mentalwelfare
commission for scotland

INVESTIGATION INTO

The death of Ms MN

JANUARY 2016

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Summary report

This report is about Ms MN, a 44-year-old woman with complex needs, who died in December 2012 after hanging herself in the care home to which she had recently been moved following a period of inpatient care. We investigated the care and treatment which Ms MN received in the months leading to her death.

The full report is available on the Mental Welfare Commission's website.

Terms of reference

This investigation was conducted under section 11 of the Mental Health (Care and Treatment) (Scotland) Act 2003. The terms of reference were:

1. To examine all relevant health care, social work, and registered care setting documentation relating to Ms MN's care and treatment, with a particular focus on the period from January 2012 until her death in December 2012.

2. In particular, to review the transfer of Ms MN's care from Health Board A to the care home, primary care, and Health Board B, and to focus on the care plans in place and exchange of information to support her new placement.

3. To determine whether there was any deficiency in Ms MN's care and treatment during the period from the end of August 2012 until her death in December 2012.

4. To produce a report on the findings from the above, with recommendations for services, if appropriate.

Method of investigation

We obtained case records from Health Board A, the GP practice, the care home and Council A. We reviewed these records and also the investigations that had been conducted by these services following Ms MN's death. We then interviewed those we identified as key staff members. We contacted Ms MN's family but they did not wish to take part in the investigation.

About Ms MN

Ms MN was on the autism spectrum, but did not have a learning disability. She was diagnosed with Asperger Syndrome and at one point with schizophrenia. She was born and brought up in Area A, and had one sibling. She lived at home with her parents until her early 20s. At the time of her death, she had had no direct contact with her family for many years.

She had a range of complex needs and behavioural issues. She was socially isolated and was unable to manage her personal affairs. For some years she lived alone in a local authority flat. Her flat became uninhabitable due to neglect of her personal hygiene. When living at home she was supported mostly by the Area A Community Outreach Team (COT) who described her as living in squalor. Any change in routine or in her environment could cause her to become agitated.

History of Ms MN's involvement with services

Ms MN had a history of contact with mental health services which started in 1986 at the age of 18, when she was reported to have a four-year history of anxiety, panic attacks and obsessional thoughts and rituals.

Ms MN had 25 admissions during 2010 and 2011 for detoxification following harmful misuse of alcohol, severe self-neglect, suicidal thoughts and aggression towards others. She was noted to be vulnerable to physical and financial abuse; she was robbed and assaulted in her own home. She was referred to the regional autism service in 2009 for a specialist review but the team could not access her. Following this failed attempt, there were no further attempts to obtain a specialist assessment.

Ms MN was placed on the care programme approach (CPA), and considered for a rehabilitation service rather than an acute admission mental health ward, because of how difficult she found the hospital environment. She was turned down for rehabilitation and admitted to the acute ward. In August 2011, Ms MN was placed on a hospital-based Compulsory Treatment Order which remained in place until her death in December 2012.

Ms MN's care in 2012

Ms MN was an inpatient in hospital A, a psychiatric hospital in Health Board A. In early 2012, a care plan was established whereby Ms MN was permitted to leave under suspension of detention and return to the ward as she wished.

When Ms MN was back living at home, there were numerous incidents of severe self-neglect, self-harm, intoxication and breaches of the peace that involved police intervention. Suspension of detention was stopped because Ms MN was assessed as being a severe fire risk in her flat.

When on the ward, Ms MN had frequent episodes of agitated and aggressive behaviour towards staff and other patients. She was, on occasion, physically restrained and sedated.

The pattern continued for several months. During her period on the ward, Ms MN was very frequently administered 'as required' medication for agitation, including zopiclone, midazolam, methotrimeprazine, quetiapine, lorazepam and chlordiazepoxide. Ms MN strongly influenced the type and frequency of medication she was given.

The transfer to the care home

In May, Ms MN's social worker identified a possible placement for her at a care home within Health Board B. The publicity for the unit within the care home described it as a purpose-built advanced specialist care home, designed to facilitate the special needs of individuals with a learning disability and other mental health complications. A process of admission planning took place over several months, before the move on 8th November.

Ms MN's views about the move to the care home fluctuated. On four occasions, in June, August, October and November, she appears to have attempted to hang herself, using her pyjama bottoms.

Ms MN was moved on 8th November 2012 under suspension of detention. There was no transfer of responsibility to specialist services in Health Board B.

A range of information was passed to the care home. There was no written care plan agreed between Health Board A and the care home about how staff should respond if Ms MN repeatedly asked for 'as required' medication, although there was a general verbal offer that care home staff could phone the ward regarding any aspect of her care.

A fax was sent by the consultant psychiatrist to the local GP practice on 23rd November 2012, two weeks after Ms MN's transfer. In the fax he apologised to the GP practice for the poor communication and wrote that a full discharge letter would follow. A junior psychiatrist wrote a discharge summary report, which eventually arrived at the GP practice nearly a month after Ms MN had died.

The GP practice had several contacts with the care home during the period of Ms MN's stay, but never met her.

During the period in the care home, there were several incidents where Ms MN sought 'as required' medication, and became distressed if it was not provided. This included expressing suicidal intentions.

Day of Ms MN's death

On the day of her death, support workers and domestic staff noted Ms MN's heightened levels of anxiety, and informed the registered mental nurse at lunchtime that Ms MN was talking about suicide.

Having given Ms MN 2mg of lorazepam 'as required' medication in the morning, the nurse rang the GP practice at 1.45pm. She had just given her 2mg more, and wanted to find out if she could give her another 2mg above her prescription. Ms MN was still agitated and the nurse was sure she would demand more later. The GP (who had never met Ms MN) suggested the nurse 'sticking to her guns', 'she can have two more now but would get no more later. Due meeting to which original psychiatrist is invited. Suggest staff bring this up at the time'. There was due to be a six-week review with the consultant psychiatrist in Health Board A the next day.

There was a short period of time during which Ms MN went to her bedroom. When this was noticed, the new member of staff went along to see if she needed support, and found her hanging from a rail in her wardrobe. She had used her trouser leg as a ligature. Resuscitation attempts began immediately and emergency services reached the unit within 15 minutes, but Ms MN could not be revived and she was pronounced dead at approximately 5.45pm.

Analysis

Assessment of Asperger Syndrome

There was never any specialist assessment of Ms MN's Asperger Syndrome. Even within the general context of people with autistic spectrum disorders, Ms MN's needs were particularly complex and challenging. We believe further attempts at specialist assessment would have been justified.

Even if this could not have been arranged while Ms MN remained in the community, her period of inpatient detention under the Mental Health Act would have afforded the opportunity to undertake this assessment.

Assessment of capacity

Ms MN's care was influenced by a clear view of the consultant psychiatrist that she had capacity in the context of the Adults with Incapacity Act. With autistic spectrum disorders, it is important to be clear that the absence of an identified learning disability, or a psychotic delusional state, is not conclusive proof of capacity. The test of incapacity at s1(6) of the Adults with Incapacity Act could be met where a person's disability means their ability to cope with a decision-making process is severely compromised. Ms MN's behaviour over a long period suggests someone whose responses were driven largely by an inability to cope with choices; an inability that was essentially a consequence of her disability.

Ms MN met the criteria for detention under the Mental Health Act. One of the necessary grounds for this is 'significant impairment of decision-making ability'. This is not the same test as incapacity, but addresses similar issues.

We believe that a specialist assessment of Ms MN's capacity to make decisions about her treatment and personal welfare should have been undertaken.

Responsibility for care

We believe people diagnosed with autism or Asperger Syndrome too often fall between mental health and learning disability services, or are pushed into one or other category, when their needs are distinct.

Formally, the consultant psychiatrist in Health Board A retained a lead role while Ms MN remained subject to the Mental Health Act. When Ms MN transferred to the new care home in Health Board B, no other consultant psychiatrist had accepted responsibility for her care, and there was no instruction for staff in the care home or the local GP practice to refer all complex decisions regarding her medication and treatment directly to her responsible medical officer, the consultant psychiatrist in Health Board A.

This left the local GP practice struggling to manage her medication, treatment and care, having never met Ms MN and having only minimal information about the complexities of her care.

GPs provide general medical services for individuals with a wide range of conditions. However, it should not be assumed that they can provide the specialist input and treatments required for residents with complex needs in care homes. This can often only be provided by doctors with the necessary skills and clinical expertise.

Handling discharge

We accept that attempts were made to pass over information to the care home so that they were aware of, and able to cope with, Ms MN's complex needs.

We do not believe that the care home understood the full range of Ms MN's needs, particularly in relation to responding to demands for medication and self-harming behaviour or threats. More should have been done to ensure that Ms MN's needs, and the approach which the hospital had taken to accommodating her behaviour, were fully communicated to the home, and an appropriate strategy to respond to this agreed amongst all concerned.

From the contact we can see between the care home and the GP practice, it is clear that the careful consideration and planning that would have been essential to ensure good communication and handover by the medical team from Hospital A was not in place. Once the medication that Ms MN was given by the hospital to take away with her had run out, the care home staff had to struggle to obtain repeat prescriptions and had to pass on information themselves to the GPs.

Overall, we conclude that there were significant clinical failures in the planning and execution of the transfer to the care home.

Was specialist care being provided?

One reason that a specialist clinical assessment may not have been obtained, even after Ms MN was detained in hospital and it would have been easy to arrange, was that shortly after her admission a specialist care home provider was identified. The care home advertised itself as providing advanced, specialist care, for people with a learning disability and behaviours that challenged services.

None of the individuals who identified the care home had previous experience of using it, and no detailed check was made that it was able to deliver the specialist service it advertised.

The consultant psychiatrist felt it was likely the care home would fail to manage Ms MN, but believed it was the best available option, and better than continued admission in the acute mental health ward, or discharge back to her own tenancy.

The care home was struggling to find staff with the essential skill; they were often reliant on agency nurses who had little or no experience of autistic spectrum disorder or Asperger Syndrome, and they were stretched coping with another resident who demanded a lot of staff time. The local manager had been given responsibility for the unit within the care home in addition to her already busy role. For many of the frontline support workers, it was their first experience of work in a care setting of any kind, and their induction was mostly by shadowing.

We do not believe the service was justified in claiming to offer a specialist service appropriate for Ms MN's needs at this time. We also conclude that the Health Board did not do enough to assure itself of the suitability of the placement. Notwithstanding the lack of any obvious alternative, there should have been a more thorough examination of the ability of this service to meet Ms MN's needs.

Training in ASD

One of the problems facing Ms MN was that, as well as the absence of specialist assessment, none of the medical or nursing staff we spoke to who worked with her had any significant training in the needs of people with autistic spectrum disorders. This was true even after she moved to the specialist care unit.

Management of risk of suicide

Even had the care provider been better established with experienced staff, they would have struggled to manage Ms MN. Her care plan was complex. She presented many demands on a service that needed a responsive and well-trained staff group, familiar with her needs.

The consultant psychiatrist did not think Ms MN presented as a high risk of suicide. When she said she wanted to kill herself, this was, in his opinion, an expression of distress and not an intention to die. For this reason there were no risk assessments completed to guide care staff regarding suicidal ideation. The care home staff we interviewed could not recall being told about her regular threats to kill herself, and none was aware that in the months prior to her transfer to the unit she had attempted suicide on four occasions, using exactly the same method that she eventually used in the care home.

In our view, there was a known and high risk that Ms MN would attempt to harm herself and, whether intentionally or otherwise, end her life. The response to this should have been clearly identified and agreed.

Managing medication

During her last admission to the hospital ward, Ms MN frequently demanded her medication be changed, and often increased. If this did not happen almost immediately, it was well recorded that her behaviour would become challenging, and she would threaten self-harm or become aggressive to others. When she was discharged from the ward on suspension of detention her medication was still in flux, changing on a regular basis with junior doctors routinely being called to the ward to discuss and authorise changes in her medication.

Staff in the care home were aware that she may demand additional ‘as required’ medication, but there was little thought given as to how this might be agreed or altered and authorised. In this situation, it was inevitable that Ms MN would struggle when she felt she needed more medication, and her anxiety would have been considerable when she discovered, as in fact she predicted, that staff did not know how to respond to her in these circumstances.

As a result of the confusion, and poor communication, transfer letters arrived too late, and GPs who never met Ms MN were being expected to make decisions about her complex medication regime based on minimal knowledge or understanding of her complex needs.

Investigation of the incident

When the Commission first heard about the death of Ms MN, we were told that Health Board A did not feel it was their responsibility to carry out a critical incident review. If the Commission had not followed this up, there would have been no review into the circumstances of the death of Ms MN.

When a Health Board A review did proceed, it took place without any representative from the care home and focused on Ms MN's care in hospital and was very positive about the standard of care she had been provided in hospital. It did not identify any learning. The review barely mentioned that she was still on suspension of detention at the time of her death, did not mention any of the several similar attempts she had made on her life in the preceding months, and did not link the disorganised transfer of her follow-up medical care over to Health Board B, and the GPs, as a possible factor in her death.

The wider policy context

Autism can be a serious, lifelong and disabling condition that affects the way a person communicates with, and relates to, other people and how they experience the world around them. Some people with this diagnosis can manage with very little or no support, many need a wide range of supports to live their life, and a few can only manage with 24-hour care. In Scotland, specialist autism services are not widely available, although the situation is improving, with a few providers offering a limited range of services in each area, but with few services on offer specifically for adults with autism within the NHS.

In 2011 the Scottish Government announced the *Scottish Strategy for Autism*, a national 10-year autism strategy to put focus on the implementation by Health Boards and local authorities of existing legislation and duties. At the launch, the Minister for Public Health announced that the Scottish Government would provide £13.4 million, over four years to support implementation of the strategy. None of this funding was used specifically in Health Board A.

The implementation of the Scottish Autism Strategy appears to have been piecemeal across Scotland, with areas of excellence and others where it has had less impact. In December 2015, the Chair of the National Project promoted the need for local authorities to focus on access to integrated service provision across a person's lifespan and the importance of building on the capacity and awareness of mainstream services to understand the needs of people with autism[1].

There is no easy and quick solution, but we cannot accept that people with autistic spectrum disorder and complex needs should expect to be fitted into services designed for very different client groups, with a tacit acknowledgment that, while people are doing what they can, it is unlikely to succeed. No-one is beyond help, and Ms MN's tragic death has lessons which we need to heed.

[1] http://www.autismnetworkscotland.org.uk/scottish-strategy-for-autism-fourth-annual-conference/

Recommendations

Specialist assessments

For joint health and social care bodies

1. Where behaviours related to Asperger Syndrome and other autistic spectrum disorders are a significant factor in a person's presentation, and the clinical lead or responsible medical officer has not had training in autistic spectrum disorders, a specialist assessment should be obtained to aid management and care planning.

For psychiatrists and social workers

2. Where an adult with Asperger Syndrome or other autistic spectrum disorder is behaving in a way which puts themselves at serious risk, and this behaviour is felt to be attributable to the condition, a specialist assessment of capacity and decision-making ability should be undertaken to inform possible interventions under the Mental Health (Care and Treatment) (Scotland) Act 2003, the Adults with Incapacity (Scotland) Act 2000, or the Adult Support and Protection (Scotland) Act 2007.

Commissioning specialist services

For the local Health Board

3. Health Board A should review its commissioning procedures to ensure it can be satisfied that, when commissioning a specialist service from a third sector or independent sector provider, the agency is able to deliver a service which is appropriate for the needs of the person/s receiving care or treatment, including having appropriately trained and experienced staff.

For the Care Inspectorate

4. The Care Inspectorate should review how it can be satisfied that specialist services which are predominantly designed for people with learning disabilities or mental health problems are able to meet the needs of people with autistic spectrum disorders placed in their care.

Discharge planning

For Health Boards and integrated joint boards

5. Bodies discharging people with complex needs to specialist services should ensure that there is a robust and safe process of preparing for discharge and managing the handover to specialist services, including:

   - formal discharge planning meetings, involving all relevant staff including from the care provider, sufficient to ensure effective handover of information and allow good quality care and treatment to be provided following discharge;

   - an agreed medication care plan where there is a complex medication regime in place, to assist the care provider in managing medication, and to make clear whether changes to medication should be through the responsible medical officer or the GP;

   - information immediately available at discharge to the GP followed by a comprehensive discharge letter within locally agreed timescales, usually within 7-10 days. In complex cases the consultant psychiatrist should telephone the GP prior to discharge to discuss the case; and

   - clear follow-up and secondary care arrangements which are understood by all parties involved.

For Health Boards and Responsible Medical Officers

6. Where an individual remains subject to the Mental Health Act following discharge, for instance on suspension of detention, the RMO, or their clinical team, unless clearly agreed otherwise, should be the first point of contact by support staff regarding medical treatment that is not standard in general practice. The RMO should be satisfied that he or she is able to carry out their Mental Health Act responsibilities for the care and treatment of the individual following discharge.

For the Scottish Government

7. Arrangements for registration with GPs should be reviewed to ensure that information can be passed on and responsibilities agreed before a person moves to a new service, not only after the move has taken place.

Investigation of serious incidents

For the Scottish Government

8. The review to be held into the investigation of deaths of detained patients and inpatients under section 37 of the Mental Health (Scotland) Act 2015 should also consider deaths by suicide of patients who are under suspension of detention.

For Health Boards

9. Pending the outcome of the s37 review, NHS Boards should ensure that a critical incident review takes place when an individual dies by suicide while on suspension of detention or a community-based Compulsory Treatment Order, or within 12 months of moving from inpatient mental health care to community-based residential services.

Development of services for people with autistic spectrum disorders and complex needs

For the Scottish Government and the Autism Strategy Governance Group

10. The Scottish Government should audit the availability of specialist services for individuals with highly complex needs who are not appropriately accommodated in learning disability or mental health settings, and identify how gaps can be filled.

11. The Autism Governance Group should review the issues raised by this case and consider the implications for the implementation of the current autism strategy, particularly what more can be done to ensure staff in mental health and learning disability services are trained to meet the needs of autistic spectrum disorders who use their services.

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