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'One Chance to get it Right' – A Missed Opportunity

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In a joint statement released to mark the first anniversary of the recommended abolition of the Liverpool Care Pathway by the Neuberger Report of July 15 2013, Alert and Distant Voices wish to express our concerns that One Chance to Get it Right, new guidance produced by the Leadership Alliance for the Care of Dying People, retains the central flaws of the discredited end-of-life protocol and therefore represents a cynical exercise in rebranding.

We contend that the New Priorities for Care, which will replace the LCP, will offer nothing new to protect those who are not dying from being unlawfully killed in the same way as the many whose lives were ended under the pathway.

The Neuberger Report recognized that a central flaw of the LCP was its unscientific claim that medical professionals could definitively diagnose dying, which led many families to suspect that their loved ones were put on the pathway when they might have otherwise survived.

Baroness Neuberger recommended research into the biology of dying and the use of evidence-based prognostic tools (including awareness of their limitations) which might help to predict death. We are dismayed that these recommendations are NOT accepted by the alliance, which refers to the “dying” person throughout the 168 pages of its report.

Furthermore we are alarmed that the alliance defines “approaching the end of life” as any patient “likely to die within the next 12 months”: this is to include not only those patients with advanced incurable conditions but also people with “general frailty and co-existing conditions that mean they are expected to die within 12 months”.

Yet there is no scientific evidence to support a diagnosis that a patient is in “the last hour or days of life”, let alone in the last year of life. **We fear that once again, as with the LCP, vulnerable people will be unfairly discriminated against and labelled as “dying” and then denied medical treatment which could have sustained life and may well have promoted recovery.** We are also gravely concerned that:

- the alliance’s promotion of Advance Care Planning will encourage even greater abuses than those previously experienced on the LCP;
- the alliance dangerously downplays the Neuberger Reports condemnation of the use of the “chemical cosh”, where some patients were over-dosed to the point of euthanasia, instead choosing to emphasise better communication with families. A syringe driver of sedatives and pain-killers may not just “make you sleepy”, as the alliance asserts, but can KILL you if you are not dying;
- the alliance has ignored calls to halt the anticipatory prescription of drugs, by which patients were routinely sedated, sometimes resulting in respiratory depression hastening death. We fear that the abuses we witnessed on the LCP caused by anticipatory prescribing will continue;
- contrary to reports in the media, no real power is being placed in the hands of patients and their families, with the alliance still insisting on a “best interests” assessment of the patient according to Mental Capacity Act 2005 criteria. The real decision about how, or whether, to treat a “dying” person therefore remains firmly with the medical team.

We believe that all attempts at creating “pathways” or “priorities” for the “dying” should be stopped until an adequate prognostic tool is developed that can at least assist in determining those at risk of dying. In the present climate it is essential to establish an End of Life Care Bill of Rights because this would be the only way to avoid abuses.

Elsbeth Chowdharay-Best, the honorary secretary of Alert, said: "We cannot support the alliance report as it repeats the errors of the Liverpool Care Pathway in abandoning evidence-based medicine for the personal, subjective judgment of the medical team members about perceived quality of life (best interests) and likelihood of death within a year. If we were to accept the alliance's rebadged version of the LCP we would be accepting that euthanasia is part of the standard way of dying on the NHS."

Nikki Kenward of the Distant Voices disability rights group said: "We fear that adoption of the 'One Chance to Get it Right' will only mean that the murder continues in the same fashion, the number of patients with non-terminal conditions put on palliative sedation regardless of the nature of their illness will continue as before, and induced coma will continue to be the reason so many frail and vulnerable patients die on admission to NHS hospitals."

For further information

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Follow us on Twitter: @thedistantvoice

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<http://noliverpoolcarepathway.com/who-we-are/>

Notes to Editors:

ALERT aims to warn people of the dangers of any type of euthanasia legislation and pro-death initiatives. These have included the promotions of living wills and advance directives, which create a climate for the acceptance of euthanasia.

ALERT was founded in December 1991 to provide well-documented information on these and related issues, and to defend the lives and rights of the medically vulnerable, recognising that all human beings are of equal value.

ALERT defines euthanasia as “any action or omission which is intended to end the life of a patient”. The law in every country until recent years protected all citizens against being killed, regardless of their status or condition and the first infamous exception to this rule was in Nazi Germany. Such laws change the attitude of society towards its members.

It has never been part of doctors’ duty to prolong the dying process by extraordinary interventions. But they should never deliberately harm those in their care. ALERT is calling for the restoration of the law against homicide, which has served our citizens well for centuries.

ALERT is a campaigning organisation, not a charity, and is funded solely by donations from our supporters.

Distant Voices was launched in 2009 with a declaration about the human rights of disabled people, read by Nikki Kenward the Fourth Plinth in Trafalgar Square, London, during Anthony Gormley’s rolling display of art.

Distant Voices campaigns against euthanasia using a variety of creative media, including art, sculpture, music, demonstrations, flash mobbing, photography