Scottish Parliament Region: Highlands and Islands

Case 201301611: Highland NHS Board

Summary of Investigation

Category

Health: Hospital, Carer Involvement, Adults with Incapacity

Overview

The complainant (Mrs C) raised concerns about inadequate consultation and involvement of her as a carer for her husband (Mr C) during his admissions to two hospitals run by Highland NHS Board (the Board) in 2011.

Mrs C had Financial and Welfare Power of Attorney (POA) for Mr C and was also Mr C's Named Person for the purposes of the Mental Health (Care and Treatment) (Scotland) Act 2003. Mr C had a diagnosis of Advanced Alzheimer's Disease.

Specific complaint and conclusion

The complaint which has been investigated is that the Board did not reasonably include Mrs C in decisions about Mr C's care and treatment from February 2011 onwards (*upheld*).

Redress and recommendations

The Ombudsman recommends that the Board:	*Completion date*
(i) apologise to Mrs C for the repeated failures to adequately and properly involve her in decision making around Mr C's care and treatment;	22 October 2014
(ii) review their approach to carer communication and participation for people with dementia to ensure a coherent, bespoke and planned approach in all cases. This should be carried out with due regard to the national Dementia Standards, the principles under-pinning the Mental Health (Care and Treatment) (Scotland) Act 2003 and the Adults with Incapacity Act 2000, and the rights of 'Named Persons' and those with POA status. The Board	17 December 2014

	should advise this office of the outcome of this review; and	
(iii)	review their current documentation of carer involvement in light of the record-keeping failings identified in this report and advise this office of the steps taken to address these omissions.	17 December 2014

The Board have accepted the recommendations and will act on them accordingly.

Main Investigation Report

Introduction

1. Mrs C had Financial and Welfare Power of Attorney (POA) for her husband (Mr C). Mrs C was also Mr C's Named Person for the purposes of the Mental Health (Care and Treatment) (Scotland) Act 2003. Mr C had a diagnosis of Advanced Alzheimer's Disease, Type 2 Diabetes and Ischaemic Heart Disease.

2. Mr C was admitted to the County Community Hospital, Invergordon (Hospital 1) on 9 February 2011 following a home visit by a community psychiatric nurse. Later the same day he was detained under a Short Term Detention Order and an application was made for a hospital-based Compulsory Treatment Order (CTO) which was granted on 15 March 2011. Both orders were made under the terms of the Mental Health (Care and Treatment) (Scotland) Act 2003.

3. In September 2011 Mr C was transferred to New Craigs Hospital (Hospital 2) where he stayed until he was discharged to a nursing home in December 2011. The CTO was suspended at that point and ultimately revoked on 28 February 2012. Mr C was later readmitted to Hospital 2 in December 2012 and transferred to Migdale Hospital (Hospital 3) in May 2013.

4. Mrs C was concerned at the lack of consultation and involvement she had with clinical staff during Mr C's admissions to Hospital 1 and Hospital 2 in 2011. With the assistance of a Patient Advice and Support Service (PASS) adviser, Mrs C made a complaint to Highland NHS Board (the Board) on 12 November 2012. The Board responded on 4 January 2013. Following this reply and further correspondence a meeting was arranged between Mrs C and a dementia nurse consultant for her to describe her experience of the NHS in caring for Mr C, with the hope that this might improve matters for others in the future.

5. Mrs C remained concerned that her involvement in Mr C's care planning had been insufficient and, supported by a PASS adviser, she brought her concerns to this office on 18 July 2013.

6. The complaint from Mrs C which I have investigated is the Board did not reasonably include Mrs C in decisions about Mr C's care and treatment from February 2011 onwards.

Investigation

7. The investigation of this complaint involved obtaining and reading all the documentation provided by Mrs C, PASS and the Board. This included the Board's complaints file and Mr C's relevant clinical records. Independent advice was obtained from a specialist mental health nurse adviser (the Adviser) and this has also been taken into account.

8. While this report does not include every detail investigated, I am satisfied that no matter of significance has been overlooked. Mrs C and the Board were given an opportunity to comment on a draft of this report.

Complaint: The Board did not reasonably include Mrs C in decisions about Mr C's care and treatment from February 2011 onwards

What Mrs C told us

9. Mrs C explained to my complaints reviewer that she was Mr C's main carer prior to his admission to hospital in February 2011. They had been married for many years and as his wife, his Named Person and as the person holding POA for him, she believed she should have been extensively involved in any decisions about Mr C's care and treatment during his hospital admission. Mrs C was unhappy with the level of consultation she had with staff and also with her lack of involvement when she raised concerns about this. Overall, she explained, this had left her feeling excluded and that the decisions were being made in-line with systems and processes and not in response to Mr C's individual circumstances or needs.

The Board response

10. In their responses to Mrs C, the Board noted a number of occasions when social work, nursing and medical staff had discussed aspects of Mr C's detention and medication with Mrs C. The Board acknowledged that dementia is a cruel illness which engenders a sense of powerlessness to those involved. The Board noted that staff had made considerable and extra efforts to give Mrs C as much support as was possible and reasonable.

11. The Board stated that the dementia nurse consultant discussed Mrs C's concerns about communication, care planning and involvement, the role of the

Named Person, carer rights and provision of information, in order to examine where improvements could be made. Specifically the Board noted that:

- additional resources were being put into post diagnostic support and specific inclusion of the requirement in the Dementia Integrated Care Pathway;
- all Highland Operational Units have been sent details of appropriate signage which complies with requirements of dementia friendly environments; and
- the person centred care approach is the aim throughout NHS Highland which is aided by opportunities for service users to use self-directed support.

12. In their response to my office the Board noted that they had consistently attempted to provide full, detailed responses to the issues Mrs C raised and that they were sorry they had not been successful in addressing her concerns.

Relevant Legislation and Guidance

13. The Scottish Government Standards of Care for Dementia in Scotland. Action to support the change programme, Scotland's national dementia strategy, Edinburgh 2011 states that:

> 'I have the right to have carers who are well supported and educated about dementia.
>
> People with dementia and their carers have the right to be provided with accessible information and the support they require in order to enable them to exercise their right to participate in decisions which affect them.
>
> Carers will be recognised and valued as partners in care and be supported in their role.
>
> Carers will feel valued and properly supported in their role and will know where to get help if needed.
>
> Carers are involved in the assessment, planning and review of support, care and treatment for the person with dementia.'

14. Mental Health (Care and Treatment) (Scotland) Act 2003 states that:

> 'Respect for carers

Those who provide care to service users on an informal basis should receive respect for their role and experience, receive appropriate information and advice, and have their views and needs taken into account.'

15. The Mental Health (Care and Treatment) (Scotland) Act 2003 also creates a new support role for the patient - the Named Person. The Named Person has similar rights to the patient to apply for, appear at and be represented at Tribunal hearings concerning CTOs, and to appeal against short-term detention. The Named Person can act independently of the patient's wishes and is entitled to be given information concerning compulsory measures that have been taken or are being sought. Under the Mental Health (Care and Treatment) Act 2003, any person involved in the care of a patient subject to a CTO must take account of the views of their Named Person.

Advice obtained

16. My complaints reviewer asked the Adviser to consider Mr C's clinical records. The Adviser provided me with a number of comments relevant to Mrs C's concerns. I will address the relevance of these in relation to each admission in turn.

Communication in Hospital 1 February 2011 to September 2011

17. The Adviser told me that in his view the relationship between Mrs C and hospital staff seemed to be strained a lot of the time. The records show this to have been the case more or less from the outset. Mrs C mentioned on a number of occasions to staff that she believed she was not being communicated with effectively but this does not appear to have resulted in the development of a coherent carer communication plan. The majority of communication between her and the ward nursing and medical staff seems to have been initiated by Mrs C herself. There are very few occasions when staff appear to have been proactive in this regard. The mode of communication seems to have been to inform her retrospectively after decisions had been taken and to respond to her questions as she raised them.

18. The Adviser also noted that the nursing assessment templates do not have sections relating to the needs/views of carers. He considered this to be a significant omission; noting that the carer's perspective of needs in the Single Shared Assessment had been left blank. The Adviser commented that these

omissions gave the sense that the views of carers, and their participation, were not viewed as priority matters.

19. The Adviser told me that a number of 'Ward Rounds' took place during Mr C's stay in Hospital 1. These are the multi-disciplinary forums set aside, usually on a weekly or fortnightly basis, to review each person's care and make decisions in relation to future care. The Adviser identified 16 records of these meetings in Hospital 1 and there was no reference in any of the case-note entries to indicate that Mrs C was either involved in the discussions or present at the time.

20. On 12 February 2011, three days after Mr C's admission, Mrs C asked to make an appointment to see a doctor. She was informed that it was too soon and that family meetings usually were arranged three to four weeks post-admission. The Adviser noted that this seemed a rather rigid approach centred on the ward's usual routines rather than a strategy designed to meet the needs/wishes of the carer concerned. When Mrs C saw the doctor on 6 April 2011, she expressed concern that she had not been spoken to personally by a member of the medical staff – this was two months after Mr C's admission. She was advised (by the doctor) that they had had discussions at the CTO planning meeting on 2 March 2011, and at the Mental Health Tribunal hearing on 15 March 2011. She was also told that she could have made an appointment with any of the medical staff at another time. The CTO meeting is noted to have occurred but nothing was recorded to indicate that anything was discussed with Mrs C or that she was even present – as his Named Person she should have been fully involved.

Communication in Hospital 2 September 2011 to 14 December 2011

21. The Adviser noted that although the care plan did not include a bespoke carer communication plan, and the admission assessment did not include carer's views, Hospital 2 records indicated a slightly improved, but not ideal, pattern of communication between the care team and Mrs C. Once again most of the communication with nursing staff was initiated by Mrs C raising issues and voicing her concerns. However, there is some evidence of nursing staff being a little more proactive in relation to updating her after she complained about being 'out-of-the-loop' on 15 September 2011. There is clear evidence of medical staff scheduling some meetings with her to keep her informed and the records indicate that Mrs C voiced fewer concerns about Mr C's care during this phase of his hospitalisation which is suggestive of her being happier overall.

22. The Adviser commented that Mrs C visited Mr C most days and while the nursing notes reflected that she asked questions or raised concerns, there was a lack of opportunities made by the staff to proactively communicate with her and involve her for the most part. The Adviser noted again that communication was mostly ad hoc rather than planned around Mrs C's needs and wishes. There was a tendency for her to be informed of things after they had occurred rather than been involved in the decision-making process as she should have been as Mr C's carer and Named Person. The Adviser found clear evidence of Mrs C being involved in decision-making in relation to Mr C's eventual placement in a nursing home and of her being proactively kept up-to-date in this regard.

23. The Adviser highlighted that the admission care pathway document includes sections related to agreement being reached in relation to the nature of the care plan. Large parts of the document have been left almost entirely blank and it does not include a section to record 'carer agreement' with the care plan. The Adviser told me that this is an important aspect of the care of people with dementia, made even more so in this case by Mrs C's POA status. The Adviser told me that this should be included in the care pathway template. The Adviser said that the multi-disciplinary meeting sheets include sections to record attendees, including family, however, none of the completed templates showed Mrs C's involvement in these meetings.

24. The Adviser also commented on the response from the Board to Mrs C's complaint. He told me that it was inappropriate of the Board to suggest that the communication which took place at the tribunal was an example of carer participation. This is because the parties were compelled to attend the tribunal and the tribunal had a specific purpose, that is, to consider the CTO application before it. The Adviser said that a tribunal is not a forum for routine care-team and carer communication. Furthermore, informing Mrs C that she could have made an appointment to see a member of medical staff anytime, ignores the fact that she did, namely on 12 February 2011. It also places the onus to maintain communication on her the carer, when in fact it is the responsibility of the clinical team to ensure the meaningful participation of carers and to ensure that they are effectively communicated with.

25. The Adviser concluded that there was a lot of communication between Mrs C and staff during Mr C's stay in Hospital 1, however, most of this was

initiated by Mrs C herself. While staff updated Mrs C regularly, it was usually reactive, in response to her questions and concerns. For the most part, she was retrospectively informed of decisions and does not appear to have been provided with scheduled opportunities to participate in care-planning. In addition, there seemed to have been no coherent carer communication plan or means of supporting Mrs C's participation in Mr C's care in a systematic and premeditated manner. The lack of apparent involvement in multi-disciplinary meetings is a particular concern in the absence of any other planned and regular communication forum. Despite there being some improvement in communication between the care-team and Mrs C in Hospital 2, there was no bespoke carer communication strategy built around Mrs C's needs and wishes and recorded in the notes. The care pathway document does not prompt meaningful carer involvement, which is a fundamental aspect in the care of people with dementia. Neither do the records reflect Mrs C being invited to, and participating in, multi-disciplinary meetings. Communication was predominantly retrospective and reactive rather than planned and proactive. The Adviser summarised this by telling me that 'Mrs C's rights as Mr C's Welfare POA and Named Person have not been afforded appropriate respect. The Mental Health (Care and Treatment) (Scotland) Act 2003 principle of 'respect for carers' has not been effectively observed'.

Conclusion

26. Mrs C held Welfare POA status in respect of Mr C and should have been involved in decision-making about his care and treatment. Mrs C had the right for her views to be heard and considered with respect. Similarly, as Mr C's 'Named Person' under the Mental Health (Care and Treatment) Act 2003, Mrs C had a right to be fully and proactively involved in decision-making in relation to Mr C's care and treatment.

27. The Adviser stated that there was a clear lack of evidence of appropriate inclusion of Mrs C as carer for Mr C while he was admitted to hospital in 2011. The Adviser noted that the documentation was both incomplete and lacked the opportunity to ensure Mrs C's views were taken into account in decision making and this resulted in communication being reactive rather than proactive on most occasions. He concluded that Mrs C's rights had not been observed in this regard.

28. Based on the advice above I conclude that the Board did not reasonably include Mrs C in decisions about Mr C's care and treatment from February 2011

to December 2011 and I uphold her complaint. Whilst I note that the Board have made a number of improvements following Mrs C's meeting with the dementia nurse consultant, I have a number of recommendations to make in order to address the failings I identified.

Recommendations

29. I recommend that the Board:

		Completion date
(i)	apologise to Mrs C for the repeated failures to adequately and properly involve her in decision making around Mr C's care and treatment;	22 October 2014
(ii)	review their approach to carer communication and participation for people with dementia to ensure a coherent, bespoke and planned approach in all cases. This should be carried out with due regard to the national Dementia Standards, the principles under-pinning the Mental Health (Care and Treatment) (Scotland) Act 2003 and the Adults with Incapacity (Scotland) Act 2000 and the rights of Named Persons and those with POA status. The Board should advise this office of the outcome of this review; and	17 December 2014
(iii)	review their current documentation of carer involvement in light of the record-keeping failings identified in this report and advise this office of the steps taken to address these omissions.	17 December 2014

30. The Board have accepted the recommendations and will act on them accordingly. The Ombudsman asks that the Board notify him when the recommendations have been implemented.

Annex 1

Explanation of abbreviations used

Mrs C	The complainant
POA	Power of Attorney
Mr C	Mrs C's husband
Hospital 1	County Community Hospital,
CTO	Community Treatment Order
Hospital 2	New Craigs Hospital
Hospital 3	Migdale Hospital
PASS	Patient Advice Support Service
The Board	NHS Highland Board
The Adviser	A specialist mental health nurse adviser to the Ombudsman

Annex 2

List of legislation and policies considered

Mental Health (Care and Treatment) (Scotland) Act 2003
Adults with Incapacity (Scotland) Act 2000