

VISIT REPORT

Dignity and respect:
dementia continuing
care visits

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Our aim

We aim to ensure that care, treatment and support are lawful and respect the rights and promote the welfare of individuals with mental illness, learning disability and related conditions. We do this by empowering individuals and their carers and influencing and challenging service providers and policy makers.

Why we do this

Individuals may be vulnerable because they are less able at times to safeguard their own interests. They can have restrictions placed on them in order to receive care and treatment. When this happens, we make sure it is legal and ethical.

Who we are

We are an independent organisation set up by Parliament with a range of duties under mental health and incapacity law. We draw on our experience as health and social care staff, service users and carers.

Our values

We believe individuals with mental illness, learning disability and related conditions should be treated with the same respect for their equality and human rights as all other citizens. They have the right to:

- be treated with dignity and respect
- ethical and lawful treatment and to live free from abuse, neglect or discrimination
- care and treatment that best suit their needs
- recovery from mental illness
- lead as fulfilling a life as possible

What we do

Much of our work is at the complex interface between the individual's rights, the law and ethics and the care the person is receiving. We work across the continuum of health and social care.

- We find out whether individual care and treatment is in line with the law and good practice
- We challenge service providers to deliver best practice in mental health and learning disability care
- We follow up on individual cases where we have concerns and may investigate further
- We provide information, advice and guidance to individuals, carers and service providers
- We have a strong and influential voice in service policy and development
- We promote best practice in applying mental health and incapacity law to individuals' care and treatment

Introduction

About 86,000 people in Scotland have dementia and one-third of them are in care homes or hospitals. The nature of the illness means that these people need a lot of care and support and they are more at risk of having their rights overlooked. People with dementia may have lost some, or all, of their ability to be involved in decisions about their care, express their wishes, ask others for help, or exercise their right to make a complaint.

This report details what we found when we visited 52 NHS units providing longer-term care for people with dementia. We reviewed the care of 336 people and spoke to 129 carers/relatives. While we found that many people were receiving good quality care in a suitable environment, we also found units where the care and/or the environment were poor, and where the rights and dignity of people with dementia were not adequately respected. We were disappointed that too many people with dementia were not receiving care which met acceptable standards. Based on our findings we have made a series of recommendations.

Key findings

Most people who lacked capacity to consent to medical treatment had a section 47 certificate in place. However, only 76% had an accompanying treatment plan; this means that 24% of people may have treatment that is not properly authorised.

Where welfare proxies were in place, staff were unaware of the specific powers granted in 42% of cases.

Most welfare proxies felt recognised by staff and involved in decisions.

Only half of the units had advocacy input in the previous six months.

Most units were locked to protect vulnerable individuals. A number of units did not have a locked door policy to ensure the safety, and respect the rights, of the individual.

We found that 84% of people were on at least one psychotropic medication with 34% on three or more, in many cases without evidence of regular review.

There were significant levels of use of antipsychotics, anxiolytics and sedative antidepressants, often in combination. These medications all potentially carry risks of side effects, particularly in older people.

Only around half of people with stressed or distressed behaviours had a care plan in place which was person-centred, reviewed regularly and which considered alternatives to medication.

A quarter of people only had a generic care plan with no person-centred information, one in ten had no care plan at all.

We found that 43% of people were not receiving adequate levels of social or recreational stimulation.

We found that 73% of people had not been on an outing from the unit in the previous three months.

We found that 98% of carers/relatives felt welcome on the unit and 77% felt they were encouraged to remain involved in care. Nearly all were satisfied with the care being provided.

We found that 63% of units had no regular pharmacy input beyond a top-up service.

We found that 71% of units had no regular occupational therapy input.

Only 54% of people had a documented care review within the previous six months.

Only 21% of carers/relatives had been given any written information about the unit.

Only 71% of units had undertaken dementia specific training in the previous 18 months or had firm plans for such training. One unit had undertaken no training in the previous 18 months and had no dates set for future training.

Only 71% of units had easily accessible gardens and only 37% of units had gardens which we considered to be safe, attractive and well maintained. We found that 53% of people had not been outside in the previous month even though it was summer.

Seven units were institutional, bare and stark, with much needing to be done to improve them.

Only about half of units incorporated dementia-friendly environmental features.

Many people were still being cared for in small dormitories with shared facilities.

Recommendations

For NHS boards:

Legal matters and safeguards

- Section 47 certificates should be accompanied by a treatment plan specifying the medical treatment being authorised.
- Where someone has a welfare proxy, staff should know the powers the proxy has been granted.
- People with dementia should have access to specialist advocacy services.
- Every unit with a locked door should have a policy which respects the rights and ensures the safety of individuals.

Medication and management of stressed/distressed behaviours

- Medication should be used as a last, not first, resort in the management of stressed and distressed behaviours.
- People with dementia on multiple psychotropic medications should be prioritised for multi-disciplinary review, including pharmacy, to ensure that continued use is appropriate.
- All people with dementia receiving psychotropic medication should have their continuing need for this reviewed, at least, every three months. Where the benefit of medication is not clear it should be gradually withdrawn with appropriate monitoring of target symptoms.

Care planning and activities

- Life histories are an essential starting point for planning care. If we are to treat an individual with dignity and respect and meet their needs, we must know and understand them as an individual; their likes and dislikes, their achievements and what is important in their life.
- Everyone should have access to a range of activities which provides them with a meaningful day. The provision of activities is an integral component of dementia care.
- Care should be based around a person-centred care plan addressing the complex mental health and physical needs of the individual. This should be reviewed on a regular basis (at least every 3 months).
- Units should provide relevant, accessible, written information to carers at the person's time of admission.

Access to outdoors and the community

- Opportunities to get outside should be included as an essential element of everyone's care; whether this is to a unit garden or to participate in activities within their local community. Too many people continue to spend long periods of time within the units, without any access to fresh air or the world outside. We know that access to fresh air and green space has positive benefits for mental and physical wellbeing.

Multi-disciplinary team input

- Every person within specialist dementia units should have access to the full range of Allied Health Professionals, specialist nurses and psychology on a referral basis, where this is required.
- Full multi-disciplinary reviews should be carried out at least annually, proxies and carers should be actively encouraged to participate in this. Pharmacy should be included as a core discipline within the unit Multi-disciplinary team.

Staff training

- People with dementia and their families have the right to be supported and have care provided by staff who have the values, skills and knowledge which are set out in the Promoting Excellence Framework, developed on behalf of the Scottish Government by NES and SSSC in 2011. NHS Boards should continue to develop the workforce, ensuring education and training is aligned with the Promoting Excellence Framework and ensuring that staff providing direct care in units have the knowledge and skills set out at the 'enhanced' or 'expertise' level of the framework.

Environment

- This remains an issue. Despite the wealth of literature around dementia-friendly design there is much that still needs to be done to ensure that the accommodation is of a consistent standard, which is designed to meet the needs and support the independence and dignity of people with dementia.

End of life care

- Many of the people with dementia we visited will spend their final days in their current unit. Therefore, it is essential that all units have staff who are adequately trained in palliative care utilising roll out of the approved national Promoting Excellence Training Programme and have access to specialist palliative care support where this is indicated.

For the Scottish Government:

- A plan to deliver commitment 11 of Scotland's National Dementia Strategy (2013-2016), to improve specialist NHS dementia care, should be set out. NHS units providing longer term dementia care should be prioritised for improvement.
- A plan to deliver commitment 13 of Scotland's National Dementia Strategy (2013-2016), to reduce inappropriate prescribing of psychotropic medication in people with dementia, should be set out.
- There is huge variation in the level of provision of continuing care beds across NHS boards. This should be reviewed to ensure the level of provision is appropriate and there is equity of access.

Why we visited people with dementia in NHS continuing care

For people with dementia, NHS units may be their home for a considerable period of time. They have the right to care and treatment which is high quality, individualised, properly authorised, and which takes place in an environment suitable to their needs. We last undertook a themed visit to NHS dementia continuing care units in 2007 and you can read our findings in our report **Older and wiser**.

Some of the key messages from the 2007 report were:

- Staff want to provide excellent care in the right kind of environment but feel constrained by limited resources. Staff need support to improve existing care environments;
- Many of the units did not give information to patients and relatives in an accessible manner;
- Relatives we spoke to were very positive about staff but thought that they should be able to spend more time with patients;
- Service providers should take a fresh look at the environment of their continuing care units and use the extensive guidance available to see how their facilities match up to best practice standards;
- Greater use of life histories would help in the assessment and provision of care and treatment;
- Physical and mental activities for patients are valued by patients themselves, relatives and staff. However, options appear to be limited in many units and too few patients are involved.

Since then, there have been a number of national initiatives to improve care, treatment and support for people with dementia.

In 2009, the Commission and the Care Inspectorate jointly published **Remember, I'm still me**. This report looked at care provision for older people in care homes.

The first dementia strategy was published in October 2010. The strategy included a commitment to the development of standards of care for people with dementia, based on the Charter of Rights for dementia. This states that a person with dementia has the same civil and legal rights as everyone else.

The Standards of Care for Dementia in Scotland were published in June 2011. These stated that everyone with dementia has the following rights:

- the right to a diagnosis
- the right to be regarded as a unique individual and to be treated with dignity and respect
- the right to access a range of treatment, care and supports
- the right to be as independent as possible and be included in the community
- the right to have carers who are well supported and educated about dementia
- the right to end of life care that respects their wishes

The two key priorities in the first dementia strategy were, improving rates of dementia diagnosis and implementation of the dementia care standards in acute general hospitals. To aid this, the Promoting Excellence Framework, a knowledge and skills resource for staff, was introduced and Dementia Champions have been trained across a variety of care settings.

Scotland's second dementia strategy, published in 2013, makes a commitment to improve specialist NHS care for people with dementia by 2016. This includes the units visited in this report.

We chose to revisit NHS continuing care dementia units to see the care and treatment experienced by individuals and how services have changed since *Older and wiser*.

During our visits we focussed on the following issues:

- Legal matters and safeguards
- Managing money
- Managing distressed behaviour and the use of medication
- Care that respects the individual
- Activities and being part of the community
- Multi-disciplinary team input
- Staff knowledge and training
- The environment in which people live
- End of life care

How we carried out our visits

The Commission contacted each health board and asked them to identify their continuing care dementia units. We identified 52 units in total.

These units were not all called 'continuing care units' by the health boards. They were described variously as: 'dementia and challenging behaviour unit', 'assessment and treatment unit' or 'tertiary enablement unit'. However, they all met our criteria of providing NHS continuing care. Of these, 13 units (25%) were contracted out by the NHS to private care home settings.

To be eligible for an NHS continuing care bed there must be a need for ongoing and regular specialist clinical supervision of the patient as a result of:

- the complexity, nature or intensity of the patient's health needs, being the patient's medical, nursing and other clinical needs overall;
- the need for frequent, not easily predictable, clinical interventions;
- the need for routine use of specialist healthcare equipment or treatments which require the supervision of specialist NHS staff; or
- a rapidly degenerating or unstable condition requiring specialist medical or nursing supervision

The level of provision varied significantly between health boards.

Health Board	Total Beds	Rate per 100,000 (GRO MYE 2012)
Western Isles	14	50.8
Ayrshire and Arran	96	25.7
Fife (HB)	88	24.0
Lothian	194	23.0
Lanarkshire	127	22.2
Greater Glasgow and Clyde	258	21.2
Forth Valley	54	18.1
Highland (HB)	47	14.7
Dumfries and Galloway (HB)	22	14.6
Borders	16	14.1
Tayside	20	4.9
Grampian	24	4.2
Scotland	960	18.1

Orkney and Shetland were not visited as part of this process.

We visited all 52 units over a five-month period, between May and September 2013. We met with, and looked at, the care of 336 individuals with dementia. Where we had concerns about the care and treatment being provided, we raised these issues with the nurse in charge at the time of the visit. Where necessary, we followed this up as casework.

There are a total of 960 continuing care NHS dementia beds. On average, 787 (82%) were occupied at the time of our visit.

Fifteen (30%) of the units we visited were single sex, split evenly between male and female units. Forty (77%) of the units we visited were designated as dementia specific units. However, at the time of the visit four of these units were also providing care for people without a diagnosis of dementia.

Five of the units were designated as dementia and frail elderly and seven as dementia and functional illness.

Unit size ranged between six and 35 beds. Some of the units provide care for a wide range of people, from younger, physically fit, active individuals who presented with distressed behaviours which challenged services, to very frail individuals receiving end of life care.

We are aware, from speaking to staff, and from our wider visit experience, of the difficulties in meeting the complex needs of such a diverse range of people within one unit.

We saw 195 men (58%) and 144 women (42%). This may be due to men posing more difficult behavioural challenges or being more difficult to place in social care settings.

The majority of people with dementia will have their care needs met either in their own home or in nursing homes. NHS continuing care beds provide care for those individuals whose care needs cannot be met in other settings. This means that the individuals in these units will have more complex health needs which require specialist intervention and more intensive nursing supervision.

Whilst dementia is predominantly a disease of old age, some people develop dementia whilst still relatively young. We saw 28 (8%) individuals under 65 years of age. The youngest was just 45. This is important when considering recreational and social activities for individuals.

It is worth comment that, having reviewed a third of the people in our target population, we only saw one person from an ethnic minority. No one we met with required the use of interpreters. In Scotland 0.8% of people over 65 are from an ethnic minority; therefore, if our sample was representative of the population, we would have expected to see two or three individuals.

Of the individuals we met, 104 (31%) were able to tell us how they felt about their care. However, due to the nature of their illness very few were able to discuss this in any detail.

As it was sometimes challenging to gather the views of people with moderate to advanced dementia directly, we sought the views of the people who knew them best – their relatives and carers. We asked units to publicise our visits and to ask carers if they would be willing to meet with us. Due to this, we spoke with 129 carers from across the country. We have included comments from people with dementia and carers throughout the report.

In each of the units, we interviewed a senior member of nursing staff and undertook an assessment of the environment.

Legal matters and safeguards **Adults with Incapacity (Scotland) Act 2000**

Much of the care and treatment of individuals with dementia is undertaken under the Adults with Incapacity (Scotland) Act 2000 (the 2000 Act). This sets out how decisions can be made on behalf of an individual when they no longer have capacity to make decisions on their own behalf. The 2000 Act allows individuals to plan for the future by nominating someone as a welfare power of attorney and/or a continuing attorney for financial matters. This person can then make certain decisions on the individual's behalf if they lose capacity. The 2000 Act also allows for the appointment of welfare and/or financial guardians, by the court, for individuals who have already lost capacity to make decisions necessary to safeguard their health, welfare and/or finances.

Where there is a welfare power of attorney or guardian they are referred to as a 'proxy decision maker' and have a duty to make decisions in keeping with the principles of the AWI Act, which are set out below. Proxies are given specific powers to act or make decisions where the adult lacks capacity to do so.

The 2000 Act states that anyone authorised to make decisions on behalf of someone with impaired capacity must apply the following principles:

- Any action or decision taken must benefit the person and only be taken when that benefit cannot reasonably be achieved without it;
- Any action or decision taken should be the minimum necessary to achieve the purpose and restrict the person's freedom as little as possible;
- In deciding if an action or decision is to be made, and what that should be, account must be taken of the present and past wishes and feelings of the person, as far as this may be ascertained;
- Take account of the views of others with an interest in the person's welfare. The 2000 Act lists those who should be consulted whenever practicable and reasonable. It includes the person's primary carer, nearest relative, named person, attorney or guardian (if there is one);
- Encourage the person to use existing skills and develop new skills.

Capacity is the ability of a person to make decisions and to understand the consequences of their decisions. Therefore, it is important that, for individuals with dementia, their capacity to make decisions is assessed and recorded.

Where an individual no longer has the capacity to make decisions about their health care, a section 47 certificate of incapacity should be completed by a doctor, regardless of whether there is a proxy with powers to consent to medical treatment. The section 47 certificate states that the individual lacks capacity to consent to treatment, gives the reasons for this, and the accompanying treatment plan should state what treatment is being authorised. Where a proxy has the power to consent to medical treatment they must be consulted, where practicable, by the adult's relevant medical practitioner. Should the proxy disagree with the proposed treatment the medical practitioner must request a second opinion organised by the MWC.

What we expect to find

We expect to find documented evidence of assessment of capacity and, where an individual lacks capacity, section 47 certificates with a treatment plan in place. We expect staff to know whether there is a proxy decision maker in place. There are a wide variety of powers which can be held by proxy decision makers. We expect to find a copy of the powers held by the decision maker in the care file as it is important that staff know what decision making powers the proxy has. We also expect to find proxy decision makers and carers being consulted and involved in decisions about care.

What we found

Only 196 (58%) of the individuals we saw had an assessment of their capacity documented in their care file.

Of the people we saw, 323 (96%) lacked capacity and, of these, 310 (96%) had a section 47 certificate completed, authorising their medical treatment.

Of the section 47 certificates we saw, 237/310 (76%) were supported by a treatment plan where this was required. This means that for 24% of the people who were being treated under part 5 of the AWI Act, their treatment may not have been properly authorised.

Of the people we saw, 178 (53%) had welfare proxies. For 73 (42%) of these, there was not a copy of the powers held on file.

We also asked the carers we interviewed if they held a welfare power of attorney, or guardianship, and whether they felt these were recognised and respected.

We found 89 (69%) carers held proxy status: 71 (55%) carers held welfare power of attorney and 18 (14%) held guardianship, and 31% did not.

Proxies and carers alike felt recognised by staff and involved in care decisions. Only seven proxies (five with power of attorney and two guardians) said that their powers had not been recognised by the staff.

Examples given to support this included:

- changes being made to treatment and the proxy being informed after the event, rather than consulted in advance;
- staff failing to ask the proxy for consent prior to an invasive procedure, requiring sedation.

The majority of proxies, however, reported no concerns and several made positive comments about staff consulting and communicating with them.

"They keep me informed about everything and phone me up all the time and ask if it's okay to do anything."

"Staff consult me about all decisions to do with my wife. I trust them anyway to always act in her best interests."

"My dad gets changes made to his treatment and then we are told. We would prefer any changes were discussed with us prior to them happening."

Recommendations

Section 47 certificates should be accompanied by a treatment plan, specifying the medical treatment being authorised.

Where there is a welfare proxy, staff should know the powers that have been granted.

Treatment under the Mental Health Act

The majority of people with dementia who are in hospital will receive care on an informal basis. For a small number of individuals who express their objection to being in the hospital in a sustained way, require significant restraint or make purposeful attempts to leave, it may be necessary to use the Mental Health (Care and Treatment) (Scotland) Act 2003 (the 2003 Act) to provide authority to detain them in hospital and treat them. Detention under the 2003 Act provides safeguards to the individual, such as the right to appeal their detention and to have it reviewed by the mental health tribunal at least every two years. They also have the right to have treatment for their mental disorder, given for more than two months, reviewed and authorised by a designated medical practitioner if they are not consenting to this. This is done on a form called a T3.

The 2003 Act also gives the individual the right to access independent advocacy. Advocacy is there to ensure an individual has the information they need and to help support them in expressing their views and participating in decisions about their care.

What we expect to find

Where there is evidence that someone is not consenting to stay in the hospital or unit, either by telling staff or making purposeful attempts to leave, we would expect to find that there is a legal authority in place to detain them. We expect to find a T2 form completed where an individual is consenting to their treatment or T3 forms in place authorising medication, where this is required.

We expect to find information about advocacy available to staff and service users within all units. We also expect to find evidence of advocacy services being proactively used to ensure that service users are supported to participate in decision making.

Where units have locked doors we would expect to find a locked door policy which clarifies how access and exit of the unit is controlled.

What we found

Of the people we visited, 32 (10%) were subject to detention under the 2003 Act. We also met seven individuals who were trying to leave the unit, or expressing a desire to leave, but were not subject to detention. We raised this issue with staff at the time. One of these individuals was reviewed by their consultant and detained the following day.

Of the 32 people who were detained under the 2003 Act, almost all (30) were on compulsory treatment orders (CTOs) and two were subject to short-term detentions (STDCs).

Four (12%) were receiving treatment which was not properly authorised under part 16 of the 2003 Act. This was because either there wasn't a valid T2/3 where required or the T3 didn't cover all of the treatment prescribed. This was addressed with staff at the time of the visit.

Only six (12%) of the units have regular visits from advocacy. The remaining units (88%) were aware of advocacy services and said that they can refer to them. We were told that about half (24 of 52) of the units had advocacy input during the last six months.

The majority of units were locked for exit and entry to protect vulnerable people from leaving without supervision. We found a small number where visitors could access the unit without waiting for staff intervention by using an access pad, however, in the interests of safety, a key code or swipe card was needed to exit the unit.

Twelve units did not have a locked door policy in place. However, two of these units told us that they undertake individual risk assessments and one did have someone who could leave the unit without support. They just had to ask a nurse to let them out.

Recommendations

Every unit that has a locked door should have a policy in place that ensures the safety and respects the rights of the individual.

Managing money

We also looked at the financial arrangements. Often individuals with dementia are no longer able to manage their own finances, and this is done on their behalf, either by a proxy under the AWI Act or by a DWP appointee.

What we expect to find

We expect to find evidence that individuals are benefiting from their finances, and that this is being spent in ways which met their needs and enhanced their quality of life.

What we found

We found evidence that 132 (39%) individuals were benefiting from their finances, through the provision of items such as toiletries, favourite foods, clothes and larger spends for example, specialist chairs, beds or televisions for their rooms. Funding was often used for personal care such as hairdressing and podiatry. We also found some more creative use of money to fund outings and activities such as theatre trips, aromatherapy sessions and the provision of befrienders.

In 14 cases (4%) (including five (1%) individuals from the above group) there were financial concerns such as difficulty obtaining funds on a regular basis from an appointee or proxy, or concerns that funds were not being used for the benefit of the individual. These issues were being addressed through appropriate procedures.

For the remaining 195 (58%) people we saw, there was little or no information about their finances available within the unit, therefore, we were unable to form a view on whether their finances were being used to optimal effect. Often their finances were being managed by an AWI proxy or DWP appointee.

Standards of care for dementia

We wanted to see how the dementia standards were impacting on the care which people were receiving. We identified aspects of care which related to each standard and looked at these.

Managing distressed behaviour and the use of medication

The Standards of Care for Dementia in Scotland state that people with dementia have the right to receive treatment that is likely to be of benefit.

Psychoactive medication may be used in people with dementia to improve cognition or functioning, to treat associated mental disorders, e.g. depression or psychosis, or to treat symptoms of stress and distress such as agitation or aggression. The potential dangers of sedative medications, such as falls, and the particular risks of antipsychotics, including stroke and increased mortality, are increasingly recognised. Psychoactive medication should only be used for stress and distress symptoms when other management approaches have been tried, when the symptoms cause distress to the individual or put the individual or others at risk, and, if used, should be reviewed regularly.

The second dementia strategy gives a specific commitment with regard to medication:

"We will finalise and implement a national commitment on the prescribing of psychoactive medications, as part of ensuring that such medication is used only where there is no appropriate alternative and where there is clear benefit to the person receiving the medication."

What we looked at

We examined the medication records of everyone we saw. We took details of six classes of psychotropic medication: anxiolytics, antidepressants, antipsychotics, cognitive enhancers, hypnotics, and mood stabilisers. We looked at care plans, treatment authority under AWIA or MHA and medication dose. We were particularly interested in people receiving multiple psychoactive medications.

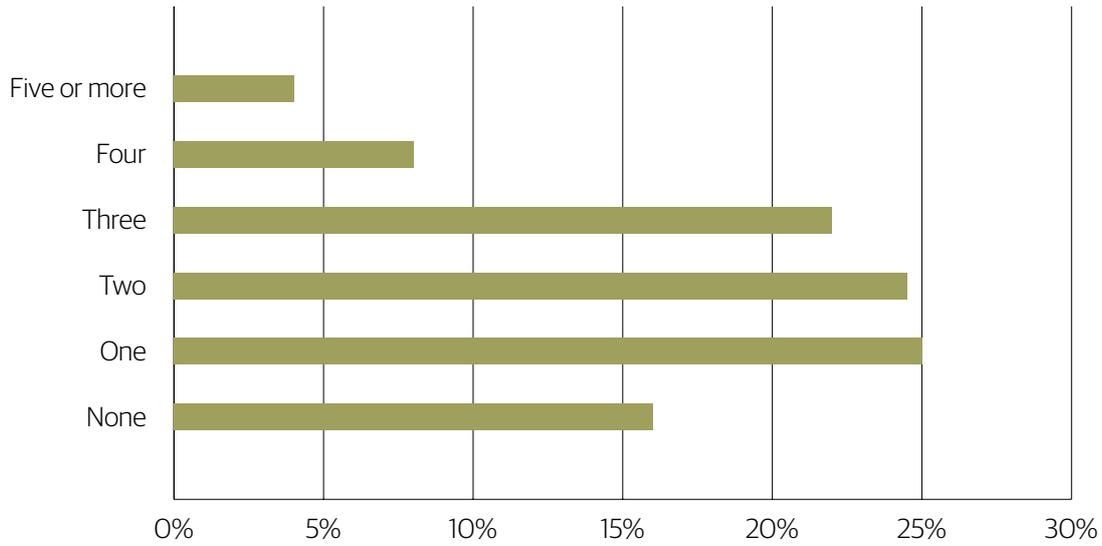
What we expect to find

We expect to find that use of regular psychotropic medication would be supported by a clear care plan, for the management of stress and distress. We expect that both the care plan and the continued need for medication would be reviewed on a regular basis and that combinations of psychoactive medication would be unusual.

What we found

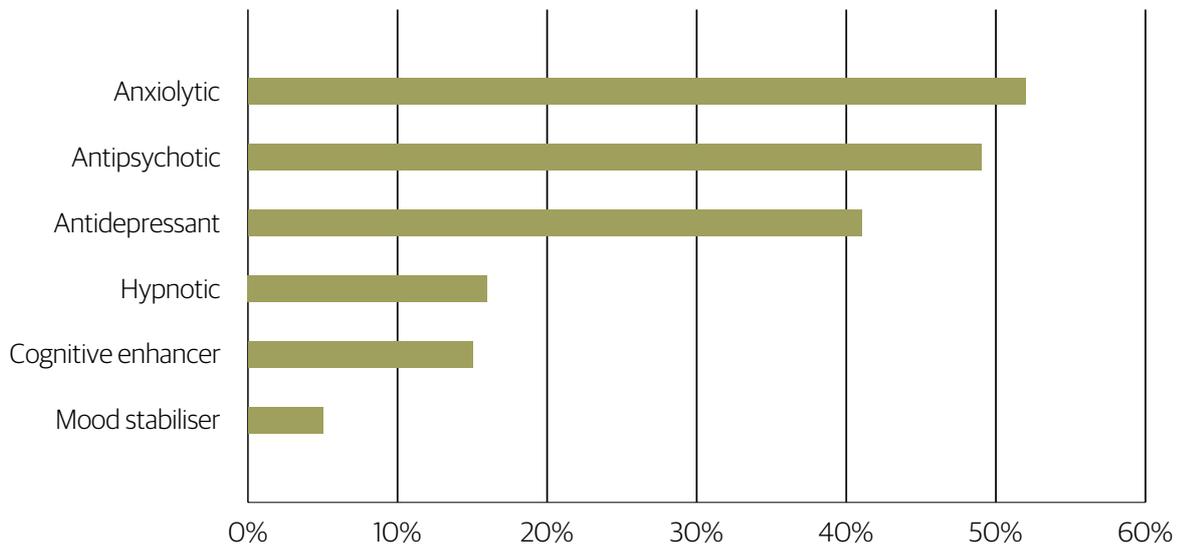
Of the 336 people we looked at, 284 (84%) were on at least one psychotropic medication, with many people on multiple medication: 117 people (35%) were on three or more. The chart below provides a more detailed breakdown of the number of psychotropic medications being used in individuals. We were concerned at the level of polypharmacy in many cases without evidence of regular review. We saw an individual on seven different psychotropic medications who, surprisingly, did not have a behavioural care plan as it was not felt to be needed.

Psychoactive medications received by individual (n=336)



Mrs A is a lady in her late 60s, she has severe dementia and is receiving Quetiapine 175mg twice daily, Trazodone 150mg daily and Diazepam 20mg daily. Her last documented multi-disciplinary review was 18 months ago. She has a care plan in place for the management of symptoms of stress and distress but this has not been reviewed for two years.

Percentage of people on psychotropic medication (n=336)

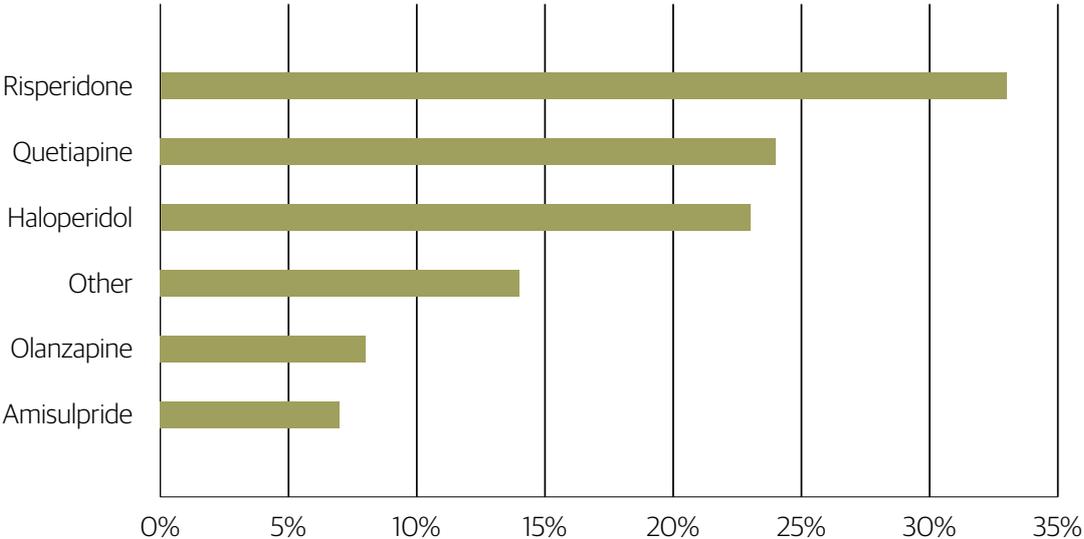


The above chart shows the percentages of the total sample prescribed different types of psychoactive medication.

- 175 people (52%) were taking anxiolytic medication, mainly Diazepam or Lorazepam, with 65 of the 175 (37%) receiving this on a regular basis. This level of use is concerning and is much higher than the level of use we found in *Remember, I'm still me* where only 19% of people with dementia in care homes were prescribed anxiolytic medication. The British National Formulary (BNF) states "Anxiolytic benzodiazepine treatment should be limited to the lowest possible dose for the shortest possible time."
- 166 people (45%) were taking antipsychotic medication. While this may be helpful in relieving symptoms such as hallucinations, delusions, agitation or aggression, there are known risks for people with dementia. All antipsychotic medications increase the risk of stroke and death, many can impair mobility and increase the risk of falls. No individuals were on high dose antipsychotics, though there were a few individuals on higher doses than would be usual in people with dementia, especially when combined with other sedative medication.

Although people with dementia in NHS care may present with more challenging and complex problems than people with dementia in other care settings, staff skills and knowledge, and staff numbers, should be better. We were concerned at the high usage of antipsychotic medication often in combination with anxiolytics or sedative antidepressants.

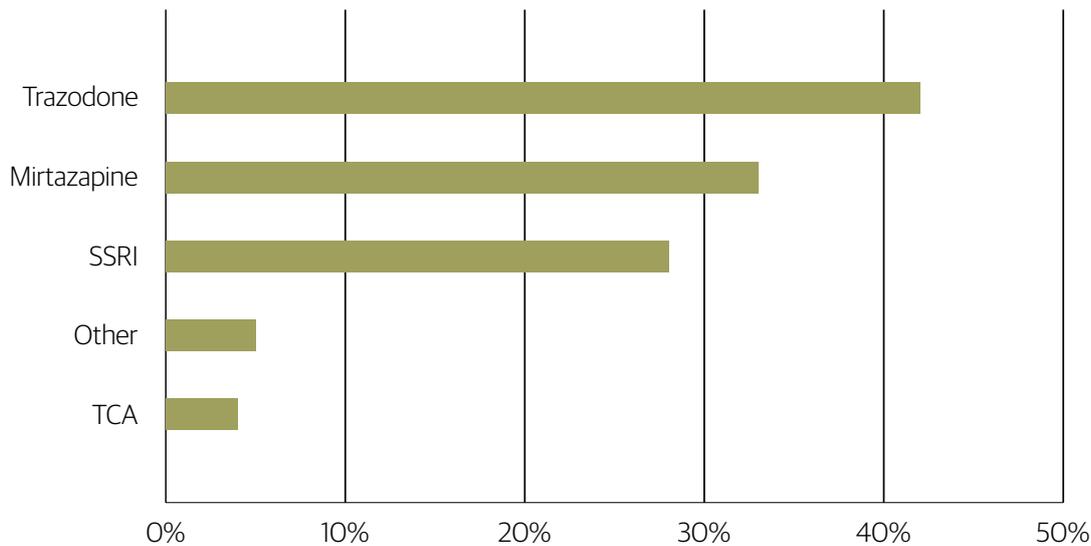
Use of antipsychotic medication (n=166)



A third of individuals taking antipsychotic medications (54, 33%) were prescribed Risperidone. It is the only antipsychotic specifically licensed for use, for up to six weeks, in people with dementia. Thus the majority of antipsychotic medication being prescribed was unlicensed. The BNF states "Unlicensed use of medicines becomes necessary if the clinical need cannot be met by licensed medicines; such use should be supported by appropriate evidence and experience." We found that 24% were prescribed Quetiapine, this is unlicensed and has little evidence to support its use in treating stress and distress symptoms in people with dementia. Just over a fifth (39, 23%) were prescribed Haloperidol: it is an older drug which often causes significant side effects in people with dementia, we were concerned by this level of use. Several individuals were on more than one antipsychotic. This is not good practice.

- 138 people (38%) were taking antidepressant medication, of these 138 people, 98 (71%) were taking a sedative antidepressant such as Trazodone or Mirtazapine. This may represent an appropriate choice of treatment for a depressive illness but it could also mean sedative antidepressants are being used as alternatives to antipsychotics as treatment for symptoms of stress and distress. We found many people on doses of Trazodone which would not effectively treat depression and some who were on as required Trazodone. This would support our view that they are often being used as treatments for dementia. Such use may be the best option for the person with dementia but, as these medications carry risks associated with sedative medication of falls and drowsiness, their use must be monitored. We were pleased that the use of tricyclic antidepressants (TCA) was very low, only 4%, as these medications can cause significant side effects in older people with dementia.

Use of antidepressant medication (n=138)



- 49 people (13%) were taking cognitive enhancers such as acetylcholinesterase inhibitors or Memantine, 49% of cognitive enhancer prescriptions were for memantine. Of the 49 people on a cognitive enhancer, 30 (61%) were also taking at least one other sedative medication including 20 (41%) who were also on regular antipsychotic medication.

Recommendations

Medication should be used as a last, not first, resort in the management of stressed and distressed behaviours.

People with dementia on multiple psychotropic medications should be prioritised for multi-disciplinary review, including pharmacy, to ensure that continued use is appropriate.

All people with dementia receiving psychotropic medication should have their continuing need for this reviewed at least every three months. Where the benefit of medication is not clear it should be gradually withdrawn with appropriate monitoring of target symptoms.

Care plans for managing stress and distress

The Standards of Care for Dementia in Scotland state that people with dementia have the right to receive treatment that is likely to be of benefit, including a range of non-drug based treatments.

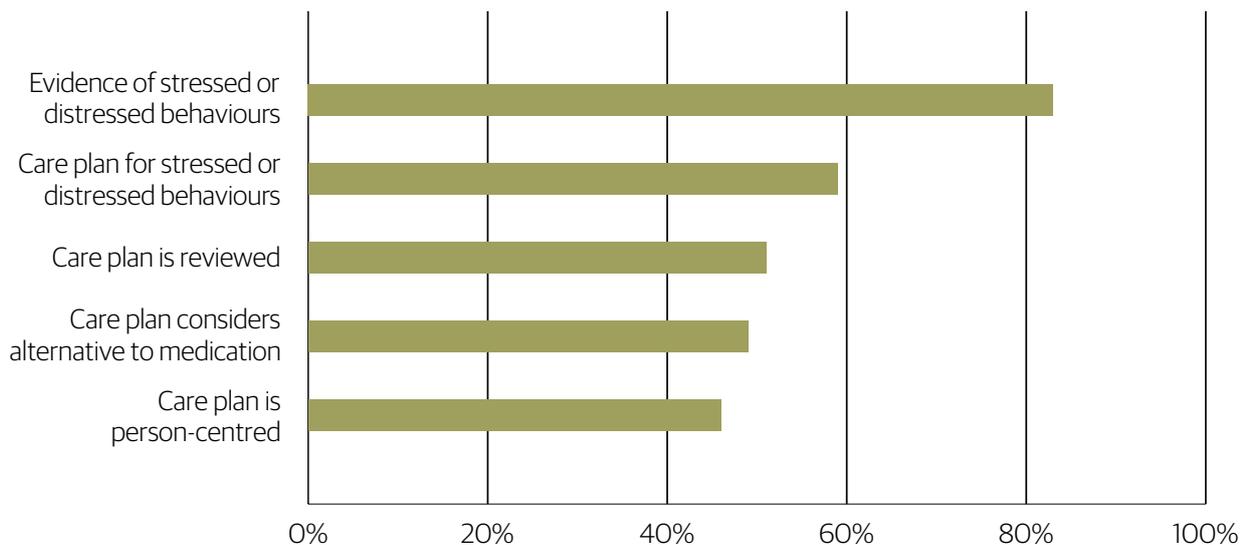
Due to the nature of their illness, individuals with dementia can experience stress and distress which can be expressed in many different ways. What triggers this, and how best to alleviate it, will vary considerably from individual to individual. Therefore, care plans for stressed/distressed behaviours must be person-centred and identify the individual's triggers for distress and strategies for de-escalating and alleviating this which work for the individual.

We would expect to find a care plan which sets out strategies which can be used before resorting to medication, we would also expect the care plan to identify the threshold at which medication should be considered. We would expect this to be reviewed on a regular basis (at least every three months).

What we found

We saw 278 (83%) individuals who showed evidence of stressed or distressed behaviours. Just over half of these had a care plan that was person-centred, was reviewed and which considered alternatives to medication to manage stressed/distressed behaviour.

Care plans (n=336)



The quality of care plans for distress varied significantly. Some of the best examples were very person-centred, contained clear indications of potential triggers to distress and how this manifested itself in the person's behaviours, and provided a number of detailed strategies for alleviating this prior to use of medication. They also gave a clear indication of the threshold at which as required medication should be considered. A small number were based on the Newcastle Clinical model and had been drawn up in consultation with psychology; there was evidence that these were successful in reducing distress. The Newcastle Clinical model is described in the enhanced practice level of the NES Excellence in Practice resource.

We also found some particularly poor examples, which were clearly created by cutting and pasting from other plans. Although the person's name was included they were not personalised in any meaningful way. In some the name or gender changed part way through. In one example, reference was made to communication with the spouse yet the person had been widowed for 30 years. There was also reference to use of as required medication which was not prescribed and there were references to use of de-escalation and distraction techniques, with no explanation of what these were for the individual concerned.

Recommendations

Where individuals are prescribed psychotropic medication for distressed behaviour it is essential that this is linked to a clear, person-centred care plan for managing distress, which includes a range of strategies and identifies the threshold at which as required medication should be used.

Care that respects the individual

The Standards of Care for Dementia in Scotland state people have the right to be regarded as unique individuals and be treated with dignity and respect.

Life history

Our experiences, family relationships, working life, hobbies, friendships, beliefs and our likes and dislikes make us the unique individuals that we are. Knowing about some of the influences which have shaped a person's life can help us understand them better and provide person-centred care which recognises their individual needs and strengths and ensures their preferences and aspirations are respected. Conversations about their family and their interests help us to build relationships and engage with the individual on a personal level.

In our previous report in 2007, we commented on the importance of life history information being accessible to staff involved in the care of individuals with dementia. As an individual's dementia journey progresses they may lose the ability to tell us this information, therefore much of this information is often gained from carers.

What we expect to find

We expect to find information about their family and important relationships, their hobbies, work, significant life events and details of their personal likes and dislikes.

What we found

- 240 (71%) people we saw had life histories in place. These were generally accessible to staff.
- In 190 (79%) cases where there was a life history, family had been involved in completing these.
- We also asked carers if they were involved in providing a life history. 101 (78%) said they had been involved, either by completing the life history themselves or by providing information and pictures to enable staff to do this.

The quality of the life histories we saw varied considerably. In some cases we found a partially completed "this is me" which contained only very basic information and gave no real feel for the individual. However, we also found comprehensive life histories providing detailed information about the individual's working life, hobbies, names of pets, names of family members and information about relationships and significant family events such as anniversaries and birthdays. Many of the life histories had pictures attached, or there were pictures in the person's room which related to their past.

Some families had gone to considerable efforts putting together a detailed record of their relative's life in pictures and words either in book or story board format. Staff found these a useful tool in their daily interactions with the person.

Some carers commented that they had completed life histories when their relative was in a previous placement, but were asked to do so again on transfer and were unsure if this information had been transferred with the person.

A small number of relatives had declined to provide any information, feeling that this would serve no useful purpose. We think there is a role for staff in explaining, educating and supporting families to understand the value of this information at all stages of the dementia journey.

Recommendations

A comprehensive life history should be available for every individual to support person-centred care planning and engagement.

The Standards of Care for Dementia in Scotland state that people with dementia have the right to receive the support and treatment that they need to stay well and lead a fulfilling life on a timely and co-ordinated basis.

Care plans

When an individual has a limited ability to communicate their needs and wishes, it is important that there is a person-centred care plan which sets out what that individual's care needs are and how these can best be met, taking account of their personal preferences, strengths and abilities.

We expect this to address not just their routine physical and personal care needs, but also the complex care needs which arise as a result of their dementia. It is essential that care plans contain detailed information which is specific to the individual and gives staff the information they need to enable them to deliver person-centred care.

We expect to find care plans reviewed at least every three months. Reviews should be meaningful, looking at how effective the interventions are, and whether the individual's care needs have changed.

What we found

- 218 (65%) had a person-centred care plan in place, 81 (24%) had a generic care plan with no person-centred information at all and 37 (11%) had no care plan.
- Only 187 (56%) care plans were both person-centred and addressed the person's complex needs relating to their dementia.
- 259 (77%) of the care plans were reviewed at least three monthly.

Less than half (159, 47%) of the individuals we saw had care plans which were person-centred, addressed their complex dementia needs and were reviewed at least every three months.

The quality of the care plans we looked at varied considerably. We found examples of excellent practice, where there were thoughtful, detailed holistic care plans compiled with the involvement of relatives. For some there was input from speech and language therapists to address communication difficulties; or psychology in relation to specific behavioural issues.

However, we also found some examples of unacceptable practice; in one health board area there was a core care plan in place which was not designed for use in mental health and consisted of a series of tick boxes. These were unsuitable for care planning for the complex needs of individuals in NHS continuing care.

In other areas we found the same typed care plan in every file we looked at within one unit. In one case we found a pre-printed care plan with space for the person's name to be written in, this was completed as "patient".

Recommendations

Care should be based around a person-centred care plan which addresses the physical and complex mental health needs of the individual. This should be reviewed on a regular basis (at least every three months).

Activities

The Standards of Care for Dementia in Scotland state that people with dementia will have the opportunity to be included in community life and meaningful activities as they wish.

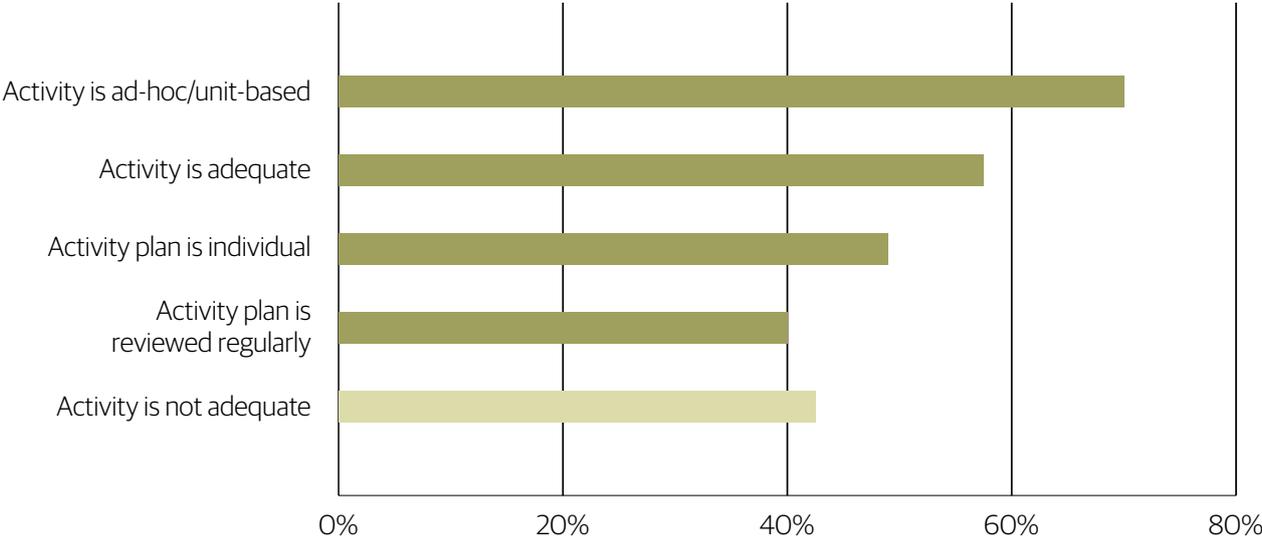
This means that people should have access to a range of recreational and social activities which provide them with a meaningful day, and be given the support and encouragement they require, to participate in these.

Activities play an important role in helping people to maintain their existing skills, alleviating boredom, providing stimulation and exercise, providing structure to the day, and reducing agitation by providing distraction from distress.

We expected to find individual activity plans which identify suitable meaningful activities, taking account of the person's previous skills and interests and their current abilities and preferences. There should be a record of participation in, and outcome of, activities and for this to be reviewed regularly to ensure that it remained appropriate as the individual's needs and abilities alter.

What we found

Social and recreational activity (n=336)



The range of activities carried out varied greatly, some units had a varied programme of group activities.

Less than half (166, 49%) of the people we saw had an individual activity care plan and only 134 (40%) had plans which were reviewed regularly. However, the majority (235, 70%) of individuals took part in social or recreational activities on an ad-hoc basis or as part of a unit-centred activity programme, rather than as part of a person-centred plan. For more than half (193, 57%) we found the activities provided were adequate to meet the individual's needs. This does still leave a very significant number of people, at least 143 (43%) who were not benefiting from adequate social and recreational stimulation.

Group activities included:

- Sonas groups (a multi-sensory programme designed to activate communication);
- remembrance on a group or individual basis;
- cognitive stimulation groups;
- exercise or gardening groups;
- concerts;
- quizzes, simple board and ball games, singalongs

Individual therapies included:

Doll therapy, pet therapy, hairdressing, pamper sessions, aromatherapy and massage, and 1:1 time simply spent chatting or reading.

Some units did not have an organised programme of activities but undertook these on an ad-hoc basis when staffing allowed.

We asked staff about who was involved in providing activities.

We found that only 24 (46%) of units have dedicated activity staff. The level of input in these units varied considerably from only 6 hours per week in one 28-bed unit to one 30-bed unit having 95 hours of dedicated activity time. However, in all but four units, the nursing staff were also involved in providing activities.

We were interested in what impact dedicated activity staff had on the quality of activity provision. We found that where there are dedicated activity staff, 68% of people enjoyed adequate activity provision. Where there were no dedicated activity staff, a smaller number, 49%, were benefiting from adequate social and recreational activity.

Occupational therapists also provide activities in 14 of 52 units we visited. A small number of units had physical activity groups provided by a physiotherapist. Others had volunteers who provided group activities.

Recommendations

We did find one unit which had no dedicated activity staff and no other staff involved in activities. The only activities provided were via outside groups such as pet therapy providers and Elderflowers (an organisation similar to the Clown Doctors, but working specifically with the elderly). Several other units without dedicated activity staff clearly had difficulty in delivering an adequate programme of activities on a regular basis due to staffing issues and the need to prioritise personal care.

Everyone should have access to a range of activities which takes account of their life history, previous interests and skills and current abilities, to provide them with a meaningful day. Where there are no dedicated activity staff other mechanisms need to be put in place to maintain a focus on activity as an essential component of dementia care.

Community involvement

We also looked at wider community involvement in activities and the life of the units.

Whilst bringing the community into the unit is important, we also wanted to know if residents were being supported to venture out into the community.

For many older people religion has played a significant part in both their spiritual and social lives and being able to continue with this is important to their wellbeing. Therefore, we looked at input to meet spiritual needs and access to religious services.

What we expect to find

We expect to find evidence of people having the opportunity to leave the hospital and enjoy outings on a regular basis and local community involvement in the social life of the unit.

We expect to find that units had regular input from hospital chaplains and faith representatives, and that there is access to religious services both on site and at local places of worship for those who wish to attend.

What we found

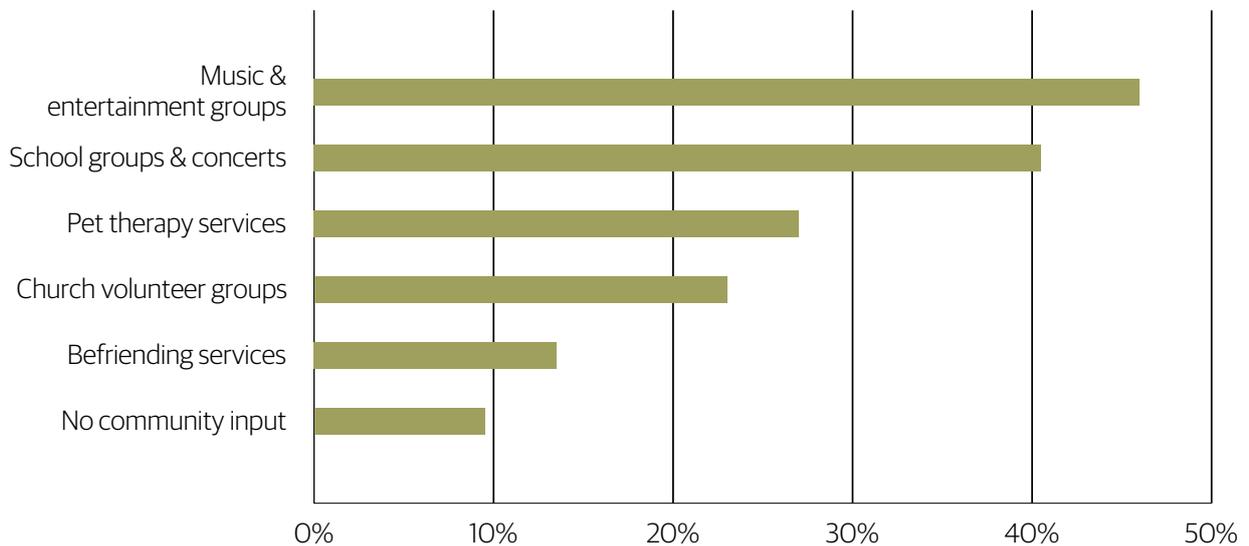
We tried to look at how long it had been since individuals had been on an outing other than to attend an outpatient appointment.

- 43 (13%) had been on outings out with the hospital in the last week,
- 46 (14%) had been away from the hospital in the last three months,
- For 73% we could find no record of them having been out of the hospital in the last three months.

It is concerning that for the majority of people we were unable to find any record of them participating in outings.

Most units had some level of involvement with their local community; however, the level of this varied considerably with some units having input from a range of groups. Input from schools was mainly school student concerts. Other groups providing music and entertainment included performance groups such as Elderflowers and Music In Hospitals. We found five units had no community input.

Units with wider community input (n=52)



At least 55% of units reported that residents are supported to access church services if they wish. Eight units told us that although there was no regular access to any form of chaplaincy service they could request visits from local ministers if required. Three units reported having no service despite one of them having made repeated requests.

Recommendations

Opportunities to get outside must be an essential element of everyone's care; whether this is to a unit garden or to participate in activities within their local community. Too many people continue to spend long periods of time without any access to the world outside, either to a unit garden, or further afield. We know that access to fresh air and green space has positive benefits for mental and physical wellbeing.

Visiting and carer involvement

The Standards of Care for Dementia in Scotland state that people with dementia have the right to preserve the relationships important to them and feel involved and included in their community wherever they live.

Visits are important for people with dementia and visitors alike. They are often a highlight in the person's day and allow people to maintain their relationships and their involvement in the life of their family and community.

Therefore, we wanted to look at the visit experience including the level of flexibility in visiting hours, the welcome provided, and the facilities available to make the visit a pleasant experience.

We also wanted to find out if carers were supported to continue with their caring role following admission to hospital.

What we found

We were pleased to hear from carers that 98% of them felt welcome when they visited.

- In 33 (67%) units, visitors were either offered tea or coffee or there were facilities available to make their own.
- 40 (77%) units had flexible visiting hours.
- 11 (21%) units have restrictions on visiting, though all but three stated there was a degree of flexibility with prior arrangement.

"Visiting can be very strict to times; my nephew has been turned away."

In the majority of units, relatives could choose to either visit in a bedroom or a public area of the unit. However, seven units didn't offer any choice about where the visit occurred. Relatives commented on the issue of choice of location when visiting.

Only 24 (43%) units provided a dedicated visiting room. This is clearly an issue for some relatives who do not feel comfortable visiting in communal sitting rooms or bedrooms.

"I feel the unit is too clinical and does not have enough seating areas to visit. I had to be clear that I did not wish to visit with mum in her bedroom."

Several carers commented on the welcome they received.

"All the staff greet me, from the cleaners to the Charge Nurses. They have time for me and offer me a cup of tea or lunch if it is lunchtime. They are very responsive to anything I raise."

"I am always greeted and told how he is getting on and offered tea/coffee. There is good communication with unit staff."

We asked carers about their experience of being involved in care:

- 98 (77%) carers said they were encouraged to remain involved in care, this included helping with shaving, doing hair, feeding.
- 7% stated they wouldn't wish to be involved, preferring just to visit.
- Only nine (7%) said they were actually discouraged from being involved in care.

Seventy-four (58%) carers said they were encouraged to be involved in the life of the unit, attending parties, helping with fundraising events, helping in the garden etc. We received a number of comments telling us how much carers valued this.

"The unit are always having celebrations and we are always invited. It's lovely. They are having a big party for her 90th and the conservatory is really made to look beautiful."

Multi-disciplinary input to care and care reviews

The Standards of Care for Dementia in Scotland state that people with dementia have the right to access a range of treatments, care and support.

Dementia is predominantly a disease of old age; therefore, as well as the complex needs which can arise from dementia itself, people with dementia may experience any number of other health problems which require to be treated and managed if they are to attain the highest possible standard of physical and mental health.

Whilst the majority of care is provided by nursing staff, there are a wide range of healthcare professionals who can make a positive contribution to the provision of high quality dementia care. Therefore, we looked at the input of a range of medical and allied healthcare professionals into both direct care and care reviews.

Medical input

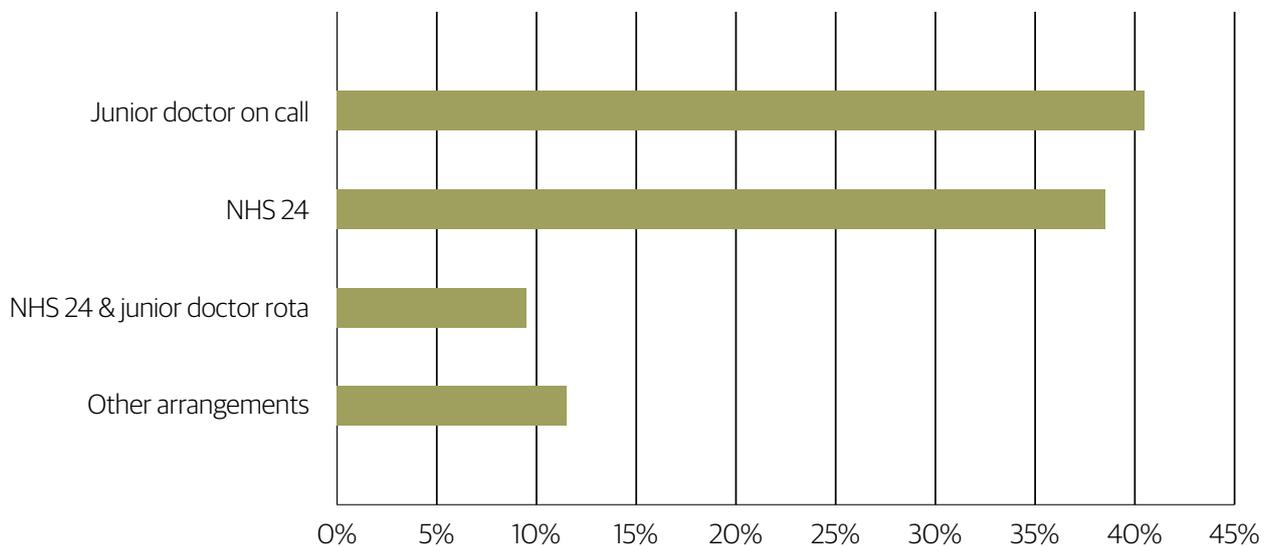
We expected to find that care was regularly reviewed by a psychiatrist. We also expected to find there was regular medical input to address physical healthcare needs and adequate arrangements to access medical care out of hours.

What we found

- In 46 (78%) of the units we visited people are reviewed by their consultant at least monthly
- 33 (63%) units have input from a psychiatrist, other than the consultant, weekly or more often
- 12 (23%) units do not have any GP input, however, all these units had several visits a week from medical practitioners

Out of hours medical cover is provided in a variety of ways via access to the junior doctor on call rota and NHS 24, or via other arrangements including access to unscheduled care teams or local arrangements with GPs.

Out of hours medical cover (n=52)



In all but two units, the charge nurses were satisfied with the level of medical input available. One charge nurse commented that their experience varied considerably depending on the attitude of the junior doctor on call and their level of understanding of dementia. Whilst local GP services were generally found to be good, in some cases there have been difficulties with test results being sent to the person's last GP, due to the individual not being registered with the surgery which provides cover for the unit. This had resulted in unnecessary delays in treatment. This issue is being pursued by the service managers.

Allied Health Professionals and specialist nursing

We also looked at the input from the wider multi-disciplinary team (MDT). We expected to find that units had regular input from occupational therapists, pharmacists and physiotherapists, and ready access to other specialist AHPs, as required, on an individual referral basis.

What we found

- We found that only 15 (29%) units had regular input from OT services. Five (8%) told us they couldn't even access this service on a referral basis.
- Physiotherapy services had regular input to nine (17%) units and of the rest, all but one unit could access this service by referral.
- 19 (37%) units had regular input from a pharmacist (over and above a top-up service) and a further 23 (44%) could access pharmacy input via referral.
- Speech and language provided a referral only service to all units.
- Psychology services provided a referral-only service to 40 (81%) units but the remaining 10 (19%) had no access at all.
- Podiatry was available on a regular sessional basis in 19 (37%) units, and by referral to all but two of the rest.

Other services such as audiology, opticians and dentistry were available via referral. Some units also reported input from other professionals such as dietician, diabetic nurse, incontinence nurse, tissue viability nurse, liaison CPNs and behaviour support nurses when this is required.

We think it is essential that all units have access to pharmacy for advice, especially given the multiple medications which many older people are prescribed, and the issue of covert medication administration which can arise in dementia care.

"There are no pharmacy reviews. Waited two and a half weeks for pharmacy to remove non-required drugs. SCN then returned to pharmacy himself."

"There is limited input – can get advice. Don't attend WR."

"Pharmacist did previously attend regular unit meetings but this has stopped over past couple of months."

All units should have ready access to AHPs and psychology on a named patient referral basis as an absolute minimum.

Units should have ready access to the full range of AHPs, specialist nurses and psychology on a named patient referral basis, as a minimum.

Case reviews

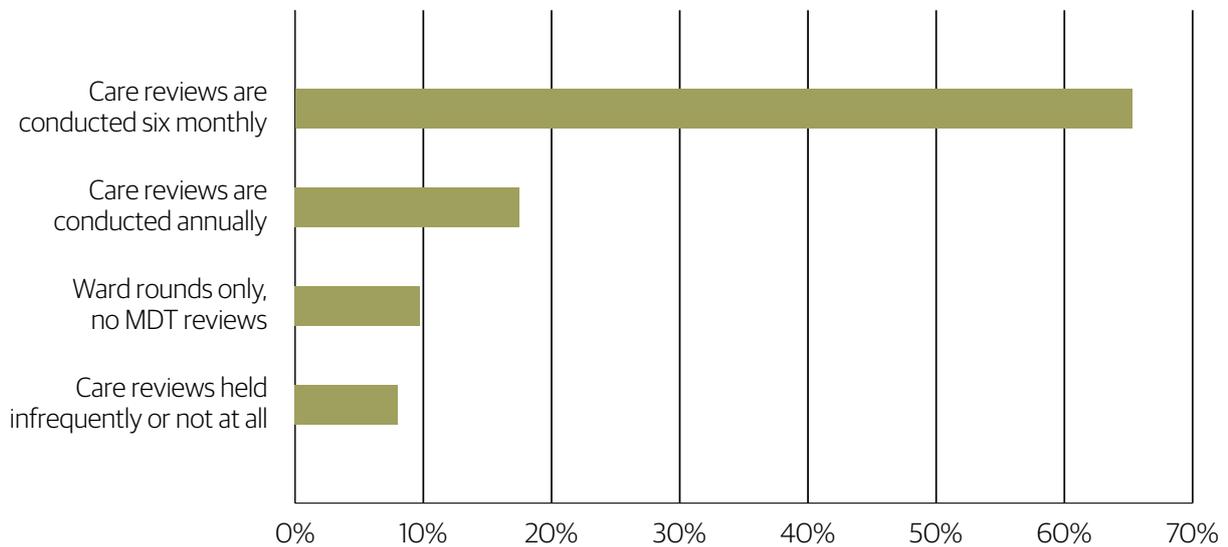
We also wanted to look at the level of multi-disciplinary input to decision making; therefore, we looked at the frequency of multi-disciplinary reviews and the range of disciplines involved in this.

Case reviews are an opportunity for the full multi-disciplinary team to consider the individual's needs and to discuss any changes required in their care. We believe it is important to review care and treatment on a regular basis and we think that there should be a multi-disciplinary care review at least annually. Good practice would be to review care at least every six months.

What we found

From our interviews with charge nurses we were told that on the majority of units care reviews occur at least six monthly; however, other units conduct reviews far less frequently or via unit rounds only. Four units held reviews very infrequently or not at all.

Frequency of care reviews (n=52)



We looked at the frequency of reviews as documented in case files. In over half (181, 54%) of the files we looked at we found a review within the previous six months, with a further 51 (15%) within the previous year.

We were interested in looking at the range of disciplines involved in care decisions:

- In 13% of files where there were reviews, there was no record of who attended the review.
- 71 (19%) of the reviews documented involved only nursing and one member of medical staff.
- Occupational therapy were involved in eight (2%) reviews,
- Pharmacy, nine (3%),
- Social work, 16 (5%).

None of the individuals we saw had the benefit of speech and language therapy or psychology input to their reviews, and only one individual had physiotherapy attendance noted.

Full multi-disciplinary reviews, involving a range of disciplines, were the exception rather than the rule.

We believe that many of the people we saw would benefit from greater multi-disciplinary input into their care.

In some units the nurses told us that individuals were discussed during regular 'unit rounds' rather than holding dedicated MDT reviews for each individual. We do not consider that this is an adequate alternative to a properly convened and minuted multi-disciplinary case review which considers how best to meet the individual's care needs and whether they still meet the criteria for NHS continuing care.

Recommendations

Everyone should have a full MDT review at least annually; proxies/carers should be actively encouraged to participate in this. Pharmacy should be included as a core discipline within the unit MDT.

Case reviews – carer involvement

The Standards of Care for Dementia in Scotland state that people with dementia and their carers have the right to full participation in care needs assessment, planning, deciding and arranging care, support and treatment.

Participation is also enshrined in the principles of the AWI Act, which expressly refer to the need to consult with relevant others. The majority of people we met with on this visit had lost capacity and would not have been able to contribute to case reviews in a meaningful way. Therefore, we looked for evidence that carers and/or AWI proxies were being included in the decision-making process and were routinely invited to multi-disciplinary case reviews.

Forty-one (79%) charge nurses told us they invite carers to reviews. We also asked the carers we met with if they had been invited to reviews.

Of the carers we spoke to, 101 (79%) said they were invited to case reviews with a further seven (5%) being unsure if they were invited.

However, when we reviewed files to confirm this, only 84 (25%) of the reviews documented involved carers and a further seven (2%) involved proxy decision makers.

Some charge nurses told us that if there were any changes to care, the nurses met with the family to feedback decisions. We do not consider that this provides adequate opportunity for carer involvement in the decision-making process. This also doesn't take account of the legal responsibility to consult with AWI proxies where they have power to consent to medical treatment.

We believe it is important that carers and proxies are actively involved in care reviews due to their unique knowledge of the individual's preferences and personality prior to their illness.

We also wanted to find out if the need for NHS continuing care was being kept under ongoing review and if alternatives were actively being considered. This is in line with the principles of least restriction and the dementia standards.

Surprisingly, in less than one-third of cases (108, 30%), we found evidence that the appropriateness of continuing NHS care or the possibility of alternatives was actively considered.

The Standards of Care for Dementia in Scotland state that people have the right to have carers who are well supported and educated about dementia.

This care standard applies both to informal family carers or proxies and to professional staff within the care setting. Informal carers and proxies have particular information and support needs, whereas professional staff require training, to ensure this standard is met.

Information for carers

Admission to hospital can be a stressful experience, both for the individual admitted and their family and carers. A new environment can be confusing and frightening to someone with dementia. Having less direct involvement in care can be difficult for carers, and they may still be struggling to come to terms with the diagnosis. It is important that staff anticipate the information that might be required by the individual or relatives concerning what to expect from the unit (e.g. information about visiting times, meal times, who does what and what involvement they can have in care and decisions about care) or about their loved one's diagnosis (e.g. what sort of symptoms they may experience and what can be done to treat or alleviate these).

We would expect staff to meet with carers around the time of admission to provide verbal and written information about the unit and the diagnosis of dementia, and to give them an opportunity to ask questions. The comments we made in *Older and wiser* about the provision of unit and diagnosis specific written information remain relevant today.

What we found

We asked carers about their experience at the time of admission and found that:

- 98 (77%) of the carers we spoke to had been shown around the unit and been given verbal information
- 14 carers told us that they were given the opportunity to visit the unit and meet staff prior to admission, either with their loved one or on their own
- However, only 27 (21%) were given any written information about the unit

People who were given the opportunity to visit found this very helpful in allaying their anxieties and helping them come to terms with their loved one's admission.

People may not remember everything they are told, due to the stress of the admission and the unfamiliar environment, and having written information to refer back to can be very helpful.

"The staff are very good and spent a lot of time with mum and the family and gave an open invitation for us to come back to speak to staff at anytime."

"I visited prior to admission and was shown around and allowed to personalise the room with bedding and furniture, it made a difference."

We did find examples of emerging good practice. One excellent example of carer involvement in service improvement was when family carers noticed there was no written information when their father was admitted. They spoke to the charge nurse and are now writing a relatives' information leaflet for the unit.

- 43 (30%) of the carers we spoke to said they had been given information about dementia at diagnosis or during an earlier admission
- Another 42 (30%) were given information on the current unit
- Some said they felt they didn't require any information due to their existing knowledge (10) or because they gained their information mainly from their own research on the internet (10)
- Worryingly, 13 people told us they had not been given any information.

A handful of carers (6, 5%) told us they had been involved in some way in staff training, and one had also been involved in recruitment.

Recommendations

Units should provide relevant, accessible, written information to carers at the time of admission.

Support to carers

We were interested in whether carers had access to a support group either on the unit or elsewhere:

- 65 (51%) carers were aware of a support group they could attend.
- 44 (34%) had access to a support group in the unit.
- However, only two (2%) carers who didn't have access to a support group said they would attend one if it was available.
- 64 (50%) said they would not like to attend a support group.
- Six (5%) were not sure. Some of these found that the support they received from unit staff was adequate for their needs. Others commented that when they had really needed a group was when the individual was still at home.

Staff training

In units caring for people with dementia we would expect to find all staff trained to the level of practice as defined in *Promoting Excellence: A framework for all health and social services staff working with people with dementia*, their families and carers (Scottish Government, 2011) appropriate to their role as detailed below.

The '**Dementia Skilled Practice Level**' describes the knowledge and skills required by all staff that have direct and/or substantial contact with people with dementia and their families and carers. Within specialist dementia units we would expect all staff with patient contact to be trained to this level. This would include AHPs, Pharmacists and Domestic staff.

The '**Enhanced Dementia Practice Level**' outlines the knowledge and skills required by health and social services staff that have more regular and intense contact with people with dementia, provide specific interventions, and/or direct/manage care and services. All healthcare assistants and trained nurses should be trained at least to this level.

The '**Expertise in Dementia Practice Level**' outlines the knowledge and skills required for health and social care staff who by virtue of their role and practice setting, play an expert specialist role in the care, treatment and support of people with dementia. We would expect a number of the senior trained staff to be working at expert practice level.

We would also expect to find an ongoing programme of training to ensure all staff across the multi-disciplinary team have the opportunity to maintain and continue to develop their learning and practice.

What we found

There was considerable activity around training in the units we visited. Outwith mandatory training the main focus was on dementia specific training and training for managing stressed and distressed behaviours.

We found that 37 (71%) of units reported that they had undertaken (in the last 18 months) both dementia specific training and training in managing stressed or distressed behaviours or had plans for training in both topics.

We found that 60% of units told us they were using the learning resources produced by NHS Education for Scotland (NES)/Scottish Social Services Council (SSSC) as part of the national workforce development programme to support implementation of the 'Promoting Excellence' framework. The NES/SSSC workforce development programme offers staff working in mental health services the opportunity to participate in training relevant to their area of practice. The specific national programmes offered to this staff group were cognitive stimulation therapy training and palliative care in dementia training for trainers. However, the uptake of places on both programmes was very low.

In addition, staff working in mental health services participated in the NES psychological interventions and therapies for stress and distress in dementia training for trainers programme. To date, only a small number of staff working in the units visited had undertaken training as part of the further roll out of this training.

Many units are now using e-learning such as the learn-pro modules provided within the NHS.

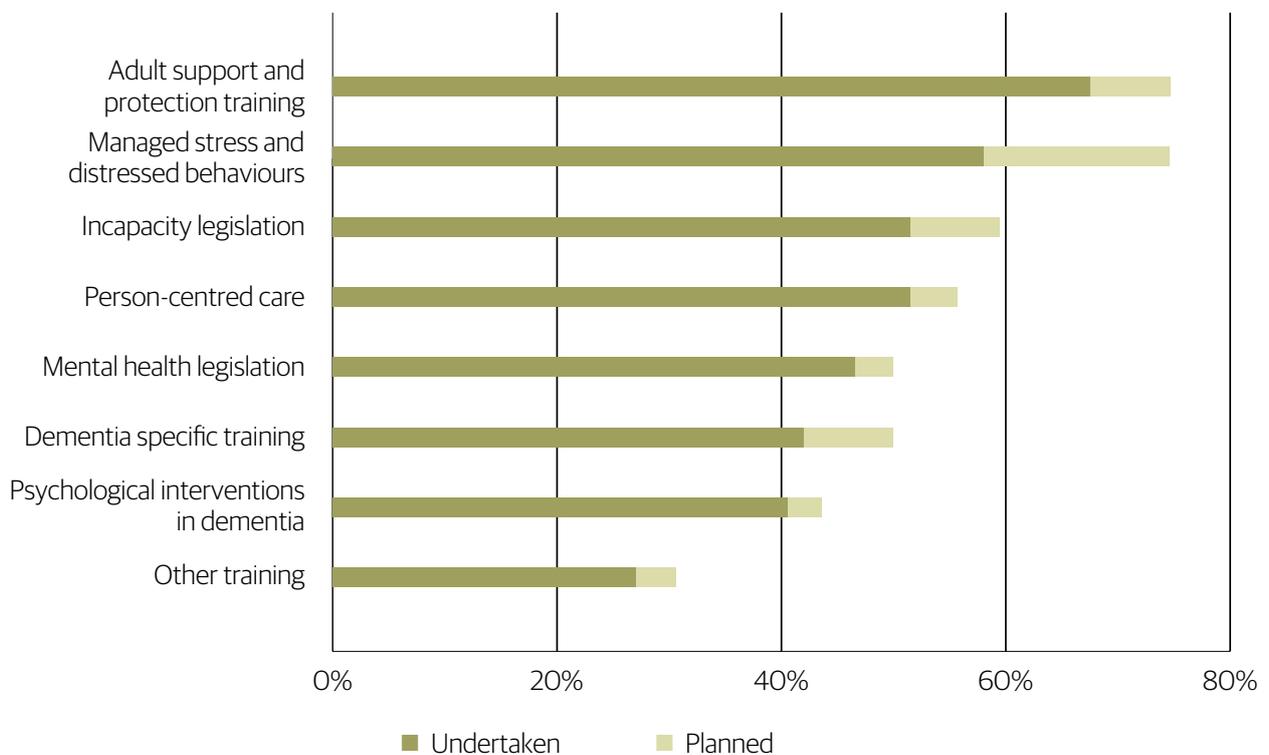
Adult Support and Protection training has been undertaken, or is planned, by 39 (75%) units. This higher level of uptake reflects the fact that this training has become mandatory in many areas.

11 (22%) of the units we visited had staff trained as Dementia Champions by the West of Scotland University. This training is designed for staff in acute general hospitals and is not designed to equip nurses to work in specialist dementia units.

16 (30%) units had accessed training from the Stirling Dementia Centre. Units were also accessing a wide variety of other in house and external training.

We found one unit where there had been no training provided in the last 18 months and no dates set for future training.

Staff training (n=52 units)



Recommendations

People with dementia and their families have the right to be supported and to have care provided by staff who have the values, skills and knowledge which are set out in the Promoting Excellence Framework, developed on behalf of the Scottish Government by NES and SSSC in 2011. NHS boards should continue to develop the workforce, ensuring education and training is aligned with the Promoting Excellence Framework and ensuring that staff providing direct care in units have the knowledge and skills set out at the 'enhanced' or 'expertise' level of the framework.

Environment

People with dementia will:

Be valued and treated at all times as a person with dignity and respect.

Feel safe, secure and live as independently as possible.

The environment in which care is delivered has a significant impact on both the recipients of care and their carers. It affects people's moods and impacts on their ability to function as independently as possible. The quality of the environment we provide for individuals to live and work in also sends a strong message about how we, as a society, value them.

When we published *Older and wiser* in 2007, we found that there was a wide variation in the quality of environment across the country. Generally there was a lack of dementia-friendly design features, including access to safe and pleasant outdoor areas, which can do much to promote independence and reduce distress.

The units we visited are likely to be people's homes for a considerable period of time. Therefore, it is important that they are homely, and reflect the dementia standards' in relation to treating individuals with dignity and respect and supporting their independence.

Dementia-friendly design can make a real difference to an individual's experience in hospital. The appropriate use of colour and pictorial signage can improve orientation, enabling individuals to locate their bedroom or the toilet. Good lighting and calm, uncluttered surroundings can reduce falls and prevent misidentification of objects or people. A warm and homely environment can be reassuring and comforting. An interesting and stimulating environment and an element of choice about where you spend your time can support engagement and prevent boredom, all of which can reduce distress.

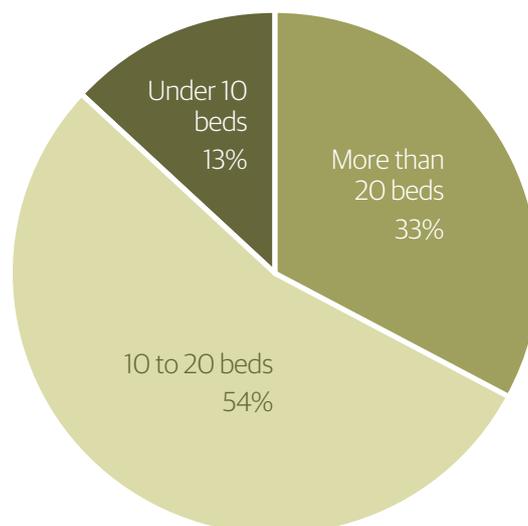
There is a growing body of evidence¹ to support the view that access to exercise and green space has a significant impact on our emotional and physical wellbeing.

When we looked at environments during these visits, we hoped to see significant improvements in the six years since we last reported on this area. We expect to find dementia-friendly design features and signage as standard. We expect to find clean, well-maintained units with pleasant decor and furnishings, just as we would expect in our own homes. We expect to find ready access to a pleasant, safe, outdoor space.

¹ Would You Be Happier Living in a Greener Urban Area? A Fixed-Effects Analysis of Panel Data, Mathew P. White, Ian Alcock, Benedict W. Wheeler and Michael H. Depledge, *Psychological Science*, published online 23 April 2013, DOI: 10.1177/0956797612464659
Chapman, N. J., Hazen, T., & Noell-Waggoner, E. (2007). Gardens for people with dementia: increasing access to the natural environment for residents with Alzheimer's. *Journal of Housing for the Elderly*, 21(3-4), 249-263.
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Pachana, N. A., McWha, J. L., & Arathoon, M. (2003). Passive therapeutic gardens: A study on an inpatient geriatric ward *Journal of Gerontological Nursing*, 29, 4-10.
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What we found

Number of beds in unit (n=52)



A third of the units (17, 33%) had more than 20 beds. Just over half (28, 54%) had 10-20 beds, and a relatively small proportion had under 10 beds (7, 13%).

The three largest units, with 30 or more beds, told us they cared for people with functional illnesses as well as those with dementia. We are aware from this visit, and our wider experience, of the challenges inherent in caring for such a diverse range of needs in one area, and how this is further compounded when staff are caring for large numbers of people within one unit.

- In 27 (52%) of the units all of the beds were in single rooms
- 17 (33%) of the units had less than half of their beds in single rooms

The size of unit wasn't a significant factor in this. However, we did note that all contracted-out beds were in single rooms.

Generally, units were well maintained, although the standard of accommodation varied considerably. Some were purpose-built, well designed, modern, ground floor facilities with en-suite single rooms. Others were old, institutional units which, whilst attempts had been made to refurbish them, were not really fit for purpose. We were surprised to find that odour remained a problem, with our visitors identifying unpleasant odours in five (10%) units.

- In 2007, people in just over half the units we visited had direct access to a garden.
- In 2013 this has risen to over 35 (71%) of the units visited having gardens which were easily accessible and used regularly
- Only 18 (37%) of these are considered by us to be safe, attractive and well maintained.
- Six (12%) of the units we visited were upstairs, which meant there was no direct access to outdoor space

We did find some examples of excellent garden facilities. For example in East Ayrshire a garden had been created with the support of staff, relatives and the local community, including school children. Many of the bedrooms and part of the living area look out onto the garden. There is a safe, non-slip pathway meandering around the garden, which is beautifully landscaped with features such as a bus stop, a rockery, raised beds, a washing line, a summer house and an old-fashioned lawn mower in case anyone wishes to mow the grass. The garden contained a number of benches and some of these are separated from the main garden by trellises, giving a feeling of privacy. There is a memorial wall with the names of past patients who have died or moved on to nursing homes; some relatives of past patients continue to visit and support the unit. One relative told us she thought this garden added to her husband's quality of life as there was so much going on outside the unit that he could see/take part in.

We asked visitors across all the units we visited if they were able to take their relative outside:

- 92 (72%) said they were
- 29 (23%) either said no or that it was not appropriate. For many people, this was due to physical frailty

Three (6%) of the visitors we interviewed who said that they couldn't or didn't go out cited concerns about being unable to manage behaviours, and difficulties with getting their relative outside due to unit location or physical frailty. We believe there is a role for staff to provide more support to facilitate individuals spending time outdoors with their visitors. Lack of opportunity to get outside is a real issue for some.

"My wife cannot go outside. The room window does not open, and my wife hasn't had fresh air in 2 years."

"Often my dad doesn't want to go and I would need someone with me."

"I would need the correct equipment."

We also looked at medical and nursing notes and spoke to staff to find out how long it was since individuals had had access to the garden or other outside space and fresh air. We found:

- 112 (33%) had been outside in the last week
- A further 14% having been outside in the last month (the Commission visits were conducted over the summer)
- 28 (8%) didn't go out due to personal choice or physical frailty
- For 27% of individuals, there is no record of them having been outside in the last month.
- Unfortunately, for the remaining 93 (28%) individuals we saw, this information was not recorded.

Two unit environments gave us particular cause for concern. These were where the light in the common sitting/dining areas was provided by skylights or high windows and there were no windows that people could see out of; nor was there easy access to a safe garden space. We find it unacceptable that people on these units, who spent their day in the communal areas, would spend most of their day with no opportunity to see the world outside.

We found that noise was an issue in a small number of units (4, 8%), this included loud music, doors banging, and competing noises (music/television). Being subjected to a noisy environment can be stressful and may be a trigger for distressed behaviours.

75% of units had a number of public areas which were organised and furnished in a way which supported interaction between individuals and carers.

Ten (18%) units had only one communal area which functioned as a living/dining room. This is less than ideal because people should have choice about where they spend their time and the opportunity to withdraw from a noisy room.

It is important that the environment is interesting and engaging. There is much that can be done to enhance the environment; pictures, flowers, and books offer visual interest. Soft furnishings in a variety of textures can do much to give a pleasant homely feel. Various rummage items, such as a box containing beads, bracelets etc, or a chest of drawers, with drawers left partially open to reveal items such as tambourines and maracas, dusters and cleaning equipment, a washing line, with a box of pegs and small items which residents can hang up and take down, can add interest and provide distraction.

We found seven units where the environment was particularly impoverished, with visitors commenting that the units were institutional, bare and stark, and that much needed to be done to improve them.

"The flooring is broken and fixed with duct tape, the whole place needs money spent to modernise it."

"It is ever so slightly clinical... it could benefit from a bit more use of colour."

The majority of units, however, had made efforts to provide a stimulating environment, and we found some particularly good examples of this. Some units used artwork such as large pictures of local landmarks, pictures of children playing or people engaged in a variety of pastimes or tasks, all of which provided focal points for discussion. We found rummage boxes left on tables, large rummage boards fixed to the wall, bubble tubes and snoezlen equipment in use, toy cats and dogs which moved and purred or barked when stroked.

We looked at the issue of signage and orientation; we found that:

- 42 (86%) public areas had toilets nearby
- Only half (24, 49%) were well signposted with dementia-friendly signage and only a third (16, 33%) were easily visible from a seated position
- All units we visited had disabled-equipped toilets
- Only 27 (55%) of the units had incorporated dementia-friendly design, such as contrasting toilet seats and toilet roll holders and signage to make soap and towel dispensers easily identifiable.

We also noted that there was not enough room in some toilets to allow for assistance by two staff. Given the complex physical and emotional needs of people with dementia in NHS continuing care, this is often required.

Given that these units provide care for individuals with dementia, the lack of attention to dementia-friendly environmental features was disappointing. Good signage and design can support individuals with dementia to find and use the toilet without assistance, maintaining their independence, and their dignity, for longer.

Personal care can be challenging for people with dementia. Their cognitive impairment may mean they feel vulnerable and distressed during bathing or showering and they may need the assistance of several staff. We found units where people were not able to make the choice between a bath or a shower as only one or the other was available. There were also issues about bathrooms being too small to allow staff to provide adequate support to individuals should they become distressed.

One relative commented on the quality of toilet and bathing facilities.

“Most care homes have better facilities these days. It is Dickensian, the shared toilets.”

The overall layout and design of a unit can impact on people’s behaviours, for example, corridors which do not lead anywhere and end at locked doors can cause people to become frustrated and distressed when they cannot open them and get out. One relative commented on this.

“The staff do their best in a situation there that is not ideal. There are corridors, doors off corridors, patients walking into each other. All those doors for an Alzheimer’s patient – it must be a complete nightmare. Every time I see my husband he’s trying to open doors and a lot of them are locked – they have to be.”

Yet simple steps can be taken to address this, such as disguising locked doors by painting a mural on them or colouring them to blend into the surrounding walls.

It is important that individuals are able to identify their own bedroom. For people with mid to late stage dementia, who may also have impaired vision, a name on a door may not be enough.

- 29 (59%) units had orientation cues such as pictures or memory boxes for all or some of the bed areas
- However, this does leave 41% which have no aids to orientation on bedroom doors

Bedroom provision varied with 34 (69%) units having some or all single en-suite rooms. The remainder of the accommodation was in small dormitories with shared facilities.

Within the bedroom, access to personal items and memorabilia can provide a sense of identity and comfort, acting as a focal point for discussion and can help staff to engage with the person.

Unfortunately, in four units we found that there was no evidence of personalisation at all in bed areas. These were noted to be stark and institutional. In other areas the quality and degree of personalisation varied greatly, with some units having made significant efforts to personalise rooms. Some residents in single rooms had brought in furniture and ornaments from home and had a large number of personal items and family photos on display. In other areas, we noted that the level of personalisation was entirely dependent on relatives' input, leaving some people with little family contact, with very sparse and impersonal rooms. We feel it is important that staff actively facilitate personalisation of rooms for everyone.

One relative commented very positively on the level of personalisation and its importance.

"The care has been very person-centred. They made his room a safe environment for him with padding on walls and floor mats, as he liked being able to move on his knees and literally rolling on floor. Have made sure he gets music he likes, e.g. Black Sabbath."

We looked at smoking facilities; we found that only a small number of people in the units we visited smoked. Nine units had a smoking room and 11 had a smoking shelter in the garden. In the remainder of the units, people would have to go outside either into the garden or the grounds to smoke.

Staff were very aware of the limitations of the environment they worked in and the impact this had on care. Several commented on the lack of dementia-friendly signage and design and limited bathing and showering facilities.

Recommendations

Whilst we found that many units had incorporated some elements of dementia-friendly design, there is still much that needs to be done to ensure the accommodation is of a consistent standard, which is designed to meet the needs and support the independence and dignity of people with dementia. Given the extensive body of evidence around the benefits of this and the ready availability of dementia-friendly environment audit tools, it is disappointing that more hasn't been done with regard to environment. This should be achievable in our modern NHS.

End of life care

The Standards of Care for Dementia in Scotland state "I have the right to end of life care that respects my wishes".

It is important that the individual's current or previous wishes and their views are taken into account where a decision not to resuscitate is being considered, and that there is a clear rationale for this decision. Whilst DNACPR (an instruction not to attempt resuscitation in the event of cardiac arrest) is a medical decision, this should be discussed with the family and/or AWI proxy, and the decision should be reviewed on an ongoing basis.

We expected to find evidence of carers being involved in decisions. We expected units to have staff trained in palliative care and access to palliative care services, to enable people to be cared for within these units by staff who are familiar to them, rather than being moved to a strange environment with unfamiliar staff at the end of their life. All units should be able to provide good quality compassionate care for the individual and their carers, and respect their previously expressed wishes.

What we found

We asked carers whether they had been consulted about end of life decisions:

- 90 (70%) carers we spoke to told us they had been consulted about whether their relative should be resuscitated if they suffered a cardiac arrest
- 79 (62%) had discussed with staff what to do if their relative's condition deteriorated
- We did not discuss end of life care decisions with 23 (18%) of the carers we spoke to, either because they did not wish to or it would have been inappropriate at that time

Three-quarters (253) of the people we saw had DNACPR forms on file. However, in 24 cases there was no record of this having been discussed with the family or AWI proxy.

In one case the form had been reviewed on five occasions and although there was a visiting spouse, there was no evidence that this had been discussed with them.

We also found seven forms where there was no reason stated for not attempting resuscitation.

- All units could offer single rooms and all but one offered open visiting for end of life care
- 34 (65%) units provided facilities for relatives to stay overnight if they wished
- 50 (96%) charge nurses told us they discussed end of life care plans with families
- 41 (81%) units used an end of life care pathway
- 45 (87%) units were using pain assessment tools
- 40 (77%) units had staff trained in palliative care
- Four units told us they didn't have access to specialist palliative care support

Recommendations

Many of the people with dementia we visited will spend their final days in their current unit. Therefore, it is essential that all units have staff who are adequately trained in palliative care using the approved national Promoting Excellence Training Programme and have access to specialist palliative care support where this is indicated.

Carers' overall satisfaction

Overall, carers were positive about the quality of care within the units. 98% were satisfied with care (114, 89% 'very satisfied', 11, 9% 'fairly satisfied').

Several relatives commented, not just on the care for their loved one, but on the holistic approach which recognised the importance of addressing the needs of the family and supporting the adult in maintaining those relationships.

"It's family support, not just care of the patient." "I couldn't wish for her to be in a better place at this point in her life." One described staff care as fantastic. "They have a good rapport with mum and relatives." "They spend time with Betty looking through photo albums and reminding her who her relatives are. They ensure Betty is aware of changes in her family – a great grandson was born last week. Staff regularly remind her and show her photos."

"The staff are fantastic. The culture of the unit is excellent. The staff recognise the family as partners in mum's care. I feel that the unit manager truly understands person-centred care and importance of family." "We are made to feel very welcome and encouraged to bring in food to eat with mum." "The initial decision to put a parent in a care home is very hard and challenging and can be made harder by professionals. This is thankfully not the case here in this home. Staff work with the family to meet mum's needs. Couldn't ask for more here."

When asked specifically about whether their relative was treated with dignity and respect, the response was 100% positive, with comments such as:

"This is excellent care, they treat him as a human being. They consider his feelings in everything they do."

"I am especially impressed with the protection of dignity as mother removes her top clothing on regular basis."

"Dad was always a shirt and tie man, very dapper and that is adhered to here. It matters. He was a teacher, young staff call him Mr Smith."

"Self-care and hygiene are always attended to. He is always dressed as he would want to be. Even toileting needs are attended to with utter respect and dignity."

"I cannot thank the staff enough for what they do for my dad. They treat them like their own. I have never had any cause for concern."

Staff's views of the dementia standards and the delivery of care

We asked the nursing staff what impact the dementia standards had made to the care in their unit.

Improved staff training and stronger carer involvement came out as the two most commonly-mentioned themes, followed by greater focus on activities and a more person-centred approach. Improved staffing levels and stronger community links were each cited three times, whilst only one charge nurse felt that end of life care had improved as a result of the standards.

When asked what was the best thing about the care they delivered, the majority of nurses commented on providing person-centred care, good relationships with carers, highly motivated staff who 'go the extra mile', provision of good basic care, treating individuals with dignity and respect.

We also asked what got in the way of delivering good care.

- 17 (33%) commented on the amount of paperwork getting in way of care delivery
- Eight (15%) commented on environmental issues, e.g. design of bathrooms, lack of access to outside, general lack of space
- 15 (29%) commented on inadequate staffing levels. We did not routinely gather information on staffing levels as staff numbers alone do not provide sufficient information for us to make a judgement on whether staffing is adequate. Staffing requirements are influenced by many factors, including unit size, layout, dependency and clinical activity and can fluctuate over time
- Two commented on health and safety issues getting in the way. One unit had to shut down a water feature due to potential legionella risk and was not allowed a unit cat, although the charge nurse told us his patients would love this and the unit environment is ideal. The other commented on the delay in implementing therapy visits due to delays in receiving health and safety approval.

Conclusion

We acknowledge that there has been some progress since the publication of *Older and wiser* in 2007. Some NHS dementia units have become more dementia friendly with better signage and more stimulation. Provision of outside space has improved and innovative activity projects have been developed in some areas. We felt that some units provided excellent care which respected the rights and dignity of people with dementia. However, the care and/or environment in too many units is failing to meet acceptable standards: lack of access outwith the unit, lack of stimulating activities, poor care planning, limited multi-disciplinary input and significant levels of multiple use of sedative medication without regular review. This is not acceptable.

The Standards of Care for Dementia in Scotland were published in 2011. Whilst these are, to some extent aspirational, the high quality of person-centred rights-based care they describe can be achieved by services and is being delivered in some areas. It should be delivered in all NHS units for people with dementia.

Appendix 1 – Wards we visited

Name of NHS hospital or care home	Ward/unit name	Number of patients seen
Ailsa Hospital	Iona/Lewis	7
	Jura	6
Cumbrae Lodge	Iona	7
	Jura	6
	Kintyre	4
East Ayrshire Community Hospital	Marchburn	5
Borders General Hospital	Melburn Lodge	8
Allanbank Nursing Home	Glensone	6
	Kissock	6
Darataigh	Darataigh	4
Queen Margaret Hospital	Ward 3	4
	Ward 4	2
Stratheden	Bay View	5
	Cairnie House	2
Bo'ness Hospital	Ward 2	9
Clackmannan County	Ward 2	11
Stirling Community	Ward 2	10
Royal Cornhill	Lauriston	3
	Strathbeg	4
Birdston	North	12
	South	3
Darnley Court	Carmichael House	8
	Fleming	8
Dumbarton Joint Hospital	Glenarm Ward	8
Gartnaval Royal	Iona	8
	Tate	7
Mansionhouse Unit	North 1	6
	South 1	3
Ravenscraig	Dunrod F	3
Rowentree	Stonelaw	12
Mid Argyle	Cara Ward	4
	Knappdale	5
Migdale	Strathy	5
New Craigs	Torvean	2
St Vincent's	Lynwilg	4
Cumbernauld Care Home		16
Hatton Lea Nursing Home	Millwood	7
	Mossend	2
	Orbiston	6

Craigenhall	Maple Villa	4
Ferryfield House	Willow	15
Findlay House	Prospect Bank	14
Herdmanflat	Lammerlaw	8
Maple Villa	Maple Villa	11
Midlothian Community	Glenlee	8
The Royal Edinburgh	Jordan	5
	Myreside	3
	Pentland	5
Tippethill House	Roseberry	13
Royal Dundee Liff	Ward 18	5
	Ward 19	4
Western Isles	Chisholm	3
		336





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