mentalwelfare
commission for scotland

Dementia: decisions for dignity

Our visits to people with dementia in general hospitals

September to December 2010

Who we are and what we do

The Mental Welfare Commission is an independent organisation working to safeguard the rights and welfare of everyone with a mental illness, learning disability or other mental disorder. Our duties are set out in mental health and incapacity law.

We are made up of people who have understanding and experience of mental illness and learning disability. Some of us have worked in healthcare, social care or the law. Some of us are carers or have used mental health and learning disability services ourselves.

We believe that everyone with a mental illness, learning disability or other mental disorder should:

- Be treated with dignity and respect;
- Have the right to treatment that is allowed by law and fully meets professional standards;
- Have the right to live free from abuse, neglect or discrimination;
- Get the care and treatment that best suits his or her needs; and
- Be enabled to lead as fulfilling a life as possible.

Our work

- We find out whether individual treatment is in line with the law and practices that we know work well.
- Challenge those who provide services for people with a mental illness or learning disability, to make sure they provide the highest standards of care.
- We provide advice, information and guidance to people who use or provide services.
- We have a strong and influential voice in how services and policies are developed.
- We gather information about how mental health and adults with incapacity law are being applied. We use that information to promote good use of these laws across Scotland.

Our visits

One of the ways in which the Commission monitors individual care and treatment is through our visits programme. We visit people in a range of settings throughout Scotland; at home, in hospital or in any other setting where care and treatment is being delivered. As part of this programme we carry out three national themed visits each year. The aim of national themed visits is to enable us to assess and compare care and treatment for particular groups of people across Scotland. Our aim is to help services learn from good practice and to respond to any issues that are identified.

This report reflects our findings from a special programme of visits that took place across Scotland between September and December 2010 to people with dementia in acute wards in general hospitals.

Why we visited

There are currently around 71,000 people with dementia in Scotland and this number is expected to double over the next 25 years. The risk of developing dementia increases with age: one person in twenty over the age of 65 years rising to one in three people over the age of 80.

As the population in Scotland ages, this will be reflected in increasing use of the acute care setting (general hospitals and accident and emergency departments) by people with dementia.

It is estimated that people with dementia over 65 years of age are currently occupying up to 25% of hospital beds at any time. In Scotland, up to 30% of all people admitted to medical wards are described as having significant memory problems but, of this group, only 30% will have a diagnosis of dementia. Many older people admitted to general hospital will have symptoms but no formal diagnosis of dementia.

When admitted to hospital, people with dementia can experience increased levels of confusion and loss of their abilities and, where possible, alternatives to admission should always be explored. On average, people with dementia stay longer in hospital than other people who are admitted for the same medical procedure.

A report published in 2009 by the Alzheimer's Society revealed that half of all carers interviewed felt that being in hospital had a negative effect on the general and mental health of the person with dementia. It also revealed that over a third of people with dementia who go into hospital from living in their own homes are discharged to a care home setting.

We hear general concerns from relatives and staff about the difficulties some people with dementia face when admitted to a general hospital and also hear about individual cases where things have gone very wrong and resulted in complaints.

Scotland's National Dementia Strategy was launched in June 2010. The strategy stated the Scottish Government's commitment to work to "improve the response to dementia in general hospital settings including through alternatives to admission and better planning for discharge."

We had already stated our intention to visit people with dementia in general hospitals prior to the publication of the strategy. The timing of our visits has come at an opportune moment to promote current best practice in this area and identify areas where we believe improvements need to be made. We hope that our findings will be useful in implementing the dementia strategy.

This was a new initiative for us. We have visited general hospitals before but on a very limited basis, e.g. visits to departments of liaison psychiatry. Taking this opportunity to visit general hospitals on a larger scale allowed us to evaluate how and when we should visit in future. It helped us to make contact with general hospital staff to let them know of our functions, safeguarding role and best practice guidance.

How we carried out the visits

We wrote to all NHS Board Chief Executives to let them know we intended to visit and to clarify with them our powers in relation to visiting. As we had not visited general hospitals before, we thought that the staff would need to understand why we were visiting and under what authority. When visiting, we are allowed under the Mental Health (Care and Treatment) (Scotland) Act 2003 to have access to anyone who may have a mental disorder (this would include anyone with dementia) and also to look at clinical notes.

We selected fifty hospital wards across the country, mainly acute medicine for the elderly, and gave each ward about six weeks notice of our visit. Although we have the authority to visit on an unannounced basis we thought that this series of visits should be announced in advance to increase the chance of being able to talk to key staff members.

Because of extreme weather conditions in December 2010, we had to cancel some of our planned visits. Despite this, we visited 41 wards in total and met with and reviewed the care of 194 people with dementia.

Each ward was visited by one or two MWC visitors. Following a discussion with the charge nurse, we identified all patients in the ward who had a definite or likely diagnosis of dementia. We met with as many of these people as possible and also carried out a review of their care and treatment based on the information in their case file and discussion with the staff. Many of the people with dementia that we wanted to meet with were very physically unwell and it was not possible to carry out a full interview with them.

We completed a structured interview with the senior nurse on each ward, gathering information about the range of services the ward provided and any difficulties encountered when caring for people with dementia. We also carried out an audit of the physical environment on the ward and this focussed on how dementia-friendly and enabling the ward was.

If we had concerns about an individual person's care, we discussed these with staff on the day. We followed up any recommendations we made about an individual's care. Also, we gave the ward staff both verbal and written feedback on what we considered was good practice and what we felt needed to be addressed.

Our visits were warmly welcomed by general hospital staff and managers. We are grateful to them for their help and would also like to thank the patients and relatives who shared their experiences with us.

What we examined

We focussed on the following areas when we carried out our visits:

- Admission to hospital;
- The care journey;
- Consent and lawful medical treatment;
- Safety and restrictions;
- The care environment;
- Staff training and specialist mental health support; and
- Discharge from hospital.

Summary of findings and recommendations

Positive findings

We found many positive aspects of the care and treatment of people with dementia in general hospitals. These include:

- People with dementia are being admitted appropriately when referred to hospital (although, in some cases, earlier intervention in the community may have prevented the need for admission);
- People with dementia are, in general, not being moved unnecessarily between wards;
- There were good examples of ways to obtain and record information about the person with dementia and use this to provide better care;

- There was good attention to nutrition, a known risk for people with dementia in hospital;
- People with dementia were generally appreciative of the care they received;
- We found that staff were dedicated, caring and had access to guidance on best practice; and
- Specialist mental health services were generally available for advice and support.

We had several concerns and have made recommendations for improvement. Our concerns are reflected in our key messages and our recommendations to NHS Boards and their local authority partners.

Key messages

We have developed the following key messages so that NHS Boards, local authorities, hospital managers, clinical and professional leaders and others can use them to consider the care they provide and make improvements where necessary.

Key message 1

Few admissions could have been avoided at the point where people were referred to hospital. If more flexible and responsive care services for people with dementia and their carers had been available earlier, it may have been possible to prevent some admissions.

To address this, NHS Boards should

- With their local authority partners, give priority to falls prevention work in the community for people with dementia and review services for early intervention and support.

Key message 2

We were pleased to find few moves between wards and good attention to nutrition. General hospital staff did not always obtain and record information about their patients with dementia and involve relatives and friends in their care. Screening tests for dementia were performed routinely but the absence of information from relatives made it difficult to differentiate delirium from dementia.

To address this, NHS Boards should

- Ensure that information about the person with dementia is routinely requested from carers and care managers on admission and shared with people who will be having direct contact. This should include personal details, personal preferences and usual routines.
- Establish and audit tracking systems in general hospitals to ensure that patients with dementia are not moved to a different ward unless clinically necessary.
- Provide guidelines and training in the management of delirium for all staff who provide care to acutely unwell people.

Key message 3

Legal safeguards for people who lack capacity to consent to medical treatment are not being applied. Proper procedures should be followed so that they can receive necessary treatment lawfully. Their capacity to consent should be regularly reviewed. Clinicians do not always take specialist advice before prescribing psychoactive medication. They do not always follow best practice guidance on administering medication covertly and on making decisions not to resuscitate.

To address this, NHS Boards should

- Establish and audit processes for assessment and review of capacity to consent to medical treatment.
- Audit the use and review of psychoactive medication for people in general hospital wards.
- Establish protocols for the administration of covert medication. The MWC guidance (Mental Welfare Commission 2006) can be used for this.
- Audit the recording of “do not attempt resuscitation” decisions to ensure that clinicians follow best practice.

Key message 4

General hospital staff must ensure that measures to keep people with dementia safe are used lawfully and proportionately. They need to be more aware of human rights and incapacity legislation.

To address this, NHS Boards should

- Ensure that information about welfare guardians and powers of attorney is collected on admission and highlighted on the patient record.
- Update training for staff in general hospitals in the provisions of the Human Rights Act (1998), the Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003.
- Make sure that people who have dementia and/or are seriously ill do not sign legal documents if they do not have the capacity to do so. Posters and information leaflets may help.
- Establish protocols for the use of “wandering technology”. This should include individual risk assessment. It should involve consultation with relatives but nobody should be asked to “consent” to its use unless they have specific powers under the 2000 Act.

Key message 5

Given the high number of people with dementia in general hospital wards for older people, it is disappointing that many wards do not have an environment which is dementia friendly. Much more could be done to make the environments enabling for people with dementia and afford them greater privacy and dignity.

To address this, NHS Boards should

- Conduct regular audits of the physical environment using the dementia design checklist and take appropriate action to meet any deficits.
- Ensure that managers of older people’s wards and infection control discuss the balance between infection risks and maintaining an environment that helps people with dementia to orientate themselves and recover.

Key message 6

It was encouraging to see the benefit of training and support for general hospital staff. Specialist mental health expertise was usually regarded as valuable and should be properly resourced.

To address this, NHS Boards should

- Make sure that all general hospitals have quick and easy access to specialist older people's mental health liaison services for assessment and advice.

Key message 7

People with dementia are very often discharged from general hospitals to care homes on a permanent basis instead of returning to their own homes. When someone with dementia who was living at home is discharged from hospital, facilitating a return home should be the starting point whenever possible.

To address this, NHS Boards should

- Along with local authority partners, ensure robust systems are in place to review decisions taken to transfer someone with dementia who previously lived at home to a care home. This may include a timescale for review, involving care managers, before the placement is made permanent.

Comments from individuals and staff

We spoke to people with dementia to find out their views on being in hospital.

We spoke with staff about what they found difficult in responding to the particular needs of people with dementia.

Views of people with dementia

People who were able and willing to comment on their treatment and care were almost all positive about it. Most thought the ward 'always' had 'a calm atmosphere'. There were a few adverse comments from patients. Two who were ex-nurses were a little critical and one person said that nurses had no time to talk to patients. A very few said they could not see their cards and other personal things from their bed. Examples of comments were:

> *"The nurses are lovely. They couldn't be any better. I do have some fun with them."* (Lady with mild dementia)
>
> *"The doctors always introduce themselves but the therapists – there are so many of them, I am never sure what they do and I don't think they always tell me their names."*

Views of staff

We asked staff about what made it particularly challenging in caring for people with dementia on their ward. The main problem they identified was the physical layout of the wards; a lack of general privacy and too few single rooms. Our visitors thought that staff did their best while under a lot of pressure.

> *"Very busy ward. Staff aware of needs of patients with dementia but clearly struggle to manage them within this environment".* MWC visitor

> *"Dynamic and responsive. Meaningful efforts to change things while balancing challenge of busy, acute medical ward. Winter crisis has affected what they are able to do "fire-fighting on a daily basis."* MWC visit to Crosshouse Hospital

> *"Ward impresses as having a caring and calm approach. Good multi-disciplinary working – active involvement of occupational therapy, physiotherapy and speech and language therapy professionals."* MWC visit to Monklands Hospital

We have more to say about these issues in the rest of this report.

Admission to hospital

Key message 1

Few admissions could have been avoided at the point where people were referred to hospital. If more flexible and responsive care services for people with dementia and their carers had been available earlier, it may have been possible to prevent some admissions.

What we looked at

We looked at the reasons for admission to hospital and if consideration had been given to alternatives to admission. We gave some thought to how admission could have been prevented by better services or by better "gatekeeping" when the person was referred to hospital.

What we expect to find

We expect that people with dementia are admitted only when there is no reasonable alternative to that admission.

What we found

Prior to admission, most people with dementia had been living at home either alone or with their family. Only a few were living in a care home. We asked about the reason for admission to the ward for everyone we met and whose file we reviewed.

About half of all people with dementia were admitted following a fall. The other main cause for admission was a serious infection. (See appendix for full details.) Of the people with dementia admitted due to a fall, the majority were living alone at home prior to admission.

We looked to see if alternatives to admission had been considered but we found written evidence of this in only a very few cases. Usually, this was because the person's illness or injury was so severe that there was no alternative at that time. Our visitors came across few cases where they considered the admission to have been unnecessary.

One exception was:

> *"Admitted due to chair lift not working, will take one to two weeks to repair."*
> MWC visitor

Although the people we met with were very ill and needed to be in hospital, earlier intervention may have prevented the admission. This is particularly the case with the high number of people admitted following a fall at home. A greater focus on fall prevention within homes and care homes may help prevent some of these admissions. Examples of our findings were:

> *"No alternative at time of admission. Mr M has Parkinson's disease which was showing signs of deteriorating prior to this fall."* MWC visitor

> *"Already concern about his vulnerability at home prior to admission, GP has referred him to medicine for elderly about falls and old age psychiatry regarding confusion and emotional lability, not seen yet, now urgent admission due to fall."* MWC visitor

> *"Fall and acute confusion, suspected head injury, requires further assessment and investigation, situation reported to have been deteriorating for some time."* MWC visitor

Unfortunately, we came across some cases where admission had become inevitable due to the stress and ill health of the carer of the person with dementia. Perhaps intervention at an earlier stage may have prevented admission.

> *"Mrs A admitted after both she and her husband, her carer, fell. Think that she lost consciousness and he fell trying to help her. He is exhausted looking after her."* MWC visitor

> *"Admitted with general physical deterioration, number of physical illnesses. Refusing all medication, increase in aggressive behaviours, family struggling to cope."* MWC visitor

Recommendation:

NHS Boards should, with their local authority partners, give priority to falls prevention work in the community for people with dementia and review services for early intervention and support.

The quality of individual care

Key message 2

We were pleased to find few moves between wards and good attention to nutrition. General hospital staff did not always obtain and record information about their patients with dementia and involve relatives and friends in their care. Screening tests for dementia were performed routinely but the absence of information from relatives made it difficult to differentiate delirium from dementia.

What we looked at

- We looked for the use of screening tests to identify people who may have dementia.
- We looked at the information available about people with dementia, including their likes, dislikes and at least some information about their lives, family and interests.
- We wanted to find out how often they were moved since admission.
- We looked at the provision of food and drink.
- We looked at the role of carers.

What we expect to find

General hospital staff should use simple screening tests such as the mini-mental state examination (MMSE). This should be supplemented by further information from relatives and carers.

Not all people with dementia will have problems communicating their needs. Even so, it always helps staff to have information including individual preferences and the names and relationships of people who are important. This helps staff to communicate well with the person with dementia.

Moving a person with dementia from ward to ward can be a problem. It can worsen disorientation and cause distress. We expect to find that people with dementia are only moved from ward to ward where it is essential for their care and treatment.

Nutrition is very important. We expect careful attention to nutrition, especially where the person needs assistance to eat.

All of this can be helped by good communication with carers. We expect to find evidence that relatives and friends are encouraged to join in the task of caring for people with dementia in hospital.

What we found

A. Information about the person

We asked staff about the information they collected on admission about the person with dementia. We were told that this happened in most of the wards we visited and there was evidence of good practice in this area.

All hospitals were using screening tests, usually the MMSE, and we found that this was performed on admission or at an appropriate time after admission if the person had been too unwell to test. We found that getting further information about the person was generally not carried out routinely. Also, there was patchy practice in recording information about the person's background, likes and dislikes. Good practice examples were:

> *"Thoughtful care plans and they also keep information re some personal preferences above bed and mini life story, which then follows the individual to next placement."* MWC visit to Biggart Hospital

> *"Good Information obtained from care homes, sent in routinely with patients. When people are admitted from own home, staff seek information from family about their care needs, nutritional needs and life histories, occupational therapist and nurses do that."* Royal Victoria Hospital, Edinburgh

Sometimes, we found that information was available but not well recorded.

> *"Fascinating man. (lots of personal details given) Keen walker tends to walk about the ward a lot but is at risk of getting out and getting lost. Relatives visit and take him for walks round the grounds. None of this in care plan."* MWC visitor

> *"Staff give relatives a "This is Me" form to complete on admission. It asks for information about the person with dementia. Unfortunately, it was then filed in the middle of a huge set of case notes; I only found it because I had set out to look for it."* MWC visitor

B. Moves since admission

We found that most people had not been moved since admission (apart from a brief stay in an acute medical assessment unit). A few people had been moved out of their original ward and we found two people with dementia who had been moved three times. We asked staff if there were protocols in place to track the movements of people with dementia from one ward to another but only half of the hospitals said they carried this out.

C. Ensuring adequate food and fluid

Food and fluids are essential to ensure a good recovery from illness and we often hear concerns that people with dementia are left without the help they need to eat and drink. About half of those who responded to the questions we asked said they got their own choice of food, they liked the food and they got enough to eat.

All but one of the wards we visited said they had a system to ensure that assistance at mealtimes was provided to all who needed it and all but two operated a protected mealtime system. This means that all non-essential activity is stopped during meal times to ensure that staff can give all their attention to helping people with their meal. We found that nutritional needs screening had been completed and nutritional care plans were in place for most people.

Although it appeared good attention was being paid to this in the wards we visited, we have heard of cases where people with dementia do not receive the help they need. Services must ensure that they continue the good attention to nutrition that we found on these visits.

D. Carers' roles

We asked ward staff if there were opportunities for carers to carry on their role during the admission e.g. helping with personal care. Most wards said there were but how enthusiastic staff were about this varied from ward to ward. We found a few examples where this helped. Carers may be able to help in more cases and hospital staff should encourage this.

> *"Especially in care of person with challenging behaviour, man with dementia with Lewy bodies who had terrible night terrors, his daughter would come in and settle him. Avoided need for any sedation."* MWC visitor

E. Additional comment – delirium

Delirium is described as an acute change in mental status characterised by hallucinations, clouding of consciousness, misinterpretation of events and sleep disturbance. Delirium can occur in up to half of all patients aged 65 years or over who have been admitted to hospital and the number is even higher for surgical and intensive care admissions. People with dementia who are physically ill have a high risk of developing delirium and consequently have a greater risk of dying. Where someone without dementia develops delirium, there is a greater chance of going on to develop dementia in the future.

During our visits, we heard concerns from staff about the high number of patients with delirium. We did not set out to visit people with delirium. Staff thought this was an area that required attention. They need more guidance and support when managing people with delirium. This may form part of Scotland's dementia strategy.

Recommendations: NHS Boards should:

- Ensure that information about the person with dementia is routinely requested from carers and care managers on admission and shared with people who will be having direct contact. This should include personal details, personal preferences and usual routines;
- Establish and audit tracking systems in general hospitals to ensure that patients with dementia are not moved to a different ward unless clinically necessary; and
- Provide guidelines and training in the management of delirium for all staff who provide care to acutely unwell people.

Consent and lawful medical treatment

Key message 3

Legal safeguards for people who lack capacity to consent to medical treatment are not being applied. Proper procedures should be followed so that they can receive necessary treatment lawfully. Their capacity to consent should be regularly reviewed. Clinicians do not always take specialist advice before prescribing psychoactive medication. They do not always follow best practice guidance on administering medication covertly and on making decisions not to resuscitate.

What we looked at

- We looked to see if a person's capacity to consent to treatment was assessed prior to treatment.
- We looked for legal documentation to authorise treatment for people who lacked capacity to consent.
- We examined the use of psychoactive medication to find out how often it was used, whether it was started after admission and who made the decision to prescribe.
- We looked to see whether medication was being administered covertly.
- We looked at decisions on whether people should be resuscitated if there was cardio-respiratory arrest.

What we expect to find

We expect that people dementia will receive treatment that is in line with the law and care that respects their and legal and human rights. Case records should demonstrate that:

- The person's capacity to consent to medical treatment has been assessed;
- For people who lack capacity, legal documentation is in place to authorise medical treatment;
- Where there is a welfare attorney or guardian with the authority to consent to treatment, there is a record of consultation with that person;
- Covert medication has been administered lawfully and in line with best practice guidance; and
- "Do not attempt resuscitation" (DNAR) decisions are made for sound reasons and after consultation with the person (if possible) and relatives.

What we found

A. Consent to medical treatment/Section 47 of the Adults with Incapacity (Scotland) Act 2000.

If people are not able to consent to their own medical treatment then hospitals should use the law properly to safeguard them. From the visits we carry out to people in hospitals, care homes and their own homes, we know that often this is not happening. The 2000 Act gives a general authority to treat a person who is incapable of consenting once a certificate of incapacity (section 47 certificate) has been issued. The Code of Practice makes it clear that this certificate is required except for emergency treatment.

For people who require them, we would expect to find these certificates in place and an attached treatment plan for people requiring multiple or complex healthcare interventions. This ensures that treatment is legally authorised and shows that the principles of the 2000 Act have been observed (benefit, least restriction, taking account of the person's wishes and consulting others where possible).

We came across only a few people with dementia where their capacity to consent to medical treatment had been assessed and recorded in the notes and even fewer who had a completed certificate and treatment plan. If people with dementia cannot give valid consent and no certificate has been completed, their treatment does not comply with the law.

> *"Focus is on medical care – very little awareness of human rights issues such as consent, capacity etc. Very caring overworked staff."* MWC visitor

> *"No section 47 certificate in place. No assessment of capacity. No evidence of contact with welfare POA (son) but evidence of regular communication with daughter."* MWC visitor

According to the ombudsman *"It is unacceptable for health practitioners not to show proper understanding of the legislation and policies that exist to ensure that patient's human rights are not breached."* (SPSO 200902396) Unfortunately, it appears to us that very few practitioners correctly applied the law on medical treatment for adults with incapacity.

B. Lawful and appropriate use of psychoactive medication

Of the 194 files we reviewed, we came across 90 people who were prescribed psychoactive drugs (antipsychotic drugs, antidepressant drugs and benzodiazepine drugs for treating anxiety).

Of these 90 people, there were 36 prescriptions for antipsychotics, 53 for antidepressants and 22 for benzodiazepines (some people were taking more than one of these drugs). Just under half of these 90 people had the medication prescribed since their admission.

Where psychoactive medication was prescribed there was evidence that a psychiatrist was consulted in only a minority of occasions. Although there is no legal requirement for a psychiatrist to be involved, there are some well established potentially dangerous side effects of these medications in people with dementia. Good practice is illustrated in the following:

> *"Anti-psychotic medication is prescribed and reviewed under supervision of consultant psychiatrist and also regular reviews of managing challenging behaviour care plan by liaison mental health nurse."* MWC visit to Biggart Hospital

Only a few people who were prescribed these particular medications had their capacity to consent to medical treatment reviewed and recorded in their notes. The following example is typical of what we found:

> *"Has been prescribed and given Haloperidol. Could not find anything in medical/nursing notes regarding assessment prior to this or of reason for prescription nor of capacity to consent. No legal documentation. No contact with dementia liaison nurse so far."* MWC visitor

C. Covert medication

Covert medication is the administration of any medical treatment in disguised form.

We came across two occasions when people with dementia were being given medication covertly. On one ward it was being done following best practice guidance (Mental Welfare Commission 2006) but not in the other where they had no policy in place.

D. DNAR (do not attempt resuscitation):

We found 56 people where clinicians had recorded a decision not to resuscitate in the event of cardio-respiratory arrest. We looked to see whether the reasons for the decision had been documented and what account was taken of the views of the patient or relatives. We wanted to see if best practice was being observed as per the joint statement from the British Medical Association, Resuscitation Council (UK) and Royal College of Nursing (2007).

In most cases, we found good use of standard documentation. An example of good practice was:

> *"Notes indicate how DNAR arrived at, extensive discussion with family. Is on "Liverpool Care Pathway" for terminal care."*

In a few cases, we were not satisfied that there had been sufficient consultation. Also, as the person's condition may change, the decision should be kept under review.

> *"DNAR was written in a previous ward and was signed by medical staff but not in consultation with family. Needs to be updated now she's better."*

We were particularly concerned to find a case file where someone had written "not for 2222" (code for calling the arrest team). There was no signature or date and the form that should have specified the reasons for the decision and the consultation undertaken was left blank. We immediately raised this with clinical staff.

Recommendations: NHS Boards should:

- Establish and audit processes for assessment and review of capacity to consent to medical treatment;
- Audit the use and review of psychoactive medication for people in general hospital wards;
- Establish protocols for the administration of covert medication. The MWC guidance can be used for this; and
- Audit the recording of "do not attempt resuscitation" decisions to ensure that clinicians follow best practice.

Safety and restrictions

Key message 4

General hospital staff must ensure that measures to keep people with dementia safe are used lawfully and proportionately. They need to be more aware of human rights and incapacity legislation.

What we looked at

- We looked for people who were being deprived of liberty, privacy or dignity.
- We looked at the use of the powers of welfare attorneys and welfare guardians.
- We identified other legal or ethical issues that were of concern to staff.

What we expect to find

We expect that people with dementia will receive care and treatment which respects their legal and human rights. Staff should have knowledge of relevant legislation. Case records should demonstrate that:

- "Restraint" in its broadest sense (including technology to prevent the person leaving the ward) is necessary and based on an individual assessment of risk.
- Where the person is being deprived of the right to leave when they wish to do so, this is done in line with mental health and incapacity legislation.

What we found

A. Restraint and deprivation of liberty.

Use of restraint: Forty-four people with dementia had bed rails in place to prevent them accidentally falling out of bed. In the majority of cases the necessity for this was documented in the care plan. However, some wards appeared to use them indiscriminately with little attention paid to whether they were needed or not.

“Wandering technology”: Five visitors made reference to the use of “WanderGuard” or “tagging “on the wards visited. This is a system where a patient wears an electronic wrist tag that sets off an alarm if they leave the ward. These systems are used increasingly and the aim is to alert staff when a particularly vulnerable patient is leaving. The system may have benefits for individual patients but we found it to be used on some wards in a blanket fashion for anyone with dementia who was able to walk around. Relatives were usually asked for their “permission” by staff to use this system. Unless there is a specific legal power for a proxy to give consent to this, there is no lawful basis for this permission, although the principle of consulting relatives should be observed. The Scottish Public Services Ombudsman raised concerns about the lack of a specific policy in a hospital for a WanderGuard bracelet. (SPSO 200801921)

“De facto” detention: People with dementia may wish to leave hospital but are prevented from doing so. While there may be good reasons for this, it must be done lawfully. If not, we call this “de facto” detention. In one hospital the charge nurse reported that at any time up to one third of all the patients on the ward had dementia but in all the 7 years she had worked there, she had never known the Mental Health Act to be used. We are confident that she has been caring for people who were being “de facto” detained.

As an example, we met Mrs S, a person with dementia. She had recovered from a serious illness but was still in hospital because her safety at home could not be guaranteed. She told us, *“Even the staff in here wonder why I’m in here, wandering about. I walk around like a lost cause.” “I just came in because I was tired, worn out, couldn’t cope. I’m not so ill I need to be here forever.”* We asked staff about her and were told that when other people go home, Mrs S can mention wanting to leave a few times in a day. We were concerned that no thought appeared to have been given to formal measures to keep her in hospital. We asked the staff to review this and a mental health assessment was carried out. Fortunately, with sensitive management, it was possible to reassure Mrs S and she accepted the need to be in hospital while options for her future care were explored.

B. Involvement of welfare proxies

The 2000 Act allows families, carers and sometimes the local authority to make welfare decisions for a person who lacks capacity. When a person has capacity to do so, they can grant a power of attorney (POA). This gives a person they trust, often a family member or a solicitor, the power to make certain decisions or take certain actions on their behalf if they lose their ability to make decisions themselves.

The 2000 Act also allows for the appointment of welfare (and/or financial) guardians for people with impaired capacity. It sets out how decisions can be made for them. Such appointments are authorised by the Sheriff Court.

We came across only a few people with dementia who had a welfare proxy (welfare guardian or welfare POA). In about half the cases where staff were aware of the existence of a welfare proxy, they did not know if the powers included making health care decisions. Most hospitals had no place in the patient record to highlight if there was a Welfare POA or Guardian. Proxies with relevant powers concerning consenting to medical treatment must be consulted under Part 5 of the Act, where it is reasonable and practicable to do so.

Some staff found that relatives did not make them aware of their proxy powers until there was a difference of opinion. Also, it is important that welfare and financial proxies use their powers responsibly. Staff must take action if this does not appear to happen. The following case is an example where staff had to take action:

> *"Miss B was wearing a hospital gown and has not had her own clothes with her since her admission several months ago. The person holding Power Of Attorney has been asked repeatedly to bring them in by ward staff – she promises to do so, but then doesn't follow through. Social worker now involved."* MWC visitor

C. Other legal issues

In one ward, staff highlighted the problem of solicitors or family members coming into the ward and asking people with dementia to sign legal documents, such as granting Power Of Attorney without approaching staff first to ask about the appropriateness of this. Staff often only found out about these visits after they had happened and had serious doubts about the capacity of some of these people to understand what it was they were signing.

Recommendations: NHS Boards should:

- Establish protocols for the use of "wandering technology." This should include individual risk assessment. It should involve consultation with relatives, but nobody should be asked to "consent" to its use unless they have specific powers under the 2000 Act;
- Ensure that information about welfare guardians and powers of attorney is collected on admission and highlighted on the patient record;
- Update training for staff in general hospitals in the provisions of the Human Rights Act (1998), the Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003; and
- Make sure that people who have dementia and/or are seriously ill do not sign legal documents if they do not have the capacity to do so. Posters and information leaflets may help.

The care environment

Key message 5

Given the high number of people with dementia in general hospital wards for older people, it is disappointing that many wards do not have an environment which is dementia friendly. Much more could be done to make the environments enabling for people with dementia and afford them greater privacy and dignity.

What we looked at

It is well recognised that a dementia friendly physical environment can be enabling for someone with dementia but a poor environment can add to levels of confusion and stress. We looked closely at the physical environment in the ward.

What we expect to find

- We expect to find flexible accommodation, including some single rooms that can ensure extra privacy when required.
- We expect that attention has been given to making the environment as dementia friendly as possible.
- People with dementia should be able to use equipment to call staff for attention.

What we found

The majority of wards had signs pointing to key areas such as bathrooms. Signs were large enough, bold and distinctive in fewer than half of these wards. People with dementia were able to see signs for the toilet from their bed or the main door into the bed area in just under half of the wards we visited. In three wards, we found items such as the soap dispenser, bin etc. that were clearly labelled with pictures as well as words.

Most of the newer buildings provided increased privacy by having a higher number of single rooms, but at the expense of providing communal areas. Three wards we visited had no single room provision at all and in about half of the wards less than a fifth of beds were in single rooms.

We found individual cases of people whose accommodation did not help their recovery. We did not think their accommodation was meeting their needs or their right to privacy and dignity. We were told that some changes to the environment that would benefit people were rejected because of infection risks. This included personal items such as soft toys, cards and pictures. It is very important to reduce the risk of introducing infection. It is also important that people with dementia have care that offers them comfort, dignity and orientation to help their recovery. Hospital managers need to balance these issues carefully.

Some examples of good practice were:

> *"Environmental audit was completed and redesign has taken place in line with recommendations from the audit. Evidence that patients were given buzzers and encouraged to use these. These are responded to."* MWC visit to Aberdeen Royal Infirmary

> *"Have new toilet signs that have been specially made in bright colours to stand out. Conform to best design for dementia."* MWC visit to Monklands Hospital

Unfortunately, we found many examples of less good accommodation:

> *"Corridors are very narrow. I found that wider corridors had equipment, trolleys etc. parked at the side where the handrail was. Frail patients would be unable to negotiate the corridors. Signage generally poor. One tiny pictorial sign on one toilet only. Cannot identify toilets in bed areas. Sign (words only) is on the outside. Not visible if door is open. Some signs in corridors point in direction of nearest toilet."* MWC visitor

> *"Only four single rooms. Often taken up with patients with MRSA or close to death. Very occasionally relatives of non-dementia patients will complain about having to share with someone with dementia."* Ward nurse

> *"Patient was in single room with door open. Noisy corridor near nurse's station. No TV or radio or means to summon help. Not even well placed to look out of the window."* MWC visitor

> *"Charge nurse said no problems with the ward layout but when questioned further said only two side rooms, too many exits and layout is poor and there is a lack of privacy".* MWC visitor

Recommendations: NHS Boards should:

- Conduct regular audits of the physical environment using the dementia design checklist and take appropriate action to meet any deficits; and
- Ensure that managers of older people's wards and infection control discuss the balance between infection risks and maintaining an environment that helps people with dementia to orientate themselves and recover.

Staff education and specialist mental health support

Key message 6

It was encouraging to see the benefit of training and support for general hospital staff. Specialist mental health expertise was usually regarded as valuable and should be properly resourced.

What we looked at

Education and training form an important part of Scotland's dementia strategy. We looked at how much training and information was available to general hospital staff. We also looked at the "liaison service" provided by mental health practitioners.

What we expect to find

- Staff should have knowledge of good practice guidance for the care of people with dementia and the legal framework for their care.
- Staff should have ready access to mental health practitioners for advice and support in the management of people with dementia.

What we found

A. Staff knowledge of best practice in dementia care and training in dementia.

We found that most wards had available a copy of the guideline from the Scottish Intercollegiate Guidance Network *SIGN 86, management of patients with dementia*.

A minority of wards had available a copy of Caring for People with Dementia in Acute Care Settings, A resource pack for staff.

The majority of wards did though have copies of the Alzheimer Scotland publication, Coping with someone with dementia.

The majority of wards reported that they had received training in the Mental Health Act and the 2000 Act, but in most cases this was many years ago and required updating.

The majority of wards said their staff had access to and attended dementia awareness training. We found some good examples. In Gartnavel General Hospital, nurses and health care assistants are attending a best practice in dementia awareness day that includes input from carers of people with dementia and a session on pain assessment.

B. Access to dementia specialists

One of the 41 wards we visited was unable to supply this information. Of the forty wards for which we have information:

- 18 wards reported access to a specialist dementia liaison nurse and a dedicated liaison old age psychiatrist;
- 14 wards reported access to a specialist dementia liaison nurse or a dedicated liaison old age psychiatrist; and
- 8 wards reported no access to a specialist nurse or old age liaison psychiatrist (they could still refer individual people, but not to a dedicated team).

We found that specialist advice was often, but not always, regarded as helpful. Where it was seen as unhelpful, it appeared to damage the relationships between services and denied other people access to specialist advice. It is important to discuss and resolve disagreements and gain a shared understanding of some of the challenges faced by staff in general hospitals. Here are some examples of what we were told:

> *“Really helpful to have advice and support from specialists, their approach is calm and they share their knowledge and experience and work closely with ward staff. Gone are the days of “flattening” people with drugs, in fact the reverse is now true.”* Nurse in Hairmyres Hospital

> *“Dementia nurse gives excellent advice on management of agitation and distress during dressing changes. This made medication unnecessary.”* Nurse in Royal Alexandra Hospital, Paisley

> *"We were having real difficulty managing the behaviour of one elderly lady with dementia and some paranoia and we thought her dignity was at risk. We contacted the dementia nurse specialist for advice but she told us there was nothing she could do as the patient had capacity and had to be allowed to do whatever she liked .We didn't find this accurate or helpful so doubt we will ask again for advice!"*

We looked at wards where there was specialist input to see if that had an impact on any other areas of care, including whether it was more likely that an assessment of an individual's capacity was recorded. There was some improvement in these numbers but they still remained very low with only a few people receiving an assessment.

We found that most people who were prescribed psychoactive medication had not been seen by a mental health specialist. Some individual cases we looked at clearly demonstrated the benefit for the person with dementia when ward staff were able to quickly access dementia specialists for advice, support and assessment.

Recommendation:

NHS Boards should make sure that all general hospitals have quick and easy access to specialist older people's mental health liaison services for assessment and advice.

Discharge from hospital

Key message 7

People with dementia are very often discharged from general hospitals to care homes on a permanent basis instead of returning to their own homes. When someone with dementia who was living at home is discharged from hospital, facilitating a return home should be the starting point whenever possible.

What we looked at

We wanted to find out what plans were being made for discharge. In particular, we wanted to see whether the aim was to establish the person back in his/her own home or whether a care home or continuing hospital care was the plan.

What we expect to find

Discharge planning should start early in the person's stay in hospital. For people admitted from their own homes, the aim should be to help them to function at their best. The presumption should be that they will return to their own homes and that alternatives should only be sought if this is not practicable. We expect that the views of the person with dementia and their carers are respected.

What we found

The majority of people we met with had been in hospital between 2 weeks and three months, although we did come across two people who had been in hospital for over a year. We examined the discharge plans for people that we met with and found of those admitted more than two weeks previously, the majority had a discharge plan. Of those who had been in hospital for less than two weeks, about half had a discharge plan. We would not expect a discharge plan for people who are still seriously ill.

We found 44 people where a decision had been made for them to be discharged to a care home but only 10 of those people had lived in a care home prior to their hospital admission. The majority had been living at home alone or with relatives. This seems to reflect the concerns raised by people with dementia, carers and care professionals about high numbers of people not returning to their own homes and this is highlighted in Scotland's National Dementia Strategy.

Very important decisions about the future of people with dementia are often made in the general hospital setting immediately following a time of crisis. Decisions to move a person with dementia to a care home rather than return to their own home are often taken with the intention of minimising risks for the person with dementia and discharging them quickly from the acute care setting.

Particular concerns about people with dementia moving directly to a care home from hospital include:

- The person with dementia being incapable of consenting to this and not understanding the implications;
- The person with dementia agreeing to go so as not to be "a burden";
- Pressure put upon the person with dementia to agree to the move by family and care professionals; and
- The person not being given enough time and opportunity to recover from their trauma or illness before undertaking such a huge life change.

> *"It has now been decided that care home placement will be sought for Mr B due to unsuitability of his flat and increased care needs. Mr B says he is not "bad enough yet "to need a care home. Clear with me he wants to go home soon, care plan and discharge plan does not mention his resistance to move."* MWC visitor

> *"Miss A waiting for a care home placement for three weeks now, being "boarded" in ward x, niece keen Miss A goes to care home. Miss A seems reluctantly compliant and says she will do what they think is best but would prefer to go home."*
> MWC visitor

> *"There's nothing in the notes about trying her at home. The nursing home bed was found as an emergency but she may have had an infection that was causing the paranoia. Concerned that no attempt has been made to reintroduce her back to her home environment."* MWC visitor

There will of course be some occasions when returning to a person's own home may not be possible.

> *"Referred to social worker as it appears needs care home. Awaiting allocation which generally takes a few weeks. Then needs assessed for 24 hour care. Only agreed today but need for referral discussed at 2 previous ward rounds."* MWC visitor

When people were to be returning to their own home, we found evidence of good liaison between the hospital and community care services. We found delays in getting people back home in seven cases and these were mostly due to delays in putting a care and support package in place.

> *"Mrs G should be discharged in next couple of days. Hospital has been in contact with son and with care provider to resume care package on her return. Awaiting information of date they will reinstate service. In sheltered housing."* MWC visitor

> *"Some safety concerns. Possible fire risk – smokes at home. Son considering alternative. He is recorded as having Power Of Attorney but not clear if welfare or financial and what the powers are. Good record of involvement of family. Clear that their concerns about risks at home are documented and that there is a plan to address them."* MWC visitor

> *"Lives with husband who is struggling with wife's decline – increase incontinence/falls/confusion, but wants her home and so does she. OT and physiotherapist visited home – some changes and aids plus referral to SW for respite and increase in home care. (Panel agreed funding for increase.)"* MWC visitor

Although efforts are made to get people home, sometimes we felt that more attention needed to be paid to the risks.

> *"Complex problems of Parkinson's disease and dementia. Going home. Evidence in notes of geriatric medicine input via clinic appointments. Cannot determine if mental health services ever involved. Staff did not know. No referral to dementia nurse. Referral needs to be made."* MWC visitor

> *"Evidence of contact with son to advise Mum going home tomorrow. Causing concern and difficulty as home care not in place and house not ready. Discharge re-arranged at son's insistence to allow home to be ready and assessment for care package to be completed."* MWC visitor

Recommendation:

NHS Boards should, along with local authority partners, ensure robust systems are in place to review decisions taken to transfer someone with dementia who previously lived at home to a care home. This may include a timescale for review, involving care managers, before the placement is made permanent.

Conclusions and further action

We hope that the key messages in this report help in the implementation of Scotland's dementia strategy. Staff in general hospitals should bear these messages in mind when caring for people with dementia. There is some action already being taken.

For example, in NHS Lothian, we learned that the Alzheimer Scotland nurse consultant has developed 10 good practice statements that five of the acute hospital wards have signed up to. These have been very well received. They are currently being evaluated and will be rolling out to other wards in the service. The statements address:

- Staff knowledge and awareness of dementia;
- Making the diagnosis known;
- Sharing and gathering information;
- Screening and assessment;
- Dementia friendly environment;
- Staff approach and communication;
- Behaviour that challenges;
- Managing risk;
- Legal considerations; and
- Discharge arrangements.

This should improve care and would be in line with many of the messages and recommendation in our report, Other NHS Boards should adopt a similar approach.

References

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Appendix: definitions, lists and tables

Definition of terms used in this report

- Most = more than 80%
- The majority = 56-80%
- About half = 45-55%
- A minority = 20-44%
- A few = less than 20%
- Very few = less than 10%

Reason for admission to hospital:

Reason for admission	No.	percentage
fall	92	47%
infection	37	19%
confusion	17	9%
general deterioration	8	4%
Stroke	7	4%
other	31	16%
No information	2	1%
Total	**194**	**100%**

People admitted because of a fall: home circumstances before admission

Home circumstances	No.	percentage
Alone	62	67%
With carer or relative	24	26%
Care home	4	4%
Not known	2	2%
Total	**92**	**100%**

Hospitals/wards visited

Health Board	Hospital	Ward	No of Beds	Description (by the NHS Board)
Highland	Raigmore	5A	25	Care of the elderly
Highland	Western Isles	2		General medical
Highland	Mid Argyll Hospital	Glassary Ward	10	Care of the elderly and rehab
Grampian	Woodend Hospital	Oak/ Westview	20	Slow stream rehab
Grampian	Woodend Hospital	Ward 6	24	Slow stream rehab+-
Grampian	Aberdeen Royal Infirmary	Ward 3/4	26	General medical
Grampian	Dr Grays	Ward 7	27	General medical
Tayside	Perth Royal Infirmary	Tay Ward	30	Medicine for the elderly
Tayside	Ninewells	Ward 31	18	Medicine for the elderly
Forth Valley	Forth Valley Royal Hospital	WA31	32	Care of the elderly rehabilitation
Greater Glasgow & Clyde	Southern General	Ward 55	30	Assessment and rehab.
Greater Glasgow & Clyde	Victoria Infirmary	Ward North 2	25	Assessment and rehab.
Greater Glasgow & Clyde	Stobhill	W46	20	Assessment and rehab.
Greater Glasgow & Clyde	Royal Infirmary	Ward 11	11	Assessment and rehab.
Greater Glasgow & Clyde	Stobhill	11B	24	Assessment and rehab.
Greater Glasgow & Clyde	Gartnavel General	3C	24	Assessment and rehab.
Greater Glasgow & Clyde	Gartnavel General	3A	24	Assessment and rehab.
Greater Glasgow & Clyde	RAH	W3	30	Assessment and rehab.
Greater Glasgow & Clyde	Inverclyde	Larkfield Unit 2	30	Assessment and rehab.
Greater Glasgow & Clyde	Inverclyde	Larkfield Unit 3	30	Assessment and rehab.
Dumfries & Galloway	Royal Infirmary	W12	27	Medicine for the elderly - acute
Dumfries & Galloway	Royal Infirmary	W18	25	Medicine for the elderly - acute
Dumfries & Galloway	Moffat Hospital		21	Medicine for the elderly - mixed
Dumfries & Galloway	Annan Hospital		24	Medicine for the elderly - mixed
Ayrshire & Arran	Biggart Hospital	Drummond	30	Continuing care
Ayrshire & Arran	Biggart Hospital	Urquhart	30	Geriatric rehabilitation

Health Board	Hospital	Ward	No of Beds	Description (by the NHS Board)
Ayrshire & Arran	Ayrshire Central	Pavilion 3	25	Rehabilitation
Ayrshire & Arran	Crosshouse Hospital	5D	30	Geriatric assessment
Ayrshire & Arran	Crosshouse Hospital	5E	30	Geriatric assessment
Lanarkshire	Hairmyres Hospital	W16	30	Rehab
Lanarkshire	Hairmyres Hospital	W3	20	Assessment/rehab
Lanarkshire	Monklands Hospital	W20	24	Assessment/rehab
Lanarkshire	Monklands Hospital	W22	24	Assessment/rehab
Lanarkshire	Wishaw General Hospital	W9	25	Assessment/rehab
Lanarkshire	Wishaw General Hospital	W12	25	Rehab/GORU
Lothian	Liberton Hospital	W4	20/22	Assessment/rehab
Lothian	Liberton Hospital	W7	20	Assessment/rehab
Lothian	Royal Victoria Hospital	W4	24	Assessment/rehab
Lothian	Roodlands	1b	30	Assessment/rehab
Lothian	Roodlands	3	14	Medical

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