mentalwelfare commission for scotland

dignity & rights ethical treatment respect care & equality

EXECUTIVE SUMMARY

Left alone - the end of life support and treatment of Mr JL

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This investigation was conducted under Section 11 of the Mental Health (Care and Treatment) (Scotland) Act 2003. Section 11 gives the Mental Welfare Commission (the Commission) the authority to carry out investigations and make related recommendations as it considers appropriate in a number of circumstances, including where an individual with mental illness, learning disability or related conditions may be, or may have been, subject, or exposed, to ill treatment, neglect or some other deficiency in care or treatment.

We are particularly keen to investigate when we think other people may be having similar problems and where there have been mistakes that we feel other professionals could learn from.

Background

Mr JL lived in a remote area of Scotland. He had cognitive difficulties and significant communication difficulties due to a stroke and past alcohol misuse and had a history of depression. He could be uncooperative with medical and social care staff if they went against his wishes.

He died after refusing medical examination and treatment and refusing food/drink. The post-mortem concluded that the cause of death was pneumonia and carcinoma of the tongue and floor of the mouth. We had concerns that he may not have had the capacity to consent to or refuse medical treatment and that both social care and health service staff may have missed opportunities to intervene and afford him the benefit of a new assessment and a palliative care plan to give him as comfortable and dignified a death as possible.

Chronology of Events

In 2006, Mr JL was referred, by his GP, to the community mental health team in area A for anxiety and depression and was seen by a community psychiatric nurse. There was no further contact until April 2009.

April 2009 – the police contacted social work after contact with Mr JL. Mr JL was found disorientated in his local post office and was taken to hospital. A CT scan provided a provisional diagnosis of cerebral atrophy consistent with ischaemic change or small vessel disease. He was noted to have severe difficulties with comprehension and communication of both written and spoken language. He was seen by a psychiatrist who confirmed the earlier diagnosis and identified the need to assess capacity.

May 2009 – a case conference was held with Mr JL present. Although no definite diagnosis was confirmed, it was thought he had some form of dementia. A referral was made to advocacy services. Outreach staff, from a social care provider, were allocated for one hour daily to monitor his medication, nutrition and self care as he was still living in a caravan.

June 2009 – he was referred to a neuropsychologist, and the assessment report noted cognitive difficulties and significant receptive and expressive language deficits. It also identified the need for occupational therapy (OT), SALT input and increased social opportunities and improvement in his housing situation.

July 2009 – a review meeting noted the lack of hot water, a working shower, and laundry facilities in his caravan, though he would not consider alternative accommodation. He also needed staff support with paying bills and other financial matters.

October 2009 – his GP noted that he was sad and tearful on occasions with low mood but he had no suicide plans.

December 2009 – he was found unconscious at a bus stop with a minor head injury.

January 2010 – concerns about his capacity and the possible need for welfare guardianship were discussed at a case conference. It was decided that an assessment of his capacity should be pursued.

March 2010 – he was seen again by the neuropsychologist but formal assessment proved difficult. It was the neuropsychologist's view that there was some deterioration in functioning. Social care staff,

however, reported he was developing good relationships with them and with advocacy and, although the situation with the caravan remained concerning, there was no urgent need to remove him. He was discharged from neuropsychology at this point.

July 2010 – an assessment by the consultant psychiatrist, on a joint visit with his MHO/social worker, found Mr JL to be cognitively impaired, and possibly vulnerable, regarding his finances. The psychiatrist diagnosed a fixed dementia of mixed aetiology (permanent rather than fluctuating with alcohol intake or mood) and it was determined he was likely to lack capacity in various areas and should be assessed where appropriate. This information was put in a letter from the consultant psychiatrist to the general practitioner.

September 2010 – Mr JL moved to a new tenancy after staff worked hard to persuade him of the benefits of this. He appeared to settle quickly into his new sheltered housing with continuing support from his social care workers, employed by the local authority.

November 2010 – the MHO decided to close Mr JL's case following his move to his new tenancy and it is reported that he was keeping well at this time; the only problem recorded being occasional pain in his legs. There was daily contact from social care staff and they noted continuing improvement in his speech and understanding. Although the MHO had no contact thereafter, the case was not formally closed and coordination of his care passed to the care provider until July 2011.

December 2011 – staff noticed that Mr JL might be developing an abscess in his mouth but he did not want to go to the dentist.

February 2012 – Mr JL, with support from social care worker A, contacted a solicitor to make a will. With staff assistance he had recently sorted out his work pensions and lump sum. He was still noted at this time as having a swollen cheek.

March 2012 – one of the social care workers phoned the GP without Mr JL's consent as the workers were concerned about a swelling on the left side of his face, some weight loss and a decline in his wellbeing. Mr JL had refused to make an appointment to go to the GP, despite many attempts to persuade him by the social care staff. Mr JL was visited by GP A on 16 March 2012. He refused examination of the swelling but agreed to take a course of antibiotics. On 30 March 2012, he was seen by GP A on a home visit. It was noted that the swelling looked no better, but he again refused an examination, bloods or a dental referral. A second course of antibiotics was prescribed and he reluctantly agreed to take these.

6 April 2012 – he was seen again by GP A at a home visit. Staff had asked GP A to complete a do not attempt cardio-pulmonary resuscitation (DNACPR) form but GP A was reluctant to do this as he was not clear if Mr JL had capacity to make this decision. The social care worker present indicated that he was refusing food in order to die.

GP A wrote a letter of referral marked 'urgent' to the community mental health team (CMHT). He sought advice about Mr JL's capacity to request the DNACPR, his capacity to instruct a solicitor about his will and his concerns that Mr JL was refusing food so he could die. There were conflicting accounts of the sending and receiving of this letter, which we were unable to determine satisfactorily. We know that it was not processed by the CMHT and GP A did not follow up the lack of response from the CMHT.

6 April to 3 May 2012 – Mr JL cancelled many of his daily visits from the social care staff. In the last three weeks of his life he was receiving only three visits per week from the same member of staff, social care worker A.

3 May 2012 – another social care worker was called to help social care worker A, who was trying to assist Mr JL to sit up in bed to drink. When she reported the situation back to her line manager, the senior social care worker, he called GP A against Mr JL's expressed wishes. He told GP A that Mr JL had last eaten something three weeks previously and that he wanted to die and did not want to go to hospital. GP B, the duty GP, made a home visit later the same day. Mr JL was lying in bed and GP B was reportedly shocked by what he saw. He decided to leave it until the next morning to discuss with his colleague, GP A.

Social care staff made three visits to Mr JL on 3 May and the senior social care worker and manager of the service made four visits the following day to support Mr JL.

4 May 2012 – GP A visited Mr JL with the duty MHO as he was unsure about his legal authority to admit Mr JL to hospital.

Following discussion with the duty MHO, Mr JL agreed to being admitted to hospital. There was confusion at the hospital as to whether they needed to inform and involve his next of kin and whether they were expected to actively treat Mr JL or not.

The consultant hospital physician told us she wanted to discuss the situation with the next of kin to find out if they knew about any previously expressed wishes but was told categorically by the social care provider that he did not want this. The social care provider told us they had not said this.

The consultant physician took the decision to make him comfortable as she did not believe she could save his life by this point.

6 May 2012 – Mr JL died aged 65. The post-mortem concluded that the cause of death was pneumonia and carcinoma of tongue and floor of mouth.

Reason for investigation

To examine in detail the care, treatment and support Mr JL received in the 18 month period prior to his death on 6 May 2012.

We gave particular attention to:

- the assessment of Mr JL's capacity in relation to making decisions about medical treatment;
- the eight weeks prior to his death and the actions taken by care staff and the multidisciplinary team in response to his changing physical and mental presentation;
- the knowledge and understanding of capacity and consent to treatment of the care staff and multidisciplinary team caring for Mr JL during this period of time;
- making recommendations about the medical care and treatment of people where mental illness may impact on their ability to make decisions about their medical treatment.

We wanted to find out more about what led to Mr JL's poor physical condition before his admission to hospital. The Commission decided to review the care, support and treatment he received in the period prior to his death. We were concerned that he seemed to have eaten very little and had little fluid over an extended period of time, despite receiving care at home from a registered care provider. On admission to hospital Mr JL was found to weigh 29kg (4½ stone).

We had concerns that Mr JL may not have had the capacity to consent to or refuse medical treatment. Social care and health service staff may have missed opportunities to intervene and afford him the benefit of a new assessment and, if necessary, a palliative care plan to give him as comfortable and dignified a death as possible.

We had concerns about how the social care provider managed the care of Mr JL and we looked closely at this.

Summary and conclusions

Mr JL died of cancer of his mouth and tongue. In the last month of his life and possibly before that, he did not, in our view, receive appropriate medical care. The causes of this were:

- the failure of GP A to arrange follow up action when he was concerned about Mr JL's condition, in particular when he was told he was not eating in order to die. He also failed to follow up an urgent referral he made to the CMHT.
- the failure of the social care provider to identify and escalate concerns about an adult at risk, partly due to their reliance on a sole worker and partly due to ineffective supervision and management of that worker
- the failure of both agencies to initiate multidisciplinary discussion about the issues with Mr JL – his deteriorating health, his failure to eat and his expressed wish to die, the dubiety about his capacity in specific areas and his reluctance to accept medical treatment. Crucially there was a lack of communication between GP A and the care provider and between GP A and the CMHT
- the failure to put a palliative care plan in place despite a general view that Mr JL wanted to die at home
- poor knowledge on the part of some key medical staff of the relevant legislation and the options available under the legislation
- uncertainty over Mr JL's capacity to consent or refuse consent to medical treatment. Despite the need for assessment of capacity having been raised on three occasions and the psychiatrist's view that "he was likely to lack capacity in various areas and should be assessed where appropriate", no specific assessment was carried out on his capacity to refuse or consent to medical treatment
- lack of effective governance arrangements within the local authority which was responsible for assessment, care management and service provision
- Mr JL's reluctance to accept medical intervention and the pressure he exerted on care workers in order to avoid visits that he did not want.

In addition we had concerns about:

- the quality of the Critical Incident Report and the lack of a clear action plan and time scales for addressing the issues above to ensure corrective action has been taken by health and social work
- the failure to provide information to Mr JL's next of kin, including the funeral arrangements.

RECOMMENDATIONS

We make the following recommendations to the care provider, local authority, the NHS Board responsible for Mr JL's care and treatment and the Scottish Government.

We would especially like to highlight our recommendations to the social care providers and feel that the lessons that can be learnt from this should be noted by other similar organisations across Scotland.

A. General medical practice

- The practice should ensure that there is an effective system in place for follow-up where patients have ongoing issues of urgent concern.
- Whilst we appreciate that the practice has made improvements, for instance in the completion of certificates of incapacity under Part 5 of the AWI Act, we recommend a training needs assessment for all relevant members of the primary care team in relation to assessment of incapacity and the requirements of incapacity.
- Again, whilst noting improvements, for instance, in their referral systems and availability of time to follow up patient issues, the practice should ensure that there is an agreed method of referral to mental health services and that this is operating efficiently.

B. NHS Board

- The NHS Board should ensure that medical practitioners in the area have sufficient training in incapacity legislation and the basics of mental health and Adult Support and Protection legislation to understand their functions and responsibilities under the Acts.
- The NHS Board should review the role and function of consultant psychiatry in the area and focus their expertise on the more complex aspects of incapacity and mental health assessments. The NHS Board should ensure access to peer support and access to a greater range of expertise via an obligate clinical network.[1]

[1] Obligate networks should be established between NHS Boards to sustain core services and ensure access to four key specialist services not routinely available in Rural General Hospitals (RGHs), including Child Health, Mental Health, Radiology and Laboratories

C. Local authority

Governance

- The local authority must review governance arrangements to ensure clarity in line management responsibilities and better communication within and between assessment and care management services and those responsible for service provision.

Social Care Provision

- Sole working should be kept to a minimum as it can increase the risk to the service user and the provider. Team working allows cross checks to be put in place and avoids singleton workers getting so involved with a service user that they lose perspective on the situation. While sole working may be appropriate or necessary in certain circumstances, nevertheless, the management of the social care service needs to ensure measures are in place to safeguard the service user in such situations. Spot visits by managers, checking with other professionals where they are visiting, reading daily records, and more frequent supervision are among the measures that should be considered.

- Line managers must be proactive in investigating the circumstances when a service user is disengaging with their care plan by, for instance, cancelling visits or cancelling visits by particular social care workers. In such circumstances line managers should be enquiring further into the circumstances from the social care worker, reading the daily records or visiting the service user themselves to assess the situation.

- Managers of the service need to be proactive in referring to social work services or triggering a multidisciplinary discussion where there are concerns, particularly where there is doubt about capacity or possible adult protection issues, or the potential need for an anticipatory/palliative care plan.

- Training is required to ensure social care workers understand the threshold for sharing issues with their line manager.

- The local authority should ensure that Adult Support and Protection training and refresher training provided is meeting the needs of all their staff in order that they can recognise and alert their line managers to situations where an adult is at risk of harm or neglect.

We are aware that the local authority social care provider has identified and is acting on most of the recommendations above. Other social care providers should take note of these recommendations.

Assessment and care management services

- Multidisciplinary case discussions, where an adult is at risk, should always review the relevance, need and potential usefulness of incapacity or adult protection legislation. The reasons for using or deciding not to use such legislation should be clearly documented following such discussions.
- There needs to be clarity within the local authority on the respective roles and responsibilities of social work assessment and care management services and their relationship with the council's social care providers. This should include, on an individual case basis, details regarding communication between different parts of the council when concerns arise about individuals and the support they are receiving.
- The service should audit case records to ensure these are of an acceptable standard and indicate the contacts with other professionals and with the service user.

D. NHS Board, local authority and the Adult Protection Committee

- The NHS Board with their local authority colleagues, including the Adult Protection Committee, should review their system for critical incident reviews to ensure it meets the recommendations of the 2013 HIS report. In relation to Mr JL they should, with their social work colleagues, ensure that a detailed action plan is in place and the implementation of this is reviewed and updated.

E. Healthcare Improvement Scotland

- Healthcare Improvement Scotland (HIS) should review "Learning from adverse events through reporting and review: A national framework for NHS Scotland" to take account of the national guidance on serious case reviews which is being developed by the Scottish Government. In particular, HIS should make reference to local authority responsibilities under Adult Support and Protection legislation and carry out its stated intention to integrate the management of adverse events across health and social care. Where the adverse event involves social care management or takes place in a social care setting a social work professional with experience relevant to the event being reviewed should be involved in the review.

F. Scottish Government

- The development of national guidance on serious case reviews for local authorities should make reference to Healthcare Improvement Scotland's "Learning from adverse events through reporting and review: A national framework for NHS Scotland" and consider the integration and coordination of these processes wherever possible.

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