Submission from Atheist Ireland on the Draft General Scheme for Advance Healthcare Directives for Incorporation into the *Assisted Decision-Making (Capacity) Bill* (2013)

1. Introduction

1.1 Atheist Ireland is an Irish advocacy group. We promote atheism and reason over superstition and supernaturalism, and we promote an ethical, secular society. We are participants in the dialogue process between the Government and religious and philosophical bodies. We participate in events organised by international bodies such as the United Nations, the European Union, the Council of Europe and the OSCE. We work with other advocacy groups who are seeking to bring about an ethical society. You can read details of our policies on our website at http://atheist.ie. Our general policy on healthcare is that there should be a secular State healthcare system where decisions are based on compassion, human rights and the medical needs of patients, and not on religious ethics.

1.2 Atheist Ireland welcomes both *the Assisted Decision-Making (Capacity) Bill 2013* and the move to legislate for Advance Healthcare Directives along with moves to ratify the UN Convention of the Rights of Persons with Disabilities. Atheist Ireland also welcomes that the guiding principles of the *Assisted Decision-Making (Capacity Bill*; the presumption of capacity, respect for the autonomy of the individual, and that capacity will be assessed functionally on an issue- and time-specific basis. Atheist Ireland also welcomes the guiding principles of Advance Healthcare Directives; a patient-centred model of healthcare, non-discrimination and equality before the law, the right to autonomy, bodily integrity, privacy, and the right to maintain control over medical treatment when capacity is lacking or lost.

1.3 Atheist Ireland has main concerns around two aspects of the draft scheme for Advance Healthcare Directives; that the validity or applicability of an Advance Healthcare Directive should be called into question or not upheld in the instance of a pregnant woman and that the issue of the informed consent, capacity and the right to die.

Our recommendations are:

> *1. Remove Head 5 Subsection 6. Respect the right of women to have their advance healthcare directives respected when they are pregnant, unless they have explicitly stated that they do not want to refuse treatment when pregnant.*
>
> *2. The Bill should be expanded, or accompanied by separate legislation, to alter the existing law on homicide under which both euthanasia and assisted suicide are illegal, and to enable people making advance healthcare directives to request intervention to help them to die peacefully, painlessly and reliably in specified circumstances.*
>
> *3. The Bill and/or the Code of Practice should explicitly recognize the right of a person to have a request accepted for maximum painkilling treatment in an advance healthcare directive, while knowing that that will hasten their death.*
>
> *4. A person should be entitled to specify in an advance healthcare directive that, under certain circumstances, they wish to refuse oral nutrition and oral hydration, while knowing that that will hasten their death.*
>
> *5. Remove Head 3 Subhead 2(d) which replicates what is already in 2(c) and gives unnecessary prominence to religious beliefs.*

2. Purpose and Guiding Principles

2.1 Head 3 subhead 1 states that the purpose of this part of the Act is:

> *(a) to promote the autonomy of persons in relation to their treatment choices,*
> *(b) to enable persons to be treated according to their will and preferences,*
> *(c) to provide healthcare professionals with important information about persons and their choices in relation to treatment.*

Subhead 2 states that the following principles shall apply:

> *(a) An adult shall be presumed to have the capacity to prepare an advance healthcare directive unless there is evidence to the contrary.*
> *(b) An advance healthcare directive should be made on the basis of informed decision-making.*
> *(c) An adult with capacity is entitled to refuse treatment for any reason even where it appears to be unwise or not to be based on sound medical principles, even where this refusal may result in his or her death, and*
> *(d) An adult with capacity is entitled to refuse treatment for religious reasons, even where this may result in his or her death.*

2.2 The explanatory memorandum on this states that the right to autonomy (self-determination) relates to " *an individual's right to think and act as s/he wishes, free from any external influences…the principle of autonomy refers to an individual's right to decide for him/herself with regard to his/her treatment and care*".

> "*It is legally recognised in Ireland that, stemming from personal rights of autonomy, bodily integrity and privacy, an adult with capacity has the right to refuse all forms of treatment (including life-sustaining treatment) even where this may result in his/her death*" and that "*such decisions could be made for personal reasons which could include religious reasons*".

2.3 The guiding principles outlined in Section 8 of the Assisted Decision-Making (Capacity) Bill (2013) state:

> *An intervention in respect of a relevant person shall—*
> *(a) be made in a manner that minimises:*
> *(i) the restriction of the relevant person's rights, and*
> *(ii) the restriction of the relevant person's freedom of action,*
> *and*
> *(b) have due regard to the need to respect the right of the relevant person to his or her dignity, bodily integrity, privacy and autonomy*

3. Validity and Applicability of an Advance Healthcare Directive and pregnant women

3.1 Head 5 subhead 1 states that an advanced healthcare directive is not valid if the person who made the directive -

> *(a) did not have capacity at the time of its making,*
> *(b) did not make the advance healthcare directive voluntarily,*
> *(c) has, at a previous time when he or she had capacity to do so, communicated an alteration or revocation of that advance healthcare directive,*
> *(d) while he or she had capacity to do so, has done anything clearly inconsistent with the advance healthcare directive remaining his or her fixed decision"*

Head 5 subhead 2 states that an advance healthcare directive is not applicable if:

> *"(a) at the material time the person who made the advance healthcare directive still has capacity to give or refuse consent to the specified treatment,*
> *(b) the treatment in question is not the treatment specified in the advance healthcare directive,*
> *(c) any circumstances outlined in the advance healthcare directive are absent"*

The above criteria ensure the effectiveness of an advance healthcare directive by reducing ambiguity and protects the individual's decision, ensuring it is made voluntarily and without coercion.

3.2 However, Head 5 subhead 6 goes on to state that:

> *(a) Where a woman lacks capacity and is pregnant, but her advance healthcare directive does not specifically state whether or not she intended her treatment refusal to apply if she was pregnant, and it is considered that the treatment refusal would have a deleterious effect on her pregnancy, there should be a presumption that treatment be provided or continued (even where the terms of her directive would have been upheld if she was not pregnant).*
>
> *(b) Where a woman lacks capacity and is pregnant and her advance healthcare directive specifically states that she would want her treatment refusal to apply even if she were pregnant, and it is considered that the treatment refusal would have a deleterious effect on the pregnancy, an application should automatically be made to the High Court to determine whether her advance healthcare directive is valid and applicable.*

3.3 Two scenarios are outlined above. The first refers to a woman who has not specified that she wishes her advance healthcare directive to be enforced if she is pregnant, the second refers to a woman who has explicitly specified that she wishes her advance healthcare directive to be enforced if she is pregnant. We would argue that making such a distinction is erroneous. The fact remains that the woman has, acting with capacity and using informed consent, created a legally-binding document. To second-guess what a woman actually means in her advance healthcare directive and to deny her right to refuse treatment based on this second-guessing goes directly against the guiding principles of bodily autonomy and self-determination and goes against Assisted Decision-Making (Capacity) Bill.

3.4 The reasoning given in the explanatory memorandum on this issue is not rational. It says that:

> *This provision clarifies that since the woman has not specified, in her directive, her will and preferences regarding treatment if she were pregnant and it is considered that the treatment refusal outlined in the directive would have a deleterious effect on the pregnancy, in light of the State's obligation to vindicate the right to life of the unborn under Article 40.3.3 of the Irish Constitution, it should be presumed that the woman would have wanted her pregnancy to continue.*

But how could the existence of an obligation on behalf of the state have any bearing on presuming what an individual citizen would want to do? The two concepts are unrelated.

3.5 The reasoning in the explanatory memorandum on subhead 6 also contradicts the reasoning in the explanatory memorandum about subhead 5. It says that:

> *The presumption in favour of providing or continuing treatment also reflects the approach taken in Subhead 5 above, which favours the preservation of life in cases where doubts about the validity and applicability of an advance healthcare directive cannot be resolved.*

But that is not what the explanatory memorandum actually says about subhead 5. What subhead 5 does say is this:

> *Given that an advance healthcare directive represents the most authoritative indication of an individual's will and preferences regarding treatment, where any ambiguity arises a high threshold of doubt must be satisfied before a treatment refusal in an advance healthcare directive can be disregarded.*

Subhead 6 not only lowers this required "high threshold of doubt" when a woman is pregnant, but it actually reverses it.

3.6 The decision not to uphold a legally-binding advance healthcare directive made by an adult who meets all the outlined criteria amounts to direct discrimination based on the sex of the individual as stipulated by Article 14 of the European Convention on Human Rights "*The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status*" and Article 26 of The International Covenant on Civil and Political Rights states: "*All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status*".

3.7 If a woman wished for her advance healthcare directive not to apply if she is pregnant than she would state that as part of the directive. To presume in favour of providing or continuing treatment irrespective of the fact that she has stated her choices regarding treatment in a legally-binding document is an abuse of her human rights.

3.8 Recommendation: Remove Head 5 Subsection 6. Respect the right of women to have their advance healthcare directives respected when they are pregnant, unless they have explicitly stated that they do not want to refuse treatment when pregnant.

4. Respecting Informed Consent and the Right to Die

4.1 Several sections of the Draft touch on the right of a person to, in effect, choose to die by refusing treatment, and to specify this in an advance directive.

4.2 Head 6 subhead 5 states that:

> *Nothing in this Part of the Act is to be taken to affect the law relating to murder or manslaughter or the operation of Section 2 of the Criminal Law (Suicide) Act 1993 (assisting suicide).*

The explanatory memorandum states that this is intended to clarify that the provisions do not alter the existing law on homicide, under which both euthanasia and assisted suicide are illegal. The memorandum then distinguishes between not giving treatment, which is legal, and helping a person to die, which is illegal.

4.3 The High Court in the Marie Fleming case stated that the Government can legislate to allow assisted suicide, if it can put in place appropriate safeguards in order to protect vulnerable people.

4.4 Recommendation: The Bill should be expanded, or accompanied by separate legislation, to alter the existing law on homicide under which both euthanasia and

assisted suicide are illegal, and to enable people making advance healthcare directives to request intervention to help them to die peacefully, painlessly and reliably in specified circumstances.

4.5 Head 3 subhead 1(b) states that one purpose of the this part of the Act is:

> *(b) to enable persons to be treated according to their will and preferences,*

The explanatory memorandum on this distinguishes between treatment requests and treatment refusals.

> *An individual's will and preferences can encompass both treatment refusals and treat requests... However, an individual's autonomy is not absolute and s/he cannot demand that specific treatments or interventions be provided in all circumstances... Accommodating treatment requests requires a balance to be struck between the wishes of the individual on one hand and the demand and opportunity cost this would place on healthcare resources (e.g. personnel, technical and financial), which would no longer be available to another patient.*

4.6 One of the treatment requests that a person might want to make is that they be given the maximum dosage of painkillers to manage their pain, while knowing that that will hasten their death. Facilitating this request would not place demand or opportunity costs on healthcare resources (whether personnel, technical or financial) or make them unavailable to another patient.

4.7 Recommendation: The Bill and/or the Code of Practice should explicitly recognize the right of a person to have a request accepted for maximum painkilling treatment in an advance healthcare directive, while knowing that that will hasten their death.

4.8 Head 5 subhead 4 states that:

> *An advance healthcare directive is not applicable to the administration of basic care to the person who made the directive.*

The explanatory memorandum states that basic care is care that is provided in order to keep an individual comfortable, and is not encompassed by the definition of treatment provided under Head 2 above, therefore, an advance healthcare directive refusing basic care would not be applicable and would not be upheld. Head 2 states that basic care includes, but is not limited to, warmth, shelter, oral nutrition and oral hydration and hygiene measures.

4.9 Recommendation: A person should be entitled to specify in an advance healthcare directive that, under certain circumstances, they wish to refuse oral nutrition and oral hydration, while knowing that that will hasten their death.

5. Unnecessary reference to religious beliefs

Head 3 subhead 2 states that:

> *(c) An adult with capacity is entitled to refuse treatment for any reason even where it appears to be unwise or not to be based on sound medical principles, even where this refusal may result in his or her death, and*
> *(d) An adult with capacity is entitled to refuse treatment for religious reasons, even where this may result in his or her death.*

5.1 Recommendation: Remove Head 3 Subhead 2(d) which replicates what is already included in 2(c) and gives unnecessary prominence to religious belief.