



Department
of Health &
Social Care

From Caroline Dinenege MP
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Your Ref: 10161/CLB
Our Ref: PFD-1161197

Ms Alison Mutch OBE
HM Senior Coroner, Manchester South
HM Coroner's Court
1 Mount Tabor Street
Stockport
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19th February 2019

Dear Ms Mutch,

Thank you for your correspondence of 20 December to Matt Hancock about the death of Maria Katarina Hryniw. I am replying as Minister with portfolio responsibility for end of life care and I am grateful for the extra time in which to do so.

Firstly, I would like to offer my sincere condolences to Ms Hryniw's family and loved ones. I appreciate that this must be a very difficult time for them.

I have noted carefully the concern raised in your report about a lack of co-ordinated decision making in the best interests of Ms Hryniw in relation to the continued use of clinically assisted nutrition.

You will appreciate that I am not in a position to comment on the quality of end of life care provided by the nursing home and others to Ms Hryniw. I expect the Care Quality Commission to respond to you as regulator of health and adult social care in England on its consideration of the matters of concern raised with regard to the provision of services in this case.

My response will seek to address the wider concerns this case raises about the management of end of life care, including the provision of clinically assisted nutrition.

The primary aim of medical treatment is to benefit the patient by restoring or maintaining health as far as possible, maximising benefit and minimising harm. If, however, all suitable treatments fail, or cease to provide benefit to the patient, they may, ethically and legally, be withheld or withdrawn, and the focus of treatment changed to the relief of symptoms.

In practice, the decision to withhold or withdraw life-sustaining treatment is often very difficult. Patients who have the mental capacity to decide whether they wish to continue to receive treatment should be provided with as much information as possible about their prognosis as well as any likely burdens and benefits of continuing treatment.

Under the Mental Capacity Act 2005¹, a person with capacity may make either an Advance Decision to refuse treatment or an Advance Decision to refuse life-sustaining treatment (ADRT) at a future date when they have lost the mental capacity to decide. To be valid and applicable, an ADRT has to be in writing and witnessed, and contain very specific information. This includes a clear statement that it applies in the event that life is at risk and information about the circumstances in which it should apply. If drawn up, an Advance Decision must be followed by healthcare staff.

For patients who lack capacity, a decision must be made in their “best interests”. This involves a careful assessment based on discussions with those close to the patient, and should take into account what is known about the patient’s beliefs and values. It is not a purely “medical” decision.

Artificial nutrition and hydration (ANH) bypasses the natural mechanisms that control hunger and thirst and has a number of consequences that require careful ongoing clinical monitoring. The current evidence about the benefits, burdens and risks of these techniques as patients approach the end of life is not clear-cut. It is administered by tube or drip and is regarded in law as medical treatment. Whilst ANH may provide symptom relief or prolong or improve the quality of the patient’s life, it can also present problems, for example bloating, cramps and shortness of breath. As with other forms of medical treatment, it therefore requires a careful clinical assessment of whether its provision will be of overall benefit to the patient.

Extensive clinical guidance is available to support clinicians in ensuring the decisions they make in relation to the provision or withdrawal of ANH are timely and in the best interests of patients. For example, the National Institute for Health and Care

¹ <https://www.legislation.gov.uk/ukpga/2005/9/contents>

Excellence (NICE), has produced a range of guidance including:

- *Nutrition support in adults* (CG32)²
- *End of life care for adults* (QS13)³
- *Care of dying adults in the last days of life* (NG31)⁴ and (QS144)⁵

Recommendation 1.3.4 in Clinical Guideline 32, *Nutrition support in adults*, discusses withdrawing nutrition support and the need to consider ethical and legal principles, including considering General Medical Council guidance on end of life care, as follows:

1.3.4 Healthcare professionals involved in starting or stopping nutrition support should:

- *obtain consent from the patient if he or she is competent*
- *act in the patient's best interest if he or she is not competent to give consent*
- *be aware that the provision of nutrition support is not always appropriate. Decisions on withholding or withdrawing of nutrition support require a consideration of both ethical and legal principles (both at common law and statute including the Human Rights Act 1998).*

When such decisions are being made guidance issued by the General Medical Council^[5] and the Department of Health^[6] should be followed.

[5] Treatment and care towards the end of life: decision making. General Medical Council.

[6] Reference guide to consent for examination or treatment, 2nd edition (2009). Department of Health.

In the abovementioned Quality Standard 13, *End of life care for adults*, guidance is given covering care for those adults approaching the end of their life. This includes people who are likely to die within 12 months, people with advanced, progressive, incurable conditions and people with life-threatening acute conditions. It includes a statement (statement 3) on the importance of people approaching the end of life being offered full assessments to ensure they are getting the best care and support for their circumstances. This includes the opportunity to develop and review a care plan.

² <https://www.nice.org.uk/guidance/cg32/chapter/1-Guidance>

³ <https://www.nice.org.uk/guidance/cg32/chapter/1-Guidance>

⁴ <https://www.nice.org.uk/guidance/ng31>

⁵ <https://www.nice.org.uk/guidance/qs144>

Care of dying adults in the last days of life, NICE guideline 31 and *Care of dying adults in the last days of life*, Quality Standard 144, cover the clinical care of adults who are dying during the last two to three days of life. They discuss assessing signs and symptoms, discussing the person's preferences and needs and providing individualised care, and the role of the multi-professional care team.

Further clinical guidance has been developed by organisations such as the medical Royal Colleges or other professional clinical bodies. For example, *Treatment and care towards the end of life: good practice in decision making*, published by the General Medical Council in 2010⁶. This guidance includes extensive advice on management of ANH.

It is important to note that clinical guidance is not designed to replace the skills, knowledge and experience of clinicians, who remain responsible for deciding, in discussion with patients, their families and/or carers the most appropriate forms of treatment and care.

The Government, and previous governments, have worked to set the direction to the health and care system for high quality, personalised end of life care services, including taking appropriate action where significant concerns were identified.

For example, following an independent review of the Liverpool Care Pathway (LCP), commissioned by the Government, 21 national organisations, including the Department and its key system partners and stakeholders, came together to form the Leadership Alliance for the Care of Dying People. The purpose of the Alliance was to take collective action to secure improvements in the consistency of care given in England to everyone in the last few days and hours of life, and their families. Its objectives were to:

- Support all those involved in the care of people who are dying in responding to the findings of the review; and
- Be the focal point for the system's response to the findings and recommendations of the LCP review.

In 2014, the Leadership Alliance published its response to the independent review of the LCP. The *One Chance to get it Right*⁷ report confirmed the phasing out of the LCP and set out the approach that should be taken in future in caring for all dying people in England, including around withdrawal of treatment. The approach focuses on achieving Five Priorities for Care. These make the dying person themselves the

⁶ www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life

⁷ www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations

focus of care in the last few days and hours of life and exemplify the high-level outcomes that must be delivered for every dying person.

The Priorities for Care are that, when it is thought that a person may die within the next few days or hours:

- i. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
- ii. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
- iii. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
- iv. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
- v. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

The Department published a one year on report⁸ in August 2015 detailing progress. The report set out that there had been a genuine, sustained commitment across the health and care system to the principles set out in the Priorities for Care and to deliver improvements to the care of dying people. This included preventing and avoiding repetitions of the poor care identified by the Independent Review of the LCP.

Following the withdrawal of the LCP and implementation of the Priorities for Care, action has been, and continues to be, taken nationally and locally to support reduction in variation and drive up standards in end of life care. Progress includes:

- The Care Quality Commission implementing its new inspection approach which fully incorporates the Priorities for Care and addresses specific issues arising from the *One Chance* response, such as education and training and advance care planning;
- Professional regulators, including the General Medical Council and the Nursing and Midwifery Council, updating codes of conduct, improving education and training requirements and curricula and raising awareness of end of life care in general and the messages from *One Chance to Get it Right*;
- NHS Improving Quality (now part of NHS England) taking a leading role in supporting and advising end of life care providers to adopt the Priorities for

⁸ www.gov.uk/government/publications/improvements-to-care-in-the-last-days-and-hours-of-life

Care and in sharing and disseminating good practice based on the principles set out in *One Chance to Get it Right*;

- Health Education England working to develop end of life care education and training; and,
- The National Institute for Health Research completing key pieces of research on areas of concern such as the use of opioids and the use of medically assisted nutrition and hydration.

Furthermore, this Government's end of life care Choice Commitment⁹, published in 2016, fully aligned with the Five Priorities of Care, and builds on previous end of life care strategies. The Commitment states that everyone should be able to expect:

- Honest discussions between care professionals and dying people;
- Dying people making informed choices about their care;
- Personalised care plans for all;
- The discussion of personalised care plans with care professionals;
- The involvement of family and carers in dying people's care; and
- A key contact so dying people know who to contact at any time of day.

The report set out plans to support delivery of this commitment, including measures to increase personalisation; to improve care quality and education and training in end of life care, and to encourage the spread of innovative models of care. This includes enabling greater use of advance care planning and electronic care records to record people's choices and preferences, and building services around people's needs and preferences.

I hope that this response is helpful and sets out clearly the important work underway to improve end of life care. Thank you for bringing these concerns to my attention.



CAROLINE DINENAGE

⁹ www.gov.uk/government/publications/choice-in-end-of-life-care-government-response