

# Starved of care

Investigation into  
the care and treatment  
of “Mrs V”

# Contents

<b>Who we are and what we do</b>	<b>1</b>
<b>Why we conducted this investigation</b>	<b>2</b>
<b>Terms of reference</b>	<b>3</b>
<b>Methodology</b>	<b>3</b>
<b>Chronology of events</b>	<b>3</b>
<b>Overview of a complex problem</b>	<b>6</b>
1. Transfer to acute ward for mental health care	7
2. Decision making process on intervention	10
3. Management of physical and emotional distress	15
<b>Summary of findings</b>	<b>21</b>
<b>Conclusions and recommendations</b>	<b>22</b>

## Who we are

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 law.

We are made up of people who have understanding and experience of mental illness and learning disability. Some of us have a background in healthcare, social work 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.

## What we do

- We find out whether individual treatment is in line with the law and practices that we know work well;
- We 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 mental health and learning disability 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.

### Why we conducted this investigation

Mrs V died in a general hospital in December 2008 at the age of 80. She had dementia and was subject to a compulsory treatment order (CTO) at the time. Two months later, we received a phone call and then a report from the psychiatrist (Independent Doctor) who provided an independent medical report for the “curator ad litem” for Mrs V prior to the Tribunal hearing for the CTO. He had thought that we had received information about his concerns following the tribunal hearing, but we had no record of any contact. He then sent us his report in March 2009.

Independent Doctor was concerned that Mrs V was experiencing distress and agitation as a result of being prevented from eating. He also was concerned that the administration of rectal and intramuscular medication was very likely to cause physical discomfort and emotional distress. The situation appeared to him as follows:

- She had difficulty swallowing, and there was a risk of aspirating food into her chest;
- The clinical decision was that she was not to take anything orally;
- She was given fluid by infusion but no food;
- She was distressed by not being allowed food, and this was made worse when she witnessed other people eating;
- The staff responded to her distress by frequent administration of sedative medication given rectally and by injection.

Once a decision was made to allow her to have food by mouth and accept the risk of swallowing, she was given appropriate palliative care and died of pneumonia about a week after Independent Doctor saw her.

In the 16 days between 03/12/08 until her death on 19/12/08 she received:

- **13 intramuscular injections of chlorpromazine;**
- **16 intramuscular injections of lorazepam;**
- **57 administrations of rectal diazepam**
- **Latterly, 9 administrations of oral chlorpromazine.**

We were extremely concerned about the amount, frequency and route of administration of medication and about the reasons for it being given. We decided to investigate further to determine the reasons for this.

### The investigation team

The Commission’s investigation team consisted of:

Susan Tait, Nursing Officer

Donald Lyons, Director

## Terms of reference

- To examine the care and treatment of Mrs V from her admission to hospital in August 2008 until her death in December 2008.
- To examine the appropriateness of clinical decisions about her general management and especially her nutrition.
- To determine the reasons for an apparent excessive use of sedative medication.
- To make recommendations about the care and treatment of people with dementia admitted to general hospital wards with similar problems.

## Methodology

- We undertook a detailed examination of Mrs V's case records from her time in the general hospital.
- We constructed a timeline of significant events and used this as a basis for asking questions of key practitioners.
- We interviewed all the senior medical staff involved in her case.
- We were not able to interview the ward manager because of that person's ill health, but we interviewed the clinical nurse manager for the service, even though she had not been in post at the time.
- We obtained further information from the speech and language therapy department involved in her care.
- We approached members of Mrs V's family and met them to discuss their concerns and to share our findings.

We interviewed the following key individuals

Dr 1, Consultant Psychiatrist

Dr 2, Consultant in Medicine for the Elderly

Dr 3, Consultant in Medicine for the Elderly

Patient Care Manager 1, Head of Patient Care and Nursing, (she was not involved in Mrs V's care at the time, but gave us her views on what she read in Mrs V's case file).

Independent Doctor, independent psychiatrist

DMP 1, designated medical practitioner under the 2003 Act

We also report statements in case notes from nursing staff, training grade medical staff, especially "foundation year 2" (FY2) doctors and speech and language therapists.

## Chronology of events

Mrs V first developed memory problems following an operation to treat a fractured hip in 2005. She lived in sheltered housing and was described as having no significant problems with self-care and only required personal care once a week to help with bathing.

In January 2008 there was deterioration in her mental state. She was noted to be anxious and distressed, believing that she was being chased by people and that there were ghosts in the house. This led to her frequently knocking on neighbours' doors, often at night. She also telephoned her son approximately forty times a day because of her agitation.

She was then provided with day care services in April 2008 and attended an old age psychiatry day unit. She had community nurse input, but was still experiencing anxiety symptoms.

She continued to knock on neighbours' doors and at times was not eating and refusing to go to her day centre. Respite care was provided in July 2008, but this had to be ended prematurely because she frequently left the unit. She was returned home, but was admitted to a psychiatry of old age ward in a mental health hospital on 23 July 2008. She had been found wandering the street late at night by a member of the public.

She remained agitated and distressed. This was managed with support and reassurance from nursing staff and small amounts of oral medication. She had recurrent chest infections during September and October.

On 2/10/08 a case conference was held where it was felt that Mrs V might be able to return home. She had become more agitated. It was thought that this was because she functioned at a higher level than others in the dementia admission ward. She was transferred out of the dementia ward in to the "functional" admission ward the next day ("functional mental illness" meaning illnesses other than dementia e.g. depression and paranoid illnesses).

On 20/10/08 it was noted that she was very deluded and trying to leave the ward. It was felt that chest and urine infections were perhaps causing delirium, and an emergency detention certificate was applied.

On 21/10/08 she was detained further under a short-term detention certificate by Dr 1.

On 29/10/08 she became physically unwell. She had a rapid pulse and signs of a chest infection. She was transferred to a medical admission ward for older people in the nearby general hospital where she was treated with

intravenous fluids and antibiotics.

On 1/11/08 she was transferred back to the functional ward in the psychiatric hospital.

On 4/11/08 she was described as being still very deluded, banging doors and she needed two nurses to restrain and reassure her. She was continually trying to leave the ward because she thought she had to get home to look after her children. Dr 1 decided to recommend an application for a compulsory treatment order. Mrs V was transferred back to the dementia admission ward.

On 19/11/08 she was reviewed by the ward doctor. Again, she had a fever, rapid pulse and pain in her hip. She was transferred to the medical admission ward for older people in the general hospital for a second time. She was treated for a chest infection with intravenous fluids and antibiotics.

On 02/12/08 notes indicate that Mrs V was much brighter, but had difficulty swallowing. This had been reported over the weekend, and it was decided that she should have nothing by mouth. The plan was to have a speech and language therapy assessment on that date and to continue with IV fluids. The speech and language therapy assessment recommended "nil by mouth at present but query alternative feeding if appropriate." Diazepam was prescribed on a regular basis for agitation and was to be administered rectally. Both chlorpromazine and lorazepam were prescribed for administration by intramuscular injection on an "as required" basis if she was still agitated.

On 03/12/08 the speech and language therapy review was noted, and her management remained unchanged.

On 04/12/08 Dr 2 noted that Mrs V remained confused. Her hydration was better. He said that she was to continue nil by mouth and awaited further input from speech and language therapy.

On 05/12/08 Dr FY2 wrote "remains agitated" and noted a six kilogram weight loss since 23/11/08. A speech and language therapy entry noted: *"appears to be at risk of aspiration on textures but slightly better able to cope with thicker textures. Discussion with doctor re appropriate management. Doctors to discuss with family and if appropriate to consider oral feeding whilst attempting to minimise aspiration risk."* It was also noted on this day that she was very agitated and attempting to climb out of bed.

On 07/12/08 it was noted that Mrs V was agitated, had been receiving nothing by mouth all week and was not getting regular Chlorpromazine. The intention was to try to get Mrs V to take oral Chlorpromazine. Discussed with duty Consultant in Medicine for the Elderly who would rather not use IM drugs but nursing staff were not prepared to "force" oral meds. Mrs V was then prescribed rectal diazepam four times a day and lorazepam 1mg by intramuscular injection as required.

On 08/12/08 Dr 2 noted that "behavioural aspects of condition are of concern" and she was for light sedation. The Dr FY2 entry was 'asked by nursing staff to review patient's medication due to increased agitation.' She was still to receive nothing by mouth. It was said at this point that a joint decision was required to be made regarding ongoing care and that Dr 1 was to review this and liaise with Dr 2 and Mrs V's family. The speech and

language therapist contacted Dr 2 about the decision on nutrition and was told that no decision had been made yet.

On 09/12/08 SPR noted in files. *"Now agitation is the main issue as is nil by mouth based on speech and language therapist assessment. Administration of treatment is difficult and that the IM route is not a good long-term option likewise the PR".* Dr SPR said *"it may be that we have to treat Mrs V with oral meds and allow her to take comfort from foods and fluids in order to ensure she gets medication despite risks of aspiration"*. Dr 1 noted in her review *"prescribed nil by mouth at present"* and she suggested that Mrs V continue on diazepam four times a day rectally and that intramuscular injections of lorazepam should stop. She also said that Mrs V could be given 10mgs of chlorpromazine twice a day intramuscularly and if she became agitated and required additional medication it would be worth using an additional dose of diazepam rectally. Dr 1 wanted to discuss with Dr 2 whether or not a trial of hydrating and feeding Mrs V by mouth was feasible before returning to psychiatric care.

On 11/12/08 Dr 1 noted that she had spoken to Mrs V about the pros and cons of a trial of oral fluids and Mrs V stated that she would like to be given fluids by mouth even although there is a risk associated with this. Following this, Dr 1 was on sick leave for the next week.

On 12/12/08 Dr SPR notes *"discussed with Mrs V's son that she has been nil by mouth but is asking to eat and drink. Given her agitation naso-gastric feeding is not a realistic option. At present our options are to keep nil by mouth or to provide a modified diet accepting that there will be a risk of aspiration."*

*This would also allow medication to be given orally.*" The son was in agreement with this.

On 14/12/08 duty Dr FY2 wrote that he noted that Mrs V was still nil by mouth, but was settled and well at the moment and not disturbed. Other entry on this day by a different Dr FY2 stated that she had been started on thickened fluids yesterday, i.e. 13/12/08. The speech and language therapist was told that feeding with thickened fluids had started.

On 15/12/08 Dr 3 took over her care from Dr 2 as part of a regular change of responsibilities. She noted that, following discussion with the family, Mrs V can now have a thickened diet and oral medication.

On 16/12/08 it was noted that she was becoming increasingly frail and on 17/12/08 that she was trying to sit up and get out of bed.

On 18/12/08 Dr 3 noted that Mrs V had probably developed further aspiration pneumonia, and it was necessary to discuss the deterioration with her son. This was discussed with Mrs V's son on the same day. It was explained that Mrs V had further pneumonia and there has been a continued decline in her condition. The aim was to ensure that she was comfortable with agitation under control. Notes stated that treatment was *"for best supportive care"*. The mental health tribunal granted a compulsory treatment order that day.

On 19.12.08 Dr 1 noted a deterioration in Mrs V's condition. A designated medical practitioner (DMP 1) saw Mrs V for an opinion on further medication and granted a certificate authorising oral or intramuscular treatment with diazepam and chlorpromazine. DMP 1 recorded that she was alert but agitated. Also, Dr 3 completed a

certificate authorising treatment for physical problems under section 47 of the Adults with Incapacity (Scotland) Act 2000.

At 11.30pm on 19/12/08 nurses noted that Mrs V appeared no longer to have a pulse and appeared not to be breathing. Death was confirmed at 11.50pm.

We identified all the sedative medication she received between 03/12/08 until her death on 19/12/08. She received 13 intramuscular injections of chlorpromazine, 16 intramuscular injections of lorazepam, 57 administrations of rectal diazepam and latterly 9 administrations of oral chlorpromazine.

### Overview of a complex problem

Mrs V had a mixture of problems with her physical and mental health. She had dementia that was thought to be of vascular type. This illness has an unpredictable course, and the deficits can be patchy. She had become highly distressed at home and remained so when she was in hospital. She also developed swallowing difficulties which resulted in her aspirating food and developing chest infections. The complexities of her problems were a significant but common challenge to mental health and general hospital services. We recognise the difficulties that Mrs V's problems posed, but they were not unusual and many aspects of her care gave us cause for concern. This was one of the main reasons for investigating this case; if we can get it right for Mrs V, we can get it right for most older people with complex physical and mental health problems.

## Key problem areas

We analysed the information we have from case records and interviews with key staff involved with Mrs V's care. Our analysis points to three broad problem areas. These are:

- 1. Transfer to acute ward from mental health care;**
- 2. Decision-making process on intervention;**
- 3. Management of physical and mental distress.**

### 1. Transfer to acute ward from mental health care

#### A. Anticipatory care

Mrs V had a diagnosis of vascular dementia. This makes it difficult to anticipate decline. In Alzheimer-type dementia the decline is more predictable and more thought can be given to advance planning. When we interviewed Independent Doctor, he suggested that more could have been done to plan for abrupt declines in her condition.

While this would have helped, we did not think it was a major issue here. Dr 1 and her team were treating Mrs V for the distress that her memory difficulties were causing. Had this been successful, there was still a possibility of a good quality of life. We think that most practitioners would have been focussing their attention on improving her mental and physical health, certainly up to the point where she was transferred to the medical ward.

Knowledge of advance wishes may have helped. We have no evidence that Mrs V had ever made an advance statement about what

she wished to happen as her dementia progressed. It may have helped the process of decision-making if she had done so.

Learning point: People with dementia should be encouraged and assisted to consider how they wish to be treated as their illness progresses. This should be part of the process of support and counselling after diagnosis.

#### B. Management in mental health care

From her admission in July 2008 Mrs V was agitated, distressed and prone to chest infections. Her original admission was to a dementia ward, but she was moved to a ward for older people with "functional" mental illness because she was "functioning at a good level" (Dr 1). Over a seven week period from October 2008 she had five moves:

- Dementia ward to functional ward;
- Functional ward to general hospital ward;
- General hospital ward to functional ward;
- Functional ward to dementia ward;
- Dementia ward to general hospital ward.

Moving a person with dementia from one environment to another can be unsettling: It is a key aim of the dementia strategy to limit the number of moves. In hospital, people with dementia should only be moved from ward to ward where absolutely necessary. Family members told us that they felt the moves had an unsettling effect on Mrs V. We wanted to determine whether or not these moves were necessary in Mrs V's case.

The decision on whether she was best managed in a "functional" or "dementia" ward within mental health care was not an easy one. People with relatively mild dementia may need

care in mental health facilities because of anxiety, depression or paranoia. Assessment wards are usually divided so that older people with “functional” illness are not managed in the same environment as people with dementia who show significantly challenging behaviour. A mix of patients can be distressing, and there is a risk that neither group gets the best care. The split between the two populations sometimes makes it difficult to know which ward would be more appropriate.

We appreciate that Dr 1 was acting for Mrs V’s benefit in transferring her to a functional ward. Unfortunately, it did not work as well as hoped, and she was transferred back. This might not have been a problem had she not been transferred to the general hospital for medical care in the course of this. We think the critical issue was the need for transfer to the general hospital.

Mrs V was transferred on two occasions from mental health care to acute medical care because she was physically unwell. The mental health service had good input from medicine for the elderly, an experienced training grade physician providing up to three sessions a week for the mental health service. This has improved further since Mrs V’s admission, and there is now regular input from a consultant physician. Despite this, she was transferred because her physical problems were considered too complex for management in mental health care. The main issue was that the mental health service did not attempt to manage people who needed fluids or antibiotics via a “drip” (subcutaneous or intravenously).

We heard a range of views on this subject:

- Independent Doctor told us that his preference was to keep people in mental health care. “Mental health nurses can have difficulty managing drips but can do so with training and support.”;
- Dr 1 told us: “Even if we could give IVs then it was still very complex. We do not give intravenous fluids. This decision has been reviewed but managers of mental health nursing staff opined that training for an event that would only occur once a year would not be worthwhile.”;
- Dr 2 told us: “She had an aspiration pneumonia that was probably recurrent. There was scope for better physical management in mental health care but she was appropriate for transfer.”;
- Dr 3 told us: “I can’t understand why psychiatric hospitals cannot manage drips. When I took over her care her problems could have been managed in a mental health setting.”

We asked old age psychiatrists and nursing staff in elderly mental health wards across Scotland about their use of intravenous or subcutaneous fluids and antibiotics. We received 70 responses from staff from all but one mainland NHS Board responding. Our findings were:

- About 75% of respondents had experience of giving subcutaneous fluids;
- Over half had experience of using intravenous fluids and syringe drivers;
- About a third had given intravenous antibiotics;

- On average, the need for one of these interventions was about five times a year (range 1-20).

Examples of how this was managed were:

“Medical staff insert canula. Nursing staff maintain site and administer fluids but medical staff administer intravenous antibiotics.”

“For intravenous fluids, we have local guidance for nursing staff as many lack confidence due to lack of practice and infrequent use.”

Where the practice was to transfer the patient, we looked at the explanations for this.

“The problem with intravenous fluids seems to be nursing competencies – if you are not doing it often enough, you are not allowed”

“In a challenging behaviour unit, other patients present a risk [to those receiving intravenous or subcutaneous fluids]”

Some clinicians expressed concern about a policy not to administer parenteral fluids.

“Senior nurses now say that mental health nurses have not had the appropriate training and would not be able to carry out these tasks. This is something that I think needs to be addressed as there are occasions where patients should not be transferred.”

We find evidence to support the view that Mrs V could have been managed in mental health care without the need for transfer. We also have evidence to suggest that the need is likely to be greater than “once a year.” With good training and support, mental health nurses can manage drips and medical staff can give parenteral antibiotics.

A broader issue is that other mental illnesses, for example severe depression, can result in a need for artificial hydration. We are concerned that the mental health service may not be able to provide people with the care they need if nursing staff cannot manage fluid infusions.

### Key points

- **Mental health nurses should have training and support to manage intravenous and subcutaneous fluids;**
- **Nurses from medicine for the elderly could provide liaison support for mental health care to supplement the medical expertise already available.**

### C. Best option for transfer

While it is possible that Mrs V could have been managed in mental health care, we considered the best options for her care if she did need to be transferred. Her admission was to an acute medical receiving ward for older people. There was a general view that this may not have been the best option.

- Dr 2 told us that *“an acute, pressurised ward was not ideal. The ideal environment would have been a non-acute assessment ward with slower throughput and less pressure.”*;
- Patient Care Manager 1 agreed. *“A medicine for the elderly assessment unit, not an acute receiving ward, would have been better.”*;
- Dr 1 thought there was an argument for a joint unit. *“There had been consideration of a joint continuing care ward but it was rejected.”*

We agree with these statements. If Mrs V needed to be transferred, the high turnover in an acute receiving ward would not be conducive to the difficult process of care for a person with such a combination of needs. While this is important, Mrs V may well have been admitted from a community setting with similar problems, so the root causes of the problems lie elsewhere.

**Key point: the NHS Board should review the pathway of care for people in mental health wards who need to be transferred to general medical care because of physical illness.**

*Summary of findings on transfer to an acute ward:*

- Shortly before the transfer took place, there was still the aim to improve Mrs V's mental health with a view to possible discharge home. Active intervention to treat her problems was still indicated;
- A record of her previous wishes about intervention as her illness progressed may have helped the process of decision-making;
- She had five moves of ward over a seven week period. This would have been likely to worsen her agitation and distress;
- The mental health service was unable to manage infusions of fluid and intravenous antibiotics. Many mental health services for older people can manage these aspects of care;
- There was good medical liaison from general medicine to the mental health service, but additional nursing support and training might have helped;
- Ultimately transfer was considered necessary, but she was transferred to an acute receiving ward. This was not ideal: A post-acute assessment ward would have been a better option.

## 2. Decision making process on intervention

Independent Doctor in his report raised serious concerns about Mrs V's lack of nutrition during this period of time. We share these concerns. From December 2nd, Mrs V received only hydration but no other nutrition for a period of at least ten days. We understand that Independent Doctor raised these concerns with Dr 1 in a conversation on the day he saw her. Unfortunately he did not raise the concerns directly with Dr 2. By that time Mrs V had not had any nutrition for nine days. We examine why no nutrition was given.

### A. Task: Risk assessment

Mrs V was assessed by a speech and language therapist to determine the risk posed by problems when swallowing. The assessment suggested that she could manage thickened liquids, but the instruction from the Consultant was "nil by mouth." We looked at the reasons for that decision and its consequences.

Mrs V was seriously unwell on 2nd December. She was receiving intravenous fluids and antibiotics. She was having serious difficulties swallowing, and an initial speech and language assessment advised nil by mouth at that time. A further assessment by a more experienced speech and language therapist three days later suggested that she could take thickened fluids. It was not without risk, but

the alternative was artificial feeding and her opinion was that Mrs V was too frail for this to be appropriate. There was no further direct assessment by speech and language therapists, but they stayed in contact and asked for updates on Mrs V's management on two further occasions. They were informed on 14/12/08 that oral feeding had started and they discharged her from their service on 16/12/08.

Dr 2 told us that antibiotics and nutrition were the most important interventions for Mrs V's recovery. He was considering artificial nutrition, but this was never given. Therefore, for several days Mrs V was being given fluids and antibiotics only. Also, despite the SLT assessment of 5th December, Dr 2 did not amend the "nil by mouth" instruction. We asked practitioners about the decision as to whether or not to risk oral feeding in this situation:

- Dr 2 told us: *"We usually allow people to have small amount of food. I considered her a major risk. She had multi-infarct dementia – has she had another small stroke? Her progress was difficult to predict. The family has a role in discussing the ethics. It is a team approach but the physician coordinating care has overall responsibility." He suggested that there might be scope for a range of options for allowing some small amounts of food rather than a strict "nil by mouth" instruction. He also admitted that "Continuity of junior medical care is an issue. Ward managers are very hard pressed."*
- Patient Care Manager 1 told us: *"The dietician, speech and language therapist and nurses should be getting together to*

*look at nutritional needs. A risk management discussion was needed and should have been documented."* With regard to the instruction itself, she told us, *"I would not feed but would want to know how long the instruction was for."*

- Dr 1 was not part of the process for making this decision, but told us: *"I was expecting a decision on the nil by mouth instruction."*
- Dr 3 told us that she took over Mrs V's care after the decision was made to adopt a palliative approach and accept the risk of aspiration. *"We often care for people at end of life with swallowing problem. We weigh up the risks and benefits of oral feeding. Families are usually happy with decisions to take risk of feeding. Artificial nutrition is usually not appropriate."*

We did not find evidence of a reasoned decision on the risks and benefits of oral feeding. This was especially important given the distress that Mrs V experienced when she was not allowed to eat, yet witnessed other people eating. We found the fact that she received no nutrition (apart from artificial fluids) for several days surprising in that Dr 2's approach appeared to be to intervene and treat. We also find it surprising that no other member of the clinical team appeared to raise concerns about nutrition. We deal with this below.

**Key point – the NHS Board should ensure that there is a multidisciplinary risk assessment process for decisions on feeding people with swallowing difficulties**

## B. Task: Capacity assessment

Most, but not all, interviewees thought that Mrs V lacked capacity regarding the critical decision whether or not to risk oral nutrition. This was an issue raised by Independent Doctor when we interviewed him but, based on information from others, we think it unlikely that she had capacity in relation to this decision:

- Independent Doctor told us: *“It was not clear that she lacked capacity re the specific decision on eating. She thought she had no swallowing difficulty. I explained that she did have difficulty and asked “If I gave you food now and it went the wrong way, would you take that risk?” She said yes.”;*
- Dr 1 expressed a clear opinion. *“She did not have capacity to decide on the issue of swallowing. She could not weigh and balance the information about risk. This made her very distressed when she saw others eating.”;*
- Dr 2 and Patient Care Manager 1 agreed. They both expressed the view that Mrs V was not able to understand the risks of oral feeding and therefore not able to make decisions. Patient Care Manager 1 added the important point that her wishes still had to be taken into account.

Appropriate certification was in place, and the family were involved in discussions. Given her lack of capacity, the decision should be based on principles and was ultimately the responsibility of the medical practitioner in charge. We think the issue of capacity was properly considered and managed.

## C. Task: Intervention vs palliative approach

This is a major area of concern. The initial approach was intervention to treat her pneumonia. Dr 2 told us that antibiotics and nutrition were described as the cornerstones of intervention. At some point, the plan changed from intervention to palliation. We could not determine from the case file when this was and what factors were taken into account when this decision was made. We asked practitioners for their account:

- Patient Care Manager 1 made the valid point that Dr 1 had adopted an approach of intervention, hence the decision to transfer her to the general medical ward for treatment. It was therefore reasonable for Dr 2 to go along with this;
- Dr 2 was the consultant in charge of her care. He focussed on the physical aspects of her care and told us: *“We were trying to treat her aggressively. The plan was to get her better and reassess the situation. Her anxiety and the unease of nursing staff made it difficult. We needed to explore PEG feeding and antibiotics.”;*
- Despite having been the consultant initially in overall charge of her care, Dr 1 appeared to be less involved in the decision about continued intervention. She told us that she was not consulted until a week after the decision to withhold oral nutrition (although she had been on annual leave for most of that time). No attempt had been made to contact another consultant in psychiatry of old age during that time. She had been expecting the feeding problems to be resolved. We did not get the impression that Dr 1 was significantly involved in the

ethical decisions about the approach being used, despite the fact that she had known Mrs V for longer than any of the other medical staff;

- Dr 3 was absolutely clear about her approach. *“When I took over her management on 15/12, she was a very frail lady lying on her side. The decision about feeding had been made two days earlier – soft diet and thickened fluids. I decided that I would need to speak to the family about decisions if she aspirated again. I set a limit of oral antibiotics but not intravenous treatment. She had a poor quality of life and a palliative care approach was appropriate.”*

Clearly, at some point between December 2nd when IV treatment was started and December 15th when Dr 3 made a clear statement about the strategy for care, the approach shifted away from intervention and toward palliation. The factors and reasoning behind this were not clear. There was discussion with family members who told us that they felt that they were being asked to make the decision on whether or not to risk oral nutrition.

We were not able to interview the nurse in charge at the time, but we believe that the approach was not fully agreed among all members of the care team. Dr 2 referred to the unease of nursing staff, but any disagreement was not voiced openly nor recorded in case records.

We were left with little evidence that there was clarity during this time about whether the team was treating her with a view to achieving recovery or primarily treating her to relieve

distress. The lack of clarity of approach appears to us to have been critical in the two main problems – the fact that she was not given nutrition and the fact that she received multiple administrations of medication to try to alleviate distress.

It is important to note that, once a palliative approach was agreed, Mrs V was able to eat, albeit with some risk. Her distress was much reduced, and there was no longer a need for multiple administrations of sedative medication. The decision to risk oral feeding and not institute artificial nutrition was in line with guidance from the Royal College of Physicians and the British Society of Gastroenterology (published since this event).

Changes of consultant in overall charge may not have helped. It was difficult for Dr 2 to make some crucial decisions when Dr 1 knew Mrs V better. Improved communication between the two consultants may have helped. We have already considered whether transfer was appropriate and where she should have been transferred to. The geographic separation between the mental health and general hospital teams that resulted from the transfer may have got in the way of good collaboration when major ethical decisions were needed.

Our conclusion is that she was not given any nutrition during this period because there was no shared understanding of the strategy for her care. The fact that no member of the care team took sufficient action to address the lack of nutrition during this time is in our view extraordinary and unacceptable. Each individual team member must reflect on their own role in this and their duty of care towards a very ill, distressed patient.

### Key points

- **Decisions about the degree of intervention in people with dementia with serious physical illness, reasons for the decisions and the views of relevant individuals should be clearly recorded in clinical notes.**
- **Where a person has been transferred from mental health to general hospital care, both teams should be involved in ethical decisions about the nature and degree of intervention.**

### *Findings on decision making process on intervention*

- There was a lack of a clear assessment of the risks versus the benefits of oral feeding. Despite an assessment from speech and language therapy that Mrs V could manage thickened fluids, she was denied oral food and fluids for at least a further week with only artificial hydration being given;
- During the course of her treatment there was a change of emphasis from intervening to treat her physical condition aggressively towards palliative care with the emphasis on comfort. It was not clear from case records or interviews where this change of approach occurred;
- Difficult decisions need a multidisciplinary approach. It was not clear that all members of the team were in agreement with the plan of care, and consultation between the general medical and mental health services over the general approach to her care was minimal for much of this time;
- Family members felt that they were being asked to make decisions. It is important to involve relatives and obtain their views about proposed plans of care. It is also important that clinicians are the decision-makers and that relatives do not feel they have the burden of difficult clinical decisions;
- When there was clarity that the approach was largely palliative, this appeared to greatly reduce the distress that Mrs V experienced;
- We were pleased to see that Mrs V's capacity had been considered and that others were appropriately consulted. It is not clear how much Mrs V's own views were taken into account at an earlier stage, but her wish to eat was obviously a factor when the decision was made to allow soft diet and thickened fluids;
- We are greatly concerned that no member of the clinical team took sufficient action to address the lack of nutrition and the distress that this caused Mrs V.

### 3. Management of physical and emotional distress

We were astonished to see how much sedative medication Mrs V received and by the fact that, over a ten day period, so much had been administered rectally or by injection. Everyone we interviewed agreed that, either in Mrs V's specific case or as a general comment, this administration of medication was unacceptable. We wanted to look at why it was given.

Mrs V had been agitated and distressed before her transfer to the medical ward. She thought that she should be at home to care for her children and was hard to reassure and distract from this. This was why she was treated under the terms of mental health legislation.

Family members told us that she had been distressed for some time, but especially when she was transferred to the medical ward. She was agitated during their visits and especially when they tried to leave, when Mrs V begged to go with them.

Her distress was heightened by her physical ill health, her transfer to the general hospital and the fact that she was not allowed to eat because of the risk of aspiration. She did not understand why she could not eat and became distressed at the sight of other people eating. We looked at the way her distress was managed.

#### A. Physical environment

Mrs V was nursed in an open ward. She was generally agitated and distressed because of her memory difficulties. She was distressed by watching others eating. This appeared not to have been recognised at the time. It was raised with us by Independent Doctor when he contacted us with concerns about her care. We sought the views of practitioners about her management in the admission ward. We drew their attention to the distress she experienced when observing others eating and asked what could have been done to lessen this.

- Independent Doctor recorded that Mrs V said to him: *"Please help me. Everyone else is having dinner and I can't."*;
- Dr 1 did not feel the environment was ideal. She told us that a single room with one-to-one nursing would have been far preferable;
- Patient Care Manager 1 was also clear that a single room was needed. She said: *"I would not have exposed her to witnessing other people eating."*

We observed above that frequent moves and transfer to an acute medical ward risked increasing Mrs V's disorientation and distress. This was compounded by an apparent lack of realisation that she would be distressed if she were not allowed to eat, did not understand why and witnessed others eating. Also, her distress would have been upsetting for other patients and, above all, undignified for Mrs V.

**Key point: admission of acutely unwell people with dementia to acute medical wards must be handled sensitively to avoid distress to the individual and to other patients in the ward. Single rooms should be used wherever possible.**

## B. Staff attitudes

When Independent Doctor contacted us, he told us of statements made by nursing staff that may have indicated a negative attitude to Mrs V. We wanted to find out more about this and asked others for their views:

- Independent Doctor told us that the nurses appeared to be adopting a purely technical approach. Their concern was to minimise the risk of aspiration, and he did not feel they were sympathetic to her distress;
- Dr 1 provided additional information that appeared to support this. *“The charge nurse had very strong opinions on Mrs V’s management. Her background was management of stroke patients.”*;
- Dr 2 appeared to agree that there was a problem. *“Senior nurses felt that she should go back to mental health care. This possibly reflected a negative attitude to psychiatric patients.”* He also referred to *“unease”* of nursing staff over the interventions on which he had decided.”;
- Patient Care Manager 1 mentioned culture when addressing the issue of medication. *“She was given too many injections. There is a culture of giving injections in acute wards.”*

Interviewees have expressed views about negative attitudes to Mrs V. We took particular note of Dr 2’s concern that some of the negative attitude stemmed from a belief that she should have been in mental health care, not acute medical care. Also, members of Mrs V’s family told us that they felt that the nurses did not want her in that ward. Nurses thought that she should have been in mental health care.

We were not able to meet the nurse in charge of the ward at the time due to that person being unwell. Despite this, we have sufficient evidence to conclude that there were negative attitudes among nursing staff to Mrs V. We cannot say whether the overall culture of the staff was one of antipathy to people with dementia or the negative attitude was because some staff thought that she should have stayed in mental health care. We consider that negative attitudes were important in the way Mrs V’s distress was managed, especially the excessive use of medication.

We have already addressed the issue of appropriateness of transfer. We think the other factor was the amount of training and support nurses received in general and with Mrs V’s management in particular. This is dealt with below.

**Key point: staff must demonstrate a culture of respect for the rights of the individual.**

## C. Training and support for general hospital nurses

From our visits to “medicine for the elderly” wards we have identified that general hospital nurses need training and support in the care of people with dementia. In the case of Mrs V we wanted to know how much support they had in managing her impairment and the distress she was experiencing. We found that help and support could have been more available, but it appears that it was never sought. There was a dementia liaison nurse, but he did not appear to have been consulted. Nurses in the mental health ward who know Mrs V well could have been called on for advice but were not. We wanted to examine why this was.

- Dr 1 was the only apparent link for advice. There had been telephone exchanges between nursing staff, but these were largely when the mental health staff phoned asking for updates. Dr 1 told us: "It would have helped if the liaison nurse was involved. The liaison nurse had no record on file of being contacted by ward staff. He was referred to in nursing notes as being contacted on 8th December. (Our understanding is that he merely passed on information to Dr 1.) There is only one liaison nurse. There is backup from the community mental health team, but this one nurse is not a satisfactory level of cover. There is inequity in liaison provision for people over 65." Dr 1 also told us that, when she received a referral on December 8th (the day she returned from annual leave) she recorded that she might discuss the situation with the mental health nurse manager. Mental health staff might have been able to offer assistance to the general hospital staff. This discussion appears never to have taken place. In any event, this was a week after Mrs V started to receive multiple administrations of medication for distress and agitation;
- Dr 3 agreed with the inequity of mental health liaison provision. *"There is a fantastic liaison nurse who gives a high standard of advice. There is only one of him for the (large teaching) hospital. This is insufficient time."*;
- Patient Care Manager 1 was also concerned that there was a lack of nursing advice and support. *"They never considered mental health nurses. There was no request for nursing help. Liaison nurses should be in*

*advising the nurses. Perhaps the fact that she was under section made it different."*

We were heartened to hear from Patient Care Manager 1 that the NHS Board had appointed a nurse consultant in dementia care with a particular view to improving training for general hospital nurses.

Our impression is that the relatively small provision of mental health liaison nursing meant that only selected cases were brought to his attention. Also, as Patient Care Manager 1 said, the ward may have assumed that people transferred from mental health care were not part of his responsibility. Either way, the lack of advice from mental health nurses was a problem. Mental health nursing staff would have been able to help the general hospital nurses manage Mrs V's distress by looking more widely at the causes and a greater range of options for management. We believe this was a major factor in the excessive use of medication.

### Key points

- **The NHS Board should examine the scope and equity of provision of mental health liaison services to people in general hospitals;**
- **In developing dementia training, the nurse consultant in dementia care for the NHS Board should examine the findings from our report in order to help determine the training needs of general hospital nursing staff;**
- **Where a detained person is transferred to medical care from mental health care, there should be a procedure for discussion on a case by case basis as to the need for mental health nursing input.**

#### D. Prescribing and administering medication: roles and responsibilities

Dr 1 had prescribed small, judicial doses of medication to reduce Mrs V's level of anxiety and distress over several months. When she was transferred, the role of prescribing fell to Dr 2. Nursing staff were administering medication, and several doctors examined Mrs V for various reasons during this period. Despite this, nobody appeared to identify that the amount of medication prescribed, and the routes of administration, could have been excessive, inappropriate and could have added to her distress. We wanted to look into this;

We asked interviewees what they thought of the way medication was prescribed and administered. We wanted to find out whether they thought there was excessive administration of medication and who they thought should have been looking at this and might have raised concerns;

- Dr 2 was the consultant in charge of her care in the general ward and therefore had overall responsibility for prescribing. He told us: *"Large amount of regular diazepam were not ideal. I tried to keep amount of sedation down, hence smaller but frequent intramuscular chlorpromazine."* He went on to say: *"The decisions on medication were based on ward discussions. I was not aware how often the "as required" medication was given. I do not routinely check but expect nurses to bring it to my attention if they are concerned. I was taken aback when I saw how much rectal diazepam had been administered but was not concerned about the route, more about the risk of over-sedation."* In this context he thought that lack of continuity of junior

medical staff contributed to the problem. Junior doctors now work a partial shift system as a result of the European working time directive. He also raised the issue of the pressure on nurses from a rapid turnover in the ward as an explanation for why they did not raise the medication issue with him;

- Dr 1 reviewed Mrs V on December 9th, a week after frequent administration of medication started. *"The nurses did not raise concerns about the amount of medication with me. I was not consulted before December 8th. She had been prescribed diazepam, lorazepam and chlorpromazine by the general ward staff. I thought the feeding problems would be sorted out. Intramuscular and rectal medication needed frequent review. I did not count the number of "as required" administrations but I am concerned about the amount of medication she received."* She told us that she was not entirely happy with the use of rectal diazepam but thought that the nurses would not be happy if they had to *"force oral medication"*;
- Patient Care Manager 1 agreed with us that the administration was excessive. She had not been involved at the time and could not identify if concerns had been raised. If they had been, she would have expected to see concerns escalated if not resolved, but there was no evidence that this happened. She thought that a syringe driver might have been a better option;
- Independent Doctor was concerned about the management when providing an independent report examining the grounds for the compulsory treatment

order. He expressed concerns about the discomfort of giving medication by injection and by rectal administration. Even he had not counted the actual number of times this happened;

- DMP 1 examined Mrs V as a designated medical practitioner appointed by the Commission under part 16 of the 2003 Act. She agreed with a plan of treatment that included rectal and intramuscular injections. She told us that her recollection of Mrs V was that she was clearly dying and she did in fact die later that day. In retrospect, she thought it might have been better to authorise medication via a syringe driver. She also did not recall looking back to see the amount, frequency and route of administration of medication.

We have already identified that the lack of clarity over the approach to Mrs V's care was at the root of the problem. If it had been clear that a palliative approach was needed, we think that a kinder route of administration of medication would have been found, e.g. using the Liverpool care pathway and giving medication via a syringe driver. We also do not think that the option of oral medication had properly been explored.

We agree with Dr 2's stated aim of giving small doses to avoid over-sedation, but we were surprised that this was achieved by repeated painful injections. Other routes, for example oral dispersible tablets or syringe drivers, were not considered.

The ward appeared to have no system to identify the amount of "as required" medication given. Nobody appeared to

appreciate that multiple administrations of medication by injection and via the rectum could be unpleasant. Ultimately, it is our view that the consultant in charge of her care must have an overview of the amount of medication being given. He did not, and no other member of the clinical team raised it as an issue. Clinical pharmacy input may have helped, but was not available on this ward. We think that all team members must reflect on their own practice here but there is a systemic problem to address.

**Key point – The NHS Board should ensure that there is a procedure for administration of "as required" sedative medication to be documented and brought to the attention of the medical practitioner in overall charge of the patient's care.**

### E. Procedures and protocols

General hospital staff need good guidance on appropriate management of delirium and the distressed patient in general. We heard from Dr 1 and Patient Care Manager 1 that there had been guidelines on the intranet, but they had been removed. There is work ongoing on a delirium pathway.

We think that better guidance on the management of delirium would have been helpful in Mrs V's case. However, many of the problems we identified did not need guidelines and simply needed staff to reflect on what they were doing and why.

**Key point – the NHS Board should ensure that guidelines on the management of delirium are available to all staff who may be treating a delirious patient.**

### *Findings on management of physical and emotional distress:*

- The environment of the ward was not ideal and resulted in Mrs V witnessing other people eating when she was being denied oral nutrition and did not understand why. A single room would have reduced her distress and given her more dignity;
- Some members of staff may have had a negative attitude to Mrs V because they thought she should have been in mental health care, not an acute medical ward;
- Mental health nursing expertise was available, but not used. We found uncertainty as to the role of the dementia liaison nurse where the patient has been transferred from mental health care, especially under the Mental Health Act. We also found a general view that the amount of liaison nursing time was well short of what was required;
- The number of times medication was given rectally or by injection was unacceptably high. Everyone we spoke to accepted this, but nobody looked critically enough at the use of medication at the time. Ultimately, the prescribing practitioner must have an overview of the amount and frequency of administration of "as required" medication. We think this was Dr 2's responsibility, but other members of the team should have raised concerns. The fact that nobody took this overview is a matter of major concern;
- There is a need for guidance on the management of delirium and the distressed patient with cognitive impairment in general. This guidance had been withdrawn pending a review and, at the time of writing, is still not available.

## Summary of findings

In summarising our findings, we have tried to address problems with the system of care for Mrs V.

### *Summary of findings on transfer to an acute medical ward:*

- Shortly before the transfer took place, there was still the aim to improve Mrs V's mental health with a view to possible discharge home. Active intervention to treat her problems was still indicated;
- A record of her previous wishes about intervention as her illness progressed may have helped the process of decision-making;
- She had five moves of ward over a seven week period. This would have been likely to worsen her agitation and distress;
- The mental health service was unable to manage infusions of fluid and intravenous antibiotics. Many mental health services for older people can manage these aspects of care;
- There was good medical liaison from general medicine to the mental health service, but additional nursing support and training might have helped;
- Ultimately, transfer was considered necessary but she was transferred to an acute receiving ward. This was not ideal and a post-acute assessment ward would have been a better option.

### *Findings on decision making process on intervention:*

- There was a lack of a clear assessment of the risks versus the benefits of oral feeding. Despite an assessment from speech and language therapy that Mrs V could manage thickened fluids, she was denied oral food and fluids for at least a further week with only artificial hydration being given;
- During the course of her treatment, there was a change of emphasis from intervening to treat her physical condition aggressively towards palliative care with the emphasis on comfort. It was not clear from case records or interviews where this change of approach occurred;
- Difficult decisions need a multidisciplinary approach. It was not clear that all members of the team were in agreement with the plan of care, and consultation between the general medical and mental health services over the general approach to her care was minimal for much of this time;
- When there was clarity that the approach was largely palliative, this appeared to greatly reduce the distress that Mrs V experienced;
- We were pleased to see that Mrs V's capacity had been considered and that others were appropriately consulted. It is not clear how much Mrs V's own views were taken into account at an earlier stage, but her wish to eat was obviously a factor when the decision was made to allow soft diet and thickened fluids;
- We are greatly concerned that no member of the clinical team took sufficient action to address the lack of nutrition and the distress that this caused Mrs V.

### *Findings on management of physical and emotional distress:*

- The environment of the ward was not ideal and resulted in Mrs V witnessing other people eating when she was being denied oral nutrition and did not understand why. A single room would have reduced her distress and given her more dignity;
- Some members of staff may have had a negative attitude to Mrs V because they thought she should have been in mental health care, not an acute medical ward;
- Mental health nursing expertise was available but not used. We found uncertainty as to the role of the dementia liaison nurse where the patient has been transferred from mental health care, especially under the Mental Health Act. We also found a general view that the amount of liaison nursing time was well short of what was required;
- The number of times that medication was given rectally or by injection was unacceptably high. Everyone we spoke to accepted this. Nobody looked critically enough at the use of medication at the time. Ultimately, the prescribing practitioner must have an overview of the amount and frequency of administration of “as required” medication. We think this was Dr 2’s responsibility. but other members of the team should have raised concerns;
- There is a need for guidance on the management of delirium and the distressed patient with cognitive impairment in general. This guidance had been withdrawn pending a review and, at the time of writing, is still not available.

### **Conclusions and recommendations**

We consider that Mrs V was not given the care, dignity and respect she deserved. It can be argued that her rights to privacy and dignity and right to be free from degrading treatment (articles eight and three of the European Convention on Human Rights) were infringed. While all members of the care team must reflect on our findings and examine their own individual attitudes and practice, we strongly advise the NHS to examine the performance of individual practitioners. Poor clinical decision-making and negative attitudes to people transferred from mental health care appear to have played a significant part in the problems we identified with Mrs V’s care and treatment.

We acknowledge that there was a case for continuing to manage Mrs V within mental health care or to transfer her to a different sort of ward. Despite these issues, we consider that Mrs V’s care could and should have been better managed in an acute medical ward. Mrs V could just as easily have been admitted from home with the same problems. We also acknowledge that better availability of mental health liaison would have helped.

We consider that the **root causes** were:

- **Many of the staff involved in Mrs V's care did not display the knowledge, behaviour and attitudes necessary to provide care for a confused elderly person;**
- **The consultant in charge of her care failed to make a clear decision on provisions of nutrition because it was unclear whether the purpose of Mrs V's care was active treatment or palliative care;**
- **Nobody thought it was their responsibility to identify the appropriateness, amount, frequency and route of administration of medication;**
- **There was a lack of shared understanding, across medical and mental health services for older people, about the best way to manage people with dementia who become physically unwell while in mental health care.**

### **Main recommendations to address root causes**

Our recommendations are addressed to the NHS Board responsible for Mrs V's care. Other NHS Boards should take note of our findings and recommendations and ensure that their staff learn from Mrs V's case.

#### **Main Recommendation 1**

The NHS Board, as a matter of urgency, should provide training to address the culture and attitudes of clinical staff towards people with dementia in acute receiving wards caring for older people. Training should involve learning from this particular case and include:

- Human rights, mental health and incapacity legislation
- Management of delirium
- Equality issues, including direct and indirect discrimination against people with dementia
- Use and misuse of medication

#### **Main Recommendation 2**

The NHS Board should ensure that there is clear guidance on decision-making on nutrition for people who lose the ability to swallow. This guidance should include:

- Assessment of risk;
- Assessment of capacity to decide;
- The factors determining which intervention to choose;
- A "decision tree" giving the options available;
- Consultation within the clinical team and with appropriate others.

### Main Recommendation 3

The NHS Board should devise a system to monitor the use of “as required” psychoactive medication administered to confused elderly people. This should include:

- Guidance of the options for appropriate choices of drug, dosage and route of administration;
- Recording and reporting to the medical practitioner in charge of all psychoactive medication administered;
- Trigger points for advice from mental health specialists.

### Main recommendation 4

The NHS Board should review the pathway of care for people in mental health wards who need general medical care because of physical illness with a view to determining:

- The level of physical health treatment that can be given in mental health care;
- The need for extra support for mental health staff to provide care and treatment;
- Thresholds for transfer to medical wards;
- The type of medical ward suitable for transfer;
- Arrangements for decision-making and continued mental health support after transfer.

### Other recommendations

We consider that the care of others like Mrs V would be improved by attention to the other points we raise in this report:

- Admission of acutely unwell people with dementia to acute medical wards must be handled sensitively to avoid distress to the individual and to other patients in the ward. Single rooms should be used wherever possible;
- The NHS Board should examine the scope and equity of provision of mental health liaison services to people in general hospitals;
- In developing dementia training, the nurse consultant should examine the findings from our report in order to help determine the training needs of general hospital nursing staff.

### Recommendation for the Scottish Government

The Scottish Government should examine the recommendations and learning points from this investigation. They will be helpful in implementing Scotland’s dementia strategy. In particular, we draw the Government’s attention to the need for:

- Guidance on the management of people with delirium;
- Training for general hospital staff, especially in attitudes and human rights;
- Improved mental health liaison and support.





Thistle House  
91 Haymarket Terrace  
Edinburgh  
EH12 5HE

Tel: 0131 313 8777

Fax: 0131 313 8778

Service user and carer  
freephone: 0800 389 6809

[enquiries@mwscot.org.uk](mailto:enquiries@mwscot.org.uk)

[www.mwscot.org.uk](http://www.mwscot.org.uk)

May 2011