

27 May 2015

Duncan McNeil MSP
Convener of the Health and Sport Committee
The Scottish Parliament
EDINBURGH
EH99 1SP

Dear Convener,

Palliative Care

I would like to thank the Committee for the invitation to give evidence about palliative care. In my response, I set out the details of one family's experience which I think highlights the importance of good end of life care and the damage that can be caused when failings occur. I also suggest how such individual experiences can be used to help support improvements in care and, finally, I highlight the need to listen to NHS staff to ensure we give them the support they need to have some very difficult conversations.

The nature of my role means I hear the experiences of those who have been distressed and are unhappy with the NHS. This letter, of necessity, concentrates on what goes wrong. Before I do so, I should like to put on record that I know there is much good and excellent care provided daily by the NHS and real desire by the NHS as a whole and on behalf of individual staff to provide the best end of life care possible whether that occurs at home, in a hospice or in hospital and acute care settings.

What we are told about the experience of end of life care

As the Committee know, it is the role of the SPSO to respond to concerns raised by the public about their individual experiences of public services, to investigate and, when we find a failing, to try to put it right. Some of the most difficult cases we face are where that final stage is simply not possible. And that is particularly the case when something goes badly wrong with care at the end of someone's life. We cannot give the family the time back to help them prepare and say goodbye. We cannot reduce the pain that the person should not have been in before they died. We cannot erase the memories of a loved one being treated without the dignity and care we would expect.

My office receives few if any complaints about the direct application of palliative care. We hardly ever receive comments or concerns about care provided in a hospice setting¹. This means it is difficult for me to comment directly on the systems or guidance in place when palliative care is being provided. We do though hear from the family and friends of people where the end of life of a loved one was made more difficult because such care was not provided or confusion about when end of life care would have been appropriate.

Confusion over whether end of life care was appropriate

I would like to mention one such case which brings together themes we have seen elsewhere². By coincidence, this report had been finalized and was awaiting publication when I received your request to give evidence.

Mr C was not old, only 61, but he was unwell and had been cared for by his family at home. He was admitted to Hospital with increased confusion and difficulty swallowing. He died in Hospital nine days after admission. My report³ about what happened in those nine days identified a number of failings. I wanted to highlight this particular report because a key cause of those problems is that staff appeared confused about whether they were providing active treatment or palliative care. The family were told he was too ill to leave hospital but were then contacted by occupational therapy about arranging a bed for him at home. There was also a significant failing about the decision to give Mr C a gastroscopy on what proved to be the day he died. Mr C, at that stage, was unable to consent or not consent and this decision was made without the safeguards put in place by the Adults with Incapacity legislation for such decisions being followed.

The family chose to talk to the press after the report was published and I wanted to use some of their own words to describe this experience: “ It was just one failure after another. Sometimes doctors would tell me he was dying and then another time I was told he wasn’t. We didn’t know whether we were coming or going or who to trust. ... Even when I said he was too far too frail, they still took him for a scope. My husband didn’t deserve to get treated that way. I didn’t even get a chance to say goodbye to him as the doctors took me outside to speak to me and my sister had to come and tell me that he was away”.

Particular difficulties we see in the care of the elderly in acute settings.

The nature of my work means I can only respond to and comment on cases that are brought to me. This means the cases that come to me may or may not be representative of care received as a whole. However, it is known that people are often reluctant to complain about NHS care and we consider that it is likely that others are also experiencing the issues we see. This is why, in my monthly commentaries and annual reports, I highlight themes that I am seeing in our cases that cause me concern. I have set out a few examples of these below. I have

¹ Only NHS provision is under our jurisdiction and this can extend to care funded by NHS in other settings but hospices themselves are usually out of our jurisdiction as independent charities.

² Such issues are not unique to one Board or the UK as can be seen in the recent reports issued by the English Health Ombudsman and the Irish Ombudsman: <http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity>; and

<https://www.ombudsman.gov.ie/en/publications/investigation-reports/health-service-executive/a-good-death/>

³http://www.spsoc.org.uk/sites/spsoc/files/communications_material/commentary/2015/SPSOCcommentaryMay2015.pdf

chosen these because they relate to the particular problems facing the older person in acute care. This, strictly, is not limited to palliative care but many of the complaints are brought to me by family members after someone has died in hospital and the ability to deliver good end of life care is affected by these issues. For example:

- In July 2013, I highlighted the importance of ensuring legal safeguards to protect vulnerable patients without capacity are followed;⁴
- In April 2014, I was concerned to again be raising concerns about a failure to prevent and manage pressure sores;⁵
- In November 2014, I referred to repeated issues around the failure to properly assess the needs and risks of patients (often elderly when the conditions are more complex) when they enter acute settings⁶ and
- In January 2015, I pointed to the additional distress that is caused when Boards fail to investigate and accept failings⁷

Dealing with an older person with multiple conditions and either limited or fluctuating capacity to make decisions themselves about their own care is complex. The difficulties of coping with someone with dementia (or confusion caused by any other condition) in an acute setting brings these issues together to a sharp focus and this may explain why I regularly publish investigations in that area. This can be particularly distressing for families when the failings in care are part of their experience and memory of a loved one's final days⁸.

Using individual experiences to improve care for all

When people come to me having had such experiences, they know we cannot put it right, but they desperately want to understand why things went wrong and to prevent other families from going through those experiences. I also feel for staff in the NHS who are, in my experience, highly motivated to prevent such situations and must also feel deep distress when this has occurred and want to be involved in putting it right.

In recent years, scrutiny organisations and boards themselves have moved to involve lay people and also the experience of their patients directly in the process of monitoring and assessment. This provides for important feedback on the service provided. In addition, individual cases where things go wrong, can provide the tools to unpick complex systems and work out where the stresses and strains are and what can be done better. To give an example, significant work was done around this in NHS Scotland recently when HIS led a project looking at how to improve the way significant event analysis was undertaken. Best practice on the use of tools such as root cause analysis emphasise the importance of involving front-line staff and the family and ensuring their perspectives informs both the analysis of the issues and of the solution.

⁴http://www.spsso.org.uk/sites/spsso/files/communications_material/commentary/2013_07_24_SPSO_Commentary.pdf

⁵http://www.spsso.org.uk/sites/spsso/files/communications_material/commentary/2014/2014.04.30%20SPSOCommentary.pdf

⁶http://www.spsso.org.uk/sites/spsso/files/communications_material/commentary/2014/SPSOCommentaryNov2014.pdf

⁷http://www.spsso.org.uk/sites/spsso/files/communications_material/commentary/2015/SPSOCommentaryJan2015.pdf

⁸ For example see case published in November 2014

http://www.spsso.org.uk/sites/spsso/files/investigation_reports/2014.11.19%20201301767%20Lothian%20NHS%20Board.pdf

Individual experiences can provide unique glimpses of how the system works and, therefore, unique solutions. Those involved in analysing such experiences in such a detailed way often find that the power of the stories in themselves help to drive improvement and change. It would not be possible to use such tools for all such situations but it would certainly be possible to include significant, unintended distress around the end of life as a potential trigger for such investigations.

The critical role of communication

Many of the failings I see can be traced back to bad or inadequate or confused communication whether internally between NHS staff or between the NHS staff and the family and friends of the patient. The irony of this situation is that better communication, particularly involving the family directly would often have averted issues. Again this is evident when someone is admitted to an acute setting whose capacity is limited. It is often only the family or friends who have the important information that is needed to ensure someone receives the best, safest treatment. Think of an older person who falls in hospital because the information the family know about their mobility is not included in assessments.

I was struck when I read through the previous evidence session in April of the emphasis by all on the need to ensure that plans are made early and anticipatory plans are in place. At the root of that is good communication and the need to communicate early about these issues. That can be difficult and, as a society we are not traditionally good at talking about death. This means NHS staff may need not only to have the conversation but also to help families have those conversations.

Good communication and the need to communicate difficult information is a skill that is being increasingly recognised as crucial to NHS care. It is also one where, in asking staff to be more active around end of life conversations or in the proposed duty of candour. We are increasingly emphasising the responsibility and obligations of NHS staff to communicate well in difficult situations and communication skills are now more likely to be scrutinized. I know the Committee are considering their approach to an inquiry around palliative care and it would be interesting to hear from NHS staff what they feel about this emphasis and what support they need to prepare for and undertake these type of conversations. What support and practical tools do they have already. What do they think would help them involve families better? Do they have the time or the space to have those conversations? Are there situations which cause them real concern and where they would appreciate additional support?

Ultimately, there is a need to encourage society as a whole to start talking more honestly and earlier about death and dying. I hope that one of the effects of the Committee's highlighting the issue of palliative care is to help support more discussion of these very sensitive issues.

Yours sincerely

Jim Martin
Ombudsman