

# Starved of care

**Summary  
investigation report  
into the care and  
treatment of Mrs V**

# Contents

<b>Who we are and what we do</b>	<b>1</b>
<b>About this report</b>	<b>2</b>
<b>About Mrs V</b>	<b>2</b>
<b>About our investigation</b>	<b>3</b>
<b>What we found</b>	<b>3</b>
<b>1. Transfer to acute ward for mental health care</b>	<b>4</b>
<b>2. Decision making process on intervention</b>	<b>4</b>
<b>3. Management of physical and emotional distress</b>	<b>5</b>
<b>Conclusions and recommendations</b>	<b>6</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.

## About this report

This is a summary of our investigation into the care and treatment of Mrs V. Under mental health legislation, we can investigate the care of people with mental illness or learning disability if we think they have suffered abuse, neglect or deficiency of care.

Mrs V was a woman with dementia who died in hospital in December 2008. We decided to investigate because we heard concerns that her treatment had not been as good as it should have been. Our findings show that Mrs V was treated poorly, so we produced this report to help the hospital learn from what happened. Also, we want everyone providing care for people with dementia in the NHS in Scotland to read this report. Mrs V's problems were complex but not uncommon. Our findings and recommendations will help to make sure that other people with dementia receive better care.

## About Mrs V

We heard about Mrs V from a Consultant Psychiatrist who had completed an independent medical report. He was asked for an opinion because of an application for a compulsory treatment order (CTO) for Mrs V. At the time of her death, Mrs V was 80 years of age and suffered from dementia. Because of physical health difficulties, she was being treated in a general hospital when she died. The independent doctor found Mrs V to be distressed and agitated. He found that part of her distress was because she was not being allowed to eat. He was concerned about the amount of sedative medication she was being given.

Mrs V had been having memory problems for about three years. She was admitted to a mental health ward in July 2008 because she was too agitated to be able to manage at home. She continued to get worse and needed to be detained in hospital in October 2008. She needed small amounts of medication and a lot of help from mental health nurses when she became distressed.

During this time, it was hard to decide what type of ward was best for her. The mental health staff tried her in two different wards. She developed chest infections because of difficulty swallowing. This resulted in two spells in a general hospital ward for older people. We looked in particular at the second admission from November 19th 2008 until her death a month later. When transferred, she had a fever, rapid pulse and signs of a chest infection.

Mrs V found it difficult to swallow without choking. From December 2nd until December 12th, she was given fluids via a drip. She had no food, either by mouth or via a tube. A specialist assessment by a speech and language therapist on December 5th concluded that she could manage thickened fluids by mouth.

Mrs V was distressed by being in hospital, and by not being allowed food. She became even more distressed when she saw other patients eating. The general hospital response to her distress was to give medication to sedate her. They were concerned about her ability to swallow, so they gave medication by injection and via her rectum. To sedate her, over a 16 day period, they gave rectal medication 57 times and an additional 29 injections.

Eventually, they decided to allow Mrs V to have food. This was risky but better than leaving her without food and in distress. They were able to greatly reduce the need for sedation. By this time, Mrs V had become very frail. She soon developed another episode of pneumonia, which led to her death.

### About our investigation

We decided that Mrs V's case needed further investigation. We wanted to find out why she was sedated so often and in such undignified and painful ways.

We reviewed Mrs V's general hospital case records. We then interviewed consultant medical staff and the clinical nurse manager for the service, who had not been in post at the time. We were not able to interview the ward manager because she was on sick leave. We obtained information from the speech and language therapy department, which had been involved in her care. Finally, we met with family members to discuss their concerns and to share our findings with them.

### What we found

Though the complexities of Mrs V's problems were significant, they were not, in our view, uncommon in mental health and general hospital services. We had concerns about many of the aspects of her care. We broke these down into the following 3 specific areas:

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

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

Mrs V suffered from vascular dementia, which makes the anticipation of decline difficult. It was difficult to decide, in advance, how much treatment to give when her physical and mental health worsened. It may have helped if Mrs V had made a record of her own wishes for treatment before she became worse.

We were very concerned that Mrs V was moved several times. Moves are likely to cause or worsen agitation. She was moved five times within the mental health hospital, and between there and the general hospital, during a seven week period. Mrs V's family confirmed that these moves had had an unsettling effect on her. She was transferred to the general hospital because the mental health service could not manage the care of someone who needed fluids and antibiotics via a 'drip' (subcutaneous or intravenous).

The different doctors involved in this case held different views on whether people with dementia and complex physical health problems were better managed in a mental health setting or in a general hospital. We surveyed medical and nursing staff in older people's mental health services across Scotland. Most, but not all, could manage intravenous or subcutaneous fluids in mental health wards. Mrs V could have been managed in mental health care, but mental health nurses would have needed better support and training.

We also considered whether the acute medical receiving ward for older people to which she was transferred was the most appropriate option in a general hospital

setting. We do not believe that this was the best option for Mrs V in light of the problems she presented. A ward with less pressure would have been better.

While it was important to look at why Mrs V was transferred, we were aware that she could just as easily have been admitted from home to the general hospital. The transfer could have been avoided or managed better, but this ward would need to be able to care for people with dementia. We needed to examine her care in the general hospital to find out what went wrong.

## 2. Decision making process on intervention

Mrs V had difficulty swallowing and was given no nutrition during a ten-day period. On the third day, a speech and language therapist suggested that Mrs V could manage thickened fluids. This would still be risky, so the Consultant's instruction was 'nil by mouth.' He decided against artificial feeding because Mrs V's was very frail. When a different consultant took over her care on the 11th day, Mrs V was started on thickened fluids.

We expected to see a clear account of the risks and benefits of oral feeding. Only when the second consultant took over her care did we find this. Professionals from various disciplines should be involved in the decision. The patient (if possible) and relatives should give their views. In this case, relatives felt that they were being asked to make the decision. This added weight to our view that the clinical team's indecision was a major problem.

There were mixed views as to whether Mrs V had the capacity to make an informed decision

on the swallowing of food. We are inclined to agree with the majority view that she did not. We are content that the issue of capacity was appropriately considered and involved all relevant parties, and that the decision was based on principles. The appropriate certification was on file.

At some point, the approach changed from providing active treatment for her pneumonia. This only became clear when the second consultant took over her care. She adopted a “palliative care” approach and was clear on the limits to active intervention. A palliative approach led to Mrs V being fed, with some risk, and meant that the sedative medication could be greatly reduced.

Until then, we do not think the team was clear on what they were trying to achieve. They appeared uncertain as to whether they were trying to promote Mrs V’s recovery, or trying to relieve her distress. This, in our view, contributed greatly to the indecision around whether she be fed or not, and to the frequent administration of medication to alleviate her distress. We found it extraordinary and unacceptable that no member of the care team addressed the lack of nutrition over an extended period.

### **3. Management of physical and emotional distress**

We looked into why such a high level of sedative medication was administered to Mrs V and the way in which her distress on the ward was managed.

The ward environment was not ideal. Mrs V was in a bed bay with other patients. She was agitated and distressed, especially when

watching other people eating. It was disappointing that the use of a single room appeared not to be considered for her. It is our opinion that a single room would have helped to maintain Mrs V’s dignity and prevented her distress from upsetting other patients.

We found evidence that some staff demonstrated negative attitudes towards Mrs V. It is not clear if their negative attitudes stemmed from a general antipathy toward people with dementia, or Mrs V specifically because of a view that she should have been in mental health care. In our view, the negative attitudes had an impact upon the way Mrs V’s distress was managed, especially the excessive use of medication.

General hospital nurses need support when managing people with dementia who experience agitation and distress. They did not receive support, and we found no evidence that they asked for support. There was a dementia liaison nurse who could have helped. Nurses in the mental health ward, who knew Mrs V very well, could have given support and advice to general nursing staff.

Staff appeared to have been uncertain about the role of the dementia liaison nurse where a patient has been transferred from mental health care. A further reason may have been that only a selection of cases were brought to the liaison nurse’s attention because resources were tight. Having access to mental health nursing staff would have allowed a thorough look at the causes of Mrs V’s distress and would have provided a greater range of options for management. We believe this was a major factor in the excessive use of medication.

Mrs V was prescribed medication to reduce

her level of anxiety and distress. When transferred, prescribing was carried out by a different doctor. During this period, nursing staff were administering medication and Mrs V was examined by several doctors for different reasons. Despite this input from various quarters, it appears that no-one sought to question whether the amount of medication prescribed and administered was excessive or was contributing to her distress.

The staff interviewed accepted that the medication administered was unacceptably high and that other, less painful, routes for medication should have been considered. There was no system in place to establish the amount of “as required” medication that was being given. This did not allow the consultant in charge of her care to have an overview of the amount of medication being administered. This was never raised as an issue by the clinical team.

We feel that general hospital staff would have benefited from guidance on the management of delirium and of the distressed patient in general. We were informed that guidance had been available on the hospital intranet but that this had been removed pending a review. Although the guidance would have been helpful in Mrs V’s case, many of the issues identified did not need guidelines and staff simply needed to reflect on what they were doing and why.

## Conclusion and recommendations

We consider that Mrs V was not given the care, dignity and respect she deserved. While it could be argued that she should not have been moved from the mental health service, it is also clear that the care she received in the acute medical ward could, and should, have been better than it was. Poor clinical decision-making and negative attitudes to people transferred from mental health care appear to have contributed greatly to the problems we identified with Mrs V’s care and treatment. The Board should look at the way some individual practitioners acted, but it also needs to look at systems to prevent anything like this from happening again.



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 became physically unwell while in mental health care.

In order to address these root causes, a number of main recommendations have been made. The recommendations are mainly addressed to the NHS Board responsible for Mrs V's care. However; other NHS Boards should take note of our findings and recommendations and ensure 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.





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