Supplementary written evidence submitted by Dr Matthew Doré (ADY0527)

On behalf of the witness, Dr Matthew Doré in the Health and Social Care committee Assisted dying/suicide inquiry on the 4th July 23, composed by the Association of Palliative Medicine for Great Britain and Ireland

How good is Palliative and End of life Care in the UK?

The National Audit of Care at the End of Life (NACEL) (1) measures the experience of care in hospitals for dying people and those important to them in England, Wales and N Ireland. NACEL results were referenced as evidence of good EOL care however the report paints a less positive picture. Whereas most bereaved family respondents are satisfied with the care their family member who died received, one fifth are not. This means that every year tens of thousands of people who are dying in our hospitals are receiving suboptimal end of life care. This is reflected in the NACEL recommendations (Round 3, 2021) which include:

- Ensuring that all hospitals have access to 24/7 specialist palliative care advice (currently only 60% do) although this is a requirement of the 2004 NICE guidance (2);
- Training for staff, including the recognition of possible imminent death (the time between first recognition of dying to death is short, at a median of 44 hours, by which time only a quarter of patients are able to be directly involved in conversations);
- Ensure that people who are recognised to be dying have a clearly documented and accessible individual plan of care developed and discussed with the dying person and those important to them: currently only 73% do.
- Ensure the needs of people important to the dying person, are identified, assessed, and addressed in a timely manner, both before and after death: only 57% of bereaved family respondents agreed that they were asked about their needs, and only 51% were given enough practical support.

We were also interested to hear the End of life care clinical networks spoken about as a measure of support for Palliative and End of Life Care. Our understanding is that the future of the Palliative and End of Life Care networks is not yet clear and the focus of a consultation with NHSE.

Inequality in access to palliative care

In terms of equality of access to palliative care, the committee mentioned a report from 7 or 8 years ago demonstrating inequality of access to specialist palliative care services. Since then, a systematic review in the British Medical Journal in 2021 has confirmed that these inequalities remain, with the oldest old, ethnic minorities, people with non-cancer illness, those living in rural areas and areas of social deprivation having unequal access to hospice care. (3) In addition, Hospice UK produced a report in 2021 which demonstrates that the issues identified in the earlier report remain. (4) Hull York University and Marie Curie have produced a report "Mind the Gaps" which exposes the lack of availability of palliative care out of hours. (5)

Palliative care sedation

Within the UK and Ireland, sedation is used to treat distress and agitation in the last hours or days of life – sometimes called 'Terminal agitation'. In these situations, sedative medication is used in doses that are just enough to treat the symptoms. The intention is not to render the patient deeply sedated. Used in this way, it does not shorten life. (6)

However in many other parts of Europe the phrase 'Palliative Care Sedation' has a very different meaning and is a protocol to sedate the patient with the intention of hastening death. The starting doses of sedative drugs used are 5-10 times higher than in UK practice, and often several drugs are combined. The intention is to render the patient unconscious as a way of treating suffering. This approach is widespread in assisted dying jurisdictions, but it not recognised practice in the UK. A 2023 paper looking at legislation for palliative sedation (PS) across Europe

acknowledges that in the UK; "*There is no formal legal framework specifically addressing PS (mostly because this is used differently in the UK).*" (7)

Since the introduction of a national guideline on continuous deep sedation in the Netherlands in 2005, the practice has become commonplace with 41% of doctors surveyed believing that this type of sedation hastened death. (8) In contrast, the national reference for palliative care, the Palliative Care Formulary, has no guideline for palliative sedation rather the use of sedatives for the treatment of agitation in the imminently dying only. (9)

The committee has already heard that 44,000 unmonitored palliative care sedation cases were estimated to occur in the Netherlands in 2022. There are no checks or balances regarding this practice, no monitoring or regulation. (10)

It is worth pointing out that the negligent, and possibly criminal, use of excessively high doses of drugs is currently the focus of the Gosport Memorial Hospital Inquiry. When it occurs, as in Gosport, it should be highlighted, investigated and progress through the judicial system. We support the use of the Medical Examiner system in identifying cases of inappropriate or "deep sedation" in the UK.

Withdrawal of treatment and specifically ventilation

Withdrawal of treatment is legally protected in the UK, either by a patient with capacity for this specific decision, or in a patient who lacks capacity, following a best interest meeting with key decision-makers. It is always your right to refuse treatment, even if the consequences of that refusal are 'unwise'.

We are grateful to the committee for raising the November 2015 APM guidance on withdrawal of NIV found on the APM website. We would draw the committee's attention to the more recent 2021 guidance updated during COVID-19, also to be found on the APM website and reproduced below; (11)

"Should be managed with Specialist Palliative care team in daytime hours
NIV may be withdrawn when;

- *The MDT considers it is no longer effective or*
- *the patient is not tolerating it and, knowing they will die, wishes for it to be removed*

For NIV dependent patients NIV withdrawal may be associated with significant increases in symptoms of breathlessness and agitation and death may follow very rapidly on NIV withdrawal. NIV withdrawal will usually be a shared process between NIV medical team, nursing staff and Specialist Palliative Care team present or advising.
Ensure the patient, NOK and nursing staff are informed about the situation and process
Offer an EOL visit to the NOK.
If on NIV - this will usually only be one person for a short visit in full PPE. They will need to self-isolate for 10 days afterwards with their household. The NOK needs to be informed of the risk they place themselves in and offered a video call as an alternative if available.
If NOK visit is after NIV withdrawal and with patient in non-NIV area, may be able to support more than one visitor but may be distressing for NOK if symptoms not well controlled, or death follows NIV withdrawal very rapidly

Ensure patient is symptom controlled prior to NIV withdrawal by giving morphine 5-10 milligrams SC and midazolam 5-10 milligrams SC. Repeat after 20mins until patient is comfortable.
Many patients will already be on a syringe pump for symptom control but consider starting one with morphine 10-20 milligrams/24 hours and midazolam 10-20 milligrams/24 hours if they are not and death is not expected immediately after NIV withdrawal (if they are not NIV dependent).
Turn off or mute monitor if leaving on
Once comfortable start weaning pressure support or inspired oxygen in stages, waiting to assess comfort at each stage and giving further doses of midazolam and morphine if required. Once patient is comfortable and settled, turn off respiratory support and remove mask, replacing with 10-15L oxygen via non-rebreathe mask.
Continue symptom control as required. Consider further weaning oxygen to 5L/min via nasal cannulae. Review syringe pump doses based on symptom control already required."

Suffering and a "bad death"

Palliative care cannot eliminate suffering or all symptoms. However, there is very good evidence that the involvement of specialist palliative care reduces symptoms and increase quality of life. (12) The approach of palliative care which emphasises that the individual matters despite their illness and limitations addresses the very core issue which may result in people wishing to end their lives prematurely. (13)

Furthermore, suffering does not appear to diminish in jurisdictions with legalised assisted dying. The quality of dying as a result of euthanasia or assisted dying was reviewed in two studies which concluded;

"In our study, physicians estimated that patients who died as a result of euthanasia or physician-assisted suicide were similar to patients who died from other causes in terms of ... the frequency of feelings of pain, despair, fear, choking, and anger." (14)

And;

"The quality of death experienced by those who received lethal prescriptions is no worse than those not pursuing PAD [Physician Assisted Dying], and in some areas, it is rated by family members as better." (15)

As Dr Doré pointed out in his oral evidence, bad care results in bad deaths, but the answer to bad care is not to end the person's life. To quote Dr Robert Twycross, internationally renowned teacher of palliative care. '*You do not have to kill the patient to kill the pain'*.

This is well illustrated by the recent and well-publicised case of Noel Conway, whose motor neurone disease led him to be highlighted as the perfect example for the case for assisted dying by proponents. He had been led to believe he would either choke or suffocate to death and consequently campaigned for the legalisation of assisted dying. However, with the support of the local hospice team and that of the ventilation team, his ventilation was withdrawn at home at his request, which is current law. His wife describes that:

"…the local hospice team and ventilation nurses had "ensured Noel had a painless and dignified death, demonstrating empathy and concern for us all. Noel was in control, which was so important,"(16)

It was mentioned that patients are facing odour from fungating tumours, faecal vomiting, haemorrhage and 'people drowning'' and distressing pain. There are several problems with this claim as it takes archaic historical fears and portrays them as current reality. It feeds a narrative to the public that you should be fearful of dying naturally, thus pre-empt it. These symptoms are very uncommon, although we agree, can be distressing when they occur, there is no evidence they correspond with requests for assisted dying. In studies looking at the causes of requests for assisted dying, desire for control and fears about the future are more common that the presence of rare issues such as these.

The impact on non-assisted suicides

Considering that specialist palliative care teams see patients with the most difficult and complex problems, suicides are rare. The risk of suicide is increased in the time immediately after the diagnosis of a life-limiting illness, but then wanes, especially with appropriate care. (17)

It is often claimed that legalising assisted dying would reduce the number of non-assisted suicides. The evidence does not show this. No assisted dying jurisdiction has seen a drop in non-assisted suicides, and several have seen an increase. (18)

Consequences of dying from AD on bereavement of relatives

The committee asked about the consequences of dying from assisted dying on bereavement. A study involving assisted dying in Canada (known as Medical assistance in dying – MaiD in Canada) identified five areas where grief and bereavement had been impacted for relatives of patients who had died after MAiD. These included; complicated grief where family members do not agree with the patient's decision; a feeling of responsibility for the premature death in relatives who supported MAiD decisions; anxiety about MAiD caused by secrecy and stigma in some cases

causing complicated grief; feelings of regret from family members where MAiD was requested but not carried out; and stress and anxiety caused by conflicting views about MAiD from healthcare care providers. (19)

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