mentalwelfare
commission for scotland

Ms R Report

Challenges in providing physical healthcare for an individual who cannot understand or consent

Contents

Who we are

We put individuals with mental illness, learning disability and related conditions at the heart of all we do: promoting their welfare and safeguarding their rights.

There are times when people will have restrictions placed on them to provide care and treatment. When this happens, we make sure it is legal and ethical.

We draw on our knowledge and experience as health and social care staff, service users and carers.

Our values

Individuals with mental illness, learning disability and related conditions have the same equality and human rights as all other citizens. They have the right to:

- Be treated with dignity and respect;
- Ethical and lawful treatment and to live free from abuse, neglect or discrimination;
- Care and treatment that best suits their needs;
- Lead as fulfilling a life as possible.

What we do

Much of our work is at the complex interface between the individual's rights, the law and ethics and the care the person is receiving. We work across the continuum of health and social care.

- We find out whether individual care and treatment is in line with the law and good practice.
- We challenge service providers to deliver best practice in mental health and learning disability care. Sometimes we investigate where something has gone seriously wrong with a person's care.
- We identify and promote good practice in mental health and learning disability services.
- We provide information, advice and guidance to service users, carers and service providers.
- We have a strong and influential voice in service and policy development.
- We promote best practice in mental health and incapacity law.

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. Section 11 of the Mental Health (Care and Treatment) (Scotland) Act 2003 gives the Mental Welfare Commission (the Commission) the authority to carry out investigations and make related recommendations where we believe that a person might have been ill- treated, neglected or received deficient care or treatment.

Ms R was subject to welfare guardianship in terms of the Adults with Incapacity (Scotland) Act 2000 (the 2000 Act). In April 2011, we received a telephone call for advice about the care and treatment of Ms R. The mental health officer (MHO) who exercised the day-to-day delegated functions of the Chief Social Work Officer of the local authority as welfare guardian contacted us. Ms R was in a care home, seriously unwell with suspected cervical cancer, lacked capacity and refused treatment. She had suffered a major vaginal bleed, appeared to be in discomfort and refused intervention. The MHO asked us for advice on how to proceed. We were concerned that staff had decided not to intervene, so we gave advice about how they might treat her. Shortly after that, we heard that Ms R had died.

We agreed with the NHS, local authority and care home staff that they would review Ms R's care and report to us on their findings. Following this, we arranged to meet most of the practitioners involved. We wanted to examine the difficulties staff experienced when deciding whether or not to intervene when Ms R refused care and treatment for physical health problems. This case came to light as we were finalising good practice guidance in this difficult area.

The terms of reference for this review were:

- To examine the care and treatment of Ms R from the time that cancer was suspected in 2006 until her death in 2011;
- To examine the process by which practitioners made decisions about her care and treatment when she lacked capacity and refused intervention;
- To make recommendations about practice in this difficult area.

Methodology

In undertaking this review, we undertook to:

- Review relevant case records for the time period in question;
- Examine the internal review of Ms R's care;
- Conduct a further review meeting with relevant staff;
- Analyse the information in order to determine whether there had been any deficiency in Ms R's care, the causes for this and the action needed to address the causes.

Investigating team

The investigation was conducted by the following MWC staff:

Mrs Susan Tait, Nursing Officer.

Dr Donald Lyons, Chief Executive.

Practitioners interviewed

We were grateful to the following staff for their input to the investigation process.

The practitioners who participated in the review meeting were:

- The mental health officer (MHO) who exercised the delegated guardianship functions of the Chief Social Work Officer;
- The staff and managers of the care home where Ms R lived for the last six months of her life;
- The general practitioner (GP2) who provided input to the care home.

We also heard separately from the consultant psychiatrist who acted as the responsible medical officer (RMO) for Ms R under mental health legislation and maintained input after the episode of compulsory mental health treatment ended.

Relevant background information about Ms R

Ms R was a single woman who had worked as a schoolteacher for many years. During the time of her contact with mental health and social care services, she lived in a large house that had formerly been bed and breakfast accommodation. It was left to her by her parents. She lived there up to, and following, her initial admission to mental health care in 2003, until she was admitted in October 2010 to the care home where she eventually died.

Ms R was known to have a significant degree of brain damage, mostly as a result of previous heavy drinking, with possible additional damage from head injuries.

She had a prolonged admission to mental health care in 2003-04 under the Mental Health (Scotland) Act 1984. Before admission, she had been found lying by the side of a road apparently having been drinking and had sustained a head injury.

In hospital, records indicate that she had very poor short-term memory, spells of aggressive behaviour and also significant depression. She improved during her stay in hospital, although was upset because she spent some of her time in a ward with older people who had more severe degrees of dementia. This experience may have led to the fear of hospitals that resulted in her later reluctance to accept medical investigation and treatment.

She was granted leave from hospital and returned home with support from family and paid carers. This was mostly successful, although she remained reluctant to accept that she needed extra help because of her poor memory. She also appeared to lack the ability to consent to medical treatment. The RMO revoked the compulsory order and medical care reverted to her own GP (GP1) with continued advice from the RMO.

The local authority applied for welfare guardianship. This was granted in June 2005 for three years. The Chief Social Work Officer was granted the powers to:

- Decide where she should live;
- Consent or withhold consent to medical treatment;
- Pursue, defend or compromise any legal action in relation to her personal welfare;

- Provide access to medical treatment, dentistry etc;
- Make decisions on her social and cultural activities;
- Decide with whom she should or should not consort;
- Take her on holiday, or authorise others to do so;
- Secure access to carers in order to provide care, including care in her own home.

The MHO who alerted us to subsequent problems exercised the delegated day-to-day functions of the Chief Social Work Officer. Ms R had previously granted financial power of attorney to a solicitor.

An officer of the Commission visited Ms R at home in July 2005 and reported that her accommodation, treatment and support were of good quality. Problems started from 2006 onwards.

Chronology from 2006 until death in 2011

In 2006, Ms R was found to have a positive cervical smear test. This meant that further investigation was indicated to look into the possibility of cervical cancer. The local review supplied us with an account of the events that followed this finding.

17 March 2006

Ms R attended hospital for an appointment to investigate the smear findings. She became very distressed and refused all investigations.

9 May 2006

The MHO, psychiatrist, gynaecologist and carers held a planning meeting to look at how Ms R could be best supported to have further investigation. She would stay overnight with carers, and receive some sedation before going to hospital. Unfortunately, she again resisted all interventions.

12 June 2006

A further meeting looked at the options available. The practitioners agreed not to pursue further investigation in view of the distress caused to Ms R.

29 November 2006

Ms R was found unconscious on the floor at home and admitted to hospital. She made a good recovery but refused all investigations. The cause of the episode of unconsciousness was never found. After this, she was recorded as having a further similar episode. She was not taken to hospital. She stayed with a family friend overnight.

4 June 2008

The Sheriff renewed the welfare guardianship order for a further five years. The powers of the guardian were not changed.

29 May 2009

GP1 and the MHO were concerned about Ms R's physical health. She was losing weight. They visited her together at home. Ms R was angry, had not wanted a visit and only allowed GP1 to examine her standing up.

3 August 2009

The MHO attempted to take Ms R to an appointment with GP1. She refused to attend.

27 July 2010

Ms R was admitted to hospital under an emergency detention certificate. She was aggressive to carers, and had started fires in her house due to smoking in bed. Her health and safety were at risk.

28 July 2010

She was detained further under a short-term detention certificate. This certificate stated that she required investigation into her weight loss and reiterated the concerns about her safety at home.

29 July 2010

The MHO provided further information in a social circumstances report. She recorded concerns about the amount of care and supervision needed at home. She also mentioned poor diet, weight loss and evidence of bloody discharge on Ms R's undergarments. The source of the discharge was unclear, but the report draws attention to the previous abnormal cervical smear.

12 August 2010

The RMO revoked the short-term detention certificate. This was because Ms R was not stating a desire to leave hospital and was accepting treatment. During her hospital stay, it was recorded that she allowed vaginal examination, but she refused to attend for a specialist gynaecology appointment.

2 September 2010

Ms R was transferred from hospital to the care home. The welfare guardian had decided on her place of residence. Ms R initially refused to go. The Sheriff had granted a compliance order under section 70 of the Adults with Incapacity (Scotland) Act 2000 but she eventually agreed and the order was not enacted. At first, she was eating better, put on some weight and was allowing staff to assist with some personal care tasks. She was registered under the care of the GP who provided input to the care home (GP2) on 7 September and GP2 first saw her two days later.

21 January 2011

The MHO convened a review meeting to examine how the residential care placement was progressing. Ms R remained underweight, although her weight was described as stable at that time. She ate at least one good meal a day. There was dietician involvement. The GP was unable to attend the review but had obtained satisfactory results from recent blood tests. Again, the question of serious underlying physical illness was discussed. The view of the psychiatrist was that attempts at further investigation would be difficult due to Ms R's resistance. Also, as it would be very difficult to gain her cooperation with treatment, the benefit of any further investigation was likely to be minimal. However, this was to be kept under review as her views may change, especially if she experienced pain.

February 2011

Ms R was suffering increasingly heavy, blood-stained vaginal discharge. GP2 discussed her case with the gynaecologist who recommended hormonal drug treatment to reduce bleeding. Ms R refused to take the drug. GP2 and the psychiatrist discussed whether or not to administer medication covertly and decided against this.

4 April 2011

Relatives expressed concern. Ms R was refusing to wear pads and only accepting a shower once a week. Diet was poor; she would only eat yoghurt, pudding and biscuits. The diet problem was not new; she had unusual eating patterns of this sort while she was at home.

8 April 2011

Relatives asked that force be used to provide Ms R with care and treatment. GP2 was asked, by letter, for advice on this. Unfortunately, GP2 was on leave until 16 April.

10 April 2011

Ms R had a large vaginal bleed. She allowed pulse and blood pressure to be taken but refused all other interventions, including personal care to make sure she was clean. GP3 (covering for GP2) was called for advice and recommended a palliative approach only. The MHO recorded that she took advice from the Commission on covert medication.

13 April 2011

The MHO held a discussion with care home staff about possible covert medication and the difficulty they were having providing ongoing care due to Ms R's refusal to accept intervention.

19 April 2011

The MHO and GP2 discussed Ms R by telephone. GP2 told the MHO that her legal advice was that force could not be used. Intervention under the Mental Health (Care and Treatment) (Scotland) Act 2003 was not advised as treatment was for physical disorder, not mental disorder.

20 April 2011

Ms R had stopped eating and drinking. She lay in bed, refused intervention and refused to have soiled bedclothes changed. Emergency detention to admit her to hospital was considered and rejected. She did not appear to be in pain or distress. The MHO and GP again discussed covert medication. A care pathway form was completed but then filed in GP records and not used.

21 April 2011

Ms R was heard wailing in her room and refused to let carers in. Staff again wanted Ms R to be admitted to hospital. They felt unable to use restraint to provide care. The MHO contacted the Commission who sent draft guidance on the use of force for physical healthcare. However, Ms R accepted care later in the day.

22 April 2011

By this time, it was clear that Ms R was dying. The Liverpool care pathway was used, and she died peacefully that day.

Overview of the problem

Ms R was a professional woman. She wanted to be independent and had previous bad experiences of being in hospital. Despite her brain damage and poor memory, it appeared that she had some memory of unpleasant experiences of hospital. She had increasing evidence of a likely cervical cancer, starting from her abnormal smear in 2006, through the decline from mid-2009 onwards and progressing to her eventual death in April 2011.

When we heard about the problems in administering health care to Ms R, we were concerned that, despite the Chief Social Work Officer's authority to consent to treatment, there were some important aspects of healthcare that were not being provided because of Ms R's refusal. We examined the documentation held by the practitioners involved, including the record of their own review of Ms R's care. We met most of the practitioners in November 2011 to review further the actions taken during the final days of Ms R's life. The following analysis is a combination of the initial internal review and the subsequent discussions at the November meeting.

Good practice

We found much to commend in the care and treatment of Ms R. Some of this is reflected in our analysis of the critical decision points during this period. The general points we wish to highlight are:

- A strong focus on Ms R's own views. For example, she was so distressed about being in hospital that there was an agreement to allow her home with as much support as could be provided, even though more would have been ideal. The risk was carefully considered and the situation closely monitored;
- The use of welfare guardianship to provide care in her own home. In many previous reports, for example 'Best of Intentions[1],' we identified that this option had not been given enough thought. It was good to see that the local authority and the NHS staff had used guardianship in this way;
- The continued involvement of the MHO. It was good to see that the MHO stayed heavily involved and was active in trying to secure the best care and treatment for Ms R;
- The attention from general practitioners, especially GP2. In a difficult situation, GP2 did her best to attend to Ms R's needs and maintained good contact with the care home staff and the MHO;
- The attentiveness of the care home staff. They were clearly very fond of Ms R and had a difficult task trying to provide the best care they could when she resisted interventions. She was a native Gaelic speaker and the care home made sure that she had contact with staff who spoke Gaelic;
- The continued involvement of the consultant psychiatrist. He had been her RMO while she was detained in hospital and remained involved and supportive to Ms R, the MHO, GPs and care staff;
- The time limits on the duration of welfare guardianship. We have expressed serious concerns about the use of indefinite guardianship especially for people with alcohol-related brain damage as there can often be improvement in this condition. It was good to see that guardianship was authorised for time-limited periods.

1 http://reports.mwcscot.org.uk/web/FILES/Investigationsreports/Best_Intentions.pdf

Critical decision points

There were, broadly, three major decisions to make in relation to Ms R's resistance to medical treatment. These were:

1) Her refusal of further investigation following the initial abnormal cervical smear in 2006;

2) Her refusal of further physical healthcare when there was evidence of decline from mid-2009 onwards;

3) Her refusal of care in April 2011 following a major bleed, following which a palliative approach appeared to be indicated.

We have used the practitioners' own review of these decision points and added our own views and recommendations, especially when considering the last of these decision points.

1) The abnormal cervical smear

We have already stated that there was discussion among practitioners and carers about this. We read a detailed account of a multidisciplinary case conference held on 12 July 2006 to examine the options for further investigation when Ms R refused this. The conference involved many of the practitioners directly involved and included the principal mental health officer for the council.

We were pleased to see that the case conference addressed all the issues in a thoughtful and logical manner. This included:

- Confirmation that medical assessment had been undertaken and that Ms R lacked the capacity to consent or refuse consent;
- Consideration as to whether or not the use of force could be justified, with reference to S47 of the 2000 Act;
- A record of all the steps taken to avoid any use of force, including all possible support for Ms R and relaxation of usual procedures to give her maximum opportunity to engage with treatment (such as allowing her to keep her own clothes on when going to theatre). A psychologist was working with carers on ways to encourage Ms R to accept care and support;
- A careful analysis of the pros and cons to the use of force to achieve the desired intervention, by reference to the principles of the 2000 Act. There was particularly detailed analysis of benefit versus harm, Ms R's own views and the views of all practitioners, relatives and carers.

The outcome of the meeting was that practitioners would not pursue further investigation. The decision was made in the knowledge that she may have cervical cancer. Intervention at that stage may have resulted in effective early treatment, but the distress that she would have experienced would have been so severe that it would have been disproportionate to the possible benefit from the procedure.

The meeting appeared to have been well-conducted and all parties appeared to agree on the outcome. We understand the view that they reached and have no reason to argue with it. Had they decided that force may have been an option the MHO or any other party could have made an application to the Sheriff under S3 of the 2000 Act for a direction as to whether the guardian could authorise force. Alternatively, the guardian could have sought a compliance order under S70 of the Act. We are satisfied that it was not appropriate to make such an application, given the careful consideration given to all the issues.

We were also pleased to see that this decision would be reviewed. There was no subsequent evidence that Ms R's views and decision would have changed.

The implication of this decision was significant. If there was cancer present and it was not treated at this stage, the chance of future treatment having any major impact on her length and quality of life would be much less. Also, as was stated by many practitioners, it would be very difficult to provide ongoing treatment in the face of Ms R's strong resistance.

2) Deteriorating health

The MHO and GP were concerned about Ms R's general health and weight loss from the middle of 2009 onwards. The weight loss and evidence of discharge, likely to be vaginal, made the possibility of serious physical disease likely. The MHO recorded her attempts to encourage Ms R to keep medical appointments. Ms R continued to resist, stating that she would rather be dead. We are satisfied that the MHO did all that she could reasonably have done in the circumstances. The GP (GP1) reported that Ms R had never tended to seek medical attention. This gave further weight to the principle of taking account of past wishes as well as present wishes.

Subsequent decisions were consistent with the previous decision not to intervene when the smear result was abnormal. These included:

- The decision not to force her to undergo gynaecological investigation during in-patient treatment in mental health care in 2010;
- The decision at the review of guardianship in January 2011 where there was a decision not to investigate the weight loss further.

At the latter meeting, there was a note that staff should observe for further vaginal bleeding. The GP (GP2) was not present at that meeting. It was not clear what action staff should take if vaginal bleeding occurred.

GP2 admitted to us that she had not been fully aware of a cancer diagnosis and the possible need for palliative care. She was aware of the diagnosis of alcohol-related brain damage. The information about the likelihood of cancer may have existed in notes passed on from the previous GP. GP2 had the view that she should have taken time at an earlier stage to find out more about additional health concerns. These would become more of a priority as Ms R's health deteriorated.

This was one opportunity to consider an 'anticipatory care plan'. It was a significant possibility that Ms R had cancer. Practitioners could have considered, at that point, how to intervene if there was a significant deterioration in her health. Given her continued resistance to interventions, the subsequent problems were predictable but there was no management plan in place to anticipate gradual or sudden decline in health.

3) Palliative care

We became concerned when we heard about the difficulty staff were having when Ms R became seriously ill during April 2011. At this point, we were concerned that continuing to allow her to refuse basic care seriously

interfered with her personal comfort and dignity. In the discussions we had with practitioners, it was clear that:

- Care home staff and managers were unclear as to their authority to use any form of force to provide Ms R with the care she appeared to need;
- Some key practitioners were on leave, including GP2 and the consultant psychiatrist. They knew Ms R's case well, but the lack of an anticipatory care plan meant that colleagues providing cover had no plan to follow;
- GP2 and her colleagues struggled to find help and advice and were unaware of the advice functions of the Commission;
- Care home staff were directing questions about the use of force to the MHO (with delegated day-to-day authority to exercise the powers of the guardian) who had no clarity on the medical treatment that required her consent. We agreed that this question should have been addressed primarily to the GP who could then have made a decision that force was necessary and, if practicable, then consulted the MHO;
- Care home staff appeared to think that detention in hospital for treatment under the 2003 Act was the proper way to proceed. As the MHO pointed out to them, this is incorrect where treatment is for physical disorder;
- Relatives expressed considerable concern about the fact that staff allowed Ms R to refuse care. Again an agreed anticipatory care plan would have helped;
- We also heard that Ms R was an intelligent lady with a good social facade. This may have made it more difficult for staff to intervene against her wishes.

We agreed with the practitioners' own review that there was a failure to provide necessary care and treatment during this time for Ms R. Her dignity was compromised by the smell from her discharge and her refusal of attention, especially after a particularly heavy bleed. We used the process for decisions on the use of force (contained in our 'Right to Treat?' guidance[2]) to provide a framework for decisions. Had our guidance been available at the time, the process for decisions may have been along the following lines.

1) Does the person lack capacity?

Yes. This had been assessed when guardianship was granted. It is likely that her lack of judgement resulted in her refusal to allow staff to at least intervene and clean her, for her own dignity, after a heavy vaginal bleed.

2) Is the treatment necessary?

This was not clear. In the past, it had generally been decided that the harm outweighed the benefit. An urgent reassessment of the need for treatment was important, even in the absence of an anticipatory care plan. In our view, there was evidence that basic care was needed to relieve discomfort and preserve dignity.

[2] http://reports.mwcscot.org.uk/web/FILES/MWC_RightToTreat_prf2.pdf

3) Is force necessary?

Staff did their best to avoid using force. They kept going back to try to catch Ms R at a moment where she might be more receptive to being cared for. This was an approach that the consultant psychiatrist had advocated. It had worked before in the care home for "the right staff on the right day." However, it appears to us to have been inappropriate to leave Ms R in discomfort in the hope that she may at some point allow care.

4) Is the force proportionate to the purpose of intervention?

We discussed with practitioners whether or not the use of force outweighed the distress that intervention may cause. Given the severity of her bleeding and discharge, we think it is easily argued that a proportionate response would have been intervention, using the minimum force necessary and perhaps using some mild sedation, would have been justified.

5) Is the use of force lawful?

Minimal amount of force in an urgent situation for the minimum amount of time necessary is lawful. This could have been authorised under a S47 certificate of incapacity covering at least fundamental healthcare procedures. Even without this, intervention in an urgent situation after a bleed could be justified under the doctrine of necessity.

For ongoing treatment, there were powers in place within the guardianship order which authorised medical treatment. The GP could have asked the guardian to consent to the short-term use of force "where immediately necessary and only for as long as is necessary" under the terms of S47 of the 2000 Act.

Care home staff thought that, because of Ms R's vehement opposition to nursing intervention, it was neither appropriate nor lawful to intervene. It was written in care notes that they were unable to clean her up as it would be "deemed as assault." We disagree with this assertion. It is important, however, for staff, managers and other practitioners to be clear about the legal and ethical basis for intervening when the patient cannot consent to physical healthcare.

Conclusions and recommendations

Ms R presented several difficulties due to her refusal to accept care for physical health problems. She had alcohol-related brain damage and lacked capacity in relation to important decisions about medical treatment. We were impressed with the consideration given to important decisions when it was suspected that she had cervical cancer. We commend many aspects of her care, but we consider that the care afforded to her when her illness suddenly worsened was poor. Staff meant well by not forcing care and treatment on her, but this resulted in her suffering discomfort and lack of dignity. Despite this, care at the end of life was good and she died peacefully and with dignity.

In our view, the root causes of the failure to intervene were:

- The lack of an anticipatory care plan, taking account of Ms R's views but also involving relatives and carers;
- The lack of legal clarity about using force to provide physical healthcare for people who lack capacity;
- The lack of access (at that time) to best practice guidance in this difficult area.

The internal review identified similar points and undertook to take local action to address them. We agreed with the findings of the internal review. We have expanded them to provide learning points for future care:

1) **General practitioners who take over the care of individuals entering care homes should have procedures for familiarising themselves with previous care and constructing anticipatory care plans in conjunction with the patient, relatives and care staff.**
2) **General practitioners should have information about the advice and guidance available from the Mental Welfare Commission, including links to key guidance documents on good practice. In particular, GPs should be aware of MWC guidance on covert medication and the use of force for physical healthcare.**
3) **The care home managers should ensure that relevant staff are given updated training on legal and ethical aspects of care and treatment, especially the appropriate use of legislation in the provision of physical and mental health care. They should also ensure that there is support for staff for complex decisions where there may be conflict and disagreement.**

We also considered the need for the Commission to be more active in promoting our advice and guidance to primary healthcare practitioners.

The Commission will provide briefing notes for general practitioners on important reports, practice guidance and our telephone advice service.

In addition, we make the following recommendation to Scottish Ministers:

Ministers should take note of the content of this report and our recommendation in 'Right to Treat?'

"There are problems with the compliance order under section 70 of the 2000 Act. Its purpose was not in relation to forcible medical treatment. There may be a need to revisit parts 5 and 6 of the 2000 Act to identify a clearer route to provide physical healthcare for people who lack capacity and actively refuse or resist."

In our view, the case of Ms R provides further support for our recommendation. While many practitioners have found our guidance helpful, we still consider that the law on forcible treatment for physical health problems needs revision and clarification. Without that revision, practitioners will remain uncertain and people like Ms R may receive inadequate or unlawful treatment.

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