

**Should everyone, including the intellectually/learning disabled - the autistic man and woman - have the right to a good death, a death with dignity and the least pain and suffering?**

### **A question for Europe**

**I am giving a 15-minute presentation at the Budapest Congress of Autism Europe in September. If your ageing specialist has time to read these questions and provide answers, that will be very helpful for my presentation. Michael Baron, founder member, National Autistic Society (UK) and Chairman 1962-1967, and parent of a 57-year- old son in residential care.**

#### **Introduction**

Should every man, woman and child in the course of terminal illness be cared for and treated without distinction between the intellectually able, including those with mental capacity for decision-making, and the intellectually disabled, lacking in such mental capacity? And how is that to be achieved? For we need to understand and accept that for the intellectually disabled there comes that time when loss of quality of life is unbearable for the cared-for and the carer, and needs to be addressed in decision making.

Note: For the purposes of these questions, 'intellectually disabled' (ID) has the same meaning as 'learning disabled'. Both descriptions are in use in public health literature. These are questions that seem to have received partial answers. .As surviving into old age affects global populations, we need now to understand and plan for end-of-life care and end-of-life decisions. For a death with dignity.

Whilst the following questions are addressed to the communities of autism (ASD) in Europe and North America where ageing is now of profound importance, the same questions apply to any ID community - communities where speech and comprehension range from bizarre to silence, and behaviour from challenging to eccentric or just different, and where no answer to the tsunami of questions about ASD may be taken for granted.

1. The prime principle of the UK 2005 Mental Capacity Act is that it assumes there is capacity to make decisions.
2. Subject to that prime principle, Section 24 of the 2005 Mental Capacity Act gave legal sanction to a person with capacity, as confirmed in writing by a medical practitioner, to write an **advance decision to refuse treatment (ADRT)**. This authorises for a set of given physical conditions that, given a medical prognosis of terminal illness, treatment

should be withheld other than in the cause of relieving suffering. Formerly, ADRT's were titled 'living wills'.

It is likely that an ID person in the UK has no capacity to make an ADRT. Section 24(1) of the Act is as follows: 'Advance decision' means a decision made by a person after he has reached 18 and when he has capacity to do so that if

(a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and

(b) at that time he lacks the capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.

The human rights issue (see United Nations Enable (2008) Convention on the Rights of Persons with Disabilities ([www.un.org/disabilities/default.asp?id=150](http://www.un.org/disabilities/default.asp?id=150)) ratified by the EU in December 2010; and the 2013 Report on Ageing from Autism-Europe ([www.autismeurope.org](http://www.autismeurope.org)) is that no ID person should be in any worse position to manage or have managed the end-of-life care than any person with legal capacity.

The social, religious and ethical context of illness and death is complex and varies from close family involvement to relying on the unselfish kindness of health professionals to make difficult 'best interests' decisions.

Key care decisions in the UK are made in a prescribed form and recorded (MCA1- Record of a Mental Capacity Assessment). And actions taken to reach a best interest decision are in a prescribed form (MCA2). See [www.dca.gov.uk/legal-policy/mental-decision/capacity/mca-cp.pdf](http://www.dca.gov.uk/legal-policy/mental-decision/capacity/mca-cp.pdf)

Note that there may be many ID individuals who have capacity for some decisions - food preferences- but not others , -medical treatment. In UK law capacity' depends on the nature of the decision to be made.

### **QUESTION 1:**

Is there legislation in your national state by which a family member or relevant carer (manager/social worker,for example) may lawfully indicate to a hospital/ hospice/care home that in certain circumstances it is right that medical treatment may be withheld? Examples of the general principles of an ADRT will be found on many UK websites. dedicated to end of life issues.

### **QUESTION 2:**

If in your national state there is no such law authorising the withholding of treatment, would you welcome the idea of family member/s or specified relevant carer/s filing a statement on an ASD/ID person's medical record that in given circumstances, e.g. that the patient's illness (specified) is terminal, treatment could be withheld?

This statement would not be legally binding on health care professionals, nor in judicial proceedings. But UK law allows proceedings for a declaration that a doctor may lawfully

discontinue and/or withhold life-sustaining treatment. See *W v M and G* (2011) (Fam) and accessible at [www.bailii.org/ew/cases/EWHC/Fam/2011/2443.html](http://www.bailii.org/ew/cases/EWHC/Fam/2011/2443.html) - a case in the Court of Protection. This would usually be when there are differences of opinion about treatment between family members and health care professionals. In the UK the judiciary has an inherent jurisdiction to make certain 'best interests' health care decisions for people without legal capacity when such decisions are outside the powers of a deputy or independent mental health advocate (IMC) appointed under Sections 19 and 35 of the 2005 Mental Capacity Act. In any event, all carers (lay and professional) are bound by the 9-point checklist of Mental Capacity Act 'best interests' processes. For any state that does not have legislation similar to the MCA this check list is a useful framework.

The suggested voluntary statement below is an expression of wish only. It is a breach of human rights for a third party to be allowed to make a life-and-death decision for another person.. Such a statement might be in this form, with alterations as necessary for citing relevant legislation.

*(Parent, brother, sister, uncle, aunt, carer, social worker, care manager) have discussed issues of medical treatment that may arise for our son/daughter/brother/sister/XYZ resident ... born on 19../20.. and presently living at ... and in particular his/her quality of life, life expectancy, and the right as far as possible for the amelioration of pain and suffering in the context of respect for his/her human dignity.*

*We have also considered religious, ethical and social matters relevant to the life of XYZ. It is our wish that in any of the events listed below medical treatment for the preservation of life should be withheld. We understand this statement is only an expression of our wishes. It is not intended to interfere with the clinical judgement by a health professional, and, if applicable, submissions to a relevant court by a deputy or an independent mental health advocate or other authorised representative. However, our careful consideration of what will be the best interests of XYZ may help in the decision making process when XYZ is deemed to be terminally ill. In the event of life preservation issues being the subject of legal process, then we ask that judicial notice is taken of this statement by family members.*

*Events (list these, such as inoperable cancers, strokes, dementia...)*

*(Signed and witnessed, etc.)*

### **QUESTION 3:**

Would you prefer to have the issue of decision making at the end of life, i.e. to spare the ASD/ID person pain and suffering, left to medical practitioners/hospital/hospice authorities to exercise their clinical judgment?

Or should decision making be safeguarded by legislation in particular the 'best interests' process similar to the UK's MCA and its codes, and must take into account as part of the decision making process the opinions of family members/social worker/care home manager/care manager?

#### **QUESTION 4:**

What is the medical/ethical/hospital managerial practice in your national state for any patient whom those authorities exercising clinical judgement decide are at the end of life without prospect of recovery?

In the UK and USA, certainly a patient's record may be endorsed 'DO NOT ATTEMPT RESUSCITATION'. This indication - that the patient will be left to die - is, in the UK, in the discretion of the senior doctor/medical team. It is not authorised by any legislation but arises out of a doctor's duty to his terminally ill patient. In the UK, there is prior consultation with family members. But with ID patients, or patients without family, can one be sure beyond doubt clinical judgement is exercised with the same care?

#### **QUESTION 5:**

What are the mortality rates among the ID population of each European state ?

A study from the University of Bristol, commissioned by the National Health Service and published in March 2013 (summarised in the British Medical Journal at 2013: 346:f1853... People with learning disabilities are more likely to die prematurely) concluded that 'patients with a learning disability' died on the average 16 years earlier than the average death age. There is a 2013 Swedish report on its Health Service which inter alia reaches a similar conclusion.

Is this the experience, or the expectation, in your national state?

#### **QUESTION 6:**

When an ID person is admitted to hospital for treatment in your national state, is he or she:

(a) in possession of a 'health passport' that describes the ID person, his likes and dislikes, behaviours and so on (see [www.talkback-uk.com/our-work/health-passport](http://www.talkback-uk.com/our-work/health-passport))

(b) accompanied by a family member, if living at home, or a care worker if living in sheltered housing/supported living unit/care home, and

(c) are there facilities for the accompanier to stay at the hospital, for example until an operation is concluded and the patient discharged?

(d) an end of life plan (see 6B). Do you agree that every hospital must have a sufficiency of nursing and medical staff trained and able to understand/interpret the needs, etc., of non-verbal patients, whether or not in possession of a 'health passport'?

The Bristol University report (above) suggests reasons for the high mortality rates ('Confidential inquiry into premature deaths of people with learning disabilities'-

[www.bris.ac.uk/cipold/confidential-inquiry](http://www.bris.ac.uk/cipold/confidential-inquiry) ; and also [www.improvinghealthandlives.org.uk/projects/](http://www.improvinghealthandlives.org.uk/projects/) deaths

(e) do you agree that the completion of a 'health passport' should be required, by law or regulation or EU directive, for everyone with an intellectual disability? And that every ID person admitted to hospital/hospice for medical treatment or end-of-life-palliative care should only be admitted provided he or she has such a health passport ?

#### **Some references**

The palliative care needs of people with intellectual disabilities - Tuffrey-Wijne Palliative Med 2003.17.55 - and the further references cited in that review.

Death by Indifference. Mencap 2007

Living and Dying With Dignity. Mencap- see [www.mencap.org.uk/endoflifecare](http://www.mencap.org.uk/endoflifecare). See also list of publications and references in the report. Downs' syndrome and dementia: a framework for practice to support people with Down's syndrome and dementia living in generic care homes. Wilkinson and Watchman in Hughes et al 'Supportive Care for the Person with Dementia', OUP 2010. See also the references in this chapter.

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