about getting up. Hugh wanted to bring her home but was told he wouldn't manage at night. He says they decided Iris should go into a care home:

"Much as I didn't want her to do, I've been not forced but persuaded that she's got to go into care and I feel I've let her down. I feel that, after 50 years, I mean I've broken a promise that I made her 50 years ago."

Hugh and Iris celebrated their golden wedding in 2013. He is tearful. He's been told by lots of people that he hasn't let her down but that's how he feels. He had to give the Social Worker a list but there were no beds available in those particular homes. He is happy with the way it's all been handled by the Social Worker. She tried at the start to put in a package of four home care visits a day. Hugh would have liked the extra visit but because of the state Iris is in now, he wouldn't have been able to get her up at night. She can't get to the toilet and she has no confidence in the Zimmer. Hugh says *"She just sits in the chair and that's it"*. He has reluctantly accepted the decision. Iris is quite happy in hospital. She knows what she wants to tell you even though it just comes out like a babble but he can work it out. She is happy. Hugh is not sure if he would consider an interim place in another care home. He knows about the homes he's found out about but he's not sure about the others which he hasn't looked into. It's important to have confidence in the home. If it wasn't good, he would take Iris out immediately. Hugh is surprised she's been kept there in hospital. He thought they might transfer her to a community hospital. He is quite happy with her being there because the staff are very good with her.

Patient story 44

Nina's mother was delayed in hospital for about 3 months, waiting for a care home place. The Social Worker gave them the names of homes and her mother, Jean, went on waiting lists. It was a matter of waiting until a room came up. Nina says *"She classed Raigmore as home"*. They gave Jean a trial day in her own home to see how she could cope. Jean knew where she was but didn't remember how to get to the toilet and she wouldn't make herself a cup of tea. She poured herself a glass of hot water instead of cold. When they left, she asked if she was going home now, meaning hospital. Nina is happy with the decision:

"We did it as a family. We discussed it you know and obviously it's the best thing for her ... somebody would've had to give up work to watch her".

Nina remembers her mother saying if she was no longer fit enough to look after herself then put her in a home. When she first went in she was uneasy but now she's settled she's fine. Nina is not sure her mother would have coped with an interim place in a care home:

"I just think taking her from the hospital to a home that was one thing but if you'd taken her like to somewhere else and then to say this care home ... Just uprooting her all the time ... No, I don't think she would've coped with that. She'd have gone, she'd have done it but, you know, I think it would've been too much for her."

Nina is happy with the care home. It's clean and it doesn't have a "horrible smell" you can get when you go in care home. It is well maintained and the staff are really nice. They phone her if Jean needs anything and when she needs a flu injection or chiropody.

Patient Story (49)

Sandra wanted to keep her mother-in-law, Peggy, in her own home which was in a nearby street. It was her own GP who suggested a care home. The family wanted a trial period at home but the GP felt that Peggy's needs were greater than could be provided for in the community. The family thought if she went into care then may be her general condition would improve and they could try to get her home again with a home care package. At the time Sandra thought it was the right decision because the family couldn't provide the amount of care required. They couldn't leave Peggy during the night and they couldn't find any other source of help. It gave them peace of mind that she was well looked after with 24 hour care, but they were hoping she would get home. The GP talked to Peggy at length and she did agree that she would go into the nursing home on a trial basis. Ideally both she and the family would have liked to have got home at some point. However, Peggy's condition deteriorated and they weren't able to bring her home. She took several chest infections and got weaker. The residential home felt her dependency level became too high for them to cope with and they recommended she needed nursing care. Sandra felt that communication between everybody had been good. She was happy with the Social Worker who had been very good and kept them well-informed.

Remote Rural Areas ²³

"Everybody has a right I think to equity of care or equity of access to services irrespective of whether they're in Inverness ... or whether they're up in Caithness."
(40)

Living in a rural area has particular challenges for the older population with the most common issues emerging from these interviews outlined below.

Lack of public transport

This is particularly important for older people who have given up driving and live in areas where services are sparse. They have to rely on family, friends and neighbours to take them to the shops, medical appointments and social activities. Transport is highly valued and utilised. For example, people were happy to use T4T (Transport for Tongue) or a subsidised taxi service. Annie (27) is 82 years old and used to get her medication sent with the post. Now they have just heard that they will have to collect it which will be a round trip of about 36 miles. There is no bus service and they are reliant on being able to drive. At the moment Annie cannot drive herself because she is waiting for a cataract operation. She was wondering why this had stopped because it had been so helpful.

Lack of care services

In remote rural areas there are very few opportunities for day care and respite care. Older people have to move out of their communities to access respite or care home places, which necessitate long car journeys for visitors. It is a widespread view that people should be able to stay in their communities and there should be more local respite. Fiona (11) was trying to find activities for her partner with dementia to help him to maintain his social skills. She did not find the CPN very helpful. Fiona asked for greater support and more opportunities but the CPN said to her *"Well what are you doing living up here?"* Fiona felt it was quite hurtful and was almost made to feel guilty that she is in the wrong place and her expectation is unrealistic. She is very frustrated:

"If you ask, well what's going to happen, and what can he expect in terms of support? ... 'Oh, well he won't get that, not really; because we're so far away from everything. We're so remote.' And that is constantly used as a yard-stick for nothing happening." (11)

Home care

Interviewees think that more local people would take up home care jobs if they fitted in with their existing pattern of part-time working.

Mental health

The problem of mental health services in remote rural areas was highlighted. In particular the issue of escorting patients to New Craigs from remote rural areas was raised. If there is no transport available, then someone with sufficient skills and knowledge has to stay with the patient until the appropriate escort arrives. There is not necessarily a formal 'place of safety'. It could be the local GP but that could mean taking them out of circulation for hours. Tina (40) said it might happen rarely but it is important to know that it will be handled properly. She also pointed out the difficulty of getting to the nearest mental health drop in centre if you do not have transport, saying "*you hate being dependent on somebody else*".

Primary care

On the whole interviewees in remote rural areas were very satisfied with their primary care service and often felt they were better cared for than in an urban area. There is a strong sense of a personal link with the primary care team, who are also seen as part of a closely knit community. Sheena (19) says people feel confident they can ring up for help if they need it:

"I think we're well looked after up here especially if you come from a town ... You know they're just at the end of that phone, they wouldn't do that down the road."
(19)

Interviewees praise caring and hard-working GPs and nursing teams. However, where problems had been experienced with a local practice, it was highlighted that there was very little choice of GP in a remote rural location. Fiona (11) describes how isolating this can be:

"I felt like the rug had been pulled from under me. I felt like she was saying I'm not really interested in you. So therefore how does that make me feel as a patient if I need help, to go down to her when I've already been told 'go away I'm not listening to you.' How do you then present as a patient for anything else? So I felt I'd lost almost like 50% of my support in a rural area where I'm again isolated with no proper medical back up for those times after that. For anything else that might happen I felt really discouraged about going to see the doctor because ... she wasn't at all sympathetic ... to anything I was saying" (11).

Hospital appointments

Older people find it difficult to make long journeys to Raigmore or Wick for what is sometimes a 10 minute consultation. Sheena (19) has taken the school bus from her village to Ullapool, where she has to wait an hour before catching the bus to Inverness. She finds it is a nightmare leaving her "*nearly in tears*" because of her

arthritis. The narrow seats are “*absolute agony*”. It takes at least two hours get to Inverness and the whole round journey takes a whole day. Her son has to take a day off work if she needs to go to hospital.

Calum and Wilma are both 79 and they have to go to Raigmore Hospital in Inverness once a month at least, sometimes twice. Calum has rheumatoid arthritis and it is a 100 mile trip, which is a long drive for his wife. Sometimes they stay over in a hotel but this is expensive. If the appointment is before 10am, he will get £40 towards the hotel bill but Wilma does not get anything. Calum cannot attend the appointment without her because he needs her to drive. Sometimes he has had to go two or three times in one week, which he describes as “*going back and fore there for sort of more or less useless clinics*”. Calum asks why does he always have to go there and why the specialists cannot come to the area. He says “*you see some nurse and she fills in some form*”. Calum thinks it can be a waste of time and money. He believes it could easily be done by video conferencing with a specialist nurse or even a consultant.

Iain’s (28) stroke has left him with severe mobility problems and he finds it difficult to get in and out of a car. He needs someone strong to guide him in and out, but it depends who comes in the ambulance in car. Doris, his wife, says it is very exhausting. The appointment lasts 10 minutes or maybe 15. Then they tell him he is alright and to come again in 6 weeks. Once they went to the eye clinic and it turned out the scanner was not working. Doris hopes they would have phoned to tell them if they knew.

Patient transport

Patient transport to hospital can be cancelled at short notice which means older patients miss appointments and have to wait weeks for them to be re-scheduled. With its recent acquisition of a new accessible vehicle, it was suggested that Transport for Tongue (T4T) could also offer patient transport to hospital, thereby improving the service for patients and relieving the burden on the existing services. If Scottish Ambulance Service (SAS) transport is booked, but is cancelled at short notice, then this does not allow the time required to organise the volunteer drivers. At the moment T4T can use the new vehicle for patient transport but the patient has to pay the full cost. A similar service has been operating in East Renfrewshire for the last 14 years. The community transport scheme arranges volunteer drivers using their own vehicles and pays them a mileage rate to enable patients to attend appointments at hospital, clinics and GP surgeries following GP referral. It is funded by the Community Health and Care Partnership.

Patient story (9)

Sandy lives in a remote rural area but has to attend clinics at Raigmore. He says they are threatening him with dialysis in hospital which means he would have to go to

Inverness or Wick three times week. He says *"in the winter that means black dark when I leave and black dark when I get back."* It was suggested to him he should move to Inverness in case he couldn't get to hospital in time because of the weather or lack of transport. Sandy says that the weather and the transport are their problems – they are being paid to keep him alive. At 73 he has a house he really likes for the first time in his life. He has a view of the sea which puts him at rest every day. He said to them they had to get him a house with a view of the sea - not one 10 miles away. Everybody knows him in the community and everybody is nice. Sandy says he's *"too old to have bad neighbours"*. He wants good neighbours like he has now. Sandy says he is not moving. He has peace and quiet and no worries with people although he is a long way from his family. It's a very nice area with very nice people. They know him and they are very caring:

"I'd probably been here less than a week and everybody had my name even the bairns".

Patient story (25)

Mary is 91 and lives in a small community on the coast in a remote rural area. She says *"distance is the total disadvantage"*. She gave up driving about 10 years ago. There is a private subsidised taxi which you can use locally but it won't take you as far Inverness or Ullapool. Mary thinks *"It's just getting anywhere that's so difficult"*. The home help often gives her a lift to the main community which has a bank, health centre and a couple of shops. Mary says every vehicle in the community has more than one use. You can use the school bus but not in the holidays. She says transport is inadequate but wonders what can you expect. She's sure the transport doesn't pay. People say they're going somewhere and ask if they can get things for you but sometimes you can wait a long time in such a small community. Often a family member will take a person, but her son lives about three hours' drive away. Her son brings her things when he comes over for the day. Mary says *"it's an event if you have to go to hospital"*. She once had to use hospital transport which was okay but it tries to link up so many people.

The home help takes her over to the local shop to do a week's shopping but recently they had to walk because her car wasn't working. It was the longest Mary had walked for a while. She thinks the area is underpopulated. Everything has to serve more than one purpose and everything is shared. Mary says *"quite honestly it was my own fault for coming here"*. She thinks there's not enough information about what's available. You can't get a leaflet about the bus in the shop. The internet here is very slow. Mary finds people have to find their own answers:

"Everyone's got their own solution ... because we produce our own solution"

Dementia

"I didn't really have a clue about dementia. I knew the name but that was it. I didn't really know anything about the illness until my Mum got it." (2)

In 2013 it was estimated that there were 5,742 people aged 65+ with dementia in Highland and Argyll and Bute.²⁴ The Dementia Strategy was launched in 2010 aiming to improve support and care for people with dementia and their carers. From April 2013 every person diagnosed with dementia is entitled to post-diagnostic support via a Link Worker for a minimum of one year. The Scottish Government intends to increase diagnosis as this is the "gateway" to support and services²⁵. Dementia specialist nurses have been put in place by Alzheimer's Scotland with support from Scottish Government to advise on improvement in dementia care in every NHS Board.

Interviews with carers of people with dementia raise the following issues:

Diagnosis

It can be difficult to find support at first and to be given a diagnosis. The GPs are often the first point of contact. These interviews suggest that some GPs could be more supportive and could communicate more with families. For example, Fiona felt she was not being listened to and found it extremely difficult to get a diagnosis for her partner, Andy. She found it very frustrating as she tried to explain her worries to the GPs but she felt they would not take any notice of her:

"They were aware of something but not willing to progress it further or to do anything about it At what point do you start becoming involved then? ... It's been identified but then you have to wait. What do you wait for? You obviously wait for a crisis, that's what you wait for." (11)

Fiona was very frustrated because she knew a diagnosis as the key to getting help and support. However, the GPs appeared reluctant to progress it. One said they could not discuss Andy's condition with her because of patient confidentiality. Fiona then organised power of attorney so this was no longer a barrier.

Similarly, Heather (38) cries when she thinks about her 78 year old father, who is believed to have dementia but did not get a formal diagnosis:

"I feel like they've just given up on him." (38)

Without the diagnosis, the family are unable to get any extra support.

Asking for help

Carers can find it very difficult to ask for help. They can feel very isolated and overwhelmed by the difficulty of their situation as they try to adapt and come to terms with changes in their relatives. This intensifies as the situation deteriorates and needs become greater.

Lack of information

People report that there is a lack of information on dementia and sources of support. They also find there is not a great deal of dementia awareness in the general public.

Lack of support services in rural areas

In remote rural areas there are few services available for people with dementia and their carers.

Respect

Carers of people with dementia want their relatives to be treated with respect as individuals. Alison emphasises the importance of recognising the person as an individual:

"They're still people ... they're still individuals. It's not like you should treat them like they don't matter anymore, it doesn't matter what you give them." (2)

Hospital care

Carers find staff do not always have the training and the time to deal with the additional needs of a person with dementia, who may also disturb other patients in the ward. Where staff are trained in dementia care, it is appreciated by carers. The Butterfly Scheme has been praised because it is a positive development to help both carers and patients by recognising the person as an individual and acknowledging their extra needs in a sensitive way. Alison thinks it is a "*nice way to signify what they have*" (2). It enables people to have their individuality recognised and to specify their preferences with, for example, how they are called and what they like to eat.

Patient story (3)

Bob says his Dad went wandering at night. About 2 in the morning he got a call from his Mum. It was sleeting and freezing cold. Bob drove round looking for his Dad and phoned the police. The police had found him and taken him to hospital. Bob went to get him. His Dad was wearing his slippers and a jacket. He told Bob that he had stolen the jacket.

At least three times he left suddenly on his mobility scooter. Once he was heading south on the wrong side of a dual carriageway. It ran out of fuel and his Dad was left there in a short sleeved shirt and shorts in freezing weather.

Patient story (5)

When Alex and his wife moved to the area to be nearer their son, Alex got extremely worried about her condition. He got a Social Worker involved. He took her out in the car and she said she wanted to get out as they were driving along. She was hammering on the window as they were going at 60mph. He thinks the psychiatric services did a "*wonderful job*". They settled her down and got rid of her terror of sudden noises or being confined (e.g. in car). She became contented. She went into a care home permanently. Alex says she only spent a few days in their new house.

Patient story (2)

Alison had started to worry about her mother's behaviour. She thought her mother should not be self-medicating. One night she took four antibiotics instead of steroids. The family agreed Alison should take over medication. Her siblings thought Alison had been molly coddling her. They believed what her mother was telling them. Alison felt totally misunderstood and was trying her best. She thinks it would have been useful to have someone to talk to then. It was probably one of the worst times. Alison says:

"I didn't really have a clue about dementia. I knew the name but that was it. I didn't really know anything about the illness until my Mum got it."

It was a struggle coping with new challenging behaviour:

"Sometimes things happened and I didn't know what to do. I didn't know how to deal with it. Like this leaving the house. I'd never seen my Mum like that. She turned, you know, and she'd go nasty, really nasty and say that she was leaving and I didn't know what to do for the best."

Alison found the dementia resource centre very helpful. They gave her information which helped her to develop more confidence as a carer which she thinks is vital:

"People with dementia are not stupid they are just forgetful ... They still have feelings and they can pick up on things, pick up on vibes from people. My Mum is doing it all the time in the home and I think if they feel you are confident caring for them that will help them."

Alison was desperate to get help because it was all so difficult and exhausting:

"When you are looking after somebody like that you are absolutely exhausted you're just drained emotionally mentally and also if it's somebody like your Mum or your husband or something like, it's really upsetting and when you've got to go and it's a lengthy job to get help, you just don't feel up to it".

She wanted to know what kind of thing to do with her Mum in the home and she wanted to learn strategies to help. Her Mum went through a spell of forgetting her husband had died and then forgetting the death of her own mother. There was a very distressing incident at tea time:

"It was almost as if I had told her for the first time that her mother had died and she wouldn't stop crying."

In the middle of tea she was trying to calm her mother down. There was a horrible atmosphere in the house. Alison was trying to be normal for daughter, who had a friend around for tea. Alison's sister came round to help. They called the GP who said their mother was just grieving. Eventually their mother calmed down but it had been very distressing for them all while they were trying to pretend everything was okay.

Complaints

"You're frightened to rock the boat in case things happen." (16)

For many there was no cause to complain at all while others did not want to complain even if they thought something could be improved. Reluctance to complain is a common issue for the following reasons:

- Complaining is perceived negatively - people do not 'like' complaining and do not identify with it
- Fear of repercussions and adverse effects on their care and treatment – power imbalance between patient and staff
- Too exhausted and stressed at the time of the problem
- When the crisis is over, they want to put the experience behind them
- Feeling no one will listen to them
- Feeling it will make no difference in the end

A few people were prepared to complain verbally to a member of staff on the ward or by letter sent directly to the consultant or GP. Only one person (55) in this group of interviewees made a formal complaint via the NHS complaints procedure and he was extremely dissatisfied with the process and the outcome. This is described in more detail in the patient account below.

Experiences are usually very complex with a varying mixture good and bad elements. Interviewees will not necessarily isolate a very poor experience for complaint if most of the patient journey and/or outcome has been positive. Maureen (31a) was unhappy with the way her mother was treated when she was admitted to hospital. She found her mother on her own crying out in pain. She could not find anyone to help for 10 minutes. When she did find someone, she made it clear that she was going out for half an hour and hoped to find her mother in a more comfortable position when she returned. Maureen did not make a formal complaint:

"The reason why I didn't go ahead with it is because she received such good treatment afterwards ... When she was in the appropriate ward ... we just couldn't fault them, they were so good. It wasn't just my mother. You could see they were the same to everybody there ... I just felt it had crossed out what had happened."
(31a)

Jen (16) was distressed that her mother had been given medication to which she was allergic. At visiting time she was shocked to see her mother in a terrible state and was told not to worry, her mother would not be given that medication again. The daughter thinks her mother should not have had it in the first place as the allergy was clearly noted in her medical records. However, she did not make a formal complaint. Her mother was later discharged to a community hospital where Jen felt her mother's long term mental health problems were not treated appropriately. Her

mother was screaming out as if in pain although staff insisted that sufficient pain relief had been given. The family found it very distressing but did not complain:

"We all felt that she was very badly treated but because it was a local hospital and we knew a lot of the people ... there wasn't really an awful lot that we could do."
(16)

Jen wanted to say something to her mother's GP because she felt something had been missed prior to the hospital admission. However, other family members would not allow her because they shared the same GP. Elsie (37) recounted how a physiotherapist had insisted on making her get up and try to walk after a hip replacement although she said she couldn't. She was in a lot of pain and said she could not walk but he said to her "yes you can". Elsie said the only time he would stop was if she started to cry. It turned out her hip was broken in four places. A second operation was successful but she says she was not told about the high risk (37). Elsie did not complain about either aspect of her treatment. Often older people are reluctant to complain on the ward. On her most recent stay in hospital Elsie (37) relied on a good friend to find out things for her:

"I depended on her because she was a very good friend ... If she thought anything wasn't right she would get onto them because I wouldn't ...I don't like complaining so Shona would complain for me." (37)

When Agnes (7) had first seen the consultant, he said he would see her in two weeks' time. No appointment came, so a third sector support worker told her to go to casualty with a flask of tea and sandwiches because she was not happy Agnes had not been seen by anyone. Agnes sat in casualty for about three hours. When she saw the consultant, he said it had been a mistake and they ought to have booked her in for two weeks' time but it had been done for two months' time. She did not make a formal complaint.

Patient story (3)

Bob had wanted to complain about his experience but he gave up. He feels that he should have done. His partner, Isla, explains what it feels like to cope with a prolonged and stressful experience of this kind:

"Events were kind of piling up round about that time. It was like that's another effort that has to be made to do something about something that's actually past and we're on to now dealing with this and this and this and this. So it just fell by the wayside. One day rolled into two days away from it, two days rolled into a week away from it ... From a point of view of hoping that other people didn't have to go through that, then yes, we should have pursued a complaint about it ... You find there's something else more important standing in front of you right now, needing to be dealt with."

Bob wonders if he would achieve anything by doing it. Isla says you feel a "*level of despondency kicking in*" and thinks:

"There's only so many times that you can bang your head against a brick wall before it gets so sore that you think no".

Bob says "*we'd all like to change the world*" but goes on to explain the problem with complaining:

"I suppose there's two aspects, one is will you achieve anything and another one is you're going to piss off the people who you need to help you. So do you achieve anything by doing it? You might get somewhere but there's a whole load of people who aren't going to be too happy."

This puts him off complaining because "*these people have power, we don't*". Bob says you need energy and the will to go on and do it. It's hard work.

Patient story (55)

Harry is totally dissatisfied with the complaints procedure and describes the formal complaint process as "*appalling*". He has never had to complain about health services before. He was receiving regular treatment at an outpatient clinic. On one occasion he felt it hadn't gone well and normal procedures hadn't been followed. A different doctor carried out the procedure. Harry didn't feel right and he wasn't happy so he went to A & E to get help. Instead of being seen immediately, he was given an appointment for a month's time. Letters were exchanged which could take a month or six weeks to come back. Harry wasn't satisfied with the response:

"You get a reply back which is 'oh let's pass this old guy off, we'll just send him a letter.'"

It was nearly a year when they decided they should talk to him. He got to see Head of Department and another senior staff member. He thinks they were more interested in protecting themselves and believes "*what they're wanting is for the complainer to go away*". He gave up the fight because he knew his condition would have deteriorated in a few years anyway. He feels he lost a couple of years because the treatment could have delayed the deterioration of his condition. Harry believes they wanted to protect their staff:

"To hell with what the complaint's all about, let's make sure that our staff and our hospital doesn't get blamed for anything. Nothing to do with the complaint. You can learn from complaints and mistakes but not if you close your mind and say ooh it can't be us, which is the attitude they took".

Harry wanted to know what should have happened that day. He wanted some kind of explanation, an *“admission that something went wrong was all I was after”* and an apology would have been nice. He thinks they should be open and honest:

“You will never learn anything from taking a protective attitude. What you've got to do is listen to the questions, answer the questions and then say, right, that's where we went wrong. How can we stop it from happening again? But they just don't seem able to do that. Maybe behind the scenes they are doing that but they are not prepared to come forward and say they're doing that.”

Harry thinks their main worry is that they will get sued. His wife thinks a lot of elderly people are brought up with authoritative figures and just do what they say because they are meant to know what they're doing. Harry also feels that he should have been seen straight away when he went back to the hospital and not left waiting for a month. He said it just wasn't good enough. When he did see the doctor, he found it totally unsatisfactory. Harry felt it was too late for him and he gave up. He says he got very selfish and thought he would no longer be able to benefit. He was demoralised and thought there was nothing he can do about it now. Harry tried to forget it.

Primary Care

"I think we're well looked after up here especially if you come from a town ... You know they're just at the end of that phone, they wouldn't do that down the road."
(19)

A high level of satisfaction was expressed with the quality and treatment received from their GP and community nursing teams, particularly in rural areas. Where people felt dissatisfied with treatment from a GP practice the factors involved were:

- Not listening to patient concerns
- Perception of mistaken or delayed diagnosis
- Not getting them other sources of help
- Lack of anticipatory or routine care to prevent hospital admission
- GP practice had not been informed when someone discharged

Fiona was frustrated because she found information leaflets on dementia which told her to see her GP as a first point of contact:

"If you have a problem see your GP, that's what it says. Every one of them says see your GP. My GP, it was like hitting a wall. I couldn't get through it or past it to get help" (11).

Her partner, Andy, would not visit the GP because he did not think there was any problem. The GP told Fiona that she could not talk about Andy because of patient confidentiality. Fiona was frustrated because Andy would not come with her, but she was desperate to get help and information.

Rona (46) was critical of the GP practice who routinely send out letters to her mother asking her to phone to discuss recent results, etc. She has asked them not to send them but to come out and see her mother because she cannot pick up the phone and talk. Her condition means she has great communication difficulties. Rona says:

"For the sake of a bit of, you know, proactive care, could stop a lot of this really active care which at the end of the day must be expensive" (46a).

Her mother has an in-dwelling catheter and is prone to urine infections. Rona thinks there should be routine monitoring and testing. Her mother was put on a low dose anti-biotic but there was no monitoring to see if it was effective. When she was admitted to hospital a month ago it turned out she was resistant to the anti-biotic.

Patient story (30)

Hugh cares for his wife with dementia. He thinks his GP is "*fantastic*" and the support staff are "*all first class*" including the reception. They are very friendly and good at getting you what you need. He feels he can talk to the GP:

"I'm still old fashioned enough, I hate the doctor asking me what to do. They give you an option, that's no use to me. I mean I'm that old fashioned enough ... I was a mason, I didn't expect the doctor to tell me how to build a wall. I don't expect to tell him what's best for me. He should be able to say right that's it. They never say that but they always push me the way they want me to go."

Hugh has recently found out he's got prostate cancer and they're going to be treating it. The GP had given him an information sheet which had the Macmillan nurses on it. He contacted the Macmillan nurses to try to get answers. They said he wasn't on their list and he thought they didn't want anything to do with him. He was very angry and distressed by the apparent attitude and when he was on the phone to the doctor, he just 'lost' it. The receptionist thought it wasn't like him and got the doctor to phone him to see what had happened. Hugh doesn't want anything to do with the Macmillan nurses now and told the GP he wasn't happy. With caring for his wife and finding out about the cancer, Hugh says: "*it had just been building up and it just burst*".

Community Services and Miscellaneous Issues

The main focus of the interviews was on home care and hospital services, but interviewees also discussed the following services:

Third sector

The most frequently used third sector support organisations were Alzheimer's Scotland, Sight Action, Macular Society, Citizens Advice Bureau and Age Scotland. On the whole these organisations were praised as a means of accessing valuable information, advice and support, often unlocking other NHS and Social Work services.

Community facilities

Community-run facilities offering day care, lunch clubs and social activities were highly valued, particularly in remote rural areas, where they are a life-line to many older people and carers.

Pharmacy

Bob praised his community pharmacist who had been excellent and very helpful (3). However, Martin (6) had tried to stop medication being sent home while his mother was in hospital. He phoned the chemist but it came anyway which he thought was such a waste.

OT Services

On the whole there was satisfaction with both the provision and timing of aids and adaptations. People did not feel they had waited too long. However, Martin (6) felt his mother had had to wait too long for a stair lift to be installed, saying:

"We didn't want to jump up and down too much ... everybody is very aware of the pressure that all the services are under but I think it is so important for people to get a thing when they need it." (6)

Jen's step-father (16) arranged and paid for a stair lift to be put in after he was told that it was not feasible. They could not get Jen's mother down the stairs and she was up in the bedroom for weeks.

Physiotherapy

Keith (61) and his wife thought that physiotherapy services were overstretched in Lochaber. If the physiotherapist is away, there is no cover in the area.

Telecare

Most views on community alarms are positive with a high level of satisfaction expressed over the quality of the service. Elsie says:

"It's great. It saved my life ... Oh yes it's a good thing." (37)

However, not everyone is aware of them and many do not take them up. Some families reject community alarms because they either think they are not necessary (they live with the relative) or they feel the older person may misuse it and press it when no help is required. There is a problem with some older people wearing it. One interviewee said she had never had to use it and didn't know where it was, saying *"it's upstairs somewhere, I suppose"* (26). Eileen had had to use it and said:

"I was so glad that I was wearing the pendant because in the early days I used to keep it in the drawer ... So it's worth it." (48)

Most interviewees were not very familiar with telecare and the range of devices available.

| Summary | | | | |
|--------------------------------|-----------------------------------|--|-------------------------|---------------------|
| Use of telecare devices | Total no. of service users | <i>Sheltered housing with emergency pull cords (Housing Association)</i> | <i>Community alarms</i> | <i>Living alone</i> |
| Yes | 12 | 2 | 10 | 8 |
| No | 40 | | | 13 |
| Total | 52 | | | |

Social Work Services

On the whole interviewees were very satisfied with the assistance given by social workers. Jessie (17) found she got incorrect information from her Social Worker about day care which she eventually arranged herself. Bob (3) said a Social Worker had made a mistake arranging transport to a day centre. His father who has dementia was not picked up and was found by a neighbour walking along the road looking for his wife who had been picked up first to go to the physiotherapist.

Blue disability badges

Following heart problems, Sadie says she does not want any help around the house but she would like a blue badge because she explains:

"I get so frightened in town when you have to walk far. You get anxious then. You're on your own." (41)

She would like to be able to have the car "that bit closer" in case anything happens. She applied and was turned down because she can walk. Her medical condition not enough even though she couldn't breathe very well. She stresses the importance of having confidence.

Respect for older people

Fiona was trying to tell her GP about her partner's comprehension and communication difficulties. The GP linked them to age and said to her that they were both getting older:

"He said 'well you're getting older' ... If people say that one more time ... It's so frustrating. They seem to think that you've lost your faculties completely, that you can't comprehend anything ... It's amazing that one minute you're working and being taken seriously and ... doing reports and then the next minute you're not acknowledged as a person that can make those judgements". (11)

Fiona and Andy are aged 67 and 68 respectively.

Another person finds she is the one expected to get out of the way as children come out of the school and says "I don't think they see us." (52)

Health and Social Care workers

Six Health and Social Care Workers were interviewed as part of the project. They were not the main focus of the research but their comments on home care and hospital discharge agreed in large part with those of service users. The main points were as follows:

- Lack of home care capacity which meant they had to cover gaps in provision
- More support and training required for home care workers
- Lack of communication over discharge between hospital and community services – difficult to arrange equipment and services on time
- Lack of respite in remote rural areas resulting in people leaving the area to stay in care homes or hospitals a long distance from home

- Local respite or emergency beds available locally would prevent older people going into acute care in remote rural areas
- Older people want to stay at home and in their communities
- Lack of public transport in remote rural areas and difficulties with the reliability of patient transport

SUMMARY AND CONCLUSIONS

"I was treated like a personal person to them and nobody else. I was treated just with dignity." (32)

Summary of Research Findings

The main purpose of this research has been to explore some of the important issues for older people and carers in the delivery of health and social care services in NHS. It has been conducted against the back ground of the integration of health and social care for adults, the Re-shaping Care for Older People initiative to shift the balance of care to the community and the drive towards "*person-centred*" care outlined in the Healthcare Quality Strategy. This is a qualitative research project aiming to give an in depth examination of the diverse experiences and views of older people. Qualitative interviewing and analysis show the complexity of people's experiences, feelings and expectations of their services and the decisions they make about their care. Interviewing is more than a simple satisfaction measure and provides an understanding of what older people value as well as what they think could be improved. It is individuals who are important here and the delivery of 'person-centred care'.

Generally interviewees express satisfaction with medical treatment and care across primary and secondary care in NHS. The interviews reflect the recent Health Improvement Scotland inspection report finding of high patient satisfaction with care in Raigmore Hospital (September 2013)²⁶. Older people appreciate being treated as individuals, receiving accurate and useful information, being spoken to with sensitivity and understanding, feeling they are genuinely cared for and treated kindly. People understand that services are under pressure and staff can be overstretched. They appreciate hard-working, caring professionals who provide the vital services on which they rely to live their lives as fully as possible. They value knowing they can ask for help when they need it and knowing they will get it even if they have to wait.

However, recurrent issues emerge which interviewees would like to be improved. It is important to stress that the themes arising from the interviews do not necessarily indicate global dissatisfaction with their services. People talk about what they see happening, their views and experiences. It is usually an intricate story with varying degrees of good or bad experiences, reflecting their individual circumstances and subjective interpretation of events. On the whole interviewees do not want to be seen as complaining. If someone thinks a service needs improvement, it does not mean they do not appreciate all the difficulties involved in service delivery, that they want to criticise staff on the 'frontline' or are generally dissatisfied with their quality of care. People also use different combinations of services in varying locations and comment on their own experience of these services. It must be stressed that these

problems are not encountered by everyone. The focus is on the impact on the individual as he/she navigates the care pathways and experiences the way in which services interact. With this in mind, the emergent issues from the interviews are summarised below:-

Home care

- *Lack of home care* in some areas – insufficient capacity to meet new need or offer enhanced packages if a person's need increases. Potential risk to patient safety and well-being has been highlighted.
- *Service reliability* – patients reported the service was sometimes unreliable, highlighting reasons, e.g. inadequate cover for annual leave/sickness, inefficient travelling plans, break-down of pre-agreed rotas. Inappropriate timing of some visits. Consistency of carers is extremely important especially for frail older people/people with dementia.
- *Longer visits* required for vulnerable people with complex needs.
- *Having different service providers* can be confusing.
- *Lack of flexibility* with the range of tasks.
- *Social contact* - Patients and carers recognised that the home care visit was also meeting a social need for a person who could be very lonely and isolated, but carers were not provided with time to meet this need.
- *Recruitment of home care staff* in remote rural areas needs to reflect local working patterns – 4 day on 4 day off rota can be incompatible with other part-time work.

Hospital discharge

- *Discharge planning* – short notice of discharge causing problems for relatives and community service providers e.g. arranging transport, re-instating home care, providing equipment, etc.
- *Raigmore pharmacy* - Patients report waiting for hospital pharmacy to dispense medication before they can be discharged and sometimes medication taken by 'taxi' following patient discharge.
- *Medication information* - not always explained adequately to patient and relatives on discharge.
- *Delayed discharge* – older patients can deteriorate physically due to lack of mobility and stimulation resulting in a loss of confidence about returning home. Lack of support to overcome this issue.
- *Lack of care home places and home care* to enable timely discharge.

Hospital care

- *More staff* – patients can find the wards are very busy and some are concerned about perceived understaffing. Sometimes patients and relatives do not like to 'bother' busy staff with questions or requests.
- *Lack of dementia awareness and training for staff* in some wards. Having patients with dementia on shared wards can cause distress to relatives and

other patients, who may be disturbed by behaviour like walking around and shouting which are difficult to manage on the ward. Staff do not necessarily have the training or time to deal with the added care issues for people with dementia. The Butterfly Scheme has been praised.

- *Falls* – some frail patients had fallen on the ward, sometimes sustaining further injuries, although relatives do not usually attach any blame at all to the staff.
- *Dignity* - male staff members assisting older female patients with intimate personal care can cause distress.

Communication in hospital

- *Inadequate information* for patient and relatives.
- *One point of contact* desirable for updating relatives. Conflicting information for relatives from different members of staff.
- *Lack of access to senior staff* who can answer questions, which can then remain unanswered for some period of time.
- *Completion of DNACPR forms sometimes handled insensitively.*
- *Perception of power imbalance* impacting on relationships with staff.
- *Reluctance to ask questions* or seek help if staff appear very busy and overstretched.

Age- related Macular Degeneration

- *Lack of information* given to patients attending eye clinic about local support and services.
- *Lack of post-diagnosis counselling and/or peer support.*
- *Low vision clinic* – some patients unaware of the service. It has been criticised for long waiting times for appointments, not meeting people's needs and giving confusing information.
- *Inadequate information on the range and provision of low vision aids.*

Support for carers

- Timely support, advice and information – carers report they struggle routinely to get adequate support and information about services.
- Lack of respite in remote rural areas, resulting in older people being sent to care homes outside their communities.
- Lack of day care – long waiting lists for existing facilities reported.
- Emotional stress and fatigue of caring needs to be recognised and alleviated.
- Carers feeling they are not valued or listened to.

Care homes

- *Concern over the quality* of care homes in Highland.
- *Decisions about care homes often made under pressure* e.g. patient medically fit and should leave hospital, but unable to return home.
- *Professional input* is a key influence in deciding to move to a care home.
- *Significant characteristics* of good quality care home include high quality. motivated staff, low staff turnover, cleanliness, welcoming environment, high quality food, good leadership, good and trusted communication with relatives.

Dementia services

- Carers not being listened to or believed resulting in difficulty and delay obtaining a diagnosis and early referral.
- Some GPs could be more supportive and communicate more with families.
- Lack of information on dementia and support.
- Lack of support services in remote rural areas.
- Lack of dementia awareness and difficulty providing appropriate care on wards.
- Carers want patients with dementia to be treated with respect and as individuals.

Remote rural areas

- *Travelling to appointments* at out-patient clinics requiring long and often uncomfortable journeys which can be stressful. Timing of appointment may necessitate overnight stay.
- *Lack of public transport* – greater impact on older people who have given up driving and have to rely on other people to access shops, medical appointments and social activities. In this study about one third of the older people living alone or with a spouse owned a car.
- *Patient transport* can be unreliable and cancelled at short notice.
- *Lack of services for people with dementia* and their carers.
- *Lack of day care.*
- *Older people forced to move out of their communities to access respite and care homes.*
- *Perception of inequity of services but accepted by some as inevitable consequence of living in a rural area.*

Complaints

- *Unwillingness to complain* because patients fear repercussions for their medical care or they are left too stressed and exhausted after their experiences. People feel that no one will listen and their complaint will not change anything.

Community-based services

- *Primary care* – cases of perceived mistaken or delayed diagnosis, not signposting other sources of help, lack of anticipatory or routine care to prevent hospital admission. High level of satisfaction with primary care in remote rural areas.
- *Lack of information about third sector advice organisations* who can offer vital help and information and can unlock services.
- *Telecare* – a large number of interviewees did not use telecare and most of these had not been offered it. Telecare users valued the service.

Conclusions and Key Areas of Need

This project has used qualitative research methods to provide an additional source of data to that routinely gathered by NHS patient surveys and offer another perspective from which to inform service planning and delivery. It enables the collection of in depth information which cannot be accessed using other methods of feedback collection. The focus is on the individual care pathway which enables the examination of the quality and practice of 'person-centred' care.

'Person centred care' is a way of delivering what older people value, namely to be treated as an individual, receive relevant timely information, be treated sensitively and kindly as well as receive an excellent standard of medical and nursing care. These interviews highlight the necessity for person-centred care as well as the challenges inherent in its delivery. The project illustrates the diversity of individuals and how little chronological age reveals about a person, their aspirations, needs, relationships and capacities, although it is routinely used as the key to unlock and signpost services. It is necessary to appreciate the individuality of the person behind his or her chronological age. Interviews have been conducted with a very wide range of older people with varying degrees of health and care needs which are not simply indicated by chronological age. Some interviewees with the most debilitating conditions were in their 60s while many others in their 80s and one person aged 91 were living independently without any need or desire for any formal care. People do not necessarily identify with their age or other older people. Annie was placed in a care home temporarily to recuperate after treatment in an acute setting following a fall. The community hospital was unavailable because of an infection outbreak. Aged 82, Annie did not like the idea of going to a care home:

"I thought I don't want to go in there with all that old people and then it dawned on me, I was probably old myself." (27)

Harry said *"I'm not one of these people that goes around joining old folks' societies"* (55). He prefers to go to the local pub where he drinks with *"normal people"* and the bar staff are *"well trained"* to accommodate his visual impairment.

The research questions focussed on what had worked well for people and what they thought could be improved. Medical treatment and nursing care are generally satisfactory. People praise hard-working staff in both primary and secondary care. Similarly on the whole people are happy with the quality of home carers coming into their homes. Good quality care homes with motivated staff, good leadership and a welcoming environment are valued highly. Although these interviews show that these older people value their services and are very happy with many aspects of health and social care, there are common issues that arise. Areas for improvement include home care capacity and organisation, discharge planning, communication with relatives in hospital, the eye clinic for AMD patients, anticipatory care and 'rehabilitation', support for carers, the quality of local care homes, services for people with dementia, transport in remote rural areas and the complaints system.

Audit Scotland's recent report on RCOP shows how very difficult and complex it is proving to shift the balance of care from traditional institutional and hospital settings to the community. Although the report finds progress has been slow, it acknowledges the scale of the challenge and calls for more targeting of resources on ways of supporting people to stay in their homes²⁷. These interviews reinforce this policy drive to keep people in their homes for as long as possible. Older people and carers express their wish not only to stay in their homes but also to stay in their communities with their established social networks. The stories show how a fundamental cultural change on behalf of both service users and service providers is required to achieve the objective of shifting the balance of care. It represents not only a huge logistical challenge requiring major re investment in home care, telecare and community based resources, it also challenges existing attitudes to risk assessment and service culture. In addition to conventional support services like home care, the need for older people to feel secure, confident and socially connected in their homes is also fundamental to ensuring that people live well in their communities.

For the most part interviewees have agreed to take part so they can have their views heard in the belief that it will help improve service delivery for older people in the Highlands. Some want to praise the care they have received and to recognise hard-working staff who treat them as individuals with respect, dignity and kindness. Conversely those who have had poor experiences want to help improve services by telling providers where things went wrong. In *'The Role of Co-production for Better Health and Well-being: Why We Need to Change'*, Bovaird and Loeffler highlight the complexity of the processes and relationships involved:

“The creation of quality in services often occurs during service delivery, usually in the interaction between the customer and provider, rather than just at the end of the process. This means that customers do not evaluate service quality based solely on the outcomes (e.g. the success of a medical treatment in a hospital) – they also consider the process of service delivery (e.g. how friendly and responsive were the hospital medical staff and how comfortable was the ward.” (p. 20)

They find that determining quality is not simply about achieving a successful outcome but is dependent on the relationships and experiences which make up the patient journey. This research aims to reflect the dynamic and multi-layered nature of the care pathway experience from the older patient’s point of view. Older service users and carers appreciate high quality services and support, but they are also clear about the difficulties encountered and the issues they would like to see improved. The following areas of need arise from these interviews with older people and carers.

Home Care

"We know you have to fight for a care package." (16)

It is acknowledged that NHS have begun to implement plans to re-design the care at home service and adopt a re-ablement model to prevent admission to hospital or a care home. In recognition of the need for increased capacity to meet a growing demand, a new joint approach with the independent sector has been initiated in NHS²⁸. The interviews reinforce the need for this development of the home care service. Increasing home care capacity is essential to fulfil both older people’s explicit wish to stay at home for as long as possible and the policy imperative to shift the balance of care to the community. Following emergency hospital admission, older patients and families commonly express a desire for returning home. Interviewees believe lengthy delays in hospital can result in physical and mental deterioration and a loss of confidence about returning home.

The NHS Care at Home Survey (50% response rate) in 2013 found a high level of satisfaction with the overall service while aspects like consistency of care input, timings and flexibility of visits could be improved²⁹. These interviews also show people appreciate the quality of carers coming into the home, but they often find service organisation could be more efficient in areas which have an impact on the reliability of their care, such as carer travelling plans and relief cover. Suggestions include having a bank of relief carers and zoning to improve travelling plans. For example, Martin’s mother got on really well with her carers and enjoyed their company, but he found the service was often poorly managed:

"Their objective is to care. Well that's not caring when the system is breaking down and the staff are under pressure and there's no backup." (6)

Interviewees also ask about opportunities for 'rehabilitation' to restore and promote independence. Sandra said carers *"have a job to do and they do it very well but they don't have time to promote independence"* (49). The JIT Care at Home Support Programme aims to shift the emphasis to re-ablement and rehabilitation models that *"seek to optimise the capabilities of older people"*³⁰. Ensuring people remain at home is not simply achieved with short visits to enable people to get up, shower and go to bed. Quality of life and well-being issues are also key to staying at home. People want home carers to have more time to spend time with the person and focus on their individual needs. Alison's sister sometimes took their mother who had dementia out for a little walk and she says *"that's the kind of care that she needed and it couldn't be done in 45 minutes"* (2). Other assistance is required to tackle social isolation, loneliness and loss of confidence following injury and hospital admission. Befriending and telecare services can also help promote confidence and independent living. Relief for family carers is also essential, both traditional 'sitting' services during the day and also night care. Carers say this would enable them to safeguard their own health and therefore increase their capacity to care for the relative and keep them at home. Irene wanted to bring her mother home from hospital but they told her that her mother would need help at night. Irene could not find any:

"The family has to be prepared to sleep there which I was ... but I would not have been able to do that for more than a night or two. I wouldn't have slept. I'd have been waiting for the alarm to go off ... and then I wouldn't have been able to do her day care because I would have been completely exhausted. So you don't have an alternative. There's nobody you can find whose willing to do this. So it wasn't that the hospital were saying that you have to, it's just that they were saying that well without some kind of night supervision, she's not going to be able to [come home]." (50)

Edinburgh City Council offers a wide range of support including a night care service³¹. Older people also indicated a need for help with other jobs e.g. domestic tasks, home maintenance, cleaning and gardening particularly if they have no local support from family or other networks. These services improve their mental wellbeing in addition to ensuring that they are physically safe.

Hospital Care

Discharge planning

"I think it was just a Friday afternoon and they wanted to get as many people out of the beds as possible." (12)

Hospital discharge is commonly raised in these interviews. Relatives do not always feel involved in discharge planning and are not necessarily given enough notice of discharge to allow transport, home care and other services to be organised. Raigmore pharmacy is criticised by patients for apparently delaying departure from

hospital. The Health Improvement Scotland OPAH inspection report on Raigmore Hospital found little evidence of *"proactive discharge planning"*³².

Denis (46b) visited his wife, who has Multiple Sclerosis, on Sunday night and he asked a nurse if there was any word on her getting out. He was told no, she would be in a few days and she might be moved to another ward. Denis is over 65 himself and works full-time. On Monday he was driving away from the town when he got a call at about 10.30am from the hospital saying *"Oh Trish is getting home today"*. Denis says *"this is happening all the time ... It's soul destroying"*. Trish needs to be wheeled directly into an accessible vehicle and it was about 4 pm before they could bring her home.

Interviewees do not generally think there is sufficient anticipatory care planning. They worry that relatives are discharged too soon before they are fully recovered and are quickly re-admitted.

Communication

"When you do ask a nurse, it's almost like goodness don't ask me, almost like a rabbit in the headlights, it's almost like oh no, no it's not my problem ... head down." (14)

These interviews suggest that relatives often experience greater communication difficulties than older patients themselves. The importance of sensitive, useful and timely communication is a dominant theme from the interviews. It prevents misunderstandings, misinformation and reduces problems between staff and relatives. Carers are meant to be 'equal partners in care'³³ and they have information useful to staff. The impact of hospital admission and/or diagnosis on patient and relatives can mean that information provided to the patient and carer is not always immediately taken in. In some cases assumptions are made about what a patient or relative knows. Interviewees would like a clear means of accessing information with a nominated person(s) or allocation of a time slot to allow them to obtain updates both for information and reassurance without taking too much staff time. For example, Heather felt communication was pretty poor and she did not feel she got answers to all her questions:

"Sometimes when, you know, you phone up to the hospital, it's like they're too busy you know. Oh can you phone back later and right ok. And you phone back and you're getting a one word answer and you feel like you're just being a bloody pest you know and yeah I know they're busy. I appreciate that you know. I do appreciate what they're doing but it doesn't help when you're wanting answers and you can't get them" (38).

Patients do not always feel involved in decisions. Linda (58) had been used to being in charge at home and at work but with a sudden deterioration in her health, she found everybody was taking over:

"I just felt everything had changed for me ... it was really ... a terrible, terrible feeling but you can't say that to a lot of people because they maybe feel you're being ungrateful ... I wasn't ungrateful. I knew they were doing for it for the best." (58)

Even if she was happy with the decisions, Linda wanted to be consulted. For example, they put in a railing by her bed and she wondered why because she had never asked for it. Linda said it turned out to be the "*greatest thing*", but it would have been better if they had involved her and given her some sense of control. Coming to terms with her unexpected and severe illness was very hard and she just wanted someone to ask her opinion: "*What do you think, Linda? We're thinking of doing this or that.*"

It is also essential that DNACPR forms are treated with sensitivity. The Health Improvement Scotland OPAH inspection report identified continuing to ensure the correct completion of DNACPR forms as an area of continuing improvement.³⁴ Catherine (4) discovered a doctor had filled in a DNACPR form without apparently consulting her mother, Isobel, or the family. Isobel herself did not seem to be aware of it. She was deaf and Catherine thought the staff did not ensure she heard and understood everything. Catherine looked at the form and found there was no printed name only the signature of a doctor with no date. The staff nurse took her into a room and explained what it was all about. Catherine was very shocked.

Advocacy

"A person who needs something, like an elderly mother, is not just a little Lego figure that can be placed here and there ... she is the matriarch in a family and that family has also to be sure that the decisions they're taking for your mother, who has done so much for you your whole life, are the correct ones when it comes towards the end of hers." (50)

The interviews give insight into the complexity of the decision-making process for patients and relatives in view of the stressful circumstances and the shock of hospital admission. Relatives are also individuals with differing attitudes, experiences, expectations and knowledge which means they react differently to the situation. They do not necessarily understand how the hospital and care systems work and do not always anticipate having to decide on care homes. They may have imagined taking their older relative to see round a care home but this may become impossible, which makes choosing even harder. Patients and relatives can find it difficult because of the stressful situation and perceived power imbalance affecting communication with staff. To the family the older person is primarily a father or mother or spouse, not a patient. The interviews highlight the significance to families of placing a relative in a care home and the emotions involved. Coming to terms with what has happened takes time and relatives are shocked by the rapid deterioration of older person. An advocacy service for patients and families could support people making difficult decisions about care if they wished and improve communication with staff.

Eye clinic

"Be nice to talk heart to heart as it were." (54)

According to the UK wide Macular Society, AMD is the most common cause of sight loss in the developed world affecting over 500,000 people in the UK³⁵. It occurs mostly in people over 65³⁶ and therefore should be a key concern in health service delivery for older people. On the whole AMD patients are extremely happy with their medical treatment at Raigmore Hospital and very appreciative of the positive impact on their lives but they also find other aspects of service delivery could be improved. Interviewees think there should be some opportunity for either professional post-diagnosis counselling or peer support in the clinic. In particular patients feel anyone receiving a diagnosis of 'dry' AMD, for which no treatment is currently available³⁷, should be offered appropriate support having been told nothing more can be done for them clinically. Harry explains:

"At the time you've been diagnosed, you're shell-shocked and what you need is, you need to talk to someone and have somebody there to listen to you." (55)

Interviewees compare it to being given a cancer diagnosis and not receiving support. They do not think the onus should be on a patient just in receipt of a life-changing diagnosis to access information. This diagnosis should automatically trigger the hand-out of an information leaflet by clinical or reception staff. As it appears out-patient clinics are organised according to specific eye condition, most people attending on a particular day would require broadly similar information. Every patient should leave the clinic with appropriate information. The UK Macular Society itself offers a telephone counselling service, which could be signposted. Interviews also suggest that the low vision clinic is poorly signposted and patients do not necessarily hear about the service. Patients also ask for information and appointment letters to be available in large print.

Although they are generally happy with their medical treatment, AMD patients are calling for improvements to be made. As Moira said:

"We don't want more vapid discussions and patting on the back and patronising quite frankly. We want them to get out and do something." (8)

Dementia care

"I never ever felt ... at ease when she was in hospital. We felt every spare moment we had we should be up there spending time caring for her and doing what the staff didn't have time to do." (2)

Dementia patients require specialist care which relatives realise is difficult to provide on the ward. They also find understanding of dementia care varies between wards.

Carers would like more staff to receive specialist training in dementia care. The Butterfly Scheme has been praised by relatives because it can facilitate appropriate care and enable patients to be treated as individuals.

Falls

"They were as sorry as we were." (31)

Several older patients had fallen while on hospital wards. Blame is not generally attached to the ward, but some patients do sustain injuries. Maureen's mother had just been transferred to another ward. She had been put in a single room on her own. She was confused and tried to get up to go to toilet but did not know how to call for help. Maureen thinks it could have happened at home but it was upsetting seeing her mother with a badly bruised face and eye. She did not blame the ward and praises the care:

"She'd just arrived in that ward. She couldn't have got better treatment anywhere from the doctor and his staff. They were so good." (31)

Dignity

"I thought the ladies should have had ladies looking after them." (34)

Patients should if they wish it be given some choice where possible over gender of the staff member who does personal care. It should be acknowledged that many people have no difficulty at all with this issue, but for some it can be very distressing to be washed by someone of the opposite gender. They feel embarrassed about talking about it or 'complaining'. Personal care is seen differently to medical examinations which do not present the same problem.

Carers

"I had no sleep and I couldn't have carried on much longer with no sleep because otherwise I would've, you know, probably had a nervous breakdown or been ill or something and it was a case of either him or me." (42)

The need for more support and information for carers is a dominant theme of the interviews which also highlight the specific problems of older carers. Carers commonly report they have to struggle to access support and services. The Carers' Strategy refers to older carers as a "major strength and resource" (p. 20). However, it is clear from these interviews that older carers also have their own health needs and are made more vulnerable due to the pressures of caring.

"You just carry on because you think well this is my duty to my husband. I've got to be strong enough to do it but I think again you become invisible to the person you're caring for because they live in their little world and everything ... is theirs for them, you know, and it can get very depressing and lonely." (51)

In particular a carer of someone with dementia can find seeking help in the first place very difficult. They can feel very isolated and overwhelmed by the difficulty of their situation as they try to adapt and come to terms with changes in their relatives.

Care Homes

"Good care homes, they don't grow on trees. You have to wait until somebody dies in one of them for a place to become available. That's not going to happen overnight... a family has to have time to look round places." (50)

Two interviewees visited their nearest care home – one to see a friend and another as a member of a local group who came in regularly. Without relatives in the home, they felt able to comment on the conditions there and felt free to make a formal complaint if necessary. They felt able to speak out on behalf of vulnerable residents in the home. One of them made a point of being around at meal-times to check on the quality of food. On one occasion she had to ask that a resident was given help to eat her meal. She believes she has been able to make a positive difference by becoming a regular and trusted visitor. This type of active involvement by the interviewees suggests that a 'lay' inspectorate of volunteers could play an important role visiting local care homes on a regular basis to observe and comment on conditions. By getting to know their local care home, they could work in partnership to improve standards and ensure residents were not afraid to speak out if they were unhappy about anything.

Remote Rural Areas

"Everybody has a right, I think, to equity of care or equity of access to services irrespective of whether they're in Inverness ... or whether they're up in Caithness." (40)

Communities in remote rural areas present particular challenges for service delivery. For example, the '4 day on 4 day off' rotation of home carers does not fit in very well with staff who may have other part-time jobs. This pattern makes it difficult to recruit new staff who need to keep other jobs to sustain themselves. Interviewees suggest that this employment pattern has to be more flexible in such remote rural areas, where part-time working is common. One interviewee described it:

"Most people aren't lucky enough to have one job. Most people have several jobs." (21)

The Dementia Health Care Needs Assessment highlights the “*substantial challenges*” involved in delivering dementia services to rural areas, where transport issues and service availability make it difficult for people with dementia and their families to access provision³⁸. Interviewees call for local respite care so older people are not sent out of their communities. The lack of public transport is a major issue, especially for older people who have given up driving and have to rely on other people to access shops, medical appointments and social activities. Hospital transport can be cancelled at short notice which means older patients miss appointments and have to wait weeks for them to be re-scheduled. Community transport schemes like Transport for Tongue (T4T) provide a valuable and effective service to local people. With its recent acquisition of a new accessible vehicle, it was suggested that T4T could also offer patient transport to hospital, thereby improving the service for patients and relieving the burden on the existing services. If Scottish Ambulance Service (SAS) transport is booked, but is cancelled at short notice, then this does not allow the time required to organise the volunteer drivers. At the moment T4T can use the new vehicle for patient transport but the patient has to pay the full cost. A similar service has been operating in East Renfrewshire for the last 14 years. The community transport scheme arranges volunteer drivers using their own vehicles and pays them a mileage rate to enable patients to attend appointments at hospital, clinics and GP surgeries following GP referral. It is funded by the Community Health and Care Partnership.

Complaints Procedure

"If somebody complains they're always a marked person ... [the staff are] on guard, you know, kind of suspicious. I just knew it wouldn't do me any good." (52)

Patients would like the complaints system to be less intimidating. People are concerned that complaining will have an adverse impact on medical care and treatment. Bob is put off complaining about his experience because "*these people have power, we don't*". Bob says you need energy and the will to go on and do it because it is hard work. He explains:

"I suppose there's two aspects, one is will you achieve anything and another one is you're going to piss off the people who you need to help you. So do you achieve anything by doing it? You might get somewhere but there's a whole load of people who aren't going to be too happy." (3)

Summary

In summary the following key areas of need arise from the interviews with older people and carers:

Home care

An integrated and reliable home care service with increased capacity and extended service range along a re-ablement model with longer visits and night care.

Hospital admission and care

- Involvement of relatives in discharge planning and medication ready at discharge.
- Relatives know who to contact for information and feel questions are answered.
- Advocacy for families and patients making decisions about care.
- Information, advice and support for AMD patients.
- High quality specialist care for people with dementia and extension of Butterfly Scheme.
- Anticipatory care planning to reduce admission.
- Falls reduction on wards amongst frail older patients.
- Dignity in personal care arrangements.

Carers

Recognition, support and information for carers with opportunities for respite and day care.

Care homes

High quality local care homes with support from local volunteer 'lay' inspectors.

Remote rural areas

Local innovative solutions to service delivery issues like public transport, patient transport, respite and dementia care services.

Complaints system

Patients are supported to give their feedback and reassured that there will be no impact on care.

Older patient voice heard

Independent user-led collection of feedback for quality assurance and service innovation.

NHSH faces a huge challenge to extend home care, improve care home quality, tackle delayed discharge and plan services for an increasing older population with diverse and complex needs. It is not just about chronological age because it does not simply reflect identity, capacity or need. Older people are individuals and are clear that they expect to be treated as individuals. What is clear is that older patients need to be trusted and allowed to contribute to the planning and delivery of their care in order to ensure it is 'person-centred'. They want the opportunity to express their views and feelings so they can explain to providers what it is like to be an older patient or carer. This dialogue would enhance understanding that could underpin policy and service delivery. Bovaird and Loeffler (2013: 26) point out that future public service should encourage people to engage in co-production and ensure they feel appreciated and want to continue. In this project older patients and relatives have taken time to share their personal experiences, some of which are very distressing. People want to know they have been listened to:

"I think what you are doing here is great because maybe it will feedback through the system but it could also end up just in a great big thick document stuck down the back of a chair somewhere." (3)

Bob's comment expresses both hope and cynicism. It conveys the sense of an individual struggling against a system rather than being in control. Similarly another person expresses this feeling of powerlessness:

"I know what can be done and what can be achieved if you know the right people - but I've always just been a patient." (52)

In 'Assets for health'³⁹ Sir H Burns highlights that a sense of control is associated with better health and finds traditional approaches can disempower service users. A power imbalance is experienced by some patients and is illustrated by a reluctance to engage in the complaints system which reinforces a sense of powerlessness. Isla explains what that feels like:

"There's only so many times that you can bang your head against a brick wall before it gets so sore that you think no." (3a)

The danger here is that people do not feel their views are taken seriously and they will give up wanting to tell their stories.

This research shows that older people are very satisfied with many aspects of their services but several areas for improvement emerge. Some issues are relatively straightforward while others are very challenging and would require significant resources and a cultural shift to implement. The key challenge is keeping older people at home and in their communities where they want to be. A more integrated and holistic home care service is necessary to achieve this key RCOP objective. In addition it also requires the development of other vital support services such as transport as well as strategies to tackle social isolation. Older people are individuals

with diverse needs but it should also be recognised that they make a valuable contribution to their communities.

It is hoped that Highland will be able to bring about the changes required to shift the balance of care, ensure person-centred care and enable co-production. By working creatively with older people, families and representative groups, services can be improved and needs met in partnership with providers. This project aims to encourage a dialogue between service users and providers. Older people have said that they want to be listened to but more than that, they want what they are saying to count and directly influence service delivery for the better. Fiona points out how older people's views and ideas should be heard and valued:

"I know people in their eighties who have got very infirm bodies but very acute and active minds and still got lots to give. Lots to give, lots of experience, a lot of common sense. They should be listened to for that alone." (11)

Older people and carers should not struggle to be heard. They do not want to be the ones that have to shout the loudest. Older people should have more control over their lives and be allowed to participate in the planning, design and delivery of services on which they rely for their health and well-being.

APPENDIX A

1. Patient story (35 & 36)

Joan is 91 years old and was diagnosed with vascular dementia in 2012. She has three daughters who live nearby and who are actively involved in her care. Until her admission to hospital on 13 May 2013, Joan was living independently on her own in her home without any formal support. She had given up driving three years before, but appeared to her daughters to be in very good health. The family helped her with anything she needed.

Just before her admission she had been unwell and lost her voice. The daughters thought it was a virus, but their mother did not seem to be getting better and didn't seem herself. Recently they had started to notice that she was getting very forgetful, sometimes unusually aggressive and she seemed depressed. She was prescribed anti-depressants by her GP a few weeks before admission. Her daughter, Sally, found "*when the doctors always came out she was as right as rain with them*". Gail said "*it made us look like idiots ... she'd say yes doctor, no doctor*". The GPs never discussed the dementia diagnosis. Gail had taken her mother to the memory clinic in 2012 where the doctor told her that her mother had a bad memory and had suffered a series of mini-strokes. The doctor diagnosed vascular dementia but the family say they weren't told. The daughters accepted their mother's forgetfulness as a sign of her age.

On 12 May Joan fell downstairs but at first she seemed to be fine. She doesn't know what happened but she remembers falling and trying to catch at the banisters to stop herself but she was going too fast:

"I didn't forget what happened ... I can still see myself lying down there and ever so thankful. What did I say? What did I say, the words I thought? ... 'Oh I'm still alive', I think, when I reached the bottom of the stairs."

The following day one of the daughters called in and didn't think her mother was great so she called the GP who came out. Joan had a sore leg and was very confused. The GP thought she should go to hospital. She was admitted to one ward and then transferred after one night to another. The family were very worried by their mother's rapid deterioration and they were concerned about her mental state. Gail had left on holiday but she returned early and was very shocked by her mother's condition:

"She went from being our mother to this person we didn't know, talking absolute rubbish. Things coming out of the walls, just hallucinating beyond words ... totally unbelievable".

The daughters think it was about a week before they found out that their mother had vascular dementia:

"It wasn't made clear to the family that's what she had. We just thought she had a bad memory ... it was said to me that she was taking mini strokes but the actual word dementia was never mentioned ... so when she was went into hospital Dr ___ just assumed that we knew she had vascular dementia and we were so taken aback at how ill she was, her behaviour and then one day Dr ___ had said ... 'well your mother does have vascular dementia' and we thought what, my mother doesn't have dementia and of course things went from there." (Gail)

The daughters say the communication wasn't good at this point. Gail doesn't want to blame anyone for this and thought there were faults on both sides. It had been assumed that the family knew about the dementia and understood what was happening. Gail says *"We were dumbstruck"*. The family was in shock. Within the first month of her stay, the daughters thought their mother had also fallen in the hospital three times and at least once had been taken for an x-ray. The third sister had a negative exchange with the Consultant on the phone and demanded to have a meeting. The family wasn't happy with the information received so far and felt they didn't know what was happening:

"We hadn't got a clue in the beginning and we just felt they were just doing their thing and we were left in the dark ... At the same time they were assessing her and doing all that and maybe they didn't have anything to tell us but we didn't know anything either." (Sally)

At the meeting the Consultant pointed out to them that information had been given to them on different occasions and this was documented. Gail said at the meeting:

"We don't doubt any of that Dr ___, but you must appreciate that a) we didn't know Mum had dementia b) we were stunned at how she's deteriorated since she's been in here."

The daughters feel that that the hospital didn't realise that they hadn't taken it in and they were all shocked by their mother's condition. Gail describes how she felt:

"I just felt a wee bit more time spent with us and a wee bit more explanation really would have been nice".

The daughters believe that the Consultant did understand this and he then explained everything to them. He was *"super"*. They felt things finally started to make sense:

"All we wanted was him to tell us what was wrong with Mum, how long she had, what her state was, what to expect and he could have done that in half an hour." (Gail)

They want to thank him for making everything clear. The meeting resolved a lot of their issues and things went more smoothly after that. However, they would still have liked more communication with senior staff. It was made clear that the Consultant was very busy and they should ask his team for information. He said he

wouldn't speak to them on the phone. However, they felt that the junior doctors were unable to answer their questions, which went unanswered. Sally thought only the Consultant was able to say anything definite. Gail says:

"I did feel a wee bit fobbed off at times, just a wee bit, but we didn't make a fuss. We were happy she was well looked after. We were in shock for quite a while to see how she'd deteriorated so much."

The family were worried about her hallucinations and Gail mentioned this to a doctor:

"We feel that you, the doctors, don't hear what we're hearing. We feel that you don't hear what she's coming out with and she just went 'Och well, it's not bothering her is it?'"

However, the family were extremely concerned and disturbed by them. Joan would look out the window and see the boats coming in even though there wasn't even any water out there. Gail says it sounds very innocent but the daughters were worried about what would happen if Joan was at home. Perhaps she wouldn't come down stairs because she might see water there.

After about a week the hospital started to talk about sending Joan home:

"We kind of panicked ... We thought how can we take her home? There's nobody at home there for her" (Gail)

The family did not think Joan was physically or mentally fit to be discharged:

"This whole experience was more about, to be quite honest, the family. How shocked we all were, how upset we were because we were in tears sometimes about the state Mum was in ... I'm close to it now when I think about how bad she was." (Gail)

The hospital suggested the possibility of going into a care home. The family did not think Joan needed to go into a care home and they knew their mother was totally against it. Gail thought *"we'll look after her fine"* but she deteriorated so much that they began to think they couldn't look after her. It was a dilemma and they didn't know what to do. They feel they had to do everything themselves. Gail wasn't interested in support groups as such but they wanted to know what services were available. No one mentioned the possibility of home care and they did not know what a care package was. The daughters think that if home care had been discussed earlier, this would have been very helpful. They had to bring up the subject of home care themselves. An acquaintance mentioned home care to them and one of the daughters asked the Social Worker about getting it. Neither they nor their mother had wanted any help up to then but at this stage they began to think they couldn't cope:

"We said right we can't take her home like this because we don't know how to look after her and they said ... that makes sense and we'll see about a care package. So of course we thought next week, the week after she'd be home." (Gail)

At first the family hadn't want Joan to go home because they couldn't be with her 24 hrs a day. However, they began to think if the doctors thought she was fit, then they could try her at home with the care in place. Gail says it sounds "selfish" but it was for them because they wanted to know she was safe. At one point Joan said she didn't want to go home if carers were put in place. They weren't happy that the hospital accepted everything their mother said to them:

"They accepted everything that Mum said and wanted ... we thought that wasn't right ... they kept saying your mum wants to go home and we said my mother doesn't want to go home and they said oh yes she said to us that she wants to go home and we said well I am sorry, I don't care what's she telling you ... she didn't want to go home." (Gail)

Her daughters believe their mother wanted to stay in hospital. Joan told them there was nothing wrong with where she was and her daughters think she would go back to hospital tomorrow if she could. They were concerned that their mother was losing her confidence. Gail asked if there was anything for their mother to do on the ward and was told the Physio came round:

"Maybe she shouldn't be in hospital. The argument there could be she shouldn't even be here but where should she be? She can't come home. We don't want her to go to a home. She's not ready for a home." (Gail)

Gail wonders if an outside carer could come in to do activities with the older patients. Joan wanted to talk to the other patients but she said to her daughters that she had been told to sit down. Sally thinks her mother was probably being a pest. Sally says *"I just felt that she was safe and she was looked after"* and she knew the nurses can't entertain them. The family went in every day twice a day, but their mother still deteriorated. Joan said she got used to hospital but there was nothing to do:

"I had nothing to do ... there was two people opposite me and I used to go back and fore to them a lot and then they got not very happy because they thought I was doing their work, but I was just going back and fore to please them really as much as I myself, I suppose. I never thought of myself. But I know there was a bit of a problem over that."

The daughters were very happy with the medical and nursing care that their mother received in hospital. The staff were all very good. She was treated *"like an old lady"* but they don't think she had much dignity left herself. They say there were more positives than negatives. The nurses were nice although Gail thought they spent too long doing paperwork and not enough time with the patients, but this was not the nurses' fault. The daughters had no reason to complain – the communication was

their only negative issue. Joan was also very satisfied with her care at Raigmore saying: *"Oh no the hospital was good. Oh yes, I couldn't complain, oh heavens no"*. She says: *"I got that used to it ... I think that's what put me off home"*. However, she did say that she was expecting the OT every day for a week to help her practise climbing the stairs. In fact the OT only came one day:

"That's the only fault I found with them that they forgot to keep me going and I didn't like to say anything."

Joan was particularly worried about the stairs at home because of her fall and said *"I did worry about what I would be like"*. She says she didn't worry about anything else and adds *"I knew I had to come home and that was it."* However, she has had no problem at all going up and down the stairs now she is home. Asked if she was happy to come home, Joan says yes but she wasn't as keen as she had been:

"I was away so long that I wasn't so keen as I had been if you like. It was a long time four and a half month."

The daughters weren't happy that their mother had to wait for so long for home care and they believe she deteriorated in hospital:

"The answer was take her in, assess her, see that she's not injured, check her medication and get her home with care." (Gail)

They don't blame the hospital. Gail says: *"We are not faulting the hospital. We are really not but it's the system more than the hospital."* Sally believes it is just a hospital and it is asking too much. However, Gail thinks something should be done about it. It was a strain waiting for so long:

"The up side of it was she was in hospital and we felt she was safe ... the down side of it was she was deteriorating every day she was in there. We knew there was nothing they could do for her ... I thought it was a disgrace personally whether you want to blame the NHS, the Highland Council, the government ... I just think it's just a disgrace that she had to wait so long." (Gail)

Gail just assumed they were waiting for someone to die so their Mum could get their care. They were dreading taking her home because of her deterioration. Gail felt they didn't keep her informed about what was going on and she had to keep phoning to find out. However, Sally said the Social Worker had contacted her a couple of times, saying she had been ringing up to find out about home care but there was nothing available. Gail was happy with the Social Worker as a single point of contact and felt able to contact her anytime – she was very good. When asked how they would have felt about some interim arrangement to allow their mother to leave hospital earlier, they were definite they would not accept fewer than three home care visits. They weren't sure about a temporary care home place because they knew their mother did not want to go into a care home. Joan had been assessed as needing four home care visits but the Social Worker asked the family if

they would accept three in order to get their mother home and cover the last visit themselves. The family agreed because they wanted their mother to go home.

Sally went to fetch her mother, having been told the day before that she was going to be discharged. Gail thought her mother would be over the moon to be home but she didn't seem to be. Everything was ready when Sally went to pick her mother up. The daughters are also satisfied with the equipment and adaptations put in for their mother's return e.g. toilet seat, bath seat, handrail on stairs. Joan has been followed up by the GP who has called in regularly and been very attentive. The home care had also been put in place when she came home. The family are very happy with it and find it reliable. The daughters refused a community alarm because they thought their mother wouldn't wear it and may also abuse it by phoning for non-essential reasons like her Hoover breaking down. Gail says her mother had already started to phone them at all hours before her admission. They also turned down a pillow or bed sensor because their mother gets up in the night for long periods to let the cat in and out of the house.

Joan likes her home carers but she thinks it's a waste of money because she doesn't need them. She has her family "*back and fore*":

"They're very nice. They're good company but then it only lasts for 5 minutes 10 minutes. They are very good ... They make a cup of tea for me and I just sit down and drink it but I could go and make it myself if I wasn't so lazy [Laughing] or if they weren't here ... so I honestly think it's quite a waste but maybe that's me. Am I bad saying that?"

She says she is happy to be home because "*it's home, my goodness. After all said and done it's home*". Joan says she has got "*lazy*" and isn't doing her housework. Her daughters are cleaning the house, but Joan says this is temporary and she will have to get used to doing it herself:

"If I get into the working mode that I should get into, that I haven't got into, I should get back to normal, I hope ... I'm hoping to get back to normal."

The daughters are happy that this is now the best outcome for their mother for the time being. Gail says the minute she got home, she was "*back to herself*" (Gail). Their mother is looking good, eating well, getting up and down the stairs and as far as they know sleeping well. Joan did very well at the recent memory clinic test, even getting the date right, and the doctor was delighted. She has been a bit up and down but now she is at home she is a different person:

"At the end of the day ... everything has worked out the best for her at this moment in time." (Gail)

The daughters are happy to look after their mother and do things for her up to a point. If her mind deteriorates, Gail says they will cross that bridge when they come to it.

2. Patient story (37 & 44)

Elsie is 95 years old and now lives in a care home in Inverness. Her daughter lives in England and comes up every three weeks. Until this admission into hospital Elsie was living at home on her own with three home care visits a day. A close friend, Sheena, came over to help put her to bed at night.

At first Elsie said she couldn't remember why she had been admitted to hospital and then she said it was after breaking her hip. She had fallen one morning and pressed her community alarm to summon help. She could hear the voice of the call handler in the bedroom but they couldn't hear her. She thought she had been waiting a long time for assistance, probably about an hour. She found it very frightening. The paramedics couldn't get in because the key was in the locked door and they had to get the police to ram the door open. The two key holders were away. Elsie was taken to hospital and had her hip replaced. She said the alarm was a great thing and *"it saved my life and oh yes, it's a good thing"*. Elsie had to have *"two horrible operations"* because the first one hadn't worked. She doesn't like Physios because one of them had made her get up and try walking even though she said she was in a lot of pain. It had been very distressing. The Physio kept telling her that she could do it and the staff got annoyed with her. She says *"the only way that he would stop was if I started to cry"*. Following further investigation it was discovered that her hip was broken in four places which is why she was in a lot of pain. After another operation the surgeon told her that the second operation is usually fatal and she was very surprised he had said that.

Maggie, her daughter, who was interviewed separately, said this accident had actually taken place two years ago and her mother had been admitted this time after injuring her back following another fall. Maggie had been at the house and had been called by her mother at about 5am. Elsie had fallen while trying to use the commode.

Both Elsie and her daughter were satisfied that she was cared for well on the ward. Elsie says the staff were alright and she had no complaints. She thinks she had enough information and was treated by the staff with respect and kindness. Elsie was desperate to go home but she got on fine in hospital and made friends with some of the nurses. The only negative thing that she noted was *"if you rang ... they didn't come quick enough."* If Elsie wanted to know anything, she would ask her friend, Sheena:

"I depended on her because she was a very good friend ... if she thought anything was not right she would get onto them because I wouldn't".

Elsie says *"I don't like complaining so Sheena would complain for me"*. She thinks both her friend and daughter thought she was waiting in hospital too long.

Maggie thinks the nursing care was brilliant and the nurses were *"angels"*. However the communication was *"iffy"*. She often phoned the ward and asked the staff to tell

her mother that she loved her and she had phoned. However, there was usually confusion over Elsie's name as she had always been known by a different first name to the one in her medical records. In the end Maggie gave up and phoned the friends, Sheena, who was visiting every day.

At first Elsie was clear that she didn't want to go to a care home and she just wanted to return home. Maggie was asked about a care home but she said it was up to her mother. She didn't think that her mother should go if she didn't want to. Elsie had been very happy with the home care service and liked the carers. She had been very independent at home. She didn't like the idea of a care home saying "*I thought it was terrible to go into a home*". Maggie took her mother back home one day, but Elsie became very breathless. She couldn't even look up at her beautiful garden. During the interview Elsie struggles to remember where her house is and gives a slightly incorrect address. Elsie says, laughing, "*There's nothing nice going for you when you get old*". Her daughter says the agreed plan had been for her mother to return home but she had one bad week where she wasn't eating and drinking.

Elsie says the doctor thought she should go into a home:

"He gave me this lecture. You're a grown woman and you must know that you can't look after yourself ... because you just can't do things like you used to you ... You just have to accept it." (Elsie)

According to Maggie the doctor said her mother could go home and might be great but she might also have another bad week. He said she didn't need nursing care but did require someone to be there at night. He didn't want to see her re-admitted to hospital. Maggie says she wouldn't have been happy to think her mother was at risk. Maggie thinks "*It's amazing how quickly old people go down with just that one thing*". The doctor said older people like this were on a knife edge.

Maggie believes her mother deteriorated being in hospital for such a long time. She was lying in bed for over 6 weeks and did not even get up to go to the toilet. It wasn't good for her osteoporosis either. Maggie thinks her mother should have been up and dressed more quickly. She says it's not good to spend all day in a dressing gown. Maggie believes "*She has become frail with being in hospital*" because her muscle tone went and she became institutionalised. Maggie says her mother didn't want to do anything. She wouldn't read a newspaper or anything. Maggie describes the boredom level as "*beyond a joke*". The last two weeks they got her dressed and took her to the day room to eat her meals and watch TV. Maggie found that helped because "*It's all about confidence*".

Maggie wanted to discuss the care home suggestion with the doctor but she did not get the opportunity. She had waited during visiting hours in the hope of talking to him but he never came. She was concerned that her mother didn't want to go into a care home. Maggie only saw the doctor once after she had made an appointment.

The Social Worker phoned Maggie telling her that her mother had decided to go into a care home and Maggie was astounded that her mother had agreed. Maggie took her mother round a few care homes but she says she didn't find anywhere that she felt like spending the rest of her life. Her daughter finally put her name down in three homes.

Elsie thinks an interim place in a care home would have been fine even if that meant she had to move again.

The Social Worker told Elsie that a place had come up in this home which wasn't on her daughter's list. Elsie wasn't sure about that particular home and she didn't go to see it. Her daughter came to see the home with two friends. They said it looked very nice and Elsie took their word for it. Maggie remembers the Social Worker told Elsie one morning that she was going to leave in the afternoon but she thinks her mother didn't care anymore.

Elsie is very happy in the care home and thinks both the staff and the food are very good. Elsie says the doctor was right:

"Of course I know myself that I am too old now to look after myself ... so I just accept it".

Maggie also thinks the doctor was right, although if her mother had been unhappy she would have felt differently. She says *"Going to this home has saved her life" and comments "this is not the woman who left the hospital"*. The staff are very kind and caring and Maggie thinks they must like working there because they seem to stay on. Maggie says:

"You hear that they go into a home and then six months later they're not here at all."

Maggie is delighted with the quality of the care home and says her mother now enjoying life and has *"a fabulous quality of life"*.

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