

Alzheimer's Society submission to the Mental Capacity Bill team.

July 7th 2015

Dementia and its effects.

There are nearly 20,000 people with dementia in Northern Ireland, 7000 of these do not have a diagnosis.

Dementia is a general term used to describe a number of serious, medical conditions which cause symptoms such as impairment in memory, reasoning and communication skills and a gradual loss of ability needed to carry out daily activities.

Symptoms are caused by structural and chemical changes in the brain as a result of diseases like Alzheimer's disease, which is the most common form. Different types of dementia affect people differently and a person may live for many years though their needs will become more complex in the later stages. Dementia is a terminal illness, a key feature of which is cognitive impairment leading to eventual loss of capacity to make decisions. Mental Capacity legislation is pivotal in supporting people with dementia to exercise their rights to personal autonomy.

The value of strong and inclusive mental capacity legislation to the health and social care workforce is in safeguarding, raising professional awareness and supporting and promoting good practice. From the perspective of the person with dementia it facilitates and enables communication, understanding and best outcomes in health and welfare so that people can exercise their rights to personal autonomy on the same basis as those without dementia.

The prime purpose of the Mental Capacity Bill.

The provisions of the Mental Capacity Bill must support a person with dementia to exercise their right to make decisions about their health, welfare and finance when they have capacity to do so and ensure that their 'best interests' are the basis of decisions made on their behalf by others, when they lack capacity.

'Best interests' in this context may require input from lasting powers of attorney; a nominated person, an independent advocate and/or an advance decision so that decision makers act, to the best of their knowledge, as if the person were in a position to make the decision themselves, at the material time as distinct from what a decision maker thinks a person should decide.

In Alzheimer's Society's response to the public consultation on the draft Bill the Society identified some key concerns and suggested changes or additions which

would strengthen the Bill for people with dementia. This briefing confines itself to specific points requiring amendment as follows:

Strengthen provisions with relevance to people with dementia

Alzheimer's Society remains convinced that leaving Advance decisions in common law constitutes a serious omission which will have far reaching negative consequences for people with dementia and others who rely on the Bill's provisions to safeguard their right to autonomy in decision making.

Protection from Liability and general safeguard in Part 2 include provisions which are needed to establish the person's will and preference, like nominated person, independent advocate and second opinion. This part also refers to Advance decisions as they affect Section 9, which elaborates on Protection from liability.

The fact that Advance decisions remain in common law presents a high risk that they will be ill- defined in contrast to the detail attached to other provisions; misunderstood and as a consequence subject to a 'chill effect' which will inhibit widespread understanding and use.

Alzheimer's Society takes the view that Advance decisions should be included in the Bill, as they play a pivotal role in advance care planning for a person with dementia. A person with dementia may live for many years with a good quality of life but will lose their capacity to make decisions as their condition advances and towards the end of their life. It is neither a possibility nor a probability- loss of capacity is a certainty. For this reason Advance decisions to refuse treatment have a key part to play in advance care planning.

By whichever means it chooses this Bill must support persons with dementia to exercise their right to make decisions when they have capacity and that their 'best interests' are the basis of decisions made on their behalf, when they lack capacity.

Impact of early and timely diagnosis

Early and timely diagnosis not only gives a person with dementia and family carers the opportunity to secure information, support and treatment that can help a person with dementia to live well, but it affords the person a very valuable timeframe in which to discuss future care and make their preferences known, so that those who will be responsible for making decisions about their health when the person has lost their capacity will be compelled by law to respect their decision.

For example, people with dementia towards the end of their lives are sometimes fed using a tube; a practice which has no real benefit beyond prolonging the person's life. This is invasive, uncomfortable and fulfills no purpose in relation to their quality of life. An advance decision to refuse specified treatment of this nature can be key to a person retaining their personal autonomy to exercise their rights, when they have lost capacity to express their will and preference. Knowing that certain procedures specified in an Advance decision will not be employed at a point when they are invasive and of no benefit to the person, but at a time when they are not capable of resisting, can be a huge comfort to the person and to their close kin.

Alzheimer's Society suggests the following changes/additions in red

Part 1. Best interests.

Section 7.

(6). That the person must have special regard to (so far as they are reasonable ascertainable)-

(a) P's past and present feelings (and, in particular, any relevant written statement made by P when P had capacity); **This is too vague- propose refer to AD at this point.**

(b) **An effective Advance Decision.**

(c) The beliefs and values that would be likely to influence P's decision if P had capacity: and

(d) The other factors that P would be likely to consider if able to do so.

(7). That the person must-

(a) so far as it practicable and appropriate to do so, consult the relevant people about what would be in P's best interest and in particular about matters **such as Advance Decisions** mentioned in subsection (6) : and

(b) take into account the views of those people (so far as ascertained from that consultation or otherwise)) about what would be in P's best interests and in particular about those matters.

It goes on to point to subsection (11) for a definition of "the relevant people" but does not elaborate at that point about "relevant written statement" which should include Advance decisions whether within the statute or in common law. The Bill Team's decision to leave Advance decisions outside the statute on the grounds that the law is still being developed is a serious weakness in our view, but the effects of this omission are aggravated if the common law provision is not referred to on the face of the Bill or acknowledged as having an important part to play in supporting people to exercise their autonomy, which is the prime purpose of the Bill.

Part 2. Protection from Liability and General Safeguards.

Under Protection from liability for acts in best interests of person lacking capacity.

Section 9. elaborates at (4) as follows:

The additional safeguard provisions are

(a) **Section 11 Advance decisions: effect on section (reference to AD needs to be here so it is given equivalent weight as a safeguard against treatment being given that a person has refused in an effective Advance decision.**

(b) Section 12 (conditions of any act of restraint);

(c) Sections 13 & 15 (formal assessment of capacity , and consultation of nominated person, required for serious interventions);

(d) Sections 16 & 17 (second opinion required for certain treatment0);

(e) Sections 19, 22, 24, 26, 28 and 30 (authorization required for serious treatment where there is objection from P's nominated person or compulsion, and for deprivation of liberty and certain other measures);

(f) Section 35 (independent advocate required for certain serious interventions).

11 Advance decisions: effect on section 9.

(4) Nothing in this section prevents a person from –

(a) providing life- sustaining treatment **that does not conflict with an effective Advance decision to refuse such, specified treatment**, or

(b) doing an act which the person reasonably believes to be necessary to prevent a serious deterioration in P's condition, while a decision as respects any relevant issue is sought from the court. If subsection 4 (a) is not qualified as above or similarly, it could lead to decision makers feeling compelled to treat if failure to do so had the unintended consequences of bringing about the person's death. Some means must be found to make clear and proper distinction between treating someone to save their life/ avoid serious deterioration in their health, which is a desirable outcome and the reverse, which is failing to comply with a person's properly documented (effective AD) wishes not to be treated in a specified way.

If the Bill team persists in its determination to leave ADs in common law, significant measures will have to be taken and must be evident in the Bill and in code of practice so that ADs will be a matter of public knowledge and widely understood by the general population and health and social care practitioners. In this way people will become more aware of their existence, their role in advance care planning and that they are considered a positive and responsible practice, which will be treated with due respect and implemented by decision makers if they hope to have protection from liability in law.

12. Acts of restraint. Condition that must be met.

(3) The restraint condition is that at the time the relevant act is done, D reasonably believes—

(a) that failure to do the relevant act would create a risk of harm to P; and

(b) that the relevant act is a proportionate response to—**refer to note on access to advocate to explore potential disproportionate restraint at 89(a)- may require a subsection to address conditions which can only apply post- restraint.**

(i) the likelihood of harm to P; and

(ii) the seriousness of the harm concerned.

Part 2. Additional Safeguards and Authorisations

24. Deprivation of Liberty

Alzheimer's Society feels the Bill would greatly benefit from a definition of 'deprivation of liberty' at this point and suggests a good starting point would be to use one of several which have emerged from recent Supreme Court rulings relating to MC Act 2005. A good starting point might be the ruling – in the cases of *P v Cheshire West and Chester Council* and *P&Q v Surrey County Council* - threw out previous judgements that had defined deprivation of liberty more restrictively.

“A deprivation occurs where a person is placed under continuous supervision and control and is not able to leave”.

Part 4. Independent advocates.

84. This section would benefit from a clear definition of the term 'independent advocate' as it is often understood differently by different personnel and in different settings.

The Advocacy Charter (2002) uses the following:

‘Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need.’

Advocates and advocacy schemes work in partnership with the people they support and take their side’

Advocacy promotes social inclusion, equality and social justice.

An advocate can sometimes be seen as a threat by health practitioners rather than a means of enhancing communications, building good practice and of improving outcomes for the person with dementia and the quality of their care. Raising awareness and practitioner understanding is essential to ensure access to advocacy is properly inclusive of people with dementia and in a wide range of circumstances where their involvement would enable best outcome for the person with dementia in all decision making scenarios.

86. There may be benefit in extending the instances in which an advocate may be instructed to include when restraint has been used on a person with dementia. Restraint usually happens when a person is particularly ill and vulnerable. Because it is not possible to put safeguards in place before restraint is used, it is important that the person who has been restrained has access to advocacy subsequently so they can be supported to make a complaint if they feel that restraint was not ‘proportionate’. In such a case under section 89 (a) an addition might be inserted;

89 (a) an HSC trust receives a request duly made under section 86 for the trust to instruct an independent advocate to represent and provide support to a person (“P”) in the determination of whether a particular act would be in P’s best interests **or that P should subsequent to an act of restraint have access to an independent advocate to allow for complaint to be lodged in the event that restraint was felt by P to be disproportionate..**

A significant degree of information including the specifics of raising public awareness, training of relevant personnel and ensuring properly resourced implementation of the legislation, is left to the regulations and code of practice. Experience in the post- legislative phase of the Mental Capacity (2005) Act in England and Wales suggests these are critical and valuable lessons to be learnt from their experience and that monitoring and review of how provisions meet the actual needs of those they are designed for, will benefit from those experiences in mitigating some unintended adverse outcomes here in Northern Ireland.

Alzheimer’s Society in Northern Ireland