

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

We have the legal authority to investigate cases where there have been problems with the care and treatment of an individual who has a mental illness, learning disability or other mental disorder. Our duties are set out in the Mental Health (Care & Treatment) (Scotland) Act 2003. Under the Act we have the power to carry out investigations and make recommendations where we believe that a person might have been ill-treated, neglected or received deficient care or treatment. We also have a general duty to monitor the operation of the 2003 Act and to report on issues and trends in the way the law is being used. Through this work we have identified an increased use of long-term compulsory treatment orders (CTO) in people over the age of 85. We decided to look into the reasons for this. We found that most people who were

detained in this age group had dementia. In almost all cases, we found that the Act was being used appropriately to safeguard individual rights and welfare.

Mrs I was one of the people whose care we examined as part of our monitoring process. In her case, we found statements that suggested to us that legislation may have been used too late to safeguard her welfare. We were concerned that as a result she may not have received adequate care and treatment.

A Mental Health Tribunal approved Mrs I's detention in hospital under a compulsory treatment order (CTO) on 22nd June 2006. When we read the reports submitted to the Tribunal and examined the Tribunal's reasons for granting the order, we learned that Mrs I:

- had been neglecting herself for the previous year;
- was described as suffering from malnutrition and appeared "severely neglected";
- had been found "wandering" on the main road on several occasions;
- was reported to have been incontinent of urine and faeces; and
- had been resisting personal care at home for some time.

All this had occurred despite the fact that Mrs I was well known to NHS and social work services. She was known to have dementia and there was considerable input from the community mental health team, primary health care and social work. There was a care manager in place. Mrs I died shortly after the CTO was granted. Her death was from natural causes and the hospital

where she was treated appeared to have given her good care. Our concern was why it took so long to admit her to hospital and the risks to her health, safety and welfare over the time leading up to her eventual admission. We decided to investigate to determine whether there was evidence to support earlier statutory intervention.

Terms of reference for our investigation

1. To identify the care and treatment of Mrs I from her first presentation with apparent memory impairment in 2003 until her admission to hospital in May 2006.
2. To determine whether her care and treatment during this time was consistent with legislation and best practice.
3. To examine the reasons for decisions not to use legislation to safeguard her at an earlier stage.
4. To make recommendations about the operation of health and social care services in her area.

Our investigation was carried out by members of our practitioner team and was chaired by one of our part-time Commissioners. The team was assisted by members of our casework and corporate services team.

We began with a detailed examination of all relevant health, social work and other related files and correspondence. A timeline of key information was developed from these notes. Through this process we identified and interviewed the professionals and family members who could provide important information about Mrs I's care and treatment.

We reviewed existing standards and practice guidance available to care providers.

We used these as a benchmark for the care and treatment that we would have expected Mrs I to receive. All of this information was then analysed to identify key areas of concern and recommendations the organisations involved in Mrs I's care.

We are most grateful to everyone involved in our investigation for their cooperation.

About Mrs I

Mrs I was born in Italy and was brought up under the fascist regime which she learned to distrust. She moved to Scotland after the Second World War. She married and had three daughters. Her husband had been a soldier. He left her when she was in her 60s. At some point in the 1970s, a nephew came to stay with Mrs I and her family. He was believed to have mild learning and emotional difficulties but was never formally assessed. He continued to live with her after her daughters moved out of the family home. Mrs I did a lot to care for the nephew. She stayed independent, active and houseproud until the onset of dementia.

Mrs I was first referred for memory problems in 2003. She was seen in early 2004 after some delay. She was diagnosed as having Alzheimer's disease and received treatment with medication to improve memory. She gave two of her daughters power of attorney to look after her welfare and finances. Her home situation was monitored by a community psychiatric nurse. Her illness progressed and carers found it very difficult to manage. She needed a lot of help with personal care, was demanding of attention and became aggressive to family members. More care was introduced at home but she refused to go to day care.

By late 2005, the situation had seriously worsened. Mrs I's personal hygiene was very poor and she would not eat the food made for her by care workers. Relatives were under increasing stress because Mrs I, not realising how much help she needed, was refusing care services and insisted that her family would care for her. Despite increasing services, matters worsened over the next few months. She ate rotten food from bins, threatened to throw herself in front of cars and actually clung on to care workers cars when they tried to leave because she was so frightened of being left alone. When she went out she lacked judgement and was found walking in the middle of the road. By March the house was described as filthy. Mrs I had such difficulty accepting help with personal care that her stockings were sticking to her and her toenails were cutting into her feet.

Despite all of this, it was the end of May 2006 before she was finally taken to hospital by the community psychiatric nurse and detained under the Mental Health (care and treatment) (Scotland) Act 2003. Several earlier discussions resulted in no decision to detain but to "wait for a crisis".

Our key findings

Diagnosis, initial support and treatment:

Mrs I was dealt with well during the initial diagnosis and its immediate aftermath. Despite this, we have some concerns about aspects of her care and treatment at the memory clinic.

- Follow-up arrangements appear inconsistent and were not understood by the senior psychiatric trainee.

- Her initial assessment does not include a detailed life history.

A delay from referral to her eventual clinic appointment was not a critical factor. The memory clinic, however, only has the capacity to perform a diagnostic assessment for 25% of all new cases of dementia each year. This appears to be a serious shortfall.

Assessment of need

While there was general awareness of Mrs I's needs, documentation was patchy and did not provide a clear and comprehensive record.

Many of Mrs I's needs were unmet or only partially met. Again, while there was awareness of this, assessment documentation and case records showed no systematic recording of unmet need.

There was ample documentation of serious stress on family members from the point at which Mrs I developed dementia. This affected family relationships and some family members seemed to have experienced decline in their own mental health. This made it more difficult for the family to provide consistent support and led to disharmony between some family members and some practitioners.

There were obvious stresses on carers, especially the nephew who lived with Mrs I and who was thought to have a learning disability. There was no carers' assessment despite a reminder within assessment documentation to consider the need for this.

Our impression was that single shared assessment documentation was used only as a means to access services. While this is important, it must also provide a comprehensive and regularly updated means to tracking needs and ensuring that there is a

plan in place to meet them. We found no evidence that it did that for Mrs I.

Assessment of risk

There were several obvious risks to Mrs I's health, safety and welfare. She lost weight, her skin care was poor, she tried to eat out-of-date food from the bin and risked her safety in the road.

While we think there was a general awareness of the risks there was no evidence that these had been properly documented, or that there was a coherent plan in place to manage them.

Capacity and intervention under the Adults with Incapacity (Scotland) Act 2000

Despite awareness that Mrs I was at risk, we found no formal assessment of her capacity in relation to welfare decisions at crucial points in her contact with services. From evidence available to us, we think she did not comprehend the risks and therefore may not have had the capacity to make her own decisions about her welfare.

Some members of the care team seemed to us to have limited understanding of incapacity legislation. The importance of decision-specific capacity and the need to consider a range of possible interventions under the 2000 Act were not properly understood by several key practitioners.

Mrs I's welfare attorneys did not make decisions about her welfare. Neither they, nor care practitioners, were aware of their roles. They could have made some decisions with support and advice but this was never offered. As a result, the powers that Mrs I had granted to them were never used. Guardianship was considered only as an option for removal into care rather than as a proactive tool to meet

her needs. It was quickly rejected as hospital admission appeared to be the only option if management at home failed.

The result of this was that everyone, with the best of intentions, did everything they could to help Mrs I continue to live in her own home. This was her clear wish and an important principle to observe. This wish, however, had to be considered alongside her capacity to make her own decisions and the other principles of legislation, including benefit and the views of relevant others.

Intervention under mental health legislation

Despite mounting evidence that Mrs I's health, safety and welfare were at increasing risk, there were several occasions where admission under mental health legislation was considered and rejected. We think the reasons for this were complex and understandable given the lack of framework for risk assessment and management that we identified.

The decision to use mental health legislation should have been made by the consultant with consent from the mental health officer, taking account of evidence from all involved in her care. Because of the distress this was likely to cause Mrs I, the consultant psychiatrist was reluctant to make this decision. The team continued to monitor the situation and wait for a "crisis." On the basis of our information, it appears that the situation was already at crisis point. A letter to the GP asking him to assess for emergency detention seemed inappropriate.

As her welfare attorneys, Mrs I's daughters were not consulted when she was detained. This was in line with mental health law, but did not reflect Mrs I's wishes that they should make welfare decisions on her behalf.

Analysis of decision-making

The care team, in our opinion, failed to be objective about the risk of continuing to manage Mrs I at home. The lack of regularly updated risk assessment and formal assessments of capacity were crucial. There were regular discussions but only scant records of these are available. New electronic systems now in place for recording single shared assessments may help. The team needs a clear framework for decisions in complex cases like this where there are difficult decisions to be made.

We found that there was lack of clarity about the roles of some of the key practitioners. In particular, the care manager was understood by the team to be fulfilling the role of mental health officer. This view was not shared by the care manager's supervisor. The care manager herself seemed unclear over her role. If she was acting as mental health officer, the role was not performed in line with national standards. We also found lack of clarity over the role of the GP in relation to decisions to detain Mrs I in hospital.

Several members of the team lacked understanding of issues of capacity. Knowledge and expertise around capacity seems to be regarded as a specialist area, but there is no evidence that the specialist was ever consulted.

We found an overall absence of documentation to support decision-making. Several key practitioners were unable to produce clear and consistent records of their interventions and the team failed to keep good records of all meetings where Mrs I was discussed.

There were gaps in the communication with the GP at a key point that led to a lack of clarity about what was being asked of him.

In our view, the care programme approach (CPA) provides a forum for management of complex cases such as Mrs I's. We heard that the CPA is used infrequently by the team and probably never for a person with dementia. In our investigation into the care and treatment of Mr F¹, we made recommendations about the use of the CPA. We reinforce these recommendations in this report.

We suggest that there may be issues of equality here. Had Mrs I been a younger person with a mental disorder, living in such conditions, we think that mental health legislation would have been used to protect the person at a much earlier stage. We accept that such decisions may have implications which last beyond the period of detention and treatment for a person who has advanced dementia. It may ultimately have resulted in a permanent move out of her own home. In our view, this did not justify a decision not to intervene under protective legislation where the risks to her health, safety and welfare were so obviously great.

Conclusions, recommendations and learning points

Our investigation confirmed our initial view that statutory intervention could have been used at an earlier stage to safeguard Mrs I's welfare. Practitioners acted in accordance with Mrs I's wish to stay in her own home. They did this however in the face of severe

risks to Mrs I's health, safety and welfare and severe carer stress.

We believe that there are three root causes that made it difficult for practitioners to make the decision to intervene using mental health or incapacity legislation.

Root causes for lack of legal intervention:

- **The team did not use a structured framework to make decisions about risk, capacity and the need for legal intervention.**
- **The service failed to keep accurate and comprehensive records of information, discussions and decisions that would have informed and supported the decision-making process.**
- **The roles of several key practitioners were unclear. The role of the care manager, also a mental health officer, was particularly unclear. There was a lack of shared understanding between the NHS board and local authority as to her role and a lack of application by the local authority of the national standards for mental health officer services.**

These resulted in Mrs I being left in a situation where she was at serious risk.

Other factors that contributed to the problem were:

- the lack of a comprehensive life history;
- the lack of an assessment of carers' needs;
- uncertainty over the respective roles of the GP and consultant, when detention is considered;
- some gaps in care team knowledge and experience of using mental health and incapacity legislation;

¹ <http://reports.mwscot.org.uk/investigationsreports/tooclosetosee>

- failure to consider the use of the care programme approach given the complexity and difficulty of the case;
- uncertainty over the role of a welfare attorney; and
- disparity between appointments of welfare attorneys and named persons.

Key recommendations

Our recommendations are directed to the NHS Board and local authority for the area in which Mrs I lived. Other services should take note of our findings and recommendations as there may be useful learning points. We have made one recommendation to the Scottish Government.

1. The NHS Board and local authority should ensure there is a decision-making framework for assessing needs, risks and capacity for people with dementia. Key questions to be addressed through the framework would be:
 - What are the person's needs?
 - What are the risks if these needs are not met?
 - What services are required to meet the person's needs?
 - If the person resists these services, what will be the risk?
 - Does the person have the capacity to understand the level of risk and therefore make decisions about services?
 - If not, who else has the authority to make decisions?
 - If nobody has the legal authority, what statutory intervention is needed?

2. The NHS Board and local authority should improve record keeping by community mental health teams. Necessary actions are:
 - ensuring that discussions and decisions at all team meetings are properly recorded;
 - developing a system for each practitioner to record and store their interventions in a single case record; and
 - ensuring that individual care plans are comprehensive and up-to-date.
3. The local authority should, with reference to care management guidance, review the roles of social workers who are mental health officers working within mental health teams and who also undertake care management responsibilities. This review should address:
 - the interface between care management and mental health officer responsibilities;
 - line management and supervision arrangements; and
 - the application of national standards for mental health officer services.

Other learning points

If our key recommendations are implemented, we would be confident that people with dementia will get the benefit of timely statutory intervention when they are most at risk. We identified some other learning points that the NHS and local authority should consider.

- 1 The NHS Board should ensure that a dementia care pathway addresses:
 - recording of a life story, including personal likes and preferences and

including an account of the family situation;

- clear and consistent follow up arrangements for support and counselling; and
- the capacity within the service to assess a much higher number of expected new cases of dementia.

2. The NHS Board and local authority should review the process for “single shared assessments”. We are aware that the system has changed, but need to be assured that:

- the assessment is regularly updated to provide an ongoing record of needs, met and unmet;
- information on medical needs is provided by medical practitioners with the time and knowledge to supply it; and
- assessments are audited to ensure that they are sufficiently complete and comprehensive to inform care planning.

3. The NHS Board and local authority should ensure that carers’ assessments are completed when required. To achieve this, they should:

- remind all staff of the value of carers’ assessments and the right of carers to request an assessment of need;
- audit single shared assessment documentation to find out whether the prompt for carers’ assessments is being acted on; and
- review single shared assessment documentation to strengthen the requirement to assess the needs of carers.

4. The NHS Board and local authority should examine the use of the “basic level” care programme approach (for people without forensic risks) and give guidance to health and social care practitioners on its use.

5. The NHS Board and local authority should ensure that community mental health teams understand the intention for short-term detention to be the route to compulsory admission under the 2003 Act.

6. The NHS Board and local authority should ensure that relevant clinical staff recognise the important role of welfare attorneys, give them support in exercising their role and ensure that they know what to do if attorneys do not seem to be exercising their responsibilities appropriately.

7. The NHS Board and local authority should conduct a training needs analysis of staff dealing with people with dementia in relation to relevant protective legislation and devise a training programme to address any gaps.

8. The Scottish Government should commission a review of the roles of welfare attorneys. This should address:

- the information and guidance available for them;
- support for them in undertaking their duties;
- their authority to act where the adult resists; and
- the interface with the role of the named person.

